Parkinson’s Disease and Parkinson’s Disease Dementia

A diagnosis of Parkinson’s can be devastating, even more so if you’re at risk for Parkinson’s dementia. But there is hope—and these tips can help.

What is Parkinson’s disease?

Parkinson’s disease (PD) is a progressive disorder of the central nervous system resulting from nerve cells in the brain not producing enough of the chemical dopamine, which
regulates movement. It develops gradually, often starting on one side of the body as a slight tremor in one hand, for example. As the disorder progresses, the trembling may spread to both sides of the body and be accompanied by other symptoms such as muscle rigidity, slowing of movement, and deterioration in balance and coordination. While there is no cure for Parkinson’s disease, there are medications and other types of treatment available to address the symptoms.

While most symptoms of Parkinson’s disease involve the disruption of motor functions (muscle and movement), not everyone experiences all the symptoms—even the most common ones like tremors. The way the disease progresses also varies greatly from person to person. For some people, lack of energy, pain, and changes to mood and memory can also occur as part of the disease. And as the disease progresses, some people will eventually experience Parkinson’s disease dementia (PDD), including loss of memory and other cognitive functions.

A diagnosis of Parkinson’s disease can be extremely distressing, for both you and your family. You may be worried about what the future will bring and how you will manage. The potential of developing Parkinson’s disease dementia will only increase these anxieties and concerns. But no matter your situation or stage of the disease, there are many things you and your loved ones can do to manage your symptoms, maintain your independence, and help you to continue enjoying a fulfilling life.

**Signs and symptoms of Parkinson’s disease**

The primary symptoms of Parkinson’s disease are:

**Tremors** or shaking often occur in the hands, fingers, forearms, feet, mouth, or chin. Typically, the tremor appears (or gets worse) when your limbs are at rest as opposed to when you’re moving. Some people notice that their tremor is exacerbated by stress and excitement.

**Slowed movement (bradykinesia).** You may find that your ability to move freely and spontaneously is reduced or slowed down. Repetitive movements can be especially difficult, causing problems with everyday tasks like buttoning a shirt, brushing your teeth, or cutting food. You may start to walk with short, shuffling steps, or your feet may start to drag.

**Rigidity,** or muscle stiffness, may occur in any part of your body (but most commonly in the neck, shoulders, and legs). This can limit your range of motion and cause muscle pain that
gets worse when you move.

**Poor balance**, or the tendency to be unstable when standing upright, is one of the most important signs of Parkinson’s. It happens because of the loss of reflexes needed for maintaining posture. Some people develop a tendency to sway backwards when standing or turning, which can result in backwards falls.

**Secondary symptoms of Parkinson’s disease**

In addition to the major symptoms of Parkinson’s, there are many secondary motor symptoms associated with the disease. Again, not everyone with Parkinson’s will necessarily develop all or even any of these symptoms.

- Freezing when walking, usually occurring when taking the first step.
- Small, cramped handwriting that gets worse the more you write.
- A less expressive face. People may comment that you look serious or mad. You may have a blank stare or blink less often.
- Speech may become slow, whispery, or slurred.
- Constipation.
- Emotional changes such as anxiety, depression, and fear.
- Fatigue and loss of energy.
- Loss of sense of smell.
- Trouble chewing or swallowing, drooling and excess saliva.
- Sleep problems, including waking up frequently during the night or suddenly falling asleep during the day.

**What is Parkinson’s disease dementia (PDD)?**

Parkinson’s disease dementia (PDD) is a brain disorder that occurs in some—but not all—people living with Parkinson’s disease. The brain cell damage caused by the disease can lead to a loss of memory and other cognitive functions such as problem solving and speed of thinking. These changes in thinking and behavior can impact your daily living, independence, and relationships.

In those who do develop Parkinson’s disease dementia, there is at least one year—and usually 10 to 15 years—between the Parkinson’s diagnosis and the onset of dementia. According to estimates by the Alzheimer’s Association, 50% or more of people with
Parkinson’s disease eventually experience dementia, although there are a number of risk factors that impact the likelihood of developing symptoms:

- Parkinson’s patients who experience hallucinations, excessive daytime sleepiness, and more severe motor control problems are at higher risk for dementia.
- Dementia is more common in people who are older (age 70+) at onset of Parkinson’s.
- Dementia is a bigger risk factor in non-tremor predominant Parkinson’s.
- Overwhelming stress, cardiovascular disease, and adverse reactions to the Parkinson’s disease drug levodopa can also indicate an increased risk for developing dementia.
- Dementia is relatively rare in people who develop Parkinson’s before age 50, no matter how long they have had the disease.

It’s important to remember that progression of Parkinson’s disease dementia can vary greatly from patient to patient. And while there no treatments to slow the rate of damage to brain cells caused by PDD, medications can help to ease symptoms. There are also self-help strategies that can help you maintain a full and rewarding life for as long as possible.

**Signs and symptoms of PDD**

Common signs and symptoms of Parkinson’s disease dementia include:

- Poor memory and concentration
- Slowed thinking
- Disorientation and confusion
- Delusions and paranoia
- Lack of motivation
- Trouble interpreting visual information
- Problems with planning and decision making
- Moodiness, irritability, and anxiety
- Depression
- Visual hallucinations

If you’ve noticed some of the above signs and symptoms in yourself or a loved one, it’s important to get them checked out. But don’t jump to conclusions. People with Parkinson’s often experience cognitive changes such as anxiety, lack of motivation, and slowed thinking. These symptoms do not automatically mean dementia.
Is the dementia caused by Parkinson’s or something else?

Indications that dementia may be caused by something other than Parkinson’s disease include agitation, delusions (strongly held false beliefs), and language difficulties. If the onset of cognitive symptoms is sudden, they’re more likely due to something other than Parkinson’s disease—even reversible causes such as infection, a vitamin B12 deficiency, or an underactive thyroid gland.

Depression can mimic dementia by causing similar symptoms such as apathy, memory problems, and concentration difficulties. Since depression is very common in Parkinson’s patients, it’s important to recognize the signs and symptoms of depression in older adults.

Parkinson’s disease dementia vs. other dementias

Other types of dementia that can be commonly mistaken for Parkinson’s disease dementia include:

**Lewy Body Dementia** is characterized by fluctuations in alertness and attention, recurrent visual hallucinations, and Parkinsonian motor symptoms like rigidity and the loss of spontaneous movement. In this disorder, cognitive problems such as hallucinations tend to occur much earlier in the course of the disease (within a year of the onset of Parkinson’s disease) and often precede difficulties with walking and motor control.

**Alzheimer’s disease** and Parkinson’s disease are both common in the elderly, especially in those over 85. Patients with Parkinson’s who develop dementia may even develop Alzheimer’s dementia as well. Therefore, it’s important to be aware of the signs of Alzheimer’s Disease and how it’s treated.

The similarities in symptoms between Parkinson’s disease dementia, Lewy Body Dementia, and Alzheimer’s disease, can make it difficult to determine the cause of the symptoms. Thus, obtaining a thorough consultation with a neurologist may be necessary to make a definitive diagnosis and establish an appropriate plan of care.
Coping with a Parkinson’s diagnosis

A diagnosis of Parkinson’s can be a frightening experience for both you and your loved ones. While there is currently no cure, there are treatments available for Parkinson’s symptoms and lifestyle changes you can make to slow the progression of the disease and delay the onset of more debilitating symptoms, including Parkinson’s disease dementia. Early diagnosis can prolong independence and help you to live life fully for much longer.

If you’ve been diagnosed with Parkinson’s you may feel anger, deep sadness, or fear about what the future will bring. These feelings are all normal. It’s also normal to grieve as you deal with this enormous adjustment.

Give yourself some time to adjust. As with any major change in life, don’t expect that you will smoothly snap into this new transition. You may feel alright for a while, and then suddenly feel stressed and overwhelmed again. Take time to adjust to this new transition.

Learn all you can about Parkinson’s disease and Parkinson’s disease dementia. Educating yourself and making important decisions early can help you feel more in control during this difficult time.

Reach out for support. Living with Parkinson’s presents many challenges, but there is help available for this journey. The more you reach out to others and get support, the more you’ll be able to cope with symptoms while continuing to enrich and find meaning in your life.

Adopt self-help strategies. Healthy lifestyle choices will not only make you feel better emotionally but may also help improve symptoms, make living with Parkinson’s disease easier, and slow the progression of the disease. Some lifestyle changes may even reduce your risk for or delay the onset of dementia symptoms.

Self-help tip 1: It’s critically important to stay active

Staying active is one of the most important things you can do to maintain your health and quality of life after a Parkinson’s diagnosis. And the sooner you start, the better. Regular exercise or physical activity can significantly slow the progression of the disease and reduce your risk of developing dementia. It can also ease symptoms you’re already experiencing, such as muscle stiffness, posture changes, balance problems, and movement difficulties.
That’s on top of the powerful mental and emotional benefits of exercise. Even small amounts of physical activity can add up to big decreases in depression, anxiety, and stress. The key is to make it a regular part of your routine.

Pay attention to your body. The symptoms of Parkinson’s often fluctuate through the day, so plan your active time around them. You may also find that certain types of exercise work better for you and your symptoms, so experiment. Most importantly, pick something you enjoy so you’ll stick with it.

Take regular “movement breaks.” As getting around and doing things becomes more difficult, it’s only natural to move less, but inactivity makes symptoms worse. Remind yourself to get up—or, at the very least, change position—at least once every hour. And try to avoid too much time sitting in front of the TV, computer, or reading.

See a physical therapist, if possible. Before starting a new exercise regimen, you should always check with your doctor to make sure it’s safe. But for personalized guidance, go to a physical therapist. They can recommend specific exercises and activities tailored to your needs.

Exercise tips for people with Parkinson’s disease

- Regular bending, stretching, and breathing exercises can help you combat posture and balance problems.
- If you’re having trouble or pain while exercising on the floor, try exercising in bed. There are also many chair exercises that can help.
- Don’t underestimate the benefits of walking. It’s convenient and effective. If you’re having trouble, try using a cane or holding onto something (or someone) as you walk.
- Try exercising in the water; it’s easier on the joints. Many fitness centers, hospitals, colleges, and YMCA or YWCA facilities often offer water exercise programs.
- Don’t forget to exercise your face and jaw (sing, read out loud, make exaggerated faces in the mirror). This will help with your facial expressions.

Tip 2: What—and how—you eat can make a difference

There’s no specific Parkinson’s disease diet, but by adjusting your eating habits, you can help protect your brain. Diets that are good for your heart tend to also be good for brain
Eating habits such as those promoted in the Mediterranean diet can help reduce inflammation, protect neurons, and promote better communication between brain cells. Primarily, it’s important to eat plenty of fruit and vegetables, cut down on sugary foods and refined carbs, reduce fried and processed foods, and boost your intake of healthy fats and home-cooked meals. High protein meals may also help to benefit your brain chemistry.

**Coping with dietary problems**

Many people with Parkinson’s experience various eating and dietary problems, such as constipation, chewing and swallowing difficulties, and upset stomach. The following tips can help you minimize the symptoms.

**If you suffer from constipation...** Drink lots of water and eat fiber-rich foods, including beans, brown rice, whole grains, and fruit.

**If you have trouble chewing or swallowing food...** Cut foods into smaller portions to avoid choking and to encourage digestion, and remain upright for 30 minutes after eating.

**If you’re struggling with fatigue...** Limit the amount of sugar you’re eating. Also avoid alcohol and caffeine, especially before bed, as they can reduce the quality of your sleep.

**If you take levodopa (Sinemet)...** Don’t eat meat or other protein-rich foods for at least 30-60 minutes after taking levodopa, as protein blocks your body’s ability to absorb the medication.

**If your medication gives you an upset stomach...** Take your medication with a full glass of water and a small non-protein based snack, such as a piece of toast or fruit.

Some Parkinson’s disease medications need to be taken promptly at specified times before or after eating, so it can also help to establish a regular routine for meal and medication times.

**Tip 3: Make it a priority to be socially engaged**

The more socially active you are, the more you connect face-to-face with others, the stronger your memory and cognition is likely to be. You don’t need to be a social butterfly or the life of the party, but you do need to regularly connect with people who care about you.
Connecting with others is the most effective means of relieving stress which left unchecked can exacerbate symptoms of Parkinson’s disease. Staying socially engaged also stimulates immune function that may slow the progress of disease. While many of us become more isolated as we get older, it’s never too late to meet others and develop new friendships.

**Tips for meeting new people**

- Volunteer
- Join a club or social group
- Visit your local community center or senior center
- Take group classes (such as at the gym or a community college)
- Reach out over the phone or email
- Connect to others via social media
- Get to know your neighbors
- Make a weekly date with friends
- Get out (go to the movies, the park, museums, and other public places)

**Tip 4: Make other healthy lifestyle choices**

In addition to regular exercise, eating a healthy diet, and interacting with others, there are plenty of other steps you can take to manage Parkinson’s symptoms and lower your risk for dementia.

1. **Seek mental stimulation.** By continuing to learn new things and challenge your brain, you can strengthen your cognitive skills and stay mentally sharp. Another great way to improve brain function is to learn a new skill, whether it’s a musical instrument, a foreign language, a new computer program, or a new game or sport. Classes at community centers or colleges can help you to tackle new subjects.

2. **Improve the quality of your sleep.** Good sleep is important for flushing out toxins and protecting your brain. Most adults need 7 to 9 hours of quality sleep. Establish a regular sleep schedule, create relaxing bedtime rituals such as taking a bath or doing some light stretches, and turn off all screens at least one hour before sleep.

3. **Manage stress.** Unchecked stress takes a heavy toll on the brain, shrinking a key memory area, hampering nerve cell growth, and can make many Parkinson’s symptoms
worse. Overwhelming stress may even increase your risk for developing dementia. As well as connecting face-to-face with others, exercise and relaxation techniques such as meditation or deep breathing can help you lower your stress levels.

**4. Find ways to contribute or give back.** Investing in things that you care about and give your life meaning and purpose can energize the nervous and immune systems and help preserve your health. Continue activities that were important to you before your diagnosis or find new ways to invest yourself. You might consider volunteering for a cause that’s important to you, spending more time with your grandkids, involving yourself in a religious community, or even caring for your pets—anything that makes you feel needed and fulfilled.

**5. Nourish your spirit.** Do things every day that add joy to your life. Everyone experiences pleasure differently. It could be spending time in nature, enjoying the arts, playing with grandkids or pets, traveling, or enjoying a hobby.

To learn more about putting these strategies into action, see *Preventing Alzheimer’s Disease*.

**Don’t ignore depression**

Many people with Parkinson’s disease struggle with depression at some point. If you suspect that you’re depressed (or that your loved one is), it’s important to seek help. Receiving treatment for depression can make it easier to handle the other challenges of Parkinson’s disease. As an older adult, there are plenty of things you can do to change how you feel and boost your mood.

**Caring for someone with Parkinson’s**

Caring for someone with Parkinson’s disease or dementia can be a rewarding as well as challenging experience. It will likely involve adapting to new challenges over time as the disease progresses or new symptoms emerge.

**Become informed.** Learn as much as you can about Parkinson’s disease and Parkinson’s disease dementia and how it is likely to affect your loved one specifically, given their health history, age, and lifestyle.
Communicate openly and provide reassurance, especially in the early stages following diagnosis, that Parkinson’s disease is only slowly progressive in most patients and that your loved one can still live a full life.

Modify tasks to allow for greater independence. Allow your loved one to do things for themselves even if it takes longer. If necessary, break tasks that involve fine motor skills into easier steps and focus on success, not failure.

Help your loved one find alternative means of transport if they have to give up driving. That may involve researching public transportation, ride sharing, or community shuttle services.

Exercise together. Exercising is vital for the health and state of mind—of both of you. Take a class together or simply enjoy a walk outside.

Look after yourself. Take regular breaks to avoid caregiver burnout, maintain social ties, and seek out opportunities to relax and have fun. Talking to others in similar situations can be very helpful.

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Get more help

What is Parkinson’s Disease? – Includes causes, diagnosing, symptoms, and treatment. (American Parkinson’s Disease Association)

Parkinson’s Disease Dementia – Includes causes, symptoms, and treatment. (Alzheimer’s Association)

The Carer’s Guide (PDF) – Offers guidance for caring for someone with Parkinson’s disease or Parkinson’s disease dementia. (Parkinson’s UK)

Hotlines and support

In the U.S.: Call the Helpline at 1-800-473-4636 or visit Parkinson’s Foundation for resources and support. For Parkinson’s Disease Dementia, call the Alzheimer’s Association helpline at 1-800-272-3900.

UK: Call the helpline at 0808 800 0303 or visit Parkinson’s UK to find support

Australia: Call the info line at 1800 644 189 or visit Parkinson’s Australia for links to state organizations that provide support and services.

Canada: Call 1 800 565-3000 for information or referrals or visit Parkinson Society of Canada for regional resources and support.