

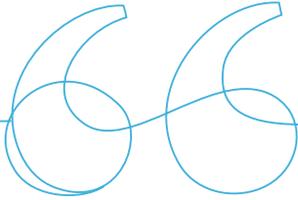


Facing Parkinson's Together

A Guide for Care Partners



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH



When you have family and friends to love and take care of you, you realize how lucky you are. Parkinson's sucks, but life is better because you have them.



Michael J. Fox
Founder

*Welcome to Facing Parkinson's Together:
A Guide for Care Partners*

In the words of Lonnie Ali, being a care partner is love in action. That action takes many forms: from the tactical — scheduling medical appointments — to the intangible, such as managing your own emotions and those of your loved one.

The Michael J. Fox Foundation developed this resource to help care partners navigate this complex journey. We worked with members of our community and experts in movement disorders, psychology and social work to create a resource that we hope will be informative as well as reassuring.

As you read the stories of other care partners and learn strategies for managing the load, we hope you take away this important fact: You are not alone.

And in case it helps to hear it, we'll say it:

You're doing a great job.

How to Use Facing Parkinson's Together: A Guide for Care Partners

This guide contains links throughout to help with navigation. When you click on a link, you'll be taken to that section.

At the bottom of each page is a link to the Table of Contents: Think of this as your “home” button.

Throughout *Facing Parkinson's Together*, keep an eye out for:



Community Quotes

Our contributors share their stories.



Care Partner Tips

Advice from our community of care partners to you.



Printable Pages

Print these resources for easy reference or to share with others.

Cover photography, clockwise from top left:

Prentis Brooks has been a care partner to his wife, Christie Brooks, since her Parkinson's diagnosis in 2013 at age 50.

Heather, Zoe and Jeff Butchen at a Michael J. Fox Foundation fundraising event.

Josip Markus has supported his dad, Alojz “Louie” Markus, since his diagnosis in 2006 at age 62.

Cecily and Bob Harmon at daughter Kate's wedding in 2023.

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Foreword

Love in Action: The Care Partner Journey

Lonnie Ali was a care partner to her husband, athlete and humanitarian Muhammad Ali. She is a member of MJFF's Founders Council and a previous member of the Board of Directors.

Care partnership is a journey of love, resilience and profound transformation. When Parkinson's disease enters a family's life, it affects more than just the person receiving the diagnosis; it reshapes the lives of everyone who loves them. I know this journey intimately. As Muhammad's partner and care partner, I learned that Parkinson's doesn't just test the body; it tests patience, courage and the very fabric of relationships. Yet within those challenges, I also found strength, purpose and an unbreakable bond.

In the early days of a Parkinson's diagnosis, fear and uncertainty can feel overwhelming. I vividly remember seeking answers, trying to understand what our future would hold. Knowledge became my lifeline. Learning about the disease, its symptoms, treatment options and the importance of working with specialists empowered me to advocate for Muhammad and our family. It's also why, in addition to working with The Michael J. Fox Foundation, we created the Muhammad Ali Parkinson Center, which provides trusted information, expert guidance and community support to people living with this disease and their families.



Being a care partner is something you figure out as you go. There's no standard list of responsibilities and no handbook to follow. But a resource like this guide is invaluable in helping care partners feel less alone. Many are traveling the same road with you — even if their road takes different twists and turns.

I wish I had a resource like this when I embarked on my care partnership journey. No matter where you are in your travels, I encourage you to use this guide however you see fit. Read it cover to cover, or flip through it when the time is right. Use or adapt what works for you; hold it close and refer to it often. Leave what doesn't work behind.

As I reflect on my family's journey, I am reminded that care partnership is not a burden — it is love in action. There will be hard days, but also moments of deep connection and joy. By caring for our loved ones and ourselves, we honor life as it is, not just the illness we face.

With gratitude,

Lonnie Ali

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to her mom.*

Personal stories as told to Lois Levine.

Community Contributors

We are grateful to the members of The Michael J. Fox Foundation community who supported the creation of this guide by sharing their experiences and feedback.



Prentis Brooks is a care partner to his wife, Christie. Christie was diagnosed with Parkinson's in 2013 at age 50, and with multiple system atrophy in 2024 at age 61. [Read Prentis' story on page 30.](#)



Heather Butchen is a care partner to her husband, Jeff. Jeff was diagnosed in 2013 at age 51. [Read Heather's story on page 55.](#)



Zoe Butchen is a care partner to her dad, Jeff. Zoe is a corporate giving relationship manager at MJFF. [Read Zoe's story on page 27.](#)



Melissa Clague enjoys a mutually supportive relationship with her wife, Stephanie Smart. Stephanie was diagnosed with Parkinson's in 2018 at age 54. [Read Melissa's story on page 13.](#)



Jessie Drew-Cates was a care partner to her husband, Billy Cates. Billy was diagnosed in 2015 at age 70 and passed away in September 2025. [Read Jessie's story on page 47.](#)



Kate Harmon was a long-distance care partner to her dad, Bob. Bob was diagnosed in 2006 at age 57 and passed away in 2024. Kate is a senior community fundraising specialist at MJFF. [Read Kate's story on page 19.](#)



Josip Markus is a care partner to his father, Alojz. Alojz was diagnosed in 2006 at age 62. [Read Josip's story on page 34.](#)



Julie Porter supports her close friend, Becca Miller. Becca was diagnosed in 2013 at age 39. [Read Julie's story on page 62.](#)



Walter Siegenthaler is a long-distance care partner to his daughter, Erika Neitzke. Erika was diagnosed in 2019 at age 40. [Read Walter's story on page 58.](#)

We would also like to thank the following members of The Michael J. Fox Foundation community, whose photos appear throughout this guide:

Patient Council members Leonard Chandler, Jimmy Choi, Denise Coley, Michael S. Fitts, Soania Mathur, MD and Claudia Revilla; community member Bernard Whitman; and their families.

The Role of the Care Partner

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What Makes a Care Partner?

Care partner. Caregiver. Ally.
Partner in Parkinson's.

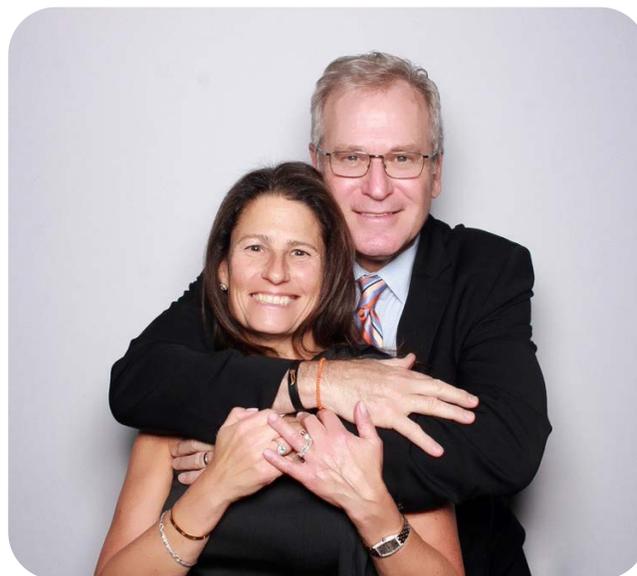
Whatever words you use to describe yourself, you are an essential part of your loved one's care team. Many people call themselves care partner. Some prefer caregiver, ally or carer. Others simply say partner, child or friend. One community member appointed himself "Chief Optimism Officer" of his wife's care team. Another refers to herself as "wife, researcher, morale booster, teacher, planner and secretary," because no one word encompasses her role.

If you support someone in their disease journey in any way — emotionally, physically, mentally, spiritually, financially or otherwise — you are a partner in their life and care. You and your loved one work together as a team, in a new type of relationship. As with any relationship, both people must commit, using open and honest communication, to work through the ups and downs of life — and life with Parkinson's.

Being a care partner is something you figure out as you go. There's no standard list of responsibilities or handbook to follow. But you don't have to figure it out on your own — and you are not alone. Many others are traveling the same road with you. They can share their approaches, learnings and trials and errors to help you on your path.

A Note on Language

Throughout this guide, we use the words care partner because the wider Parkinson's community has, by and large, voiced their preference for this term. Many say they feel care partner best describes the mutual care and support between the person living with Parkinson's and the people who love them. We know not everyone prefers this term; as with everything in life, choose what works best for you.



Heather Butchen is a care partner to her husband, Jeff, who was diagnosed with Parkinson's in 2013 at age 51. Heather and Jeff started their own Parkinson's support group in 2014, a year after Jeff's diagnosis.



You're not alone. No matter the topic — medication side effects, emotional ups and downs, constipation — someone else has experienced it. There are always people or resources to guide you.

Heather Butchen

What Does Care Partnership Look Like?

The care partner role is different for everyone. What it looks like depends on many things: your relationship to your loved one, their symptoms and needs, how they want to be supported, what you feel comfortable offering, where you both are in life, what else is going on in your own lives and more.

Anyone can be a care partner: a spouse, a child, a relative, a friend or a neighbor. You might live with the person you care for, or you might live in another state or country. You could be the primary care partner, providing most or all support. Or you may be part of a larger care partner team that includes family, friends and professional caregivers.

Some care partners might assist their loved one around the clock. Some might help for a few hours a day, like when medication wears off or during the night. Other care partners may provide only a few hours of support every week or month. Others may not be a care partner full time but stand ready to support the primary care partner as needed.

Throughout this guide, we share perspectives from different types of care partners: adult children caring for parents, parents caring for adult children, spouses, partners, friends and those caring across long distances. Every care partner relationship is unique, and we hope sharing these stories helps you see yourself and know that you are not alone in your care partner journey.



Becca is one of my closest friends. I live in Brooklyn, and she lives in New Haven, about 80 miles away. I was there for her when she had deep brain stimulation surgery, but I'm not involved in her day-to-day care. I'm a friend who checks in and is there when she needs to talk. She knows I'm always here if she needs me. And I know she's there for me, too.

Julie Porter

The Many Responsibilities of a Care Partner

Care partners provide support in many ways. What you do as a care partner can vary from day to day and over time as Parkinson's evolves. You may already do some or all of the tasks on this list; other tasks may surprise you. This list isn't comprehensive: You may also support your loved one in ways that aren't listed here, or you may find you never take any of these tasks on at all.

Health Care



- Driving to and joining medical appointments
- Picking up, organizing and managing medication
- Calling the insurance company
- Coordinating home modifications for safety and accessibility

Social



- Coordinating social visits with family and friends
- Ensuring your loved one is comfortable in social settings
- Supporting hobbies and other joyful activities
- Keeping a loved one company while the primary care partner takes a break

Emotional



- Listening without judgement
- Helping process worries or concerns
- Planning for the future, however far ahead you wish to plan
- Documenting your loved one's life stories and personal history

Everyday Life and Logistics



- Overseeing day-to-day planning and organization (such as cooking, cleaning and finances)
- Assisting with bathing, dressing, shaving or applying makeup
- Coordinating non-health related activities like home repair, pet grooming or childcare

Partnering through Parkinson's



Melissa Clague

Melissa and her wife, Stephanie, have been living with Parkinson's since 1999.

In 1999, a neurologist diagnosed my wife, Stephanie, with essential tremors. She was given medications, but the tremors kept getting worse. After years of seeking answers, she finally met a movement disorder specialist who correctly diagnosed her with Parkinson's and prescribed carbidopa/levodopa. It was life-changing.

When Steph was misdiagnosed and struggling, we were preparing for a life of disability. Getting the right diagnosis and treatment in 2018 changed everything. She was herself again. I was joyful for Steph, but I also grieved all the years lost to misdiagnosis. That grief still surfaces sometimes.

We know that Steph has a progressive disease, but we've made a conscious decision to leave the phrase "care partner" to our medical teams. For us, the term implies an imbalance — that one person is the patient who needs help, and the other is a helper. In medicine, a care team makes sense because of hierarchy and expertise. But in our relationship, we're simply life partners. The term "care partner" feels like importing medical hierarchy into our personal lives. It doesn't belong there.

As part of the LGBTQ+ community, we've always needed a medical team that respects us as partners. At every new appointment, Steph still wonders, "Will this nurse or doctor be biased? Does she say 'wife' or 'partner'?" That mental energy takes away from what we need to focus on. Thankfully, her current team treats us as we are.

I don't really think about disease progression. It's a scary thing, so I put a big rock on those feelings. I only occasionally look underneath. Living in worry doesn't help. Two years ago, we traveled through Europe with our kids and my parents: 18 days, five countries, a new hotel almost every night. Steph carried luggage, hiked, did everything. We're planning another trip. Those moments remind us of what's possible, even with Parkinson's.

Most resources are aimed at partners who are full-time caregivers. That's important, but it's not our reality. I'd love to see broader options for couples whose partners are still active and managing well. Being a partner to someone with a chronic condition is challenging, especially a progressive one. But it's dangerous to frame it only as caregiving. Right now, I don't "take care" of Steph; we are partners. I hope the Parkinson's community continues broadening its understanding of partnership across different stages of the disease.



How Can Care Partnering Change over Time?

Just as every person is unique, so too is Parkinson's. As Parkinson's changes, support needs also change. While those changes look different for everyone, there are some common experiences across the Parkinson's journey. You might go through some, all or none of these, and you might face them earlier or later than others tend to.

Diagnosis and the Early Years

In the early days of Parkinson's, movement symptoms may be mild and emotions may run high, rising naturally in response to diagnosis or as part of Parkinson's mood changes. The support you provide may be more abstract as you and your loved one adjust to a new normal.

Processing a Parkinson's Diagnosis

As you and your loved one work through what this diagnosis means, your role may be focused on offering emotional support. This support can look like:

- + Asking questions to better understand what your loved one is experiencing.
- + Validating their feelings and experiences.
- + Holding a safe, loving and nonjudgmental space for your loved one to do what they need: talk, cry, vent, express worries or fears, or escape Parkinson's for a bit.

Processing a Parkinson's diagnosis means identifying — and learning to manage — complex, mixed emotions. Some people have a hard time naming emotions and just keep to themselves. Others feel comfortable talking through emotions with someone they trust, while others have trouble sitting with emotions and may act on them without realizing it.

Everyone processes in their own way and in their own time. There's no one way to work through emotions; there's also no "wrong" way, but there are ways that are less helpful, such as ignoring emotions or pushing them aside. *[For more, turn to The Emotional Impact on Care Partners.](#)*

Sharing Parkinson's with Others

The early years bring questions around whether, how and with whom to share the diagnosis. Many choose to keep Parkinson's private — some until they've fully processed the diagnosis, others until they feel symptoms are noticeable. Everyone has different reasons for sharing, and different timing for doing so. You can help your loved one think through the pros and cons of opening up and support them when the time is right.

Some care partners say it's harder to build their own support system while Parkinson's is a secret. They may not be able to fully express their feelings or engage with the Parkinson's community. If this is the case, consider speaking one-on-one with other Parkinson's or chronic disease care partners, or with a mental health professional.

Reflecting on Your New Role

As you would at the start of any new beginning, give this new role time and attention. That helps set the stage for life as a care partner. Consider these questions:

- + What does being a care partner mean to you and for you?
- + How might care partnering impact relationships with others?
- + How will you make yourself a priority throughout this journey?

A Few Years or More into Life with Parkinson's

As Parkinson's evolves, changes in symptoms and routines create opportunities for additional care partner support. You might see areas where you can help as your loved one adjusts medications, engages in physical therapy or other treatments, or modifies their health care team.

Managing Changing Symptoms

Progressing Parkinson's may bring more or new symptoms. Motor symptoms include tremor, slowness, stiffness, and walking and balance changes. Non-motor symptoms can include mood, sleep or sexual changes, constipation, pain and fatigue, among others.

Symptoms vary from person to person. Even if symptoms are well-controlled, other changes related to medication may begin to appear, such as:

- + “Off” time, when symptoms return as medication wears off between doses or in the morning.
- + Dyskinesia, or involuntary movements.
- + Fluctuations, or ups and downs, in symptom control throughout the day.

Over time, you'll become a keen observer of the disease; you may begin to know your person's symptoms almost as well as they do, sometimes even noticing changes (especially in mood or behavior) before them. You can offer insights about daily life with the disease to medical providers who only see your loved one periodically.

As a care partner, you may continue previous tasks, like coordinating and attending medical appointments, while taking on new ones. These could include things such as:

- + Assisting with dressing.
- + Helping with household tasks.
- + Logging symptoms and medications to figure out patterns in “off” time or dyskinesia that can direct medication adjustment.

Learning Flexibility

There may be days where your loved one isn't up for their usual activities. Unpredictability requires flexibility and adjusting expectations of what a “good day” means for you both. Now is the time to adapt activities you like doing together. It's important to keep up shared interests and activities in ways that make the most sense for where you are now.

Planning for the Future

As you and your loved one discuss how symptoms impact life and how to work around them, it's natural to begin thinking ahead. Some important topics to discuss include:

- + How long your loved one wants, or may be able, to work.
- + What Parkinson's means for your children or family in the long term.
- + If it's time to do that thing you've always wanted, like taking a vacation, learning a new skill or anything else you've been putting off.

It's often easier to consider immediate issues like jobs, finances and children. But it's just as important to talk about what brings you both meaning, purpose and fulfillment. These areas serve as your compass for making decisions about the future and help fill your life with the people and things that matter most along the way.

Decades and Beyond of Living with Parkinson's

Over the long term, caring for your loved one might transition into a more intensive partnership, one that may be more hands-on and require more time. Care partnering may feel more one-sided, requiring more of you than it did in earlier years.

Navigating Increased Care Needs

As Parkinson's moves forward, symptoms gradually increase, and new symptoms can develop. These could include walking and balance problems; falls or near falls; memory, thinking or behavior changes; or seeing things that aren't there (hallucinations). Not everyone experiences all of these symptoms, and the amount of help needed varies as well. Certain activities might require assistance from start to finish, while others might require help for only a few steps of the process.

Care partnering tasks could include:

- + Helping your loved one with daily activities.
- + Putting pills into pill boxes for each day of the week and reminding your loved one to take them or handing them out.
- + Starting under-the-skin infusion medications each day or making sure deep brain stimulation batteries are charged when needed.
- + Making sure canes or walkers are accessible and reminding your loved one to use them.
- + Joining physical or speech therapy appointments and helping with exercises between appointments.

Supporting Yourself

During these years, care partners typically take on more and more. But there's only so much one person can do. Many primary care partners provide most of their loved one's care while also running the household, leaving little or no time for yourself or your health.

It can feel overwhelming and lonely, especially when relationships with your loved one, family and friends change. [Turn to *Shifting Roles, Responsibilities and Relationships for more.*](#)

That's when it's time to ask for help from family or friends, professional or paid caregivers or community services. Remember: Asking for help is a sign of strength, not a weakness. [For tips on making these requests, turn to *Pillar 2: Ask for What You Need.*](#)

Considering Care outside the Home

Depending on symptoms and needs during later years, some care partners and families may consider whether their loved one might receive the safest, fullest care outside of the home, in an assisted living facility or a nursing care home. This can be tough to think about and challenging to navigate.

While never easy, making decisions about this kind of care may be somewhat easier when you discuss the possibility early and often. It's important to understand everyone's thoughts, feelings and wishes. Your loved one's doctor, social worker and other providers can help facilitate these discussions and decisions. [Turn to *How Can We Plan for the Future? for more.*](#)

How Do Individual Circumstances Affect Care Partnership?

Beyond passing time and changing symptoms, personal, social and cultural factors further shape what care partnership looks like.

Age at Diagnosis

The care partner relationship may differ based on when in life a person is diagnosed. People with early-onset Parkinson's (EOPD), diagnosed at 50 or younger, often have different needs from those diagnosed later in life. These needs might be related to stigma and misconceptions about Parkinson's, caring for young children and continuing careers, on top of managing symptoms. Resources specific to EOPD, including support groups (if available) and outspoken advocates with early-onset disease, can offer insight and guidance. [Visit michaeljfox.com/eopd](http://www.michaeljfox.com/eopd) for more.

Relationship Status

Your relationship with your loved one before diagnosis also plays a role. Some people have a solid relationship, which creates a strong foundation for care partnering. Others have a strained or distant relationship that adds additional uncertainties and emotions. Acknowledge where your relationship stands, and work through any challenges with a counselor or other trusted source, if helpful.

Personal Life

Your personal life can impact how much and what type of support you can offer. We all have busy lives that include careers, families, hobbies and more. Some of us experience our own issues related to aging or living with medical conditions. Others are part of the “sandwich generation,” tasked with caring for both a young family and older relatives at the same time. Setting boundaries, practicing self-care and asking for what you need can help you balance caring for yourself and others.



Patient Council member Claudia Revilla at home in Texas with her husband, Carlos. Claudia was diagnosed with Parkinson's in 2010 at age 45. She is committed to education, advocacy and the search for a Parkinson's cure.

Distance

Some care partners live with their loved ones; others care from several states or countries away. Those who live at a distance may want to build a habit of regularly checking in — both with their loved one and with their loved one's main care partner(s).

You also can support in other ways:

- + Join doctor visits by telephone.
- + Schedule or coordinate appointments.
- + Submit insurance claims.
- + Make regular in-person visits. Consider scheduling medical visits during those times so you can attend in person. Look for ways to give the primary care partner a break while you're there.
- + Ship household supplies, groceries, medical devices or medications to your loved one's home.

- + Organize and cover in-home support, if needed. This could look like engaging another person to check on your loved one and their primary care partner, prep meals, organize and give medications, or do light housecleaning.
- + Research and arrange local services, such as physical or speech therapy, community exercise or meal delivery. If possible, work with a care coordinator who can serve as additional eyes and ears on the ground.



- + Support the primary care partner in their own self-care. Don't just ask if they're caring for themselves; help make it happen, in whatever way they say helps.
- + Use technology to stay connected. Consider setting up a regular video call (for example, every week or every month) to check in.

Kate Harmon (top left) stayed connected with her family through video calls.

Time Since Diagnosis

Many care partners and their loved ones say they feel very supported when first opening up about a Parkinson's diagnosis. Eventually, though, that support often fades and isn't there when it's really needed. No matter the time or distance, showing up consistently is key.

As a care partner, you may need to manage these relationships to keep them from fading into the background — or to bring them back. If you feel like people have disappeared, tell them how much their support means and how they can help. It can be beneficial to remember the reasons why people might step back: They may be busy with their own lives, unsure what to say or do to help or grappling with their own feelings about illness and mortality. In other words, it's not personal — but you still may

need to ask directly for their support. Asking directly might feel like one more thing on an already long to-do list, but asking gets you and your loved one the support you most need. [Turn to Pillar 2: Ask for What You Need to learn more.](#)

Social, Cultural and Other Factors

A person's gender identity, racial or ethnic background, sexual orientation and socioeconomic status also can affect the care partner experience.

Across all diseases, men are less likely than women to be care partners, and male care partners may be less likely to seek support. Those who are part of an underrepresented or marginalized group — members of the LGBTQ+ community and people with diverse sexual orientations and gender identities — can face unique challenges that aren't met through current support structures. These individuals may see fewer, if any, care partners like themselves and be less inclined to reach out for support or assistance. This can exacerbate loneliness and isolation, and lead to burnout. [For more, turn to Burnout Is Real — and Preventable.](#)



As part of the LGBTQ+ community, we've always needed a medical team that respects us as partners. At every new appointment, Steph still wonders, "Will this nurse or doctor be biased? Does she say 'wife' or 'partner'?" That mental energy takes away from what we need to focus on. Thankfully, her current team treats us as we are.

Melissa Clague

The Good, the Bad and the Funny



Kate Harmon

Kate provided long-distance support to her father, Bob.

My dad was diagnosed with Parkinson's disease in 2006. At that time, my parents were living in central Florida; I was attending college in Virginia, and my sister Emily lived about an hour away from them. For a long time, Dad managed his Parkinson's well. Around the time of the COVID-19 pandemic, things started to decline. When Emily decided to move to Texas in 2021, we knew we needed to make a plan, because Dad had started showing signs of dementia.

We made sure my mom knew who to call for what, but when you're the one living it every day, it's exhausting. Emily and I each had our roles: Emily called them daily. I was the "fixer" — the one Mom called when she didn't know what to do.

When Dad started having delusions (believing in scenarios or situations that never happened or aren't true), Mom would hand the phone off to us. At one rehab facility, a social worker was rude to Mom, and I handled it. Sometimes you need a person who's not afraid to be the bad cop.

Eventually, Emily and I realized we couldn't assess things from afar. I flew down and immediately saw that things needed to change. I set up in-home support so Mom could get out of the house. We added small things to make their home, and their lives, safer. We also organized outside help for Mom. I'd text her friends to ask if they could visit or bring lunch.

My family always found ways to laugh, because if you're not laughing, you're crying. Even when things were absurd, we found humor. When Dad was in hospice, Mom said at one point, "We probably shouldn't be laughing so much." I told her that if Dad woke up, he'd be pissed that we were sitting there quietly. Laughter and connection kept us going.

So many parents will say, "Don't upend your life for me." Having systems in place to help care for them relieves the guilt — both theirs and yours. It helps you make sure you're thinking ahead, not just about your ill parent, but about your parent who's doing the care partnering as well. What if something happens to them? You need contingency plans for that, too.

My parents had their wills, powers of attorney and health care directives in place. We kept digital and paper copies of everything. That helped when critical moments came up. When Dad was in the ICU, Mom called and said, "You need to come." She asked if we wanted her to put in a breathing tube until we got there, and we said no. I pulled Dad's documents up on my phone and read it aloud. That wasn't what he wanted. I have no guilt about how we protected Dad and enacted his wishes and legacies because I knew what to do.

Walking your parent — the person who raised you, who named you, whose eyes match yours — to the end of their life changes you forever. You're never mentally or even physically prepared for the thing that starts the ticking clock toward the end. Give yourself grace. It's hard and it's heartbreaking, but you do it because of love.



How Caring Affects Care Partners

In This Section:

[The Emotions of Care Partnership](#)

[Shifting Roles, Responsibilities and Relationships](#)

[The Emotional Impact on Care Partners](#)

The Emotions of Care Partnership

Caring for a loved one with Parkinson's comes with a swirl of feelings, sometimes all at once. Feelings can be overwhelming, but they can also serve as a helpful guide. By learning to understand what your emotions tell you, and to respond instead of react, you can protect your health and provide steady, compassionate support.

What Are Emotions?

Emotions aren't glitches in your system. They're the dashboard lights for your mind and body. When your stomach knots in worry before a hard conversation or your chest warms with gratitude after a kind word, that's a signal saying, "Something important is happening; pay attention."

These dashboard lights are natural alerts that help us spot danger, savor good moments and figure out what matters most. Covering up those alerts — pushing feelings aside or pretending they're not there — is like taping over your car's warning lights: The problem remains, and you lose useful information.

Inside the body, emotions ride on the autonomic nervous system — the network that controls automatic functions like heart rate, breathing and digestion. A sudden spike of frustration can accelerate heart rate and quicken breathing. When that frustration remains, it can settle into the body as stomach knots, jaw tension or a dull headache. If ignored, these bodily changes can contribute to fatigue, mood changes and other health problems.



The good news is that the same body signals warning you of rising stress can also give you a lever for relief. By paying attention to symptoms like a pounding heart or tight shoulders, and then pairing that awareness with slowed breathing, taking a short walk or doing a deep stretch, you can disrupt the cycle before it negatively impacts your relationship with your care partner or becomes a long-term issue.

Common Care Partner Emotions

Learning your loved one has Parkinson's can unleash a storm of emotions, sometimes all at once. Many people experience shock, fear and helplessness, along with a sense of relief that long-mysterious symptoms have a name.

At the same time, worry about what happens next can loom large. And as Parkinson's progresses, emotions change, too: You may feel sadness as new symptoms develop, exhaustion from managing medications or comfort that a new treatment option is working well.

Common emotions throughout the care partner journey include:

- + Frustration or overwhelm with the daily stressors of caring.
- + Anxiety or fear about the future.
- + Guilt or shame about taking time for yourself.
- + Sadness or grief about changes in your life.
- + Loss or longing for the life you once kept, plans you can't fulfill, friendships that faded or uninterrupted time for yourself.

Care partners may also feel different types of loss and grief, too:

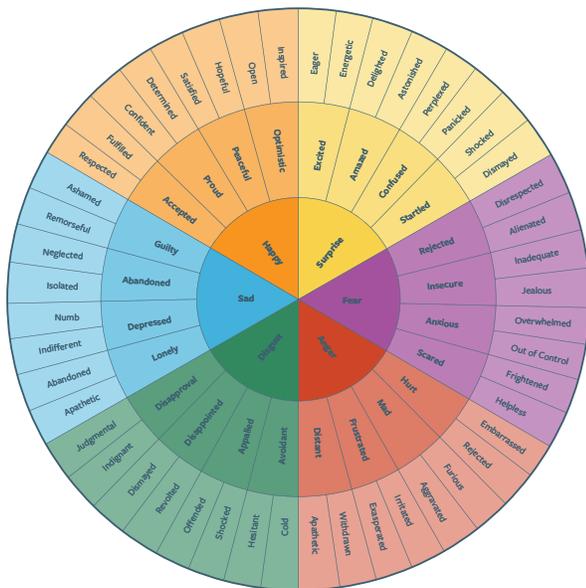
Ambiguous loss is when someone is physically present but generally "not the same" as they once were. This can happen with memory and thinking or cognitive changes, as well as with personality or behavior changes that might happen with Parkinson's. It may feel like your loved one is not the same person you married, parent who raised you or friend you grew up with.

Anticipatory grief is feeling sad about a potential loss before it happens. Some people grieve the loss of a loved one before they pass; others grieve the loss of life or retirement they might not get to experience.

It's essential to recognize that these — and all — emotions are valid, and that you have the right to feel the way you do.

Naming What You Feel

Instead of suppressing emotions, aim to acknowledge and label them. When we see our emotions as guides, they turn into tools that steer everyday choices and foster long-term well-being. Naming emotions lessens their intensity and helps you move forward with them. It allows you to dive deeper into what you feel and why, which helps you process and communicate how you feel.



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If you have trouble naming a feeling, try using the emotion wheel. This categorizes a range of emotions in three concentric circles increasing in complexity. The innermost circle represents broad primary emotions, which are basic, instinctual responses that everyone experiences, such as happiness, fear, surprise or disgust. The middle circle includes secondary emotions, which are those we feel in

response to primary emotions, like joy stemming from happiness. The outer circle includes tertiary emotions, the most specific and detailed feelings, like delight building from surprise and amazement.

Emotions and Moods: What's the Difference?

Am I sad or am I depressed?
Am I worried or do I have anxiety?

When it comes to emotions, many care partners wonder what's normal, given the circumstances and what might be a sign of something deeper at play. We all have emotions. Many people, especially those with Parkinson's and their care partners, also experience mood changes like depression or anxiety. These mood changes can cause excessive worry or sadness that interferes with daily life, loss of interest in previously enjoyable activities or emotional withdrawal from others.

Recognizing the difference between emotion and mood, and managing each, is an important part of caring for both you and your loved one.

One research study, for example, found that unaddressed emotional strain in care partners leads to poorer mental health for them as well as poorer quality of life for their person with Parkinson's.

Emotions are short-lived reactions to a clear event. Moods float in the background for hours or days with no obvious trigger. Picture the jolt of irritation when a neurologist runs late (emotion) versus the gray discouragement that lingers all afternoon (mood). Emotions are briefer but more intense, while moods are diffuse and last longer, shaping how we think about everything we do. Remember, emotions are temporary: What might seem like the worst feeling ever, one that will never go away, will ease over time.

Experiencing sadness, an emotion, after a tough physical therapy session is normal and usually lifts with a supportive phone call or a good night of sleep. Depression, a mood that affects up to one-third of care partners, persists for weeks or more and drains motivation, energy and enjoyment. Worry about

tomorrow's neurologist visit is situational, whereas anxiety does not ease once the appointment passes and spills into many other areas of life.

It's also helpful to know the difference between tiredness, the natural fatigue that follows a night of disrupted sleep, and burnout, a state of emotional, physical and mental exhaustion that builds when care partners can't take an adequate break. Burnout is linked to poorer health outcomes for both care partners and the person being cared for.

Recognizing where your feelings fall on the emotions and moods spectrum can guide your next steps. For ordinary fatigue, a nap or walk may help, while depression or anxiety may require professional support like counseling or medication. If you're feeling burnt out, consider structured time off to recharge.

How Emotions and Moods Differ

	Emotions	Moods
What starts them?	A clear event. For example, getting cut off in traffic sparks anger.	No obvious cause; they can simply come over you.
How long do they last?	Short: Usually seconds to minutes, sometimes an hour or two.	Longer: Several hours, days or even weeks.
How strong do they feel?	Intense: You might feel your heart pound or your face flush.	Milder but steady: Like a gray filter over the day.
What do they make you do?	Push you to act right away (shout, hug, run, celebrate).	Tint how you think: Everything seems easier when you're upbeat, or harder when you're down.
How should you handle them?	Name the feeling and reframe the situation. Deep breaths can help.	Change your scene or routine. Take a walk with a friend and get good sleep. Seek professional help for longer-lasting or significant mood changes.



Caregiving brings intense emotions, so learning to self-regulate is important. I thought I always needed to be strong for my father's sake. But having emotions is a gift, even when they're unpleasant or overwhelming. Let yourself fall apart when you need to, even if there's no one but yourself to catch you. Practices like meditation, breathing techniques and yoga help me stay centered.

Josip Markus

When Emotions Get the Best of You

Nobody's perfect. We all have moments of annoyance or impatience with the people we love. These are normal human reactions when things get hard. Learning how to recover and reconnect after tense moments protects and often deepens a relationship.

When you react in a way that you wish you didn't, tell your loved one, sincerely, that you are sorry. Period. No excuses, no explanations. You may feel guilty or bad, which is normal. But beating yourself up doesn't help. Give yourself grace, kindness and forgiveness so you can learn from the moment and do better the next time. [Turn to Pillar 4: Remember, You're Only Human for more.](#)

Everyone gets frustrated from time to time. But if you experience frustration constantly or consistently, you may be burned out; the current care situation may no longer be sustainable, or more support may be needed. [Turn to Burnout Is Real — and Preventable for more.](#)

Tips for Managing Your Emotions

Take a Moment in the Moment

Pause and label the feeling. Naming an emotion — “I’m feeling overwhelmed right now” — buys you a second to respond carefully rather than react with annoyance.

Notice how the feeling shows up in your body. Is your breathing shallow? Your jaw clenched? Your shoulders scrunched up? This helps you recognize the physical effects of an emotion, sometimes even before you can name it.

Ground yourself within your body. Slow, deep breaths from the diaphragm (the muscle that sits below your lungs and heart that helps you breathe) or a brief walk can quickly downshift the “fight-or-flight” response. Try breathing in for a count of four, out for a count of six.

Shift Your Mindset

Reframe the experience. Research shows that looking at a stressful event from a more positive angle helps you cope in the here-and-now and build resilience for the future. Try statements like, “My partner isn’t ignoring me; Parkinson’s is scrambling their signals.”

Remember, you are not your emotions. Emotions don’t define you. You may feel angry or anxious, but that doesn’t mean you are an angry or anxious person. Try stating it that way: “I am feeling angry right now,” not “I am angry.”

Build Emotional Management Muscles

Dig deeper. Look for what’s behind your feelings. If you often feel irritated, ask why. Is it a lack of sleep? Stress? Not feeling well in general? Journaling or talking with others can get to the root cause.

Practice mindfulness. Mindfulness is awareness, without judgment, of the present: your thoughts, feelings, sensations and environment. In one research study, nine weeks of Mindfulness-Based Stress Reduction, a program that teaches mindfulness tools and skills, raised awareness in care partners and improved patients’ quality of life. You and your loved one can practice together. Five minutes of a guided breathing or body-scan exercise can steady you both.

Seek professional or peer help. Virtual support groups, classes in which you learn mindfulness and other skills or counseling sessions can provide tools for emotion understanding and regulation and reduce any sense of isolation.

Check in with your loved one. Make checking in on emotions a habit. Ask something like, “On a scale of one to five, how do you feel?” Ask what’s behind their answer, and don’t shy away from the “big” emotions. Many care partners keep grief, guilt or overwhelm to themselves for fear their loved one might feel responsible. Your loved one may have similar feelings, even if for different reasons, and discussing them can bring you closer.



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Shifting Roles, Responsibilities and Relationships



Claudia Revilla's sons, David and Carlos (left), also provide support as care partners.

We all have roles and responsibilities within our partnerships or families. These are the everyday jobs that keep life moving, like taking out the trash, paying the bills, cleaning the bathroom or mowing the lawn. Sometimes we fall into a rhythm out of habit or preference. Other times, we discuss, divvy and assign roles.

Roles can shift temporarily, like when one person is traveling, focused on a hobby or involved in a big work project. Roles can also shift throughout life with Parkinson's, particularly as a person experiences physical or cognitive changes related to the disease:

- + Big muscle movement changes can lead to slowness and imbalance, which can make it harder or more time-consuming to do work around the house or in the yard.
- + Smaller muscle movement changes, like trouble with hand dexterity or coordination, might make doing the dishes or laundry more difficult.
- + Cognitive changes can make tasks like scheduling appointments, following a recipe or paying bills confusing or no longer doable.

Sometimes Parkinson's leads to a reversal of roles, where one person takes on tasks the other has always handled. For example:

- + Your loved one always managed the finances, but cognitive changes mean you need to step in.
- + Your loved one has to leave work or retire early, so you need to work more or make do with less.
- + Your parent needs help with bathing, dressing and other personal care, which is a switch from them caring for you throughout life.
- + You are the care partner to your adult child at a time when you may have otherwise imagined support from your child, given societal norms.

As with other life changes that Parkinson's can bring, communication and flexibility are key to managing these changes. ***For practical strategies that can help, turn to [The Pillars of Care Partnership](#).***

Embracing My Changing Role



Zoe Butchen

Zoe's dad, Jeff, was diagnosed when she was 14.

I work at The Michael J. Fox Foundation, and my dad has Parkinson's. My mom is the main care partner. I was 14 when my dad was diagnosed, and my role has changed over time. I've learned what questions to ask and how I can be more involved — maybe not as a primary care partner, but as support for my mom, too. She handles so much of the detail-oriented aspects of my dad's care — the phone calls and the doctor's appointments — but now I can step in as well.

One unique aspect of our situation is that my mom, brother and I will talk about the things the three of us are noticing about my dad. We can bring those things to a full family conversation, so my mom doesn't feel quite so alone in addressing them. We're not ganging up on him but serving as an extra set of eyes.

There's privilege in my position; I still get to be the daughter. I'm maybe not the best person to advise my dad on whether he needs a nap or what medications he should take. But I can bring up smaller things, like changes we've discussed with his movement disorder specialist, and help with that. Sometimes we do brain activities; I'll quiz him on my friends' names and give him a bit of a hard time (jokingly) for not remembering them.

When my dad was first diagnosed, it was important to my family to be a part of, and give back to, a community that impacted families like ours. Little did we know how much MJFF would impact our lives. From 2014 to 2024, my Team Fox campaign Dance Shake Donate raised \$168,000. What began as a social media challenge turned into a series of community events, including a shutdown of main street in my hometown with over 1,000 people!

I've continued fundraising for MJFF and taken on new endurance challenges. In 2025, I traveled to Guatemala to participate in the 3 Volcano Challenge alongside other passionate members of Team Fox and raised \$20,000 for Parkinson's research. I've both danced and climbed toward a cure, and I'm ready to take on whatever's next.

The Team Fox community has brought so much joy to this Parkinson's journey. Attending the MVP Celebration Weekend (an event to recognize top MJFF fundraisers) with my dad year after year has brought us together in unimaginable ways. The people we've met along the way have given us hope and inspired us. As a kid, I dreamed about one day being like the MJFF staff who supported me as a young Team Fox-er, and today, that dream is my reality. Working at MJFF feels like a true full-circle moment.



Changing with Changing Roles



Patient Council member Denise Coley was diagnosed with Parkinson's in 2018 at age 65. She lives with her husband, Bernard, in San Francisco, California. "I've been preparing for this care partner journey since the day I said 'I do,'" said Bernard.

As roles shift, your daily routine or household rhythm might be disrupted. Your relationship or individual contributions might feel off-balance, which could spark tension, conflict or resentment — from both of you.

Have regular, honest discussions with your loved one, and work together to redefine roles and responsibilities. These tips can help facilitate those discussions:

- + **Be respectful.** Avoid language that can make your loved one feel like a child. Phrases like “You can’t do this anymore” or “I’m in charge of that now” can lead to embarrassment or hurt feelings. Instead, say, “Let’s try this differently.” Remember, it can be hard for a person to accept they need help, and just as hard to receive it. [For more on communication, turn to Pillar 1: Talk Early, Talk Often.](#)
- + **Work as a team.** Don’t take over tasks or make changes behind your loved one’s back. Don’t rewash the dishes or remake the bed without their knowledge. And don’t try to take over too quickly. Encourage their involvement, adapting as needed, to preserve their contributions and independence as long as it is safe to do so. [Turn to How Can I Manage Parkinson’s Day-to-Day? for more.](#)

- + **Adjust expectations.** You may need to let go of standards you previously held. Reframing can help: The bed may not be made as neatly, but it’s still made.
- + **Don’t assume.** If you see your loved one struggling with a task don’t immediately assume you know why or what to do. Be curious: Why are they struggling? What solutions can you come up with together to preserve your loved one’s independence?
- + **Validate emotions.** Losing personal roles and responsibilities, especially ones that hold meaning and purpose, can trigger very real emotions like grief or despair. Hold space for those emotions.
- + **Revisit regularly.** Changes in roles aren’t one and done; responsibilities may shift throughout the course of Parkinson’s. Regularly check-in with your loved one about what’s working and where you might need to flex — perhaps every few months, around the time of doctor appointments.

Maintaining a Romantic Relationship

Parkinson’s care partners who have a romantic or intimate relationship with their loved one may find this dynamic evolving over time. Many factors can contribute, such as:

- + Changes in body image.
- + Movement symptoms like tremor, stiffness or dyskinesia (extra, involuntary movement).
- + Non-motor symptoms like changes in mood or desire.
- + Side effects of medication for Parkinson’s, depression or anxiety.
- + The unpredictability of Parkinson’s.
- + Care partner stress, exhaustion or uncertainty.
- + Role shifts when a care partner provides hands-on personal and medical care.



For me, being a care partner is an extension of the wedding vows that Christie and I took over 38 years ago: “In sickness and in health.” You may not understand it at the time you say it, but this is what it means. Taking care of someone in their final years is one of the most loving things you can do.

Prentis Brooks

Tips to Keep Your Romantic Relationship Strong

- + **Talk about feelings and needs.** You and your loved one may feel sadness, grief, anger and other emotions about relationship changes. Discuss not only your feelings but also your relationship — how it is now and how you’d like it to be. As in any relationship, each partner may have different wants and needs related to emotional and physical closeness.
- + **Find new ways to share intimacy.** Sex isn’t just sexual intercourse, and intimacy isn’t just sexual activity. It’s affection, shared laughter, meaningful conversation and simply being present with one another. Get creative: Express your love and connect in new and unique ways.
- + **Schedule sexual activity around symptoms.** Plan intimacy like you would any other important activity. Aim for times your loved one is typically “on,” when symptoms are lowest and medication is most effective. Also consider symptoms like fatigue or apathy, which often worsen later in the day, for optimal timing.
- + **Manage medication side effects.** Some people with Parkinson’s experience dyskinesia, or extra movement, which can increase with excitement or stress and interfere with closeness. Others, who take medications called dopamine agonists (which act like dopamine in the brain), may experience impulse-control side effects, including increased sex drive or interest. This can lead to a mismatch in desire between partners. Know about potential side effects and talk with your loved one’s doctor at the earliest sign.
- + **Ask health care providers for help.** Your loved one’s Parkinson’s doctor or mental health therapist can help with sexual symptoms and resulting relationship changes. They can add or adjust medications and refer you to couples counseling, a sex therapist or a pelvic health specialist who can address specific issues relating to sexual function.
- + **Expand your definition of intimacy.** For some people who are later in Parkinson’s, sexual activity may no longer be possible. This may bring a sense of loss, grief or loneliness. A therapist can help process these feelings. Your definition of intimacy may change: Love and connection, and how you express them, will look different. You and your partner may bond more through non-sexual or non-intimate touch, or through shared time and quiet moments together.

Connection Is Crucial



Prentis Brooks

Prentis Brooks and his wife, Christie, have been living with Parkinson's since 2013.

Many care partners struggle silently and don't reach out for help. Discussions around mental health wellness and even preparing for the eventual death of the partner — both financially and emotionally — are essential to easing that burden. I've been caring for my wife, Christie, since her Parkinson's diagnosis in 2013.

We've been married for 38 years. We were supposed to take a trip to France and Italy for our 35th wedding anniversary, but we moved it up. On the trip, we met another couple, and I recognized that the husband showed signs of Parkinson's. I mentioned that to Christie, and she spoke to him about it. It turns out that he had been diagnosed just 30 days earlier and was struggling emotionally. Her conversation with him really gave him some direction and support, and we've stayed in touch ever since.

That connection is crucial, not only for people with Parkinson's, but also for care partners. The isolation of the disease for the care partner — especially in the later stages — is something I didn't expect. After COVID-19, we discovered how limited home health care resources really are. Many professionals left the field after the pandemic due to burnout, and those remaining may not be trained in specific Parkinson's care, which is very different from general aging or dementia care.

I've built a support team of former coworkers, friends and family members, many who have been care partners themselves. We talk regularly. That support has been critical for me. I've always been the quieter, more introverted one in our relationship. But after Christie's second diagnosis — multiple system atrophy in 2024 — I've had to help her with nearly everything. She told me she never wanted me to take care of her, that it was supposed to be the other way around. I've had to become her advocate and speak up in ways that go against my natural personality. It's exhausting, but necessary.



For me, being a care partner is an extension of the wedding vows that Christie and I took over 38 years ago: "In sickness and in health." You may not understand it at the time you say it, but this is what it means. Taking care of someone in their final years is one of the most loving things you can do.

The Emotional Impact on Care Partners

As a care partner, you're focused on your loved one's health and well-being. It can be easy to forget to take care of yourself, and you may feel lonely, fatigued or burned out. Not everyone will experience fatigue or burnout, but it's important to know the signs. Don't ignore them: Take steps to address them as soon as they occur so you can maintain your own health and well-being for the long haul.

Loneliness and Isolation

Life as a care partner can feel lonely and isolating. Loneliness is a sense of being disconnected, even when you are around other people. You can be happily married and still feel lonely. Isolation comes from not feeling connected to others, whether through romantic partnership, close friendship or larger community. Feelings of loneliness and isolation don't just make us feel bad; they are bad for our health. They can increase stress, anxiety and depression, and decrease quality of life.

Many care partners say they feel alone in their experiences and cut off from others — sometimes even their loved ones. This might be a result of symptoms that interfere with social activities, changes in relationships where people are around less or act differently or simply a lack of time. It may also be a result of stigma or misconceptions around Parkinson's disease.

Stigma around Parkinson's can touch care partners just as much as a person living with the disease. Friends, coworkers and strangers may not understand Parkinson's and its symptoms; they may make awkward, hurtful or unhelpful comments. You may feel embarrassed, frustrated or left out. These experiences can make it harder to stay socially connected, adding extra weight to an already challenging role.

You can combat stigma with education: Let others know what Parkinson's is, what it looks like and how symptoms affect your loved one. But it's equally valid to not want to explain; you can come up with a go-to response to change the subject ("I appreciate your questions, but I'm much more interested in hearing how you're doing!") or point people to credible resources — like The Michael J. Fox Foundation — to learn more. Reach out to your support network and other care partners as well; they may have suggestions for addressing stigma, too. [*Turn to the Resources for more.*](#)

Strategies to Ease Loneliness and Isolation

Prioritizing positive, meaningful connections with yourself, your loved one and others can help ease loneliness and isolation.

For example:

- + Schedule a regular check-in with yourself to assess how you're feeling.
- + Plan an outing outside of the home once a month.
- + Get to know those you see regularly, like your loved one's physical therapist or your mail carrier. Mini moments of connection count.
- + Join a support group or meet with another care partner one-to-one.
- + Volunteer for a cause you enjoy.
- + Take an exercise class or join a book club.
- + Engage in faith-based activities or community, if that suits you.

Fatigue and Sleep Changes

Large surveys of Parkinson's care partners show that nearly three-quarters experience excessive tiredness, and 60 percent report chronic sleep loss.

The stresses of care partnering, your loved one's sleep troubles or changes in your own sleep can all contribute. People with Parkinson's might move a lot during sleep, have vivid dreams, yell or act out their dreams or get up during the night, which could increase risk for falls. Even if your loved one generally sleeps well, you might wake up worried or want to check on them.

Good sleep is more than how many hours you spend in bed. Experts determine the quality of sleep through three factors: how much you sleep (seven to nine hours per night is the general recommendation, but this varies from person to person), whether sleep is uninterrupted and refreshing and if you follow a consistent sleep schedule.

Not getting enough quality sleep impacts mood and decreases energy, which can make it tough to manage stress and steady emotions. Tiredness can increase irritability, lower patience and make sadness or worry harder to shake. Over time, a lack of good sleep can take a toll on you and your ability to care for your loved one.

Protect your sleep wherever you can. For example:

- + Set a consistent wake time and bedtime, within about an hour of the same time each day.
- + Create a relaxing, pre-bedtime wind-down routine in which you take a bath, read a book, meditate or journal about the day.
- + Turn off all screens at least an hour before bed.
- + Make your bedroom cool, dark and cozy. White noise or nature sounds may lull you to sleep.
- + Take a short nap in the early afternoon, if helpful, while your loved one does the same. Ideally, this is about 20 minutes and no later than 3 p.m.

Care partners who are also bed partners may choose to sleep in a different room so both they and their loved one can rest better. Some may also ask a family member or close friend to spend the night or hire an overnight caregiver to attend to their loved one's needs so they can sleep. These adjustments can be hard when you are used to sharing a bed with someone you love, but there are ways to maintain connection and intimacy. For example, make time to be together in the same bed each night before sleep or each morning just after waking up.

Mood Changes

Mood changes such as depression and anxiety are more common among care partners. Not everyone experiences these conditions, but if you do, it's important to be proactive in addressing them.

It can be difficult to know what's normal sadness or stress of being a care partner and what might be depression or anxiety. Feelings that stay with you constantly, cloud your actions and views and otherwise impact your day-to-day signal a possible mood change. [*For more, turn to **Emotions vs. Moods: What's the Difference?***](#)

Monitor moods by working with a therapist, regularly checking in with a close friend (ask them to help keep tabs on your mood) or keeping a journal. Pay attention to feelings and symptoms that can accompany mood changes, like eating or sleeping a lot more or less; regular pain, stomach upset or headaches; constant fatigue; hopelessness; lack of enjoyment; or sadness or worry that won't let up.

Seek help at the first sign of mood changes: There are many treatment options, including medication, talk therapy and exercise. Mood changes aren't something you can (or should) try to pull yourself out of alone. They also aren't character flaws or signs of weakness. They are treatable medical conditions, and the right treatments can help you feel better and care better for both yourself and your loved one.

Feelings of extreme distress or thoughts of harming yourself or others are a medical emergency. Get help immediately by calling or texting the [*988 Suicide and Crisis Lifeline*](#).

Burnout Is Real — and Preventable

Burnout happens when care demands go beyond what one person can, on their own, reasonably provide. It's more than being tired or mentally drained; it's a state of physical, mental and emotional exhaustion that occurs when stress reaches a harmful level.

When a care partner burns out, the only solution is to get support and relief — whether through additional help in the home, an extended break through respite or a move for their loved one outside of the home.

Tips to Prevent Burnout

The goal is, of course, to prevent burnout. Doing so requires regular, honest check-ins with yourself and with others, and making changes in the day-to-day structure as needed.

Know the signs of burnout. Common symptoms of burnout include:

- + Waking up exhausted even after a full night's sleep.
- + Increased irritability or a short fuse.
- + A lack of motivation and a sense of hopelessness.
- + Withdrawing from family, friends or social obligations.
- + Physical symptoms like headaches or changes in appetite.
- + Unhealthy coping mechanisms like drinking too much, drug use or overeating.

Check in with yourself regularly. Every morning or at least once a week, ask:

- + How am I feeling, physically and emotionally?
- + How am I managing stress? What are the ways it's showing up? What tools are working or not working?

- + What do I need to do to care for myself?
- + What do I need to keep caring for my loved one? More help? Different help?

Get in touch with your feelings. There are no good or bad feelings, but some (like anger or bitterness) are more negative. We might push those feelings aside, hoping that they'll go away. Instead, they're expressed through behavior, mood or other changes — ultimately leading to burnout. It's important to name your feelings and work through them with a therapist, support group or other helpful resource.

Recognize the importance of rest. Don't expect yourself to do everything, especially not alone or to the highest standards. Think of it like exercise: To build strength and stamina, you must let your body rest. Recovery is just as important as work. Allow yourself to take breaks by taking advantage of respite care. If you don't take a break, your body will eventually force you to do so.

Speak up. At each doctor's appointment, make it a point to share not just how your loved one is doing, but also how you are (or aren't) managing at home. Staying on top, and ahead, of home care needs can get you support — sometimes even before you know you need it. The care team can also guide you toward additional resources for now or the future, such as additional in-home care or alternative living arrangements.

A Journey of Love and Transformation



Josip Markus

Josip moved back home in 2019 to provide care for his father.

My father, Alojz (or Louie, as many know him), came to Ohio in 1967 as a political refugee from Croatia. He was diagnosed with Parkinson's in 2006. By 2019, his Parkinson's had progressed and his mobility declined. I left California and returned to my childhood home to care for him full-time.

I approached caregiving the way I approached everything else in my life: with research, planning and a belief that I could control outcomes if I worked hard enough. I thought if I could create the right environment, find the right help and establish the right routines, everything would fall into place. I thought I understood what I was stepping into.

Being an only child and my father's sole caregiver has been the hardest and most transformative experience of my life. I wish we had another caregiver I could fully trust and depend on, someone who feels like family. We're on our third caregiver now; hopefully she'll work out. But most days, it's just us, figuring it out as we go.

In 2022, my father broke both of his arms and became completely dependent on me for most of the year. That's when I learned what caregiving actually requires: surrender to the uncertainty of each day, to my limitations and to my discomfort. I needed to be kind and compassionate to myself and acknowledge that I was always doing my best — even when I had nothing left to give.

My job is to show up and love my father, even if I disagree with his choices. He's still a sovereign being. I can't force him to make the choices that I think are best. It's his life and his body, and he gets to decide. I offer support, invite him to try things and plant seeds of possibilities. We take a walk together every day. That routine keeps us connected to each other and to life itself. If he says no to other things, I let it go. If he resists, I give him space. The most meaningful support doesn't come from equipment or systems; it comes from the love, patience and presence that guides everything we do.

Initially, I focused on everything I was walking away from to be a caregiver. Over time, I realized I've been blessed with a profound gift. I've sacrificed so much — freedom to travel, access to my communities, the flexibility of my old life — but I no longer say I "lost" anything. What I've gained caring for my father has changed me in ways I never imagined.

My father guided me into this world; I'm slowly guiding him out of it. The sacred circle of life is closing, and I'm honored to bear witness and to show up in service each day. The time I've spent caring for my father will stay with me for the rest of my life as one of my most cherished memories.



The Pillars of Care Partnership

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The Pillars of Care Partnership

Everyone comes to care partnership in different ways. Whether you're a spouse or adult child, a full-time or part-time care partner or close by or far away, these guiding principles can help you and your loved one navigate the complexities of Parkinson's — together.

Pillar 1: Talk Early, Talk Often

Communication is crucial in any relationship, especially when care partnership is involved. Approach conversations with kindness, empathy and love, for both yourself and your loved one.

Pillar 2: Ask for What You Need

Asking for help is a strength, not a weakness. It helps you to be a better care partner. Know what you need (or ask others to help you figure that out!) and how to ask for support.

Pillar 3: Commit to Your Own Self-Care

Self-care isn't selfish; it's self-preservation. You can't pour from an empty cup, and taking time to care for yourself is another way to care for your loved one. Even five minutes a day just for you makes a difference.

Pillar 4: Remember, You're Only Human

You, like every single one of us, are human. You are imperfect. You make mistakes. Be gentle and understanding with yourself. You're doing the best you can, and that's all any of us can do.

Pillar 5: Embrace Life Outside of Parkinson's

You are more than a care partner. Take the time to honor and appreciate all of who you are and cultivate the life you live beyond Parkinson's disease.



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Pillar 1: Talk Early, Talk Often



Bernard Whitman (right) and husband Constantin Mitides at their home in New York City. Constantin has supported Bernard since his Parkinson's diagnosis in 2018. Bernard underwent deep brain stimulation surgery in 2023.

Communicate: It's our — and our community's — top tip for navigating life and care partnership with Parkinson's. Communication is more than “just talking”; it involves active listening, understanding and working together. Most importantly, it involves connection.

It may sound simple on the surface, but many things can get in the way good communication, including the following:

- + Digital devices can be distracting or lead to miscommunications. While some people prefer communicating over text or email, others may find it frustrating (especially when Parkinson's impacts hand movements).
- + Some topics are simply hard to talk about. We tend to push those aside because we don't want to think about, deal with or put energy toward them.

- + Parkinson's — and general aging — can bring symptoms, like hearing loss or lower vocal volume, that impact how we hear and converse with others.

One of the hallmarks of good communication is when both people feel safe being open and honest. Each can share their true thoughts and feelings, essentially “putting themselves out there” without worry about what the other person thinks or how they'll respond. This vulnerability creates connection, which boosts brain health, deepens your relationship and lessens loneliness.

Understand How Parkinson’s Impacts Communication

Parkinson’s symptoms can impact how your loved one communicates, from how loudly they speak to how quickly they process what they’re hearing. It can also decrease nonverbal communication cues, such as facial expressions and gestures, which are vital forms of emotional communication. These and other motor and non-motor symptoms can create or exacerbate communication challenges.

Motor Symptoms	
Stiffness and slowness of facial muscles, or facial “masking,” may decrease both facial and emotional expression, including smiling. This can be interpreted as lack of interest, upset or depression.	Slower, smaller movements may limit body language, like gestures and nonverbal cues, which can impede full expression.
Stooped posture, or the head tilting forward, can interfere with eye contact and vocal volume.	Dyskinesia, or involuntary movements, increase with stress or excitement, so certain conversation or situations may heighten these symptoms.
Non-Motor Symptoms	
Changes in volume and clarity of voice — like a softer voice, monotone speech, slurred words or mumbling — can relay less emotion.	Cognitive changes can slow processing and response or cause difficulty finding words or following conversation.
Mood changes like depression or apathy may blunt the ability to express emotions.	Parkinson’s itself can decrease the ability to interpret others’ emotions and social cues.
Fatigue can slow processing, decrease attention or make harder conversations even more difficult.	Pseudobulbar affect, or trouble regulating emotions, may lead to involuntary laughter or crying that is out of proportion to what a person feels or is inconsistent with the situation (like laughing at a funeral despite feeling sad).

Address Symptoms Where Possible

As a care partner, you can help identify and address Parkinson's symptoms that get in the way of communicating. Because everyone's symptoms and experiences are different, there's no one-size-fits-all solution, but there are many options.

Speech therapy can boost voice volume, make speech clearer and increase facial expression. It may also help word-finding and other cognitive changes. Speech and occupational therapists can suggest devices or tools to enhance communication.

Physical therapy can increase movement size and speed, as well as improve posture, for better nonverbal and emotional expression.

Medications can treat mood changes, pseudobulbar affect or emotional dysregulation. Counseling and exercise can also ease mood changes.

Hearing aids, when needed, can correct hearing or amplify sounds. Hearing aids also support brain health and limit the risk of cognitive changes.



Patient Council member Leonard Chandler and his wife, Grace. Leonard, a United States Air Force veteran, was diagnosed with Parkinson's in 2014 at age 65 and is passionate about participating in Parkinson's research.



As my dad's voice has become quieter and sometimes slurred, he's become less conversational — especially after we've asked him to repeat himself. Rather than allowing him to sit in frustration, we'll probe him with questions and encourage him to tell us stories or lead the conversation. He can practice good speaking habits, and it keeps him engaged in the conversation. If he pivots the story to my mom, my brother and I will jump in and remind him that we want to hear the words in his voice. It's become increasingly important for him and for us to maintain our family dynamics with good banter.

Zoe Butchen

Ask, Don't Assume

Parkinson's can change so much for your loved one. Symptoms can impact not only how they feel, but also how they carry themselves and interact with others. As you notice changes, be careful not to assume you know what's going on. Instead, ask.

For example, a person who used to be outgoing might gradually withdraw from social interactions. They may no longer seem interested in attending a weekly dinner with long-time friends. It's easy to guess the reasons, but it's important to hear directly from your loved one what's going on. Are they:

- + Worried about falling or being able to safely move through the restaurant?
- + Embarrassed about symptoms interfering with eating or using a walker?
- + Fatigued or experiencing apathy that makes it difficult to go out?
- + Fearful that medication will wear off while they are out?
- + Nervous about keeping up with conversation or whether people will understand them?

When you understand the why, you can problem-solve together. Considering changing where you eat, when you eat or how many people join. Maybe another activity not centered on food is a better choice. Identifying the why will help you stay engaged with the activities and people you love.

Make Communication a Habit

As with any skill, the more you practice, the easier it becomes. To build a habit, set aside regular time to talk. Start with 10 minutes and see where it goes. There's no agenda; talk about anything you want. You might even consider making Parkinson's and other "heavy" topics off-limits.

You could also plan a weekly check-in where you talk about one thing that went well over the past week, one thing that didn't go as well (and what you learned or will do differently), and one thing you noticed or appreciated your loved one doing. Be specific!

When communication is a habit, it becomes easier and more natural, both in and out of structured times. That's the "talk often" part of this principle: Conversations are rarely one and done. You and your loved one will want to revisit the same topics regularly as Parkinson's and life changes, and as your thoughts and approaches change along with them.



Every day at 4 p.m., after Billy's nap, we sat down and had a beer or a cup of tea. Billy had trouble hearing, processing and speaking. Sometimes it would take him up to 30 seconds to respond. He often used thumbs-up/thumbs-down. It also helped to ask simple, short answer questions.

Jessie Drew-Cates

The Rose, Bud, Thorn Tool

Rose, Bud, Thorn is a tool used to reflect, solve problems and share experiences. Each part of the flower represents a different area: a success (the rose), an area for improvement (the bud) and a challenge (the thorn). Take turns sharing rose, bud, and thorn in a daily or weekly check-in with your loved one.



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Rose

A positive highlight or something that went well

Questions to ask:

What worked well today (or this week)?

What's one positive thing you noticed about your loved one or about your situation?

What are you proud of?

Thorn

A stressful challenge or a negative situation

Questions to ask:

What didn't work?

What was our low point today (or this week)?

How can we fix it?

Bud

An opportunity for improvement or an area for growth

Questions to ask:

What have we learned? Where can we improve?

How can I be more supportive toward you?

What are you looking forward to?



Make Time for Difficult Discussions

Once everyday communication feels more manageable, you can turn toward harder discussions — those that can be scary, uncertain or emotional. In Parkinson's, these topics often include memory and thinking changes (whether current or potential), driving, getting care outside of the home and end-of-life planning.

It's understandable to want to avoid talking about these things. But not talking about difficult topics now doesn't make them go away; it may even create challenges or regret down the line. Try to begin discussions long before you feel the need. Here are some tips for discussing tougher topics:

- + **Normalize challenging conversations.** "I don't like talking about this either, but I want to make sure I'm doing the best for you in every way I can..."
- + **Share your own feelings.** "I also worry about later life. That's why I wrote down what care I do or don't want toward the end of life and who can make those decisions for me. It's not fun, but it's necessary, and I feel better having taken care of it."
- + **Pull from others' experiences.** "Grandma chose hospice, and what I liked (or didn't like) about that was..."

Before starting a difficult conversation, make sure your loved one feels up for it. Consider having these discussions during "on" times, when medication is working well: your loved one may have fewer symptoms, like fatigue or foginess, that can affect conversation.

Your communication will likely never be perfect. But working on it means you care and are making progress. You aren't in it alone: There are always people who can help, especially with the more challenging conversations, such as your loved one's doctor, a social worker, a mental health therapist or a palliative care team.

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When Communication Becomes Challenging

Over time, Parkinson's may increasingly impact a person's ability to communicate. If speech, cognitive or other changes interfere with communication, consider these tips to optimize your connection:

- + **Give your loved one plenty of time to speak.** Don't guess what they are saying or finish their sentences, unless they ask you to. In group settings, make sure everyone holds space for your loved one, or opt for one-on-one chats if groups are too much.
- + **Consider yes/no, rather than open-ended questions.** Ask, "Do you want to sit on the patio?" instead of, "What do you want to do this afternoon?"
- + **Use tools to enhance communication.** A speech or occupational therapist (or other care partners) can recommend technology and devices to strengthen speech or communicate without spoken words.
- + **Find nonverbal ways to connect.** Can you listen to music, look at old photos or watch a favorite program together rather than talk? Get creative: Where and how can you connect beyond words?



Our communication reflects our internal state. When someone is living with chronic illness or pain, their words often carry the weight of that struggle. I've learned to stay grounded and meet my father's words with patience, understanding and compassion. If I stay calm, that energy carries over to him.

Josip Markus

Five Keys to Unlock Good Communication

While we all have different communication styles, there are some basics that all of us, with Parkinson's or not, can build on to establish and maintain solid lines of communication. Keep these five keys in mind as you communicate.

Key 1: Set the Stage

Sit together, facing each other, in a quiet space. Don't shout from opposite ends of the house. Commit to focusing only on each other and remove distractions: Turn off the TV or radio, eliminate background noise and silence your phones. Plan important discussions for when your loved one is "on" (when medications are most effective), especially when the topic may be difficult.

Key 2: Get on the Same Page

Be clear about what you hope to get out of the conversation. Do you want advice or feedback? Do you want to brainstorm or problem-solve? Or do you need to vent and be heard? Defining goals sets you and your loved one up for a successful conversation.

Key 3: Listen Actively

Don't just think about how you're going to respond; really hear what your loved one is saying. Don't interrupt, correct or jump in. When they're done talking, repeat back what they said and ask questions to go deeper. Let each person fully express themselves — even if you disagree. Talk first, then revisit points of contention later.

Key 4: Address Emotions

Acknowledge when the conversation is difficult. Allow your loved one to express emotions and refrain from reframing any negative emotions with a positive spin. For example, if your loved one is sad, don't rush to remind them of the bright side; instead, hold space for sadness. Despite good intentions, this quick, positive reframe — known as "toxic positivity" — can be dismissive of others' feelings.

Key 5: Be Patient and Be Okay with Disagreement

Give your loved one time, especially if they experience speech or cognitive changes. Don't finish their sentences (unless they've asked you to) and pause before you respond; become comfortable with silence.



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Pillar 2: Ask for What You Need

Nobody can do everything on their own. Yet care partners tend to take on more, and more, and more. At some point, even the helpers need help. Checking in with yourself and asking for what you need — clearly, directly and regularly — can keep you going strong as a care partner and prevent burnout or other health problems.

How to Ask for What You Need

There are many reasons care partners may not ask for support. You might not know where to start or even what you need. You may not know what kind of support is available or how to access the support that's out there. Maybe your loved one is against the idea of outside help, out of pride, privacy or embarrassment. Maybe you're worried about imposing on others. But often, others want to help; turning to family, friends, professionals or your community can lighten your load. It takes courage to ask for help. It is a sign of strength — not weakness — to know what you need and speak up about it.

Step 1: Know When You Need Help

When you're focused on getting through each day, it can be hard to see that you can use some help.

It's time to reach out when you feel sustained overwhelm, wonder how you're going to get it all done or have trouble sleeping or eating. It's also time when you can't find time to care for yourself, can't remember the last time you took a short break or a loved one or medical professional suggests you get some additional support.

Step 2: Outline Your Needs

Once you identify and agree on the need for support, the next step is to list what kind of support you need. Some people don't know where to start; that's okay. To begin, consider some common needs:

Making sure your loved one is safe. Parkinson's can cause problems with falls, memory and thinking (cognition) or hallucinations. You may need help to make sure the home is safe for walking and other daily activities or that your loved one has in-person supervision or support available much or all of the time.

Getting out of the house. It can be hard to navigate all the outside tasks that enable your household to run smoothly while caring for your loved one. You may wind up staying at home, unable to run errands

or take care of your own needs. A change of scenery, natural light and interacting with others are essential for your well-being.

Taking a break. Nobody can maintain constant care partnership. Taking breaks (even just a few minutes a few times per week) can help you recharge.

Engaging in exercise. Physical activity can boost your energy and your mood as well as your overall health and well-being.

Caring for your kids. If you have children at home, you may feel the pressure of caring for your loved one and your kids at the same time. Asking for help with childcare can free up your mental load, allowing you to be the best care partner and parent possible.

You may want to keep a separate list of medical care and other needs to discuss with your loved one's doctor or social worker. If you don't want to ask during an office visit, call to speak with the doctor ahead of time, or ask them to step into the hallway for a quick chat after the exam. [*Turn to How Do I Build a Parkinson's Care Team? for more.*](#)

Don't forget to ask for what you need from your loved one, too: They are your partner in Parkinson's. Give and take on both sides of any partnership is crucial.

Step 3: List Who, Or What, Can Meet Each Need

Once you have a list of needs, you can brainstorm who or what can meet each. Consider options like:

- + Family members, friends, neighbors, other care partners, religious or spiritual communities or support group members.
- + Paid or professional caregivers.
- + Your loved one's health care team or providers you can add to the team, like social workers or palliative care clinicians.
- + Community services, like adult day programs, meal delivery services, transportation to medical appointments, assistance with health insurance questions, volunteers who visit or call to reduce isolation and loneliness and much more. Your local department on aging is a hub for many of these services.
- + Employee assistance programs; faith-based organizations; or federal, state and local government initiatives. Your doctor or social worker can help you find these programs.

Keep in mind that not everyone is suited for every task. Consider the skills and interests of your friends and loved ones: Asking a friend who doesn't drive to pick up groceries probably won't work. But asking a fellow parent to pick up your kids at the same time and place they pick up theirs might be an easy yes.

Step 4: Be Clear, Direct and Specific

Now comes the main event: asking for what you need, even when you aren't sure what to ask for. It can be as simple as saying, "I need help caring for my dad." When needed and where possible, it can be more direct: "I need help getting my husband dressed in the morning."

Friends and family members often say, "Let me know if I can help." (If that's you, be more specific: Try asking, "Would it be helpful if I pick up prescriptions, do laundry or bring over dinner?")

Be prepared to respond with a task from your list: "Could you drive John to his physical therapy session on Thursday?" or "Can you sit with Jane on Monday afternoon so I can go grocery shopping?"

If you're worried about burdening friends and family, ask for something time-limited with a clear ending ("Can you pick the kids up from school Monday, Tuesday and Wednesday of next week?"). By making these types of requests, you won't feel like you're asking too much, too often. And remember, not everyone will be able to say yes. They may not be able to help right now, with a specific task or at all. Be prepared for no's and don't take them personally.



If you want to help someone with Parkinson's, you need to be specific. Ask something like, "Can I take your daughter to school?" In general, people are more likely to help if you're direct.

Julie Porter



Left: Soania Mathur, MD with her husband, Arun. Soania was diagnosed with early-onset Parkinson's disease in 1999 at age 28. She is a co-founder of PD Avengers, global alliance of Parkinson's advocates, and a member of MJFF's Patient Council.

Right: Patient Council member Jimmy Choi and his wife, Cherryl. Jimmy was diagnosed with early-onset Parkinson's disease in 2003 at age 27. Jimmy has competed on American Ninja Warrior seven times since 2017.

Accepting Help

Some people find it difficult to accept help. If that's you, practice saying, "Thanks for asking. Here's what you can do." Remember, others love you and your loved one and want to help. You're giving them that opportunity.

Each fulfilled request frees up some of your time and energy so you can focus on precious resources — perhaps things only you can do for yourself or your loved one, or the things you do best.

Tips to Ask for Help

Consider keeping a separate list of needs to share with your loved one's doctor or social worker: "We're struggling with bathing and showering, and I don't know what to do," or "I'm having trouble managing Jim's medications." If you don't want to ask during an office visit, call to speak with the doctor ahead of time, or ask them to step into the hallway for a quick chat after the exam is over. [Turn to How Do I Build a Parkinson's Care Team? for more.](#)

Normalize asking for help, even when you're not sure what to ask for. If it's hard to ask, set up a shared calendar, start a group chat or use a caregiving app where you can post your request and let others choose how and when to help. These strategies mean that you're asking people who have already bought in and expressed their desire to help you. If using technology feels overwhelming, ask a tech-savvy friend to pitch in: They're not just helping you, they're helping everyone involved in your loved one's care.

Not everyone you ask will be able to say yes. They may not be able to help right now, with a specific task or at all. Be prepared for these "no" answers and don't take them personally.

Caring and Grieving at the End of Life



Jessie Drew-Cates

Jessie cared for her husband, Billy, until his death in 2025.

Billy was first diagnosed with Parkinson's in 2016. Medications didn't help him much, but exercise did. He rode a stationary bicycle four or five times a week. He loved reading and was very engaged with sports (especially the Buffalo Sabres). Some of my favorite moments took place during our daily ritual: at 4 p.m., after Billy's nap, we would sit down together with a beer or tea and talk.

In May 2025, four months before Billy passed, we took a cruise together. Billy saw his brother at a stop in Georgia, and friends from high school at a stop in South Carolina. Those friends drove hours to see him; it was a very meaningful experience. When we got back, I asked Billy what else he wanted to do. He said, "I've just done it." It was clear that he'd seen the people he wanted to see — the people who he cared about — and that he was ready.



On the cruise, Billy was walking independently. By the end of the summer, he declined rapidly. We were fortunate to connect with a wonderful neuropalliative care team who supported Billy through the last months of his life. It got to the point where he could barely chew, swallow or suck through a straw. His words were garbled and difficult to understand. He lost his hand function and could no longer use the computer. Then he lost his eyesight and could no longer read. That was the final blow.

Billy and I had talked about his death. Billy chose how he wanted to die. It was a very personal decision, and not a decision everyone can make. There's dignity in choice.

I'm a retired rehabilitation and neurology nurse practitioner; caregiving is built into my DNA. I still feel like I didn't do enough. We tried everything: every medication and multiple physicians, but there was nothing we could do that would make his life better.

After Billy died, I gave a speech at a local Parkinson's group about end of life. I'll share the same advice here: *Do not do this alone*. I was surrounded by people: Billy's daughter, our grandson, long-term care aides, faith leaders. The care partner needs to have their own support system in place.

Billy knew that I was exhausted. He knew how tired I was trying to take care of him, and I think that was part of his decision. I still feel his presence in the house; it will probably never be gone. I miss him like crazy.



Pillar 3:

Commit to Your Own Self-Care

“Put your oxygen mask on first.”

“Make sure you take care of yourself.”

“Don’t let your battery run dry.”

Chances are, you’ve heard these phrases — maybe one time too many — and wondered, “How am I supposed to find time for that?” You, like many other care partners, may feel there’s no time or space for self-care. You might feel guilty about not caring for yourself when you know you should, or you might feel selfish for attending to your needs and well-being when your loved one “needs you more.”

Self-care isn’t a luxury or an extra: It’s a necessity. *Self-care isn’t selfish.* It’s part of your job as a care partner. Taking care of yourself allows you to care for your loved one as best you can and as long as you can. When you don’t regularly refill your tank, you eventually run out of gas. And that can mean mood changes, sleep problems and burnout, all of which can lead to poorer health for both you and your loved one.

Still, knowing and doing are two different things. How can you care for yourself when the day is already full?

What Is Self-Care?

Self-care is everything you do to support your physical, emotional, mental and spiritual well-being. Each aspect of your well-being is equally important, but different areas may need more attention than others at different times or at different points in Parkinson’s.

Physical self-care. Keeping your body as healthy as possible (particularly with aging), getting care for symptoms or diseases you live with, spending time moving your body each day.

Emotional self-care. Managing your moods and feelings, coping with difficult situations, practicing gratitude and optimism, where possible.

Mental self-care. Caring for your brain like you do your body so you can think clearly, practice good judgement, make decisions and solve problems.

Spiritual self-care. Knowing your purpose, finding meaning and hope in life, connecting to something bigger than yourself.

Self-care is also about setting boundaries. Reduce your load by setting realistic expectations and turning down demands or activities that contribute to stress, like hosting holidays or organizing events. Clear your calendar of activities that drain you whenever you can. Know your limits and remember that “No” is a complete sentence. Sometimes saying no is the kindest thing you can do for yourself.



Honestly, I’m not great at self-care. I tried to stay connected with friends, go out and talk about what was happening. You have to let yourself feel normal sometimes.

Kate Harmon

What Does Self-Care Look Like?

There are many ways to care for your whole self, some of which support more than one area of well-being. Yoga, for example, can meet the physical, emotional and spiritual self simultaneously. Experiment with different self-care tools to create a menu of useful options from which to choose, depending on the day or moment.

Physical



Do aerobic (walking, biking) or weight-bearing (pushups, squats) exercise

Eat a healthy, well-balanced diet and drink plenty of water

Prioritize good sleep hygiene practices

Schedule regular medical check-ups and visits

Engage in a mind-body practice like meditation, yoga or Tai Chi

Emotional



Connect with a close friend

Attend a support group

Seek counseling and take mental health medication, if needed

Take a warm bath

Secure respite care to disconnect from Parkinson's for a few days

Mental



Learn a new skill

Journal

Practice a hobby

Read (or listen to) a book

Do a jigsaw puzzle or play a board game with others

Spiritual



Attend a religious service

Spend time in nature

Practice meditation or mindfulness

Read spiritual or religious texts

Volunteer to help others

I support Erika and her family from a distance. She's mindful of making sure her husband has the time he needs to care for himself. It's important to be a care partner to the care partner, too, making sure he takes care of himself.

Walter Siegenthaler

Make Self-Care Part of Your Day

Self-care doesn't need to take a lot of time, energy or money. It's less about how much time or money you spend, and more about showing up regularly and getting the most out of whatever time you can commit. To start, find five minutes each day to focus on yourself. Some suggestions:

- + First thing in the morning, before you get out of bed, take three deep breaths.
- + While you are brushing your teeth or drinking your coffee, do a few squats, lunges or push-ups or stand near a window to get morning light.
- + When your loved one is napping or resting comfortably, put your feet up, make a warm cup of tea or journal for a few minutes.
- + As you get ready for bed or just before you fall asleep, name three things for which you are grateful.

You can also spread self-care throughout the day. If it's hard to get 30 minutes of continuous exercise, can you do three 10-minute sessions instead? If it's tough to find quiet time to meditate, can you bring mindfulness to another activity, like eating a meal or doing a care partnering task? Mindfulness is simply being in the moment by paying close attention — without judgement — to what you see, feel, hear, smell or taste. You can do this anywhere, anytime.

As you begin your self-care journey, start small. Maybe aim for a short activity one to three times a week and, once you achieve that, aim for every day. Continue to build from there. Try to start each day by asking, "How can I best care for myself today?" Commit to doing one thing each day.



Bernard Whitman makes yoga a consistent part of his personal self-care routine.

Setting Self-Care Goals

Goal setting is motivating. Setting self-care goals can keep you accountable, give you a sense of purpose and help you feel accomplished when you reach them. But both setting and achieving goals can be difficult, even without the complexities of care partnership added to the mix. Here are some strategies to help you set and stick to your goals.

Identify Your “Why”



It can be easier to work toward goals when you identify the why behind them. Naming the why makes it more meaningful and clarifies the steps you need to take toward achieving a goal. Instead of “I need to exercise more,” try, “I want to have energy and stamina to play with my grandchildren or hike with my loved one.” The why gets you started or keeps you going on the days when life or care partnership might otherwise get in the way.

Celebrate Your Wins



Prioritize progress, not perfection. Celebrate throughout the process: not only when you achieve a goal, but as you make progress with every step along the way. If your goal is to finish a 5K, applaud yourself for getting out the door, taking a walk and beyond. Acknowledge each success and pat yourself on the back for every positive step.

Make Your Goals Specific



A specific goal is easier to track. Something concrete — like “I’ll meditate for five minutes every morning for one week” — is easier to measure than “I’ll work on taking better care of myself.”

Give Yourself Grace



Like care partnership itself, accomplishing goals isn’t always straightforward. There will be setbacks, challenges and detours. Anticipate and embrace these as part of the process, use them as opportunities to learn and adjust and keep moving forward.

Self-Care as a Long-Distance Care Partner

Care partnering from a distance can bring its own challenges and stressors. You may feel guilty about not being physically present, not spending enough time with your loved one or like you're not doing enough to support your loved one and their primary care partner. You might even experience feelings of envy toward the primary care partner, who sees your loved one every day.

As a long-distance care partner, you may experience different emotions from someone who cares in-person. You might feel jealous that someone else is with your loved one more than you're able to be. You might feel guilty that you're not there, especially during challenging times. You might even feel guilty while you are there, because you have the ability to leave. These emotions are normal, valid and understandable. Recognize and work through them. [Turn to The Emotional Impact on Care Partners for more.](#) Remember that no matter where you're physically located, you can still experience the emotions and strain of being a care partner. Build your own network of support and take care of yourself.

Practicing Gratitude as Self-Care

Sparks of gratitude, humor and joy are not indulgences; they are proven ways to care for yourself and refill your emotional tank. Research shows that small everyday practices — pausing to notice three good things or sharing a light-hearted video — can boost your mood and resilience, even when life, work and care partner demands are high. As Michael J. Fox has said, “Gratitude makes optimism sustainable.”

Looking for silver linings, or upsides, to not-great situations can lighten heaviness and boost mood. For example:

+ I am thankful for the stranger who held the door for me, for my favorite coffee mug or for the sunlight streaming in the window.

+ I am sad my loved one is in the hospital, but glad for the time together it's given us.

+ I wish Mom wasn't sick, but I'm grateful my siblings and I are working together to help her and each other.

This doesn't mean you should always be positive. As with anything, there can be too much of a good thing. Life and Parkinson's bring difficult emotions and situations. Try to accept those difficulties, using positivity as a support. But never use positivity to dismiss others' feelings, hide yours or bring guilt for having less positive — yet completely normal — feelings, such as sadness or worry. [Turn to Avoid the Trap of Toxic Positivity for more.](#)

Building a Gratitude Practice

Studies have found that gratitude exercises, whether penning a quick thank-you note or reflecting on the day's good moments in a nightly journal, reliably brighten mood and build resilience to stress. Daily practice can change the way your brain perceives and processes situations and what you focus on. Energy flows where attention goes!

Look for natural moments to be grateful, like when you first open your eyes in the morning or put your head on the pillow at night, over breakfast with loved ones or when tucking your children into bed. Appreciate and share one or two small, specific things about that moment or that day, or point out things or people you're grateful for in real-time. Take an extra beat to feel and express that gratitude.

There's no one right way to practice gratitude, and your personal practice can take many forms and change over time. Whether you're new to gratitude or well-versed in the habit, consider the strategies on the following page to create a sustainable gratitude practice in your life.

Strategies to Build a Gratitude Practice

Keep a Gratitude List



In a notebook or the notes app on your phone, write down three to five things you're grateful for each day. Be specific: the smaller, the better. Don't just say that you're grateful; really feel the appreciation in your heart or chest. Flip back through this list whenever you need a pick-me-up.

Take a Gratitude Walk



During this walk, actively focus on the positives and small miracles that surround you: the crisp air on your face, the sunlight through the trees or the crunch of gravel or leaves under your feet. Use your steps to ground yourself physically, emotionally and spiritually.

Create a Gratitude Jar



A specific goal is easier to track. Something concrete — like “I'll meditate for five minutes every morning for one week” — is easier to measure than “I'll work on taking better care of myself.”

Express Gratitude to Others



A handwritten letter or thank-you note to someone you're grateful for — detailing what they did or why you're grateful for them — can benefit you just as much as the person you write to.

Practice Gratitude Meditation



Instead of focusing on your breath and body as in traditional meditation, visualize the people and things in life for which you're grateful. Look for free, guided meditations online or through phone apps.

Find a Gratitude Token



Get a small stone, rock, figurine or photo to keep in your pocket or wallet, or pick an item you walk past or use regularly. Whenever you touch or see this object, think about what you're grateful for.

Avoid the Trap of Toxic Positivity

Toxic positivity is the belief that people should keep a positive mindset, no matter how difficult their situation. Unlike optimism, which involves positive thinking while acknowledging and validating the reality of challenges, toxic positivity doesn't allow difficult or negative emotions. This way of thinking pressures people to suppress normal and valid emotions with the goal of keeping positive — which isn't healthy.

Even if well-meaning, toxic positivity can cause harm by dismissing emotions, increasing isolation, blocking genuine support and minimizing your burdens or needs as a care partner. It can also make care partners feel shame or guilt for having emotions, sharing needs or seeking help, and it can lead to loneliness and burnout over time.



If you tend to minimize your emotions, avoid difficult conversations to keep the peace or experience feelings of shame because you're struggling, consider whether you might be slipping into toxic positivity. If that's the case, try to reframe your thinking: Instead of saying, "Everyone has challenges; mine aren't so bad," validate your feelings: "Parkinson's is challenging, care partnership is difficult, and that's okay."

If others approach you with toxic positivity — telling you to look on the bright side, find the silver lining or that everything happens for a reason — recognize their intent to be supportive and explain how their words affect you. Say something like, "I appreciate the support, but saying that happiness is a choice makes me feel bad about being sad and having hard days. It's important for me to express those feelings and work through them, and I'd love your help to do that."

Living Intentionally



Heather Butchen

Heather and her husband, Jeff, have been living with Parkinson's since 2013.

My top care partner life hack is this: Don't feel guilty about taking time for yourself. It's not selfish. Exercise, go meet a friend, take a walk — whatever you think will reset you. Even an hour to yourself can make a huge difference.

My husband, Jeff, was diagnosed with Parkinson's when he was 51. We started our support group in 2014, a year after Jeff's diagnosis. Speaking with others in real time about shared experiences has been invaluable. We exchange information on doctors, treatments and day-to-day challenges. No matter the topic — constipation, medical side effects, emotional ups and downs — there are always people or resources to guide you. I also lean on my kids, especially my daughter Zoe, who works at The Michael J. Fox Foundation. [You can read Zoe's story on page 27.](#)



I also subscribe to newsletters and webinars from organizations like MJFF. When a topic like deep brain stimulation or nutrition becomes relevant, I revisit saved articles. Local programs have also helped. I still wish I had more connections with people in the same exact situation. It's kind of like becoming a new parent; you want to meet others who are right there with you, going through exactly what you are.

We're starting to plan for things like needing a one-floor home, maybe hiring a driver and maybe being in warmer climates for long periods of time. His deep brain stimulation surgery in March 2024 gave us a reset, but we're staying mindful of future needs. Caring for someone with Parkinson's is a job, like any other. There are responsibilities, emotional labor and practical demands. It's about managing my husband's Parkinson's journey from beginning to end.

Jeff's diagnosis has made us live more intentionally. We've traveled, made memories and done things we might have put off. On the other hand, our partnership has changed. I care for him more than he does for me. We used to be 50/50 in everything, including running the business we own together. Now, the dynamic has shifted. I am more of a caretaker. And that transition has been emotionally complex for both of us.



Pillar 4:

Remember, You're Only Human

Caring for someone with Parkinson's is a bit like starting a new job without a training manual. When everything feels heavy, remember this: The stress or struggle you feel isn't a personal weakness. It's a normal response to a demanding role that none of us were formally taught to do.

On top of that, you're only human: You're imperfect, and you make mistakes. Each day, you do the best you can with the information, tools and energy you have. And you give all you can, knowing your "all" will vary from day to day.

Be Kind to Yourself

Self-compassion is one of the most important tools you can add to your care partner toolkit. Like self-care, self-compassion isn't selfish; it's an essential part of showing up for both yourself and someone else. When you treat yourself kindly, you're able to treat your loved one with that same kindness, patience and love.

Self-compassion can also be an antidote for times you lose your cool or feel worn out. It's a reminder that getting frustrated doesn't make you a bad care partner or person; it makes you human. Meeting your mistakes with understanding and grace turns missteps into moments of learning, rather than a source of guilt. [Turn to *Managing Your Emotions for more.*](#)

Build Your Self-Compassion Muscles

Being gentle with yourself can lower stress, reduce anxiety and depression and improve emotional resilience, which is the ability to adapt to stressful situations. It also helps you stay (or regain) calm, bounce back from setbacks and keep a positive outlook.

Like anything else, self-compassion is a skill that can be learned. Just as exercise builds physical strength, self-compassion builds emotional strength, or your ability to sit with and work through emotions — even the most difficult ones.

Tips for Self Compassion

Reframe self-talk. Notice how you talk to yourself. If that involves criticism or harsh words, stop and imagine how you'd react if you heard someone talking to a good friend the same way. Treat yourself with the same warmth and gentleness you'd give a family member or young child.

Talk back to negative thoughts. Stop negative thoughts in their tracks. Say something like, "No, thank you, we're not entertaining that idea right now." Some people even name the "bully" in their head so they can more directly challenge unhelpful thoughts: "No, Mr. Mean Guy, not today."

Work with a therapist. Techniques like talk or cognitive behavioral therapy can help identify and challenge unproductive thoughts and negative self-talk.

Recognize shared humanity. If you find yourself thinking, "I'm the only one who struggles with this," take a moment to gather evidence — through support groups, readings or personal conversations — that other Parkinson's care partners face similar challenges and feelings.

Practice loving-kindness meditation. Through free, guided practices, you can generate genuine care and love for yourself and others.

Learn from missteps. Select one care partnering “mistake” that you replay in your mind. What lessons did the experience offer? How might that learning transform the event from a source of self-criticism into a stepping-stone for growth?

Give yourself positive feedback. Reflect on a time when you felt rested and kind toward yourself. How did that mindset influence the patience, empathy or creativity you brought to your loved one’s care, compared with a time when you felt exhausted or self-critical?



We asked: What’s one thing you want other Parkinson’s care partners to know?



Prentis: While friends and neighbors often want to help the person with Parkinson’s, care partners need emotional and physical support, too. We must ensure care partners feel seen and valued.



Josip: The person you’re caring for is still a sovereign being. As a caregiver, your job is to show up and support them; you love and accept them as they are, not as you wish they were. I’m here to walk beside my father for as long as he needs me, however he needs me — even when we disagree.



Jessie: Everything slows down. I’m usually good at being patient, but I do fail sometimes — I’m human. Patience is absolutely critical.

Embrace Flexibility

Parkinson’s is unpredictable. Sometimes you might feel like anything that can go wrong, is going wrong. Being flexible can help ride the ups and downs more easily. Start by adjusting expectations: Before Parkinson’s, a good day might have looked like waking up early, hitting the gym and preparing a full dinner. After Parkinson’s, a good day may be defined by doing just one of those things.

Another way to practice flexibility is to know that plans will change — and to roll with those changes. Maybe your doctor is late for an appointment, your loved one’s medication wore off earlier than expected or your grocery delivery is delayed. Take a beat, assess the situation and adjust from there. You can’t control your doctor’s schedule; you can control whether you get annoyed with the delay and what you do with the extra, unexpected time. Sometimes staying flexible is as simple as giving others grace.

Remember: You can only control your own thoughts, responses and behaviors, not those of others. Trying to control what you can’t control is a surefire way to set yourself up for anger or disappointment.

It Takes a Village



Walter Siegenthaler

Walter provides long-distance support to his daughter, Erika.



My wife Lydia had Parkinson's. She passed away in 2006 after living 22 years with the illness. My daughter Erika was diagnosed in 2019, two months into her husband's yearlong deployment overseas.

I live in North Carolina, and Erika lives in Florida with her family. I've made several trips to Florida to support her, especially after her deep brain stimulation surgery in 2022.

Erika also gets additional support from her sister, who has a PhD in biology. Her degree helps; she understands the details of Parkinson's a lot better than I do.

At home, Erika's daughters are supportive, too. They're 16 and 12, and they understand what's going on and do a really great job helping. The roles between Erika and her husband have somewhat flip-flopped. Her husband has taken over cooking duties and become an amazing cook. Erika is mindful of making sure her husband has the time he needs to care for himself. She always makes sure he has time to work out and time to play — surfing or going on trips with friends. It's important to be the care partner to the care partner, letting them take care of themselves. She needs him to be healthy because he's the one who's going to take care of her in the future.



Pillar 5: Embrace Life Outside of Parkinson's

People living with Parkinson's often hesitate to share their diagnosis because they don't want to be treated differently, pitied or seen through only the lens of a disease. As a care partner, you may also be unsure about sharing your loved one's Parkinson's diagnosis or your role in their journey. This reluctance is normal and reasonable: No one should feel reduced to a single role, condition, success, mistake, hobby or preference.

We can't control how others see us. We can, however, choose how we respond to their views and how we define ourselves. You both are — and deserve to be seen as — many things: a sibling or best friend, a teacher or volunteer, a gardener or cyclist, a world traveler or puzzle lover. Having Parkinson's or being a Parkinson's care partner is one part of you, not the whole story.

Still, Parkinson's is now part of your life and identity. And Parkinson's requires space, time and attention. So, the question is: How do you give Parkinson's what it needs, and no more?

Redefine (or Refine) Yourself

Major life changes like a Parkinson's diagnosis create a natural pause to check whether you're living life in line with your values. For example, if family is important but you visit only once a year and talk sporadically between, you might want to look for ways to connect more often.

Many people say that, while of course they wouldn't choose Parkinson's, the diagnosis gave them a chance to re-evaluate their life and priorities and to bring them into better alignment.



I quilt with a group of friends. We text and meet regularly, especially during the winter. We even met over Zoom during COVID-19. That group is a lifeline.

Jessie Drew-Cates

Ask yourself:

- + Who and what matter most?
- + What do you value?
- + What makes you you?
- + When are you most content or fulfilled?
- + What brings you joy or meaning?

These answers serve as your compass for bringing more of who and what is most meaningful into your life, both within and outside of Parkinson's.



We asked: What brings you joy as a care partner?



Julie: The joy in our relationship comes from our friendship; it's not specific to Parkinson's. Having good phone conversations, spending time together, seeing our kids together, who are like cousins. Despite this disease, it's not rare for Becca to just enjoy herself.



Heather: Jeff's deep brain stimulation surgery was a moment of joy for both of us. The transformation was amazing. His shaking stopped, and he looked more comfortable and at ease in his own skin. I really felt like I got my husband back, and even our friends noticed the change. That brought me immense joy.



Jessie: We laughed together — that's really important. Seeing friends is a joy, though it happened less often; Bill had trouble eating and didn't like to do it in public, so we socialized less. But when people visited and could handle his needs without being uncomfortable, that was a real joy. Those are true friends.



Zoe: My family found a theme song to keep us going. Every time we hear it in public, it's a reminder that keeps us motivated and connected to the Parkinson's community. Find your theme song. Find the thing that keeps you going.

Keep Your Old Life — and Your Own Life

You are still the person you were before becoming a care partner. Maintain your favorite hobbies and interests, adapting as needed. Keep up with pre-Parkinson's friendships. Connection with other care partners is valuable, but so is spending time with people outside of Parkinson's. That time can be refreshing and give welcome distance from the disease.

Also continue to invest in activities and relationships that are yours alone. Partnerships thrive when each person keeps their own sense of self.

Create “No Parkinson’s” Zones

Make Parkinson's updates or check-ins off limits during certain times or activities. You might say to a friend, “I'm looking forward to an afternoon off from care partnering, let's skip Parkinson's talk today.” You can create “No Parkinson's” zones with friends and family, as well as with your loved one. Just as couples might avoid discussing household logistics on date night, block an hour each week to talk about anything but. (Make it a game: Whoever says “Parkinson's” first does the dishes or another chore!)



Left: Zoe Butchen was 14 when her dad, Jeff, was diagnosed with Parkinson's. Zoe Butchen, her mom, Heather, and her brother, Cole, discuss health concerns with Jeff as a family. "My mom doesn't feel quite so alone in addressing things that way," Zoe explained.



Right: Kate Harmon embraces her dad, Bob, at her wedding in 2023. She encourages other care partners to give themselves grace: "It's hard and it's heartbreaking, but you do it because of love."

Put Process Around Parkinson's

Separate Parkinson's-related communication and materials from the rest of your life. Create a dedicated email address for Parkinson's news, research or care correspondence, and other disease-related updates. Keep medical notes and educational materials in clearly labeled folders or binders. Containing the paperwork contains the mental load.

Welcome Moments of Lightness

There's a reason why the saying "laughter is the best medicine" has such staying power: Laughter benefits the body and the mind. A single bout of laughter can markedly lower stress hormones, relax muscles and calm breathing.

Many care partners and their loved ones use humor to ease tension, laughing with and sometimes at Parkinson's. Some laugh when situations go sideways, recognizing that at least they're making memories. Others joke about misunderstandings caused by speech changes or communication mishaps. Letting in lightness doesn't mean you're ignoring or diminishing the seriousness of Parkinson's. It means you're giving your brain and body the rest they need to show up again and again.



Take pictures and do weird things. Just be weird because you don't know what's going to happen. I have a picture of the last time Mom kissed Dad on the cheek. She won't look at it, but one day, she might want to.

Kate Harmon

A Helping Hand



Julie Porter

Julie provides long-distance support to her lifelong friend, Becca.

Becca and I have been friends since we were 10 months old. Despite the physical distance between us, we've always been there for each other. Becca was diagnosed with Parkinson's at 39, after giving birth to her daughter as a single mom.

The joy in our relationship comes from our friendship; it's not specific to Parkinson's. It's from having good phone conversations, spending time together, seeing our kids together, who are like cousins. Despite this disease, it's not rare for Becca to just enjoy herself.

When Becca decided to have deep brain stimulation surgery in 2021, I helped coordinate support with another one of our childhood friends. She had the surgery in two parts, one side of her brain at a time.

The first time, our friend stayed with her immediately before and following the surgery, and then I took over a few days later. We made sure we had all her local contacts and created a system to communicate updates. We basically acted as her informal support team, gathering and distributing key information.

I happen to be well-connected in the neurology community because of my work with the Huntington's Disease Foundation. That background can be a helpful resource. When she was first diagnosed with Parkinson's in 2013, I referred her to a neurologist I knew, so I was somewhat involved from the start.

Becca still drives, works and takes care of her daughter and her dog. She has someone helping with basic tasks — more like a personal assistant — as she's still very independent. Although her Parkinson's has progressed to a certain degree she still manages well, largely because of the deep brain stimulation surgeries.

If you want to help a friend with Parkinson's, you need to be specific. Ask something like, "Can I take your daughter to school?" And in general, friends are more likely to help if you're direct. That's sometimes different from how it works with family.

Don't be afraid to have a full friendship. Talk about your own life, too. It should go both ways. When my dad passed away, Becca asked how I was doing during that time. She doesn't want to only talk about herself. I'm not just here to support her Parkinson's journey. We're part of each other's lives in a full, rounded way.



Navigating the Everyday Experiences of Parkinson's

In This Section:

[How Do I Build a Parkinson's Care Team?](#)

[How Do I Advocate for My Loved One?](#)

[How Can I Manage Parkinson's Day-to-Day?](#)

[How Do I Address Concerns About Driving?](#)

[How Do I Manage Parkinson's Mood and Memory Changes?](#)

[How Can We Plan for the Future?](#)

How Do I Build a Parkinson's Care Team?

Building a care team is crucial. This care team is, of course, primarily for your loved one — but they are there for you as well. Get clear about who is, or should be, on your care team and what their role is. That makes it easier to know where to turn when different symptoms and situations arise.

Everyone with Parkinson's should ideally see a Parkinson's doctor (a movement disorder specialist). If none are available in your area, find a general neurologist who has experience with Parkinson's and consider visiting a specialist once a year (or more, virtually) if possible.

Outside of your Parkinson's doctor, your team may include:

- + **Advanced practice providers**, like a nurse practitioner or physician assistant, who partners with your doctor on your Parkinson's care.
- + **Allied health care providers**, like a physical, occupational or speech and swallowing therapist who treats walking, balance or speech and swallowing symptoms.
- + **A social worker**, who helps with care partner support, care in and out of the home, community resources, insurance issues and medication costs and long-term planning.
- + **A mental health therapist** or counselor who provides talk therapy and emotional support.
- + **A primary care, internal medicine or geriatric physician**, who manages general medical care and care for conditions outside of Parkinson's.
- + **Other physicians** with expertise in sleep, mood changes, constipation, urinary or sexual problems and other non-motor symptoms of Parkinson's, as well as those who treat conditions outside of Parkinson's (like a cardiologist for heart disease).



PPMI participant Yvette Larrieu with Neha Prakash, MBBS, a movement disorder neurologist at the Institute for Neurodegenerative Disorders in New Haven, Connecticut.

- + **A pharmacist**, who can answer questions about medication dosing or interactions, ensure safe use of prescription and over-the-counter drugs and help navigate medication costs and complex medication regimens.
- + **A palliative care team** that offers additional symptom and emotional support for both the person with Parkinson's and the care partner, and can help with later life planning. (Palliative care is available from diagnosis and throughout the disease; it's not just for end of life, and it's not just hospice.)

As Parkinson's evolves, your loved one's health care team should evolve, too. While your Parkinson's doctor and core team remain, you will likely call on other providers at different points: Your loved one might see a physical therapist at diagnosis and then once or twice a year for check-ins (or more frequently if there are balance problems or falls), a mental health doctor (like a psychiatrist) if mood changes develop or persist, or a palliative care team if both you and your health care team need more support in easing Parkinson's symptoms or burdens.

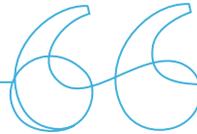
Keep a list of all care team members, noting what symptoms or conditions they manage, the treatments they prescribe and their contact information. Know who to call for what, especially between your Parkinson's physician and internal medicine (or general health) doctor, as well as any other specialty health care providers. Ask them for this information if you're unsure! Always request that providers share notes or speak directly with each other if needed, such as when two providers help manage the same symptoms. Keep copies of visit summaries that you can take to other appointments, too, just in case.

Building Your Own Support System

Your own personal care team and support network is just as important as your loved one's health care team. This is a group of people and resources that assist you, the care partner and the person you are outside of care partnership. It's a system that cares for you and your health and helps you carry the weight of care partnering. It's a place where you can share feelings and let out stress, fears and worries. Everyone's support system looks different and changes over time. Your support system might include:

- + Doctors who help manage your health and conditions you live with.
- + Friends or family members to whom you can reach out when you're feeling sad, stressed or alone.
- + Groups that don't focus on Parkinson's, which can provide social support and time to disconnect from your role as a care partner. These can include running or walking clubs, exercise classes or sports teams, art classes, drop-in hours at a local yarn store where you can knit and socialize, a free class or book club at the library or a volunteer group.
- + Religious or spiritual communities like those found through your place of worship.
- + Other care partners, informally or formally through a care partner support group (either online or in person), with whom you can learn, discuss and share.

If you're interested in a support group, ask your loved one's doctor or social worker for recommendations. There may be options through the clinic, another medical center or other organizations in the community. You can also look online for resources such as MJFF's Buddy Network, which offers a space to connect with other care partners and people living with Parkinson's. [Turn to the Resources for more.](#)



Write everything down. Keep medication schedules in writing. Maintain a journal of your experiences. Go to medical appointments prepared, take notes and clarify what the doctor says. It's critical to ensure both you and the person you're caring for understand everything.

Prentis Brooks

How Do I Advocate for My Loved One?

Advocacy is a core way to partner in care. It means speaking up with or for your loved one, especially in medical settings, so they get what they need.

As a care partner, you make a great advocate because **you know your loved one as a whole person, not just as their Parkinson's symptoms.** You recognize what matters to them and what they want from their care. (If you're not sure, ask. These conversations make you a better advocate.) You may also notice early or subtle changes in mood, thinking or behavior that your loved one may miss. With their permission and best interests at heart, raise these observations first with them and then as partners to their clinician.

Advocacy can feel intimidating. You might worry about asking the wrong questions or taking too much of a provider's time. Remember, you and the care team share the same goal, which is to help you and your loved one live as well as possible with Parkinson's.



Effective advocacy ensures that both you and your loved one are heard, your questions are answered, you understand why tests or treatment changes are recommended (or not), you know what to watch for with Parkinson's and its therapies and you feel confident in the care team.

Advocacy beyond the Doctor's Office

Your advocacy may take place primarily during routine doctor appointments, but you may also need to speak up in emergency room, hospital or long-term care settings. Here, advocacy can be even more critical because staff may not know your loved one or their Parkinson's-specific needs as well as you or the regular care team. You might need to insist on home medication schedules, request consultation with your loved one's Parkinson's specialist or a neurologist or even educate about which medications can worsen Parkinson's, like certain antipsychotic, sleep or nausea medications.

Don't worry about having all the information. You can point providers to credible information, such as that on the Foundation's website, and ask pointed questions: What drug are you giving or prescribing? Is that okay with Parkinson's? Can you clear that with their Parkinson's doctor?

Advocate for Yourself, Too

Advocacy also includes speaking up for *your* needs. Care partners can feel invisible; clinicians may not ask how you're doing, and you may not know when to speak up, given that focus is, rightfully, centered on your loved one. But it's important to make your voice heard. Share how you are feeling: "Here's what we're struggling with..." or "I think we need some help with..." and fill in the blank — whether that's tracking medications, keeping your loved one safe during the day or feeling worn down by symptoms like apathy or mood changes. You can do this during a visit or separately by phone, electronic message or a quick word with the medical assistant. Ask about social workers or patient advocates, too, who can speak to the care team on your behalf. Even the advocate needs an advocate, sometimes. **[For more, turn to Pillar 2: Ask for What You Need.](#)**

How to Advocate for Your Loved One

<p>Identify Your “Why”</p>	<p>You always want the best care for your loved one with Parkinson’s. But at times, you’ll have specific goals around care, like relieving anxiety or depression, understanding a new symptom, coordinating communication among providers or arranging more in-home help. Knowing what you hope to achieve or gain helps you take the right steps to do so.</p>
<p>Ask Your Loved One’s Permission</p>	<p>Explain why you want to help and ask what feels supportive to them. Do they want you to take notes, complete medical questionnaires, ask clarifying questions or summarize next steps? During the visit, check in with them: “Would it be helpful if I...?” or “Is it okay if I...?”</p>
<p>Touch Base before Appointments</p>	<p>A day or two before a visit, set aside time to review with your loved one: What’s changed since the last appointment? Are things better, worse or the same? Why do you feel that way? Share what you’ve noticed. Together, choose the top three topics you want to discuss with your provider. If you’re requesting something specific — for example, more in-home care — list concrete reasons, like falls or safety concerns, to make your case.</p>
<p>Speak Up during Visits</p>	<p>You are part of the care team. Introduce yourself and your role: “I’m Jane’s husband and care partner.” Take notes or, with the clinician’s permission, record the conversation. Ask questions and confirm understanding: “Can I repeat that back so I’m sure I’ve got it right?” or “We’re adding a bedtime dose of Parkinson’s medication to help with sleep, correct?” If something isn’t clear, ask for another explanation, a diagram or written information. Document the plan, medication changes, referrals and next steps. (Or ask for a printed summary with that information.) Be respectful of both your loved one and the clinician, but stay firm about what you need.</p>
<p>Complete Any Necessary Paperwork</p>	<p>To comply with health care privacy laws, make sure you fill out the necessary forms — with your loved one’s permission — that allow you to communicate directly with their medical team both during and outside of visits. This paperwork will allow you to call, message and speak on your loved one’s behalf, when needed.</p>

Other Ways to Advocate for Your Loved One

Participate in Research

Joining a research study may feel impossible when your days already feel too long. Yet many care partners describe research participation as a way to gain control when so much else feels uncertain. It is also a way to give back to your loved one, the Parkinson's community and future generations. Research connects you to something larger than yourself, which bolsters brain health and overall well-being.

Research participation is also a way to advocate. Some studies focus on care partner experiences and needs. Adding your voice can shape the services and resources available to families like yours. Other studies aim to improve brain health, understand Parkinson's more deeply, test new treatments or develop better diagnostic tools. Many of these studies need volunteers both with and without Parkinson's. You could help your loved one enroll, accompany them to in-person visits or help them complete online questionnaires, or even join the same study.

There's a research option for everyone, no matter your schedule or interest. Some studies examine new medications or tests; others collect information about symptoms or day-to-day experiences. Some are one-time only while others track blood tests, brain scans, walking, thinking and more over time to distinguish normal aging from disease-related change. Formats differ, too: Studies could involve online surveys, phone interviews, single in-person visits or periodic follow-up every few months. The Foundation's landmark study, the Parkinson's Progression Markers Initiative, launched in 2010, follows people with and without Parkinson's over time to learn how the disease starts and changes to develop better tools and treatments. [Visit michaeljfox.org/ppmi to learn more.](https://michaeljfox.org/ppmi)

Every therapy available today, and every step toward tomorrow's cure, exists because of the generosity of people who volunteer for research. [To explore current Parkinson's studies, visit foxtrialfinder.org.](#)



Michael S. Fitts (left) and Grace and Leonard Chandler attended the 2025 Parkinson's Policy Forum in Washington, D.C. to advocate for policy change.

Engage in Policy Advocacy

Public policy and advocacy are also areas where your voice can make a difference. As a policy advocate, you can shape state and federal policies on topics across Parkinson's research and care — from environmental influences on disease and research funding to telemedicine and other care access challenges. By sharing your personal story and experiences with policymakers, you put a face to a disease they may not otherwise know. You help them understand what truly matters to those living with Parkinson's and inspire action to drive change.

Anyone can be an advocate, and every action counts. Advocates can send emails or call lawmakers, sign petitions or meet with elected officials (virtually or in person). These simple steps, multiplied across hundreds of thousands of voices, can lead to meaningful policy wins for the Parkinson's community.

[Visit michaeljfox.org/advocacy to learn more and become a Parkinson's policy advocate.](https://michaeljfox.org/advocacy)

How Can I Manage Parkinson's Day-to-Day?

Activities of daily living, or ADLs, are the things we do every day: brushing our teeth, showering, getting dressed, going to the bathroom and moving from place to place. People with Parkinson's may have trouble with some of these tasks, especially as the disease increasingly impacts movement over time.

Instrumental activities of daily living, or iADLs, are more complex tasks that we might not do every day but that allow us to care for ourselves and live on our own: scheduling appointments, grocery shopping, managing finances, keeping track of mail and driving or using transportation. These tasks can become more challenging as Parkinson's progresses, especially if memory or thinking changes arise.

When Parkinson's makes its way into the day-to-day, work with your loved one to identify any changes and figure out what's behind it. Are they having trouble tying a tie, keeping groceries stocked or getting to and from appointments? Then, figure out what's behind the change. What's causing the trouble? Is hand stiffness making buttons a challenge? Is a lack of motivation or apathy making it impossible to stay on top of household tasks?

Whenever you notice a change, talk with your loved one's doctor. They'll help you make a plan to address these changes and the challenges they present. That plan could include:

- + Medication changes to better control motor or non-motor symptoms.
- + Physical therapy for walking and balance problems, freezing or falls.
- + Occupational therapy for exercises and tools to make daily activities easier.
- + A home safety evaluation to make the house easier to navigate.
- + In-home caregiving for specific tasks, such as showering, dressing or light cleaning.

Recognize When to Step in — and When to Step Back

When it comes to daily activities, many care partners wonder when to assist, when to take over and when to let their loved one keep on, even if an activity is more difficult or takes longer. The biggest deciding factor is the safety of you and your loved one. Are they at risk of injuring themselves, or you, in some way? If the answer is yes or maybe, it's probably best to intervene.



Allow your loved one to continue performing tasks that are within their ability and comfort level. If they appear to be frustrated or struggling, don't immediately jump in or take over. Instead, gently offer: "Would it be helpful if I put that on the shelf for you?" or "Can I pick that up off the floor for you?"

Recognize your own irritation or discomfort, too. When you feel friction, ask why. Is it sadness that simple things are no longer so simple? Frustration with how Parkinson's is impacting your lives?

Some tasks also may be done in different ways or to different standards than previously set. Maybe the bed isn't made as neatly, or the dishes aren't stacked as cleanly. Consider whether it's time to adjust your own personal expectations, preferences or approaches.

This is another area where communication is key. In a quiet, relaxed moment — not in the middle of a task — ask your loved one how they feel about certain activities, where you think you could help and how they want you to do so. Use a recent example if you have one. "You looked tired folding the laundry, so I took over. I realize that I should have asked how you felt and if you wanted my help. Do you want to keep folding every time we do laundry? Would you rather collect the dirty clothes or load the washer, or step out of laundry duty altogether?"



I didn't anticipate how much I would have to take over. You think of your partner as an independent adult, but eventually, it becomes more like a caretaker role. It's a shift in dynamics — you're now the one overseeing everything.

Heather Butchen



Bernard (right) and husband Constantin sit down to breakfast at home in New York City. Constantin enjoys cooking for Bernard.



Team Bill – Need for Speed prepares for the start of the 2025 Houston Run/Walk. The team, captained by Nicole Darby (center), participates in memory of Bill Brodhead.

Adapting the Activities You Enjoy

Throughout Parkinson's, your loved one may, for a variety of reasons, find it difficult to participate in activities they (and perhaps you, too) previously enjoyed. This can lead to a sense of loss — of identity, of purpose or of meaning — along with mood changes like depression.

When Parkinson's changes the ability to do favorite activities, find new and creative ways to keep enjoyable activities in your loved one's life. It's also important to maintain and adapt activities you enjoy together. These are places where you can connect and deepen your relationship. If you love traveling, but international trips are too much, would a day trip in the car be a good adventure? If you were a dynamic pickleball duo but had to hang up your paddle, would watching a tournament be a new way to experience the sport?

Exercise



Adapt timing or type of exercise.

Golfers can play shorter or virtual courses.

Runners can adjust medication timing and shoe support.

Seated yoga, floor stretches or a recumbent bike are good options for people with balance or blood pressure symptoms.

Music



Use adaptive options like ergonomic guitar picks or pianos with weighted keys.

Explore a new playing technique.

Consider teaching others to play.

Arts and Crafting



Consider changing mediums, like switching from acrylic painting to digital art.

Experience art in a different way, like through a virtual museum gallery tour.

Use weighted or ergonomic crochet hooks or circular knitting needles and thicker, bulky yarn for fiber crafts.

Reading and Writing



Add thick, padded covers to pens and pencils, or try heavier writing utensils.

Dictate thoughts into a smartphone or voice recorder, then have them transcribed.

Audiobooks, short stories or podcasts may be easier than reading a novel.

Cooking



Schedule weekly meal prep during “on” time, when medication is at its most effective.

Take advantage of tools like non-slip knives, cut-proof gloves and food processors.

Embrace shortcuts like precut foods and batch or one-pot cooking.

Professional Engagement



A teacher could volunteer to help students with homework or read to children at the library.

A lawyer could take on pro bono work or mentor law students.

A handyman could teach others do-it-yourself home tricks through videos or blogs.

How Do I Address Concerns About Driving?

Is it safe to drive with Parkinson's? How do you know when it's time to stop?

As people get older or live with chronic, progressive diseases like Parkinson's, the topic of safe driving will likely come up. Neither getting older nor having Parkinson's alone means your loved one can no longer drive, but age and disease can impact driving. Age can decrease hearing and vision, or slow reaction time. Parkinson's causes movement symptoms that could make it difficult to steer or brake; it can also affect thinking, which could interfere with multitasking or seeing where you and your car are in relation to others. (The latter are called visuospatial skills.) That could make it hard to follow maps or signs, merge into traffic, change lanes or park a car.

Driving is a sensitive subject because it represents freedom and independence. No one wants that taken away, especially when age or Parkinson's has already altered other areas of life. And no one wants to "take away" driving, either. So even those who are concerned might avoid discussing driving for fear of how their loved one will react or what might happen to their relationship.

Tips to Discuss Driving Concerns

Gather information. If you live with or near your loved one, go for a drive together or follow them in another car from a safe distance so you can evaluate more closely. If you're providing care from a distance, ask their spouse, close family or neighbors for observations.

Align with others. Get others' thoughts. If you agree to discuss driving with your loved one, decide how. Who will lead? Should others be there? Will that present a united front or be perceived as an attack? Should you bring up concerns with their doctor or ask a social worker to help? (Involving your loved one's care team can take you off the hook for making challenging decisions on your own.)

When to Raise Driving Concerns

If possible, bring up driving long before you have concerns. Talk about it in a hypothetical way: "If there comes a time when driving isn't safe, how should I approach you? What might alert you that driving is no longer safe? What can we do now to be ready if that happens? What did aging relatives do or not do about driving that can guide our plans?"

You might worry about your loved one's driving if you notice any of the following:

- + Near misses or close calls.
- + Going too slowly or quickly for the posted speed.
- + Other drivers honking.
- + Getting lost or taking longer to travel to familiar places.
- + Drifting when turning or changing lanes.
- + Trouble merging into traffic or parking.
- + Not obeying traffic signs.
- + Not signaling correctly.
- + Scrapes, dents or other damage to the car, garage or mailbox.

When concerns do arise, plan carefully for the discussion.

Approach gently. Don't raise the topic in a stressful moment or while they are driving. Make sure you are in a calm, quiet place without distractions. Start with something like, "I'm worried about your driving," not, "You need to stop driving." Ask how they feel about driving and if they've noticed any changes. Gently share what you've observed.

Anticipate emotion. As with any tough conversation, both you and your loved one will likely experience a mix of emotions. There may be anger, defensiveness, frustration and sadness. Listen for these emotions. Pause and take a deep breath before responding. Acknowledge and validate: "I hear you are upset; that's okay and normal."

Find areas of agreement. You likely both agree that you want your loved one — as well as other motorists, pedestrians and cyclists — to be safe. Where else might you see eye-to-eye, even if you disagree in the moment?

Lead with love. Start by affirming that you care about your loved one. Go back to that as often as you need. Be understanding. Tell them you know how important driving is and that any changes would be a big transition.

The first conversations (yes, there may be a few!) may be more emotional than practical. But wherever you can offer solutions or suggestions, do it from a place of partnership. Use statements like, "We'll figure this out together," or "Here's how I'll help."

In some situations, you may feel the need to take more extreme or immediate actions to keep your loved one — and others on the road — safe, like hiding car keys or removing your loved one's car. While these actions come from a place of concern and prioritizing safety, they may lead to conflict or confusion. Talk with your loved one's doctor, social worker and others in the Parkinson's community to gather input and guidance.

Other Tips to Keep in Mind

As you talk about driving with your loved one, also keep in mind:

A driving assessment may be useful. A driving rehabilitation specialist (typically an occupational therapist) evaluates whether a person can safely drive and makes recommendations, such as stopping or limiting driving to only during daylight, side roads or a few miles from home, for example. They also can suggest driving courses or adaptations to support safe driving. Ask your doctor for a referral, or search online, for a driving rehabilitation specialist. Insurance coverage varies; if this is cost-prohibitive, you might consider taking a driving test through the Department of Motor Vehicles or another organization, such as the American Automobile Association (AAA).

Consider other transportation options. Even if you have limited public transportation, there are ways to get around. Family, friends and neighbors can pitch in. There are also rideshare and senior or medical transport services. Check the local department on aging and ask your social worker for specifics. Consider other modes of transport as well, such as walking or biking to certain activities, if safe.



I'll ask the kids to help reinforce things like driving concerns. I also track what I observe, because Jeff's self-perception doesn't always match what I see. It's a delicate balance.

Heather Butchen

How Do I Manage Parkinson's Mood and Memory Changes?

Not everyone with Parkinson's experiences mood or memory and thinking (cognitive) changes. For those who do, these changes happen in different ways and to different extents. For some, these symptoms are, unfortunately, among the most challenging aspects of Parkinson's. Cognitive symptoms in particular can be difficult to fully address with current treatment options.

There are two main drivers of mood and cognitive changes. The first is disease biology: It affects the brain chemicals — like serotonin, dopamine and others — that regulate emotions and thinking. The second is stress and the emotional strain of living with a long-term illness. Stress can temporarily worsen any symptom, both motor and non-motor.

Depression and Anxiety

Fifty percent or more of people with Parkinson's can experience mood changes like depression or anxiety. Mood changes impact quality of life and lifestyle choices; they can also worsen movement symptoms, make medication feel less effective or interrupt sleep or muddy thinking. For these reasons, it's important to recognize and treat mood symptoms as they arise. As a care partner, you may be the first to notice mood changes, even before your loved one does.



If sadness, constant worry or a lingering “cloud” start to affect daily life, remind your loved one that this isn't a personal failure; it's part of Parkinson's. Choose a calm, private moment to share what you've noticed and speak from a place of care: “You haven't been laughing at the shows you usually enjoy.”

Let them know that many people feel better talking with a mental health therapist or taking medication, and that counseling and medication are normal, proactive steps, much like seeing a physical therapist for help with movement. Counseling provides a safe space to process emotions, learn coping strategies and sort through the uncertainties of Parkinson's.

Offer to reach out to their Parkinson's doctor or to find a therapist covered by their insurance, schedule the first appointment or arrange a video visit if travel is difficult. Remind your loved one that mood changes can — and should — be treated. Medication, therapy and even exercise are all very effective, especially in combination. This isn't something to try to “pull yourself out of.”

Apathy

As Parkinson's progresses, many people may notice a different feeling taking hold: apathy. Apathy is a common but often overlooked symptom. It's more than just feeling tired or unmotivated for a day or two: it's a loss of interest, drive or emotional engagement that can affect daily life. It's not the same as sadness or depression — although it can accompany depression. It's a symptom of Parkinson's disease, linked to brain changes. Sometimes, though, apathy can be mistaken for not caring or laziness.

A person experiencing apathy might stop initiating activities they used to enjoy, like gardening or meeting with friends. They may not get dressed for the day without prompting. They may seem indifferent to things they once cared deeply about, such as hobbies, social events or household projects. Apathy can also show up as taking much longer to start simple tasks, not following through on plans or seeming emotionally “flat” during moments that would usually bring excitement or concern. This can be frustrating for care partners whose encouragement to engage in beneficial activities, like exercise or socializing with others, can seem to fall short.



We asked: How do you motivate your loved one?



Jessie: Billy's apathy was strong. But he loved sports, so TV was a motivator. He also helped me when I cooked and got motivated to see his daughter.



Prentis: Motivation must come from the individual. I ask Christie questions with intention, like "Are you going to ride the bike today?" rather than "When are you going to..." That gives Christie the space to make the decision while also signaling that I think it's important.



Heather: I frame it as something not just for Jeff, but for us. For example, we decided on deep brain stimulation because it was affecting all of us. I encourage Jeff to socialize, travel and exercise because it's good for his health — and our relationship.

Addressing apathy requires patience and consistency. Try breaking activities into smaller, more manageable pieces; instead of, "Let's clean the garage," start with, "Let's spend 10 minutes organizing this shelf." Creating a daily routine also can reduce the need for constant decision-making, which can feel overwhelming for someone with apathy.

Gentle encouragement works better than pressure. Invite your loved one to join you for a short walk rather than insist they get up and exercise. Make activities collaborative. Frame them as something you can enjoy together, such as cooking a favorite meal or listening to music while folding laundry. Celebrate even the tiniest of efforts, and remind yourself that it's Parkinson's causing the apathy, not your loved one intentionally being difficult.

Memory and Other Cognitive Symptoms

Some people experience changes in memory and thinking (cognition) with Parkinson's. Like all symptoms, if and how these symptoms show up varies from person to person. Some might experience mild problems with multitasking or following the thread of a conversation; others might have difficulty learning or processing new information, making decisions or exercising good judgment (using a walker to avoid falling, rather than jumping out of a chair unassisted, for example). Generally, the cognitive changes in Parkinson's are less memory-related and more specific to thinking: trouble paying attention, multitasking (like walking and talking on the telephone at the same time), seeing where things are in space (visuospatial skills) and getting words out.

While cognitive changes don't happen in everyone, they are more common the longer a person lives with Parkinson's. That means for some who live decades or more with the disease, there can be significant difficulty both with moving and thinking, which can be doubly tough to manage. On top of that, cognitive changes can sometimes also bring hallucinations (seeing things that aren't there), delusions (believing things that aren't true, like a spouse is unfaithful or children are stealing money) or behavior changes, like agitation.

Talk with your loved one and their doctor at the first sign of memory or thinking changes (or better yet, long before they come on). Many people are, understandably, concerned about the possibility of memory and thinking changes, and that can make them even tougher to talk about. Knowing what to watch for can help you prevent, prepare and stay on top of changes.

If memory or thinking symptoms occur, medications may slightly boost cognition and attention, ease hallucinations or lessen behavior changes. There are many things you can do beyond medication, too:

- + Ask yes/no, rather than open-ended questions.
- + Keep a regular routine, with a clear, shared calendar for your loved one to easily refer to.
- + Maintain a calm environment, especially at night, with soothing sounds, scents and activities.
- + Address hearing or vision changes, which can make it harder for your loved one to interact with you and the world around them. Make sure they use hearing aids or corrective lenses as needed.
- + Look for what's behind behavior changes: Might your loved one be in pain, tired or anxious?
- + Reassure and redirect around hallucinations or delusions. Don't argue or try to convince them otherwise. Instead, gently change the topic or focus.
- + Have go-to relaxing activities handy like coloring, looking at family photos or listening to music.
- + Employ additional carers, cameras and alert bracelets or pendants as needed for extra supervision and safety around wandering or falls.

These are just a few of the many ways you can support your loved one when cognitive changes are part of the picture. [*Turn to the Resources for more on thinking and memory symptoms.*](#)

How Can We Plan for the Future?

Some care partners think of the future as a far-off, distant thing. Other care partners think of the future as more immediate: tomorrow, next month, the next stage of Parkinson’s disease. As you read this guide, you and your loved one may be more focused on the here and now — and that’s okay. Together, you will approach and think about the future — and whatever timeframe that may encompass — in a way that works for you. As with the rest of this guide, use the information in this section in whatever way you find most helpful: Take what you need and leave the rest.

Know Who Can Help

As you think about the next stages of life and life with Parkinson’s, you may find yourself asking questions: How can I find services and support, and what is my loved one eligible to access? Who can help us manage our finances? How do I plan for later and end-of-life care? As you read the rest of this section, refer back to the following list to remind yourself who can help with what tasks. Keep in mind that this list isn’t comprehensive: There may be others in your life — religious or spiritual leaders, personal trainers or life coaches — to whom you can turn.



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Doctors and Allied Health Care Providers	Your loved one’s current care team — including their primary physician, Parkinson’s doctor and others — is a good place to start when questions or issues arise. See How Do I Build a Parkinson’s Care Team? for specific information about the different health care providers you can turn to.
Social Worker	A social worker can help you understand your insurance coverage and benefits and direct you to resources for financial planning and medication assistance. They can also talk through advanced care options; connect you with resources like your local Area Agency on Aging; research housing options; help you vet professional caregivers, companies or facilities; and provide tips on touring and interviewing.
Mental Health Professionals	Mental health professionals can help you work through anxiety or depression, feelings of guilt and other emotional challenges. A couples counselor can help manage communication issues that may arise as well as navigate conversations around advance care planning or other care preferences.
Health Insurer	Your health insurance provider can detail what is and isn’t covered by your plan, clarify what services and providers are in or out of network and suggest ways to potentially lower health care costs.

Elder Law or Other Attorney	An attorney can help navigate legal, financial and health care challenges, including disability coverage, long-term care planning, estate planning, asset protection, advance directives, care and facility costs and more.
Financial Planner or Certified Public Accountant (CPA)	A financial planner or CPA can conduct a comprehensive financial review, assess health care costs, create a plan to approach long-term care, navigate challenges like loss of income or insurance coverage, coordinate with legal professionals about wills, trusts and power of attorney and more.
Family, Friends and Other Care Partners	Family and friends can support by tapping into their own skills, and other care partners who are going or have gone through similar experiences can help you navigate your personal journey.

Financial Planning

Many people are concerned about the cost of health care, especially when living with a lifelong condition like Parkinson's. Over time, costs add up and new, sometimes unexpected, expenses can arise. When Parkinson's leads to early retirement or a care partner's absence from work, it can further affect the ability to make ends meet. Planning around finances — for both now and the future — is another part of care partnering.

Costs to Consider

The first step in financial planning is getting a handle on your current Parkinson's-related expenses while thinking about possible future costs. Some costs — like medical visit co-pays, medications and insurance premiums — will be constant throughout Parkinson's. Others, like therapy sessions or home modifications, might arise once or over a shorter period.

Potential Parkinson's-related expenses include:

- + Medical visits and medication co-pays
- + Health insurance premiums

- + Physical, occupational, speech or other therapies
- + Exercise and other Parkinson's-related classes
- + Disability, long-term care and/or life insurance premiums
- + Travel to and from doctor visits
- + Time off work or childcare needs for medical care or care partnering
- + Surgical procedures
- + Paid professional caregivers
- + Medical devices or equipment, such as a walker or wheelchair
- + Home modifications or moves
- + Long-term care expenses

Keep a spreadsheet or use an app to track and understand your average monthly care expenses. The goal isn't to monitor every single expense, but rather to get a general sense of how much care generally costs each month so you can budget.

Parkinson's care can be costly, especially when it requires medications, surgical treatments, home modifications and more. Support is available to offset these costs:

Shop around. Different pharmacies have different prices for medications. Online programs like GoodRx can show the cheapest options in your area.

Check for assistance. Drug manufacturers offer different types of aid: financial aid for people who meet income and other requirements, free or subsidized medications for un- or under-insured people, and co-pay cards that reduce costs for those with commercial (non-Medicare or Medicaid) insurance.

Look for nonprofit help. Certain organizations provide grants for Parkinson's medications, equipment or care.

Prioritize in-network providers. Co-pays and other visit costs are lower when doctors are in-network with your insurance plan.

Schedule virtual appointments. When available, virtual appointments lessen travel and related expenses.

Use tax-free dollars. Private or commercial health insurance plans may allow you to add pre-tax dollars to Flexible Spending Accounts or Health Savings Accounts. These funds can be used for co-pays, medications and much more related to health and care.

Ask about payment plans. For larger expenses like hospital stays or surgical procedures, ask about options to pay over time rather than all at once.

Financial Resources to Help Manage Costs

Familiarize yourself with what resources and benefits you currently have, what each does and does not provide and where you may need to adjust for the best financial coverage. Resources may include:

- + Monthly income and/or retirement benefits, like Social Security

- + Health care insurance
- + Disability insurance
- + Long-term care or life insurance
- + Savings accounts
- + Investments and other assets

Understanding Medicare Coverage

As with private or commercial health insurance, Medicare may not cover all costs. Medicare generally does not cover home modifications, assisted living or skilled nursing and long-term care facilities. However, veterans' benefits, long-term care insurance and the Medicaid waiver program can be used to provide your loved one the care they need while allowing them to stay at home.

Legal and Estate Planning

Part of financial planning may also include completing legal documents that spell out your wishes related to financial management in later life. **Financial power of attorney** grants a person you designate the power to manage your financial affairs, accounts, businesses and more, should you become unable to. **A will and testament** outlines who you'd want to inherit property or other assets and assigns an executor to handle your estate.



With early-onset Parkinson's, there's no clear path toward the future. When you're diagnosed at 35 or 40, you live a long time with the disease. You need to mentally prepare for what might come and decide how to handle it.

Walter Siegenthaler

Health Care Planning

No one can predict what their long-term health will look like, but we can all prepare for the possibilities. As a care partner, your focus may be, understandably, be on your loved one's future health and well-being. While it's important to understand their wishes around topics like later and end-of-life care, it is equally as important to have those plans in place for yourself, too. Many care partners wonder what will happen to their loved one if something happens to them. Advance care planning can bring peace of mind to you both and is a crucial part of your own self-care.

Start planning by asking questions. Think about your own goals, wishes and values. What's most important to you? This will likely be an emotional exercise. The feelings that may surface are valid; take the time to acknowledge and honor them.

After you identify what kind of later or end-of-life care you want, formalize those wishes through written, legal paperwork known as advance directives. Advance directives typically include the following:

A **health care power of attorney** (or **health care proxy** or **medical power of attorney**) is a person you appoint to make care decisions on your behalf if you become unable to do so. This should be a person who understands your wishes and who will direct your care accordingly.

A **living will** outlines how you wish to be cared for at end of life if you become seriously ill or unable to communicate. It often includes information about whether and when you'd want interventions like breathing or feeding tubes, CPR, antibiotics or other life-sustaining supports, as well as directives around tissue or organ donation.

Know that you may never need to use these plans. As the saying goes, plan for the worst and hope for the best.

Advance Care Planning Considerations

As you and your loved one begin advance care planning, consider the following prompts to start conversations:

- + What makes life worth living? Feeling and giving love? Having purpose? Spending time with loved ones?
- + What does quality of life look like to me? What kind of care will support that?
- + What care do I want — or not want — to receive at the end of life?
- + What are my hopes for the next five, ten or 20 years?
- + Do I hold faith-based beliefs that impact the type of health care I'd like to receive? How can my cultural, spiritual or religious beliefs be honored?
- + Are there medical conditions that might change my treatment goals?
- + Where do I want to live long-term? Will I prioritize staying at home as long as possible?
- + How do I feel about bringing more care, like professional caregivers, into the home?
- + What Parkinson's symptoms worry me most?
- + If symptoms prevent me from living on my own or at home, where would I like to live? What would the best place, and best care, look like?

Once you and your loved one's advance directives are in place, share these documents with your respective medical teams and health care proxies. Keep a copy for yourselves as well: consider creating a physical binder or digital folder containing your advance directives in a place that's easy to access.

Our guide to future care planning, *Looking Ahead with Parkinson's*, can help you navigate these conversations. Visit michaelfox.org/lookingahead for more. [*Additional later and end-of-life care planning resources are available in the Resources section.*](#)

Exploring Options for Additional Help

For some — not all — care partners and families, there may come a time when Parkinson's requires more than you can safely give on your own or in your own home. Recognizing this need can be difficult and emotional for both you and your loved one. There may be resistance to change, discomfort with getting care from new or different people or a desire to stay in one's own home — no matter what. Many care partners feel guilty, as though they are not living up to vows of “in sickness and in health” or keeping promises to never put their loved one in a home.

Deciding You Need More Help

As you think about whether your loved one needs more or different care and what that might look like, consider:

Symptoms and severity. Does Parkinson's significantly affect your loved one's ability to perform everyday tasks? Do they need 24/7 care and supervision? Are stairs hard to climb? Does the current home and setup work? Will it accommodate changing abilities and needs as the disease progresses?

Safety. Do symptoms impact safety for you or your loved one? Do they risk injury from falls? Do you risk hurting yourself when helping them up from falls, or when assisting with tasks like showering or moving in and out of bed? Do cognitive changes or hallucinations increase safety risks, like forgetting to turn off the stove or wandering from home?

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We asked: How are you planning for the future?



Heather: We're starting to plan for things like needing a one-floor home, maybe hiring a driver and being in warmer climates longer. Jeff's deep brain stimulation surgery gave us a reset, but we're staying mindful of future needs



Prentis: We're actively preparing for the next stage of the disease. At our next appointment with her movement disorder specialist, we'll be continuing those conversations. We've updated our wills and advance directives. Christie has decided to donate her body to research, which was emotional for our daughter. We keep our children informed, and our planning has made things easier so far.



Melissa: I don't really think about disease progression. It's a scary thing, so I put a big rock on those feelings. I only occasionally look underneath. Living in worry doesn't help.

Costs. Can you afford more help in the home or full-time living at a care facility? Are repairs or home modifications an option? What insurance or other coverage is available? Does your loved one have long-term care insurance? What does that cover?

Quality of life. Are you and your loved one isolated or lonely? Do you need more connection, community or social activity?

Proximity to loved ones. Do family members, children or close friends live nearby? If you move, who will visit?

Emotional factors. Did you promise that you'd never move your loved one into a nursing home? Did you vow "Till death do us part?" Does considering a move for your loved one make you feel guilty?

Care partner well-being. Are you struggling physically or emotionally, or feeling overwhelmed or burned out? Are you managing in the moment but concerned you may begin to struggle soon? Do you need more help?

Understanding Care Options

There are many options for increased or expanded care. Some bring more care into the home, while others involve moving to facilities that provide more hands-on, around-the-clock care.

Note that while experiences vary by state and insurance coverage, most of these services come with an out-of-pocket cost.

Home Modifications

- + An occupational therapist can conduct a home safety evaluation.
- + Ramps, stair lifts and shower grab bars increase safety and accessibility. .
- + Arrange Arranging a bedroom and full bathroom on the first floor eliminates the need to navigate stairs.

Paid Caregivers

- + Professional or paid caregivers provide personal care, like bathing, dressing, toileting and administering medications. Some offer lifestyle support, like companionship or light housekeeping.

Other In-home Care Professionals

- + Visiting nurses measure vital signs and address medical needs like medication management.
- + Physical or occupational therapists provide structured exercises and tools to help with movement, balance and other daily activities.
- + Speech therapists provide exercises and tools to help with speaking clearly and swallowing safely.

Community Programs

- + Adult day centers and senior programs offer recreation, exercise and social activities. Contact your local Area Agency on Aging for information on meal delivery and medical transportation services.

Respite Care

- + In-home respite care offers short periods of assistance to give the primary care partner a break for a few hours or days at a time.
- + Residential or facility-based respite centers offer short term stays (one night, a weekend or several weeks).

Finding the Right Out-of-Home Care for Your Loved One

Many people say they never want to move outside the home. That's normal and understandable. Sometimes, though, remaining at home becomes untenable due to symptom progression or safety concerns. Remember: everyone's Parkinson's is different and not everyone with Parkinson's needs long-term care. If issues arise, it may be time to consider moving your loved one to a setting that is better equipped to provide the care they need.

Important Considerations for Long-Term Care

There are several options for long-term care. No matter which type of care you may be considering, it's important to visit in person and to assess the general spaces and resident rooms, how staff interact with residents, how well the residents seem to be cared for and more. Visit a few different times, if possible — during a morning check-in, a mealtime and an organized activity, for example. You'll want to have a list of questions, such as:

- + Do you have experience caring for people with Parkinson's? What kind? Do the staff have certifications or expertise in Parkinson's?
- + Do you have physical, occupational or speech therapy on site? Do they have Parkinson's experience?
- + How many residents are assigned to each nurse or staff member? What happens overnight and on weekends?
- + Who provides medical coverage, or manages my loved one's medications or surgical devices, like deep brain stimulation?
- + What exercise, social, religious, spiritual or recreational activities are available?
- + Do you provide transportation for errands or to medical appointments?
- + Do you provide all meals? How do you handle dietary needs (such as for swallowing difficulty) or preferences?
- + How often will my loved one get a shower or bath?
- + How do you prevent and monitor for falls?
- + How do you handle memory or behavior changes or hallucinations?
- + What are your protocols if my loved one's condition worsens?

- + What preventive protocols are in place for infections, such as the flu or COVID-19?
- + Are there restrictions on visiting?
- + What are the costs? What will I need to cover on my own, like shower supplies, incontinence products or snacks?
- + Who is my main point of contact? How often do we check in? Do we regularly assess how my loved one is doing and if this remains the right place for them?
- + How can I best support my loved one while they live here?

Supporting Your Loved One from a Distance

You are still just as much of a care partner when your loved one moves to a new location. But now your role shifts again, as it has throughout life as a care partner. Your care may now focus more on the following areas:

Advocacy. Your advocacy may be more necessary and specific as staff get to know your loved one. You may also need to advocate more during times of transition — for example, if medications change. Complete any necessary HIPAA forms or other paperwork so you can easily communicate with the care team.

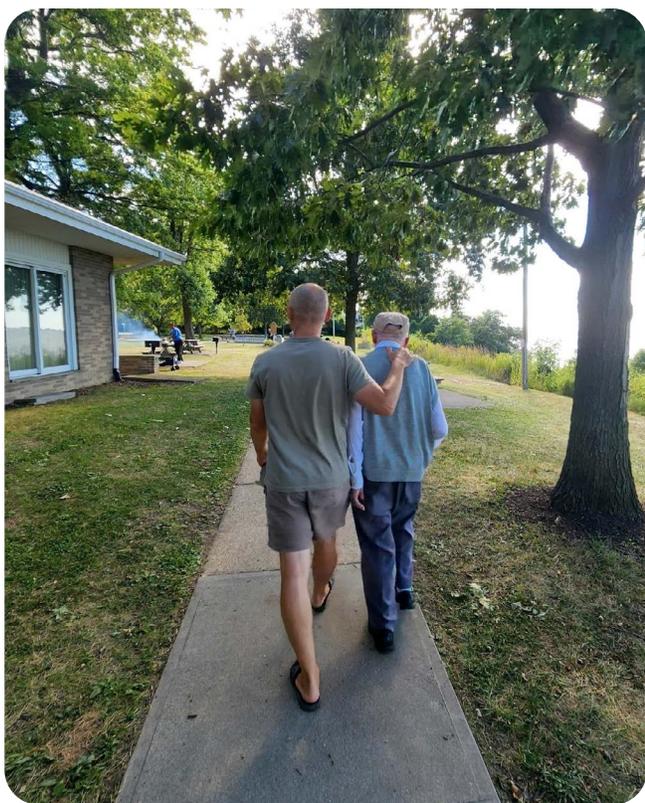
Partnering with the care team. Get to know the staff caring for your loved one. Have a main point of contact and keep lines of communication open. If possible, attend care planning meetings where staff and family come together to discuss the loved one's care. This is an opportunity to learn more and ensure your loved one is getting the care they need.

Visit, when possible. Regular visits can improve your loved one's care and well-being as well as give you peace of mind. Most importantly, visits keep you connected to each other. You'll learn their routine, find ways to bring light to their days and see how you can be their best care partner in this new arrangement.

If in-person visits aren't possible, consider how you can use technology. Staff may be willing to set your loved one up with the necessary tools; otherwise, use the telephone to stay in touch.

Navigating the Road Ahead

As you've seen throughout these pages, no two care partner — or Parkinson's — experiences are the same. You and your loved one are walking this road together. Communicate, ask for help when needed and take care of yourself. Success as a care partner doesn't look like doing everything right, it looks like showing up with love, grace and compassion. No matter where you and your loved one are in your journey, this guide and the resources within will be here to inspire you as you navigate the road ahead.



Josip and his dad, Alojz, take a walk together every day. "What I've gained caring for my father has changed me in ways I never imagined," Josip said.

Resources

This resource list is intended to point you in the right direction and highlight available resources. It is neither comprehensive nor an endorsement of any specific organization, provider or program.

Resources from The Michael J. Fox Foundation

Educational Guides

[Paving Your Path over Time: Practical Tips for Progressing Parkinson's](#)

Living with Parkinson's for years or decades can bring new or more symptoms, different care needs and a range of emotions for people living with Parkinson's, their care partners and their families. Learn more and get practical tips for progressing Parkinson's.

[Looking Ahead with Parkinson's: A Guide to Future Care Planning](#)

No matter where you are in life or with Parkinson's, it may be helpful to think about and plan for the future. Get step-by-step guidance, information and tips for talking with loved ones and future planning.

[Thinking, Memory and Parkinson's Disease: A Guide for People with Parkinson's and Their Loved Ones](#)

Thinking and memory changes are among the most concerning potential Parkinson's symptoms. We developed this guide in collaboration with patients, families and clinicians to offer definitions of cognitive changes and strategies to manage changes if they occur.

View all of MJFF's guides for living well with Parkinson's at michaeljfox.org/guides.

Other MJFF Resources

- + More care partner resources are available at michaeljfox.org/care-partners
- + Join our Policy Network at michaeljfox.org/advocacy
- + Find a clinical trial through Fox Trial Finder at foxtrialfinder.org
- + Join monthly webinars on Parkinson's research and care: Listen to the audio from our Third Thursdays Webinar on destigmatizing Parkinson's disease at michaeljfox.org/webinars
- + Check out Dr. Dolhun's resources for life with Parkinson's at michaeljfox.org/ask-md

Alone, it's a test. Together, it's a breakthrough.

Support your loved one by taking a free
scratch-and-sniff test to advance Parkinson's research.

mysmelltest.org/takethetest




THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

General Aging Resources

AARP

AARP represents people age 50 and older. They are dedicated to ensuring quality, accessible health care for all older Americans.

Health In Aging

Health in Aging, created by the American Geriatrics Society's Health in Aging Foundation, provides resources and tools for older adults and their care partners.

National Council on Aging

The National Council on Aging delivers resources, tools, best practices and advocacy to ensure every person can age with health and economic well-being.

National Institute on Aging

The National Institute on Aging — one of the 27 Institutes and Centers of the National Institutes of Health — provides research-backed information about aging and health for older adults.

Advance Care and End-of-Life Planning Resources

Advance Directives by State

This AARP database allows users to search and find advance directive forms on a state-by-state basis.

Aging with Dignity

Aging with Dignity is a nonprofit organization that defends the rights of individuals as they approach end of life. They publish the [*Five Wishes*](#) program, a popular advance care planning resource.

American Bar Association Tool Kit for Health Care Advance Planning

The American Bar Association Commission on Law and Aging created this resource to aid in the creation of advance directives and other advance care planning tasks.

Ariadne Labs

Ariadne Labs, a joint center of Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health, shares tools to support care partners and their loved ones through conversations about later and end-of-life care.

Compassion & Choices

Compassion & Choices provides resources on end-of-life decision making, advocates for compassionate dying and empowers individuals to choose end-of-life care that reflects their values and beliefs.

The Conversation Project

The Conversation Project aims to help every person talk about their care wishes through end of life with free tools, guidance and other resources.

Hospice Foundation of America

The Hospice Foundation of America provides education and resources on hospice, grief and navigating loss.

National Alliance for Care at Home

The National Alliance for Care at Home is an alliance between the National Association for Home Care & Hospice and the National Hospice and Palliative Care Organization. The Alliance engages in education and advocacy to transform access to health care in the home.

Care Partner Resources

ARCH National Respite Network and Resource Center

ARCH promotes quality respite and crisis care programs across the country. Their National Respite Locator service helps care partners locate respite care services in their community.

Caregiver Action Network

The Caregiver Action Network works to improve the quality of life for millions of family caregivers across a spectrum of diseases.

Family Caregiver Alliance

The Family Caregiver Alliance provides services to family caregivers of adults with physical and cognitive impairments. Services include care planning, wellness programs, respite services and more.

National Alliance for Caregiving

The National Alliance for Caregiving uses policy and research to build health, wellness and financial security for family caregivers. Visit caregiving.org.

Community Resources

Your loved one's doctor or social worker can help connect you with Parkinson's-specific resources in your area:

- + Your local [Area Agency on Aging](#) or [Aging and Disability Resource Center](#) to locate resources in your community.
- + A Senior Living Broker provides free, personalized assistance for locating residential care facilities.
- + A geriatric care manager is a paid service providing individualized support where you need it. They could visit you at home, attend doctor's appointments with you, advocate for you at the hospital or rehab facility, tour senior living facilities with you and more. Find a geriatric care manager through the [Aging Life Care Association](#).

Estate Planning Resources

National Academy of Elder Law Attorneys

The National Academy of Elder Law Attorneys is dedicated to improving the quality of legal services provided to older adults and people with disabilities. Use their searchable database tool to find an elder law attorney.

National Association of Estate Planners and Councils

The National Association of Estate Planners and Councils is a professional organization for estate planners and estate planning law specialists. Use their searchable database tool to find an estate planner or specialist.

Financial Resources

Financial Planning Association

The Financial Planning Association is a trade organization for certified financial planner professionals and others involved in the financial planning process. Their website includes tools to search for financial planner and other resources.

Flexible Spending and Health Savings Accounts

Provide or commercial health insurance plans may allow you to add pre-tax dollars to [*Flexible Spending Accounts*](#) or [*Health Savings Accounts*](#). These funds can be used for co-pays, medications and more.

GoodRx

GoodRx compare prices for prescription medications and provides consumers with pharmacy coupons.

Life Happens

Life Happens provides comprehensive consumer-focused financial education.

National Association of Personal Financial Advisors

The National Association of Personal Financial Advisors represents fee-only financial advisors.

Government Resources

Centers for Medicare & Medicaid Services

The Centers for Medicare & Medicaid Services provides health coverage to more than 160 million Americans, including Medicare and Medicaid.

Eldercare Locator

The Administration for Community Living maintains an eldercare locator database. Search by location to find eldercare options in your community.

Medicaid

Learn more about Medicaid waiver programs and home and community based services resources.

Medicare

Find home health care and skilled services, such as physical and speech therapy; and residential care facilities, such as assisted living or nursing facilities, in your ZIP Code and review their ratings.

Veterans Affairs

If your loved one is a veteran who receives care through the U.S. Department of Veterans Affairs, they may qualify for benefits. Find your local VA office at [va.gov/find-locations](https://www.va.gov/find-locations).

Mental Health Resources

For help finding a therapist, ask your doctor for a referral, ask community members for recommendations, contact your insurance for a list of in-network providers or use an online search tool like [Psychology Today](https://www.psychologytoday.com).

National Suicide and Crisis Lifeline

Call or text 988, or visit 988lifeline.org.

Crisis Text Line

Text HOME to 741741 for 24/7 crisis counseling via text message, or visit crisistextline.org.

Support Groups

Your loved one's doctor or social worker can help you find local support group organizations.

The Michael J. Fox Foundation hosts the [Parkinson's Buddy Network](https://www.michaeljfox.org/online-community), an online forum where care partners can connect to learn from others and share experiences.

Note

The information in this guide was accurate at the time of publication in February 2026. For the latest on care partnership, visit michaeljfox.org.

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

About The Michael J. Fox Foundation

As the world's largest nonprofit funder of Parkinson's research, The Michael J. Fox Foundation is dedicated to accelerating a cure for Parkinson's disease and improved therapies for those living with the condition today. The Foundation pursues its goals through an aggressively funded, highly targeted research program coupled with active global engagement of scientists, Parkinson's patients, business leaders, clinical trial participants, donors and volunteers.

In addition to funding more than \$2.5 billion in research to date, the Foundation has fundamentally altered the trajectory of progress toward a cure. Operating at the hub of worldwide Parkinson's research, the Foundation forges groundbreaking collaborations with industry leaders, academic scientists and government research funders; creates a robust open access data set and biosample library to speed scientific breakthroughs and treatment with its landmark clinical study, PPMI; increases the flow of participants into Parkinson's disease clinical trials with its online tool, Fox Trial Finder; promotes Parkinson's awareness through high-profile advocacy, events and outreach; and coordinates the grassroots involvement of thousands of Team Fox members around the world.

michaeljfox.org

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This publication was made possible by Acadia Pharmaceuticals. Partner support allows us to furnish high-quality educational content to the Parkinson's community while maintaining our commitment to allocate donor dollars to high-impact research. The Michael J. Fox Foundation is solely responsible for the content in this guide.



Printable Pages



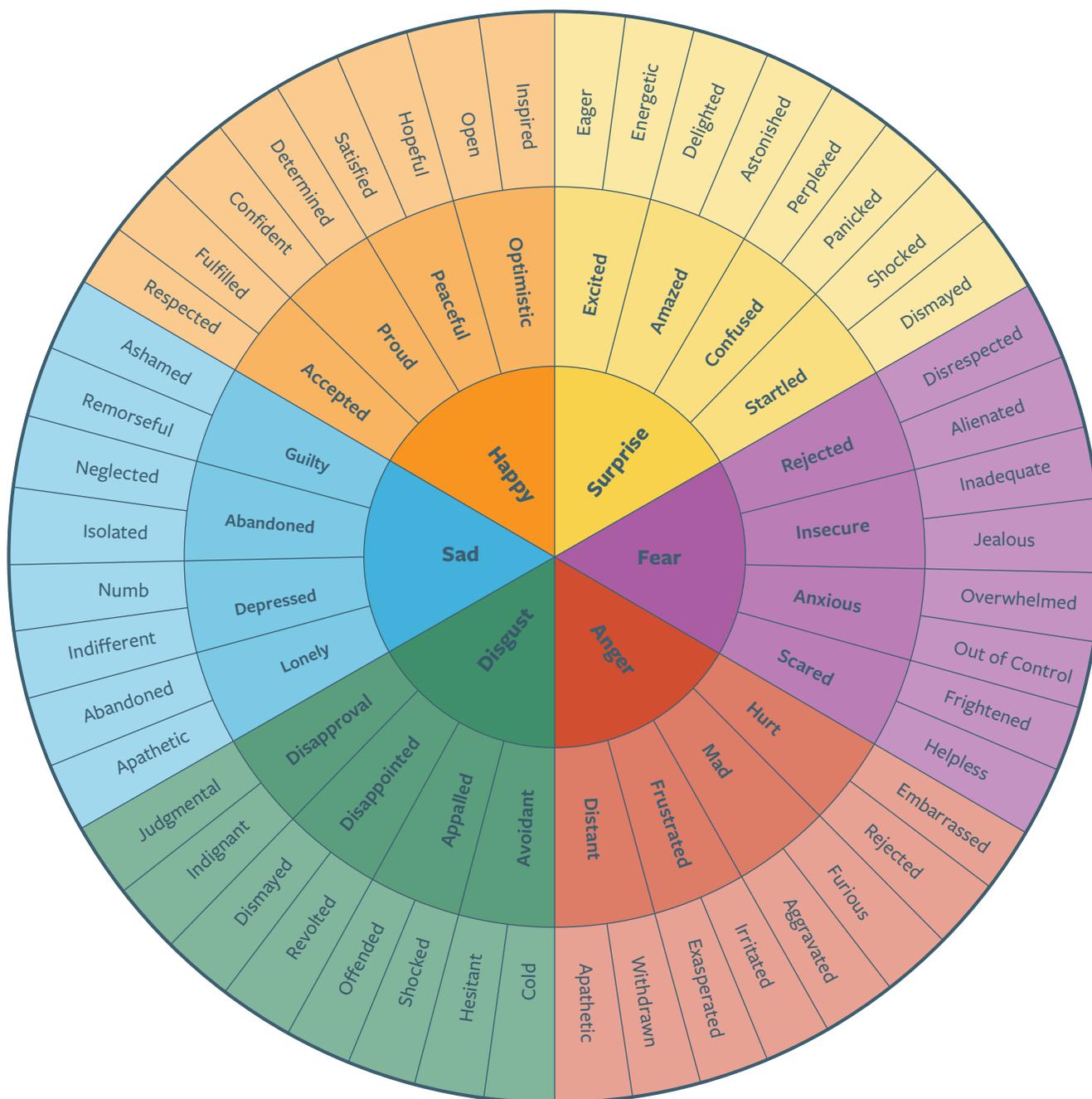
This section includes printable versions of key resources from this guide, designed for easy reference.

Download and print what's most helpful for you.

The Emotion Wheel: Naming What You Feel

Care partners experience a range of complex and sometimes confusing emotions, from guilt and grief to joy and affection. Naming what you're feeling can help you respond instead of react. The Emotion Wheel is a tool to help you identify your emotions.

Starting at the center, complete an "I feel..." sentence that identifies the broad, primary emotion. Then work your way out, defining your emotions in more detail and complexity. Defining your emotions can help you better process and communicate how you feel.



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Practical Tips for Managing Your Emotions

Nobody's perfect. We all have moments of annoyance or impatience with the people we love. These are normal human reactions when things get hard. Learning how to recover and reconnect after tense moments protects, and often deepens, a relationship.

Take a Moment in the Moment

Pause and label the feeling.

Naming an emotion — “I’m feeling overwhelmed right now” — buys you a second to respond carefully rather than react with annoyance.

Notice how the feeling shows up in your body.

Is your breathing shallow? Your jaw clenched? Your shoulders scrunched up? This helps you recognize the physical effects of an emotion, sometimes even before you can name it.

Ground yourself within your body.

Slow, deep breaths from the diaphragm (the muscle that sits below your lungs and heart that helps you breathe) or a brief walk can quickly downshift the “fight-or-flight” response. Try breathing in for a count of four, out for a count of six.

Shift Your Mindset

Reframe the experience.

Research shows that looking at a stressful event from a more positive angle helps you cope in the here-and-now and build resilience for the future. Try statements like, “My partner isn’t ignoring me; Parkinson’s is scrambling their signals.”

Remember, you are not your emotions.

Emotions don’t define you. You may feel angry or anxious, but that doesn’t mean you are an angry or anxious person. Try stating it that way: “I am feeling angry right now,” not “I am angry.”



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Build Emotional Management Muscles	
Dig deeper.	Look for what’s behind your feelings. If you often feel irritated, ask why. Is it a lack of sleep? Stress? Not feeling well in general? Journaling or talking with others can get to the root cause.
Practice mindfulness.	Mindfulness is awareness, without judgment, of the present: your thoughts, feelings, sensations and environment. In one research study, nine weeks of Mindfulness-Based Stress Reduction, a program that teaches mindfulness tools and skills, raised awareness in care partners and improved patients’ quality of life. You and your loved one can practice together. Five minutes of a guided breathing or body-scan exercise can steady you both
Seek professional or peer help.	Virtual support groups, classes in which you learn mindfulness and other skills or counseling sessions can provide tools for emotion understanding and regulation and reduce any sense of isolation.
Check in with your loved one.	Make checking in on emotions a habit. Ask something like, “On a scale of one to five, how do you feel?” Ask what’s behind their answer, and don’t shy away from the “big” emotions. Many care partners keep grief, guilt or overwhelm to themselves for fear their loved one might feel responsible. Your loved one may have similar feelings, even if for different reasons, and discussing them can bring you closer



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The Pillars of Care Partnership

Everyone comes to care partnership in different ways. Whether you're a spouse or adult child, a full-time or part-time care partner, or close by or far away, these guiding principles can help you and your loved one navigate the complexities of Parkinson's — together.

Pillar 1: Talk Early, Talk Often

Communication is crucial in any relationship, especially when care partnership is involved. Approach conversations with kindness, empathy and love, for both your self and your loved one.

Pillar 2: Ask for What You Need

Asking for help is a strength, not a weakness. It helps you to be a better care partner. Know what you need (or ask others to help you figure that out!) and how to ask for support.

Pillar 3: Commit to Your Own Self-Care

Self-care isn't selfish; it's self-preservation. You can't pour from an empty cup, and taking time to care for yourself is another way to care for your loved one. Even five minutes a day just for you makes a difference.

Pillar 4: Remember, You're Only Human

You, like every single one of us, are human. You are imperfect. You make mistakes. Be gentle and understanding with yourself. You're doing the best you can, and that's all any of us can do.

Pillar 5: Embrace Life outside of Parkinson's

You are more than a care partner. Take the time to honor and appreciate all of who you are and cultivate the life you live beyond Parkinson's disease.



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Five Keys to Unlock Good Communication



While we all have different communication styles, there are some basics everyone can build on to establish and maintain solid lines of communication. Keep these five keys in mind as you communicate.

Key 1: Set the Stage

Sit together, facing each other, in a quiet space. Don't shout from opposite ends of the house. Commit to focusing only on each other and remove distractions: Turn off the TV or radio, eliminate background noise, and silence your phones. Plan important discussions for when your loved one is "on" (when medications are most effective), especially when the topic may be difficult.

Key 2: Get on the Same Page

Be clear about what you hope to get out of the conversation. Do you want advice or feedback? Do you want to brainstorm or problem-solve? Or do you need to vent and be heard? Defining goals sets you and your loved one up for a successful conversation.

Key 3: Listen Actively

Don't just think about how you're going to respond; really hear what your loved one is saying. Don't interrupt, correct or jump in. When they're done talking, repeat back what they said and ask questions to go deeper. Let each person fully express themselves — even if you disagree. Talk first, then revisit points of contention later.

Key 4: Address Emotions

Acknowledge when the conversation is difficult. Allow your loved one to express emotions and refrain from reframing any negative emotions with a positive spin. For example, if your loved one is sad, don't rush to remind them of the bright side; instead, hold space for sadness. Despite good intentions, this quick, positive reframe — known as "toxic positivity" — can be dismissive of others' feelings.

Key 5: Be Patient and Be Okay with Disagreement

Give your loved one time, especially if they experience speech or cognitive changes. Don't finish their sentences (unless they've asked you to) and pause before you respond; become comfortable with silence.



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The Rose, Bud, Thorn Tool

Rose, Bud, Thorn is a tool used to reflect, solve problems and share experiences. Each part of the flower represents a different area: a success (the rose), an area for improvement (the bud) and a challenge (the thorn). Take turns sharing rose, bud, and thorn in a daily or weekly check-in with your loved one.

Rose

A positive highlight or something that went well

Questions to ask:

What worked well today (or this week)?

What's one positive thing you noticed about your loved one or about your situation?

What are you proud of?

Thorn

A stressful challenge or a negative situation

Questions to ask:

What didn't work?

What was our low point today (or this week)?

How can we fix it?



Bud

An opportunity for improvement or an area for growth

Questions to ask:

What have we learned? Where can we improve?

How can I be more supportive toward you?

What are you looking forward to?



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Setting Self-Care Goals



Goal setting is motivating. Setting self-care goals can keep you accountable, give you a sense of purpose, and help you feel accomplished when you reach them. But both setting and achieving goals can be difficult, even without the complexities of care partnership added to the mix. Here are some strategies to help you set and stick to your goals.

Identify Your “Why”	It can be easier to work toward goals when you identify the why behind them. Naming the why makes it more meaningful and clarifies the steps you need to take toward achieving a goal. Instead of “I need to exercise more,” try, “I want to have energy and stamina to play with my grandchildren or hike with my loved one.” The why gets you started or keeps you going on the days when life or care partnership might otherwise get in the way.
Celebrate Your Wins	Prioritize progress, not perfection. Celebrate throughout the process: not only when you achieve a goal, but as you make progress with every step along the way. If your goal is to finish a 5K, applaud yourself for getting out the door, taking a walk, and beyond. Acknowledge each success and pat yourself on the back for every positive step.
Make Your Goals Specific	A specific goal is easier to track. Something concrete — like “I’ll meditate for five minutes every morning for one week” — is easier to measure than “I’ll work on taking better care of myself.”
Give Yourself Grace	Like care partnership itself, accomplishing goals isn’t always straightforward. There will be setbacks, challenges and detours. Anticipate and embrace these as part of the process, use them as opportunities to learn and adjust, and keep moving forward.



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Building Your Support Team



Building a support team is crucial. As you navigate Parkinson's with your loved one, you may find yourself asking questions: What type of doctors does my loved one need to see? How can I find services and support? What is my loved one eligible to access? It's important to have clarity around who can help with what, and what their role is.

Keep in mind that this list isn't comprehensive: There may be others in your life—religious or spiritual leaders, life coaches, personal trainers or nutritionists, for example—to whom you can turn.

Health Care Providers	
Advance Practice Providers	These include nurse practitioners or physician assistants who partner with your doctor to provide your care.
Health Insurer	Your health insurance provider can detail what is and isn't covered by your plan, clarify what services and providers are in or out of network, and suggest ways to potentially lower health care costs.
Mental Health Professionals	Mental health professionals can help you work through anxiety or depression, feelings of guilt, and other emotional challenges. A couples counselor can help manage communication issues that may arise as well as navigate conversations around advance care planning or other care preferences.
Movement Disorder Specialist	A movement disorder specialist is a doctor with specific training in Parkinson's disease. If a movement disorder specialist isn't available in your area, find a general neurologist with experience in Parkinson's and consider visiting a specialist once a year (or more, virtually) if possible.
Occupational Therapist	An occupational therapist helps your loved one maintain their independence, providing tools and strategies to safely engage with activities of everyday life.



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<p>Other Specialty Physicians</p>	<p>Physicians with expertise in sleep, mood changes, constipation, urinary or sexual problems, and other non-motor symptoms can help manage other Parkinson’s symptoms if or as they arise. Other specialists will manage other non-Parkinson’s conditions, like a cardiologist for heart disease.</p>
<p>Palliative Care Team</p>	<p>Palliative care providers offer additional symptom management and emotional support for both you and your loved one. Palliative care isn’t just for end of life and isn’t just hospice; it’s available from diagnosis and throughout the disease.</p>
<p>Pharmacist</p>	<p>Pharmacists can answer questions about medication dosing or interactions, ensure safe use of prescription and over-the-counter drugs, and help navigate medication costs and complex medication regimens.</p>
<p>Physical Therapist</p>	<p>A physical therapist can help manage challenges with walking and balance, mobility, and more. They can also recommend or modify exercise plans.</p>
<p>Primary Care, Internal Medicine, or Geriatric Physician</p>	<p>This doctor manages your loved one’s general medical care and cares for conditions outside of Parkinson’s. If your loved one is older, consider seeing a primary care provider who specializes in geriatric medicine.</p>
<p>Speech Therapist</p>	<p>A speech therapist can address challenges with speech and communication, cognition (memory and thinking) and swallowing.</p>



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Other Support Providers	
Elder Law or Other Attorney	An attorney can help navigate legal, financial and health care challenges, including disability coverage, long-term care planning, estate planning, asset protection, advance directives, care and facility costs, and more.
Family, Friends and Other Care Partners	Family and friends can support by tapping into their own skills, and other care partners who are going or have gone through similar experiences can help you navigate your personal journey.
Financial Planner or Certified Public Accountant (CPA)	A financial planner or CPA can conduct a comprehensive financial review, assess health care costs, and create a plan to approach long-term care, navigate challenges like loss of income or insurance coverage, coordinate with legal professionals about wills, trusts and power of attorney, and more.
Paid Caregivers	Professional or paid caregivers have a wide range of training, skills and experience, and offer different types of assistance. Some provide personal care (like help getting ready in the morning or administering meds) while others offer lifestyle support (like companionship or light housekeeping). Cost and insurance coverage for these services varies.
Social Worker	A social worker can help you understand your insurance coverage and benefits and direct you to resources for financial planning and medication assistance. They can also talk through advanced care options, connect you with resources like your local Area Agency on Aging, research housing options; help you vet professional caregivers, companies or facilities; and provide tips on touring and interviewing.



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Finding the Right Out-of-Home Care

Many people say they never want to move outside the home. That's normal and understandable. Sometimes, though, remaining at home becomes untenable due to symptom progression or safety concerns. Remember: everyone's Parkinson's is different and not everyone with Parkinson's needs long-term care. If issues arise, it may be time to consider moving your loved one to a setting that is better equipped to provide the care they need.

There are several options, including retirement communities, assisted living facilities, skilled nursing home or memory care homes. No matter which type of home you may be considering, it's important to visit in person. You'll want to have a list of questions, such as:

- + Do you have experience caring for people with Parkinson's? What kind? Do the staff have certifications or expertise in Parkinson's?
- + Do you have physical, occupational or speech therapy on site? Do they have Parkinson's experience?
Will my loved one have access to these experts? How often?
- + How many residents are assigned to each nurse or staff member? What happens overnight and on weekends?
- + Who provides medical coverage, or manages my loved one's medications or surgical devices, like deep brain stimulation?
- + What exercise, social, religious, spiritual or recreational activities are available?
- + Do you provide transportation for errands or to medical appointments?
- + Do you provide all meals? How do you handle dietary needs (such as for swallowing difficulty) or preferences?
- + How often will my loved one get a shower or bath?
- + How do you prevent and monitor for falls?



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- + How do you handle memory or behavior changes or hallucinations?
- + What are your protocols if my loved one's condition worsens
- + What preventive protocols are in place for infections, such as the flu or COVID-19?
- + Are there restrictions on visiting?
- + What are the costs? What will I need to cover on my own, like shower supplies, incontinence products or snacks?
- + Who is my main point of contact? How often do we check in? Do we regularly assess how my loved one is doing and if this remains the right place for them?
- + How can I best support my loved one while they live here?



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The Michael J. Fox Foundation

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