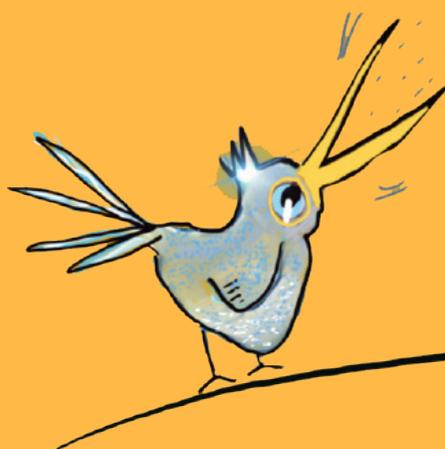


# PARKINSON'S CARE PARTNER TRAINING PROGRAM HANDBOOK

**A collaboration between the Davis Phinney Foundation  
and Jori Fleisher, MD, MSCE, building on work  
supported by the National Institutes of Health**



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YOU  
CAN  
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THIS



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# INTRODUCTION

Dear Parkinson's care partner,

Welcome to the Davis Phinney Foundation's Parkinson's Care Partner Training Handbook! We look forward to helping you **improve your knowledge, attitudes, and skills as a care partner for your person living with Parkinson's—and for yourself.**

This program has been designed with a variety of learners in mind, from those who want to do one session each week (or more) to those who prefer to watch or listen to only the sessions relevant to them right now. Choose your own adventure and do what works for you on your own time.

**Note:** Whether you choose to watch the videos or listen to the audio from this course, please note that the first participants who took this course were able to attend each session live, so you will hear the host and instructors mention comments and questions from the chat.

## A Request

Work leading up to this course has been supported in part by the National Institutes of Health (NIH), and this course is offered free of charge to our community thanks to a grant from AbbVie Grants. As part of our grant reporting, we must provide pre- and post-course surveys and knowledge check results. Before you dive into the content, please take a few minutes to complete the following:

[Parkinson's Care Partner Training Pre-Course Survey](#)

[Parkinson's Care Partner Training Pre-Course Knowledge Check](#)

Your responses are anonymous and extremely helpful to us when updating this course, as well as developing and delivering programs for Parkinson's care partners in the future.

## Training HUB

All the content for this course can be [found on this page.](#)

Password: carepartner (it's case sensitive)

You will have access to this training hub for as long as needed. If you have questions about this program, please email us at [carepartners@dpf.org](mailto:carepartners@dpf.org).

## How to Use This Handbook

Each session chapter in this handbook includes the following subsections:

**Conversation Starters:** These help you prepare for each session and consider your goals, concerns, and feelings regarding each topic. You may quickly read through them, or like others, you may use them as journal prompts and capture your learnings throughout the course that you can refer to later.

**Pre-Session Resources:** This section includes links to articles, webinars, and podcasts that are great primers for each topic. They help prepare you for the recorded sessions; however, they are not necessary to listen to or watch each session.

**Knowledge:** This section includes foundational content on each topic, as relevant, and links to the recorded video, audio, and transcript.

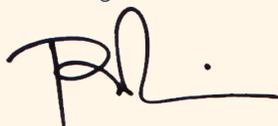
**Post-Session Resources:** This section includes resources mentioned during the live sessions, shared by fellow care partners in the chat during a session, or requested after a session. Some resources show up more than once. We included resources whenever they were mentioned or discussed during a session in case future participants only engage with certain sessions.

**Homework Ideas:** This section is offered if you want to implement strategies and ideas discussed during the session or that our instructors recommended.

This is a lot, and **we know you are busy**. Being a Parkinson's care partner takes much time and energy—especially as Parkinson's advances. Our goal is not to add more to your already very long to-do list but to allow you to learn more about Parkinson's and being a Parkinson's care partner from an expert medical team and others traveling a similar. Do as much or as little as works for you.

Thank you for being a part of this program.

With gratitude,



Polly Dawkins, Executive Director



# TOPICS

Having spent the past two decades working with Parkinson's care partners, we know that very often, care partners feel ill-equipped to handle the various roles they play throughout the ages and stages of Parkinson's. A recent survey of our Parkinson's care partner community indicated that care partners want and need specific training on advanced symptoms, medications and medication management, sleep, cognition, falls, how to manage acute symptoms and episodes, and how to manage not just Parkinson's care but other health-related concerns and comorbidities. During this program, we spotlight you as the care partner and offer education and training to improve your knowledge and skills in all these areas.

Additionally, this program provides:

- Tools for building self-efficacy
- Strategies for managing change
- A game plan for navigating the complications of Parkinson's

The topics addressed in this Parkinson's Care Partner Training Program include the following:

## Session 1

- Program Aims
- Care Partner Roles
- Strain and Outcomes

## Session 2

- Managing Change
- Falls
- Exercise
- Constipation
- nOH

## Session 3

- Parkinson's Medications
- Complications
- Advanced Symptoms

## Session 4

- Parkinson's Nutrition

## Session 5

- Depression
- Anxiety
- Apathy
- Loneliness
- Isolation

## Session 6

- Guilt
- Anger
- Symptom Management
- OFF

## Session 7

- Cognition
- Sleep
- Hallucinations and Delusions

## Session 8

- Healthcare System
- Medicare
- Patient and Care Partner Support

## Session 9

- Uncertainty
- Anticipatory Grief
- Ambiguous Loss

## Session 10

- Wrap-Up and Q&A

You may be familiar with some of these topics, and some may be new to you. Each care partner comes to this training with a different background and life experience. We aim to provide you with knowledge, skills, and resources to help you and your person with Parkinson's live well today and for many years to come.

Some of the topics we cover may be unpleasant to think about—especially during earlier phases of your journey. We have included those topics in this training because for over 20 years, we've heard from families how alone, underinformed, and under resourced they feel. We hear about misdiagnosis, the pain of uncertainty, isolation, out-of-date information, misinformation, and a lack of access to Parkinson's specialists who are equipped to support care partners. This program is our attempt to change that.

# INSTRUCTORS



**Jori Fleisher, MD**, is the Leslie Nan Burridge Endowed Faculty Scholar in Parkinson's Research and an associate professor of neurological sciences at Rush University Medical Center. She is a movement disorder neurologist and epidemiologist who leads the Rush Advanced Interdisciplinary Movement Disorders Supportive Care (AIMS) Clinic and the CurePSP Center of Care and directs the Rush Lewy Body Dementia Association Research Center of Excellence, which was recently ranked as the top Center of Excellence nationally. Dr. Fleisher received her Master of Science in Clinical Epidemiology from the University of Pennsylvania, where she completed neurology and global health equities residencies and a movement disorders fellowship. Dr. Fleisher has additional training in health services research, palliative care, and implementation science. Supported by the National Institutes of Health, foundations, and philanthropy, Dr. Fleisher has several studies underway focused on interdisciplinary home visits, telemedicine, interprofessional education, and peer mentoring to improve the lives of people and families living with advanced movement disorders. She collaborates nationally and internationally on several Parkinson's, PSP, and Lewy body dementia-related grants and task forces. She graduated from the American Academy of Neurology Emerging Leaders Forum and Palatucci Advocacy and Leadership Forum. She serves on the Editorial Board of AAN's patient-facing Brain & Life magazine and has been awarded the 2020 CurePSP Standout Achievement Award and the CurePSP 2020 Inspiration and Innovation to Cure Award.



**Polly Dawkins, MBA (Moderator)** has an extensive tenure as the executive director of the Davis Phinney Foundation, spanning over a decade. Recognized as a tireless advocate, Polly's deep-rooted ties to the community, forward-thinking vision, and unwavering compassion for individuals living with Parkinson's have played a pivotal role in meeting the Foundation's goal of providing actionable tools and resources to enhance the quality of life of all those affected by Parkinson's. Polly holds an MBA from Thunderbird School of Global Management and a BA in International Studies from Earlham College.



**Serena Hess, MA, MSN, RN**, served as the home visit nurse during the research project for three years, completing >300 visits to homebound individuals with Parkinson's and related disorders. She is an expert Parkinson's nurse who has seen everything in people's homes, including medication management and family dynamics, and is currently earning her DNP in geriatric psychiatry.



**Sarah Mitchell Chen, LCSW, APHSW-C**, has been a social worker in the Rush Movement Disorders Clinic for over ten years and the AIMS clinic since 2019. In her private practice, Sarah focuses on caregivers and care transitions. She is an expert in navigating the healthcare system, patient/caregiver support, what Medicare/insurance covers and doesn't, and much more.



**Kristin Gustashaw, MS, RDN, LDN, CSG**, is an advanced-level clinical dietitian and certified specialist in gerontological nutrition, the go-to dietitian for a movement disorders practice for many years, and the AIMS Clinic dietitian since 2019. She is an expert in all things nutrition, constipation, unintentional weight loss, food adjustments, and liquid textures.

# **SESSION 1**

## **Program Aims, Care Partner Roles, Strain, and Outcomes**



# Session 1

## Program Aims, Care Partner Roles, Strain, and Outcomes

### Conversation Starters

1. What do you hope to learn from this program?
2. What concerns do you have about being a care partner to your person right now?  
What concerns do you have about being a care partner as they progress?
3. As a care partner, are you able to take care of your own needs? If not, why not? If yes, how?
4. What are the most significant barriers you face in prioritizing your health?
5. How do you manage care partner strain?
6. Do you feel the stress of being a care partner affects your ability to care for your loved one?
7. How much time do you spend advocating for care for your loved one? Do you feel well supported by your medical team?

### Pre-Session Resources

- [Emotional Side of Caregiving - Family Caregiver Alliance](#)
- [Caregiver Emotions. Alzheimer's Association](#)
- [Who Am I Now? The Ever-Changing Role of the Caregiver - Today's Caregiver](#)
- [How to Stay Healthy and Avoid Burnout as a Parkinson's Care Partner](#)
- [The Parkinson's Care Partner's Digital Toolbox](#)
- [What is a Parkinson's Care Partner?](#)
- [Being a Care Partner for Someone with Parkinson's](#)
- [How to Build Your Parkinson's Care Partner Support Team](#)
- [Caregiver Stress](#)
- [Dealing with Caregiver Stress and Burnout](#)

### Knowledge

As you know, Parkinson's impacts the whole family—especially those most involved in the day-to-day care of the person living with Parkinson's. Having spent the past 19 years working with Parkinson's care partners, we know that very often, care partners feel ill-equipped to handle the various roles they play throughout the ages and stages of Parkinson's. We also know that Parkinson's care partners often:

- Feel alone and lack support
- Are overwhelmed by the amount of time and effort being a care partner requires
- Have a difficult time adjusting to this role
- Don't feel knowledgeable or confident about providing the kind of care their person with Parkinson's needs

- Are unsure about how to handle cognitive decline, hallucinations, and delusions
- Don't feel equipped to handle a person with Parkinson's who is depressed, anxious, and apathetic or when they are
- Are unsure of who to turn to or what specialists to call when their person's symptoms increase
- Don't know how to help with medication management, sleep issues, or balance issues
- Feel overwhelmed with the advice they're given and the resources available
- Are looking for ways to thrive despite their situation
- Want to meet care partners traveling a similar path with whom they can share ideas and solutions

Therefore, we hope that by the end of this training, you will:

- Be more aware of the type of care needed to improve your person with Parkinson's quality of life
- Have increased your knowledge about what it means to be a care partner, the skills needed to help yourself and your person with Parkinson's live well, and how to manage change
- Be more confident in your ability to care for your person with Parkinson's, make appropriate healthcare decisions, and find more joy and meaning in your everyday life
- Have improved your connection to the care partner community and learn ways to build self-efficacy and resilience
- Become aware of a variety of strategies you can employ when the emotional and physical toll of being a Parkinson's care partner increases

We know this will be a long journey for many of you, and we'll be with you every step of the way.

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

### Patient Advocacy

- [Patient Safety Kit. Parkinson's Foundation](#)
- [Hospital Action Plan. Parkinson's Foundation](#)
- [Emergency Room \(ER\) Visits: A Family Caregiver's Guide; Next Step in Care](#)
- [Advocating for Others](#)
- [Patient Advocate: An Important Role for All Caregivers](#)

## General

- [Worksheets and Checklists](#)
- [Every Victory Counts® manuals](#)
- [Meditation Course for People with Parkinson's and Care Partners](#)
- [Webinar: Sexuality and Intimacy for People with Parkinson's and Care Partners with Sheila Silver](#)
- [Parkinson's Travel Checklist](#)
- [How to Travel with Greater Ease with Parkinson's](#)
- [Podcast: Relationships and Parkinson's](#)
- [Can I Still Drive Now that I Have Parkinson's?](#)
- [Getting Paid Care for Your Person with Parkinson's](#)

## Homework Ideas

### Dear Future Me

One of our favorite exercises for care partners is “Dear Future Me.”

Here's how it works:

1. Go to [futureme.org](http://futureme.org).
2. Enter your email address.
3. Write a note to yourself.
4. Select a date you'd like the letter to be emailed back to you.
5. Hit submit.

They'll hold it until it's time to email it back to you. They have letters in their database today that will be sent to people as far in advance as 2073.

If you're interested in doing this exercise, consider writing a note to yourself about what you'd like to know, have, be able to do, etc., at the end of this course.

You might also write a note to yourself for a year from now to see how far you've come. You might tell yourself what you're afraid of, what keeps you up at night, or what's getting in your way. Or you might focus on everything you're grateful for now. This is your letter; however you think it will help is your call.

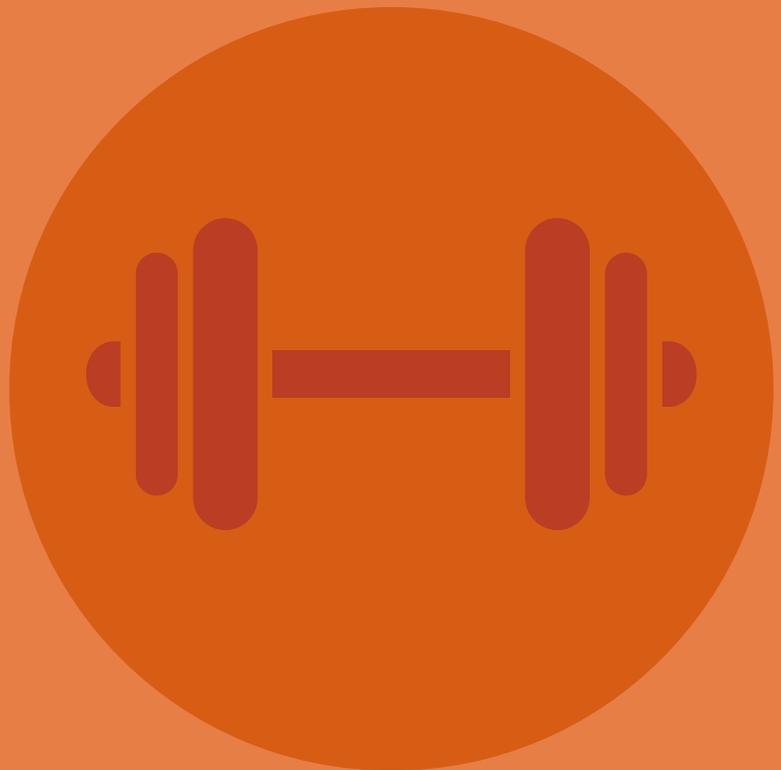
Getting letters from the future is always fun, and it's a great way to track and reflect upon growth, mindset, and fears during uncertain times.

## Reflection Questions

- In the last week, what was a situation or challenge you handled well?
- In the last week, what brought you joy?
- In the last week, what made you laugh?
- In this coming week, how can you build in MORE of these things? Who can you share these with?

# **SESSION 2**

## **Managing Change, Falls, Exercise, Constipation, and (nOH)**



## Session 2 Managing Change, Falls, Exercise, Constipation, and (nOH)

### Conversation Starters

1. Has your person with Parkinson's undergone any sudden changes? How have you managed them?
2. When sudden changes to their health or symptoms emerge, what do you notice about yourself, and how do you respond?
3. What experience do you have with your person with Parkinson's falling? Do you feel confident managing falls when they happen?
4. Have you taken steps to ensure your home feels safe for your loved one? Have you made any adjustments in your home to mitigate falling risk?
5. Does your person with Parkinson's exercise daily? Does it come easily to them? If not, what do you do to encourage them to exercise? What works and what doesn't?
6. Does your person with Parkinson's experience constipation or low blood pressure-related issues? If so, how do you deal with these issues at home?

### Pre-Session Resources

#### Falls and Exercise

- [Exercising, Freezing of Gait, and Postural Instability in People with Parkinson's](#)
- [Parkinson's Home Safety Checklist](#)
- [Retropulsion and Parkinson's](#)
- [Falls Prevention Conversation Guide for Caregivers; National Council on Aging](#)
- [Check for Safety: A Home Fall Prevention Checklist for Older Adults. Centers for Disease Control and Prevention.](#)
- [National Council on Aging. Falls Prevention Conversation Guide for Caregivers](#)
- [Neuroplasticity, Exercise, and Parkinson's](#)

#### Constipation and Neurogenic Orthostatic Hypotension (nOH)

- [Dive Deep: The Link Between Parkinson's and the Gut](#)
- [The Science of Constipation](#)
- [Movement Break for Gut Health](#)
- [What You Need to Know about Gastroparesis and Parkinson's](#)
- [Constipation and the Gut in Parkinson's](#)
- [nOH and Parkinson's](#)

## Knowledge

### Gradual Changes

Gradual changes happen over a long period of time—sometimes decades. These can include changes related to executive function, memory, attention, concentration, etc.

### Sudden Changes

Sudden changes may happen over the course of a week, day, or even minutes and may include more OFF time, new or more intense and disturbing hallucinations or delusions, an increase in falls, and more. The key is that they experience a sudden change and don't automatically adjust back to their typical level of functioning.

Your initial reaction to a sudden change may be to assume that this is Parkinson's progressing; however, Parkinson's is a slowly progressive brain disease, and sudden changes typically indicate that something else is wrong. Issues\* to look out for include:

- Urinary tract infections (UTIs)
- Upper respiratory tract infection (URI)
- Other infections (dental, pressure wounds, foot)
- Fecal impaction
- Dehydration

**\*If your loved one experiences a sudden change, immediately contact their medical team to assess what could be causing the change.**

For a great analogy about gradual and sudden changes in Parkinson's, listen to Dr. Fleisher's [description in this video](#) starting at 27:10.

### Falls

Along with tremor, rigidity, and slowness of movement, postural instability—better known as poor balance and coordination—is a common Parkinson's motor symptom. Parkinson's can cause a loss of reflexes needed to maintain an upright posture, causing some people with Parkinson's to feel unstable while standing upright. This instability can increase the risk of falling.

Fall prevention is important because falls can lead to head injuries and broken bones—two common causes of hospitalization for people living with Parkinson's.

### Fall Prevention and Home Safety

Home safety is crucial in preventing falls, especially for individuals aiming to “age in place.” The safer your home environment is for your loved one, the longer they can comfortably stay there.

It's important to note that falls are more likely to occur indoors than outdoors. The most common location for falls is the bathroom, particularly at night and in small, dimly lit bathrooms. Falls are also common when navigating thresholds, different floor levels, unsecured rugs, or stairs. To minimize these risks, secure rugs with tape or entirely remove them, use brightly colored non-skid tape on step edges or thresholds as a visual reminder to take precautions, and add grab bars to highly trafficked areas.

If your person with Parkinson's uses a cane, we recommend using a walker or poles instead. Canes can lead to falls in people with Parkinson's due to the cognitive effort required for proper maneuvering. Walkers and poles are safer. If your loved one relies on walls and furniture for support while walking in the house, they are also at a higher risk of falling. Consult their healthcare provider for fall risk management.

As Parkinson's progresses, viewing your home from a safety-focused perspective becomes challenging. Items that used to pose no issues, like a decorative throw rug, may now be a tripping hazard. **Regularly reassess home safety to adapt to changing needs.** Consider seeking professional help from an occupational therapist (OT) or geriatric care manager who can assess your needs. Implementing safety devices like a medical ID, emergency home response system, automatic pill dispenser, and auto shut-off appliances can contribute to your loved one's safety and independence, too.

It's also worth considering if your current living situation remains suitable. If maintaining a multi-story house becomes burdensome, transitioning to a single-story home, condominium, or apartment with elevator access may be a better option. Research indicates that aging within a community setting rather than a nursing home promotes better health and survival. However, it's essential to acknowledge that, in some cases, remaining at home may not be feasible for various reasons and placement in a care facility may eventually become the best or only choice.

If you or your loved one opts for independent living despite mobility or cognitive challenges, consider the following steps:

- Fill out and carry a medical alert wallet card with essential medication information for hospital visits and emergencies.
- Use a medical alert service that provides easy access to emergency assistance through a wearable bracelet or necklace.
- Assess the safety of your home. Explore home modifications such as installing bathroom grab bars or ramps for stairs. Consult your doctor or OT for a home safety evaluation.
- Discuss Parkinson's and driving with your loved one's physician and arrange a driving skills evaluation if necessary.

## **Constipation**

Constipation is very common in Parkinson's because just as the physical movements slow in Parkinson's, the normal processes of the intestines do, as well. With the slowing of the digestive system, stool accumulates and becomes harder, larger, and more challenging to pass. Many people living with Parkinson's experience extended periods without a bowel movement or only produce small, hard "pebbles," which are often followed by intense straining and very large bowel movements.

### **Preventing constipation requires:**

- Maintaining proper hydration
- Exercising regularly
- Eating a diet rich in dietary fiber
- Implementing a bowel regimen, which may involve one or more supplements or medications to limit constipation

If constipation is unmanaged, there are multiple ways it can impact your person with Parkinson's. For example:

- They may feel uncomfortable and bloated.
- Their medications may not be absorbed as well.
- They may experience issues related to cognition, including worsening hallucinations and delusions.
- They may experience more falls.
- They may experience impaction and bowel obstruction when the gut ceases to function—a condition that can be life-threatening if left untreated.

Therefore, while discussing constipation may not be the most pleasant topic, managing it daily at home is far more comfortable than dealing with the consequences of hospitalization.

## **Neurogenic Orthostatic Hypotension (nOH)**

### **What is nOH?**

There is evidence suggesting that approximately 30-50% of individuals with Parkinson's experience neurogenic orthostatic hypotension (nOH). This condition is characterized by a drop in blood pressure when transitioning between positions—particularly when moving from a seated or lying position to a standing one.

When we lie flat in bed or sit in a chair with our feet on the ground, blood pools in our legs and abdomen because of gravity. Typically, our bodies employ a reflex action to counter this, causing blood vessels to constrict, pushing the pooled blood in the legs and abdomen back toward the heart. This process enables the heart to pump blood to the brain against gravity, ensuring our ability to think, move, and function.

Under normal circumstances, this reflex action operates without our awareness, and we do not sense any change in blood pressure or how we feel. However, in many people with Parkinson's, this reflex is weakened. Consequently, when a person with Parkinson's transitions from lying down to sitting or from sitting to standing, their blood pressure may plummet. This can lead to:

- Dizziness
- Blurred vision
- Weakness
- Instability
- Discomfort in the shoulders and neck
- Confusion
- A vacant expression
- Difficulty standing or maintaining an upright position, which can increase fall risk

### **Here are some strategies to help your person with Parkinson's manage nOH:**

- Gradually change position by slowly moving from a reclined position to sitting on the edge of the bed before standing.
- Maintain hydration by drinking at least six eight-ounce glasses of water daily.
- Avoid caffeinated beverages: Caffeine can reduce blood volume and exacerbate orthostatic hypotension.

- Elevate the head of the bed by 30-45 degrees during the night. Use a triangular bed wedge pillow, readily available on Amazon and in medical supply stores, as it offers more stability than regular pillows.
- Opt for smaller, more frequent meals instead of three larger ones.
- Consider performing isometric exercises before changing position or standing up, such as raising the heels, contracting the calf muscles, holding for 30 seconds, and repeating three times.
- Explore using an abdominal binder, which should be snugly positioned just below the breast line to the waist. Your loved one should wear it before getting out of bed in the morning and remove it to avoid elevated blood pressure. You can find binders in most sporting goods stores and on Amazon.
- Consult your loved one's healthcare provider about increasing salt intake in their diet.

In some cases, healthcare providers may recommend medications like fludrocortisone or midodrine to help manage orthostatic hypotension.

**If your loved one experiences faintness, encourage them to either lie down and elevate their legs above heart level or to sit down, recline their head, and elevate their legs. Avoid having someone with Parkinson's bend over with their head between their knees, as this may increase the risk of falling.**

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

- [The Feelings Wheel](#)
- [Book: Ambiguous Loss: Learning to Live with Unresolved Grief](#)
- [Hoehn and Yahr Parkinson's Stages](#)
- [The Difference Between Lewy Body Dementia, Parkinson's Disease Dementia, and Alzheimer's](#)
- [How to Find a Parkinson's Physical Therapist Near You](#)
- [20-Minute Morning Qigong Routine](#)
- [How to Encourage People with Parkinson's to Exercise](#)
- [The Squatty Potty](#)
- [Self-Cleaning Toilet Attachment](#)
- [Three-Bean Salad](#)
- [Yogurt Maker and Recipe](#)
- [Hydration Bottles with Time-of-Day Nudges](#)

## Homework Ideas

- As unpleasant as it might be, ask your person how often they are having a bowel movement, whether it's very hard/large/difficult to pass, and whether they find themselves straining.
- If your person is experiencing dizzy spells/light-headedness when getting up, track these nOH symptoms over the next week or so, so you have the info to share with your doctor.
- If your person is not exercising (but can do so), invite them to have a conversation about it and what they are open to doing. Try to incorporate daily movement—for both of you—and track your progress.

# **SESSION 3**

## **Parkinson's Medications, Complications, and Advanced Symptoms**



## Session 3

# Parkinson's Medications, Complications, and Advanced Symptoms

### Conversation Starters

1. How do you manage your loved one's medications to ensure the proper dose on the ideal schedule?
2. What actions have you taken when medications do not do their job?

### Pre-Session Resources

- [Parkinson's Medication Management for Motor Symptoms](#)
- [Parkinson's Medication Management for Non-Motor Symptoms](#)
- [Davis Phinney Foundation Worksheets & Checklists](#)
- [Patient Access Network Foundation](#)
- [The Assistance Fund](#)
- [The Rx Helper](#)
- [Rx Help Centers](#)

### Knowledge

There are many different classes of medications that offer options for people with mild to advanced Parkinson's symptoms. Treatment discoveries are also rapidly progressing, and new medications are continually added to the growing list. Typically, Parkinson's medication treatment is divided into motor and non-motor symptom categories.

#### Medications For Motor Symptoms

**Levodopa:** Levodopa is the gold-standard treatment for Parkinson's. It was one of the first Parkinson's drugs, and it is still the primary drug prescribed to treat Parkinson's for many people. It acts to help with slowness, stiffness, and tremor.

Carbidopa is almost always combined with levodopa to enable more levodopa to reach the brain rather than the bloodstream. Carbidopa/levodopa can be used with other medications to address the same symptoms. Common side effects of carbidopa/levodopa include nausea and light-headedness.

To see a complete list of medications in this category, [click here](#).

**Dopamine Agonists:** Dopamine agonists address the same symptoms as carbidopa/levodopa: namely slowness, stiffness, and tremor. Dopamine agonists can be used alone or in conjunction with other medications to address those symptoms. Common side effects include nausea and light-headedness.

After years of use, dopamine agonists are less likely than carbidopa/levodopa to cause dyskinesias or fluctuations with OFF time. Still, dopamine agonists may not be quite as effective for control of motor symptoms, and certain side effects are more likely with dopamine agonists, including leg swelling, sleep attacks, and compulsive behaviors. To see a complete list of medications in this category, [click here](#).

**MAO-B Inhibitors:** Monoamine Oxidase Type B (MAO-B) inhibitors act to block an enzyme that breaks down dopamine, which allows more dopamine to be available to the brain. Like levodopa and dopamine agonists, MAO-B inhibitors treat slowness, stiffness, and tremor. They can be independently used, though they typically have a milder benefit than levodopa or dopamine agonists. MAO-B inhibitors are often used as supplemental medications to reduce OFF time.

Common side effects include nausea, light-headedness, and insomnia. Because MAO-B inhibitors increase and prolong the effects of dopamine, the side effects of dopamine may also be enhanced, including dyskinesia. Multiple medications are contraindicated with MAO-B inhibitors. To see a complete list of medications in this category, [click here](#).

**COMT Inhibitors:** Catechol-o-methyl transferase (COMT) inhibitors block levodopa metabolism, prolonging levodopa effects. As such, COMT inhibitors have no effect on their own and are always used in conjunction with levodopa. COMT inhibitors are used primarily to treat motor fluctuations and reduce OFF time.

Possible side effects include diarrhea and discolored urine. Because COMT inhibitors increase and prolong the effects of levodopa, the side effects of levodopa may also be enhanced, including dyskinesia. To see a complete list of medications in this category, [click here](#).

**Amantadine Hydrochloride:** Amantadine can be used alone or with other medications to treat slowness, stiffness, and tremor. Amantadine has a unique role in the treatment of Parkinson's because it's the only medication that allows more treatment of motor symptoms while potentially reducing dyskinesias. People with kidney problems need a decreased dosage.

Common side effects include nausea and light-headedness. Possible anticholinergic side effects include confusion and constipation. Other possible side effects include leg swelling, vision changes, hallucinations, and a reddish rash known as livedo reticularis. To see a complete list of medications in this category, [click here](#)

**Anticholinergic Medications:** Anticholinergic medications treat tremor and dystonia in people with Parkinson's. They do this by reducing the amount of acetylcholine: a neurotransmitter that is in balance with dopamine in the body. Anticholinergic medications are also sometimes prescribed to help with drooling.

Anticholinergic medications are usually best tolerated by younger people and should be avoided by older adults with Parkinson's because they can increase confusion, cognitive slowing, and hallucinations. Other possible side effects include dry mouth, worsening of glaucoma, blurry vision, and urinary retention. To see a complete list of medications in this category, [click here](#).

**Adenosine receptor antagonists:** Adenosine receptor antagonists block the reception sites for the neurotransmitter adenosine, which acts as a central nervous system depressant. This medication is approved for use in conjunction with carbidopa/levodopa to help reduce OFF time. These medications can increase ON time without troublesome dyskinesias for many people, but dyskinesias are the most common side effect. To see a complete list of medications in this category, [click here](#).

## Medications for Non-Motor Symptoms

### Depression and Anxiety

**Selective Serotonin Reuptake Inhibitors (SSRIs):** SSRIs are the most prescribed antidepressants for Parkinson's-related depression because of their tolerability. These medications can also be used to treat anxiety and obsessive-compulsive disorder (OCD). A therapeutic dose often takes four to six weeks for full effect. SSRIs are sometimes combined with other medications, such as SNRIs and TCAs (see tables below), but such combinations should be used with caution due to the potential for serotonin syndrome.

Possible side effects include headache, nausea, insomnia, jitteriness, sexual dysfunction, and weight gain. To see a complete list of medications in this category, [click here](#).

**Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs):** SNRIs are another class of antidepressants that can treat depression, anxiety, and OCD. Like SSRIs, it often takes four to six weeks after reaching a therapeutic dose for them to take effect. SNRIs can raise blood pressure, and other possible side effects include headache, nausea, sexual dysfunction, and dizziness.

Like SSRIs, SNRIs should be used with caution in conjunction with other serotonergic medications due to the potential for serotonin syndrome. To see a complete list of medications in this category, [click here](#).

**Tricyclic Antidepressants:** TCAs are another class of medications used to treat depression, anxiety, and OCD. They are prescribed less often than SSRIs and SNRIs due to a higher likelihood of side effects. Possible side effects include dry mouth, constipation, orthostatic hypotension, urinary retention, and confusion. People with heart conditions (such as arrhythmia or QTc prolongation) should cautiously use TCAs.

Like SSRIs and SNRIs, it often takes four to six weeks after reaching a therapeutic dose for them to take effect. These medications should be used with caution in conjunction with other serotonergic medications due to the potential for serotonin syndrome. To see a complete list of medications in this category, [click here](#).

**Other Antidepressants:** Other medications can also have benefits for depression, anxiety, and OCD. Like SSRIs, SNRIs, and TCAs, it often takes four to six weeks after reaching a therapeutic dose for these drugs to take effect. Some of these medications should be used with caution in conjunction with serotonergic medications due to the potential for serotonin syndrome. To see a complete list of other antidepressants, [click here](#).

## Other Non-Motor Symptoms

**Constipation:** One of the most common non-motor symptoms of Parkinson's, constipation can severely affect quality of life. Lifestyle changes like increasing water, dietary fiber, and exercise are the cornerstones of treatment. Lowering medications that may have anticholinergic side effects may be necessary. Specific pharmacological interventions are also available.

Common side effects include bloating, gas, upset stomach, and dizziness. To see a complete list of medications that can help treat this symptom, [click here](#).

**Drooling:** Sialorrhea, or excessive drooling, is another common non-motor symptom of Parkinson's. The medications listed below are used either on- or off-label for drooling.

Side effects vary by treatment, but the most common is dry mouth. To see a complete list of medications that can help treat this symptom, [click here](#).

**Fatigue:** Fatigue means low energy and is a common symptom of Parkinson's. Fatigue often overlaps with sleepiness and/or depression. Because medication treatment options for fatigue may be of limited benefit, treatment of any overlapping sleepiness or depression is paramount. Lifestyle changes are also significant, including budgeting energy for your most important activities, regularly exercising, eating well, drinking lots of water, getting enough sleep, and taking breaks when needed.

Spending time with other people helps some feel more engaged and energetic. Medications can have some benefits for fatigue. Possible side effects include headache, dizziness, anxiety, nervousness, and insomnia. To see a complete list of medications that can help treat this symptom, [click here](#).

**Neurogenic orthostatic hypotension (nOH):** nOH, a common symptom of Parkinson's, refers to a drop in blood pressure when changing position—especially when standing up. nOH is due to the autonomic nervous system failing to maintain blood pressure when changing position. The most common symptom of nOH is light-headedness, but it can also cause blurry vision, cognitive changes that are worse when standing up, and tightness or pain along the back of the neck and shoulders, called a “coat hanger phenomenon.”

Non-pharmacological changes can be very effective. These include increasing fluid intake, increasing salt and caffeine intake, wearing compression stockings or an abdominal binder, and raising the head of the bed during sleep.

Medications can also improve nOH in people with Parkinson's. Possible side effects include high blood pressure when lying down (supine hypertension). To see a complete list of medications that can help treat this symptom, [click here](#).

**Overactive bladder (OAB):** The bladder is a muscle, and spasms of the bladder can cause urinary urgency and/or frequency among people with Parkinson's. Lifestyle changes can be of some benefit in reducing OAB: weight loss, reducing consumption of alcohol and caffeine, and reducing fluid intake at night with no fluids within two hours of bedtime except for sips needed to take any medications. Pelvic floor strengthening with Kegel exercises can be helpful.

Medications can also reduce the bladder spasms of OAB. Possible side effects include headache, constipation, dry mouth, blurry vision, and urinary retention. Most OAB medications work via anticholinergic effects, and they can have the side effects of [anticholinergic medications](#). To see a complete list of medications that can help treat this symptom, [click here](#).

**Pain:** Pain is a frequent and often underrecognized symptom of Parkinson's. Other factors, including age, arthritis, spinal stenosis, and neuropathy, can compound pain. Lifestyle changes—especially exercising and making your home safer—are essential for pain reduction and management. Other specialists can be helpful, such as a massage therapist, physical therapist, or acupuncturist. Treatments for motor symptoms in Parkinson's, like dopamine medications and deep brain stimulation (DBS) surgery, can also reduce pain.

Check out our webinar on pain with Dr. Miyasaki here to get more information on how to specifically address pain for people with Parkinson's. To see a list of medications that can help treat this symptom, [click here](#).

**Parkinson's Disease Dementia (PDD):** Dementia refers to difficulty with thinking and memory that impairs day-to-day function and the ability to live independently. Dementia often develops in people with advanced Parkinson's. The medications used for PDD are cholinesterase inhibitors. This means they increase the amount of acetylcholine, which is involved in thinking and memory. These medications often have a modest benefit. They can also sometimes reduce freezing of gait.

Note that anticholinergic medications have the opposite effect (they lower acetylcholine), so anticholinergic medications should usually be avoided by a person with PDD. These medications are all approved for Alzheimer's disease, which is a different type of dementia. Possible side effects include nausea, vomiting, diarrhea, dizziness, and tremor. To see a list of medications that can help treat this symptom, [click here](#).

**Parkinson's Disease Psychosis (PDP):** Hallucinations refer to seeing or hearing things that aren't there. Delusions refer to persistent beliefs about things that are not true. The presence of hallucinations or delusions is technically known as psychosis. These symptoms may range from mild to severe. The medications available to treat PDD are called antipsychotics; however, careful selection of antipsychotics is very important for people with Parkinson's since one primary side effect of this class of medication is the *worsening* of Parkinson's motor symptoms. All antipsychotics are not created equal, and some are safer for people with Parkinson's than others.

Additional possible side effects of antipsychotics include drowsiness, low blood pressure, and constipation. To see a list of medications that can help treat these symptoms, [click here](#).

**Sexual problems:** Changes in sexual function and drive can occur as part of Parkinson's and possibly as side effects of certain medications—particularly antidepressants. Medications for erectile dysfunction (ED) and lubrication for pain with sex (especially for women experiencing vaginal dryness) can be helpful, but often lifestyle changes and alternative therapies are especially effective.

Consider scheduling sex for times when your medication is at its most effective or experiment to see what other ways you can show affection. Talk therapy or visiting a specialist (like a gynecologist or urologist) can also be helpful. Finally, be open with your partner and try not to be embarrassed (especially when talking to your doctor).

Sexual problems are very common in people with Parkinson's, and if you don't disclose them, you won't be able to address them. Hypersexuality and compulsive sexual behavior are side effects of dopaminergic agonists and can often be treated by reducing dosage. To see a list of medications that can help treat these symptoms, [click here](#).

**Sleep:** Sleep problems are prevalent among people with Parkinson's and include insomnia, restless legs syndrome (RLS), periodic limb movements disorder (PLMD), excessive daytime sleepiness (EDS), and REM Sleep Behavior Disorder (RBD). Good sleep hygiene may be helpful for insomnia and includes:

- Having a consistent bedtime and wake-up time
- Using the bed for sleep and intimacy only
- Reducing light in the bedroom
- Not using technology an hour or two before sleep
- Decreasing fluid consumption before bed

Medication may also have a role to play in the treatment of sleep problems for people with Parkinson's, but a combined behavioral and medication treatment plan is often best. To see a list of medications that can help with sleep, [click here](#).

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

- [Webinar: Urinary Dysfunction and Parkinson's: What You Need to Know about Urinary Tract Infections](#)
- [Drugs that are used to treat/minimize cognitive issues: Donepezil and Rivastigmine](#)
- [Common anti-depressant medications: sertraline, fluoxetine, escitalopram](#)
- [Rasagiline](#)
- [Davis Phinney Foundation Digital Medication Guide, searchable by symptom and type of drug](#)
- [Daily Medication Log](#)
- [Overall Medication Log](#)
- [Medications to Avoid](#)
- [Medication to Avoid, printable version](#)
- [Motor Symptom Medication Management](#)
- [Non-Motor Symptom Medication Management](#)

## Homework Ideas

- What challenges do you notice about your person's medications? Are they missing doses? Feeling like things no longer work as well as they used to? Mixing up medications?
- What system, if any, do you use to help your person stay on top of their medications? How do you feel it's working?

# SESSION 4

## Parkinson's Nutrition



## Session 4 Parkinson's Nutrition

### Conversation Starters

1. Has your person with Parkinson's experienced any unintentional weight gain or weight loss? Did that bring up any feelings for you? If so, how did you cope?
2. Have you discovered strategies to combat unintentional weight gain or weight loss?

### Pre-Session Resources

- [The Most Important Fact to know about Parkinson's Nutrition](#)
- [The 17 Most Commonly Asked Questions about Parkinson's Nutrition](#)
- [Weight loss and Parkinson's Disease](#)
- [Medication Protein and Parkinson's](#)
- [How to Take Levodopa](#)
- [Poor caregiver mental health predicts mortality of patients with neurodegenerative disease](#)
- [Dyadic Interdependence in Non-spousal Caregiving Dyads' Wellbeing: A Systematic Review](#)

### Knowledge

One of the topics our community members consistently ask about is nutrition. It's not an easy topic to address, though, because it has so many layers, and there's no [one-size-fits-all nutritional plan](#). The best you can do for your person with Parkinson's—and yourself—is to eat a whole food diet and pay attention to how they respond to the various foods they eat. Just as everyone's Parkinson's is different, everyone has different ways of eating.

If nutrition and hydration are a big concern for you and your loved one, in addition to watching the session linked below, be sure to dive into the pre- and post-session resources in this module, as the Davis Phinney Foundation has produced a lot of content on this topic.

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

### Post-Session Resources

- [PowerPoint Slides](#)
- [Why you must drink water with your Parkinson's medications](#)
- [Parkinson's 101 for the Newly Diagnosed](#)
- [IDDSI Framework \(Hydration levels\)](#)
- [How Sarcopenia Affects Quality of Life with Parkinson's](#)
- [Aspiration Pneumonia](#)
- Nux vomica 30C: Recommended as a potential help for nausea from an audience member – always check with your medical care team before starting anything new
- [Nosey Cups mentioned by speaker](#)

### Homework Ideas

- What concerns do you have, if any, about your person's diet and nutrition?
- How is YOUR diet? Are you feeding yourself with as much care as you are your person with Parkinson's? Food is not only fuel but also a means of self-care that some care partners minimize in their dedication to their people with Parkinson's.

# SESSION 5

Depression,  
Anxiety,  
Apathy,  
Loneliness,  
and Isolation



## Session 5

# Depression, Anxiety, Apathy, Loneliness, and Isolation

### Conversation Starters

1. Are you knowledgeable about strategies for preventing and addressing depression, anxiety, and apathy? Who can you consult regarding these concerns for yourself and your loved one?
2. Have you ever had concerns related to depression, anxiety, or apathy, for your loved one or yourself?
3. Have you encountered feelings of embarrassment or social stigma surrounding subjects like depression and anxiety? If so, how do you cope with and overcome these feelings?
4. Have you established a support network in your life? If yes, what steps did you take to build this system or seek assistance?
5. In what specific ways has your daily routine changed since you took on the role of a care partner for your loved one?
6. With whom do you regularly engage in conversations outside of interactions with your loved one?
7. To what extent are other family members aware of your responsibilities as a care partner, and how comfortable do you feel when sharing this information with them? If you've faced challenges opening up, what were the reasons behind it?
8. Have you sought assistance from a social worker, and if so, how well did the social worker understand the challenges you face as a care partner?
9. It's common for individuals with Parkinson's to lose interest in hobbies and activities, which can place the responsibility on care partners to motivate them. Has this been part of your experience, and if so, what approaches have proven effective, and what strategies have not yielded the desired results?

### Pre-Session Resources

- [Mood and Mental Health Strategies for Care Partners](#)
- [Caregiver Depression: A Silent Health Crisis. Family Caregiver Alliance.](#)
- [Depression, Anxiety, and Apathy and How to Manage Them](#)
- [Depression, Mood, and Anxiety in Parkinson's](#)
- [Parkinson's and Apathy: A Primer](#)
- [What to Do with Apathy as a Parkinson's Care Partner](#)
- [5 Ways to Manage Apathy as a Parkinson's Care Partner](#)
- [Resiliency as a Tool for Living Well with Parkinson's](#)
- [Helplessness and Hope in Parkinson's with Judy Long](#)

### Knowledge

#### Mood Disorders

The topic of mood disorders is relevant and applicable to both you—the care partner—and your person with Parkinson's. Symptoms often look the same whether you have Parkinson's or not, many treatments are the same, and many impacts are the same.

Consequences, however, can be quite different. For example, if a person with Parkinson's is depressed or apathetic which results in not exercising, not exercising has more severe consequences than it might for a care partner who doesn't have Parkinson's.

The goal of this session is to globally discuss depression, anxiety, and apathy and how important it is for your person with Parkinson's and YOU to manage them.

The more you know about the mood-related symptoms your person may be managing, the better your care, understanding, and ability to empathize will be. Additionally, the healthier your mood, the better for you and your person with Parkinson's.

### **Keep the following in mind:**

- Indications of **depression** typically include, though not exclusively, feelings of sadness, a diminished capacity to find enjoyment, reduced interest in various activities, and potential outbursts, either verbal or physical.
- Symptoms of **anxiety** frequently include panic attacks, excessive apprehension or fear, and a sensation of being inundated.
- Signs of **apathy** often include a decline in motivation which results in decreased communication, physical activity, and emotional expressiveness.

### **Managing Mood Disorders**

As a team, you and your loved one with Parkinson's can acquire the skills to practice patience and employ a range of strategies to manage mood disorders and behavioral issues. Some of these challenges can be effectively addressed by modifying the physical environment, addressing acute or chronic medical conditions, maintaining a regular exercise regimen, ensuring adequate sleep, and reducing daily responsibilities and stimuli.

### **To address mood and behavioral concerns, consider these steps in consultation with a healthcare provider:**

- Investigate environmental and social factors that may contribute to mood disorders and behavioral problems.
- Rule out physical triggers such as infection, pain, or other medical conditions.
- Review the current prescription and over-the-counter medications for any potential influences.
- When necessary, contemplate treatment with medications while monitoring for any side effects.

As a care partner, it's common for your emotional well-being to mirror that of your loved one. Feelings of despair can often arise due to a lack of robust support systems or when your emotional needs take a backseat in your daily priorities. It's crucial to check on your loved one's well-being and pay attention to your own.

### **Loneliness and Isolation**

Serving as a care partner for someone with Parkinson's can be one of the most challenging responsibilities you've ever undertaken. It's possible you've had to adjust to a disrupted routine, sacrificed your usual activities, and encountered difficulties maintaining social connections as your focus increasingly centers on your loved one. You might find yourself in a situation where you don't know others facing similar challenges, and it's normal to experience feelings of anger and resentment, as discussed in Session Six.

Social isolation, while less tangible than other topics, can be equally detrimental, affecting emotional and physical health and complicating your role as a care partner. Many individuals address isolation and loneliness by participating in support groups and meetups with fellow care partners who share a similar journey.

It's not uncommon for some care partners to find that their family and friends fall short of providing the emotional and practical support they need. Various reasons such as denial, lack of understanding about Parkinson's and its impact on your loved one, grief, anxiety, or simply not knowing how to assist, can hinder their involvement.

While you may not be able to change others, you can empower well-intentioned family and friends by educating them about Parkinson's, involving them in family meetings, or suggesting specific ways

they can be of help (e.g., asking if they can stay with your loved one for a couple of hours to give you time for personal appointments). Additionally, online tools like Lotsa Helping Hands facilitates the coordination of practical support from your social network without needing assistance from any individual directly.

Nevertheless, despite your best efforts to educate, engage, and involve family and friends, some individuals may not step up. In such instances, many care partners establish non-familial relationships that fulfill necessary emotional and social support needs. These non-family sources of support may already be a part of your life, or you may discover them by connecting with local programs, services, and faith communities. Many care partners find short-term support and lifelong friendships through these relationships and the resources listed in the pre-and post-session materials.

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

- [Parkinson's Care Partner Reflections by Susan Campanelli, EdD, RN](#) (We received this from a program participant after she reflected on the session, and we wanted to share it with you.)  
**Q:** How do we find a therapist who understands being a care partner for someone with Parkinson's to help us deal with all of this?  
**A1:** Look for a psychologist or psychiatrist with geriatric or neurological, mind/body training.  
**A2:** Our local Alzheimer's society branch keeps a list of counselors & social workers that help families of people with Alzheimer's. I would also check with that group if there's one near you and see if they have someone local to you.  
**A3:** Go to PsychologyToday, then click on "Find a therapist."
- [Webinar: Cognitive Behavioral Therapy \(CBT\) and Parkinson's](#)
- [Webinar: What is OFF and How to Manage It](#)
- [How to Encourage People with Parkinson's to Exercise](#)
- Many communities have a 211 service. For example, <https://www.211colorado.org> has information on different services offered in our state. Try inputting your state, as you might have the same thing.
- [Selegiline](#)
- [Rasagiline](#)  
**Q:** Is it better to use melatonin or Tylenol PM for sleep?  
**A:** Melatonin!
- [Mediation and Mindfulness for People with Parkinson's and Care Partners](#)
- [Webinar: Mindfulness, Mediation, Relaxation, and Parkinson's](#)

## Homework Ideas

- Do you feel that having Parkinson's in your person's (and your) life has increased or decreased your loneliness or isolation? How?
- Can you make a list of people you'd like to reconnect with if you had the time?
- Can you pick one person from that list you've lost contact with—either due to care partner responsibilities or other reasons—who you could call this week for a quick five-minute hello? Or even send an email or a text message to tell them you're thinking of them? And if you do, how did that go?

# SESSION 6

## Guilt, Anger, Symptom Management and, OFF



## Session 6 Guilt, Anger, Symptom Management, and OFF

### Conversation Starters

1. Have you grappled with feelings of guilt as a care partner? If so, how have you managed these emotions?
2. What other emotional experiences have you encountered as a care partner?
3. Are you comfortable openly discussing your emotions with your loved one? If so, how does your loved one typically respond to these conversations? If not, what barriers prevent you from doing so?
4. How have your roles and relationship with your loved one evolved or remained consistent over time?
5. Do you have a trusted confidant with whom you can freely express your emotions? If not, what proactive steps can you take this week to identify and connect with someone who can offer you a supportive and empathetic space to share your feelings?

### Pre-Session Resources

- [Notes from the Parkinson's Care Partner Meetup – Guilt](#)
- [The Upside of Negative Emotions in Coping with Parkinson's](#)
- [How to Understand and Manage OFF Times as a Parkinson's Care Partner](#)
- [How to Communicate What It Means to Be OFF](#)
- [Managing Motor Symptoms During OFF Times](#)
- [The Science of Parkinson's OFF](#)
- [Parkinson's OFF: What Is It and How to Manage It](#)
- [You Don't Have to Have OFF Times with Parkinson's](#)

### Knowledge

#### Feelings of Guilt and Anger

As Parkinson's advances, you and your loved one will encounter shifts in roles, expectations, and the dynamics of your partnership, among other changes. These transitions often come with complex emotional reactions. Regardless of the specifics of these adjustments, it's undeniable that life is no longer the same for either of you. These changes, like many aspects of dealing with Parkinson's, trigger emotions such as anger, resentment, and frustration. Additionally, you may grapple with guilt for harboring negative feelings towards your loved one.

#### Coping with Guilt and Anger

In the realm of caregiving, guilt is a pervasive sentiment. Loved ones may experience guilt due to the disruption and burden their Parkinson's imposes on their care partners. In contrast, care partners may grapple with guilt over the limitations of their caregiving abilities or the challenging decisions they must make that may cause pain to their loved ones. Guilt often evokes discomfort and vulnerability, which sometimes manifests in expressions of anger, perpetuating the cycle of guilt.

It's essential to remember that there are no wrong emotions. Negative emotions can be intimidating because they might be perceived as indicators of personal flaws or relationship issues. This apprehension can lead to suppressing these emotions, preventing you from honestly addressing your feelings. Feeling anger or resentment is not inherently wrong; how you navigate and process these emotions is what matters.

When grappling with intense emotions, it's beneficial to identify a trustworthy individual with whom you can be candid. Over time, working toward open communication with your loved one becomes crucial. This supportive person might be a friend, fellow care partner, family member, spiritual guide, or a member of your healthcare team. Recognize that experiencing mixed emotions as roles evolve is a common and normal response.

Reach out to your loved ones or your own healthcare team to address the practical aspects of role changes. As a care partner, you might face challenges such as managing finances or dealing with social isolation due to your evolving responsibilities. Your healthcare team can help identify resources to help you address these issues.

### **Symptom Management and OFF Times**

The progression of Parkinson's is characterized by its unpredictability. Some individuals can maintain a relatively high level of functioning for many years, while others experience a more rapid decline. This variability in Parkinson's progression means that there is no one-size-fits-all approach to managing it.

You may observe fluctuations in your loved one's motor and non-motor symptoms throughout the day. While this can be indicative of Parkinson's progression, it is often a sign that medications are not adequately controlling the symptoms, resulting in what is known as OFF times.

OFF times are when medication is not optimally working, and motor and non-motor symptoms aren't being managed. There are four common scenarios for when OFF times occur:

- Delayed ON
- Wearing OFF
- Unpredictable OFF
- Dose failure/partial ON

OFF times can create a lot of stress and frustration for care partners. As Parkinson's progresses, OFF times may become more frequent and unpredictable, contributing to anxiety and depression for your person with Parkinson's. Your loved one may not want social interactions because their ON and OFF times are too unpredictable, or they may feel ashamed of these fluctuations. It's a cascade of experiences and feelings that challenge everyone involved.

If your person with Parkinson's is experiencing OFF and their symptoms are not being well managed, ask yourself the following questions:

- Did your person take the proper medication in the correct dose and on time?
- Do they have the proper medications for their current situation? If OFF frequently happens, it's a good idea to meet with their doctor to determine if they need to try another or additional medication?
- Have they done all the other things that day to help their medications work best, such as taking them with a full glass of water and appropriately timing their macronutrient consumption?
- Did they do any of the non-pharmacological things they can to manage symptoms (e.g., exercise daily, get adequate sleep, connect with others, etc.)?

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

- [\[Care Partner Meetup\] Care Partners and Guilt with Dr. Aaron Haug](#)
- [The Comfort Book](#)
- [David Phinney Foundation Ambassadors](#)
- [Medication Hub](#)
- [Protein and Parkinson's](#)
- [Symptom tracking sheet](#)
- [Medical planner](#)
- [Parkinson's Motor Symptom Diary](#)
- [Mild Cognitive Impairment \(MCI\) and Parkinson's](#)
- [Pill dispenser and medication alarm](#)
- [Rotigotine transdermal patch – side effects](#)
- [Neupro patch](#)
- [Duopa and How it Works](#)
- [Webinar: Emerging Therapies in 2023](#)

## Homework Ideas

- How do guilt and/or anger show up for you? Where in your body do you feel them? What do they feel like? For example, anger might feel like a tightness in the neck and shoulders, but guilt might feel like a sour stomach. This week, pay attention to the physical cues of these emotions and try to name them. Often, bringing attention can help you recognize feelings and then let them go.
- If your person is experiencing OFF symptoms, try keeping a simple diary for three days, noting what time they took their medications, what time the OFF periods occurred, and what time they ate meals. Bring this to their next doctor's visit. If there is a clear pattern, the doctor may be able to adjust medications to improve OFF symptoms because of your diligence in tracking.

# SESSION 7

## Cognition, Sleep, Hallucinations, and Delusions



## Session 7 Cognition, Sleep, Hallucinations, and Delusions

### Conversation Starters

1. Have you observed any changes in your loved one's sleep patterns, such as struggling to fall or stay asleep? Have you implemented any strategies or used resources to enhance their sleep quality?
2. Which cognitive changes have posed the greatest challenges for you as a care partner? Have you employed tools or resources to address or limit these cognitive changes?
3. Have you had to cope with your partner experiencing distressing hallucinations or delusions? If so, what aspects of this experience are particularly challenging for you to witness? What emotions did you grapple with at that time?

### Pre-Session Resources

- [Cognitive Complications in Parkinson's](#)
- [Mild Cognitive Impairment and Parkinson's](#)
- [Dementia and YOPD](#)
- [Psychiatric and Cognitive Complications in Parkinson's](#)
- [Dementia and Parkinson's: Definition, Causes, and Management](#)
- [Memory Picture Phones and Repetitive Calling Solutions](#)
- [Sundowning; Lewy Body Dementia Resource Center](#)
- [Sleep and Living Well with Parkinson's](#)
- [Sleep, Light, and Neurodegeneration](#)
- [Exercise and Its Impact on Sleep and Parkinson's](#)
- [A Primer on Sleep and Parkinson's](#)
- [How to Bring Light to the Darker Side of Parkinson's: A Primer Hallucinations and Delusions and How to Manage Them](#)
- [Parkinson's Disease Psychosis \(PDD\)](#)
- [Impulse Control Disorders \(ICD\) and Parkinson's: What They Are and How to Manage Them](#)

### Knowledge

As you're aware from previous discussions and your own experience, Parkinson's symptoms can change a lot from day to day. However, as a progressive condition, Parkinson's brings about other changes that occur over more extended periods. These changes might be less apparent to you but more noticeable to others who interact with your loved one with Parkinson's less frequently. These gradual changes often manifest as cognitive decline, sleep disturbances, and persistent fatigue.

#### Cognitive Decline

**Parkinson's affects not only memory but other cognitive functions, including:**

- Executive function: Planning, multitasking, problem-solving, and reasoning
- Visuospatial abilities: Difficulties judging distance, depth perception, object recognition, and orientation—even in familiar surroundings
- Attention: Capacity to focus on a specific task or topic
- Concentration: Ability to sustain attention over a prolonged period

Individuals with Parkinson's often struggle with attention and concentration. For instance, multitasking skills can be impaired, making it challenging to engage in a conversation while the television is on, music is playing, or another conversation is happening nearby. This may result in the misconception that your loved one is not paying attention or is intentionally ignoring you when they're actually experiencing cognitive difficulties.

### **Tips for assisting your loved one in managing multitasking challenges:**

- Be mindful of the environment.
- Minimize distractions (e.g., turn off TV or music).
- Prevent interruptions.
- Maintain eye contact.
- Tackle one task at a time and take frequent breaks.
- Request the speaker to slow down, repeat, or present information in a different way.
- Check that your loved one has comprehended the information.

### **Another common issue individuals with Parkinson's face is fluctuating attention and alertness throughout the day. Here are some strategies to address this challenge:**

- Allocate sufficient time for tasks.
- Include regular breaks during and between tasks rather than trying to power through everything in one go.
- Establish a daily routine and select manageable activities.
- Identify patterns in attention levels at different times of day and plan accordingly. For example, your person may be better in the mornings than after lunch.
- If visual information proves challenging for your person, try out some auditory tools like voice recording apps to capture instructions or critical information.
- Help your person avoid overstimulation by limiting exposure to excessive sensory input.

### **Sleep-Related Issues**

Difficulty falling and staying asleep (insomnia) are common issues for many people living with Parkinson's. They can be linked to challenges such as difficulty turning over in bed, muscle cramps, vivid dreams or nightmares, pain, or frequent urination.

### **REM Sleep Behavior Disorder (RBD)**

This disorder can cause individuals to act out their dreams during sleep, leading to yelling, screaming, kicking, or punching, potentially resulting in self-injury or harm to a bed partner.

### **Tips for Addressing RBD-Related Issues**

- Rearrange sharp-cornered furniture away from the bed.
- Cushion the corners of nightstands.
- Cushion the floor around the bed.
- Lower the bed closer to the floor.
- Remove fragile objects or potential weapons from the bedroom.

## Excessive Daytime Sleepiness

Many people with Parkinson's experience excessive daytime sleepiness at some point during their illness. This drowsiness can be exacerbated by certain medications used to manage Parkinson's or other underlying medical conditions. Additionally, undiagnosed or untreated sleep apnea can contribute to daytime sleepiness.

### Tips for Managing Excessive Daytime Sleepiness

- Inform your loved one's healthcare provider about excessive daytime sleepiness to determine if medication adjustments or a sleep apnea evaluation are warranted.
- Some doctors advocate for naps. Others don't. Talk to your medical team to determine if napping would be good for your person and times of day and limits to consider if you choose to implement them.

## Sundowning

Sundowning refers to a pattern of increasing confusion, anxiety, agitation, hallucinations, delusions, wandering, or purposeless repetitive behaviors that arise toward the end of the day—around the time the sun sets—and into the evening. While more commonly associated with dementia, some individuals with Parkinson's also experience sundowning.

### Tips for Managing Sundowning

- Establish a daily routine that maximizes activity and exposure to daylight.
- Maintain a consistent bedtime routine and schedule.
- Limit naps after 2 pm and restrict caffeine consumption after morning hours.
- If sundowning suddenly emerges, consider potential underlying factors such as infection, dehydration, or constipation, and promptly seek evaluation from your loved one's healthcare provider.

## Fatigue

Fatigue, a persistent and pronounced sense of diminished energy, is a common and disabling symptom for over 50% of people with Parkinson's. It is often described as overwhelming tiredness or exhaustion. It's important to note that fatigue can be distinct from sleepiness, and individuals with Parkinson's may experience significant fatigue despite getting adequate sleep.

While there are both prescription and over-the-counter medication and supplement options, non-medical strategies such as avoiding alcohol, caffeine, chocolate, or lengthy late-day naps and incorporating regular exercise can help reduce fatigue. It's crucial to inform your person's medical team about all medications, including over-the-counter options and supplements, to ensure these are not contributing to fatigue.

## Parkinson's Disease Psychosis (Hallucinations and Delusions)

Psychosis is characterized by disordered thinking that results in a detachment from reality. The underlying cause of psychosis in Parkinson's is not adequately understood, although certain medications used to treat Parkinson's can potentially induce psychosis, particularly in individuals who already experience cognitive issues.

## Two Common Types of Hallucinations in Parkinson's

**Passage or presence hallucinations:** These involve a perception that someone is in the room—either a specific individual or an indistinct presence.

**Visual hallucinations:** They may initially manifest as shadows, floating colors, or vague shapes, which may develop into distinct objects, animals, or people. People with Parkinson's frequently experience visual hallucinations involving small animals or insects. These hallucinations often recur without speech or interaction with the individual experiencing them.

Common behaviors associated with subtle hallucinations may include picking at clothing, reaching for invisible objects on the table, or bending down to retrieve non-existent items from the floor. These actions are often indicative of subtle hallucinations. Initially, individuals may maintain some insight into the unreality of what they see, but over time, this insight may erode, leading to a sense of fear or agitation without the ability to explain the cause, which may indicate ongoing hallucinations.

### Tips for Managing Hallucinations

Hallucinations are more likely to occur in dim lighting, so installing night lights and additional lighting in dark areas can be beneficial. Some care partners find it helpful to provide the individual with Parkinson's a flashlight, allowing them to test whether their hallucinations are real. Often, shining a light on the source of the hallucination causes it to vanish.

### Delusions

Delusions are firmly held, illogical beliefs that persist over time and lack basis in reality. They may manifest as confusion at night and evolve into specific delusions during the day, exhibiting fluctuations in intensity throughout the day or between days. Delusions often repeat and can be intricate and elaborate.

### Common Categories of Delusions

**Jealousy:** The belief that the care partner is being unfaithful, leading to suspicion, agitation, or paranoia.

**Persecutory/Paranoid:** The individual believes they are being monitored, attacked, harassed, or cheated in some way, leading to actions such as:

- Unplugging electronic devices to prevent monitoring
- Discussing organizations or people following them
- Hiding or hoarding objects because they believe doing so will prevent someone, although undefined, from taking them
- Developing specific delusions linked to their previous employment or career, imagining that meetings, business deals, or critical professional activities are unfolding without their involvement

**Reduplicative Paramnesias or Capgras Syndrome:** The belief that there are multiple identical persons or locations or that a person or place is an imposter. For instance:

- Your loved one may ask, “When are we going home?” or say they want to return home or claim, “This isn’t the right house,” despite being in their residence.
- They might ask, “When is [your name] coming back?” or declare, “You’re not the real [care partner’s name],” or insist there are multiple versions of you.

### Addressing Hallucinations and Delusions

Severe hallucinations and delusions can lead to agitation and aggression. It’s essential to promptly report any new or worsening hallucinations and delusions to your loved one’s medical team. This step may lead to necessary medication adjustments and can provide you with validation as a care partner that these symptoms are common and not a result of your actions.

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

### Post-Session Resources

#### Homework Ideas

- If your person hallucinates or has delusions, can you pick one new strategy to use for coping this week?

**DISTRACT or REDIRECT:** For example, if a person thinks something is happening that isn’t or there are people in the home who are not really there:

“Oh really? Huh. I was going to go get a snack in the kitchen; want to come with me?” or

“They told me they’re leaving in five minutes and not returning today. Let’s go on a walk; they’ll be gone when we get back.”

**JOIN:** If the person is seeing something that’s not there, but it is pleasant, like a childhood pet, you might ask:

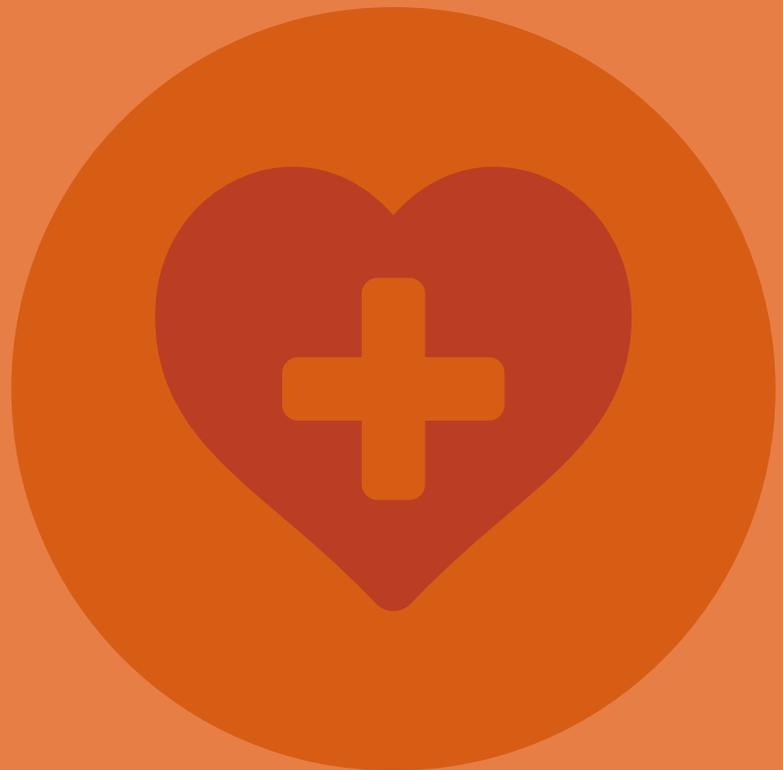
“What was your favorite thing to do with (pet’s name)? Tell me about that.”

“How old were you when you got (pet)? Tell me about that.

Consider which strategies felt easier (or harder) to use; why do you think that is?

# **SESSION 8**

## **Healthcare System, Medicare, and Patient and Care Partner Support**



## Session 8

# Healthcare System, Medicare, and Patient and Care Partner Support

### Conversation Starters

1. Are you familiar with accessing in-home care and respite care resources, and have you utilized any of them?
2. Have you made modifications to your home since your loved one's Parkinson's diagnosis? If so, which ones and how did you manage them?
3. If your loved one transitioned to an assisted living or nursing home, how have you personalized their new living space to make them comfortable? For example, have you added family photos, their favorite blanket, or established relationships with the staff?
4. Do you have any questions regarding palliative and hospice care services?
5. In what ways do you anticipate that palliative care and/or hospice might play a role in your loved one's journey with Parkinson's?

### Pre-Session Resources

#### For Help on Medicare & Medicaid

- [A Beginner's Guide to Medicaid](#)
- [Medicare Coverage and Parkinson's](#)
- [Understanding Medicare's Options: Parts A, B, C, and D \(AARP\)](#)
- [Medicare Interactive](#)

#### For Palliative and Hospice Care

- [Questions to ask when interviewing a hospice agency](#)
- [International Neuropalliative Care Society](#)

#### For Caregiver Support Systems

- [Memory Cafes](#)
- [Senior Centers or Adult Day Centers](#)
- [Websites to hire caregivers directly](#)
- [4Sitters](#)
- [Getting Your Affairs in Order](#)
- [Your Conversation Starter Kit: For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia; The Conversation Project](#)
- [Prepare for Your Care](#)

## Knowledge

### Health Coverage and Housing

As a care partner, your daily life may increasingly become challenging for your emotional and physical well-being. However, making changes can be complex due to practical constraints, financial considerations, feelings of guilt, and other obstacles. Perhaps you even made promises to your person with Parkinson's about who will provide care and where your loved one will live, which now must change and that presents emotional distress for you and your loved one. Fortunately, various resources and services are available to help you expand your support system.

#### In-Home Care

There are two types of in-home care: non-medical home care and home healthcare, each with different methods of access and financing.

#### Non-Medical Home Care (custodial care)

Non-medical home care is also known as custodial care, personal care, homemaker services, or companion services. It might include someone helping with tasks like light housekeeping, laundry, meal preparation, companionship, transportation, and assistance with personal hygiene (e.g., bathing, dressing, toileting).

The costs for non-medical home care are typically covered out-of-pocket, through long-term care insurance or by the VA or state subsidies. You can contact your local department on aging for information about available financial assistance programs in your state, such as your state's community care program.

#### Home Healthcare

Home healthcare provides skilled services, including nursing care, physical therapy, occupational therapy, and speech therapy. Healthcare professionals visit for short durations, often 60 minutes or less, one to two times per week for a limited number of weeks. Sometimes, a home health aide may assist with tasks like bathing.

These services are covered by Medicare or private health insurance and require a physician referral, including certification that the patient is homebound. After completing a course of home healthcare, insurance usually mandates a break of approximately 12 weeks before restarting therapy or services.

It's important to note that you cannot concurrently receive outpatient therapy and home health care. This would be considered "double-dipping." However, you can have a homemaker or paid caregiver while receiving home healthcare services.

#### Assisted Living

Assisted living facilities are designed to assist individuals who require help with daily care while maintaining their own room or apartment. These facilities can vary in size, accommodating a few dozen to over 100 residents, and often offer different levels of assistance at varying costs. Residents in assisted living may receive support with housekeeping, laundry, and medication management. These facilities typically provide a range of social and recreational activities while offering 24/7 supervision.

## **Nursing Homes**

Skilled nursing facilities, also known as nursing homes, provide more extensive medical and nursing care, supervision, and assistance with daily activities compared to assisted living. While some people may briefly stay at a nursing home for post-hospital recovery before returning home, most residents live in nursing homes long-term. These facilities provide daily meals, nursing care, and may offer physical, occupational, and speech therapy for specific conditions.

Certain nursing homes have dedicated memory care units tailored to individuals with dementia. These units can significantly vary from one facility to the next but often involve locked units to prevent wandering. Staff in memory care units typically receive specialized training and offer activities and social events designed for residents with dementia.

## **Medicaid vs. Medicare: What's the Difference?**

Medicaid and Medicare are government-run programs providing health coverage, but they are distinct programs funded by different government divisions and primarily serve different populations. These programs differ in terms of the services they cover and their associated costs.

### **Medicaid**

Medicaid is a state and federal program designed for people with very low incomes, currently providing coverage to over 72 million Americans.

While the federal government establishes guidelines for Medicaid programs, individual states can design programs and services within these guidelines.

Most states have multiple Medicaid programs catering to different populations, such as low-income adults, people with disabilities, and those in need of institutional or long-term care.

To qualify for Medicaid, individuals must apply through the healthcare marketplace or their state's Medicaid agency and meet specific income and asset eligibility requirements. The Medicaid system can be intricate, and you may consider seeking assistance from a certified Medicaid planner (CMP) to navigate the system. CMPs can often be found through local senior centers, area agencies on aging, the Legal Aid Society, or the [National Council on Aging](#).

### **Medicare**

Medicare is a federal program providing health coverage for individuals aged 65 and over or younger than 65 with a disability.

Eligibility for Medicare typically begins at age 65, but individuals are not automatically enrolled; they must take the initiative to sign up.

The initial enrollment period for Medicare is three months before to three months after your 65th birthday. Enrolling late may result in higher premiums.

Medicare has four essential parts, each covering different healthcare services and costs.

For additional information, you can contact 1-800-medicare.

## Understanding the Medicare Alphabet: Parts A-D

Part	What's Covered	Automatic Enrollment	Costs
<b>A</b>	<b>Hospital coverage:</b> <i>Hospital stays, hospice care, (some) skilled nursing care after hospital stays, if needed</i>	<b>Yes</b>	No premium; +deductible for each hospital stay
<b>B</b>	<b>Doctor and outpatient services:</b> <i>Doctor visits, lab tests and screenings, medical equipment, ambulance transportation, and other outpatient services</i>	<b>No</b> You must sign up; may want to defer if + other insurance	Monthly premium and annual deductible + 20% of doctor & outpatient service bills (~\$170/month & \$233/year in 2022)
<b>C</b>	<b>Medicare Advantage:</b> <i>Private insurance alternative combining various Medicare parts in one plan, everything "original Medicare" covers + additional services not in Medicare (e.g., dental &amp; vision care, wheelchair ramps, meal delivery, transportation to doctors' offices). Most include prescription drug coverage, but vary in what/how much they cover</i>	<b>No</b> Still must enroll in Parts A&B, then sign up with private insurer	Varies significantly from one plan to the next
<b>D</b>	<b>Prescription drugs:</b> <i>Private insurance covering an array of prescription drugs, however the covered list ("formulary" varies widely. Compare formulary lists with your medication list before signing up.</i>	<b>No</b> Sign up through a private insurer	Premiums, out-of-pocket costs, annual deductibles vary by plan and insurer. Past certain amounts, out-of-pocket costs may be limited.

The healthcare system in the United States excels in many aspects, but for individuals living with chronic illnesses such as Parkinson's, there are numerous unmet needs. Research has shown that individuals with chronic illnesses often experience:

- Many untreated or under-treated symptoms
- Poor communication regarding their care goals
- Lack of coordination in care
- A need for advanced care planning

In other words, there exists a significant gap between what people require and desire in their Parkinson's care and what they actually receive. This gap can be bridged through palliative care.

### Palliative Care

A common misconception is that palliative care and hospice care are the same. However, palliative care represents a broad and diverse field, with hospice as only a tiny segment of the larger landscape.

Palliative care is specialized medical care designed for individuals living with serious illnesses, primarily focusing on alleviating the symptoms and emotional stress associated with the illness. It aims to enhance the overall quality of life for individuals living with the illness and their family.

Palliative care applies to people of any age and at any stage of a severe or chronic illness, and it can coexist with curative care if such treatments are available.

In a recent study involving Parkinson's, individuals were randomized into two groups: one who received the standard care (consulting their regular neurologist and primary care doctor) and the other received an interdisciplinary palliative care team. Those who received palliative care experienced improved quality of life and outcomes for individuals with Parkinson's and their care partners. Palliative care can begin as early as the time of Parkinson's diagnosis.

Palliative care teams usually include physicians, nurses, dietitians, social workers, and other healthcare professionals working together to address the individual's physical, social, emotional, and spiritual needs, as well as those of their family and care partners. A palliative care approach emphasizes meeting the individual's comprehensive needs—not merely treating their medical condition. For individuals with Parkinson's, this includes assessing and managing both motor and non-motor symptoms, which can often alleviate pain and other distressing symptoms.

If you are interested in palliative care, start by consulting your loved one's neurologist. Many neurologists are proficient in providing primary palliative care. Some might have limited training in palliative care and may suggest consulting a palliative medicine specialist. In certain regions, there are neuropalliative care clinics specifically designed for individuals with neurological conditions where a neurologist, palliative medicine specialist, and others collaborate to offer comprehensive, one-stop-shop palliative care for Parkinson's and related disorders.

To learn more about neuropalliative care, visit the [International Neuropalliative Care Society](#).

To locate a palliative medicine specialist, you can request a referral from your physician or a local hospital or consult CaringInfo, a service provided by the National Hospice and Palliative Care Organization.

## Hospice

Hospice constitutes a smaller component within the larger framework of palliative care, involving additional services and support, typically provided in a home setting when:

- A medical professional estimates that an individual has six months or less to live.
- The individual chooses to shift to an approach focused on comfort over treatment.

Contrary to the notion that hospice signifies “giving up,” it can be more accurately regarded as an intensified effort to manage symptoms, optimize the individual's quality of life, and ensure that all healthcare aligns with their goals of care.

Hospice benefits are part of Medicare and typically encompass the services of a nurse and social worker who visit at least weekly. Hospice benefits also include bereavement support for family members and caregivers for up to 13 months after the enrolled individual has passed away.

Before transitioning to hospice, the neurologist and/or palliative care specialist may make treatment adjustments based on the individual's condition and hospice regulations. Hospice then takes over as the primary healthcare team, while the person's neurologist may remain involved as a consultant. Hospice professionals possess extensive expertise in managing challenging symptoms and addressing the emotional aspects related to end-of-life conditions. They can serve as valuable additions to the healthcare team built by the person with Parkinson's and their family throughout their journey.

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

### Homework Ideas

- Do you know how to contact your local area agency on aging? What services do they offer?

# **SESSION 9**

## **Uncertainty, Anticipatory Grief, and Ambiguous Loss**



## Session 9

# Uncertainty, Anticipatory Grief, and Ambiguous Loss

### Conversation Starters

1. Individuals confronted with an upcoming loss may grapple with emotions such as anger, sadness, irritability, or a sense of helplessness as they face the impending loss of their loved one. Have you encountered any of these emotional experiences?
2. What are the avenues of assistance or available resources that could aid you in navigating the stages of anticipatory grief and bereavement?
3. Have you previously encountered grief in your life? Did you find it necessary to seek additional support to cope with your grief? If so, what type of support did you find beneficial?
4. Could you identify some effective tools or coping strategies that you believe might be helpful in the grieving process?

### Pre-Session Resources

- [Your Conversation Starter Kit: For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia; The Conversation Project](#)
- [Prepare for Your Care](#)

#### For Managing Anticipatory Grief and Ambiguous Loss

- [Grieving Before A Death: Anticipatory Grief And Dementia Caregivers](#)
- [Ambiguous Loss And Grief For Individuals And Families](#)

### Knowledge

#### Uncertainty and Parkinson's

To live with a degenerative illness is to live with a heightened sense of uncertainty. You don't know when symptoms will increase in frequency or severity, how quickly they will progress, and whether or how well treatments will work. Even from day to day and hour to hour, you don't know if your person will feel well or sick.

This uncertainty takes a mental toll and can cause emotional distress for you and your person with Parkinson's, disrupting your perception of control.

The good news is that while you can't control the unpredictability of your person's symptoms or progression, you can control the strategies you use when faced with them. Having a plan that works to maximize health and address challenges can go a long way toward providing greater certainty, especially when anticipatory grief and ambiguous loss enter the picture.

## Self-Efficacy and Resilience

It's a bold claim: Positive thinking and positive social influences can improve your mental and physical health.

But as surprising as it may seem, there's a broad base of scientific evidence behind that claim. Dr. Albert Bandura first coined the term "social cognitive theory" (SCT) in the 1960s. This theory proposes that part of people's knowledge base comes from what they learn by observing others. Bandura also focused on the concept of self-efficacy: the idea that a person has agency and influence over their outcomes. In recent years, these theories have been extensively researched to determine their effects on people's health.

Self-efficacy affects practices related to health and adaptability to illness and treatment. For example, the relationships between a good sense of personal agency and both cancer prevention and adaptation to cancer diagnoses are strong. In broader implications, those with a high level of self-efficacy tend to make better choices when it comes to nutrition, exercise, alcohol consumption, smoking, and safe sex practices. Also, increased self-efficacy correlates to decreased physical and psychological symptoms across a range of illnesses. In short, self-efficacy causes behavioral changes that can make a big difference when it comes to living well with Parkinson's.

One subfield of self-efficacy is self-care self-efficacy: confidence in one's ability to perform behaviors related to self-care. Self-care is especially important for both people with Parkinson's and their care partners to ensure that both are living well. Self-care self-efficacy is associated with positive outcomes for mental and physical health for people with chronic illnesses. It has also been shown to positively affect anxiety, coping strategies, depression, decision-making, stress, energy expenditure, and resilience because people with better self-care self-efficacy have better outcomes. They also have a higher quality of life, better physical function, lower symptom distress, and higher goal achievement than people with lower self-care self-efficacy. A strong social support system has also been shown to be related to higher levels of self-efficacy, so for both people with Parkinson's and care partners, a strong care team and social network is essential to better outcomes.

### Four ways to improve self-efficacy include:

- Setting simple goals
- Thinking long term
- Reframing your story
- Finding a model

When you build self-efficacy, you build your resilience muscle, which is critical for managing and thriving with uncertainty.

## Anticipatory Grief and Ambiguous Loss

Being a care partner for someone with Parkinson's involves many emotions, two of which are anticipatory grief and ambiguous loss. Anticipatory grief is the feeling of loss while your loved one is still alive. Ambiguous loss arises from the recognition that your loved one is both absent in some ways and present in others. Going through anticipatory grief and ambiguous loss can be just as emotionally challenging as the loss associated with death. If you've experienced anticipatory grief, please know that you are not alone; it's a challenging but normal part of the process.

Connecting with other care partners who are currently going through or have experienced ambiguous loss and anticipatory grief can help validate your feelings and potentially offer coping strategies.

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

## Post-Session Resources

- [Creative non-fiction: Welcome to Holland](#)
- [Find a Therapist: PsychologyToday](#)

## Homework Ideas

- How do you deal with the feelings of anticipatory grief and ambiguous loss?
- What has helped? What hasn't?

# **SESSION 10**

## **Wrap-Up and Q&A**



## Session 9 Wrap-Up and Q&A

### Knowledge

- [Video Recording](#)
- [Audio Recording](#)
- [Transcript](#)

### Post-Session Resources

## Appendix A: Every Victory Counts Worksheets & Checklists

*The Every Victory Counts*® Parkinson's worksheets, checklists, and assessments are a great way to help you and your person with Parkinson's become more aware of the timing and characteristics of their symptoms, document those symptoms, note changes, and discuss them with your medical team. You can also log progress toward achieving wellness goals, such as exercise, and see how far you've both come and where you need to go.

To make them as useful to you as possible, we have designed these sheets so you can fill them out right from your computer or tablet. Simply click on the field where you want to enter information and begin typing or click a box to check something off, then save your file. You can then print it out and take it to your next appointment, conversation, or treatment session.

[Click this link to get access to the following worksheets, checklists, and assessments:](#)

**Wellness and lifestyle self-assessments.** These are designed to help evaluate needs, set priorities, and take positive steps toward living well with Parkinson's. There are also worksheets to help track progress so you can see the effects over time of changes made and set new goals for the future.

- a. Parkinson's Care Questionnaire
- b. Goal Summary for Doctor Visits
- c. Daily Medication Log
- d. Overall Medication Log
- e. Wellness Self-Assessment
- f. Pre-Exercise Self-Assessment
- g. Exercise Journal
- h. Nutrition Self-Assessment
- i. Parkinson's Psychosis Self-Assessment
- j. Deep Brain Stimulation (DBS) Self-Assessment
- k. Our Relationship Self-Assessment
- l. Parkinson's Home Safety Checklist
- m. Parkinson's Travel Checklist

**Symptom checklists.** These worksheets encourage your person with Parkinson's to become more cognizant of how and when symptoms are problematic, offering recommendations for simple things they can do to minimize and manage symptoms. Completing these worksheets will also help them organize their needs and concerns so they can clearly communicate them to their wellness team.

- a. My Symptoms Worksheet
- b. Bladder Worksheet
- c. Cognitive Wellness Worksheet
- d. Constipation Worksheet
- e. Dental Worksheet
- f. Dyskinesia and "OFF" Time Log
- g. Emotional Wellness: Anxiety
- h. Emotional Wellness: Depression
- i. Fatigue Worksheet
- j. Gait, Balance, and Freezing Worksheet
- k. Insomnia and Sleep Worksheet
- l. Low Blood Pressure and Dizziness Worksheet
- m. Speech and Communication Worksheet
- n. Swallowing Worksheet
- o. Sexual Dysfunction Worksheet

**Medical information snapshots.** These documents are intended to organize important information about your person with Parkinson's for their wellness team, including specialists such as a deep brain stimulation (DBS) programmer, dentist, or a hospital wellness team. The "Medical Summary for Your Doctor Appointment" worksheet is a one-page document that organizes the most important information about your person with Parkinson's for their doctor's appointment. The "Prepare for Your Hospital Stay" worksheet collects all your current and essential Parkinson's information into a single document for the doctors, nurses, and aides that will be caring for them during their stay.

- a. Clinical Appointments Summary
- b. Current Symptoms Summary
- c. Wellness Team Contact Information
- d. Medical Providers
- e. DBS Medical History
- f. Prepare for Your Hospital Stay
- g. Medical Summary for Your Doctor Appointment
- h. Medical Summary for Dentists

## Appendix B: Care Partner Support Group Discussion Guides

Designed to complement the *Every Victory Counts*® *Manual for Care Partners* while also being useful on its own, we created this discussion guide to help you facilitate a group discussion about what it means to be a Parkinson's care partner.

[Click this link to access the following discussion guides:](#)

- What Does it Mean to Be a Care Partner?
- Care Partners After a Parkinson's Diagnosis
- Managing the Complications of Parkinson's

## Appendix C: Housing and Healthcare Resources

If you are a retired service member or the spouse of one, you may be eligible for caregiver assistance from the Veteran's Administration. Eligibility is determined based on various factors, including the length of your service, where services are needed, your discharge status, and the specific type of assistance required.

For more information, please reach out to the VA's Caregiver Support Line (CSL) at (855) 260-3274.

### Private Pay Help

Private home care agencies offer a wide range of in-home care services aimed at helping people in need maintain their safety, independence, and empowerment within their homes. These services encompass various tasks such as light housekeeping, shopping, running errands, meal preparation, laundry, supervision, medication reminders, and assistance with bathing, grooming, and hair care.

The cost of these services varies, with an average price typically ranging from approximately \$20 to \$25 per hour or more. Costs may depend on the frequency and duration of visits. When considering private home care, you have two primary options: either hiring a caregiver directly or using a caregiver agency.

For those interested in hiring caregivers directly, there are websites available to facilitate this process, such as:

- [Care.com: www.care.com](http://www.care.com)
- [4Sitters: www.4sitters.com](http://www.4sitters.com)
- [National Resources for Locating Home Care Agencies](#)

The Home Care Association of America ([www.hcaoa.org](http://www.hcaoa.org)) provides a helpful search tool for locating private pay in-home care services, which include services like homemaker assistance, case management, and respite care. You can click on the "Find a Provider" button to search for service providers near your location.

**Additionally, there are other options to explore for seeking assistance:**

- Register with [www.createthegood.org](http://www.createthegood.org) to connect with volunteers who can aid with your next service project.
- Find volunteers in your area at [www.elderhelpers.org](http://www.elderhelpers.org).
- Reach out to faith-based organizations, such as your local church, synagogue, mosque, or other places of faith, or consider contacting chapters of organizations like Catholic Charities and Jewish Family Services.
- Contact local high schools, nursing schools, or colleges to inquire about students needing volunteer hours.
- Use [www.caringbridge.org](http://www.caringbridge.org) to post your request for assistance.
- Create a Care Team Calendar to allow family and friends to sign up for specific tasks on specific days at [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com).



# **PARKINSON'S CARE PARTNER TRAINING PROGRAM HANDBOOK**

**A collaboration between the Davis Phinney Foundation  
and Jori Fleisher, MD, MSCE, building on work  
supported by the National Institutes of Health**

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