



# EVERY VICTORY COUNTS® CARE PARTNERS DISCUSSION GUIDE

## WHAT DOES IT MEAN TO BE A CARE PARTNER?

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



### How to Use this Discussion Guide

Use the questions below or your own set of prompts to guide the discussion. Remember to allow time for everyone to share, and if someone dominates the conversation, step in and invite others to contribute. Remember, too, you're not expected to be an expert simply because you're facilitating a conversation. Take time to process what you learn during the discussion and use these reflections to help shape your plans for future conversations.



**Choose a media format and create a schedule.** Does your group want to discuss being a Parkinson's care partner as highlighted in the *Every Victory Counts Manual for Care Partners*, other books, podcasts, webinars, articles, or a combination? Invite input from attendees and plan based on their preferences. Are you planning on discussing a webinar? Organize a viewing party. Want to read a collection of essays? Take a poll to select the list. If you foster a sense of community before the discussion, participants will feel more comfortable sharing their thoughts.



**Set the Stage:** For in-person meetings, arrange the seating so all participants can see one another—a circle or U-shape works well. If your group meets online, invite attendees to share their video, which typically makes for a more intimate and personable space. (Keep in mind that attendees who choose to leave their cameras off have reasons for doing so; acknowledge this in your invitation and support those who choose not to share their video.) Whether you meet in person or online, welcome attendees and ask them to introduce themselves and say why they're interested in taking part in the discussion.

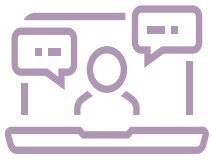


**Guidelines and Ground Rules:** Ask everyone to contribute ideas and make a list of guidelines about common language; openness and respect; a judgment-free space; equal speaking time; and acceptance of diverse opinions, values, and beliefs.

**Goals:** Invite attendees to say what they hope to learn through the conversation. Refer back to those goals if the conversation gets sidetracked; this allows you to return to the subject at hand without making someone feel dismissed.



**Discussion:** Set a firm structure before the discussion begins. Offer each attendee three minutes to offer a response to a question. If your group is large enough, you can split the group into smaller groups to allow everyone more time to share. If someone begins to monopolize the conversation, step in with a comment such as, "[Name], you looked like you had something you wanted to say. Would you like to jump in?"



## DISCUSSION QUESTIONS

The questions and prompts you use to guide your conversations will change depending on the topics and media your group chooses. Still, here are some general questions you can ask to kick off your discussion about being a care partner for a loved one with Parkinson's.

- » What did our reading/viewing/listening teach you about the care partner experience that you didn't already know?
- » What did you learn about what it means to be a care partner that was most interesting or surprising to you?
- » Does your person with Parkinson's already have a strong and integrated care team? Do you? If so, who are some key people on your team? Who are some of the key people on your person's team?
- » Has your person with Parkinson's ever switched providers because they felt they weren't getting the care they deserved? Have you? If so, what was the experience like? What would you tell someone who's feeling unheard by their providers?
- » How do you stay connected to your friends, family, and community?
- » Do you feel like your relationship with your person with Parkinson's has changed since their diagnosis? If so, in what ways?
- » What advice would you give others about having difficult conversations with your person with Parkinson's?
- » How did you feel, really feel, when you learned of your person's diagnosis? How is that different, if it is, than how you're feeling now?
- » Have you experienced any signs of care partner burnout? If so, what are they? What actions did you or can you take to mitigate this burnout? Who can you ask for help? What can you do to take care of yourself, beginning today?
- » What self-care and/or coping strategies do you turn to when things get tough?
- » What are some ways you could be an advocate for your person with Parkinson's in the next week, month, and/or year?
- » What are the silver linings you've identified about Parkinson's since your person's diagnosis?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about being a Parkinson's care partner? In what ways did it confirm or challenge the ideas you held?
- » What questions surfaced that you'd like to know more about?



## POTENTIAL TALKING POINTS

- » Living well with Parkinson's means living well in all aspects of life—physical, mental, social, spiritual. One provider can't possibly treat every part of your person with Parkinson's life; so, ideally, over time, they and you will build a holistic, integrated care team and personalized plan based on their unique symptoms, needs, and goals.
- » As your person's Parkinson's progresses, your role as the coordinator and manager of their care team will change.
- » A professional counselor or therapist can help you explore the foundations of your concerns or worries and offer advice about making positive changes. Like physicians, many therapists have specialties, so finding someone with experience with your unique challenges—whether it's burnout, irritation, relationships, depression, anger, or something else entirely—can be especially helpful.
- » The keys to maintaining any strong relationship are communication and understanding. Learn how Parkinson's can affect your person's voice, facial expressions, and mood, as all of these can affect how you “see” them when they communicate with you.
- » As a Parkinson's care partner, it's easy to become so focused on your person with Parkinson's that you put your needs on the back burner. This can lead to care partner burnout or, in its extreme, compassion fatigue, where you become overwhelmed physically, emotionally, spiritually, and socially to the point where you're unable to care for yourself or others.
- » One of the most helpful actions many of the care partners we've worked with have taken has been joining a care partner support group. These groups give you the chance to meet others who share similar experiences, make friends, and remind you that you're not alone.
- » Know that it is okay for your person to be challenged, and it's okay for you to encourage their independence. The more they can stay fully engaged in their life, the more they will build self-efficacy and resilience. And the more they continue to do on their own, the more agency and control they will feel not just about their life but about living with Parkinson's.
- » Research supports the idea that genuinely feeling your feelings by taking the time to notice them, accept them, sit with them, and give them space can make you a healthier and happier person (even when those feelings may seem negative). You are likely grieving the diagnosis just as your person with Parkinson's is. Know that this is a stage almost all people with Parkinson's and their care partners experience, and one that you should acknowledge, process, and allow to take place.
- » In your role as a care partner, find time to recognize the silver linings that give you hope and perspective in the more trying times. Reflect on what Parkinson's has made you grateful for, such as your family, or that Parkinson's isn't the diagnosis that you originally feared. Pause to embrace the fond memories you and your partner share. You can even ask yourself what good has come from Parkinson's or what gifts it has given you. Though it may sound strange, many people report receiving the gifts of time, more meaningful relationships, or new beginnings that wouldn't have been possible without Parkinson's.



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## WHAT DOES IT MEAN TO BE A CARE PARTNER?

### POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » How best to set expectations with your person about your role versus theirs in managing their Parkinson's
- » The importance of taking care of yourself first
- » How to be an advocate for your person



#### Reflection Activity

Think back to the moment/day/week when you learned about your loved one's Parkinson's diagnosis. What have you learned since that time about how to help your person live well with Parkinson's? What have you learned about how to take care of yourself while helping to take care of them? What would you tell your earlier self about processing the news and planning your path forward?



#### Call to Action

What helps you recharge when you're feeling overwhelmed or stressed? Write down a list of five to ten activities that bring you joy, and throughout the next week, enjoy one of these self-care activities each day. Pay attention to how you feel before and after each activity and plan to fit more self-care into your routine during the upcoming month.



#### Explore More

On the *Every Victory Counts* website, you can find additional Care Partners Discussion Guides, as well as Discussion Guides that complement the *Every Victory Counts* manual and focus on topics including Parkinson's symptoms, medications, exercise, therapies, and more.

# EVERY VICTORY COUNTS® CARE PARTNERS DISCUSSION GUIDE

## CARE PARTNERS AFTER A PARKINSON'S DIAGNOSIS

Designed to complement the sixth edition of the *Every Victory Counts Manual for Care Partners* while also being useful on its own, this discussion guide will help you facilitate a group discussion about the care partner experience following a Parkinson's diagnosis.



### How to Use this Discussion Guide

Use the questions below or your own set of prompts to guide the discussion. Remember to allow time for everyone to share, and if someone dominates the conversation, step in and invite others to contribute. Remember, too, you're not expected to be an expert simply because you're facilitating a conversation. Take time to process what you learn during the discussion and use these reflections to help shape your plans for future conversations.



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**Guidelines and Ground Rules:** Ask everyone to contribute ideas and make a list of guidelines about common language; openness and respect; a judgment-free space; equal speaking time; and acceptance of diverse opinions, values, and beliefs.

**Goals:** Invite attendees to say what they hope to learn through the conversation. Refer back to those goals if the conversation gets sidetracked; this allows you to return to the subject at hand without making someone feel dismissed.



**Discussion:** Set a firm structure before the discussion begins. Offer each attendee three minutes to offer a response to a question. If your group is large enough, you can split the group into smaller groups to allow everyone more time to share. If someone begins to monopolize the conversation, step in with a comment such as, "[Name], you looked like you had something you wanted to say. Would you like to jump in?" another participant]'s thoughts on the question. Care to share?"



## DISCUSSION QUESTIONS

The questions and prompts you use to guide your conversations will change depending on the topics and media your group chooses. Still, here are some general questions you can ask to kick off your discussion about the care partner experience following a Parkinson's diagnosis.

- » Has your person with Parkinson's shared their diagnosis with others? If so, what was that process like? If not, how do you feel about their hesitation and how it impacts you?
- » Have you noticed changes in your relationship and/or family dynamics following your person's Parkinson's diagnosis? If so, can you describe those changes?
- » Do you attend any/most/all medical appointments with your person? If so, what advice do you have for other care partners about attending appointments?
- » Does your person with Parkinson's exercise on a regular basis? Do they know about the many benefits of exercise on Parkinson's symptom management and neuroprotective qualities?
- » Is your person with Parkinson's still driving? Do you have any concerns about this activity? If yes, what are they?
- » Have you noticed changing and/or increasing symptoms that your person with Parkinson's is experiencing? Does your person notice them the same way you do?
- » Does your person experience mood-related symptoms like depression and anxiety? If so, have you learned any strategies to help manage these symptoms?
- » What is the hardest part about being a care partner? What are your biggest challenges in this role? How can you find ways to balance your care partner responsibilities and the responsibilities you have to yourself?
- » Have you developed a group of friends and family members who can help you with respite care? If so, can you describe the process you took to form the group?
- » Has your person's care team evolved since the time soon after their diagnosis? If so, in what ways?
- » What questions surfaced that you'd like to know more about?



## POTENTIAL TALKING POINTS

- » After a family member is diagnosed with Parkinson's, one of the most immediate changes is the shifting of family roles and identities.
- » Most care partners we know recommend you attend appointments to offer your own perspective, mention things you may have noticed that your person hasn't, take notes, and be an advocate for your person. By encouraging and expecting your person with Parkinson's to do tasks they're still capable of doing, you keep them connected to a sense of purpose and usefulness while also relieving some of your burdens and maintaining your own independence.
- » Workplace issues are some of the more stressful topics that people with Parkinson's confront. Whether to be open at work is an individual decision and learning your options will help you and your person with Parkinson's in your deliberations. Know your person's rights and consult with an attorney specializing in disability, discrimination, or workplace issues. They can help you decide how much and how soon your person wants to disclose at work and understand what may be covered by disability benefits.
- » The key to being an effective care partner is prioritizing self-care, feeling supported by your person with Parkinson's, and having something to call your own. As difficult as it may sometimes be, you must be at your best first if you want to help someone be theirs.
- » Just because your person with Parkinson's may not display any signs of feeling bad, it does not mean they aren't experiencing symptoms. They might be "playing up" for you, or they may be good at hiding their symptoms. Invite your person with Parkinson's to share how they're feeling by saying things like, "I'd love to know more about how you're feeling if you're up for talking about it." This kind of invitation shows that you can't understand all that they are feeling but that you want to.
- » Outside of taking medication, people living with Parkinson's benefit most from two things: exercise and community connections.



## POTENTIAL POINTS OF CONTENTION OR DISAGREEMENT

- » The necessity of attending appointments with your person
- » How best to encourage your person with Parkinson's to maintain their independence
- » How to advocate for your person in social settings
- » How to find balance between care partner responsibilities and the rest of your life

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## CARE PARTNERS AFTER A PARKINSON'S DIAGNOSIS



### Reflection Activity

Although Parkinson's is part of both your lives, it's essential to spend time with your person when Parkinson's isn't the most important person in the room. Think about how you connected with your person with Parkinson's pre-diagnosis. What were some of the activities that brought you both joy? Can you decide to still take time to do those activities together while talking about something other than Parkinson's?



### Call to Action

One important way you can help your person with Parkinson's live well is by ensuring their home environment sets them up for safe, productive, and enjoyable living. Invite your discussion group to explore our [Parkinson's Home Safety Checklist](#) and, if needed, to adjust their person's living space to make it safer and more functional for them.



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# EVERY VICTORY COUNTS® CARE PARTNERS DISCUSSION GUIDE

## MANAGING THE COMPLICATIONS OF PARKINSON'S

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## DISCUSSION QUESTIONS

The questions and prompts you use to guide your conversations will change depending on the topics and media your group chooses. Still, here are some general questions you can ask to kick off your discussion about being a care partner for a loved one experiencing Parkinson's complications.

- » Have you made changes to your home environment to make it safer for your person with Parkinson's? Have you downsized or considered downsizing or relocating?
- » Is apathy a symptom your loved one experiences? If so, are there any strategies you've tried that that have helped? Did you learn any strategies to manage apathy in the reading that you're interested in trying?
- » Has your person with Parkinson's experienced cognitive changes? What do they look like? Does your person recognize them in the same way you do?
- » How are YOU feeling about your person's current symptoms? What impacts you the most? What impacts them the most?
- » What strategies did you learn that you can try to help cope with your person's changing symptoms?
- » Have you explored hiring help or reaching out to family and friends to create a respite-care schedule for yourself? If so, how has this process unfolded? What advice do you have for other care partners about this process?
- » Has your person with Parkinson's been showing less interest in connecting with the community and more interested self-isolating behaviors? If so, how have you helped them avoid isolating themselves?
- » How do you and your person with Parkinson's find joy?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about being a Parkinson's care partner during later stages of Parkinson's? In what ways did it confirm or challenge the ideas you held?
- » What questions surfaced that you'd like to know more about?



## POTENTIAL TALKING POINTS

- » While it's always important that you speak up and offer your insights and observations during your person's medical appointments, as your person's Parkinson's progresses, it becomes even more crucial.
- » Because Parkinson's alters many regions of the brain and the dopamine system, it can affect executive function, language, speech, comprehension, and memory.

- » Parkinson's impact on the brain can cause delays in a person's reaction time, speed of movements, and postural "righting reflexes." This means if your body sways off its base of support, it might take too long to "right" itself. Additionally, some of the rigidity and dyskinesia associated with Parkinson's can diminish muscular control, and other factors include lightheadedness, slowness, and fatigue. All of these increase the risk of falling. Therefore, an important person to add to your person's care team, if they are not already included, is a Parkinson's physical therapist. They can assess your person's balance and work with them to develop a personalized training program to address their balance deficits.
- » Social isolation can exacerbate your person's symptoms, put them at risk for developing other health problems, increase their chances of experiencing depression, accelerate cognitive decline, and decrease their quality of life. Help your person avoid the temptation to isolate and help them stay connected to the world around them.
- » To help ensure your home is safe for your person with Parkinson's, an occupational therapist can visit your residence and learn about how you and your person live on a day-to-day basis. They can provide you with recommendations and potential resources that might be specific to your person's needs or general accessibility recommendations.
- » Apathy means that a person lacks motivation, desire, and interest to do something. Though the cause of apathy is unclear, research indicates that it's due to a chemical imbalance and structural changes in the brain. Apathy seems to parallel cognitive decline with disorganization and memory loss, and medications for cognitive problems appear to work best for people who are apathetic.
- » During medical appointments, speak up so your person's providers can be given the full story of current symptoms. You may have noticed new symptoms or changes in symptoms that your person with Parkinson's hasn't, so being present during appointments and sharing this information is extremely helpful. It can also be helpful to record the conversation and, when you get home, discuss what the physician said. You may be surprised by how much your recollections of the appointment differ.
- » A significant cognitive concern for many people living with Parkinson's is dementia. Most recent figures suggest that up to one-third of people living with Parkinson's will develop dementia, a significant cognitive change that affects how they live their daily lives. It can also impact a person's ability to live independently. If this is the case, the introduction of a professional caregiver is often necessary, even if your person's motor symptoms are still being well managed.
- » Psychosis is a non-motor symptom of Parkinson's. Parkinson's psychosis manifests in different ways, such as hallucinations (seeing, hearing, or feeling something that is not there) and delusions (irrational beliefs or convictions). People living with Parkinson's have a 50% risk of developing psychosis at some point, and it can occur at all stages of Parkinson's.
- » Even if you're the primary care partner for your person with Parkinson's, you do not have to do everything alone. There are several ways to find help, and one is finding a dedicated caregiver. Professional caregivers often help during the advanced stages of the journey. As your person's Parkinson's progresses, they may experience increasing motor symptoms, and caregivers may need to assist with walking, transfers (in and out of a chair, the shower or bathtub, and bed), food preparation, toileting, bathing routines, and more.



# EVERY VICTORY COUNTS® CARE PARTNERS DISCUSSION GUIDE

## MANAGING THE COMPLICATIONS OF PARKINSON'S

### POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » When and whether to downsize
- » The benefits versus risks of moving your loved one into a long-term care facility
- » How best to respond, in the moment and afterwards, if your person experiences hallucinations and/or delusions



#### Reflection Activity

Practicing gratitude on a regular basis can improve your quality of life, your mental and physical health, your relationships, and more. Think about five things you're grateful for today. What brings you joy? How can you take time to appreciate these moments each day? What are some "gratitude triggers" you could designate to remind you to express gratitude, such as when you pour a cup of coffee, stop your car at a red light, or wash your hands?



#### Call to Action

Think about who you could add to your loved one's care team to help them and you live well. Would it help you both to connect with a physical, occupational, and speech-language therapist? Do you need to explore home-health options? Who could help with your person's most impactful symptoms? Make a list and reach out to members of your support group or community for recommendations about health providers in your area.



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