



Paving Your Path Over Time

Practical Tips for Progressing Parkinson's



When living with Parkinson's, many people and families wonder, "What's going to happen to me?" Because every person with the disease travels their own path, this can be hard to predict.

Over time, Parkinson's disease (PD) does change. But how and to what degree, as well as the impact of those shifts, are different in everyone.

This can leave people and families feeling unprepared or uncertain about how to manage new or worsening symptoms or growing treatment or care needs. Here, we offer a roadmap for navigating the potential changes of progressing Parkinson's.

Written by movement disorder specialists, people living with PD and care partners, this guide includes information and tips on symptoms, care needs and emotions that can, but don't always, happen after many years or decades. We hope it helps you and your loved ones understand changes you may be experiencing and feel empowered to take action in finding your way through.

About This Guide

WHAT'S IN IT:

Information and tips on changes that may — but don't always — arise many years or decades into life with Parkinson's disease.

WHO IT'S FOR:

People and families who have lived with Parkinson's for some time and are experiencing changes in symptoms, care needs and other parts of life with PD. For many, this is a time to open (or reopen) a conversation about the Parkinson's journey, learn more or get more support.

HOW TO USE IT:

+ Skim the table of contents

See if the information feels right for you.
It's okay if not, or if not right now.

+ Decide your approach

Some people may want to read cover-to-cover, others only certain sections. The information is organized so that, if you wish, you can skip to what's most pertinent to you. If you're unsure what might be most useful, ask your Parkinson's doctor for guidance.

+ Set aside anything that worries you

This resource covers many parts of Parkinson's. Not everyone will experience everything discussed here. For some, learning about possibilities that may or may not happen can be stressful. Take what works for you and set aside everything else.

+ Interact with the material

Take notes or highlight areas where you have questions or want to discuss further. Use the information to start or continue conversations with loved ones and care providers. With your doctor, for example, you might say, "In this guide, I read that [fill in the blank] and I'm wondering about [fill in the blank]."

+ Take your time

For some, these topics can feel "heavy" or be a lot to process, especially all at once. Take breaks, if helpful, to digest and reflect on the material.

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Four Tenets for Progressing Parkinson's



CHANGE IS PART OF LIFE

All of us, Parkinson's or not, change over time. Our memories, appearances and even perspectives evolve. For people with Parkinson's, change may be different, earlier or more significant.

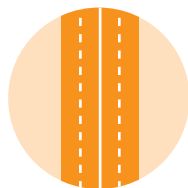
Change, especially in later Parkinson's, doesn't mean you are doing anything wrong or that you can't "live well." It simply means Parkinson's is changing. Michael J. Fox has said, "The reality is things change; the question is, how will I perceive that change, and am I willing to change along with it?"



ACCEPTANCE MAY HELP

When living with change, accepting things and emotions as they are — without judgment — can be helpful. It's natural to feel resistance to a situation that's unpleasant or unwanted. But resistance can make us feel stuck or less hopeful.

Acceptance allows us to focus on what we can control, which can help build a path forward. Michael J. Fox has said, "Acceptance doesn't mean resignation; it means understanding that something is what it is and that there's got to be a way through it." There are many ways to practice acceptance, including mindfulness, meditation and other techniques.



YOUR JOURNEY IS YOUR JOURNEY

From the day of diagnosis throughout life with Parkinson's, each person travels their own journey. Your symptoms, how they affect your life, how they change over time, and how you approach them are unique. Try to focus on your path and avoid comparing yourself to others, especially those who've lived longer with PD.

Along your journey, if and when you feel ready, think about and plan for potential next steps in PD. For many, this provides a sense of control and comfort. But don't let future possibilities consume you. Michael J. Fox has said, "If you fixate on the worst-case scenario and it actually happens, you've lived it twice."



YOU AREN'T ALONE

Many people and resources can support your Parkinson's journey. Support looks different for different people. And it often changes throughout life with Parkinson's. With new or more symptoms, it may be helpful to expand your health care team, connect with others who share similar experiences or gather educational materials.

Parkinson's can feel lonely, but you aren't alone. No matter where you or your loved one is with PD, there are people who understand and can help. About life with Parkinson's, Michael J. Fox has said, "I became part of a community. There were other people that were in the same situation I was and they had thoughts and feelings that were similar to mine, and goals and hopes that were similar to mine."

Changes That Can — but Don't Always — Emerge

Many people and families who've lived with Parkinson's disease for a while know a great deal about the disease. Others take it one day at a time, learning as they go. Still others are less familiar with the day-to-day of the disease.

Parkinson's is called a movement disorder because it causes movement — or motor — changes. These symptoms are shaking (tremor), slowness, stiffness, and walking and balance problems. Parkinson's also can cause non-movement — or non-motor — symptoms, such as mood, thinking or sleep changes, among others.

Every person's Parkinson's is unique. This includes symptoms as well as if and how symptoms affect their activities, life and relationships. It also includes how symptoms change over time. Parkinson's is a progressive disease. So, by definition, it changes gradually over time. But how that happens — at what rate and to what degree — also differs from person to person.

The longer a person lives with Parkinson's, the more changes it might bring. There is no set number of years or age at which the disease becomes more complex. But, over time, common changes may involve new or more symptoms, treatment and care needs, and emotions.

Not everyone experiences any or all of these changes. If changes do happen, like all aspects of Parkinson's, they look different for different people and families.

As Parkinson's changes, it's important to stay (or get) actively engaged in managing your Parkinson's and maintaining your well-being. Kirk Hall, MBA, who's lived with Parkinson's since 2007, says, "Staying engaged with hobbies, friends and family, and spiritual activities — if those are an important part of your life — is key. Being active adds an element of control that can positively affect quality of life."



*"The reality is things change;
the question is, how will I perceive
that change, and am I willing to
change along with it?"*

— MICHAEL J. FOX

NEW OR MORE MOTOR SYMPTOMS

Parkinson's motor symptoms include tremor, slowness, stiffness, and walking and balance problems. At diagnosis, a person has some or all of these symptoms. Over time, symptoms gradually increase. Someone who has tremor, for example, may see it spread from their hand to their whole arm. Or, it may become more significant, impacting more activities or requiring more medication to control it.

The same goes for someone who has slowness or stiffness. Gradually, they may feel slower or stiffer more of the time. Or, symptoms may affect more of their activities, such as getting dressed or working on the computer. Treatments for motor symptoms may include medication adjustments, deep brain stimulation (DBS) surgery, and/or physical and occupational therapy. (See [page 22](#) for more.)

+ Walking and Balance Changes

Over time, some people experience balance problems, which can make walking unsteady, or other gait changes, such as:

— **Slow(er) speed**

A person can't walk as quickly as they used to or "keep up" with a loved one

— **Shuffling**

The feet unintentionally drag across the floor

— **Freezing of gait**

A sudden, temporary inability to move (often in a doorway or when turning)

— **Festination**

Short, quick steps that are hard to stop

Balance and walking problems increase the risk of falls, which could lead to injuries. (In his book *No Time Like the Future*, Michael J. Fox describes the path to recovery after breaking his arm in a fall. See resource #1 on [page 34](#).) If falls happen, talk with your doctor about treatment adjustments. You may want to add or revisit physical therapy or get additional support, such as a cane or walker.

Some walking changes, such as slow speed or shuffling, may improve with medication or DBS. But balance problems, as well as other walking changes — such as difficulty getting started or navigating crowds and other "obstacles" — typically do not improve with these treatments. Clinical trials are, however, testing many new potential therapies. (See [page 33](#) for more.)

Current treatments for walking and balance may include:

— **Regular exercise**

Exercise is good for overall health and Parkinson's symptoms. It's just as important as the medication you take. Experts recommend regular aerobic exercise, such as non-contact boxing, dancing or cycling, to get your blood flowing and your heart pumping. They also recommend stretching, balance and weight-lifting exercises.

Make sure to find something you enjoy and feel safe doing so you'll do it regularly. If you have balance problems, for example, you may be more comfortable with a stationary bicycle or seated or floor exercises. Tai chi, qi gong or yoga also may be particularly beneficial for building balance. (See resource #2 on [page 34](#).)

— **Physical or occupational therapy**

Experts in these therapies provide exercises, techniques and tools to help with freezing, falling, and other walking and balance changes. They also can create a personalized exercise program.

Some physical and occupational therapists — such as those certified in the Lee Silverman Voice Treatment (LSVT) BIG program — have specialized knowledge about Parkinson's. You can search for a provider online or ask your doctor for a recommendation. (See [page 24](#) for more.) If you can't locate an LSVT clinician near you, look for someone who does telemedicine visits or who works with older people or people who have brain disease.

You may not need a doctor's prescription to get started with physical or occupational therapy. But you'll likely need one to continue treatment.

(Regulations vary from state to state.) Insurance coverage also varies and may depend on whether a provider is in your plan's network.

If possible, spread physical therapy visits throughout the year for continuous treatment. Ongoing care often is more beneficial than “bursts” of treatment every few months or so.

— **Cane or walker**

These tools can improve walking and balance and decrease risk of falls. Some people don't want to use a cane or walker because they feel it calls attention to getting older or to Parkinson's. These hesitations are understandable. But try not to let worry about what others might think (or any other concern you may have) stop you from taking the best care of yourself that you can.

There are many options, such as canes with laser beams to activate and step over if you freeze, or lightweight, rolling walkers with a seat and storage space. (Experts often recommend U-step or rollator walkers for people with PD.) For some, a wheelchair or motorized scooter also may be helpful, even if only for longer distances.

Your physical or occupational therapist can suggest the best device for you and teach you how to use it.

— **Home modifications, if necessary**

A physical or occupational therapist can identify areas of your home that may cause tripping or falling and offer ways to fix them. This could include removing loose rugs or cords or making sure you have good lighting and a clear path through each room. They also can recommend home equipment, such as a lift chair (a recliner-type chair that gives a gentle boost to help you stand) or shower grab bars or benches, which can make daily activities easier and safer.

Your doctor can order a home safety evaluation. They also can give you a prescription for any necessary equipment that is covered by insurance. (Coverage varies by insurance provider and type of equipment.) You can buy equipment online or from a medical supply store.



Tips for Care Partners

Encourage your loved one to keep moving

Work with your loved one and their care team to find ways you can support activity and movement. You might attend a workout class or go for a daily walk together. Or, you could go to physical therapy visits and do “homework” (prescribed exercises) together.

If your loved one has very limited mobility, you may want to ask the physical therapist about “passive range of motion” or similar exercises. These allow you to move your loved one's joints, while they are seated or lying down, to decrease stiffness and improve flexibility.

Learn to safely support movement

Your loved one may need help to sit, stand or get out of bed. Your physical or occupational therapist can show you techniques to help make these transitions safely and avoid potential injury to you or your loved one.

They also can teach you tricks to help a loved one with freezing. Some people respond to a light touch on the shoulder; a spoken cue, such as “Big Step!”; or a hummed tune.

Know what to do in case of a fall

Falls can be distressing for both you and your loved one. Plan for what you'll do in case this happens. Most experts recommend that you try not to panic while you call for help and make your loved one comfortable (such as with pillows or blankets), without moving them to avoid possible injury to them or you. Ask your physical therapist and physician for additional recommendations specific to you and your loved one.

+ “Off” Time and Dyskinesia

After many years with Parkinson’s, some people experience “off” time, when motor and/or non-motor symptoms return between medication doses. “Off” time is different for different people. Symptoms, such as tremor, anxiety or mental fog, could gradually come back before the next dose of medication is due. Or, they may come on in the morning or suddenly and unpredictably throughout the day. Some people might feel like medication doses take longer to “kick in” or that some don’t work at all. For some, dystonia — a muscle cramping that pulls a body part into an unexpected position — is part of “off” time. Examples of dystonia include the foot turning inward or toes curling under.

Others have dyskinesia, or extra, involuntary movement, which could be a swaying of the upper body, a writhing of the hand or leg, or fidgeting. Dyskinesia can happen when living with PD and taking PD medication for many years, but it doesn’t happen in everyone and it’s not always bothersome. Some people have both “off” time and dyskinesia.

Consider these tips for “off” time and dyskinesia:

— **Keep a log**

For a few days or weeks, write down what symptoms you have, when they come on, and how long they last. Also record when you take medication, how long until it begins to work, how long it lasts, and how it helps and/or causes side effects. Log this information in a notebook or on a worksheet from your doctor or use an online tool or smartphone app.

This can help you and your doctor see patterns, how well medication is or isn’t working, and how to best adjust treatments.

— **Videotape symptoms**

For new or hard-to-describe symptoms, take a short video to review with your doctor. This can help you determine whether extra movement is tremor or dyskinesia, for example, and what a new symptom might be.

— **Take medication on an empty stomach**

For people who have “off” time or inconsistent medication benefit, taking levodopa (brand name Sinemet, Rytary and others) on an empty stomach may help. Levodopa and protein are absorbed in the same part of the gut. So taking medication with food could mean less medication gets into your system. Try taking levodopa 30 minutes before or 60 minutes after a meal. This can be tough if you take levodopa multiple times throughout the day or if it upsets your stomach, but your doctor can offer suggestions to help.



— **Ask about treatment options**

To treat “off” time or dyskinesia, doctors may start by adjusting your medications. For “off” time, you may need a little more medication and for dyskinesia, a little less. For people who have both “off” time and dyskinesia, it can be tricky to find the right types and amounts of medication.

There are many — and growing — treatment options for “off” time and dyskinesia, including several newer medications (pills, a gel infused continuously into the small intestine, an inhaler, an under-the-tongue dissolving strip and more) as well as, for some people, deep brain stimulation (DBS) surgery. DBS doesn’t help all symptoms and can even make some, such as speech or thinking changes, worse. So, it’s not for everyone. (See resource #4c on [page 34](#).)

— **Get support for taking medication**

Some people take multiple medications (for PD and other conditions) multiple times a day. This can be a lot to remember and manage.

It may be helpful to use a pill box to separate medications for each day of the week and/or times of day. Some pharmacies offer a “pill pack” service in which they organize and package your medications according to the time of day they should be taken. You also could set an alarm to remind you to take medication throughout the day, get medications delivered (and keep a three-month supply on hand, if possible), and ask a care partner or spouse for assistance.

Keep — and regularly update — a list of prescription and over-the-counter medications and supplements, who prescribes them, what they’re for and when you take them.

NEW OR MORE NON-MOTOR SYMPTOMS

There are many possible Parkinson's non-motor symptoms: speech or swallowing changes; sleep, mood or thinking difficulties; constipation; and many others.

Not everyone experiences any or all of these. For some, they happen at diagnosis or many years before. For others, they happen much later. Like all PD symptoms, they are different in different people, and they gradually change over time.

Sometimes, one non-motor symptom can impact another. Difficulty sleeping, for example, may contribute to thinking or mood changes. A non-motor symptom also can impact motor symptoms. Dizziness or lightheadedness from low blood pressure, for instance, could worsen walking or balance. The reverse is also true: motor symptoms can impact non-motor symptoms. Significant slowness, for example, could worsen constipation.

For some, non-motor symptoms are the most troublesome part of Parkinson's. While there are many treatment options, these symptoms can be tough to fully treat. But research in this area is extremely active and many new potential options currently are in clinical testing. (See [page 33](#) for more.)

Here, we describe common non-motor symptoms that can — but don't always — happen, particularly after many years or decades with Parkinson's, as well as treatment options for each. (For more on these and other non-motor symptoms, visit michaeljfox.org.)

+ Swallowing Changes

With time, some people experience trouble swallowing. This can cause problems eating, drinking or taking medication. When significant, swallowing changes could lead to weight loss. A person with swallowing trouble may cough or choke while eating or drinking, clear their throat often, or feel a sensation of food getting “stuck” while going down. Some people accidentally swallow “down the wrong tube” into the lungs. This is called aspiration, and it can lead to lung infection, or aspiration pneumonia. Some people aspirate without realizing it, because they don't cough, choke, or show other signs of a problem. This is called “silent aspiration.”

To check for swallowing problems, your doctor may order a swallow study. This test uses x-rays and a safe-to-drink dye to see how you swallow.



“Staying engaged with hobbies, friends and family, and spiritual activities — if those are an important part of your life — is key. Being active adds an element of control that can positively affect quality of life.”

— KIRK HALL, MBA
NEUROPALLIATIVE CARE ADVOCATE, AGE 71
HIGHLANDS RANCH, COLORADO

Parkinson's medication may help swallowing, but often medication alone is not enough. Other treatments may include:

— **Speech therapy**

A speech therapist, or speech-language pathologist, can check your swallowing, prescribe exercises to strengthen swallowing muscles, and share strategies to make swallowing safer. Look for a clinician who is trained in a Parkinson's-specific program, such as Lee Silverman Voice Treatment (LSVT) LOUD or Parkinson Voice Project SPEAK OUT! (See [page 24](#) for more.)

— **Diet adjustments**

A speech therapist may recommend changes to your diet to decrease the risk of choking or swallowing down the wrong tube. Strategies might include eating only soft or pureed foods, or adding a thickener to liquids, so they can be swallowed slowly.

— **Mealtime (and other) strategies**

Your speech therapist can suggest ways to make swallowing safer. These could include taking smaller bites, chewing slowly, tucking your chin to your chest when you swallow, avoiding drinking through straws, or other techniques. There also are ways to limit swallowing down the wrong tube, such as raising the head of the bed at night, avoiding medications that make you sleepy, and others. Care partners and loved ones can help prepare food, cut food into smaller bites, and offer helpful reminders during mealtime.

— **Medication changes**

Some people who have significant trouble swallowing may have trouble taking pills. Ask your doctor if there are other formulations of your medications. Some medications come not only as pills, but also as dissolvable tablets, liquids, patches, or capsules that can be opened and sprinkled on food, for example.

— **Consideration of a feeding tube**

This is, for many, an understandably scary and emotional topic. Few people with PD, even those with swallowing problems, need a feeding tube. But for those who have severe weight loss, for example, a feeding tube can provide nutrition. (There is no strong evidence that feeding tubes decrease the risk of aspiration pneumonia.) Your doctor, speech therapist and other experts can discuss the possible benefits and risks as well as how a feeding tube may influence your daily activities, such as taking medication, exercising or socializing.

Even though you are not likely to need a feeding tube, many find it helpful to think through this possibility ahead of time, especially when planning for care around the end of life. Your doctor can help you understand your options and think about your approach. For example, some people decide they never want a feeding tube; others say they'll try one in a certain situation or for a limited duration. (See resource #4a on [page 34](#).)



Tip for Care Partners

Learn the Heimlich maneuver

Swallowing changes can increase the risk of choking. Even though dying by choking is extremely rare, care partners and families can monitor for signs of coughing or choking, and learn potentially life-saving techniques, such as the Heimlich maneuver, also called “abdominal thrusts,” in case of emergency. (See resource #5 on [page 34](#).)

+ Drooling

Swallowing changes in later PD lead to drooling for some people. Drooling happens when a person swallows less often and saliva builds up. This symptom may make going out in public or meeting with friends uncomfortable, and it can irritate the skin around the mouth. Treatments may include:

— Behavioral strategies

Chewing sugar-free gum, eating sugar-free hard candy, and taking small sips of water can encourage swallowing and limit drooling. For more significant drooling, some people wear a thin cloth or bandana around the neck or under the collar or carry a handkerchief or tissue.

— Physical, occupational and/or speech therapy

In later Parkinson's, it may be more natural for the mouth to stay slightly open and for the chin or neck to tilt forward slightly. These changes can make drooling more likely. Therapists can give you exercises and strategies to help keep your lips closed, chin up, and head upright.

— Medications

If behavioral strategies aren't enough or symptoms are significant, doctors might prescribe medication for drooling. These could include Parkinson's drugs, such as trihexyphenidyl, or medications that work similarly, such as glycopyrrolate or atropine drops. Because these drugs have many potential side effects, particularly in older people, doctors use them cautiously. Another option may be botulinum toxin injections into the salivary glands to temporarily decrease drooling.



Tip for Care Partners

Keep your (loved one's) chin up

For some, drooling can be embarrassing. Remind your loved one that, while you understand this feeling, you aren't embarrassed. You — and their other family and friends — want to spend time or go out with them. Drooling doesn't change that one bit.

Knowing they want to be comfortable, though, ask how you can help. Could you hand them a piece of gum or candy every so often throughout an event? Have a code word to remind them to close their mouth or raise their chin? Hand them a tissue, if necessary, or subtly dab their mouth? Talking about symptoms allows you to support your loved one in the best way possible.

+ Speech Changes

Parkinson's can affect speech and voice, and these changes may increase over time. People with PD often speak more softly or slowly, or without much emotion. Words may be more difficult to understand, or they may trail off at the end of a sentence. Other Parkinson's symptoms, such as decreased facial expression or thinking changes, also can impact communication.

Speech changes can make it tougher to connect with family and friends, colleagues, and health care providers. They could, for example, make it more difficult to chat with loved ones over coffee, talk on the telephone or give work presentations.

Parkinson's medication typically does not, unfortunately, significantly improve speech. Neither does deep brain stimulation, which potentially could worsen speech. Treatments may include:

— Speech therapy

The same expert who helps with swallowing, a speech therapist, can help with speech. If possible, find a clinician who is familiar with Parkinson's, such as someone certified in LSVT LOUD or Parkinson Voice Project SPEAK OUT! (See [page 24](#) for more.)

— Communication devices

Many devices and technologies can enhance your speech or communication. Examples include small earpieces that prompt you to speak up if your volume decreases, notepads or touchpads for writing or typing, and smartphone apps that speak for you or fill in gaps. A speech or occupational therapist can help you find the right tools for you.

Because hearing can decrease with age, you also may want to get a hearing test. For those with hearing loss, hearing aids can help improve communication. Your doctor's office may be able to test your hearing. If not, they can refer you to an expert who can.

— Singing groups

Singing can strengthen voice muscles and improve speech. When done with a group, it also connects you with others, which is important for boosting brain health and avoiding isolation. To find a group, you can search online or ask your doctor or others in the PD community. Kirk Hall, a member of the Tremble Clefs Parkinson's singing group, says, "Singing engages not only the voice, but also the heart, mind and spirit. It engenders an atmosphere of community and caring that can significantly impact quality of life."



Tip for Care Partners

Stop, look and listen

When speaking with a loved one who has Parkinson's, especially about an important topic, focus on each other and the conversation. Many of us try to multitask or shout from different rooms, which can contribute to communication challenges. Make sure you're in the same room, face each other, and limit noise and other distractions. Turn off the television and silence your phone, for example. If necessary, gently ask your loved one to repeat, or paraphrase, "I think you said... Is that right?"

For those who live far away and speak mostly by telephone, try to time conversations for when your loved one typically feels best. (Many avoid early morning or later evening, when symptoms may increase.) Call from a quiet place (headphones may help), and, if possible, use video. Body language can say a lot.

+ Dizziness and Lightheadedness

Some people with Parkinson's feel dizzy or lightheaded when changing positions, such as standing up from a seated position, or climbing stairs. These symptoms are caused by drops in blood pressure, also known as "orthostasis" or "orthostatic hypotension." For many, these symptoms are brief and quickly improve after letting the body adjust to a new position. Some, however, experience more frequent or larger drops in blood pressure that can cause them to pass out or fall.

If dizziness or lightheadedness happen, they are most often in people who have lived with Parkinson's for many years. They can be caused by PD itself, Parkinson's medications, medications that lower blood pressure or heart rate, or another medical condition.

If you experience dizziness or lightheadedness, your doctor may ask you to check your blood pressure at home while you are sitting and standing, and to keep a log of these readings. This helps them see if your blood pressure drops, how often it does, and how low it goes. Treatments for low blood pressure may include:

— Lifestyle modifications

To avoid dizziness when changing positions, get up slowly and in stages. For example, rather than standing quickly after waking from sleep or a nap, sit at the side of the bed for several minutes before standing. Also avoid too much time standing in one position (shift your weight from side to side if you do) and too much time in the sun, as heat and humidity worsen blood pressure drops.

— Dietary changes

Drink enough water — at least six to eight 8-ounce glasses per day, more if you exercise or spend time outdoors. And drink water in the morning, when symptoms can be most severe. If your heart and kidneys are healthy, you may want to eat salty foods or take salt tablets, if recommended by your doctor.

— Compression devices

Certain devices, such as compression stockings or abdominal binders, raise blood pressure by preventing

blood from pooling in the legs and feet. Compression stockings are tight elastic socks that extend to the knee, hip or waist. Abdominal binders are tight Velcro braces, similar to a lower back brace, worn around the midsection.

— Medications

Your doctor might adjust your medication — decreasing PD medications or medications that lower blood pressure, for example. For some people, it can be hard to find the right balance of PD medication to treat motor symptoms but not cause low blood pressure. If low blood pressure continues or is significant, your doctor may prescribe a drug to increase blood pressure.



Tips for Care Partners

Help with hydration

Ask your doctor how much water your loved one should drink each day. Fill a large jug or other container with that amount each morning and empty from there to track daily intake. You can add cucumber, lemon, or other vegetables or fruits to enhance taste, if helpful, and serve in a favorite glass or water bottle.

You can model water intake, too. (Drinking water is good for all of us!) Have a glass with each meal and ask your loved one if they'd like water each time you pour yourself some.

Know the signs

Learn your loved one's signs of low blood pressure, which might include a blank stare, paleness or wobbling. This might allow you to intervene quickly (by guiding them to sit down, for example), if necessary.

+ Mood or Behavior Changes

Depression and Anxiety

Depression and anxiety are common Parkinson's symptoms. For some, they happen many years before diagnosis; for others, at diagnosis; and still others, many years into PD. Depression and anxiety look different for different people. Depression, for example, can cause decreased mood or energy, irritability or anger, or sadness. Mood changes can impact quality of life as well as other Parkinson's symptoms. Worry could lead to trouble sleeping or more tremor, for example, and feeling down could lead to slower movement.

Mood changes are like any other Parkinson's symptom or medical condition. They're part of disease, they're treatable, and treating them can improve your life. There are many treatment options:

— **Medication**

Several medications, such as selective serotonin reuptake inhibitors (SSRIs), can treat depression and/or anxiety. Many take a few weeks to “kick in” and finding the right medication can sometimes be trial-and-error. Some anxiety medications, such as

Xanax (alprazolam), Ativan (lorazepam) or similar drugs, may cause sleepiness or confusion, so doctors prescribe these carefully. Your Parkinson's or primary care doctor can treat depression and anxiety. But if symptoms are significant or it's hard to find the right treatment, you may want to visit a psychiatrist, a doctor who specializes in treating mood changes. (See [page 24](#) for more.)

— **Counseling or talk therapy**

Speaking with a mental health professional, such as a counselor, psychologist or social worker, can help you work through feelings and find ways to lessen depression or anxiety. You can use talk therapy alone or in combination with medication. Ask your doctor for a referral or search online for a provider in your area or who offers remote visits. (See [page 24](#) for more.)

— **Exercise**

While not a treatment for mood changes on its own, regular exercise — of any kind — can help. Certain exercises, such as yoga, also may promote relaxation and calm anxiety. (See resource #2 on [page 34](#).)



Apathy

Some people with Parkinson's have decreased motivation or interest in previously enjoyable activities. This is called apathy. Someone with apathy may feel less motivated to exercise or to take action in their medical care. Apathy can be part of depression, but it can be a symptom on its own, too. It can be difficult to treat and it can be frustrating not only for the person who experiences it, but also for their family members and care partners. There is, unfortunately, no approved medication for apathy. But strategies for managing may include:

— Keeping a schedule

Go to bed and get out of bed at the same time each day. If you feel sleepy during the day, try to limit naps. (Nap no later than about 2 p.m. and for no more than 30 minutes.)

— Planning activities

Every day, arrange at least one physical, social and/or mental activity. You could take a walk around the block, call a friend, or practice a second language, for example.

— Setting goals

Start small and build from there. You might begin with a goal to take a walk with your spouse to the mailbox every other day. After a week of meeting that goal, you could gradually increase the distance and frequency of your walks.

As you set goals, evaluate your expectations. It's good to challenge ourselves. But some may expect too much of themselves or their day. Examine what feels reasonable and adjust your expectations and goals as necessary.

— Exercising

Physical activity may be the last thing you want to do when you feel tired or unmotivated. But exercise can increase energy and drive. Try to do at least a few minutes every day. You could stretch, take a bike ride, or even garden. Group fitness classes for people with Parkinson's also are a good way to get motivated, stay active and socialize. (See resource #2 on [page 34](#).)

— Partnering for accountability

Find someone you trust to help keep you honest with yourself and on track. Share your plans and goals and ask your partner to hold you to them even if you don't feel like it.



Tip for Care Partners

Speak up

Loved ones often are the first to see mood, behavior or personality changes, even before the person experiencing them. But this can be a tricky topic to bring up.

Some people find it helpful to have regular check-ins (such as every few months, before a doctor's visit) to openly discuss how things are going. Outside of this, you might try to gently raise the topic, saying something like, "I've noticed you don't seem to be... as much. What do you think?" Or, "You don't seem like yourself lately. How are you feeling?" Remind them that your questions come from a place of love and concern.

Your loved one's doctor can help, too. If you don't want to bring up concerns in front of your loved one (you might worry they won't agree or they'll be upset with you), call your doctor's office ahead of the visit to share.

And remember, changes in mood, motivation or expression are signs of Parkinson's — not signs of less love.

+ Thinking and Memory Changes

For many people and families — both with and without Parkinson's — thinking and memory (cognitive) changes are among the most worrisome future possibilities.

Not everyone with PD develops thinking or memory changes. For those who do, they can be mild, more significant, or somewhere in between. If more significant changes happen, they typically occur in the later stages of Parkinson's, often after living with the disease for many years or decades.

Like all PD symptoms, thinking and memory changes look different from person to person. But they commonly cause difficulty paying attention, doing two things at once (multitasking), or making a mental picture of your surroundings, such as while driving or giving directions. Many people also have trouble finding words, or may feel like words are “on the tip of the tongue.” Others have a hard time following a process, such as steps in a recipe, or using newer technology, such as a smartphone, tablet or computer. Some have short-term memory loss, but this is not usually the first or most pronounced symptom as it is in Alzheimer's disease.

If thinking and memory changes are significant, they can interfere with daily activities, such as paying bills, doing household chores or driving. These changes could even make it less safe to live alone or at home.

When thinking and memory changes interfere with multiple activities, they might signal dementia. Different conditions can cause dementia. Alzheimer's is the most common, but there are others, such as Parkinson's disease or a related condition called dementia with Lewy bodies.

Parkinson's disease dementia (PDD) and dementia with Lewy bodies (DLB) have similar brain cell changes and symptoms, including movement and thinking changes, as well as others. Because of this, they are grouped together under the term “Lewy body dementia” (LBD). Where they differ is in the timing of symptom onset. In Parkinson's disease dementia, movement symptoms

happen first and then many years or decades later, significant thinking and memory changes happen. In dementia with Lewy bodies, movement and cognitive changes come on at the same time or within a year of each other.

For thinking and memory changes, consider these tips:

— See your doctor

Talk with your Parkinson's doctor about changes that you're experiencing or that you notice in your loved one. If you don't have a Parkinson's doctor, a movement disorder specialist, now may be a good time to meet with one.

Ask what these changes could be and whether they're part of Parkinson's or something else. Sudden confusion or changes in thinking and memory could potentially come from infection, medication changes or other stresses. Once you determine the cause, you can figure out the best treatment.

— Boost brain health

There are many steps you can take to support brain health. In general, what's good for your body is good for your brain. Exercise, eat a healthy diet, get enough sleep, and stay connected to others.

— Manage other conditions

Mood or sleep symptoms, for example, can contribute to thinking and memory changes. If you have these changes, work with your doctor to manage them as best you can.

— Adapt, as needed

Thinking and memory changes may make living alone, driving or other daily activities less safe. You may want to consider extra support for taking medication, preparing meals, or giving the main care partner a break, for example. Extra support also could be a phone with one-touch dialing, an erasable board with the date and day's activities, or door alarms to alert in case of wandering.

With thinking and memory changes, you also may want to reevaluate driving. (This is especially important if you've had an accident or near-miss, or you've gotten lost in a familiar place.) Driving is a tricky topic for a lot of families, but your doctor can help. (If you're a worried care partner or family member, it may help to call your loved one's doctor ahead of an upcoming visit to express your concerns.) Your doctor might recommend a formal driving assessment, in which a professional observes driving and provides suggestions for safer driving. For some, this may be limited driving — not on freeways or at night, for example. For others, it may be not driving at all. There are many options for getting around, including public or senior transportation, shared trips (such as Uber or Lyft or another program), or rides from family or friends. (See resource #3 on [page 34](#).)

— **Plan ahead, where possible**

If you worry about thinking and memory changes or have early, mild symptoms, you may want to start planning ahead, if you haven't already. In fact, it's a good idea for all of us, regardless of whether we have Parkinson's or cognitive changes.

Many people find it helpful to talk and think about what care and living options they would want if extra support at or outside home is ever needed. (See [page 25](#) for more.) Naming someone to make medical decisions for you and take care of your finances if you ever become unable also can be a way to take action and control. (See resource #4a on [page 34](#).)

— **Consider medication**

For some people, medication, such as Aricept (donepezil) and Exelon (rivastigmine), may be an option to support thinking and memory. Talk with your doctor about treatment options as well as their possible benefits and risks.



Tip for Care Partners

Practice patience

Memory and thinking changes — especially if combined with increasing motor changes — may make daily activities, such as getting dressed, eating meals or even answering questions, more difficult or time-consuming. Try to give your loved one extra space and time. (Build in a time buffer when getting ready to go out, for example, to avoid feeling rushed.) Let your loved one know you're there if needed — and that you want to help — but don't hover or interfere to speed things up.

Also be patient with yourself. Being a care partner can be tough work. It's natural to feel tired, frustrated or sad. You might make silly mistakes because you're stressed and bigger mistakes because you don't know any better. There may be days when you don't feel much joy or motivation. That's normal and okay.



+ Hallucinations or Delusions (Psychosis)

After many years or decades with Parkinson's, some people may see, hear or feel things that aren't there (hallucinations) or believe things that aren't true (delusions). In PD, hallucinations most often are visual (seeing things). Typically they include children, animals or relatives who've passed away, but a person can see other people or things, too. Delusions often are paranoid in nature. A person might believe their spouse is being unfaithful or that children are stealing money. Sometimes, hallucinations and delusions are mild and not significantly bothersome. (Some people recognize that what they see isn't real, for example.) Other times, these symptoms can be troubling or frightening, or cause safety concerns.

Hallucinations and delusions can happen for different reasons. In many, they are part of Parkinson's changing over time. In some, they are brought on or worsened by certain Parkinson's (or other) medications or other medical conditions, such as infection. They also can happen in people with significant thinking and memory changes.

Tips for managing hallucinations and delusions include:

— Tell your doctor

It's important to talk with your Parkinson's doctor about these symptoms. Don't wait until your next appointment; call as soon as possible. Together, you'll talk about what may be causing them and how you and your loved ones can manage them.

Some care partners may feel the need to communicate these (or other) symptoms privately to the doctor. This can be done by phone prior to an appointment or in a separate conversation during the visit.

— Review your medications

Certain PD medications as well as other prescription and over-the-counter medications can cause or worsen hallucinations or delusions. You and your doctor may want to — carefully — adjust your medication. Doctors typically start by slowly decreasing or discontinuing one or more PD medication. The challenge is that less medication may decrease hallucinations and delusions but increase motor symptoms. For some, it can be difficult to find the right medication balance.

— **Adjust your environment**

Create a calm, soothing environment that minimizes the potential for hallucinations and delusions. Avoid watching the news or other possibly upsetting programs, for example. Keep spaces well-lit and use eyeglasses and hearing aids, if necessary. Low light and impaired vision and hearing can contribute to symptoms.

— **Consider adding anti-psychosis medication**

If medication and environment adjustments don't help enough, or if hallucinations or delusions are significant, doctors may prescribe medication for psychosis.

Options may include Nuplazid (pimavanserin), an FDA-approved medication for treating psychosis in people with PD, or others, such as Seroquel (quetiapine) or Clozaril (clozapine). Certain anti-psychosis drugs, such as Haldol (haloperidol), significantly block dopamine, and people with PD should not take them.

Before starting any medication, it's important to talk with your doctor about the possible benefits (fewer or less severe hallucinations and delusions, for example) and risks (such as sleepiness, confusion, or potentially even increased risk of death or hospitalization in older people).



Tip for Care Partners

Respect and reassure

Don't try to convince your loved one that what they see or believe isn't real. It's nearly impossible and can lead to frustration and loss of trust. Instead, try to learn about their experience. Ask what they see or why they believe what they do. This can help you understand what they are feeling (anxious or afraid, for example) and, with delusions, may help them see why a particular belief is mistaken.

Remind your loved one that they are safe and secure and that you are on their side.

For more tips, see resource #4b on **page 34**. And for recommendations specific to your loved one's experiences, speak with your personal physician.

NOT EVERY CHANGE IS PARKINSON'S

Parkinson's or not, things change as we get older. We might slow down a little, have a harder time remembering things, or have joint or back pain. When it comes to these types of changes, those with PD often ask, "Is it Parkinson's or is it age?" The answer often is that it could be Parkinson's, age, or both — or something else entirely.

Parkinson's symptoms gradually worsen over time. This happens slowly, not overnight or even over a few days or weeks. If you notice a sudden change, it could be something other than PD. Medication or sleep changes, infections and even life stress can abruptly and temporarily worsen symptoms. If you experience new or rapid changes, talk with your doctor. PD might explain part or all of it, but there may be other contributors too. Your doctor can help you figure out what's happening and how to best treat your symptoms.





“I Don’t Stop Living Because of Parkinson’s”

— **LISETTE ACKERBERG, AGE 84**
LOS ANGELES, CALIFORNIA

Lisette Ackenberg lived with Parkinson’s disease for a decade before telling her family and friends. She had watched her grandfather and her father live with Parkinson’s for years, and never wanted loved ones to look at her with sympathy. So when she finally made her announcement, she did it with bravado at her 60th birthday party.

Her concerns about others’ perceptions, along with her symptoms, have shifted over the more than three decades she has lived with PD. Today, symptoms and medication side effects can make shopping or other daily tasks difficult. An inability to anticipate dyskinesia has curbed her spontaneity. But through it all, she remains positive. “You have to know that this disease isn’t a death sentence. It just means you alter your life. You change it so it works.”

In 2004, within a single month, Lisette lost her father to Parkinson’s and her husband to multiple sclerosis. The immense stress seemed to catapult the disease, but now she credits that time with helping her define her personal formula for managing her PD: sleep, strong exercise, good food and a conscious effort to stay positive.

She took up walking and walked in a 5K for Parkinson’s on her 75th birthday, “in the hail,” as she recalls. “I was very proud of that.” Now, Lisette no longer feels any pressure to prove herself. “I exercise every day, but I don’t walk those distances.”

Watch more of Lisette’s story at
michaeljfox.org/pd360.

Treatment, Care and Support Needs That May Evolve

As symptoms evolve over many years with PD, you may need to adapt treatments and supports to meet changing needs. With more (or more significant) symptoms, finding the right combination of treatments and care can be challenging. But your doctor can help you adjust treatments, expand your care team and access helpful resources.



ADAPTING TREATMENTS TO CHANGING SYMPTOMS

As Parkinson's changes, a person may develop more symptoms, which require more or different medication or deep brain stimulation (DBS) settings. They also could develop new symptoms, such as balance problems or non-motor symptoms, that don't respond as well to medication or to DBS. (An important note: If medication or DBS works, they will always work. The reason treatments may feel less effective is because progressing Parkinson's may require more medication or different DBS settings and some symptoms don't respond to these treatments.)

In some people, certain symptoms compound one another. For example, thinking and memory changes may make it more difficult to do home physical therapy exercises or to remember to use a walker for balance. And significant slowness could make getting to the restroom on time more challenging. These types of symptoms may have a considerable impact on the daily activities and daily life of both the person living with Parkinson's and their loved ones.

In these situations, a person may need different types of care or levels of support at home, and spouses and family members may take on new or more significant caring roles. Some families may enlist the help of a paid caregiver or home health aide who can assist with personal hygiene,

medication management or other tasks. Others may seek alternative living arrangements, such as a ground-floor apartment without stairs, or an assisted living facility that can provide more help. (See [page 25](#) for more.)

As care needs shift, consider these tips:

+ **Take stock**

What symptoms are the most troublesome? How do they affect you and your loved ones? What kind of help would be beneficial? Are spouses or family members able to provide adequate support or would additional assistance be useful?

+ **Talk with your doctor**

Your physician can help you understand the best care options and access support, such as a social worker who can coordinate home or other care.

+ **Modify your care team**

Different experts can help with different parts of Parkinson's. As symptoms change, you may want to expand or adjust your health care team. Physical and occupational therapists, for example, can teach you ways to do daily activities more easily and safely. (See [page 24](#) for more.)

+ **Get support**

You may think of support as more “physical” — a walker or help from another person to get dressed, for example. While some people benefit from this type of support, everyone can benefit from emotional support. You can talk with a mental health counselor, for example, or with others like you, which can help you feel less alone and share experiences and tips. You can connect in many ways, such as through one-to-one chats, support groups or online forums, such as MJFF’s Buddy Network. (See resource #6 on [page 34](#).)

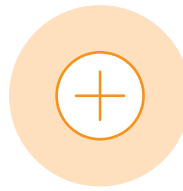
+ **Plan for the future**

If troublesome symptoms occur, it may be worth thinking about and making plans for if and when those symptoms progress. For example, if you have difficulty walking or experience falls, you may want to consider moving to a home without stairs (or relocating to the first floor of your home) in the not-too-distant future. You also may want to think about where the safest living place might be if, one day, home cannot provide the necessary level of care. (See [page 25](#) for more.) Your doctor, social worker and other experts can help you plan.

+ **Consider palliative care**

Palliative care is extra support for people and families living with Parkinson’s. It is available at any time during Parkinson’s, from diagnosis on — not only at the end of life. Palliative care is more support and more care; it’s not “giving up” and it’s not comfort care.

Palliative care provides medical, emotional and spiritual care to people with Parkinson’s and their loved ones, helps with future planning, and promotes well-being. Palliative care teams include doctors, nurses, social workers, spiritual advisors and others who work with you, your loved ones and your Parkinson’s care team. (See [page 30](#) for more.)



BUILDING YOUR CARE TEAM

Changing symptoms may prompt you and your loved ones to reevaluate your care and care team, especially if medication or surgery cannot fully address symptoms. You may want to add new or different experts to your care team.

You also may want to see a Parkinson’s doctor, or movement disorder specialist, if you haven’t yet or if it’s been some time since your last visit. Some people who regularly see a specialist find it helpful to seek a second opinion for increasing symptoms. This can confirm the current treatment regimen or offer a fresh perspective on care.

At some medical centers, different providers may be part of the neurology or movement disorders clinic. Other times, they are located outside of your doctor’s office. Your Parkinson’s physician can make recommendations for building your team and communicating across the team.

Experts who may be part of your Parkinson’s team include:

+ **Neurologist**

A doctor who treats brain, spinal cord and nerve conditions, such as strokes, seizures, headaches and others. These physicians also treat Parkinson’s and other movement disorders, but in some cases may not have as much experience as a movement disorder specialist. Some people see a neurologist because there are no PD experts nearby. If possible, it’s helpful to see a movement disorder specialist at least once a year. Telemedicine may make this care more accessible.

➤ health.usnews.com/doctors/neurologists

+ **Mental Health Provider**

- **Psychiatrist:** a doctor who specializes in treating depression, anxiety, behavioral changes, hallucinations and delusions, and other aspects of mental health. Psychiatrists can prescribe medication and other therapies.

➤ psychologytoday.com/us/psychiatrists
➤ health.usnews.com/doctors/psychiatrists

- **Counselor:** a professional, such as a psychologist, social worker, mental health counselor or chaplain, who offers talk therapy for depression, anxiety and other symptoms. Talk therapy explores behaviors and thoughts and aims to change negative patterns that may be interfering with daily activities or quality of life. Talk therapy can be used with or without prescription medication.

➤ locator.apa.org
➤ psychologytoday.com/us/therapists

+ **Movement Disorder Specialist**

A neurologist with additional training in evaluating and treating Parkinson's and other movement disorders. Many specialists lead research studies or work in centers that offer clinical trials or other opportunities for research participation.

➤ movementdisorders.org/MDS/Resources/Patient-Resources/Movement-Disorders-Specialist-Directory-Listing.htm

+ **Palliative Care Specialist**

A clinician or expert who can — at any time during disease (not only near the end of life) — help manage troublesome symptoms, provide emotional support, and coordinate care goal discussions among a patient, family and their health care team. Palliative care is extra support, in addition to your Parkinson's care team. (See [page 30](#) for more.)

➤ getpalliativecare.org/provider-directory
➤ nhpco.org/find-a-care-provider

+ **Physical or Occupational Therapist**

An expert who helps with motor symptoms, such as walking and balance problems, and builds a personalized exercise program. An occupational therapist also can suggest strategies and equipment for doing daily activities, such as showering, dressing and eating, more easily and safely.

➤ lsvtglobal.com/LSVTFindClinicians

+ **Speech Therapist**

Also known as a speech-language pathologist, a provider who evaluates and treats speech and swallowing problems, often with voice and breathing exercises, as well as behavioral strategies and diet modifications. These experts also can share tools and exercises for people with thinking and memory changes.

➤ lsvtglobal.com/LSVTFindClinicians
➤ parkinsonvoiceproject.org/providers.aspx

+ **Social Worker**

A professional who provides counseling and education for managing disease; connects people to community resources, such as support groups, meal or transportation programs, and other services; and helps coordinate in-home care, transitions to living facilities outside the home, and future care planning. Social workers also can organize communication across your health care team and guide you in navigating insurance, cost and other care concerns.

➤ onlinetherapy.com/social-workers





LEARNING ABOUT CARE OPTIONS

As Parkinson's changes, care and support needs may change. Some people — and their care partners — may benefit from extra help in the home, or from living somewhere that offers more care and safety. Whatever your needs, there are many options. (See resource #9 on [page 35](#).)

For people who are able to stay in their home, options may include one or more of the following:

+ **Unpaid or volunteer care partner**

Spouses or family members most often provide care at home. But friends, neighbors and other community members may be able to help, too. For example, they may pick up groceries or medications, drive you to an appointment, or make a meal for you. They also might spend time with you while your primary care partner runs errands, exercises or sees friends.

+ **Paid caregiver**

Sometimes, spouses or families aren't able to provide the full support necessary. This could be because of the type of care needs, work schedules or other family needs. In these situations, paid caregivers might be an option.

A paid caregiver offers different types of assistance. They can provide personal care, such as help with morning activities (getting out of bed, showering and getting dressed), or giving medications at scheduled times. They also can offer lifestyle support, such as companionship or housekeeping help.

Paid caregivers have a wide range of training, skills and experience. You can hire a caregiver through an agency or privately. They can work hourly, daily or on another schedule that works for you. Cost varies depending on the type and amount of assistance provided as well as experience, credentials and other factors.

+ **Other in-home care professionals**

These may include nurses; physical, occupational or speech therapists; or social workers or care coordinators. Each offers a different service and expertise. Often, insurance covers some or all costs for these providers.

Nurses, for example, may help with sorting medications, measuring blood pressure, or providing for other medical needs. They are especially helpful in transitioning back home after hospitalization, for example.

For people who have great difficulty moving, walking, or traveling to appointments, physical or occupational therapists can help you exercise at home. They also can make sure your home is as safe as possible and suggest adjustments or equipment to make daily activities easier.

Social workers can coordinate care, help with insurance questions, and assist in planning for potential next steps. They also can help you access resources in your community, such as transportation, meal or medication delivery, and other services.

+ **Respite care**

Respite offers care and assistance for a short period, such as a few hours a week or a few weeks at a time, either at home or at an adult day center or health care center. Respite aims to give primary caregivers a temporary break. (See resource #10 on [page 35](#).)

If it's not possible to provide enough care and safety at home, other living options may include:

+ **Assisted living**

This housing offers support for people who cannot live on their own or have needs that exceed available in-home care options. Staff may prepare meals, clean your living space, and give medications, for example. These facilities also may offer recreational and social activities as well as urgent medical assistance, if needed.

+ **Nursing home**

These locations offer around-the-clock medical and personal care for those who need help with most or all daily activities.

Many of us say, “I don’t ever want to go to a nursing home.” But fewer of us talk about where we do want to live, how we’d like to get care, and what would make us most comfortable if living at home is no longer best for our health and well-being, or for our loved ones. Talking and thinking ahead about this possibility might make a move, if it ever becomes necessary, a little easier.

+ Memory care

These facilities offer a level of care similar to nursing homes. They provide 24-hour care and supervision, meals, and help with daily activities, such as bathing and dressing. But they are specifically structured for people with thinking and memory problems. They are designed to minimize confusion and maximize safety (with locked doors or bed alarms, for example, to limit wandering). Their staff are trained in managing thinking and memory changes and associated symptoms, such as behavior changes, hallucinations, wandering and others. They also may offer recreational activities, such as art or pet therapy.

Some locations include a range of living options, from independent (on your own or with your spouse or partner in a supportive and social community, without active medical or nursing assistance) to assisted living to nursing care. If there comes a time when you need more assistance, this arrangement might ease the transition to another level of care.

Your doctor and social worker can help you understand the best support for your needs, options in your area, and costs. Once you determine the right level of support, assess different options. Interview several caregivers or visit a variety of nursing homes, for example, to see which is the best fit for you or your loved one. Visit at different times, too, such as in the morning, at mealtime and during a scheduled activity. Also be sure to ask about facility and staff experience caring for people with Parkinson’s and any relevant symptoms, such as memory changes or hallucinations.

Care costs vary widely. In general, the more and the longer support is provided, the more expensive it is. Health or long-term care insurance may cover some costs. And for military veterans, the Veterans Administration (VA) may offer benefits. In some states, government programs also may compensate spouses and family members for unpaid caring. As care can be quite costly, planning ahead for potential needs is beneficial. A financial planner and others may be able to help. (See resource #4a on [page 34](#).)



CARING FOR CARE PARTNERS AND FAMILIES

As Parkinson’s progresses — especially if it brings both motor and memory and thinking changes — spouses, partners and families may take on increasing care responsibilities. Depending on a loved one’s needs, care partners may schedule and attend doctor appointments; manage medications and monitor for side effects; take care of chores, shopping, and other household errands; and assist with dressing, bathing, and other daily activities. This can be difficult, especially for care partners who work full-time, care for other family members, or support from a distance because they live far away.

If you are a care partner or family member of someone with PD, consider these tips:

+ Take care of your own health

One of the best things you can do, when caring for another person, is care for yourself. See your physician regularly, exercise, and eat a healthy, balanced diet. Find ways to manage stress, such as journaling, meditating, or writing a gratitude list. And make plans for your own future, considering how you want to live in later and end of life as well as who might help care for your loved one if a time comes when you can’t.

+ Talk to your loved one's doctor

Your perspective and input are valuable in your loved one's care. With telemedicine, multiple family members can join doctor visits, even from afar. During appointments, speak up about challenges or concerns. Some care partners worry about injuring themselves while helping a loved one transfer out of bed or get up after a fall. Some don't sleep well because of a loved one's nighttime hallucinations or behavior changes. (If you don't feel comfortable sharing in front of your loved one, call the doctor's office beforehand to describe your concerns.)

Ask how you can best support your loved one and yourself, where to learn more about their symptoms, and what to expect.

+ Make time for yourself

Go out with friends, take a walk or do whatever makes you happy. It can be hard to take a break when you're the main care partner, but even 15 minutes to read a book, drink a cup of tea or meditate can help.

+ Get support

Ask friends and family to help with specific needs, such as picking up groceries, driving to appointments or calling the insurance company.

And connect with others in the community, who understand and can share tips, through online or in-person support groups. There are many care partner support groups, some of which are specific to adult children, husbands, wives or others. Some are for care partners of people with Parkinson's, others for those who care for a loved one with any illness. You may need to try a group more than once or try several different groups before you find your match. (See resource #6 on [page 34](#).)

If helpful, also consider seeing a mental health therapist for guidance with depression, anxiety and other emotions. (See [page 24](#).)



“While many care partners can experience mood and sleep changes and even burnout, research suggests that caring for another person may actually be associated with less disease or depressive symptoms. At first, I thought this sounded ridiculous. But on the extra tough days, I reminded myself of the benefits of being a care partner and that pulled me through.”

— MALENNA SUMRALL, PHD
PATIENT AND CARE PARTNER ADVOCATE, AGE 74
CASTLE ROCK, COLORADO

+ Fuel your strength and hope

The later years can be tough for some people with Parkinson's and their families. Strength and hope, while not always easy to find or keep, can help you through. And they can come from different people and places. Malenna Sumrall, PhD, who cared for husband Ray through PD and Lewy body dementia, offers, "While many care partners can experience mood and sleep changes and even burnout, research suggests that caring for another person may actually be associated with less disease or depressive symptoms. At first, I thought this sounded ridiculous. But on the extra tough days, I reminded myself of the benefits of being a care partner and that pulled me through."

Strength and hope also may come from learning more about the disease, getting involved in the Parkinson's community, or joining research. For many, contributing to deeper disease understanding and better treatments is

empowering. There are many resources to help you learn more about Parkinson's and many opportunities to participate in research. (See resource #11 on [page 35](#).)

+ Watch for burnout

Burnout, or feeling like you have nothing left to give or you want to give up, is common among care partners. It looks different for everyone. But many say they experience irritability, depression or trouble sleeping. If you have these or other symptoms, talk with your and your loved one's doctor.

+ Know your limit

There may come a time when you need a longer break or you can no longer safely or fully care for your loved one on your own or at home. Learn about respite and other care options and consider them in future planning, even though you may never need them. (See resources #9 and 10 on [page 35](#).)

MY TAKE: CARING FOR YOURSELF AS A CARE PARTNER

BY DAVID IVERSON

**MJFF PATIENT COUNCIL MEMBER EMERITUS, AGE 73
OAKLAND, CALIFORNIA**



We're all familiar with the advice that you can't take care of someone else if you don't take care of yourself. But I just don't think that's true! I think caregivers do it all the time because they feel they don't have much choice. It's too hard or too expensive (or both!) to find back-up help. And so they just try to get by. Now that doesn't mean the advice is wrong. It is true that care providers need to take care of themselves. It's just that it's sometimes really hard to do. And I think acknowledging that reality is important.



ENGAGING PALLIATIVE CARE SPECIALISTS

Palliative care is extra support for living with and managing disease such as Parkinson's. It's not "giving up"; stopping treatment; or hospice, which is for people who have a prognosis of six months or less. (For more on hospice, see [page 30](#).)

Palliative care is a whole-person approach to care that addresses physical, emotional and spiritual sources of discomfort. It can help people understand their diagnosis and manage troublesome symptoms, clarify personal values, and make health care decisions consistent with their wishes and goals. This care is available throughout Parkinson's disease, from shortly after diagnosis through advancing symptoms.

In many cases, your Parkinson's doctor will deliver this broad and person-centered care, helping to:

- + Ease bothersome symptoms, such as depression, hallucinations or walking problems
- + Offer emotional and spiritual support
- + Facilitate communication with loved ones and care teams
- + Avoid or manage burnout, for families and care partners
- + Set or clarify care goals for now and for the future

Some people and families may need or want support in addition to what their Parkinson's doctor can offer. Reasons for seeking extra support, particularly in advancing disease, may include care partner burnout, multiple hospitalizations over a short period of time, and others. In these cases, palliative care specialists may be able to help.



Palliative care specialists include a team of professionals — doctors, nurses, social workers, spiritual advisors and volunteers, among others — who work with you, your loved ones and your Parkinson's doctor. This team aims to help improve your quality of life, ease bothersome symptoms, and lessen care partner stress and anxiety. They also can help craft or re-evaluate care goals and plans and facilitate discussion with family and care teams.

Care partner and family support is an important and unique part of palliative care. Malenna Sumrall, PhD, a palliative care clinic volunteer, has said, "When I was caring for my husband who lived with Lewy body dementia, our palliative care neurologist was the first doctor to ask how I was doing. That was a huge sigh of relief. I have seen the same relief on the faces of so many when they realize what's available through palliative care."

If you are interested in learning more about or engaging with a palliative care specialist, speak with your Parkinson's doctor. They may be able to adjust their approach to meet your needs or refer you to a palliative care specialist. Palliative care services can be provided at home or in a clinic or hospital, and either in person or through telemedicine.



MYTHS ABOUT PALLIATIVE CARE

There are many misconceptions about palliative care, including that:

+ Myth: It is only for the end of life

Fact: That's hospice, which is comfort care for people who have a prognosis of six months or less. (Read more below.) You can engage palliative care specialists at any point in Parkinson's, even early on.

+ Myth: It does not apply to Parkinson's

Fact: Palliative care was initially established for people with cancer. But it's appropriate for anyone with a serious or lifelong condition, including PD.

+ Myth: It means giving up or stopping treatment

Fact: Palliative care is *more* care and *more* treatment. It's extra support, added to your current medications and current care team.

What Is Hospice?

Hospice is comfort care for people who have a life expectancy of six months or less.

Like palliative care, hospice is medical, emotional and spiritual care provided by a team of experts, including a physician, social worker, spiritual counselor and others. Also like palliative care, hospice aims to increase quality of life, decrease symptoms, and clarify and coordinate goals of care for both a patient and their loved ones.

A significant difference between hospice and palliative care is that with hospice, therapies aimed at curing disease (such as chemotherapy for cancer, for example) are stopped in favor of therapies aimed at promoting comfort and relieving symptoms. For people with Parkinson's, most or all PD medications, which aim to lessen symptoms, may continue during hospice care.

Because Parkinson's is difficult to predict, it can be difficult to know when hospice may be an option. It may help to engage palliative care specialists early on to learn about hospice, and to let your doctors know you are open to considering this care toward the end of life.

You can receive hospice services anywhere you call home, including an assisted living or nursing facility, or in a separate hospice center. Your Parkinson's doctor and palliative care providers can help you understand options, what questions to ask, and how to choose a hospice team. Insurance, including Medicare, typically covers most or all associated care costs, but coverage (especially of certain medications) may vary. (See resource #7 on [page 35](#).)

Feelings and Emotions That Might Arise

Life with Parkinson's can bring different emotions, often at the same time. Many people say they experience uncertainty, sadness or worry. Some feel frustrated or angry. These are normal reactions to your experience. But they can look or feel similar to symptoms of depression or anxiety. (See [page 15](#).) Your doctor can help you separate emotions from mood changes, which typically are more significant and longer lasting, and can impact your daily activities.

Common emotions in Parkinson's may include:

+ **Uncertainty**

Parkinson's evolves differently in everyone. No two people look the same or follow the same course. This can make it difficult to predict how your life with PD will change and leave you feeling uncertain. But life, too, is uncertain. That doesn't make it less distressing, especially for those of us who like to know what lies ahead. But accepting that things are uncertain and controlling what we can control — namely how we respond to change — may help.

+ **Grief (sense of loss)**

For some, Parkinson's may eventually limit driving, walking and other activities. These can feel like losses to independence, a usual way of doing things, or even plans or dreams for the future. Family members often share this sense of loss.

David Iverson, broadcast journalist and MJFF Patient Council Member Emeritus, has said, "Over time, Parkinson's is a disease of subtraction. It keeps taking things from you one by one. And one thing I've really observed is that the people who do the best with managing Parkinson's are the ones who believe in addition, who keep adding things into their lives."

These "adds" could be friends in the Parkinson's community; new activities, such as research participation; new ways of doing old activities; or new perspectives. Many adopt or grow a sense of optimism and gratitude to help reframe their situation. Michael J. Fox has said,

"Look at the choices you have, not the choices that have been taken away from you. In them, there are whole worlds of strength and new ways to look at things."

+ **Loneliness**

For many people and families, Parkinson's feels lonely, especially in later years. For some, significant movement, thinking or speech changes make it difficult to connect with friends or loved ones or to participate in activities outside the home. But maintaining positive relationships is important throughout Parkinson's — for both people with PD and their loved ones. These connections boost mood, promote brain health, and provide support and encouragement.

As PD changes, you may need to find new or creative ways to connect. If going out is tough, for example, invite friends to your home or meet virtually. You also can meet people like you online, through forums such as MJFF's Buddy Network. (See resource #6 on [page 34](#).) If you have speech troubles, ask your occupational or speech therapist about devices to help you speak more loudly or clearly. Or, connect in ways that don't require much talking, such as listening to music, playing a board game, or watching a movie together.

+ **Guilt**

Many people worry about how growing care needs might affect their relationships or their loved ones' daily lives. Some worry about "being a burden" to spouses, who become full-time carers, or to adult children, who are building careers or raising young families. Family members, too, may feel guilt or grief about the situation

or not having the time or resources to provide more support, or for taking some time for themselves or a much-needed break.

Talking to each other and planning for the future may ease guilt and provide comfort.
(See resource #4a on [page 34](#).)

Additional tips for working through emotions:

+ Name your feelings

Describing what you feel can help you understand what you're experiencing. Go beyond naming an emotion ("I'm angry" or "I feel nervous") to include physical sensations. Do you breathe more quickly and shallowly when you're anxious? Does your heart pound when you're angry? Do you feel a tightness in your chest with sadness? Recognizing how emotions show up in your body may help you manage them. And remember, strong feelings often are only temporary. (Frustration, sadness or worry may flare, for example, but their intensity typically wanes.)

+ Share with others

Many people, their loved ones and others in the PD community have similar feelings. Sharing with each other or with trusted advisors can help you learn how others approach emotions and how to work through yours. Your doctor, a mental health therapist, a social worker or other providers also can provide guidance.

+ Try to be present

Strong emotions can pull our attention away from the here and now — to regrets about the past or worry about the future, for example. Coming back to the present can help manage emotions. You can ground yourself with deep breathing, focusing on your surroundings, or writing down three things for which you are grateful. Being present can help you more fully enjoy your day-to-day life, hobbies, and time with friends and family.



**Parkinson's
Progression
Markers
Initiative**

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments.

PPMI gathers data and samples over time from volunteers around the world — both with and without Parkinson's — to increase understanding of symptoms and progression; find measurements in the earliest stages (even before motor symptoms); and advance treatments to slow, stop or prevent disease.

Whether you have Parkinson's or care about someone who does, you can help.

Find out how and join PPMI, the study that could change everything, at michaeljfox.org/ppmi.



Research toward New and Better Treatments

Currently available Parkinson's medications and surgeries are effective for many motor symptoms and some non-motor symptoms. But they are not able to adequately address all symptoms in all people throughout all of life with Parkinson's.

Researchers are working urgently to understand exactly why symptoms happen, and what brain chemicals and pathways play a role, to develop new and better treatments. Walking and balance changes, for example, likely involve chemicals and pathways other than dopamine. (This may be why currently available medications, which mostly target dopamine, don't work well for these symptoms.) Understanding which chemicals and pathways are impacted can lead to more effective therapies.

A variety of therapies are in clinical trial testing for both motor and non-motor symptoms. In general, these include:

- + Medications, both new and repurposed (available for another condition and now being tested in Parkinson's)
- + Exercise, including different forms of aerobic and other activity (walking, stretching, etc.) and physical therapy techniques
- + Brain stimulation, delivered either outside the brain, such as by transcranial stimulation, or inside the brain, as with deep brain stimulation (DBS)
- + Technology, such as vibrating socks or virtual reality systems to enhance walking, or devices to improve speech

At the same time, researchers are learning about the personal and care partner experience of Parkinson's to better support people and families living with disease.

And they also are working diligently to develop a treatment to slow or stop disease progression and, one day, prevent disease. Several treatments with the potential to change disease course now are in clinical trial testing. Some of these trials were made possible by information from The Michael J. Fox Foundation's Parkinson's Progression Markers Initiative (PPMI) study. This study gathers data from thousands of volunteers with and without PD over time to understand how symptoms start and change, and to better predict disease course, treat evolving symptoms, and stop disease progression. PPMI now is expanding to enroll more volunteers, including family members of people with Parkinson's. Learn more and join at michaeljfox.org/ppmi.

For the latest in Parkinson's research, visit michaeljfox.org. To find a research study near you, visit foxtrialfinder.org.

Resources

While not comprehensive, this list offers information and support for people and families with progressing Parkinson's.

1. NO TIME LIKE THE FUTURE

In his fourth memoir, Michael J. Fox takes on the big questions about life, illness and aging, all while navigating Parkinson's disease. Read an excerpt from the book and access related resources:

➤ michaeljfox.org/no-time-like-right-now

2. PARKINSON'S EXERCISE CLASSES

Many exercise programs are available for people with Parkinson's of all ages and fitness levels. You can find classes online or in person, do them on your own or in a group. Here are a few examples of popular Parkinson's-specific programs, many of which offer virtual classes:

- + Daily Dose: dailydosepd.com
- + Dance for Parkinson's: danceforparkinsons.org
- + Delay the Disease: ohiohealth.com/services/neuroscience/our-programs/delay-the-disease
- + Invigorate: invigoratept.com
- + Parkinson's Fitness: parkinsonsfitness.org
- + PWR! Parkinson Wellness Recovery: pwr4life.org/virtual-pwr
- + Rock Steady Boxing: rocksteadyboxing.org

3. DRIVING EVALUATION

A driving evaluation can offer an objective assessment of your skills and safety on the road. An occupational therapist or an organization such as AAA may offer these services:

- myaota.aota.org/driver_search
- exchange.aaa.com/safety/senior-driver-safety-mobility/evaluate-your-driving-ability

4. EDUCATIONAL RESOURCES

MJFF's guides provide information and tips for managing specific aspects of life with Parkinson's:

- a. *Looking Ahead with Parkinson's: A Guide to Future Care Planning*
michaeljfox.org/lookingahead
- b. *Thinking, Memory and Parkinson's*
michaeljfox.org/cognitionguide
- c. *Deep Brain Stimulation and Parkinson's*
michaeljfox.org/dbsguide

Find more resources at michaeljfox.org/guides.

5. THE HEIMLICH MANEUVER

Also called abdominal thrusts, this life-saving technique can help people who are choking. People with Parkinson's who experience significant swallowing problems may be at risk for choking, so care partners and family members should learn how to help in case of emergency:

- redcross.org/content/dam/redcross/atg/PDF_s/ConsciousChokingPoster_EN.pdf

6. SUPPORT GROUPS

Support groups are available for people with Parkinson's, their loved ones and care partners, both online and in-person:

- michaeljfox.org/news/support-groups
- parkinsonsbuddynetwork.michaeljfox.org
- **Support Groups — Family Caregiver Alliance**



7. HOSPICE

Information on end-of-life and hospice care and how hospice differs from palliative care:

- hospicefoundation.org/Hospice-Care
- nia.nih.gov/health/what-are-palliative-care-and-hospice-care
- nhpco.org/find-a-care-provider

8. PALLIATIVE CARE SPECIALISTS

A team of experts who can, at any time in disease (not only near the end of life) help manage troublesome symptoms and coordinate communication and align goals of care among a patient, family and their health care team:

- getpalliativecare.org/provider-directory
- nhpco.org/find-a-care-provider

9. CARE PROVIDERS AND PROGRAMS

Online resources to help you learn more about being a care partner and about in- and out-of-home care options:

- + AARP: aarp.org/caregiving/local
Enter your location for nearby resources.
- + Family Caregiver Alliance: caregiver.org
- + MJFF: michaeljfox.org/CaregivingGuide
- + National Council on Aging: ncoa.org
- + Parkinson & Movement Disorder Alliance: pmdalliance.org/certified-parkinson-disease-care-facilities
- + Your local department on aging: hhs.gov/aging/state-resources/index.html

10. RESPITE CARE

Respite care offers care and assistance for a short period, such as a few hours a week or a few weeks at a time, either in the home or at another location. It's designed to give primary caregivers a temporary break:

- archrespice.org/respitelocator

11. LEARNING AND RESEARCH OPPORTUNITIES

- + Fox Trial Finder: an online tool to find recruiting clinical trials in your area
➤ foxtrialfinder.org
- + Navigating Clinical Trials: what to know and ask about joining Parkinson's research studies
➤ michaeljfox.org/your-role-research
- + MJFF website: the latest in Parkinson's care and research
➤ michaeljfox.org
- + Parkinson's 360: information on clinical, emotional and social aspects of life with Parkinson's
➤ michaeljfox.org/parkinsons-360
- + Parkinson's Progression Markers Initiative (PPMI): MJFF's study following people with and without Parkinson's over time to understand how disease starts and changes, and to better predict and treat Parkinson's
➤ michaeljfox.org/ppmi

This guide was written by:

Rachel Dolhun, MD

Movement Disorder Specialist
and Senior Vice President of
Medical Communications

The Michael J. Fox Foundation
for Parkinson's Research
New York, New York

Whitley Aamodt, MD, MPH

Movement Disorder Specialist,
Instructor of Neurology, and
Edmond J. Safra Fellowship in
Movement Disorders alumna

University of Pennsylvania
Philadelphia, Pennsylvania

Thank you to the people, families and experts who offered their experiences and insights to this guide:

Kirk Hall, MBA

Neuropalliative Care Advocate
Highlands Ranch, Colorado

David Iverson

MJFF Patient Council
Member Emeritus
Oakland, California

Benzi Kluger, MD, MS

Professor of Neurology
and Palliative Care
University of Rochester
Rochester, New York

Soania Mathur, MD

MJFF Patient Council Co-chair
Toronto, Canada

Suzanna Reichwein, MSW

Manager of Research and
Clinical Programs
University of Pennsylvania
Philadelphia, Pennsylvania

Malenna Sumrall, PhD

Patient and Care Partner Advocate
Castle Rock, Colorado

Lauren Zelouf, MSW, LSW

Clinical Social Worker
University of Pennsylvania
Philadelphia, Pennsylvania

The information in this guide was accurate at the time of publication in January 2022. For the latest in Parkinson's care and research, visit michaelfox.org.

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**He doesn't
have Parkinson's.
But he can help
end it.**

Join the study
that could change
everything.





Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments. Whether you have Parkinson's or care about someone who does, you can help.

Participate today at michaeljfox.org/ppmi.



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