

# Parkinson's Disease



INFORMATION AND GUIDANCE ON LIVING  
WITH PARKINSON'S



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# About Providence Health & Services

As the third-largest not-for-profit health system in the United States, we are committed to providing for the needs of our communities – especially for those who are poor and vulnerable – across Alaska, California, Montana, Oregon, Washington, and Texas.

Our system includes more than 70,000 caregivers (all employees) serving in a diverse range of ministries from birth to end of life, including acute care, physician clinics, long-term and assisted living, palliative and hospice care, home health, supportive housing and education.

## Where we serve

We operate 33 hospitals, 447 physician clinics, 22 long-term care facilities, 19 hospice and home health programs and 693 supportive housing units in 14 locations. Our health plan serves our caregivers and other large employer groups covering 390,000 members.

## Our Mission



AS EXPRESSIONS OF GOD’S HEALING LOVE, WITNESSED THROUGH THE MINISTRY OF JESUS, WE ARE STEADFAST IN SERVING ALL, ESPECIALLY THOSE WHO ARE POOR AND VULNERABLE.

On/Off (medication):	“On” medication is when PD symptoms are well controlled with medications. “Off” is when medications have worn off or don’t seem to be working when they should.
Paranoia:	A delusion that is dominated by fear, suspicion and concern for safety.
Parkinson’s:	A progressive neurodegenerative disease. A decrease in neurons that produce dopamine in the brain. Affects both motor and non-motor systems of the body.
Parkinsonism:	Refers to a group of abnormal movements like stiffness, slowness, tremors and changes in walking; these are seen in PD, but in other disorders too.
Postural instability:	Loss of reflexes and balance that produces increased fall risk in PD.
RBD:	REM Behavior Disorder is a sleep disorder related to PD in which patients act out vivid or threatening dreams. This can produce injury to the person with PD or their sleeping partner.
Rigidity:	Stiffness in the arms, legs or trunk of the body.
Sialorrhea:	Excessive saliva (drooling).
Tremor:	Rhythmic shaking of the arm and/or leg, present in 80% of people with PD. Observed mostly at rest. Usually improves with performing tasks. Initially can affect only one side and may develop on the other side as the disease progresses.

# Terminology

Anosmia:	Inability to perceive odor
Apathy:	Loss of motivation, reduced emotion and interest
Bradykinesia:	Slowed motor movement. Reduced arm swing and hesitation with initiating a movement.
Delusion:	Altered thinking with a fixed conviction that something is real when it is not.
Dysarthria:	Motor speech disorder. Problems with effective use of muscles that help produce speech.
Dyskinesia:	An involuntary body movement. Unlike a tremor, this can be a wiggly or dance-like movement.
Dystonia:	Persistent or intermittent involuntary muscle contractions.
Executive Function:	The aspect of brain function that helps with planning, monitoring, problem solving, execution of goals and tasks, inhibition and working memory.
Festination:	Involuntary increase in taking small steps forward.
Hallucination:	A false perception of either seeing, hearing, feeling or perceiving something that is NOT there.
Idiopathic Parkinson's:	The most common form of PD, in which the cause is not known, in contrast to genetic or vascular PD.
Micrographia:	When handwriting becomes progressively smaller.
Neuroplasticity:	When the brain's neurons find a new pathway and change the connections between them.

# What is Parkinson's?

Parkinson's Disease (PD) is the 2<sup>nd</sup> most common chronic and progressive neurodegenerative disorder behind Alzheimer's disease. Over 1 million Americans have PD, and over 60,000 people are diagnosed every year, with an average age of 60 when symptoms begin. Approximately 4% of people with PD are diagnosed before age 50. More men than women have PD, and approximately 15% of those who have it have a hereditary component. Researchers continue to investigate the connection between PD and genes. Currently, there is no cure for PD, however there are many treatments and healthy lifestyle decisions that can empower you while living with PD.

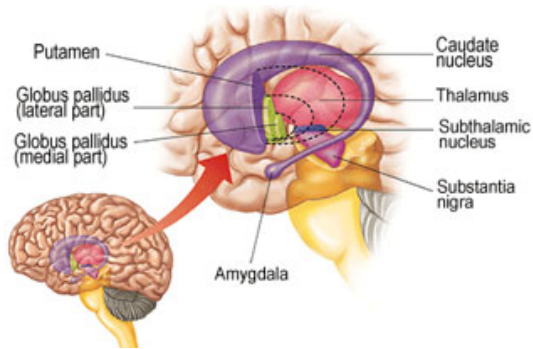
Not everyone diagnosed with PD will have the same symptoms. While blood tests and imaging can rule out other conditions, there are no tests that will confirm the diagnosis of PD. A neurologist's diagnosis of PD is based on clinical expertise. This includes a full neurological exam, a thorough medical history, identification of symptoms and the response of the person with suspected PD to certain medications; sometimes additional imaging or other tests are also obtained.

In some cases, people will be told they have "parkinsonism" rather than "Parkinson's disease". This refers to a set of symptoms that are related to the disruption of dopamine delivery in the brain, causing symptoms of tremor, stiffness, slowness and imbalance. Several disorders can cause parkinsonism, including drug induced

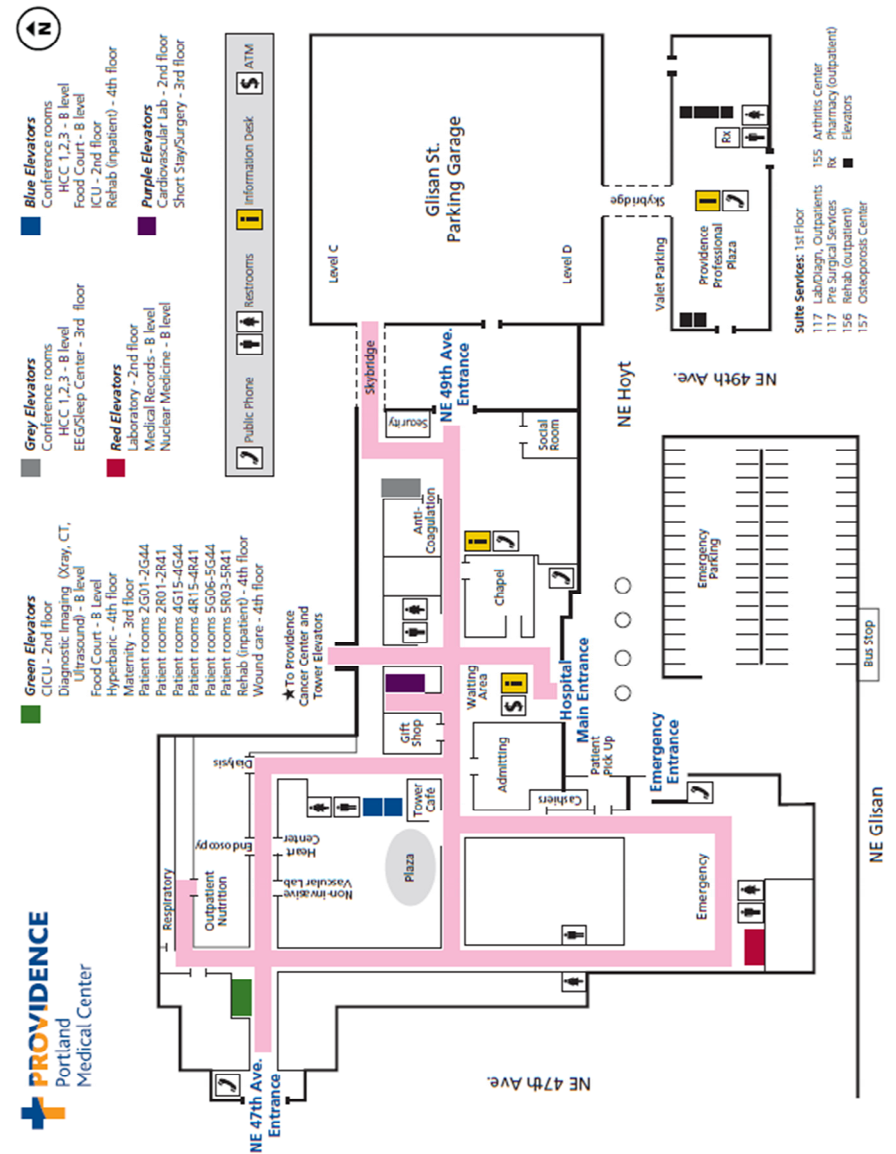
parkinsonism or stroke. A separate group of “PD plus” disorders exist that cause parkinsonism, including progressive supranuclear palsy (PSP), multiple systems atrophy (MSA), corticobasal degeneration (CBD) and Lewy Body Dementia.

PD is caused by the death of neurons that produce dopamine in the brain. Dopamine transmits signals in an area of the brain known as the basal ganglia. These signals control both movement and coordination. As PD progresses, the amount of available dopamine will decrease, diminishing the person’s ability to control normal movement.





## The Basal Ganglia

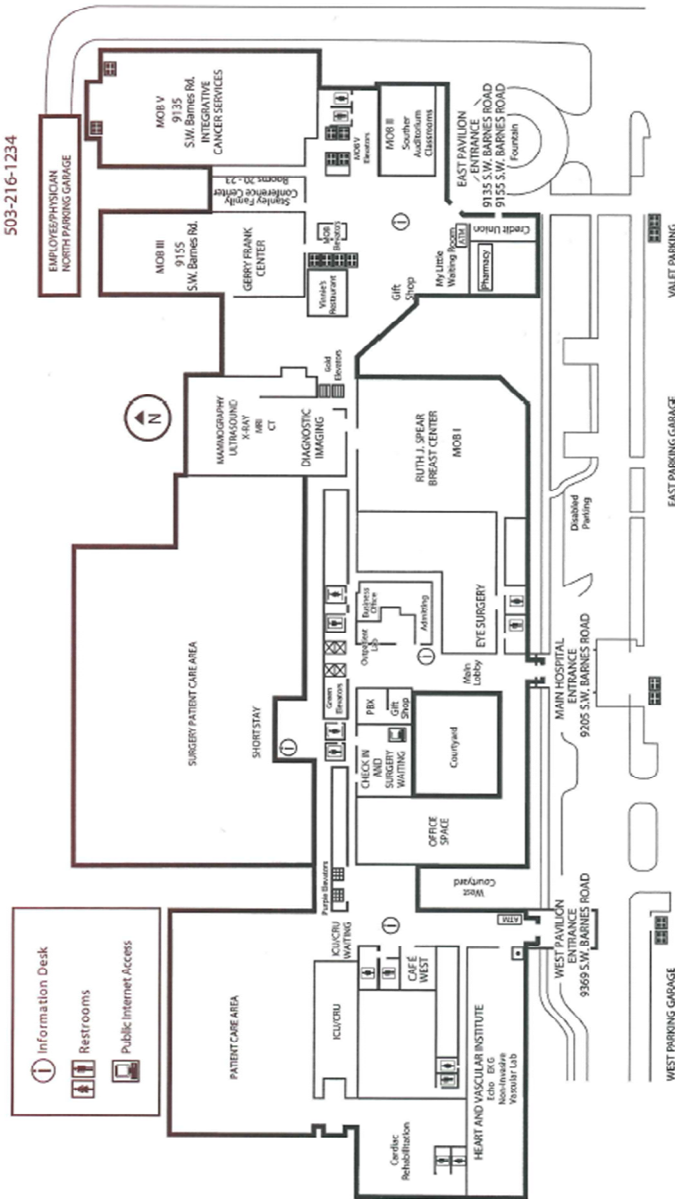


For most people with PD, there is no one cause. Certain genes increase the risk of PD in the context of complex environmental risk factors such as head trauma, exposure to industrial solvents and pesticides and certain heavy metals. Researchers continue to investigate the cause, a cure, and how to slow the progression of PD.



First Floor  
503-216-1234

-  Blue Elevators  
Lower Level(LL)  
Emergency (LL)
-  Purple Elevators  
Coronary Care Unit (CCU)  
IRU (2nd floor)  
Maternity (3rd floor)  
Emergency (LL)  
Human Resources (LL)
-  Green Elevators  
Cafeteria (2nd floor)  
Chapel (2nd floor)  
Medical Foundation (2nd floor)  
Conference Room 1-5 (2nd floor)  
Conference Room 8-12 (LL)  
Board Room (2nd floor)  
Administration (2nd floor)  
Patient Rooms (4th - 9th floor)
-  Gold Elevators  
Nuclear Medicine (LL)  
Radiation Oncology (LL)  
Family Practice (2nd floor)  
Medical Procedure (LL)
-  MOB Elevators  
Physical Therapy/Rehab (3rd floor)  
Brain Institute (3rd floor)



# Newly Diagnosed

A new diagnosis of PD can be overwhelming and bring with it questions about your future, implications for work and for family and a great deal of uncertainty. We are here to help.

There is no right or wrong way to process a new diagnosis of PD. This booklet is a resource to help fill in some gaps about PD, and your neurologist will have preferred resources to direct you to when you are ready.

The following questions might help you begin to understand how a PD diagnosis will affect your life:

- Will PD diagnosis prevent me from enjoying things that mean the most to me?
- What can I do now to continue doing the activities and hobbies I enjoy?
- Of my family and circle of friends, who do I consider to be part of my support system?
- When should I consider telling them of my diagnosis?
- How is work going, and could my symptoms affect my work performance?
- Should I join any social groups? What good would they do me?
- Do I have other health conditions that worry me?

While there are similarities in the ways that people with PD respond to their disease, there are also great differences, depending on both the disease itself and your personal goals and values.

We hope that you use this booklet as an educational guide in your journey with Parkinson's and share it with those closest to you.

No two people diagnosed with PD will have the same course of disease. Often at the time of diagnosis, symptoms are mild, and you may not choose to start medication immediately, focusing instead on exercise and lifestyle changes.

The decision of when to start medication in PD is different for everyone. Your neurologist will usually recommend a trial of medication when symptoms are starting to affect your quality of life. Most people with PD find that they do well on medication, though a smaller percentage struggle with side effects. Over time, medication adjustments are needed as your brain produces less and less of its own dopamine.

Exercise is a key component of PD management, with a particular focus on balance and cardiovascular health. While there is no cure for PD, we do know that a robust exercise program enables people with PD to preserve independence and autonomy longer. See the Fitness section in this guide for suggestions.

### [Tobacco Quit Line](#)

This free service offers advice on quitting, telephone counseling, and referrals to stop smoking programs based on your health insurance coverage. **Call 1-800-QUIT-NOW (1-800-784-8669).**





To learn more and register for these classes, call Providence Resource Line, 503-574-6595, or visit [www.providence.org/classes](http://www.providence.org/classes).

We recommend that you stop using any nicotine products. Here are more resources to help you do so.

#### [Providence Smoking Cessation Classes and Support Group](#)

Based upon the American Lung Association's Freedom from Smoking program, Providence Smoking Cessation Classes and groups are designed to help you quit smoking for good. You will learn a systematic approach to quitting through behavior modification techniques, coping skills, social support, and information on weight management, stress management and the role of medication. To register for a class, call Providence Resource Line at 503-574-6595 or 1-800-562-8964, or visit [www.providence.org/classes](http://www.providence.org/classes).

#### [Quit for Life®](#)

In this telephone-based program, a coach helps you come up with a quit plan that works for you. This 12-month smoking cessation program offers the support of scheduled phone calls, written materials, and recommendations for medicines. To register, call 1-866-QUIT-4-LIFE (1-866-784-8454) or visit [www.quitnow.net](http://www.quitnow.net).

[American Lung Association – Freedom from Smoking Online program](#) [www.ffsonline.org](http://www.ffsonline.org).

# Motor and Non-motor symptoms

These four motor symptoms are cardinal signs of PD:

- Resting tremor
- Bradykinesia (slowness)
- Rigidity (stiffness)
- Postural instability (impaired balance)

You must have two of the first three symptoms to have a clinical diagnosis of PD. For some, postural instability emerges later in the disease process.

**Tremor** is most often the first symptom of PD and typically affects the hand, a finger, or a foot on one side of the body. It can also develop in the jaw. Many times, the tremor appears when the muscles are at rest or when a person is walking. Tremor worsens when the person is under stress or anxiety. The tremor may not be noticeable with intentional movement or during sleep. Generally, people who have tremor as a first symptom have a slower progressing course of PD. Over time, the opposite side may begin to develop tremor. However, the initial side will most likely have the predominant tremor of the two sides.

**Bradykinesia** (slowness) is when movement in legs, arms, facial muscles, and the trunk of the body is slower than usual. This can be progressive and have a profound effect on walking, eating, putting on clothes, driving and other activities of daily living. People with PD may lose their voluntary and involuntary facial expressions, resulting in a masked appearance. This may give the impression that they are not listening or interested conversations or activities and can put a strain on relationships.

Bradykinesia combined with stiffness can lead to a loss of balance, placing the person at risk of falling and injuring themselves. This can happen when a person attempts to take a step, walk through a threshold, or enter a narrow space such as a closet or bathroom. The inability to initiate a step is referred to as “freezing of gait” or FOG. PD often causes a shuffling walk with small steps and a flexed forward posture, causing imbalance and increasing fall risk. Slowness and stiffness can also affect handwriting, making letters small and difficult to read.

Bradykinesia can affect the voice and result in low speech volume that is hard for others to hear and understand. The person with PD may not realize this and might need reminding to project their voice. Having to repeat themselves on numerous occasions can cause a person with PD to stop socializing due to embarrassment or the amount of energy it takes to speak. Speech therapy helps with techniques to speak out loud with intent and use less effort.

# Helpful Lifestyle Resources

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*Certain lifestyle choices and health conditions can make PD more challenging.*

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Providence dietitians can help you learn more about healthy eating with PD. Before scheduling your dietitian appointment, please check with your health insurance for benefits or if prior approval is needed. Clients may also self-pay.

[For information, or to make an appointment, please call:](#)

Providence St Vincent 503-216-2368

Portland Medical Center 503-215-5160

Providence Milwaukie Hospital 503-215-5160

Providence also offers classes in weight management, pain management, fitness, diabetes management and smoking cessation. Smoking or using nicotine products such as cigarettes, e-cigarettes, cigars, pipes and chewing tobacco can:

- Make it harder for you to recover from surgery.
- Make it easier for your blood to clot, which increases your risk of getting a blood clot after surgery.
- Decrease the amount and quality of blood that goes to the skin and bones, which increases the amount of time required to heal after surgery.

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*Always follow the instructions given to you  
from your neurologist.*

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**PLEASE CALL YOUR PROVIDER WITH ANY  
QUESTIONS OR CONCERNS**

**CALL 911**

**WITH ANY LIFE THREATING EMERGENCY**

***(Shortness of breath or Chest pain)***

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**Rigidity** causes stiffness and resistance in movement across joints. This may affect the neck, arms and legs. The stiffness can be uncomfortable and can interfere with range of motion, finger dexterity and walking. Combined with bradykinesia, this results in decreased arm swing while walking. Movement of the arms is necessary to counterbalance the momentum of the legs during walking. When the arms and legs work together, they help reduce energy consumption. Therefore, increased rigidity can produce fatigue, especially after extended walking or a long day at work.

**Postural instability** is usually seen in later stages of PD. This is an impairment in the balance and coordination centers of the brain. Postural instability contributes to the stooped posture and feet shuffling seen in PD and can lead to falls and injury. The risk of falling is increased when changing positions such as rising from a chair, turning, and pivoting and making a quick movement.

PD can also produce a variety of secondary motor symptoms. These include:

- Hypomimia: the reduction of facial expression due to bradykinesia.
- Hypophonia: soft and low volume voice.
- Dysarthria: speech disorder producing slurred or difficult to understand speech.
- Micrographia: abnormally small handwriting.
- Dystonia: involuntary muscle activation, mostly found in feet, hands, neck or torso; this can produce abnormal or uncomfortable postures of the limb.
- Akathisia: feeling of inner restlessness.

Over time, people with PD may develop involuntary movements called dyskinesia. This is a complication of long-term exposure to levodopa, a PD medication that helps restore normal movement. However, over time, the brain’s remaining dopamine receptors begin to function abnormally and respond to levodopa by producing excess, “wiggly” movement.

With advancing PD, it is also common to develop motor fluctuations. This refers to a pattern of requiring more medication to restore normal movement, followed by medication wearing off more rapidly and more abruptly. This can cause people with PD to cycle between feeling “ON” medication and more normal, then feeling “OFF” medication with worse symptoms.

**Non-motor symptoms** affect over 90% of people in all stages of PD. These can be as debilitating and as challenging as motor symptoms. Some non-motor symptoms can develop as early as 10-20 years prior to diagnosis.

The more common symptoms found early in PD are constipation, anosmia (reduced sense of smell), depression, anxiety and urinary urgency or frequency. However, some of these symptoms are reported by 66-88% of the general aging population and have no association to PD.

## Providence Movement Disorder Care Team

Care Provider	Role	Phone Number
Elise Anderson, MD	Movement Disorder Specialist	503-215-8580
Joanna O’Leary, MD	Movement Disorder Specialist	503-216-1150
Parkinson’s Nurse	Movement Disorder Program RN Coordinator	Contact through your neurologist’s office: 503-215-8580 or 503-216-1150
Seth Oliveria, MD, PhD	Functional Neurosurgeon	503-935-8500

Providence St. Vincent Medical Center Services	Phone Number
Outpatient Rehab	503-216-7762
Hospital Information	503-216-1234
Business Office	503-215-4300
Diet, Pain, or Smoking Cessation Classes	503-574-6595 or 1-800-562-8964
Providence Portland Medical Center Services	Phone Number
Outpatient Rehab	503-215-6488
Hospital Information	503-215-1111
Business Office	503-215-4300
Diet, Pain, or Smoking Cessation Classes	503-574-6595 or 1-800-562-8964

Symptoms	5 am	6 am	7 am	8 am	9 am	10 am	11 am	12 pm	1 pm	2 pm	3 pm	4 pm	5 pm	6 pm	7 pm	8 pm	9 pm	10 pm	11 pm	12 am	1 am	2 am	3 am	4 am	
On without dyskinesia involuntary movement																									
On with dyskinesia																									
Wearing off																									
Tremor																									
Slowness																									
Stiffness																									
Shuffling																									
Cramping																									
Falls																									
Medication																									
Rytary																									
Rytary																									
Levodopa short acting																									
Levodopa long acting																									
Amantadine																									
Ropinirole																									
Mirapex																									
Artane																									
Rasagiline																									

Other non-motor symptoms of PD include:

- RBD: a REM behavior disorder (acting out dreams while sleeping)
- Mood disorders, especially anxiety and depression
- Apathy: lack of interest/enthusiasm or concern
- Urinary dysfunction
- Sexual dysfunction
- Cognitive changes
- Fatigue
- Excessive saliva/drooling
- Orthostatic hypotension (reduced blood pressure upon standing)
- Restless legs syndrome
- Lightheadedness
- Body temperature fluctuations
- Hypophonia (a soft quiet voice)
- Dysphagia (difficulty with swallowing)
- Masked face (lack of facial expression)

# Young Onset

People tend to associate PD with an older population. However, about 10-20% of those diagnosed are under the age of 50. This is referred to as “young onset” PD.

Regardless of age at diagnosis, people with PD can have tremors, rigidity, and bradykinesia (slowness). Dystonia is one symptom that tends to be seen in the young onset group earlier in the disease process than in the older group. Dystonia refers to involuntary activation of muscles that causes abnormal postures of the hands, feet, and neck.

People with young onset PD generally respond well to medications. Levodopa has been prescribed for decades and remains the most effective medication for PD. Occasionally, a delay in using levodopa is recommended in order to delay the side effect of dyskinesia. The risk of developing dyskinesia increases 10% per year that a person takes levodopa. Dyskinesia is an involuntary movement that can be wiggly or dancelike, affecting the mouth and face, head, neck, and limbs.

When levodopa is not the first line of medication used, there are a number of alternatives that your neurologist may discuss with you including amantadine, dopamine agonist drugs, and trihexyphenidyl, among others.

# A Symptom Diary

The purpose of keeping a symptom diary is to identify the fluctuations of symptoms and side effects when you take your medication. This is very helpful if you are experiencing more slowness, stiffness, or tremors throughout the day. It can also help track dyskinesia. A symptom diary helps your neurologist to identify where changes in medication dosing or timing are needed.

Make copies of the following page and use one page a day when you find yourself having less efficacy from your medication and/or exacerbation of symptoms and side effects. Along the left side is a list of symptoms and names of commonly used medications. Check the box under the time (listed at the top). Do this for a week or longer to watch for a pattern. Report your findings to your neurologist to help with any changes needed to your medication regimen.



# Stages of Parkinson's

## Stage One:

Mild symptoms that affect one side of the body only.

## Stage Two:

Symptoms that affect both sides of the body, which may make daily activities more difficult, but the person with PD remains independent.

## Stage Three:

Mid-stage. Balance is affected and fall risk increases.

## Stage Four:

Symptoms are more severe. A walker or cane may be required, and more help is needed at home due to loss of independence.

## Stage Five:

Advanced PD, which can cause people to depend on a wheelchair to move or to be bed bound. Full time caregiver support is needed.

Take medications on time, every time:

- Have your Carbidopa/Levodopa medication 30 minutes before meals that contain protein or wait 1 hour after eating. This will help with absorption.

Keep your medical appointments:

- Rescheduling might postpone your visit for months.

# Early PD

Usually, a person is diagnosed with PD in the early stages of the disease, often when symptoms do not affect daily activities a great deal. Tremor is often the first noticeable symptom, but people also notice slowing of walking or running speed, muscle fatigue or heaviness in an arm or leg. These symptoms can lead to difficulty with activities that involve repetitive movements.

Some people with early PD have trouble with hand coordination and reduced shoulder range of motion. Decreased motion can become painful and cause a frozen shoulder. Some people also experience micrographia (small handwriting) and a mask-like facial appearance.

Deciding whether to start medications at this stage depends on how much symptoms affect quality of life; this is different for everyone and depends on personal preference, feelings about medications, profession, and hobbies. Your neurologist will discuss options with you. At this stage, there is a strong emphasis on exercise and lifestyle, since a robust exercise program focused on preserving balance will help people with PD maintain mobility and independence through later stages of the disease.

People with PD also experience “non-motor” symptoms, some of which can be seen years before the motor symptoms (such as stiffness or tremor) begin. Non-motor symptoms include constipation, loss of smell, depression, and REM sleep behavior

# Tips for Daily Living

Sleep well by:

- Going to bed at the same time every day.
- Having a sleep routine.
- Avoiding electronic devices and watching television in bed.

Maintain healthy eating habits like:

- Eating 3 meals a day with snacks in between.
- Eating fruits, nuts and seeds.

Regularly exercise:

- Your body.
- Your emotions.
- Your mind.

Socialize to prevent isolation:

- Seek interaction with groups (support, spiritual, hobby, exercise).
- Consider counseling (a licensed social worker, behaviorist, spiritual leader).
- Go outside (walk, dine, shop, attend local events and shows).



## Focused Ultrasound

Focused Ultrasound (FUS) is a non-invasive procedure. No surgical incisions or anesthesia are used. FUS uses a CT scan and an MRI to identify the best location in the brain and best pathway along which beams of acoustic energy can be directed to heat and destroy those areas in the brain where normal movements become affected. FUS is performed without damaging surrounding tissue. The medical team monitors symptoms during FUS treatment until the symptoms improve.

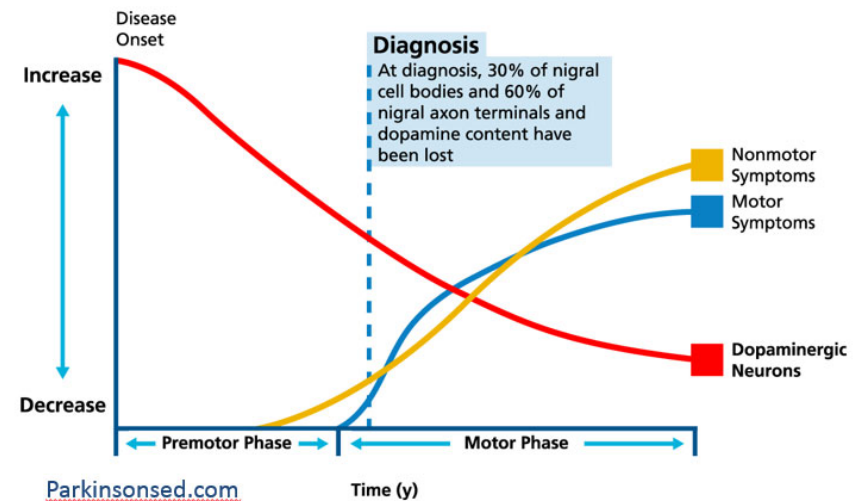
FUS is best for those unable to withstand anesthesia or craniotomy (opening of the skull to access the brain). It is most useful for those who have severe tremors on one side of the body.

FUS treatment is limited to one side of the brain since procedures on both sides of the brain can cause more side effects. Side effects may include changes in speech, swallowing or cognition, as well as numbness in the face or arm, weakness, and poor balance. Discuss further details of FUS with a specialist at an FDA-approved center.

No surgery comes without risk. Your neurologist can help identify if you are a candidate and place the referral for a consultation. The neurosurgeon can discuss any possible risks or complications that can be associated with the surgical procedure you are considering.

disorder (“RBD”), which can involve thrashing in bed and injury to self or bed partners.

The diagram below depicts a general timeline of early non-motor symptoms and when motor symptoms appear. Pre-motor symptom phase can be 10-20 years in length before diagnosis.



# Mid-Stage PD

In stages 2 and 3, symptoms affect both sides of the body and are mild to moderate. A person will typically be physically independent with minimal balance impairment.

The voice may now become softer in tone and lower in volume. It is not uncommon at this stage to be asked to either speak louder or to repeat oneself. Speech therapy can be very helpful in providing tips and tricks on vocal projection and reserving energy, while putting more effort into speaking.

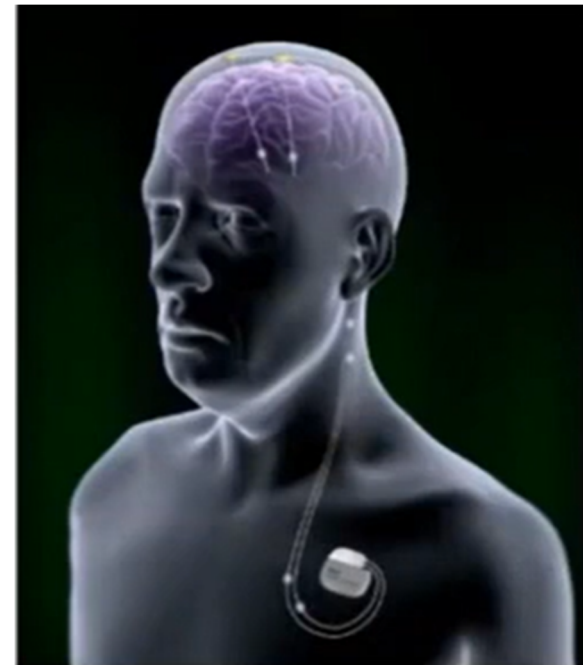
Along with vocal changes, people with PD may have mild swallowing problems, including when taking pills.

During stages 2 and 3, the body begins to move into a forward flexed position. This can create the appearance of a stooped posture and cause people to shuffle more when walking.

People in stages 2 and 3 who have been taking medications for some time to help with motor symptoms may begin to experience wearing off between doses. Or they might begin to notice dyskinesia, which is an involuntary movement of the head, arms and legs, and sometimes mouth. Your neurologist will work very closely with you to adjust medication to address these changes and may also refer you to physical, occupational and speech therapy. Sometimes this is also when your neurologist will suggest driving evaluations or surgical treatments for PD.

## These symptoms are NOT helped by DBS:

- Depression or anxiety
- Memory and cognition
- Balance difficulties
- Constipation
- Slurred or quiet speech



For more information about DBS, make an appointment with your neurologist.

# Surgical Options

**Deep brain stimulation (also known as DBS) is a surgical procedure for treatment of movement disorders including PD.**

In DBS surgery, electrodes are implanted deep inside the brain to the area that is causing your abnormal movements. The electrodes connect to a pulse generator — similar to a cardiac pacemaker — under the skin below the collarbone. The pulse generator (battery) delivers electrical pulses to the brain tissue through the electrode. The stimulator is adjustable, so you can use a simple hand-held remote to turn it on or off and control your stimulation. There are no external wires since the entire system is fully implanted under the skin.

DBS helps control many PD symptoms including shaking, slowed movement and stiffness.

Most commonly, people with PD become candidates for DBS once medication alone does not effectively control their symptoms and their lives become disrupted by reduced movement control or medication side effects like nausea, dizziness, and dyskinesia.

DBS requires both surgical and medical management by a team of neurosurgeons and neurologists. It can take up to 3 months or more to reach optimized therapy.

# Advanced Stage PD

In Stage 4, a person with PD will have significant difficulty with mobility but retain the ability to walk or stand independently, most likely using a cane or walker. Balance gets worse, increasing the risk for falls. This is often when people with PD can develop freezing of gait (also known as FOG), which is when one or both feet freeze in place. This can occur upon standing and initiating a step, when turning, when walking through narrow spaces and when the texture of the floor changes. When FOG happens during walking, it can cause the upper body to continue moving forward while the feet stay “stuck”, resulting in a fall.

Another challenge at this stage is festination. This is involuntary acceleration of walking that is caused by rapid small footsteps that move faster than the person can keep up with. At this point, it is important to avoid ramps and declines.

Some people with PD experience significant speech and swallowing difficulty at this point in the disease. Drooling may develop from the lack of the naturally occurring contraction of the swallowing muscles. Sometimes sugar-free sour candies or gum can help remind you to purposefully swallow and, in some cases, your neurologist will suggest Botox injections to decrease saliva production.

This is an important time to talk with your neurologist about another visit to a physical therapist, with training in advanced PD gait problems. A speech therapist can help with speech and swallowing techniques.

In Stage 5, a person with PD is restricted to either a wheelchair or a bed, unless they are assisted. Care at this stage becomes more challenging for the caregiver, sometimes prompting tough conversations to decide on the best living environment for the person with PD.

A Palliative Care consultation may be beneficial at this stage, or even sooner. Palliative Care specialists focus on improving quality of life with a focus on relieving physical or emotional pain. They can help you understand information about your illness, help you communicate with your existing care team and provide suggestions for you to make important decisions about your healthcare. A referral to Providence Palliative Care can be placed by your Primary Care Physician or you can call 503-215-2669.

Acupuncture and massage are known to help with digestive issues like constipation as well as with pain, muscle stiffness, sleep issues and anxiety. These may only provide temporary relief and may need to be repeated. Avoid vigorous techniques and areas that are sensitive to touch.

Improvisation is another way to stimulate your brain to cultivate focus, improve communication, reduce stress, and promote feelings of acceptance and well-being. The repetitive practice of improvisation improves neuron function by increasing how frequently they fire in the brain. This can help with muscle movement and stiffness.

# Alternative Treatments

There are complimentary options in addition to the gold standard medications and rehab therapy for PD. There is no cure for PD, and each person diagnosed with it has a different experience. Not all treatments work for everyone and some are just not needed. Be sure to discuss any alternative treatments you want to try with your provider.



Singing and music not only uplift our spirits but can also stimulate both hemispheres of the brain to help them work together. Using the rhythm of music in your walk can help with timing and gait. Singing also works your vocal cords and diaphragm, which can help with speaking and breathing. The same goes for finding time to laugh. Laughing loud and often sends the same kind of signals to your brain as singing and music.

# Symptom Management

Physical illness and emotional stress will exacerbate PD symptoms. When this occurs, your care team will focus on addressing the event that triggers the exacerbation, but exercise, support from others and strategies for mindfulness and stress management can help. Typically, a change in PD medications is not the answer, but this may have a role too.

A common cause of sudden increase in PD symptoms is a urinary tract infection (UTI). Watch for frequent urination, a burning sensation and/or small amount of urination. If the UTI is severe, it can also cause confusion or even hallucinations. If you experience these symptoms, seek care immediately. To help avoid a UTI, be sure to stay hydrated by drinking plenty of fluids. Your doctor will often check labs, including urine testing, to check for UTI and other issues.

Another common cause of increased symptoms is missing doses of PD medication, so consistency is key. There are also some medications that can worsen PD; see more on these in the section on Medication.

# Your Care Team

When considering who is on your care team, think of what you may need now and in future. Who are you willing to rely on, and who is able to support you? Who might help provide emotional support during good days and bad, assistance with any physical needs you may have and transportation to your appointments or other commitments? One person does not need to fulfill all of these support roles. Below are considerations for who could be on your team and why:

- Your primary care partner. This can be a family member, friend, hired helper or volunteer. This person must be responsive, trustworthy, and physically capable of assisting you when needed. Take into account this person’s other responsibilities such as their own health, children and/or job. Also consider whether they have drug or alcohol use behaviors that may prevent them from being available to you.
- Family and friends. Different people in your life can help fill different roles on your team. Remember that many people want to help but often need specific requests. Try saying to a trusted friend: “I want to stay social and am having trouble making my own meals. Would you go out to lunch with me every Tuesday?”
- Your primary care physician (PCP). Your PCP and their office should help coordinate all of your needs and referrals. You will need to communicate frequently and clearly with your



People with PD experiencing psychosis, severe anxiety or panic attacks who are prescribed one of the following should ask the prescriber to consider an alternative such as Seroquel first.

Haldol	Risperdal	Orap
Abilify	Geodon	Prolixin
Adasuve	Trilafon	Thorazine
Zyprexa	Navane	Stelazine
Saphris	Vraylar	Latuda
Invega		

For anti-nausea medication, people with PD are advised to take Zofran (Ondansetron) rather than Reglan, Compazine, or Phenergan.

Over time, people taking Carbidopa/Levodopa may experience times of feeling “off” their medication due to it wearing off sooner or without notice. This medication can also worsen the low blood pressure and lightheadedness many people with PD already experience.

Carbidopa/Levodopa is best taken either 30 minutes before meals or 1 hour after meals that contain protein. This is because the medication and the protein compete for absorption. Try taking Carbidopa/Levodopa with a banana or cracker to prevent stomach upset.

Carbidopa/Levodopa is converted into dopamine in the brain. Other PD medications, known as dopamine agonists, work directly on the dopamine receptors in the brain to control tremor. Dopamine agonists can also produce dyskinesia but at a much lower rate. Other side effects of dopamine agonists include sleepiness, nausea, hallucinations and, more rarely, compulsive behaviors.

### **Contraindicated medications**

Some medications prescribed for psychosis and nausea are contraindicated for people with PD. These medications can worsen PD symptoms and delay getting symptoms back on track.

PCP. If you do not have a PCP, or want to find one who is more responsive to your needs as a person with PD, contact 503-582-2185

- **Movement Disorder Specialist or Neurologist.** This provider supports your quality of life with clinical examinations, expert medical advice, and medication management. They also monitor any changes in your PD and request referrals to other specialists such as:
  - Physical Therapy to help with balance, freezing of gait, slowness, stiffness and fall prevention.
  - Speech Therapy to help with communicating effectively, swallowing evaluations, word finding skills and voice strengthening. Many speech therapists are certified in LSVT or SPEAK OUT, which teach people with PD how to conserve energy while also projecting their voice.
  - Occupational Therapy to help with stress management, relaxation techniques, dressing, grooming, eating, bathing, and adaptive equipment to support these daily tasks. An occupational therapist can also provide home safety evaluations, demonstrate how to safely get in and out of a bed and perform driving evaluations.
  - Social Worker to help with coping strategies when fatigue, depression, anxiety, and apathy directly influence your mood and emotions. Social workers can advise on financial situations, housing options, family dynamics and home care needs as well as suggest respite services.

# Medications

- Psychiatrists and other behavioral health providers to help with managing mood changes, anxiety, and depression.
- Nurse advocates. Nurses are trained in listening and navigating the complex world of medicine. A nurse might even hear your concerns and foresee what you might need in order to work towards a solution. Consider having a nurse or nurse practitioner on your team who can advise on clinical matters that may not require a conversation with your provider or decide which concerns to fast-track to your provider for review and recommendations.

Some people with PD belong to support groups. There are a variety of support groups available locally and online. Some groups focus on sharing and talking about their day-to-day experience of PD, while others might have professional guest speakers or focus on specific hobbies. Groups are often led by people with PD or their caregivers. Healthcare organizations sometimes offer groups led by nurses or other professionals. Consider and attend different meetings to see which type fits your needs.

Different PD medications act differently in the brain, producing different effects on symptoms and causing varying side effects. All medication decisions should be made between you and your neurologist. In early-stage PD, you may choose to focus on lifestyle and exercise before trying medication. If your symptoms interfere with enjoyment of life or put you or others at risk, you may need to consider starting medication.

Carbidopa/Levodopa is the main medication for treating PD and has been around since 1970. It is the gold standard to this day. Taking Carbidopa/Levodopa can also help confirm PD diagnosis. Your provider may have you try this medication to see if your symptoms change, which helps with clinical diagnosis. Carbidopa/Levodopa comes in short-acting and long-acting tablets, capsules, inhalers and intestinal gels.

People under age 60 tend to have fewer side effects from Carbidopa/Levodopa. People over 60 may experience memory issues and hallucinations. Carbidopa/Levodopa is generally well-tolerated for many years. However, prolonged, and increased use can cause unsolicited movements called dyskinesia. This is an involuntary movement of the body due to overstimulation of the dopamine receptor. This is different from a tremor, which is caused by lack of dopamine.



stay within a short distance of your home, or should stop driving at all. The sense of losing the freedom of driving can be stressful. Start planning how you will handle these concerns before decisions must be made.

Being safe on the road and preventing injury to ourselves and others is the highest priority. Be honest with yourself and your provider about how you are doing while driving.

Here are some websites you can visit to learn more:

- AARP [www.aarpdriversafety.org](http://www.aarpdriversafety.org)
- Certified Driver Rehabilitation Specialists Directory [www.driver-ed.org/custom/directory-cdrs](http://www.driver-ed.org/custom/directory-cdrs)
- AAA Senior Driving [www.seniordriving.aaa.com](http://www.seniordriving.aaa.com)
- Driving and Parkinson's Disease: Balancing Independence & Safety [www.pdf.org/en/pd\\_online\\_education](http://www.pdf.org/en/pd_online_education)
- Driving When You Have Parkinson's Disease [www.nhtsa.gov/people/injury/olddrive/Parkinons%20Web/index.html](http://www.nhtsa.gov/people/injury/olddrive/Parkinons%20Web/index.html)



Below are other professionals you might be in contact with frequently or as needed. They might benefit from knowing you have Parkinson's. At times your symptoms may need them to modify their treatment or use an alternative in their recommendations and services.

GI / Urologist

Dentist

Legal Advisors

Exercise Instructor

Massage therapist

Spiritual advisor

Dermatologist

Financial Advisors

Hair stylist

Acupuncturist

Pharmacist

# Fitness

Research clearly shows that exercise is one of the most important things you can do for yourself, especially if you have PD. Studies suggest that exercise helps prevent or delay balance issues, falls, coordination loss, freezing of gait and postural instability associated with PD.

Balance programs combined with cardiovascular exercises are the best interventions for people with PD. Improving balance by building core strength can help people with PD retain upright posture. This makes it easier to see what is ahead of you to avoid falls.

Stretching can help reduce stiffness and permit more freedom of movement, which also prevents falls. In addition to stretching, exercises that increase flexibility and agility can help with transferring your weight from one foot to the other, getting you out of a frozen state.

Balance programs include:

- Tai Chi
- QiGong
- Yoga
- Ballroom or Salsa dancing
- Walking
- Bowling
- Boxing



To assess your driving skills and cognitive ability to drive:

- Pick someone you trust to ride along with you. Have them give you their honest feedback on how you perform.
- Notice if you are driving slower than other cars on the road. Take note if you pass your destinations or have a few near misses.
- Talk to your doctor if you are having challenges being as sharp on the road as you once were.



More formal types of testing include:

- A driving assessment from Providence outpatient occupational therapy.
- A road test through the Department of Motor Vehicles.
- Cognitive testing.

It can be challenging to decide whether you should only be driving in the day light, need to have your route mapped out for you, must

# Driving

A large number of people diagnosed with PD continue to drive motor vehicles safely and for many years. Driving is a privilege. It gives us independence to go out and conduct our day without relying on others.

Each person's symptoms and disease progression differ. How should you go about determining whether it is no longer safe to drive at night, or long distance or even at all anymore? This is not always a clear-cut answer.

Many physical and psychological skills needed to be a safe driver are learned over the course of many years. These skills can be affected by PD symptoms.

Unsafe driving can result from lost or reduced:

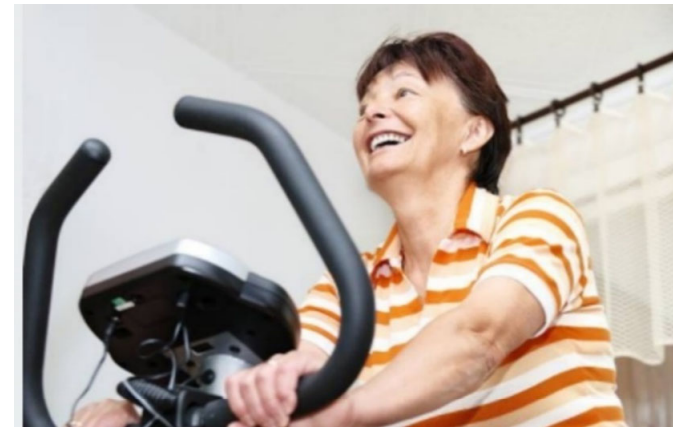
- Vision.
- Spatial awareness.
- Reaction time and reflexes.
- Mobility.
- Alertness.
- Decision making.

There are specific exercise classes designed for people with PD. These classes also help calm the inner self, improve social skills, increase coordination, and bring laughter and acceptance to people with PD.

Cardiovascular exercises include:

- Outdoor or stationary bicycle
- Treadmill
- Swimming
- Whatever aerobic exercise you enjoy doing. Consistency is key!

There is some evidence that higher intensity exercise has even more benefit for people with PD. In one study, high intensity treadmill use 4 times per week for 6 months resulted in slower disease progression than moderate intensity use. Talk to your doctor about whether it is safe for you to try high intensity exercise.



# Fall Prevention

There are 4 cardinal motor signs of PD. Tremor (shaking), bradykinesia (slowness), rigidity (stiffness), and postural instability (imbalance). These symptoms can lead to unanticipated falls and injuries.

Your trunk or core holds your body upright, while your legs provide a basis of support. In people with PD, the trunk can shift off-center, presenting challenges with balance, standing up, bending down, turning, walking with the head turned, walking while talking and navigating around objects.

If your legs and arms are moving slowly or stiffly, you may have less ability to adapt to changes in the environment. This can reduce flexibility and response time, leading to instability and loss of balance.

Some people with PD also experience freezing of gait (where feet feel stuck to the ground), shuffling, slow steps, or festination (rapid, small steps). Any of these can be a challenge with maintaining balance.

Non-motor symptoms can also precipitate a fall or imbalance. These include urinary and bowel issues, low blood pressure leading to lightheadedness, fatigue due to disrupted sleep, fear, anxiety and cognitive decline.

Double vision happens when both eyes are open and when parts of the brain that control eye orientation are not working efficiently. This causes misalignment of the eyes. See your eye doctor to discuss whether eyeglasses or prism glasses are appropriate for you.

Color vision changes are due to a loss of dopamine in the retina. You may experience decreased ability to recognize contrasting colors as they appear to become dimmer and less vibrant.

PD can also reduce the speed of your eye movements between looking at things. This can impact your accuracy of looking at a target and is most noticeable when reading.

If you notice any changes in your vision or how your eyes feel, consult with your eye doctor.

# Eyes and Vision

Everyone will experience vision changes in their lifetime. Those with PD can have additional complications due to the disease. Just as PD causes slow movement in the arms and legs, it also causes reduced eye movement and vision changes.

Decreased tear production and blinking can lead to dry or irritated eyes. The average person blinks 16-18 times per minute. A person with PD blinks about 11 times per minute. There are over-the-counter lubricating eye drops. Not all consist of the same water, oil or lubricant content. See your eye doctor to determine which kind is best for you.



Proactive interventions help reduce falls and injuries. Consider physical therapy, assistive devices such as canes or walkers, exercises designed for people with PD, an occupational health home safety check, an eye exam, counseling for cognitive impairment and/or medication review with your provider to discuss side effects that might increase your fall risk.

# Mood

## Depression

People with PD commonly experience depression due to changes in lifestyle, brain chemistry and many other factors. Depression is not your fault and, unlike general sadness, will not go away on its own. It is a complex but treatable medical condition, just like your physical PD symptoms. Please do not hesitate to tell your provider about any changes in your mood.



Signs of depression include excessive worry, persistent sadness, crying, lack of interest in daily activities, reduced energy or increased fatigue, feelings of guilt and being a burden, loss of motivation, pain and concerns with disability, death, or dying.

## Urinary dysfunction is common in the later stages of PD.

You may experience an increased need to urinate. The realization of the need to urinate can become an urgent issue. Both frequency and urgency can cause you to rush to the bathroom without using safety measures. This could lead you to lose balance, fall or fail to hold your urine long enough to get to the bathroom. This can also cause numerous visits to the bathroom during the night, which disturbs your sleep

Urinary dysfunction can be due to an irritable or overactive bladder that tells the brain it needs emptying when it does not. Consult with your provider about medications that can help with this.

Less commonly, urinary dysfunction occurs when the bladder is emptying less frequently, which can be an issue for people with PD. This can be due to incomplete emptying of the bladder or poor or restricted urine flow. Treating these causes can be more challenging, so seeing a urologist is best.

Keep in mind, any time your bowels or urinary systems are not functioning as they should, you should discuss this with your provider for treatment options. There may be times when a referral to a specialist is needed.



- Osmotic laxatives draw fluid into the intestines to promote a bowel movement. They can cause bloating, cramping, gas, increased thirst and/or nausea.
- Saline laxatives soften the stool by retaining fluid in the colon. These should not be used on a regular basis, as they can cause dehydration and electrolyte imbalance. Read the packaging for common side effects such as confusion, dizziness, muscle cramps, etc.
- Stimulant laxatives are not for long term use and should be used sparingly. These can cause diarrhea and cramping.
- Enemas also stimulate the colon and cause contractions to move the stool. These can be useful in cases of impaction but can also lead to fluid and electrolyte imbalance.
- Suppositories are wax-like and, when inserted correctly into the rectum, they will lubricate the rectum and stimulate movement.
- For more options, visit a gastroenterologist or a nutritionist.

Causes of depression can include, but are not limited to, the stress of living with a chronic progressive disease and neurochemical changes in the brain caused by PD. These PD-related changes happen in areas that also control serotonin, norepinephrine, and dopamine, all of which affect mood.

Starting treatment for depression can help you address both the mood changes and the effect that they have on your life. You can also help manage depression by getting enough sleep, addressing constipation and other GI symptoms, exercising regularly, staying socially active, eating well and consistently taking your PD medications to reduce on and off periods.

Depression makes some people with PD want to be less social and be alone more, but connection with others can be an important tool in managing mood. Try connecting with others through classes that teach stress management and relaxation techniques, therapy with licensed professionals or meeting with spiritual advisors or peer support groups.

If depression is affecting your life and your loved ones, seek help. We are here for you.

# Cognition

PD causes changes in the body's amount and use of the neurotransmitter dopamine, which can lead to changes in cognition. Changes will vary from person to person, and not all people with PD will experience cognitive changes.

Here are some specific cognitive changes to look for and mention to your provider if you or others notice them:

- Issues with problem solving, planning, strategy, understanding consequences and evaluating.
- Difficulty paying attention, especially in a crowd when more than one conversation is happening simultaneously.
- Slower thinking or more time and effort needed to process thoughts.
- Challenges with finding words. You might retain a memory bank of words but have difficulty accessing them.
- Problems with remembering facts or events from a specific time and place or problems remembering how to perform a known task like riding a bicycle.
- Forgetfulness, especially when you go to do a task that you prepared yourself to do.

Constipation can be managed with a daily plan of what works best for you. Consider the following suggestions:

- Drink lots of fluid.
- Increase your fiber intake, especially with fruits, whole grains, and vegetables.
- Consume small portions and avoid low-fiber, starchy foods like white bread.
- Increase your activity level, whether by walking, swimming, yoga or an exercise class specifically for people with PD. These are all helpful. Choose which one benefits you!

If you have been unsuccessful at managing your constipation, there are products you can purchase over the counter. Not all options work for everyone and understanding how they work in the body is important.

Over the counter options:

- Stool softeners are emollient and help by drawing fluid into the intestines. This does not stimulate a bowel movement, but rather softens the fecal matter, making it easier to pass.
- Bulk-forming products bind with the water in your intestines to create a softer stool. If taken without adequate fluids, these can worsen your constipation.
- A lubricant laxative coats the intestinal walls, making it easier for the stool to move along. Do not use these if you take Warfarin.



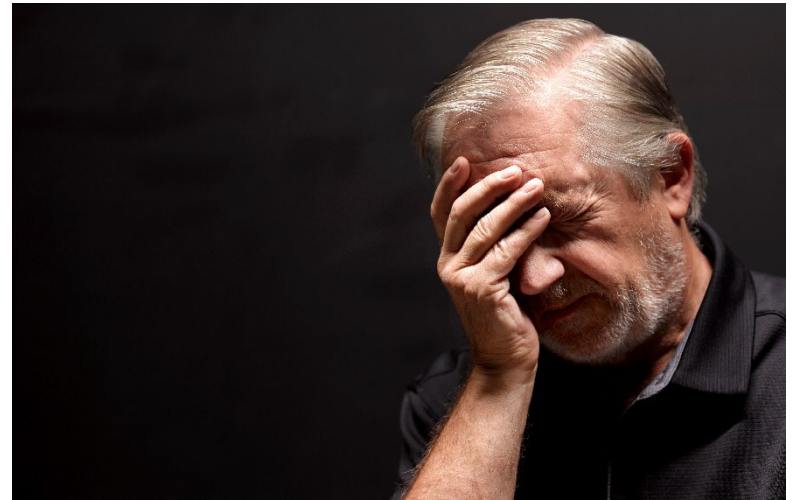
# GI / Urinary Dysfunction

**Constipation is very common for people with PD.**

People with PD tend to become less involved in activities due to slowness, stiffness, and loss of interest. Research shows that lack of physical activity can decrease the motility of the intestines. Seek out solutions to help increase your activity level.

Some causes of constipation include:

- Limited fluid intake. This can be due to no longer recognizing that you are thirsty or decreasing your liquid intake to prevent additional trips to the bathroom due to challenges with walking.
- PD medications such as Amantadine and Sinemet have been known to promote constipation. Discuss the pros and cons of these medications with your neurologist.
- People with PD have specific nerve cells in their brains that slow their movements. Similar nerve cells can also be found in the spinal cord and intestines. This can lead to slower moving bowels, causing constipation.



To treat cognitive changes, your neurologist may order labs or other tests, or evaluate if depression, sleep disturbances or fatigue are causing issues. If your provider determines that your cognitive changes are PD related, medications can help. In addition, your provider can place a referral to a psychiatrist, a speech or occupational therapist or neuropsychologist. Even before cognitive changes begin, or when they are in the early stages, your provider might suggest having a baseline test with a neuropsychologist. This is useful for later determining if changes are tied to medications or other factors such as depression.

# Psychosis

About 20% of people with PD can experience hallucinations, delusions, or illusions at some point. These experiences can be combined with confusion, fear, and challenges with communicating and understanding. This is referred to as psychosis. Not all people with PD will develop psychosis, but the chance of these symptoms appearing increases with age.

Hallucinations are when a person states that they see, hear, smell or taste something that is not there. Hallucinations can happen at any time of day or night when a person is awake, and people with PD most often have visual hallucinations. Sometimes, people recognize that the hallucinations are not real. If hallucinations are not bothersome to the person with PD, the person might develop coping skills to address them as needed. Be sure to discuss any hallucinations with your neurologist, regardless of whether or not they are distressing.

Delusions are false beliefs that a person maintains in spite of other people's assurances or evidence to the contrary. Delusions usually fall into three categories. Jealousy-related delusions, including suspicions about infidelity, are common. People might also suspect that harm has taken place or will take place, such as poisoning. Finally, delusions may involve concerns or sensations about bodily functions or appearance.

# Speech and Swallowing

Research has found that nearly 90% of people with PD experience changes in their speech. This includes a soft voice, monotone, a breathy or hoarse sound and difficulty with articulating words. Because of this, people tend to withdraw from social activities and conversation due to embarrassment or lack of confidence.

The changes in speech are related to those that affect the arms and legs. Bradykinesia (slowness) and rigidity (stiffness) can both affect the muscles of the respiratory system and the larynx (voice box).

Speech changes can sometimes be difficult for the speaker to notice. You may feel like you are projecting your voice or speaking at a normal volume, but others may still ask you to speak louder or repeat yourself. This can be frustrating, especially when it begins to happen more frequently. Fortunately, treatment is available and can help.

There are speech therapists that specialize in working with PD patients to speak with intent. These vocal treatments are effective at improving loudness, tone and quality of the voice.

Untreated speech changes can get progressively worse for people with PD. The earlier you have a speech assessment, the more likely you will be to maintain your communication skills, quality of life, confidence, and self-concept.

Caregiving can become full time in and of itself. It is useful to have arrangements for other family, friends, or respite services available to step in while the caregiver is taking personal time. Caregivers should do things that give them joy and help them recharge such as watching a movie, going to dinner, working out or seeing their own medical providers.

If your resources are low for others to help step in, reach out to your neurologist's office, a case worker at your primary care physician's office or the local PD organization for names of agencies who offer this service. Some insurance companies may provide coverage for caregiving during the week. It is worth looking into because the caregiver's health and well-being is important for themselves and for you.

Illusions occur when a person misinterprets something real as something else. This can be a physical item or a sound, for example seeing a coat rack as a human face or hearing the mechanical hum of a machine and thinking it is a song being sung. One way to reduce visual illusions is to keep lights on to reduce shadows and improve visibility.

Some PD medications that are prescribed to balance dopamine levels in the brain can contribute to psychosis. As PD progresses, so can the need for more medication, which contributes to this. Always keep your provider informed of any hallucinations, delusions or illusions so they can help you manage your symptoms and medications.

If the psychosis is not caused by PD medication, but rather due to other factors, your medical team may prescribe antipsychotic medication. Research any side effects and benefits to these medications before starting them.

Regardless of the underlying cause, any sudden onset of confusion or disorientation might be a sign of an infection in the body. If you experience these symptoms, contact your provider right away or go to the nearest emergency department.

If you are a caregiver of a person with PD psychosis, learn to recognize when they are having a hallucination, delusion, or illusion. Try to respond calmly and patiently, even if the person with PD becomes distressed or uses hurtful words. Their behavior is not directed at you, but rather is a symptom of their disease that needs

care. Do not argue with or attempt to resist someone experiencing psychosis. Helpful responses include:

- Checking the surroundings to remove any items that might cause them harm
- Gently distracting and reassuring them
- Asking them to tell you how they are feeling
- Calming them down so that you can contact their provider for further guidance.

# Caregiving

Many people with PD live many years independently or with minimal support. But, during your journey with PD, there will be progression of symptoms and new challenges that may call for a caregiver. This can be a partner, a loved one, friend or someone from an agency with skills to help with your activities of daily living, transportation, scheduling appointments, organizing your medication, meal planning and more.



There will be times when a caregiver will struggle to maintain their own personal self-care as well. It is important for the caregiver to place their own health as a priority. Otherwise, they may end up struggling to meet the needs of themselves and you.

- If you have a deep brain stimulator (DBS), tell your neurologist before you are admitted if possible. Bring your DBS remote with you. Inform the medical team of the brand of stimulator you have in case they want to order any special imaging that may not be recommended with your implant. If they are uncertain how to proceed, have them contact your neurologist. DBS stimulation can cause artifact for some tests, like an EKG, so will need to be turned off for testing; and in many cases, it is safer to have DBS stimulation turned off during surgery. Remember that treatment with diathermy should be avoided.

As you may have experienced, both stress and anxiety can worsen your PD symptoms. Being prepared for any hospitalization will help you and your medical team manage your symptoms.

# Pain

Nearly half of people with PD experience pain as one of their prominent non-motor symptoms. Pain tends to affect the side of the body most impacted by motor symptoms. Understanding what is causing the pain is essential to treating it.

Common types of PD pain include:

- Musculoskeletal pain related to rigidity and decreased movement. Some people also experience muscle cramps and tightness in the neck, back, legs and arms. One way to combat this is with exercise. The more movement you can do, the better.
- Dystonic pain or muscle spasms, commonly in the feet and toes. Dystonic spasms can happen spontaneously or be triggered by movement, often in the morning or when a person changes their PD medications.
- Neuropathic pain due to a nerve being pinched or compressed. This can cause inflammation, sending sharp, electric-like sensations down the back, legs, or arms. Neuropathic pain can also produce tingling or numbness.
- Central pain or pain all over the body. This type of pain is less common and is more difficult for people to identify and describe.

Pain treatment is individualized and based on symptoms. Your neurologist will start by verifying that your PD medications are working properly for you. If appropriate, they will consider prescribing other medications to treat dystonic and nerve pain.

Depending on your examination findings, your neurologist might suggest other evaluations such as imaging, referral to physical or occupational therapy or referral to a pain specialist.

Pain and depression have a close correlation. Depression can exacerbate pain and PD symptoms, as well as lead people to miss doses of PD medications. Getting timely, effective treatment for depression is strongly encouraged.

In addition to the interventions listed above, alternative treatments may help address pain. These include acupuncture, yoga, Tai Chi, massage, music, relaxation techniques and cognitive behavioral therapy.

Have your Aware in Care Kit with you. If you do not have one, you can contact the Parkinson's Foundation and request one for free at 1-800-4PD-INFO (473-4636), or go online to [www.pdf.org](http://www.pdf.org)



- Be aware of medications that can worsen your PD symptoms. Commonly prescribed medications for nausea can worsen PD symptoms. These include prochlorperazine (Compazine), promethazine (Phenergan) and metoclopramide (Reglan). A safe alternative is ondansetron (Zofran). Antipsychotics that block dopamine such as haloperidol (Haldol) and olanzapine (Zyprexa) will worsen PD symptoms. Safe alternatives include benzodiazepines such as lorazepam (Ativan) and quetiapine (Seroquel).

# Hospitalization

Unfortunately, PD increases the risk of longer hospital stays and the need for rehab afterwards, even if you are in the hospital for an unrelated condition. The hospital environment can be very stressful for a person with PD, particularly those who are very sensitive to getting medications on time. Good communication with your caregiver team in the hospital can help a great deal – your team will want to know how to make you as comfortable as possible, so remember to advocate for yourself.

Go to the hospital prepared with the following items:

- A typed or legibly written list of all your medications, including the name, dosage amount and when you take them. Remind the hospital staff that it is essential that you have your medication on time, every time. Missing medications can cause unnecessary anxiety and pain.
- Bring your medications with you in their original bottles in case the hospital does not stock the ones you take.
- If you use a cane or walker, bring it. Tell the medical team what your challenges are with walking such as slowness, getting stuck taking a step, shuffling, difficulty turning or imbalance.

# Nutrition

Currently there is no specific, recommended diet for people with PD to follow, nor are any diets proven to prevent PD. A healthy, balanced diet with special attention to foods that reduce constipation – a universal problem in PD – is a good idea. Be wary of internet claims about supplements and vitamins that “cure” PD, since we unfortunately do not have medical evidence for these.

Foods that might have potential benefit for brain health and to reduce PD symptoms are discussed below. Keep in mind that moderation is important – too much of any of these items is unhealthy!

- Nuts
  - Walnuts are associated with reducing the risk of dementia.
  - Pistachios have vitamin K and antioxidants, which can help neurons in the brain reconnect.
  - Macadamia nuts can increase the production of neurotransmitters in the brain.
  - Cashews have iron, zinc and magnesium, which all boost serotonin. Serotonin supports a good mood and possibly reduces memory loss.
  - Almonds contain fiber, which is helpful with digestion.

- Brazil nuts have the mineral selenium, which is shown to fight against toxins like pesticides and herbicides.
- Herbs
  - Ceylon cinnamon has potential to normalize neurotransmitter levels and other brain changes found in people with PD.
  - Rosemary contains antioxidants, which help reduce inflammation.
- Antioxidant foods are essential in balancing out free radical molecules. Ways to get antioxidants in your diet:
  - Add purple and red fruits, such as blueberries and raspberries.
  - Drink green tea, which contains both antioxidants and anti-inflammatory properties.
  - Take extra care with high-pesticide-residue fruit and vegetables such as apples, peaches, nectarines, strawberries, and grapes. Give them an extra rinse or buy organic when possible.
- Foods that can help with your motor and non-motor symptoms include:
  - Protein, which is essential in building and maintaining muscle, giving you the energy and strength needed to move and walk. However,

protein competes with Carbidopa/Levodopa for absorption, so it is best to take this medication a half hour before or an hour after meals with protein.

- Fluids and fruit high in water content, which can help with constipation, low blood pressure and dizziness.
- Fresh fruit, vegetables and whole grains, which are high in fiber and help with digestion.



In summary, eat whole foods and avoid processed food items as much as possible. Eat colorful fruits and vegetables. The brain functions best with Omega-3 fats, which are found in walnuts, flaxseeds, chia seeds, pumpkin seeds, salmon, tuna and sardines. Omega-3 fats are better for the brain than Omega-6 fats, which are mostly in processed foods.

While there is no one food item or group of foods that will slow or prevent PD, there are foods that will help you feel better while you live with PD.