

Mood

A Mind Guide to Parkinson's Disease



About this book

GLOSSARY

Definitions for all words underlined in blue can be found in the glossary starting on page 54. A comprehensive Parkinson's disease glossary can be found at [Parkinson.org/glossary](https://www.parkinson.org/glossary).

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An index of key words and topics can be found on page 59.

PARKINSON'S FOUNDATION RESOURCES

Certain pages include tip sheets with practical pointers. You can find more helpful tips for managing Parkinson's in the books, fact sheets, videos and podcasts in our PD library at [Parkinson.org/library](https://www.parkinson.org/library). In particular, watch "Depression and PD: Treatment Options" from our Expert Briefings webinar series.



Everyone experiences changes in mood over the course of any given day, week, month and year. But “mood changes” is a broad term that can mean different things to different people. This guide explains what mood changes can happen in Parkinson’s disease (PD), why people with Parkinson’s might experience these changes and how to treat and cope with them.

Not everyone develops every symptom of Parkinson’s disease, but if you’re affected, non-motor symptoms including depression, anxiety, anger and irritability can have a huge impact on your quality of life and those around you. The information, tips and stories included here will provide answers, help you organize thoughts and questions for your medical team and remind you that you are not alone on this Parkinson’s journey.

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Some information and examples in Chapters 2 and 3 are from talks by Roseanne Dobkin, PhD, Rutgers Robert Wood Johnson Medical School, at the 2016 World Parkinson Congress and in a 2017 Parkinson's Foundation Expert Briefing webinar.

This book has been made possible through the generous donations of thousands of individuals affected by Parkinson's.

CHAPTER ONE

About Parkinson's Disease

If you're reading this book, you are probably already familiar with Parkinson's disease, but here are some basics: Parkinson's is a progressive neurological disorder that affects about one million people in the United States and ten million people worldwide. It is called a movement disorder because of the tremors, slowing and stiffening movements it can cause, but its symptoms are diverse and usually develop slowly over time.

Parkinson's disease is not diagnosed with a test or a scan; instead it is diagnosed by your doctor, who asks you questions about your health and medical history and observes your movement. Your doctor may want you to have some tests or imaging; some, like an MRI, can help rule out other conditions, while others, like DaTScan, can help confirm a Parkinson's diagnosis if there is uncertainty. The goal of treatment is to help you manage your symptoms. Good symptom management can help you to stay healthy, exercise and keep yourself in the best possible shape. Although at this time there is no way to correct the brain changes that cause Parkinson's, we know that exercise can help you maintain your ability to fight the disease and that staying healthy can reduce setbacks that make PD progress faster. Great care is an important part of living your best life with Parkinson's.

6 MOOD

Lack of dopamine in people with Parkinson's was first described in the 1960s. Dopamine is a type of neurotransmitter, or chemical messenger, one of several chemicals your brain cells use to send signals to one another. Soon after, dopamine-replacement therapy using levodopa became – and remains – the gold standard treatment. However, we know that the dopamine system is not the only one affected by Parkinson's. The disease process also disrupts other brain networks, including those linked to mood, behavior and thinking (cognition). You might also hear that Parkinson's is linked to a protein in the human brain called alpha-synuclein. Researchers continue to study how cells and brain networks are affected in Parkinson's to improve our understanding of the disease and potential for treatments.

You and your family may have questions or fears about Parkinson's and genetics. While there are several genetic mutations that can increase your risk, for the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible factors involved in – not necessarily causes of – disease development.

**CHAPTER TWO**

What Is Mood?

Mood refers to a temporary state of mind or generalized state of feeling. A mood – be it happy, sad, frustrated, relaxed, cranky, surprised or any other of a long list of possible mental and emotional states – can last a few minutes or a few weeks and changes based on exposure to different stimuli. Generally, your mood changes in a manner appropriate to the situation. For example, you get promoted at work and are in a good mood for weeks. Or, you are intensely sad after your dog dies, but the grief lessens over the course of a few months. Mood changes happen to everyone, but in people with PD mood can become disordered, with changes that are extreme and persistent or inappropriate to the social context. Mood disorders can be greatly improved with medical treatment, so you can keep living your best possible life.

What Affects My Mood?

The Disease Experience

People with Parkinson's, along with your caregivers, family and friends, experience a range of emotions over the course of the Parkinson's journey: shock and denial at diagnosis, or validation that your suspicions were confirmed; fear of the loss of control; frustration or shame as symptoms worsen; satisfaction as medications improve symptoms or from caring for a loved one; concern about the future and what to expect; exasperation, relief, anger, grief, joy. As the disease progresses, you will have to come to terms with it again and again.

Biology

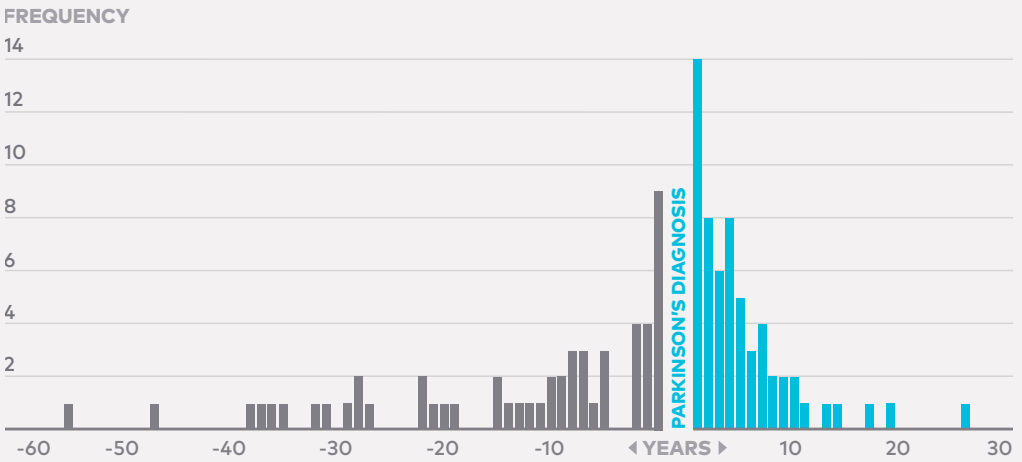
While it is understandable, and normal, to feel sad upon receiving a diagnosis of Parkinson's, for many people the sadness is more serious, and it is not just a reaction to learning you have a progressive disease. Parkinson's is also called a neuropsychiatric disease. This means it is a disease of the nervous system ("neuro") that may involve changes in mental health ("psychiatric").

Emotional and behavioral changes are common in people with chronic diseases, but these changes are even more common in PD. The same neurotransmitters (e.g., dopamine) that regulate movement also regulate our mood. Therefore, the same processes in the brain that lead to the more classical symptoms of Parkinson's disease can cause depression. When dopamine-producing cells in the brain die, movement AND mood can be affected. In this case, depression is actually a symptom of PD, not a reaction to the diagnosis. In fact, depression and other mental health symptoms often appear before the onset of motor symptoms. Only looking back after a PD diagnosis do people realize the connection. There are even studies that suggest people with depression and anxiety are more likely to go on to develop PD.

While clinical evaluation for depression and anxiety is a must, blood work should also be done to rule out common disorders that can mimic depression. For example, thyroid disease, anemia, hyponatremia, B12 deficiency, syphilis and other conditions may look like a depressive disorder but require medical intervention, not including antidepressants, to treat.

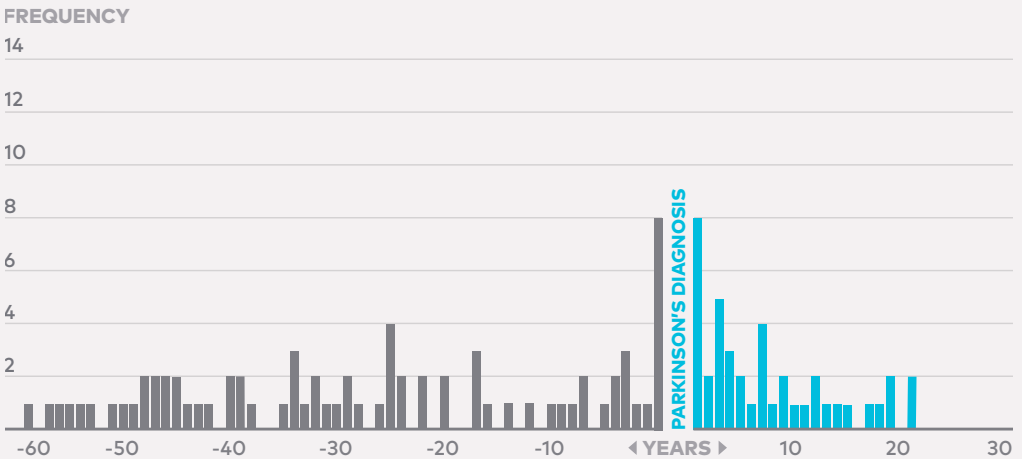
Depression and anxiety can occur at any stage of PD – even before your Parkinson’s diagnosis. These graphs show the relationship between PD diagnosis and first episode of depression (top) and anxiety (bottom). As you can see (lines in gray), many people experience depression and anxiety years before Parkinson’s motor symptoms. Lines in blue show people who first noticed depression or anxiety after their PD diagnosis.

Duration Between Earliest Depression Episode and PD Diagnosis



Ishihara and Brayne 2006

Duration Between Earliest Anxiety Episode and PD Diagnosis



Medication

Depression, anxiety, anger and other mood changes can be side effects of medication. For example, in rare cases, dopamine agonist drugs like pramipexole and ropinirole have been associated with mood and behavior changes, specifically impulsive behaviors. Interactions between your Parkinson's medications and other drugs can also affect your mood. It is always important to tell your doctors about all the medications and supplements you are taking. This may help to reduce the impact of drug interactions.

External Factors

Social, economic and other factors in our everyday environment affect our mood. This includes big things like work, family, financial issues, living circumstances and – of course – health, as well as small things, like traffic or the weather. Stress is also a major trigger for emotional changes.

TIP

The Parkinson's Foundation's *Parkinson's Outcomes Project*, the largest-ever clinical study of Parkinson's disease, found that taken together, depression and anxiety have the greatest impact on the health of people with PD, even more than the movement challenges. It is estimated that at least 50% of people will experience some form of depression during their illness, and at least 30% will experience an anxiety disorder. Good news: studies have shown that treating depression is one of the most significant ways to decrease disability and improve quality of life.

How Do I Know if Parkinson's Is Affecting My Mood?

In addition to depression and anxiety, other symptoms of Parkinson's – such as fatigue and apathy – can affect your mood, as well as other people's perception of your mood. And, as we know, mood can be defined in different ways reflecting positive or negative changes that are minor or major. Sometimes it's hard to recognize these changes happening in yourself, especially if you're not familiar with the symptoms. For example, some experts think that depression in PD often involves frequent, episodic changes in mood versus a constant state of sadness on a daily basis. It's not just getting "the blues."

The good news is that mood changes can be treated. So it is important to tell your doctor about any changes you notice. It can also help to ask your care partner, family or friends if they have noticed any changes. If you experience increasing sadness, hopelessness or anger/irritability; if you notice that you are losing interest in activities you once loved; or if someone mentions that they see changes in your mood, it is time to seek help. These may be signs of a mood disorder.

*The question is not whether the glass is half full or half empty.
The question is, can you refill it?*

CHAPTER THREE

Depression

Depression is a treatable disorder in which overwhelming feelings of sadness, loss and hopelessness interfere with your ability to function. If you feel depressed, whether occasionally or often, you are not alone. Approximately half of all people with PD will experience some form of depression.

There are many causes of depression including psychological, biological and social factors. In people with Parkinson's, an imbalance of certain neurotransmitters (brain chemicals that regulate mood) plays a major role. As with motor symptoms of PD, symptoms of depression can be improved with medications and other therapies (see page 17). Unlike motor symptoms, depression can often be treated to full remission.

Symptoms of Depression

Most people diagnosed with a serious illness will feel grief or hopelessness at some point, but clinical depression is a distinct medical condition. Each person who develops depression will experience it differently. There is a common list of reported symptoms, but not everyone will develop them all. The symptoms might appear in different orders or come and go, and some people will have more severe symptoms than others. Also, certain characteristic symptoms are similar and may overlap with symptoms of PD.

So how do you know when what you are feeling goes beyond normal sadness and frustration and becomes a depressive disorder? If you have any of the symptoms below, discuss them with your healthcare team and request a screening for depression. (See the "Diagnosis" section on page 14.)

- Feeling slower or restless
- Decreased interest or pleasure in daily activities
- Poor attention and difficulty concentrating
- Decreased energy or fatigue
- Changes in appetite
- Changes in sleep (insomnia or oversleeping)
- Feelings of guilt, blame or worthlessness
- Thoughts of death or suicide

In addition, persistent physical symptoms that do not respond to treatment, such as headaches, digestive disorders and pain for which no other cause can be diagnosed, can also be signs of depression.

How Is Parkinson's Depression Different from Regular Depression?

The symptoms of depression in Parkinson's are similar to depression in the general population (review the symptoms above) and can be diagnosed using the same criteria. However, PD depression is more commonly accompanied by anxiety and apathy than depression in the general population. Therefore, in people with Parkinson's, evidence suggests that anxiety should be included as a potential symptom for diagnosis. Additionally, depression in PD can more frequently involve dissatisfaction with life, irritability, sadness, pessimism and suicidal thoughts (but not actions).

Mood may also change during "on-off" fluctuations. A general state of unease or dissatisfaction with life (dysphoria), irritability and anxiety are the most common mood changes in the "off" state (when medications are not as effective). If you notice a relationship between mood changes and the timing of your PD medication, tell your neurologist. He or she might adjust your levodopa-replacement medications or dosing to reduce "off" time, which, in turn, may help your mood.

MORE FREQUENT IN PD

Anxiety
Dysphoria
Irritability
Pessimism
Sadness
Suicidal thoughts

LESS FREQUENT IN PD

Delusions
Feelings of failure
Feelings of guilt
Feelings of punishment
Hallucinations
Self-blame
Suicidal acts

Diagnosis

Depression is usually diagnosed by your primary care provider or neurologist. Discuss changes in your mood or interests with your healthcare team whenever you or caregivers notice differences. Similar to a Parkinson's diagnosis, there is no blood test or scan for depression. Rather, diagnosis is based on the symptoms and changes reported by you or a family member. Screening for depression can be done in a number of ways: it can be as simple as completing self-report questionnaires or as elaborate as a full neuropsychiatric evaluation with a battery of tests. Most commonly, depression screening consists of an in-person interview with your doctor, who asks a series of questions about your mood and daily function to make the diagnosis. It is important to answer these questions honestly.

Depression often goes unrecognized and undiagnosed, in general and in people with Parkinson's in particular. Changes in voice volume (hypophonia) and facial muscles (hypomimia, or facial masking) can make it hard for other people to interpret the mood and expressions of someone with PD. The contrary can also be true. If facial masking is an issue, people might assume you're upset or depressed all the time. This can lead to feelings of anger and frustration because people constantly ask, "What's wrong?" when you are feeling fine. If this begins to happen to you more often, try explaining the difficulty with muscle control and expression to those around you. This may help people to better understand how you are feeling.

Be aware of the symptoms of depression listed on page 13, so you know what to report and how to describe what's going on. Depression can be mild, moderate or severe based on the symptoms you have and how long you have them. Clinical depression is classified as either major depressive disorder or dysthymia (persistent mild depression).

Regardless of when in your Parkinson's journey you notice the symptoms, early diagnosis and treatment of depression is critical.

Symptoms such as hopelessness, thoughts of suicide or delusional beliefs associated with a depressed mood should be referred directly to a mental health specialist. Untreated, worsening depression can contribute to significant decline in overall health and quality of life. On the flip side, successful treatment of depression is one of the most significant ways to decrease disability and improve quality of life.

Depression may be undertreated in people with PD because it is often unrecognized or unreported. This is frequently because people don't notice or acknowledge their own behavior changes, or they are embarrassed to speak about them.

Parkinson's, Depression and Pain

The link between chronic pain and depression is well established. Many people with Parkinson's experience pain at some point during the disease progression, from mild physical discomfort (aching, stiffness) to pain so severe it overshadows all other symptoms, and this, of course, can have a big impact on your mood.

If you are suffering from pain, tell your neurologist. He or she may be able to adjust your medications and improve your overall symptoms. It is important to differentiate between pain that can be addressed with PD medication adjustments, pain from other causes and pain made worse or caused by depression and anxiety. Sometimes antidepressants (tricyclics and SNRIs – read more on page 25) are prescribed for nerve pain even without a diagnosis of depression, so they can be good choices for treatment of depression with co-occurring pain.

Managing Pain

Think about the following questions to help you and your doctor figure out the cause of your pain.

- Where is the pain located?
Does it stay in one place or move throughout the body?
- What does your pain feel like?
Is it continuous, or does it come and go?
- What triggers your pain?
Is it greater after certain activities or at particular times of day?
- Is the pain better when your medications are "on" and worse when they are "off"?
- What relieves your pain? What makes it worse?

Self-Management of Pain

- If pain begins suddenly or an injury occurs, it is considered acute, especially if there is swelling or bruising. Apply cold packs to the area for 15–20 minutes several times a day for 48–72 hours. Elevate the area to decrease swelling.
- If pain is long-lasting (chronic), regularly apply heat to the area for 15–20 minutes.
- If muscles feel tense or knotted, try self-massage. Apply pressure to the area with a tennis ball or massage tool, using body weight against it for deeper pressure. Scheduling an appointment with a massage therapist may be helpful.
- Keep moving, changing positions frequently, and take stretch breaks throughout the day.

If pain lasts more than two weeks, intensifies or worsens or interferes with daily function or sleep, talk to your doctor as soon as you can.

Treatment

Fortunately, there are many treatment options for depression, including therapies that require a healthcare provider, such as:

- [Psychotherapy](#)
- Medication
- [Electroconvulsive therapy, or ECT](#) (for severe cases)
- Experimental therapies

...as well as things you can do yourself with the guidance of a healthcare provider:

- Exercise
- Social support
- Nutrition
- [Complementary therapies](#)

Talk to your healthcare team to find the right treatment(s) for you. PD depression is most effectively treated with a combination of approaches, incorporating talk therapy and medication, in addition to exercise and/or social support.

Take depression seriously and treat it aggressively.

About a year after Phillip was diagnosed with PD, he began having trouble sleeping. He woke up several times throughout the night and couldn't stop tossing and turning. He felt tired during the day but assumed it was because of his PD. His daughter, Barbara, also noticed that her dad wasn't leaving the house as often as he used to and stopped going to his regular Thursday night poker group. Barbara made an appointment with Phillip's doctor, and they reported his trouble sleeping. After talking with Phillip and Barbara, the doctor realized that Phillip had a few symptoms of depression. The doctor shared that many people with PD suffer from depression that can interfere with sleep and their desire to participate in their normal activities. Together, the doctor, Phillip and Barbara worked out a plan to have Phillip try a combination of melatonin and antidepressants to see if that would help him sleep and begin to feel more like himself again.

The importance of mental health therapy is underscored by research from the *Parkinson's Outcomes Project*. Because it is the largest clinical study of Parkinson's, with more than 10,000 people with Parkinson's from around the world enrolled, we are able to compare the benefits of treatments for specific groups. For example, we can study people across health centers that have had Parkinson's for more than 20 years, people who have frequent falls or – for the purposes of this book – people with severe, long-term (at least two years) depression. In this last group, counseling plus medication was 25% more effective at resolving depression than medication alone.

So, while medication can be helpful, counseling is necessary to realize the full benefits of treatment.

Counseling plus medication is
25% more effective at
resolving depression
than medication alone.

Psychotherapy

Psychotherapy is the treatment of a mental or emotional disorder by talking. In general, it offers the opportunity to reflect on your situation and what you are feeling. A therapist can help focus your attention to resolve some of the issues that concern you.

Many people are nervous or embarrassed about seeking mental health counseling or finding the right therapist. But psychotherapy does not mean you have to lie on a couch and talk about your childhood. It means finding someone who understands your medical condition and the psychological component that is part of the disorder. Psychologists, clinical social worker, and licensed mental health professionals have different educational paths but are generally all trained in psychotherapy for treating depression (see page 20 for descriptions of these and other healthcare professionals that can be involved in treatment of your mood issues).

Cultural Factors

Help-seeking behavior, as well as expression of emotions in general, varies among cultures. For example, there is a belief in some cultures that depression doesn't exist, and individuals can "snap" out of it without medical help. Another belief is that people who admit that they are depressed have a personal weakness or character flaw. Men, especially, are often taught not to display emotion because it isn't manly. Thus, many people do not actively seek out care for this very real medical issue.

Similarly, presentation of symptoms can be different depending on your cultural background. People from many cultures, including Hispanics and Asians, tend to experience their symptoms of depression as physical complaints rather than mental or emotional symptoms. Within the specific culture there may be names for patterns of symptoms, such as "nervios" (the Spanish word for "nerves") in the Hispanic population. Although it is most like generalized anxiety disorder, the symptoms presented (physical complaints, mood instability and an overall feeling of being out of control) can make diagnosis difficult for doctors not familiar with the culture.

Who Can Help Manage Parkinson's Disease Mood Changes?

If you did not put together your comprehensive care team when you received your Parkinson's diagnosis, do it now! It makes a big difference for your care to have a team composed of many of the following healthcare professionals, who play different roles in helping manage your PD and associated mood changes. Don't forget: you and your care partner(s) are also crucial members of the care team.

NEUROLOGIST

A neurologist is a doctor who specializes in diagnosing and treating disorders that affect the brain, spinal cord and nerves (such as Parkinson's, seizure disorders and multiple sclerosis). Research from the *Parkinson's Outcome Project* shows that people with Parkinson's who see a neurologist do better than people who see only a primary care provider. **Movement disorder specialists** are neurologists who have extra training in Parkinson's and other movement disorders, so they have specific knowledge and expertise in treating the problems you may face at each stage of the disease.

TIP

To see if there is a movement disorder specialist near you, call our Helpline at 1-800-4PD-INFO (473-4636) or visit [Parkinson.org/search](https://www.parkinson.org/search).

PRIMARY CARE PROVIDER

A primary care provider (PCP) is a healthcare professional that treats common medical problems. This is most often an internist, family practice physician or geriatrician, but your PCP might be a physician assistant or nurse practitioner. Your PCP manages your overall health, so he or she should receive periodic reports from all of your doctors, including your neurologist and mental health specialist.

Nurses can also play a pivotal role in your care. They can suggest education materials, advocate on your behalf and provide care coordination, and they are often your first line of contact in a doctor's office.

MENTAL HEALTH SPECIALISTS

There are many types of professionals, with different training, that can provide individual, family and couples counseling, direct you to community resources or help you build your social support team. It might be difficult to find a psychologist or counselor that specializes in Parkinson's. However, most mental health professionals treat depression, and many are trained in cognitive behavioral therapy (which was shown to be beneficial in a study done as part of the *Parkinson's Outcomes Project*). For help finding counseling in your area, check with your insurance provider or ask your primary care provider for a referral.

Social workers can help you and your family sort out and resolve issues associated with the daily demands of Parkinson's and life in general (e.g., insurance, housing, disability, familial conflict and more).

Licensed clinical social workers and **licensed professional counselors** both provide psychotherapy and many specialize in treating depression, anxiety and relationship issues.

Psychologists work with individuals and family members to provide advice and counseling for coping with PD and other emotional stressors. Many also perform specialized testing of mood, cognition and other neuropsychiatric symptoms that can aid in diagnosis and treatment.

Neuropsychologists have additional expertise in how behavior and cognitive (thinking) skills are related to brain structure and symptoms.

Health psychologists focus on understanding the biological, psychological and sociological relationship between health and illness. They often help individuals manage the stress, anxiety and depression that can accompany a chronic illness like Parkinson's.

Psychiatrists are medical doctors who can prescribe medications and who specialize in the diagnosis and treatment of mental, behavioral or emotional problems such as depression and anxiety.

Neuropsychiatrists specialize in testing for and treating mental health issues for people with disorders of the nervous system, including Parkinson's.

Types of Psychotherapy

Cognitive behavioral therapy (CBT) is a technique that helps people change patterns of negative thinking and behavior. A cognitive behavioral therapist can help you recognize patterns of negative thought and speech and teach you skills to help you cope better and think positively, ultimately reducing symptoms of depression and anxiety. A therapist can also help you problem-solve around any physical limitations – for example, walk for 10 minutes three times a day instead of one 30-minute walk – so you can increase participation in meaningful social activities.

When my neurologist suggested that I seek counseling, I thought he was crazy. "I'm fine," I said. "I don't need to pay someone to listen to me talk. I've got friends." I gave it a shot, though, and realized that a therapist is much better trained than my friends to help me recognize my behavioral and thinking patterns, specifically those that are working for me and those that are not constructive.

A good therapist helps set goals for your treatment. Therapy doesn't go on forever. Also, I can talk about embarrassing issues, like how to manage urinary problems in public, that I'm not comfortable talking to my friends about. Further, my therapist isn't afraid to call me out when I'm sabotaging myself. A friend might not tell me the truth.

And we don't just talk about Parkinson's. Life is hard, and my therapist helped me grieve for the life I thought I was going to have. She helped me see that even without PD, life might not have turned out as I planned, because there are always obstacles and surprises. We talk about strategies to make it easier on me and on my husband. He's even come to a few sessions!

TIP

Roseanne Dobkin, PhD, a licensed psychologist who specializes in treating Parkinson's mood symptoms, says that for meaningful symptom change, it is important to consistently practice and integrate the strategies you learn in your therapy sessions into your daily life. If you don't, it's like picking up your prescription from the pharmacy but leaving the pill bottle unopened in the medicine cabinet. Hear more of her advice in the Parkinson's Foundation Expert Briefing "Depression and PD: Treatment Options" at [Parkinson.org/library](https://www.parkinson.org/library).

6 Myths about Psychotherapy or Counseling

MYTH *Seeing a therapist is a sign of weakness.*

TRUTH Seeking out a therapist is a brave step and a sign that you realize that you don't have to do everything yourself. Therapists can be helpful for both people with Parkinson's and their caregivers.

MYTH *The therapist is going to share my business with others.*

TRUTH Therapists are trained professionals, and everything you say, short of wanting to harm yourself or others, is confidential. Your therapist will not share your issues with a mutual friend, but a friend might do so by accident.

MYTH *Only "crazy" people need counseling.*

TRUTH Just as individuals may need physical therapy to increase their mobility or speech therapy to enhance their voice, many people can benefit from mental health therapy to help increase their ability to cope and strengthen their mental adaptive strategies.

MYTH *They'll make me talk about my childhood, and I'll be stuck going forever.*

TRUTH Therapy doesn't mean you will be talking about your childhood. In fact, cognitive behavioral therapy involves goal-directed steps to help change your thinking and behavior patterns, so you can feel better. Treatment can also be short-term.

MYTH *My friends can handle and provide advice for all my problems, and they want to help.*

TRUTH Your friends are not professionals. Although they can listen and are well-intentioned, they may have their own struggles and may not be able to take on yours. Also, your friends' advice doesn't come from years of experience working with people in similar situations, like a therapist's advice does. Therapists have specific skills, knowledge and techniques for dealing with depression and anxiety.

MYTH *As a caregiver, it is my job to make my loved one happy and constantly try to lift their spirits.*

TRUTH You are not responsible for making your loved one happy. Trying to keep someone else happy all the time is the surest way to develop caregiver burnout. Report depression, anxiety or mood changes to the doctor and a therapist, who will use their professional skills to help.

Interpersonal therapy is based on exploring your relationships with other people as well as how you see yourself. It is usually a time-limited program, intended to be completed in 12–16 weeks. It uses techniques such as communication analysis and role-playing to achieve symptom resolution, improved interpersonal functioning and increased social support. It has been proven in clinical trials to have a positive impact on acute and maintenance treatment of mood disorders, like depression.

Supportive psychotherapy integrates cognitive behavioral and interpersonal therapy techniques. The therapist develops a supportive and encouraging relationship with the client to reinforce behaviors and thoughts that are healthy and reduce negative or maladaptive behavior.

Group therapy involves one or more therapists treating a small group of clients together. In this setting, group members often offer advice based on their own experiences, fostering a support network beyond the therapist alone. Additionally, regularly hearing about the challenges that other people face can help you put your own issues in perspective and remind you that you are not alone in your struggles.

Medications

There is no antidepressant created specifically for use in people with Parkinson's. As with many other treatments, finding the right drug and the right dose can take time. It might take several tries, and antidepressants can take weeks or even months to work. Be patient and communicate with your physician. Antidepressants can cause side effects like dry mouth, constipation, cognitive dysfunction, blurred vision, drowsiness and sexual dysfunction. Medications work best when their effects are regularly evaluated, about every six weeks in the beginning. For these reasons, it is helpful for your primary care provider and mental health specialist to work together to determine the best treatment plan for you and monitor your status.

Most people with depression are treated with a selective serotonin reuptake inhibitor (SSRI). Serotonin is a neurotransmitter (a chemical messenger, like dopamine) that carries signals between brain cells (neurons) and is involved in mood regulation, among other functions. It has been called the body's natural "feel-good" chemical. Neurons release serotonin into the synaptic space (the area between neurons where cellular communication occurs), where it is active for a short period of time before being reabsorbed by the cell. SSRIs delay reabsorption, so there is more active serotonin in the brain. Common SSRIs you may have heard of (or seen on TV) include Prozac, Zoloft, Paxil, Lexapro and Celexa.

SSRIs are not the only type of medication used to treat depression. Other antidepressants include the following:

- Serotonin-norepinephrine reuptake inhibitors (SNRIs), such as Effexor and Cymbalta, work similarly to SSRIs, but they block reuptake of both serotonin and norepinephrine.
- Some medications, such as Wellbutrin and Remeron, work by novel or "atypical" mechanisms; in fact, we are not sure exactly how these atypical antidepressants function. Wellbutrin likely increases norepinephrine and dopamine activity, making it one of the more stimulating antidepressants. Remeron is thought to enhance the release of norepinephrine and serotonin by blocking a different pathway in the brain. Clinically these drugs also have unique properties: Wellbutrin is the least likely to cause sexual side effects, while Remeron, especially in low doses, stimulates appetite and improves sleep.
- An older class of medications called tricyclic antidepressants also works by blocking reuptake of serotonin and norepinephrine, but these drugs typically have more side effects than the newer drugs.
- A new generation of antidepressants, including Viibryd and Brintellix, has been developed that still works chiefly by modulating serotonin levels. However, they are thought to be pharmacologically different than SSRIs because in addition to blocking the reuptake of serotonin, they may also directly modulate specific serotonin receptors. It is hoped that these unique mechanisms will result in additional therapeutic benefits and fewer side effects. These drugs have not been tested in Parkinson's disease.

Antidepressant Medications by Class

This is a representative sample, not a list of all available antidepressants. For an expanded list that includes information about dosing and side effects, order your free copy of *Parkinson's Disease: Medications* by calling our Helpline at 1-800-4PD-INFO (473-4636) or online at Parkinson.org/books.

BRAND NAME GENERIC NAME

Selective Serotonin Reuptake Inhibitors (SSRIs)

Celexa	Citalopram (si-TAL-o-pram)
Lexapro	Escitalopram (es-sye-TAL-o-pram)
Paxil	Paroxetine (pa-ROX-uh-teen)
Prozac	Fluoxetine (floo-OX-eh-teen)
Zoloft	Sertraline (SER-tra-leen)

Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)

Cymbalta	Duloxetine (du-LOX-e-teen)
Effexor	Venlafaxine (ven-la-FAX-een)

Tricyclics

Elavil	Amitriptyline (ami-TRIP-ti-leen)
Pamelor	Nortriptyline (nor-TRIP-ti-leen)

Atypicals

Remeron	Mirtazapine (mir-TAZ-uh-peen)
Viibryd	Vilazodone (vil-AZ-o-done)
Wellbutrin	Bupropion (byoo-PRO-pee-on)

There is no one right medication for everyone. Each works slightly differently, and its effectiveness will depend on other medications you are taking and side effects that you may or may not experience.

Starting and Stopping an Antidepressant

There is no single rule for how to start or stop antidepressants, though in general, both should be done gradually and under the direction of a physician. When starting an antidepressant, the goal is to achieve a therapeutic dose as quickly as possible while minimizing side effects. Typically, side effects are less of a problem the more slowly dosage increases occur.

Similarly, antidepressants should not be stopped suddenly. An abrupt absence of medication can be uncomfortable, especially in the elderly population, who typically require slower tapering. Some people might even experience antidepressant withdrawal symptoms, including anxiety, insomnia, headaches, dizziness, irritability or nausea. Therefore, it is important to monitor your symptoms when reducing dosages or eliminating a medication and remember to report anything you notice to your doctor.

How Long Should I Be on an Antidepressant?

Some people are on antidepressants for years while others may resolve their depression and be able to stop taking medication sooner. In general, a first episode of depression should be treated for about 6–12 months, but people who have had many episodes of depression in their life should stay on an antidepressant long-term. You should be regularly evaluated by your healthcare provider and make any treatment decisions together.

Remember, it can take several weeks or even months to notice any effect from antidepressants, so make sure to give each drug a chance to work before making any changes.

Do not stop taking your medication without speaking to your doctor.

Finding the antidepressant that works best for you may take time. Suddenly stopping the drug can cause a "rebound effect" and make your depression worse. Report any concerns to your physician.

Electroconvulsive Therapy (ECT)

Electroconvulsive therapy (ECT) is a standard treatment option for people with severe or non-responsive depression, meaning no other treatments (i.e., psychotherapy, medication) have worked. Although in the past, movies and other media have portrayed ECT in a frightening way, it is still the fastest acting and most effective FDA-approved treatment for severe depression available today. In PD it has the extra benefit of temporarily improving motor symptoms. There are a few drawbacks to ECT, including the need to undergo general anesthesia many times, possible memory problems and temporary confusion as a complication of treatment. Additionally, following ECT you need to take antidepressants to maintain its benefits.

ECT and Deep Brain Stimulation (DBS)

ECT is generally contraindicated, meaning it should not be used, for people with DBS. However, in rare cases it may be a possibility. As with any therapy or treatment, it is important to discuss your options with your doctor.

Other Brain Stimulation Therapies

In addition to ECT, there are several newer brain stimulation therapies that might be helpful for depression and other mood disorders. Some of these therapies are FDA-approved, while others are still experimental and currently lack scientific evidence for efficacy and long-term safety.

FDA-approved:

- Vagus nerve stimulation (VNS) is approved for severe recurrent depression that has not responded to other treatments.
- Repetitive transcranial magnetic stimulation (rTMS) is approved for depression that has not responded to treatment, and studies in PD suggest that its effects are similar to SSRIs. However, not all insurance plans cover it.

Experimental:

- Transcranial direct current stimulation (tDCS) is being investigated for the treatment of both motor symptoms and depression in PD.
- DBS is also under investigation for treating depression, but results of more than 20 studies have not conclusively demonstrated efficacy.

Preparing for a Medical Appointment

At each visit, your medical team will try to assess any changes to your health status. Part of the evaluation might include asking about any changes in your mood and attitude. Many people do not recognize these changes or reveal their thoughts to their family or doctor because they are not sure what is going on, or they are embarrassed. However, it is important to be honest with your care team, so they can help manage symptoms and suggest coping strategies for both the person with Parkinson's and the caregiver. Discuss mood changes with your doctor, so all care decisions can be made with as much information as possible.

Everyone – not only people with Parkinson's – should bring a companion with us to important medical appointments, to be supportive and take notes, but also to ask questions and share information. Your care partner, family and friends have likely noticed (and been affected by) your mood changes, so it is important to bring someone to your appointments to help report these changes to the medical team, whether or not they ask about it.

Getting Ready for Your Appointment

Knowing when the symptoms started, along with any changes in your health or medications, can help the care team understand what is happening and develop a plan. Be prepared with answers to the following questions:

- When did you first experience changes in mood or energy?
- Have there been any recent changes to your medication regimen?
Have you started taking a new medication, or have there been any changes in the dose or timing of the medications you are currently taking?
- Have you experienced any recent changes in health
(e.g., recent fall with a head injury, urinary symptoms)?
- Have you had any changes in your sleep?

NOTE

Ask a family member or friend to notify your Parkinson's specialist if you are hospitalized for any reason. It is important for the medical team treating you to understand Parkinson's disease, risk factors and contraindicated medications. Bring your Parkinson's Foundation *Aware in Care* kit with you for any planned or emergency hospital visit. Get your free kit by calling our Helpline at 1-800-4PD-INFO (473-4636).

Exercise

Numerous studies have confirmed that regular exercise can help ease the symptoms of both depression and anxiety. It also seems to help symptoms from returning once you've started to feel better. Exercise releases chemicals in the brain such as neurotransmitters, endorphins and endocannabinoids that make us feel good. It reduces immune system chemicals that can worsen depression, and it increases body temperature, which may have a calming effect.

Increasing physical activity alone was shown in some studies to improve mood. Walking, gardening, housework, washing the car – any activity that gets you off the couch and moving can help improve your mood. Even adding small amounts of physical activity throughout your day can be useful. For example, park a little farther away from the entrance the next time you go shopping. You can also stand up and march in place while you watch TV and walk around your house during commercials.

In addition to reducing the symptoms of depression and anxiety, exercise has a positive effect on your Parkinson's disease. The Parkinson's Foundation's *Parkinson's Outcomes Project*, the largest-ever clinical study of PD, has shown that exercising at least 2.5 hours a week slows disease progression and delays decline in quality of life. The earlier you start, the better!

NOTE

For more exercise information specific for PD and to order your free copy of the publication *Fitness Counts*, call the Helpline at 1-800-4PD-INFO (473-4636) or visit [Parkinson.org/exercise](https://www.parkinson.org/exercise).

Social Support

Avoiding social situations is a common pattern for depressed people. Skipping activities that would normally bring happiness into your life, pulling away from others and shutting down are common first signs that you're falling into a depression. Some people with Parkinson's withdraw from social activities because they believe everyone is looking at them because of their symptoms. This is a false belief that can spiral down into a depressive episode, because isolation worsens your mood.

The value of a social support team cannot be overstated. Having friends, family and professionals around you – whom you can trust, confide in and rely on – can help you stay engaged and remain part of a community. Active participation in a faith group, community organization, club or team can help you retain a sense of routine or normalcy. Having this social support helps you feel part of something bigger than yourself and underscores that your life does not have to be defined by a disease. Symptoms affect various parts of your body, but Parkinson's is not who you are.

In addition to general socializing, you may find it helpful to attend a Parkinson's support group. Support groups offer education, social contact and understanding, as well as opportunities for sharing insights and ways of living with PD. In some areas, there are specific support groups for people who have been recently diagnosed, people with young-onset PD and care partners. Many Parkinson's and movement disorders centers offer support groups.

For more information on how to find a group near you or start your own, contact our Helpline at 1-800-4PD-INFO (473-4636).

NOTE

Dr. Roseanne Dobkin suggests that every day, you do three things to help improve your mood:

1. **Exercise!**
2. **Have some sort of social interaction – meet a friend for coffee, call a relative, or stop to talk to a neighbor while you take your daily walk.**
3. **Do something you enjoy – listen to a favorite piece of music, take a warm bath, meditate or watch a funny movie – anything that will bring you peace, comfort or joy.**

Learn more of her tips in the talk "Depression and PD: Treatment Options" at [Parkinson.org/library](https://www.parkinson.org/library).

Nutrition

Healthy eating habits are important for everyone, whether or not you have Parkinson's or a mood disorder. What you eat can affect the way you feel, physically and mentally, and how you feel can actually affect what you eat!

Healthy eating and drinking plenty of water will help keep your bones strong, boost energy and help you fight constipation, which is common in people with PD. In turn, these physical improvements can help you feel more confident and in control of your body and your disease.

As we age, our taste in food changes. We have fewer taste buds on our tongue, and our sense of smell dulls. Parkinson's can also affect the ability to smell certain things (such as bananas, dill pickles and licorice), further impacting taste. The taste for sweets is the last to go, so the older you get, the more enjoyment you may get from eating sweet things. Depressed people often find themselves craving sweets or junk food high in simple carbohydrates and sugar (think potato chips and cookies). While sugar and simple carbs can lift your mood in the short term, within two hours your blood glucose levels will crash, depressing your mood.

A balanced diet including fruits, vegetables and whole grains fuels the body, keeps the blood sugar steady and gives you the vitamins and minerals you need. Visit www.choosemyplate.gov for ideas and tips to help you build a healthy eating style. Pay attention to how you feel after eating particular foods. Remember, exercise and nutrition are not substitutes for medical care, but they are important components to improved mood and overall sense of wellbeing.

Complementary Therapies

A complementary therapy is one that you use in addition to your medications and psychotherapy, not to replace them. About 40% of people with Parkinson's use some type of complementary therapy as part of their regular treatment routine, and it is becoming increasingly common among people suffering from depression and anxiety. Complementary therapies can be helpful in reducing your medication burden – for example, acupuncture might relieve your pain so that you do not have to take as much, or any, pain medication.

There is growing interest in exploring complementary therapies and how they could affect Parkinson's disease, though there is currently little evidence to support their use. Further research is required to better understand risks, costs and effectiveness of complementary therapies to treat the non-motor symptoms of PD. As always, discuss with your healthcare provider to see if any of these therapies might be right for you. Make sure you're aware of any contraindications. For example, St. John's wort may interfere with certain PD medications and should not be taken if you are on an antidepressant.

Cultural Factors

A diagnosis of depression has most commonly been used in "Western" settings, and complementary therapies are more ingrained in some cultures than others. For example, hearing that your chi (energy flow) is disrupted might be more palatable than being told you are experiencing depression. In this case, a complementary therapy (meditation, qi gong, etc.) may be more culturally consistent as a first option than pills or psychotherapy.

NOTE

You can learn more about complementary and integrative medicine and research to support a treatment's use in chapter 5 of our book *Parkinson's Disease: Medications* and at the website of the National Center for Complementary and Integrative Health: www.nccih.nih.gov.

Also check with your insurance carrier to see if any of these therapies will be covered under your plan. A good rule of thumb is that insurance does not reimburse for experimental or unproven therapies. Therefore, insurance rarely covers complementary therapies, and some of them can be costly.

- **Nutritional supplements and multivitamins**
 - Vitamin B complex has been shown in clinical trials to improve mitochondrial function, boosting energy production and helping to fight fatigue.
 - Creatine has been shown to improve mood.
 - Melatonin may help insomnia and [REM sleep behavior disorder](#).
- **Meditation** and **mindfulness** have been shown to reduce some non-motor symptoms of PD, such as anxiety, depression and pain.
- **Music therapy** may reduce emotional distress and improve quality of life.
- **Diets** high in omega-3 fatty acids are associated with a lower risk of arthritis, stroke, depression and cognitive decline. In a placebo-controlled study, fish oil with and without antidepressants improved PD depression.
- **Massage therapy** may reduce rigidity and tremor, improve sleep and reduce anxiety.
- **Light therapy** was shown in a study to improve depression, some cognitive and behavioral aspects of PD and performance on activities of daily living.
- **Tai chi** was found to improve measures of psychological wellbeing, including depression, anxiety, general stress management and exercise self-efficacy, although authors of the meta-analysis cited significant limitations to their methodology.

Treatment Outcomes

The goal of treating symptoms of depression is to make them go away or to reduce them substantially. Research shows that people with unmanaged depression often experience significant worsening of their Parkinson's, including motor symptoms, general cognition and socialization. A minority of people will have unremitting depression that they will have to manage with medication, psychotherapy, exercise and social support. If you or a loved one has thoughts of suicide or a plan for self-harm, go to the nearest emergency room or call 911. The **National Suicide Prevention Lifeline** is 1-800-273-8255. However, research also shows that for many people PD depression is episodic and with treatment can be 100% resolved.

CHAPTER FOUR

Anxiety

Anxiety is a feeling of nervousness, worry or unease about what might happen, and it can lead to very real physical symptoms. In people with PD, this can mean the racing heart and trouble breathing of a panic attack, but it can also mean reduced motor function, such as impaired gait. Anxiety is not in itself a disorder; occasional anxiety is a normal part of life. However, while most anxiety resolves with time, some anxiety is more severe, persists for a long period, and interferes with daily activities. When this happens, anxiety is considered a disorder for which treatment is recommended.

People experience anxiety in a variety of ways. Generalized anxiety disorder (GAD) is the most common anxiety disorder in people with PD. It is characterized by severe, ongoing anxiety that can lead to behavioral changes. Social phobia – an anxiety triggered by performing tasks such as speaking, eating or writing in front of others – has been observed to have a higher prevalence in people with PD compared to the general population.

Even before Miguel was diagnosed with Parkinson's disease, he noticed that he became anxious when he was meeting new people or going into a new situation. After his diagnosis, Miguel took early retirement and remained at home while his wife continued to work, but he felt increasingly tense and anxious. His tremor would increase, his chest always seemed to be tight, and his thoughts were racing. He would call his wife at work every hour for reassurance and refused to do things like go out to dinner and visit family and friends. Miguel's movement disorder specialist started him on an antidepressant that also helped with anxiety. It helped a little, but he was still a captive of his anxiety. His doctor then referred him to a psychiatrist who added an anti-anxiety medication and suggested that Miguel begin seeing a psychotherapist who specialized in anxiety disorders. The psychotherapy helped Miguel develop the skills needed to cope better with breakthrough anxiety. After several months of therapy and medications, he was able to live a more normal life.

TIP

People with Parkinson's sometimes feel anxious before they get their next dose of dopaminergic medication, as their symptoms begin to increase. Keep notes and tell your doctor when you experience increased anxiousness, so he or she can help you manage "off"-state anxiety.

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Symptoms

Anxiety, like depression, can look and feel similar to some general symptoms of PD: difficulty concentrating, muscle tension and sleep problems are just a few. Many people with PD suffer from symptoms of autonomic dysfunction such as increased heart rate, changes in blood pressure (orthostatic hypotension), increased sweating and hot and cold flashes that can also be features of an anxiety disorder. This overlap can make it hard to distinguish between an anxiety disorder and PD itself. A thorough evaluation and medical history by a specialist is often required for proper diagnosis and treatment. In fact, treatment for anxiety in people with PD is much more likely if you are diagnosed with depression or have [motor fluctuations](#).

There are several distinct anxiety disorders, some of which are described in more detail below:

- Generalized anxiety disorder
- Panic disorder
- Social phobia
- Specific phobia
- Agoraphobia (fear of places and situations that might cause panic, helplessness or embarrassment)
- Anxiety not otherwise specified (NOS) – in Parkinson's, this is most commonly associated with "on-off" fluctuations

Episodic Anxiety

Anxiety can occur in discrete time intervals, often with sudden, "out of the blue" onset. These episodes usually resolve just as quickly as they come on, but they inspire a fear of future unpredictable attacks. Episodic anxiety may include physical symptoms such as a racing heart, butterflies in the stomach, trouble breathing and sweating. These symptoms are most common in panic disorder, which affects about 7% of people with PD. People with **panic disorder** have repeated panic attacks, which are sometimes followed by prolonged concern about the attack or its consequences.

In addition, people with PD often have episodic anxiety related to "off" periods: when the motor benefit of medication wears off, usually at the end of a dose.

Martha called the Helpline at 1-800-4PD-INFO (473-4636). Her husband, Jamal, has had Parkinson's for 7 years. For the first 5 years, Jamal seemed to be doing fine on medication. He was active, and the medicine kept his tremor, slowness of movement and rigidity from bothering him too much. Lately, though, Jamal has been having "off" periods, when levodopa wears off about a half hour before his next dose, and he has more rigidity.

Jamal's anxiety gets so pronounced that he fears he will never be able to move well again. However, after his next dose kicks in, Jamal's rigidity eases and he is back to feeling good. Still, he can't be convinced that the "off" period is only temporary, so he worries excessively every day. He needs constant reassurance from Martha that he will be okay, and this is taking a toll on Martha.

The Helpline information specialist encouraged Martha and Jamal to talk to the doctor about whether some medication adjustments could help reduce "off" times and in doing so, help with Jamal's fears. Martha called back a couple weeks later to say that the movement disorder specialist was indeed able to reduce the "off" times and anxiety with a PD medication adjustment. The doctor also suggested counseling, so Jamal and Martha could learn strategies to anticipate and manage "off" times better. Martha reported that this was helping, too.

Persistent Anxiety

Anxiety can be more constant, lasting longer depending on the severity of your condition. Persistent anxiety can be characterized by chronic and excessive worry and is typically accompanied by muscle restlessness or tension, fatigue or problems with sleep, problems with concentration and/or irritability. Generalized anxiety disorder (GAD) is an example of persistent anxiety. For a GAD diagnosis, you must worry about multiple events or activities nearly every day for at least six months. GAD occurs in about 14% of people with PD.

Avoidant Anxiety

Avoidant anxiety symptoms are usually brought on by social situations (e.g., speaking in public or talking to unknown people) or specific fears (e.g., heights, crowded places). The result is that you plan your activities to avoid situations that would expose you to your fear. Social and specific phobias occur in about 8% and 13% of people with Parkinson's disease, respectively.

Diagnosis

Overall, anxiety affects at least 30% of people with PD. It can be as difficult to detect as depression, though it generally involves a clear change in behavior. As you know, worrying about the future is a natural part of having a chronic illness. But if there is an unexplained increase in anxiety or a sense that symptoms are greater than what would normally be expected, you could benefit from a discussion with your doctor. Many people confer with their neurologist about symptoms of anxiety; others see mental health professionals like psychologists and psychiatrists.

Understanding the relationship between the onset of anxiety and the timing of your medications is important. Many people experience anxiety as their anti-Parkinson's medications wear off near the end of the dosing cycle. If you or someone close to you notices a pattern of anxiety associated with "on-off" fluctuations, talk to your neurologist about adjusting your medications. Psychotherapy can also be helpful in this situation. Because there is a pattern of "off"-state anxiety, a therapist can help you learn to anticipate the anxiety and cope with it, through relaxation techniques and other cognitive behavioral strategies.

Maximizing Energy and Endurance

Fatigue can be a symptom of both anxiety and depression (as well as Parkinson's). In addition to seeking treatment for these mood disorders, here are some strategies to help you fight fatigue:

- Avoid over-scheduling. Learn to say no to added responsibilities or tasks you don't enjoy.
- Perform regular exercise – both physical and mental – to build endurance and stamina.
- Plan ahead, and make sure you schedule adequate time for rest and sleep in your daily routine.
- Delegate or hire help for tasks you find particularly stressful or tiring.
- Recognize your limits to avoid over-exertion.
- Plan highest levels of activity for times when you are rested and your medications are working well.

Treatment

Treatment options for anxiety include some of the same medications, such as SSRIs, that are used to treat depression. However, anxiety may temporarily increase when antidepressant medications are first started, before their therapeutic benefit can occur. To lessen this spike in anxiety, fast-acting (but habit-forming) anti-anxiety medications called benzodiazepines are often used for short periods.

Benzodiazepines affect the brain chemical GABA, one of the same brain chemicals affected by alcohol. Similar to alcohol, the body can become dependent on these drugs, resulting in cravings and requiring ever-greater doses to maintain the same effect, making them difficult to stop if they are used for long periods of time. Valium, Xanax, Ativan and Klonopin are all benzodiazepines, which tend to work more quickly than other anti-anxiety medications and can be taken either continuously or on an as-needed basis. In addition to their anti-anxiety properties, these drugs may help to alleviate some motor symptoms. However, they can also cause confusion and have negative effects on memory, balance and energy.

Treating anxiety often involves an individualized approach. There are many factors that contribute to anxiety, so it is important to work with a healthcare professional to find the right combination of strategies to address your triggers. Most people require medication, psychotherapy and behavioral strategies to reduce their anxiety symptoms. And don't forget that regular exercise is a powerful tool in helping to manage the symptoms of anxiety.

You can successfully overcome your anxiety by working with your physician to manage your medications and with your psychotherapist to develop coping strategies. Your social support team can also help by encouraging exercise, relaxation techniques and other activities.

Before Simone's son got married, he asked his mom to give a speech during the reception. Simone wouldn't have been worried about this request at all several years ago; she used to do a lot of public speaking for work. However, since she was diagnosed with PD she has dreaded speaking in front of people. She worries that they will notice her PD symptoms. Her tremor is more pronounced when she is nervous, and she can have a hard time finding the right words to say. Simone talked to her wife, who said their son would understand if Simone weren't able to give the speech. She also recommended that they discuss Simone's concerns with her psychiatrist. They set up an appointment and mentioned the dilemma. The doctor was supportive and encouraging, telling Simone that she would definitely be able to give the speech at the wedding. The doctor suggested they try cognitive behavioral therapy to work on some of Simone's anxiety triggers so that she would feel more confident about giving the speech.

TIP

Not everyone with PD will suffer from anxiety. Always tell your medical and social support teams about any changes in how you are feeling. Do not stop taking your medications without talking to your doctor.

CHAPTER FIVE

Other Mood Issues

You may have heard of depression and anxiety being part of Parkinson's, but many people don't know that apathy, anger and other mood issues can affect people with Parkinson's, too. In fact, these symptoms can sometimes be harder to treat.

Pay attention to whether the anger and apathy are new or sudden mood changes. Some people experience these moods their whole lives, due to other factors. They might still benefit from treatment, but it is important to try to figure out the source of the problem.

Apathy

Apathy describes a lack of interest, enthusiasm or motivation. It interferes with the effective management of Parkinson's symptoms, since apathetic people are less inclined to do things like exercise and follow their medication schedules. Apathy is not the same as depression. Apathetic people, when asked, deny feeling depressed. About one third of people with PD will experience apathy at some point, and it can be brief or long-term.

If you feel that it is increasingly harder to get up and participate in life's activities – you can't be bothered to do anything, and it is more than fatigue – you may be experiencing apathy. Report this to your healthcare provider, and work with your team to determine the best course of action. In some cases, apathy is part of a depressive disorder or related to cognitive decline, so you should be screened for these to clarify the diagnosis.

At this time there are no proven effective treatments for apathy – no pills or special therapies – but structured activities and opportunities for socialization are a useful approach. A regular routine, continuing to socialize and exercise even if you don't feel like it, taking your medications on time every time and avoiding isolation are all important ways to manage apathy. Talking to your family and friends or taking part in a support group may also help you stay engaged and motivated.

NOTE FOR CARE PARTNERS

Apathy can be one of the most frustrating Parkinson's symptoms you will encounter. In fact, research has shown that people with apathy require more from their caregivers. It is difficult to see your loved one ignore or refuse to do things you both know are helpful for his or her Parkinson's, such as exercise. Remember that apathy is a symptom of the disease, and the person with PD isn't necessarily being lazy or making excuses.

Anger and Irritability

Like depression and anxiety, anger and irritability can be normal responses to the disease journey. "Why me?" is a common question, particularly around the time of diagnosis, as you might feel that Parkinson's has interrupted your plans. Anger can express itself in a number of ways and at different times in the PD progression.

However, if these emotions are pervasive, it could be symptomatic of an untreated or under-treated mood disorder, such as major depression or bipolar disorder. In this case, mood changes are not just a response to the disease, but a part of the disease process itself: chemical or biological changes that distort the normal range of emotion. Therefore, it is important to pay attention to what makes you angry or what is triggering your irritability.

If symptoms are triggered by something specific, they might be the result of poor coping strategies, stress or a breakdown in emotional processing. In this case, a therapist can teach you techniques to help anticipate and effectively manage mood changes when they occur.

Juan was diagnosed with Parkinson's six months before he planned to retire, and he thought PD would make his plans to travel, spend more time with his grandchildren and work on his garden impossible. He felt angry every time someone asked him what he wanted to do when he retired and started to snap at them in frustration. He visited his neurologist, who gave him perspective on his diagnosis. The doctor asked Juan to think about all of his friends who had suffered strokes or heart attacks, or received a diagnosis of cancer. Parkinson's is different because it progresses slowly and the symptoms are treatable. The doctor told Juan not to give up on his retirement plans; with treatment and planning, it is possible that Juan could still travel and work on the hobbies he had hoped to enjoy in his retirement.

A second possibility is that anger is a side effect of medication. Dopamine agonists in particular have been anecdotally linked to continual outbursts of rage, which subside when the medication is reduced or removed. If you are taking a dopamine agonist and having issues with anger or irritability, talk to your doctor about adjusting your medications and dosing.

If you cannot identify a pattern, and you feel constantly angry or irritable, a combination of psychotherapy and medication is likely the best approach.

Bipolar Disorder

Bipolar disorder, formerly called manic depression, is a condition known for extreme mood swings and its effects on energy and activity levels.

Manic episodes – when you are persistently elated and energized – usually last at least a week, and also involve many of the following:

- Inflated self-esteem
- Decreased need for sleep
- Being more talkative than usual
- Racing thoughts and being easily distracted
- Increased goal-directed activity
- Increased involvement in activities that have a high potential for adverse consequences

Depressive episodes – when you feel generally “down” and hopeless, with a loss of interest or pleasure in activities – can occur as well, and usually last at least two weeks. People with bipolar disorder can experience problems with work, relationships and cognition.

Bipolar disorder affects about 1% of people in the U.S. Little is known about bipolar disorder in Parkinson’s disease, but evidence indicates that bipolar disorder in PD has a more rapid cycling pattern: people go from manic to depressive states more quickly than the usual one to two weeks. Treating manic states in PD is also complicated, as several of the best anti-mania mood stabilizers can worsen motor symptoms. For example, divalproex sodium (Depakote) may worsen overall parkinsonism, and lithium often worsens tremor.

Pseudobulbar Affect (PBA)

Pseudobulbar affect (PBA), previously referred to as emotional incontinence or emotional lability, is characterized by uncontrollable bouts of laughing or crying that do not match your feelings or the situation you’re in. This condition can occur when brain injuries or neurologic disorders, including Parkinson’s, damage the areas of the brain that control normal expression of emotion. PBA is sometimes confused with depression, but PBA episodes are brief and spontaneous, compared to the prolonged symptoms of depression. It is possible to have both conditions, and it is important for each condition to be diagnosed and treated separately. You can learn more about PBA at www.pbafacts.com.

Personality

Personality is the combination of characteristics that form your distinctive character, including both what others observe and your inner experience. Personality is usually fixed by early adulthood, about the time the brain finishes developing, in your 20s or 30s.

Neurodegenerative disorders are sometimes thought to cause changes in what are otherwise stable traits. Like the mood issues discussed in this guide so far, personality changes in PD can be reactions to the disease, but they can also be the result of the disease process. Some research even suggests that there is a "Parkinson's personality," which may be a prodromal symptom – one that appears before the onset of PD motor symptoms – like depression, constipation and sleep problems, among others. These personality traits include caution, single-mindedness, industriousness and seriousness. If that sounds familiar, you're not alone.

NOTE FOR CARE PARTNERS

If you notice extreme personality or behavior changes in the person with Parkinson's, report it to the healthcare team. Jealousy and paranoia, for example, can be related to dopamine agonists, but they can also be signs of Parkinson's-associated psychosis, which can be caused by medication, dementia or delirium. Order your free copy of *Psychosis: A Mind Guide to Parkinson's* by calling 1-800-4PD-INFO (473-4636) or online at Parkinson.org/books.

CHAPTER SIX

Talking About Changes in Your Mood

Some people are comfortable talking to others about any aspect of their condition. Others find these conversations uncomfortable or embarrassing, and this sensitivity may be even greater when it comes to mental health. For people with PD, talking about changes in your mood can have several benefits. First and foremost, talk therapy has been proven to improve symptoms of depression and anxiety. A trained professional can help you identify triggers and negative patterns of thought and behavior and can teach you coping skills. A therapist is also a great outlet if you're not yet ready to discuss your psychological status with family or friends.

At the same time, if you let people know that some aspects of your mood are related to your Parkinson's, it may make social interaction more comfortable. You do not have to tell everyone – start with a few trusted family members and friends, and get ahead of the questions through education. Remember, staying active and involved can be your best medicine.

How Can PD and Depression Affect Relationships?

Parkinson's, like many chronic illnesses, can change the dynamics of a relationship, especially as the disease progresses and roles and responsibilities shift. If you have a regular care partner, it is particularly important to talk to this person about the emotions you are experiencing. Your feelings and actions have an impact on those around you; exploring new ways to connect and communicate can help strengthen your relationships.

This is especially relevant when it comes to intimacy and sexuality. In addition to the physical limitations associated with Parkinson's that can make sex difficult, depression can cause a loss of libido, and some medications can reduce sexual feeling. These problems can put a strain on a relationship, so it is important to discuss them with your partner as well as a healthcare professional. There are ways to improve both sexual functioning and your relationship overall.

Tips for Sustaining Meaningful Relationships

- Keep expectations realistic and accept people as they are.
- Share openly, taking time to listen and ask clarifying questions.
- Be flexible; change and growth are part of all relationships.
- Take care of yourself; if you are depleted you have little to offer others.
- Don't try to please everyone; stay tuned to your own priorities.
- Be dependable and follow through on your commitments.
- In conflicts, avoid criticism; attack the problem not the person.
- Recognize the rights of others to give their opinions.
- Ask for help if you need it, and try to be as specific as possible.
- Say thank you; openly show your appreciation and gratitude.
- Remember that relationships take time to develop and effort to maintain.
- Forgive one another, don't expect perfection and remember it's normal to experience disappointments.
- Approach relationships as a learning experience.
- Be creative; you may have to adapt activities that you enjoy doing together.



CHAPTER SEVEN

Tips for Caregivers

Coping with mood changes in someone with Parkinson's can lead to mood changes of your own! You may experience feelings of helplessness, frustration and anger, as it is generally easier to anticipate needs related to PD motor symptoms than needs related to emotional changes.

Recognizing when someone is experiencing mood changes is the first step. The person with Parkinson's may say or do things that are hurtful, and it is important to remember that it is the disease talking, not your loved one. Knowing what to do about these changes – for the health and safety of the person with Parkinson's, as well as for your own mental and emotional health – is the next step.

As a caregiver, you have a dual role – taking care of the person with Parkinson's, and taking care of yourself. These roles are equally important! A strong personal support network will help you have an outlet for your emotions and be able to take time off. Providing care for someone with a chronic condition can be emotionally and physically taxing, and you do not want to burn out.

Gary's wife, Penelope, has Parkinson's and used to experience severe anxiety when she thought about leaving the house, especially when Gary was unable to accompany her. She worried about getting stuck somewhere without her medications and about how people would react to her. She also had panic attacks if Gary left her at home alone, because she worried about falling and not being able to get up. Gary tried his best to soothe Penelope when she was stressed, but he wasn't always successful, and several times they had to cancel appointments or plans with friends because Penelope didn't want to leave the house. Their children, Matthew and Eileen, knew about their mom's PD and that Gary was very dedicated to helping her. They noticed that he hadn't been doing things that he used to do, such as going to baseball games or meeting up with his friends. He told them that he was just too tired and didn't have the energy to go. Eileen told her dad that he couldn't take care of Penelope all the time; he needed to take care of himself, too. Together they decided it would be good for Gary to go out with his friends once a week. During those outings, Eileen or Matthew spend time with their mom. Penelope is relieved to have her children's companionship, and Gary benefits from some time off.

NOTE

For a caregiver self-assessment and tips on managing caregiver stress, order your free copy of our comprehensive PD caregiving guide, *Caring and Coping*, by calling the Helpline at 1-800-4PD-INFO (473-4636) or online at Parkinson.org/books. This guide contains tips and tools to make the caring experience as productive as possible with the least amount of stress.

Signature Strengths

As a care partner, you often put out more energy than you take in, and many caregivers feel like they're "running on empty." It is important to look at your life and assess where you need more support, but also where you are doing well.

Circle 5 strengths you have used in the past or might use in the future to support yourself or a loved one through a period of stress or challenge:

ACCEPTANCE	HONESTY	PERSEVERANCE
APPRECIATION	HOPE	PERSPECTIVE
CALMNESS	HUMILITY	PERSUASION
COMMITMENT	HUMOR	PRUDENCE
COMPASSION	INGENUITY	RELIABILITY
CONFIDENCE	INSIGHT	RESPECT
COURAGE	INTEGRITY	RESPONSIBILITY
CREATIVITY	INTELLIGENCE	SELF-CONTROL
CURIOSITY	JOY	SENSITIVITY
DETACHMENT	JUDGMENT	SPIRITUALITY
DIGNITY	KINDNESS	SPONTANEITY
EMPATHY	LEADERSHIP	TOLERANCE
ENTHUSIASM	LOVE	TRUSTWORTHINESS
FIERCENESS	LOYALTY	VIGILANCE
FLEXIBILITY	MATURITY	WILLING SPIRIT
FORGIVENESS	NEGOTIATION	WISDOM
GENEROSITY	OBSERVATION	YOUTHFULNESS
GENTLENESS	OPTIMISM	
GRATITUDE	PATIENCE	

Recognize the Signs of Caregiver Stress and Burnout

The rewards that come with caregiving are real and varied. At the same time, caregiver stress is, unfortunately, a part of life when caring for someone with a chronic illness such as Parkinson's, especially when there are mood disorders involved. To address caregiver fatigue, you and the people in your support network must be able to recognize the warning signs:

- An ongoing tendency to ignore or postpone taking care of your own health needs
- Growing feelings of isolation, expressed by thoughts like, "Nobody knows or understands what is really going on with us."
- Feelings of anxiety and uncertainty about the future
- Feelings of anger at the person with Parkinson's or the situation, often followed by guilt
- Feelings of profound tiredness and exhaustion not relieved by sleep
- Emotional strain/stress, often manifesting as varying physical symptoms
- An inability to concentrate or make decisions
- Bitterness toward friends or relatives who "should help more"
- Tendency to use alcohol or drugs to try to lessen stress levels
- Depression, despair, feelings of hopelessness

This last bullet is especially important. Forty to 70% of caregivers (in general) are significantly stressed, and about half of these seriously stressed caregivers meet the diagnostic criteria for clinical depression. As you might know from your loved one's struggles, depression interferes with your ability to do normal day-to-day activities, so both you and the person you care for will suffer from your emotional distress. Assess your mental and emotional status and get help coping. Depression is not a weakness; it is an illness, and the same therapies that can help the person with Parkinson's can help you, too.



Summary

Depression and anxiety have a larger negative impact on quality of life than the movement symptoms of Parkinson's. Getting your mood issues properly diagnosed and treated can make a big difference in the lives of you and your loved ones. Once you have the symptoms under control, remember to continue your self-care practices of daily exercise, social interaction and good nutrition. It's all part of living your best life with Parkinson's!

Glossary

Glossary terms are identified with a blue underline the first time they appear in this book.

A Acetylcholine A chemical messenger (see neurotransmitter) released by cholinergic nerves; involved in many brain functions, such as memory and control of motor activity

Acute pain An uncomfortable sensation in the body that begins suddenly, usually as the result of some illness or injury; it is usually sharp in quality and short-lasting (no longer than six months); if untreated, can lead to chronic pain

Alpha-synuclein A protein in the human brain that is associated with the development of Parkinson's; it is the main component of Lewy bodies

Atypical antidepressant A medicine used to treat depression that works in a unique way and does not fit into one of the classes of antidepressants (see selective serotonin reuptake inhibitor, SSRI; serotonin-norepinephrine reuptake inhibitor, SNRI; and tricyclic antidepressant)

B Benzodiazepine A class of medication that produces sedation and muscle relaxation; used to treat anxiety; fast-acting but habit-forming

C Chronic pain Persistent pain that lasts weeks or years

Clinical depression Diagnosed depression that can be mild, moderate or severe based on the symptoms you have and how long you have them; classified as either major depressive disorder or dysthymia

Cognitive behavioral therapy (CBT) A type of psychotherapy that helps you recognize and change patterns of negative thinking and behavior

Complementary therapy A therapy that you use in addition to your medications and psychotherapy (not to replace them); examples include nutritional supplements, meditation and massage

- D Delusion** False, fixed, idiosyncratic beliefs, not substantiated by sensory or objective evidence; they are not deliberate and cannot be controlled
- Dopamine** A chemical messenger (see [neurotransmitter](#)) that is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain; in people with Parkinson's, the cells that make dopamine are impaired or die
- Dopamine agonist (DA)** A class of drug used to treat motor symptoms of Parkinson's; DAs are chemicals that have been manufactured to act similarly to dopamine – that is, attach to the same cells in the brain (receptors) that [dopamine](#) activates to produce its effect
- Dysphoria** General state of unease or dissatisfaction with life
- Dysthymia** Persistent mild depression
- E Electroconvulsive therapy (ECT)** A procedure (performed under anesthesia) in which small electric currents are passed through the brain, intentionally triggering a brief seizure, causing changes in brain chemistry that can quickly reverse symptoms of certain mental illnesses; it is a standard treatment option for people with severe or [non-responsive depression](#)
- G Generalized anxiety disorder (GAD)** The most common anxiety disorder in people with PD, it is characterized by severe, ongoing anxiety that can lead to behavioral changes
- H Hallucination** Something you see, hear, smell, taste or feel that is not actually there
- Hypomimia** Reduced facial expression; also called "facial masking"
- Hyponatremia** A condition that occurs when levels of sodium in the blood are too low; symptoms include decreased ability to think, nausea, headaches and poor balance
- Hypophonia** Soft speech, commonly from lack of coordination in vocal muscles

I Impulsive behavior Performing an act persistently and repetitively without it necessarily leading to an actual reward or pleasure; in Parkinson's, this can be a side effect of dopamine agonists and usually takes the form of uncontrolled shopping, gambling, eating or sexual urges; if you experience this symptom, tell your doctor immediately

L Levodopa The medication most commonly given to control the motor symptoms of Parkinson's; it is converted in the brain into dopamine

M Major depressive disorder Severe clinical depression

Mood disorder A psychological condition in which mood is either elevated or lowered

Motor fluctuations Changes in the ability to move, often related to being in the "off" medication state when Parkinson's symptoms reemerge; also called "on-off" fluctuations

N Neurodegenerative disorder A disease characterized by the loss of cells of the brain or spinal cord, which over time leads to dysfunction and disability; Parkinson's disease, Alzheimer's disease and Lou Gehrig's disease are all examples

Neuron Brain cell

Neuropsychiatric disease A disease of the nervous system ("neuro") that also involves changes in mental health ("psychiatric")

Neurotransmitter A chemical messenger, such as dopamine or acetylcholine, that transmits nerve impulses from one nerve cell to another, allowing them to communicate with each other

Non-motor symptom A symptom of Parkinson's that affects something other than movement, such as sleep, mood, behavior, sensory function (sense of smell, vision, pain) or autonomic function (urinary, gastrointestinal and sexual function); typically does not respond to dopamine-replacement therapy

Non-responsive depression When psychotherapy and medication fail to improve depression

Norepinephrine A neurotransmitter that plays a role in mood disorders and is released in response to stress

O "On-off" fluctuations See motor fluctuations

P Prodromal symptom In Parkinson's, a symptom that appears before the onset of motor symptoms

Psychiatrist A physician who specializes in the prevention, diagnosis and treatment of mental illness; a psychiatrist must receive additional training and serve a supervised residency in his or her specialty

Psychotherapy The treatment of a mental or emotional disorder by talking, rather than taking medication

R REM (rapid eye movement) sleep behavior disorder A sleep disorder in which you physically act out vivid, unpleasant dreams

Repetitive transcranial magnetic stimulation (rTMS)

A non-invasive brain stimulation therapy FDA-approved for treatment of non-responsive depression that uses a magnet to activate the brain; unlike electroconvulsive therapy (ECT), it can be targeted to a specific site in the brain

Rebound effect When symptoms that were absent or controlled while taking a medication come back when you stop or reduce dosage of the medication

S Selective serotonin reuptake inhibitor (SSRI) A class of antidepressant medication that works by increasing levels of the neurotransmitter serotonin in the brain

Serotonin A neurotransmitter that affects the regulation of mood, appetite, body temperature, sleep and pain

Serotonin-norepinephrine reuptake inhibitor (SNRI) A class of antidepressant medication that works by increasing levels of the neurotransmitters serotonin and norepinephrine in the brain

Synaptic space The area between neurons where cellular communication occurs

T Tapering In reference to medication, the act of stopping a medication slowly, by gradually reducing the dose and/or frequency

Transcranial direct current stimulation (tDCS) A non-invasive brain stimulation treatment in which low current is delivered to a specific area of the brain via electrodes on the scalp; being studied to relieve symptoms of PD and depression, but not approved by the FDA

Tricyclic antidepressant A class of older antidepressant medication named for its three-ring structure; works by blocking reuptake of serotonin, norepinephrine and other brain chemicals, thereby making them more available in the brain

V Vagus nerve stimulation (VNS) A treatment originally designed to prevent seizures by sending regular pulses of electrical energy to the brain via the vagus nerve; the mild pulses are created by a device similar to a pacemaker and to the pulse generator/neurostimulator used in deep brain stimulation; FDA-approved to treat non-responsive depression

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