



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## QUALITY OF LIFE AND MINDSET

Designed to complement the Sixth Edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about the many actions people can take, beginning today, to live well with Parkinson's and improve their quality of life.

### 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 learned 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 quality of life and Parkinson's as it is highlighted in *Every Victory Counts* manual, 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 else feel unheard.



**Discussion:** Set a firm structure before the discussion begins. Offer each attendee three minutes to offer a response to a question, then ask the next person to do the same. 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 of another group member], you looked like you had something you wanted to say. Would you like to jump in?" or "I'd love to hear [name of another participant]'s thoughts on the question. What do you think?"



## 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 quality of life and Parkinson's.

- » What does “quality of life” mean to you?
- » How do you feel your quality of life has been impacted by Parkinson's?
- » What did our reading/viewing/listening teach you about mindset and its role in someone's quality of life?
- » What were insights from the authors or speakers that were most compelling, interesting, or surprising to you?
- » What are some limiting beliefs you have experienced during your journey with Parkinson's? How can you reframe them?
- » Which issues most affect your quality of life? How?
- » Have you ever practiced mindfulness and/or meditation? If so, how would you describe its impacts on your mindset?
- » If your loved one is living with Parkinson's and experiencing a lower quality life than before diagnosis, how might you help them, given what you've recently learned?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard on these issues? In what ways did it confirm or challenge the ideas you held?
- » What questions surfaced that you'd like to know more about?
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## POTENTIAL TALKING POINTS

- » Data from studies about “the science of happiness” show that when you actively practice looking on the bright side, feeling gratitude, and copying the behaviors of naturally happy people, you can become happier yourself.
- » Research also shows that embracing the emotion of gratitude improves your well-being, your cognition, and your willpower. Train yourself to shift your attention to things that bring you joy instead of concerns over which you have no control.
- » Give back to boost your happiness: call a friend, write a gratitude letter, perform a random act of kindness, or donate your time to a cause.
- » When you experience things that bring you joy, whether big or small, take the time to savor them and be fully present.
- » In the cognitive behavioral therapy model, negative feelings like depression and anxiety don’t come out of the blue; feelings come in response to your thoughts and interpretations of the situations you face. Often, thoughts might come so quickly that you might not even be aware that you have them, yet they linger long enough to have a negative impact on how you feel and how you act. Importantly, the negative thoughts we observe in depression (and anxiety) are often not as accurate as they feel and are guided more by emotion than by fact.
- » Reframing your thoughts about a situation can lead to different feelings and behaviors. A primary goal of cognitive behavioral therapy is to “press pause” on negative thoughts, evaluate them to determine if they are as accurate as they feel, and to replace them, as appropriate, with more balanced, realistic thoughts.



## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The degree to which mindfulness and mindset can improve someone’s quality of life
- » How beneficial therapies such as cognitive behavioral therapy and counseling can be for a person with Parkinson’s
- » The best way to encourage a loved one with Parkinson’s to take action to reframe any limiting beliefs they may have



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## QUALITY OF LIFE AND MINDSET



### Reflection Activity

After the discussion, during which you might have talked about limiting beliefs and how to reframe them, ask participants to write, draw, or otherwise depict some limiting beliefs they have experienced during their journey with Parkinson's. Invite them to illustrate and/or share aloud how they can reframe them using techniques learned during the conversation.



### Call to Action

Set three realistic, achievable goals each day for the next week: one exercise goal, one social goal, and one other goal, which might be something productive like paying a bill or doing some self-soothing like taking an Epsom salt bath. An example of a realistic social goal could be answering the phone when your sister calls instead of letting it go to voicemail. Effective behavioral goal setting often involves collaborative problem-solving and thinking outside the box to meet the challenging demands of Parkinson's. Record your progress and celebrate your victories when you meet your daily goals.



### Next Steps

If you plan to meet again, set the date and time for your next meeting, and choose the next *Every Victory Counts* topic, webinar, book, essay, or podcast to study. If your group will only be meeting once, thank everyone for their participation.



### Explore More

On the *Every Victory Counts* website, you can find additional Discussion Guides about topics including Parkinson's symptoms, medications, exercise, therapies, and more.



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## PARKINSON'S MOTOR SYMPTOMS

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about Parkinson's motor symptoms and strategies to manage them so you can live well with Parkinson's today and in the future.

### 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 learned during the discussion and use these reflections to help shape your plans for future conversations.



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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 Parkinson's motor symptoms.

- » What did our reading/viewing/listening teach you about Parkinson's motor symptoms that you didn't already know?
- » What did you learn about motor symptoms that was most interesting or surprising to you?
- » What motor symptoms are most impactful for you? In what ways?
- » How have your motor symptoms changed over time?
- » Do your motor symptoms cause you to feel uneasy or embarrassed when you're in public? Have you ever said no to a gathering because you were concerned about your symptoms? If you have ever been accused of being drunk because of tremor or dyskinesia, how did you handle it? Any suggestions for others?
- » Were there symptom-management strategies offered in the materials that you've not explored but that you're excited to try?
- » Have you ever worked with a physical therapist, occupational therapist, and/or speech-language therapist? If so, what was your experience like? Do you still see these professionals?
- » Are there any strategies you've tried that weren't highlighted in the materials? If so, what are they? How did they work for you? What questions surfaced that you'd like to know more about?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about Parkinson's motor symptoms? 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

- » Parkinson's is a complex neurological disorder associated with a loss of dopamine-producing nerve cells deep inside the brain. Dopamine is a neurotransmitter (a chemical substance) that helps regulate the body's movement. Less dopamine in the brain means less control over movement and less mobility in general.
- » Common motor symptoms of Parkinson's are tremor, stiffness, slowness, and postural instability.
- » Parkinsonian tremor is characterized by regular, rhythmic, involuntary movements. In the early stages of Parkinson's, tremor is typically seen on one side of the body, often starting in a hand; however, as Parkinson's progresses, tremor may impact both sides and affect more body regions.
- » Poor balance and coordination are common in Parkinson's. 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, in turn, can increase their risk of falling.
- » Balance is learned. We taught ourselves as toddlers to balance by practicing, again and again and again. The key to strengthening your balance is regular practice.
- » Rigidity, when your muscles feel stiff and tighten involuntarily, is one of the most common motor symptoms of people with Parkinson's, and 90% of people with Parkinson's experience rigidity at some point.
- » One proven strategy to help improve the cardinal motor symptoms of Parkinson's is exercise. Research studies have found that people with Parkinson's who participated in high-intensity exercise experienced noticeable improvement in their overall movement and even reduced tremor after exercising.
- » A physical therapist and/or occupational therapist can be incredibly helpful if you experience Parkinson's motor symptoms. They can assess your ability to do activities of daily living, your gait, and your balance, then recommend personalized exercise and activity plans for your needs and goals. They are also experts at recommending assistive devices and exercises to prevent falls and improve safety.



## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The "best" treatment options for various Parkinson's motor symptoms (medication, exercise, surgical therapies, rehabilitative therapies, complementary therapies, etc.)
- » The efficacy of certain treatment strategies in helping manage motor symptoms
- » What to expect in terms of the progression of Parkinson's motor symptoms



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## PARKINSON'S MOTOR SYMPTOMS



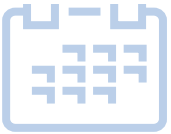
### Reflection Activity

Ask participants to think back to their response to the question about the motor symptom that most affects them. Invite them to share aloud, write, draw, or otherwise reflect on something they learned during the discussion that can help them manage this symptom.



### Call to Action

After the reflection activity, invite participants to put this treatment strategy into action within the next month. Did someone mention they'd learned how physical therapy can help with balance? Encourage them to schedule a visit to a PT in their area. Did someone get excited about how weighted spoons can help with tremor while they're eating? Recommend they buy one and give it a try. Remind everyone to keep exploring options for treatment and to celebrate their victories, big or small, when they discover something that improves their motor symptoms and quality of life.



### Next Steps

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### Explore More

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# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## DEPRESSION, ANXIETY, APATHY, AND PARKINSON'S

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about depression, anxiety, apathy, and Parkinson's, as well as strategies to manage them so you can live well with Parkinson's today.

### 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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**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, then ask the next person to do the same. 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 of another group member], you looked like you had something you wanted to say. Would you like to jump in?” or “I'd love to hear [name of another participant]'s thoughts on the question. What do you think?”



## 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 depression, anxiety, apathy, and Parkinson's.

- » What did our reading/viewing/listening teach you about depression, anxiety, and apathy in Parkinson's that you didn't already know?
- » What did you learn about these symptoms that was most interesting or surprising to you?
- » If you experience depression, anxiety, and/or apathy, in what ways is it most impactful?
- » If you experience these symptoms, how long have you noticed them? Did they begin before you noticed any motor symptoms?
- » Has anyone mentioned to you that you seemed to be showing signs of depression, anxiety, and/or apathy when you yourself hadn't named this emotion? If so, how did you react?
- » Were there symptom-management strategies for depression, anxiety, and apathy offered in the materials that you've not explored but that you're excited to try?
- » Have you ever worked with a mental health professional as part of your treatment plan? If so, what was your experience like? Do you still see this professional?
- » Are there any strategies you've tried for managing these emotional non-motor symptoms that weren't highlighted in the materials? If so, what are they? How did they work for you?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about depression, anxiety, and apathy? 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 the effects of Parkinson's on movement are often the most visible symptoms, non-motor symptoms like depression, anxiety, and apathy sometimes have a greater impact on quality of life.
- » Depression is a medical illness caused by an imbalance of chemicals, such as dopamine, serotonin, and norepinephrine, in the brain. Depression causes a persistent feeling of sadness and is associated with a lack of pleasure in things you might have once enjoyed, as well as changes in sleep and, possibly, thoughts of suicide.

- » Because symptoms of Parkinson’s and symptoms of depression can present similarly, depression is often difficult to diagnose. Parkinson’s and depression share symptoms that include slower movement, slower speech, flattened expressions, and downcast eyes. If you experience these symptoms, be sure to talk with your physician to determine the cause and appropriate treatment.
- » Anxiety is another common non-motor symptom of Parkinson’s caused by changes in the chemicals in the brain. Anxiety may present as jitteriness, nervousness, or worry. Feelings of panic, fear, tension, or feeling keyed up are also signs of anxiety.
- » One problem with not treating anxiety is that it can negatively affect your social life because you may avoid social situations that cause anxiety. Isolation can have a domino effect of increasing anxiety and depression and decreasing the brain stimulation you need for improved cognition.
- » Apathy is a loss of motivation, desire, and interest. It can occur separately from depression and may be misinterpreted as laziness, lack of interest, or lack of initiative. Though the cause of apathy in Parkinson’s is unclear, research indicates that it’s due to a chemical imbalance and structural changes in the brain.
- » Medications for cognitive problems appear to work better for treating apathy than medications used to treat depression.
- » Research suggests that social connections positively impact physical and mental health. People who feel more connected to others have reported lower levels of depression and anxiety than those who feel less socially involved.
- » There are many ways to manage these symptoms and live well with Parkinson’s today. Strategies include counseling, exercise, medication, social connection, time outdoors, and improving the quality of your sleep.



## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The “best” treatment options for depression, anxiety, and apathy in Parkinson’s The efficacy of certain treatment strategies in helping manage motor symptoms
- » The “best” treatment options for depression, anxiety, and apathy in Parkinson’s The efficacy of certain treatment strategies in helping manage motor symptoms
- » What to expect in terms of the progression of Parkinson’s non-motor emotional symptoms



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## DEPRESSION, ANXIETY, APATHY, AND PARKINSON'S

### Reflection Activity



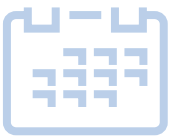
Because everyone's Parkinson's is unique to them, treatment tends to involve a personalized combination of medication, rehabilitative and complementary therapies, exercise, and sometimes surgical procedures. Likewise, the treatment for depression, anxiety, and/or apathy Parkinson's will be unique to you and may require a combination of medication and other strategies. Think about the ways you built or are building your ideal care plan for your Parkinson's motor symptoms. Can you take an equally integrative approach to treating any emotional non-motor symptoms you're experiencing? What does that ideal approach look like to you? How can you take action to bring it to light?

### Call to Action



Spending time outdoors can transform our moods, focus, sleep, energy levels, immune systems, bone density, and mental health. It can be particularly beneficial to people living with Parkinson's who experience symptoms like depression, anxiety, and apathy, with even short periods outdoors bringing countless benefits. According to the World Health Organization, getting just 15 minutes a day of natural sunlight can reduce stress and anxiety and may help you sleep better at night, which helps you feel better the next day. With this in mind, invite your group participants to set the goal of spending at least 15 minutes outside each day for the next week. Suggest they spend time weeding their garden, reading on a park bench, taking a walk first thing in the morning, going on a picnic with their favorite person, stargazing, or visiting a botanical garden or zoo. Ask them to make note of how they feel at the beginning and end of the week and to pay attention to any improvements they notice in their emotional non-motor symptoms.

### Next Steps



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### Explore More



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# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## COGNITION AND PARKINSON'S

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about cognition and Parkinson's, as well as strategies to manage them so you can live well with Parkinson's today.

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## DISCUSSION QUESTIONS

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- » What did our reading/viewing/listening teach you about Parkinson's impacts on cognition that you didn't already know?
- » What did you learn about these impacts that was most interesting or surprising to you?
- » If you have experienced cognitive changes, how would you describe them? How long have you experienced them? How have they changed over time?
- » Did you learn about any strategies for managing cognitive changes in our reading/viewing/listening that you're excited to try? What are they?
- » Have you ever worked with a neuropsychologist as part of your Parkinson's treatment plan? If so, what was your experience like?
- » Are there any "brain games" you've tried that you would recommend to others?
- » What are your biggest concerns or worries about Parkinson's impacts on cognition? What have you learned that can help you overcome these worries?
- » If you are taking dopamine agonists, were you made aware of the increased risks of developing impulse control disorders (ICDs)? Are ICDs something you have experienced?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about Parkinson's impacts on cognition? 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

- » Cognition is a general term used to describe the mental ability to process information and apply knowledge. Not only can Parkinson's slow down movement (bradykinesia), it can also slow down your ability to think and process information (bradyphrenia).
- » Because Parkinson's alters many regions of the brain and the dopamine system, it can affect executive function, language, and memory.

- » Although it can be expensive to see a neuropsychologist (a healthcare professional specializing in understanding the relationship between the brain and behavior), it can be very beneficial. A neuropsychologist can give you a cognitive evaluation and offer recommendations for maintaining or improving your thinking skills and emotional functioning.
- » In the same way physical activity improves movement and strength, brain exercises can help improve your cognitive functioning. Many games and puzzles are designed to boost the brain's fitness, from traditional crossword puzzles to interactive brain teasers modeled after video games.
- » Creativity can also enhance cognition, and many people with Parkinson's discover a newfound enjoyment by doing various art and music projects.
- » Parkinson's disease psychosis (PDD) is a non-motor symptom of Parkinson's that causes people to experience hallucinations and/or delusions. Approximately 50% of all people living with Parkinson's will experience some form of hallucinations or delusions, and the longer you live with Parkinson's, the greater the likelihood you'll experience them.
- » A hallucination is when someone sees, hears, smells, tastes, or feels something that's not there. Most of the time, these hallucinations are visual. In some cases, the visions may be disturbing and cause emotional distress, but that's not always the case. They may be friendly and not bothersome at all.
- » Delusions, which occur much less frequently than hallucinations, are specific and fixed beliefs that are very real and true to the person experiencing them, even though they are contradicted by what is generally accepted as reality or reason. They can contradict all semblance of reality and rational thought, but nothing can convince the person experiencing them that they are untrue.
- » The single most important thing to do when it comes to Parkinson's disease psychosis is to tell your care providers and partners the minute you notice changes in your vision, hearing, thinking, and behavior. The earlier they know what's going on, the sooner they can begin interventions to help you feel better.
- » Impulse control disorders, including compulsive gambling, sexual behaviors, shopping, and eating, are common in people with Parkinson's who take dopamine agonists, a class of drugs sometimes used to treat the symptoms of Parkinson's.
- » The first line of treatment when impulse control disorders are severe and destructive is to reduce the offending medication. In many cases, reducing or discontinuing the dopamine agonist reduces or eliminates the severity of the ICD. (But, never discontinue a medication without your physician's oversight.)
- » Exercise has been proven, again and again, to improve motor symptoms of Parkinson's *and* cognition.



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## COGNITION AND PARKINSON'S



### POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The impacts of dopamine agonists on impulse control disorders
- » The most effective ways to challenge your brain on a regular basis
- » What to expect in terms of the progression of cognitive changes in Parkinson's



#### Reflection Activity

Numerous members of our Parkinson's community have said that one of the silver linings of Parkinson's is enhanced creativity. Many have told us how they've become skilled in painting, dance, poetry, theater, sketching, and many other art forms following their Parkinson's diagnosis. Think about your own creative interests or other hobbies of yours. Have you noticed new or enhanced abilities or desires to create since your diagnosis? If so, describe this creative transformation. If not, think about what creative activities you might like to explore in your journey of living well with Parkinson's each day.



#### Call to Action

Trying new things creates new pathways in the brain and helps keep your brain healthier and active. By embracing and seeking out new and novel adventures and activities, you can continually challenge your brain. After sharing this information with your group, invite members to seek out novel adventures in their communities this week. You can recommend that they visit their local community center, senior center, Parkinson's support group, or community college to see what programs are available to them and their family. Many libraries, universities, school districts, and online outlets also offer adult learning programs covering a wide range of interests, so encourage them to explore the opportunities available in their area. You can also suggest they reach out to their healthcare provider for referrals to an occupational, recreational, art, music, dance, or physical therapist for more focused cognitive wellness programs. Ask the participants to set a goal of doing one new thing each week for the next month, to track their progress, and to celebrate their successes.





# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## CONSTIPATION, HYDRATION, AND NUTRITION

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about constipation, hydration, nutrition, and Parkinson's, including how you can make lifestyle adjustments in these areas so you can live well with Parkinson's today.



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**Choose a media format and create a schedule.** Does your group want to discuss constipation, hydration, and nutrition as highlighted in *Every Victory Counts* manual, 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.



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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 constipation, hydration, nutrition, and Parkinson's.

- » What did our reading/viewing/listening teach you about Parkinson's impacts on constipation that you didn't already know?
- » Is constipation a symptom you experience? If so, did you notice this symptom before the onset of other Parkinson's symptoms?
- » Have you made any dietary changes since your Parkinson's diagnosis? If so, what was their impact?
- » If you have already begun the habit of taking your carbidopa/levodopa with a full glass of water, have you noticed improvements in your symptoms?
- » Is your diet already plant based? If so, what do you feel are the benefits to this way of eating?
- » If you experience constipation on a regular basis, are there any strategies you've tried that weren't highlighted in our materials? Did they work for you?
- » Have you noticed feeling less thirsty since your Parkinson's diagnosis? If so, do you have any recommended strategies for ensuring you meet your daily hydration goals?
- » Has swallowing become a problem for you? If so, did you learn about any strategies that you believe may help?
- » What did you learn about constipation, nutrition, and/or hydration that was most interesting or surprising to you?
- » Did you learn about any strategies for managing constipation in our reading/viewing/listening that you're excited to try? What are they?
- » What questions surfaced that you'd like to know more about?



## POTENTIAL TALKING POINTS

- » Just as each person with Parkinson's experiences different symptoms, each person reacts differently to different types of food. The key is knowing that the foods you eat affect how you feel, and this knowledge can be a decisive first step in finding more ways to live well.
- » Exercise can help manage constipation; simply walking can help promote movement in your bowels.

- » A Mediterranean diet, which is not a “diet” at all but simply a way of eating that focuses on vegetables, fruits, whole grains, beans, nuts and seeds, and olive oil, is recommended by countless Parkinson’s experts as an ideal eating plan.
- » Because it is a plant-based way of eating, you can easily create a Mediterranean diet plan that is vegetarian, vegan, or lower in carbohydrates than standard diets. Eating the Mediterranean way is not only healthy but completely customizable, affordable, varied, and convenient.
- » Eating a Mediterranean diet is associated with a lower risk of Parkinson’s (studies have shown this can reduce the risk of Parkinson’s anywhere from 14 to 48%) and later age of disease onset. It also provides many benefits to people living with Parkinson’s; consistent findings show that the Mediterranean diet is proven to reduce the risk of many diseases, such as stroke, hypertension, heart disease, diabetes, depression, dementia, and cancer, proving its global impact on health.
- » Exposure to pesticides is the strongest link between the environment and Parkinson’s. Eating organic foods can reduce the ingestion of pesticides, but organic produce, dairy, and meat do cost more than conventional products.
- » Constipation is the most common gastrointestinal problem for people with Parkinson’s. Increasing the amount of water you drink and your fiber intake are two things you can do to improve constipation symptoms.
- » The amino acids in protein can compete with carbidopa/levodopa uptake both from the gut and across the blood-brain barrier and may, therefore, inhibit the effect of carbidopa/levodopa. If you take regular doses of carbidopa/levodopa, talk to your physician about taking your medicine one hour before eating, especially before high-protein meals.
- » Drinking enough water is essential to help promote general health and relieve symptoms of constipation. When someone experiences long periods of dehydration, their cells can’t function properly and die, leading to degeneration and disease. Dehydration also leads to poor circulation and blood flow, resulting in high blood pressure, organ failure, and more.
- » You may experience decreased thirst with Parkinson’s; so, it can be helpful to create a hydration plan, carry a water bottle, and track your daily water intake to ensure you’re drinking enough.
- » Certain foods have been shown to boost brain health and improve symptoms of certain mood disorders. These foods include dark chocolate, fatty fish, fermented foods, oats, berries, bananas, nuts and seeds, coffee, avocados, beans, and lentils.



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## CONSTIPATION, HYDRATION, AND NUTRITION

### POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » Why “x” diet is the best for managing Parkinson’s symptoms
- » How much water is the ideal amount to drink each day
- » The importance of eating organic
- » How strong the connection is between the gut and Parkinson’s
- » How food impacts non-motor symptoms such as depression and anxiety

#### Reflection Activity



Think about the meals you’ve eaten for the past week. Where are there opportunities to make small improvements and add fiber, vitamins, and minerals? Could you add an apple to breakfast? Salad to lunch? Black beans to dinner? Transitioning to a plant-based way of eating doesn’t mean you have to completely overhaul your diet—just look for ways you can add a serving or two of vegetables, grains, fruits, or legumes to some of your meals. Think about the plant foods you enjoy most and try to incorporate them into your meal plan for the upcoming week.

#### Call to Action



Now that you know how important it is to drink a tall glass of water with your carbidopa/levodopa, create a tracker for the next month and track how your symptoms change as you begin this new habit. Do you notice improvement in the efficacy and timing of your medications?

#### Explore More



On the *Every Victory Counts* website, you can find additional Discussion Guides about topics including Parkinson’s symptoms, medications, exercise, therapies, and more.



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## PARKINSON'S MEDICATION MANAGEMENT

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about Parkinson's medication management and how adjustments to your medication regimen can help you live well with Parkinson's today and in the future.



### 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 learned during the discussion and use these reflections to help shape your plans for future conversations.



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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 Parkinson's medication management.

- » What did our reading/viewing/listening teach you about Parkinson's medication management that you didn't already know?
- » Have you begun taking medications for your Parkinson's symptoms? If so, how long after your diagnosis did you begin taking them?
- » How long did it take to find the ideal combination of medications in the early stages of your Parkinson's?
- » What did you learn about Parkinson's medication management in this reading/webinar/podcast that was most interesting or surprising to you?
- » Is dyskinesia something you experience? If so, have you talked with your physician about strategies to manage it?
- » When you were first diagnosed, did you hear the common misconception that Parkinson's medications only worked for a certain number of years? How has what you've learned called that into question?
- » Have you noticed an increase in ON-OFF fluctuations? If so, are there medication management strategies you've learned about that you would like to explore?
- » Have you had a stay in the hospital since you've been living with Parkinson's? If so, what was the experience like? What advice would you give to someone else with Parkinson's before their own hospital stay?
- » Did you learn anything about Parkinson's medication management in our reading/viewing/listening that you're excited to try?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about Parkinson's medication management? 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

- » Choosing when to start medication for Parkinson's varies from person to person. Which medication is best for you depends on many factors, including your symptoms, age, time living with Parkinson's, and risk for side effects.

- » A good rule of thumb is to start medication when your Parkinson's symptoms become restricting or disruptive in some way.
- » During the first few years of treatment, controlling motor symptoms is also generally smooth, and missing a dose or two of medication may not even be noticeable. However, as the number of years with Parkinson's increases, fluctuations in the benefits of medication may emerge, and symptoms may begin to breakthrough before the next dose is due. During these OFF times, problems with gait freezing, anxiety, speech, imbalance, tremor, stiffness, slowness, and posture can be very pronounced. If these symptoms occur, you and your physician can adjust your medications to reduce your OFF periods. These adjustments may include taking medication doses closer together, using longer-acting medications, such as dopamine agonists, or using carbidopa/levodopa boosters, such as MAO-B inhibitors or COMT inhibitors.
- » Levodopa is the gold standard treatment for Parkinson's. It was one of first Parkinson's drugs, and it is still the main drug prescribed to treat Parkinson's for many people. It acts to help with slowness, stiffness, and tremor and can be used in conjunction with other medications to address the same symptoms. Carbidopa is almost always combined with levodopa to enable more levodopa to reach the brain rather than the bloodstream.
- » Dopamine agonists address the same symptoms as carbidopa/levodopa, namely slowness, stiffness, and tremor. Over years of use, dopamine agonists are less likely than carbidopa/levodopa to cause dyskinesias or fluctuations with OFF time, but 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.
- » The key to minimizing delayed and partial ON times is to take your carbidopa/levodopa on an empty stomach with a full glass of water. The water "flushes" the medicine quickly to the small intestine, and the absence of food in your stomach means nothing can slow its emptying. Crushing or chewing carbidopa/levodopa can also help speed the process, as can choosing a carbonated water beverage such as club soda or sparkling water.
- » To maximize your ON times, avoid protein when you take your carbidopa/levodopa and talk to your physician about how dietary changes can help you get the most from your medications.
- » Dyskinesia is an uncontrolled, involuntary muscle movement that is irregular in motion. In people with Parkinson's, it is most often associated with long-term use of carbidopa/levodopa or other Parkinson's medications that increase levels of dopamine in the brain.
- » If you're experiencing dyskinesias that are bothersome or present most of the time, one option is to reduce your carbidopa/levodopa dose or other related Parkinson's medications. However, if doing so would adversely affect the control of your primary Parkinson's symptoms, your physician may prescribe treatment to specifically target the dyskinesia.
- » Hospital stays for people with Parkinson's require special consideration, especially when it comes to medication. Before your hospital visit, make sure you have a complete, updated list of your medications, dosages, and the times of day that you take them. Keeping an accurate, up-to-date medication list decreases the likelihood of an unwanted medication interaction.



# PARKINSON'S MEDICATION MANAGEMENT

## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The benefits and risks of one Parkinson's medication compared to another
- » The best time to begin Parkinson's medications
- » The efficacy of medication compared with complementary or alternative therapies for non-motor symptoms like depression and anxiety
- » How best to manage levodopa-induced dyskinesias



### Reflection Activity

Communicating about OFF times can be a challenge. Some people equate OFF times to times when motor-symptoms re-emerge, and they discount the non-motor symptoms that tend to be present more often than not during OFF times. Some people with Parkinson's experience an increase in motor symptoms and believe it's a function of the progression of Parkinson's rather than a result of their medication wearing off. Some may choose not to share any discomfort they're having with their care partners because they don't want to be a burden. Finally, some may feel terribly uncomfortable during OFF times, but they fail to share their symptoms with anyone because they think it might be a sign that their Parkinson's is progressing, and they aren't ready to face that. If ON-OFF fluctuations are something you experience, think about how you would describe what OFF feels like to you. Can you put the experience into words? How would you describe your OFF periods to your physician? To your care partner? To a friend? Reflect on how you would communicate what OFF means to you and think about ways you can be proactive when it comes to educating and communicating with others about your OFF times.



### Call to Action

To make sure you're getting the most out of your Parkinson's medications, keep a log of your medication schedule and use it to track your symptoms. Be as detailed as possible with times, doses, etc. Keeping a record like this is a great way to help you become more aware of the timing and characteristics of your symptoms as they relate to your medication doses, to document symptoms, to note changes, and to prepare to discuss them with your doctor. Head to our *Every Victory Counts* website for numerous medication checklists and worksheets that will help you capture and share this kind of information.





# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## SURGICAL THERAPIES

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about surgical therapies for Parkinson's.

### 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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## 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 surgical therapies for Parkinson's.

- » What did our reading/viewing/listening teach you about surgical therapies for Parkinson's that you didn't already know?
- » What did you learn about surgical options for Parkinson's that was most interesting or surprising to you?
- » Is levodopa-induced dyskinesia something you experience? If so, how long have you been taking carbidopa/levodopa? What strategies have you tried to reduce your dyskinesia?
- » Have you had conversations with your physician about deep brain stimulation (DBS), enteral suspension of carbidopa/levodopa, focused ultrasound therapy, and/or other surgical therapies? If so, what did you learn in those conversations? What questions do you now have that you could ask your physician about these treatment options?
- » If you had DBS surgery, what was the process like for you? In what ways has it been most impactful?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about DBS and/or enteral suspension of carbidopa/levodopa? 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

- » As Parkinson's symptoms progress, increasing medications to address them can bring significant side effects, such as dyskinesia. Surgical therapies can be explored after medications are optimized, and the side effects of adding more medications start to outweigh the benefits the medications provide.
- » Current surgical therapies include deep brain stimulation (DBS) and enteral suspension of carbidopa/levodopa. Focused ultrasound therapy (FUS) is a non-invasive image-guided therapy that's an alternative to surgical interventions.

- » DBS, a highly effective treatment for Parkinson's, is a neurosurgical procedure in which electrodes are implanted into certain regions of the brain. These electrodes produce electrical impulses that regulate abnormal brain activity. The amount of stimulation is controlled by a pacemaker-like device located under the skin in your upper chest. A wire placed under your skin connects the device, called a stimulator, to the electrodes in your brain.
- » Carbidopa/levodopa enteral suspension (branded under the name Duopa in the US and known as Duodopa outside of the US) is a Parkinson's medication delivery system in which carbidopa/levodopa gel suspension is delivered through a surgically implanted tube directly into the small intestine, where the medication is absorbed. This medication delivery directly into the small intestine has the added benefit of bypassing the stomach, the emptying of which can become unpredictable or delayed for people with Parkinson's. The small pump, which you carry or wear, allows infusion of a constant medication dose over 16 hours each day, with your physician's ability to prescribe additional doses at certain times.
- » Focused ultrasound therapy (FUS) treats Parkinson's symptoms through focused beams of ultrasonic energy that target specific areas deep in the brain, interrupting circuits involved with tremor and dyskinesia. Using a mechanism called ablation, the focused beams can disrupt targeted brain tissue to treat motor symptoms.
- » Other FUS mechanisms can temporarily disrupt the blood-brain barrier (BBB), allowing desired therapeutics access into the brain. This disruption of the BBB is also beneficial because it enables undesirable substances to leave the brain more easily.
- » Because FUS involves no incisions, holes in the skull, or electrodes in the brain, it can be a powerful alternative to DBS with less risk of complications. It also costs less under most insurance plans. It does not require subsequent procedures, office visits for battery replacement, broken wire repair, or appointments to adjust simulator settings.



## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The "best" time to get DBS
- » The benefits and risks of DBS compared to those of enteral suspension of carbidopa/levodopa and/or focused ultrasound therapy
- » The benefits of non-rechargeable DBS systems compared to rechargeable systems
- » The efficacy and safety of new innovative Parkinson's therapies, such as transcranial magnetic stimulation, stem cell therapy, and gene therapy



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## SURGICAL THERAPIES



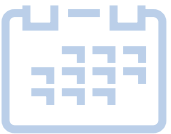
### Reflection Activity

Think about the real-life experiences people in your discussion group shared about surgical therapies they've had for Parkinson's. Write down or share aloud three questions you'd like to ask them about their experiences.



### Call to Action

Knowledge is power, and it's critical that you learn as much as you can about surgical therapies for Parkinson's before you pursue these treatments. Check out our growing collection of Parkinson's surgical therapy resources on our *Every Victory Counts* website to hear before-and-after-DBS stories, the latest research about Parkinson's surgical therapies, and much more. If you'd like to assess your situation even further so you can have a useful starting point for your next appointment with your doctor, *download and complete our Deep Brain Stimulation Self-Assessment here.*



### Next Steps

If you plan to meet with this group again, set the date and time for your next meeting and choose the next *Every Victory Counts* topic, webinar, book, essay, or podcast to study. If your group will only be meeting once, thank everyone for their participation.



### Explore More

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# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## COMPLEMENTARY THERAPIES

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about complementary therapies that can help you live well with Parkinson's today and into the future.

### How to Use this Discussion Guide



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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 complementary therapies for Parkinson's.

- » Are there any complementary therapies you enjoy on a regular basis that you would recommend to others who are living with Parkinson's?
- » Have you ever worked with a physical therapist, occupational therapist, and/or speech-language therapist as part of your treatment plan? If so, what was your experience like? Was it a one-time thing or did you go regularly? Do you still see this professional?
- » Have you ever taken part in a dance, music, art, and/or laughter yoga therapy session? If so, what was your experience like? Were you part of a group? Did you notice an impact after the session(s)?
- » Are there concerns or challenges you're experiencing with activities of daily living that an occupational therapist might be able to help with? What challenges are you running into trying to find a qualified professional to help you?
- » What did our reading/viewing/listening teach you about complementary therapies that you didn't already know?
- » Did you learn about any complementary therapies in our reading/viewing/listening that you're excited to try? What are they?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about complementary therapies for 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

- » Complementary therapies are those that are used alongside traditional medical treatment. This is different from alternative therapies, which are used in place of traditional medical treatment.
- » The three most common complementary therapies that all people with Parkinson's would benefit from having as part of their prescription for living well: physical therapy, occupational therapy, and speech-language therapy.

- » Physical therapy works to restore and maintain the body's functional performance. In general, a physical therapist (PT) evaluates and treats problems related to movement and musculoskeletal problems.
- » Although all PTs will have some knowledge of movement disorders, Parkinson's physical therapists have had additional training in neurologic physical therapy and are certified in this specialty.
- » Occupational therapy is the only profession that helps people across the lifespan to do things they want to do through the use of therapeutic activities (occupations). The goal of occupational therapy is to help you be as independent as possible for as long as possible. To meet that goal, an OT can help you maintain or strengthen your ability to care for yourself, care for your house, take care of your loved ones, and get around in the community.
- » A speech-language pathologist (SLP) evaluates and provides treatment for disorders of speech, voice, language, cognition, and swallowing.
- » Many people who live with Parkinson's say that being creative helps them focus, relax, and live more in the moment.
- » Countless people with Parkinson's have said that dancing has had a tremendous impact on their energy levels and quality of life.
- » Mindfulness practices such as meditation are designed to help people practice being in the moment, suspend judgment, practice self-compassion, and become detached from every possible outcome. If you're able to make this a regular practice in your life, you have the power to reduce stress, enhance performance, improve sleep, improve concentration, improve cardiovascular and immune health, reduce pain, increase coping skills, change your brain, and more.
- » For some people with Parkinson's, music therapy decreases freezing, improves gait and speech, increases postural control, and improves cognition. Plus, many have reported that their music therapy classes are the most fun they have all week.
- » Tai chi integrates elements of balance, flexibility, and coordination (motor function) with focused mental attention and multitasking (cognitive function). Findings show that individuals who participate in these exercises experience improvements in Parkinson's related to motor symptoms, balance, and mobility, as well as a reduced number of falls. The research also indicates that engagement in these exercises helps to reduce depression significantly.
- » Yoga therapy is one of the complementary therapies that has research proving its efficacy. It has been shown to reduce tremor, improve balance and gait, increase flexibility, improve posture, loosen painful muscles, and reduce stress. While yoga therapy is considered generally safe, it's still a good idea to talk to your physician before giving it a try.



# EVERY VICTORY COUNTS DISCUSSION GUIDE

## COMPLEMENTARY THERAPIES

### POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The benefits of one complementary therapy compared to another
- » The efficacy of herbal medicines and homeopathy to help manage Parkinson's symptoms
- » The importance of seeing a PT, OT, and/or SLP who specializes in Parkinson's



#### Reflection Activity

Think about the Parkinson's symptoms that have the biggest impact on your quality of life. What did you learn in today's conversation about complementary therapies that could help you manage these symptoms? Are there concerns or challenges you're experiencing that a rehab specialist (such as a PT, OT, and/or SLP) might be able to help you manage? Do you think any mood-related non-motor symptoms could be minimized by therapies like dance, art, music, or yoga? How can you take action today to explore complementary therapies that can help you live well now?



#### Call to Action

Ask participants to list three complementary therapies that most spark their interest. If they list a therapy that takes place in a class or group session, challenge them to find a class nearby or online that they can join. Encourage them to take part in the class at least three times. If they list rehab therapies, ask them to talk to their doctors about referrals to these professionals. Challenge the group to make a concrete plan of action to talk with their care team and then try out three complementary therapies within the next few months. Ask them to report back about their experiences, challenges, and victories.



#### Explore More

On the *Every Victory Counts* website, you can find additional Discussion Guides about topics including Parkinson's symptoms, medications, exercise, therapies, and more.





# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## RELATIONSHIPS AND COMMUNITY

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about Parkinson's impacts on relationships and how community is an essential part of living well with Parkinson's every day.

### 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 relationships and community as highlighted in *Every Victory Counts* manual, 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?" or "I'd love to hear [name of 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 relationships, community, and Parkinson's.

- » What did our reading/viewing/listening teach you about relationships and community that you didn't already know?
- » What are some of your favorite ways to stay involved in your community?
- » Have you experienced changes in your relationships since your Parkinson's diagnosis?
- » Have you felt the desire to isolate yourself following your Parkinson's diagnosis? If so, would you like to share why?
- » What advice would you give to someone living with Parkinson's who is struggling to come to terms with a friendship that is fading?
- » Is giving back to your community something you enjoy? If so, what activities bring you the most happiness? Why?
- » Following your diagnosis, did you have concerns about telling your family and/or friends? If so, how did you overcome these challenges?
- » Do you have advice for others in the group about how to communicate well with care partners, friends, and family?
- » Did you learn any strategies for staying connected to your community in our reading/viewing/listening that you're excited to try? What are they?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about maintaining relationships and staying connected to your community? 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

- » One of the most critical components of any strong relationship is ongoing, open dialogue. Whether it's with your spouse or partner, your children, your friends, your medical providers, or others with whom you are close, communication is essential to living well with Parkinson's.
- » When asked what they do to live well, countless people living with Parkinson's say that giving back is at the top of their list. Giving back gives them a purpose and helps them connect with others.

- » Whether your care partner is your spouse or partner, child, parent, or friend, your relationship with this person will undergo transformations throughout your Parkinson's journey. Soon after your diagnosis, your care partner may quickly embrace the role and seek to do as much as possible. They may deal with the uncertainty of diagnosis by taking control of medical appointments, treatment decisions, and lifestyle changes. They may be vigilant about monitoring your movements, carefully noting any changes from day to day. Conversely, some partners choose to deal with the uncertainty and fear accompanying diagnosis by distancing themselves and avoid getting involved with medical appointments or treatment decisions. Others take a middle-of-the-road approach, balancing their involvement in a way that allows you to remain in primary control.
- » Parkinson's can impact your voice, facial expressions, and mood. All of these can affect how your care partner may "see" you as you communicate with them. If you're suffering from depression or apathy, it may appear to them that you just don't care. Parkinson's can also blunt your facial expressions, a condition referred to as facial masking. As a result, your partner may not be able to tell what you're feeling based on outward cues. You may also experience softer, more monotone speech, which can sometimes cause care partners and friends and family to assume you're uninterested or uninvested in what's going on around you. Many members of your integrated care team can be instrumental in helping with these communication concerns.
- » The emotional impact of a Parkinson's diagnosis can interfere with the desire for sexual intimacy, both for the person with Parkinson's and their partner. If you're concerned about sexual intimacy, talk about it with your partner. Look at it as an opportunity for you to connect on an emotional level. Make time for this discussion and remember that intimacy is an important part of your relationship. A counselor can help you and your partner navigate these changes.
- » Although Parkinson's is part of your life, it's important to spend time together and with friends when Parkinson's isn't the most important person in the room. Take time to connect with your partner, friends, and family in ways you did pre-Parkinson's. Adapt, stay flexible, make new traditions, accept limitations, and remember that Parkinson's is a part of your life, it's not your whole life.
- » Many people say that the new friendships they've made with others living with Parkinson's are the silver lining of their diagnosis. In Parkinson's support groups, exercise classes, conferences, and other social gatherings, you can find a group of people who understand what you're experiencing and who will be there to support you every step of the way.
- » Certain Parkinson's symptoms that are especially visible such as tremor, shuffling, facial masking, and more lead some people with Parkinson's to isolate themselves.
- » The problem with disconnecting is that social isolation can exacerbate your symptoms, put you at risk for developing other health problems, increase your chances of experiencing depression, accelerate cognitive decline, and decrease your quality of life. Taking control of what you can control can make a significant difference in how well you live with it.
- » The more people come together, the more they find other ways that they are linked. That is, when a person first joins a community, they are drawn by the common interest of the group; as they stay regular in attendance, they will find other similarities with people in the community and create a deeper sense of bonding.



# EVERY VICTORY COUNTS DISCUSSION GUIDE

## RELATIONSHIPS AND COMMUNITY

### POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » How best to deal with changing relationships following a Parkinson's diagnosis
- » How best to motivate yourself to stay connected to your community
- » Why it's important to stay socially connected even if you're not experiencing feelings of loneliness



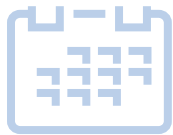
#### Reflection Activity

Think about a few of the most meaningful relationships in your life. Why are they on this list? How do you keep them strong? Why do they bring you joy or add value to your life? What steps can you take today to ensure they stay strong?



#### Call to Action

Ask your group participants to explore what social activities are available to them through their local community, wellness, or senior center; town/city events schedule; nearby support groups; library; church communities; or other local organizations. Encourage them to choose a few to attend in the next couple of weeks and report back on their experiences. Remind them to keep exploring their options and try new activities on a regular basis to stay connected, challenged, and involved.



#### Next Steps

If you plan to meet with this group again, set the date and time for your next meeting, and choose the next *Every Victory Counts* topic, webinar, book, essay, or podcast to study. If your group will only be meeting once, thank everyone for their participation.



#### Explore More

On the *Every Victory Counts* website, you can find additional Discussion Guides about topics including Parkinson's symptoms, medications, exercise, therapies, and more.



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## EXERCISE

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about exercise and Parkinson's.

### 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 exercise and Parkinson's as highlighted in *Every Victory Counts* manual, 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.



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**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?" or "I'd love to hear [name]'s thoughts on the question. What do you think?"





## 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 exercise and Parkinson's.

- » What did our reading/viewing/listening teach you about exercise's impacts on Parkinson's symptoms that you didn't already know?
- » Is regular aerobic exercise already a part of your routine? If so, how long has this been the case? How would you describe your exercise routine's impact on your quality of life? How has it affected your motor and/or non-motor symptoms?
- » If you haven't had a regular exercise routine before, what questions or concerns do you have about beginning one? Do you feel there are barriers to beginning this kind of regimen? If so, what are they and how might you overcome them?
- » Do you have a favorite form of exercise? If so, what is it? Why is it your favorite?
- » Have you ever been part of a group exercise class? If so, what was the experience like?
- » Have you made changes to your exercise routine since your Parkinson's diagnosis? If so, what were they? What has been their impact?
- » Did you learn about any forms of exercise in our reading/viewing/listening that you're excited to try? What are they?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about exercise and 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

- » Again and again, research and personal experience highlight the critical importance of exercise for people with Parkinson's. Regular physical exercise can improve mobility and coordination, boost your mood, reduce stiffness, and minimize soreness and fatigue. And each year, more studies prove that exercise may slow the progression of Parkinson's itself.

- » Exercise, beneficial for everyone, is essential for people with Parkinson’s because research has shown that it may be neuroprotective. Multiple studies explore the possibility that exercise helps protect nerve cells at risk of damage, degeneration, or cell death. In other words, the most vulnerable cells are strengthened before they experience damage – thanks to exercise. This process, called neuroprotection, may occur with high-intensity aerobic exercise.
- » It is unknown what specific type of exercise has the most significant potential for neuroprotection, but intensive, high-energy aerobic exercise has shown the most promise and is actively under study in people with Parkinson’s.
- » Exercise and movement may also help your body and brain find new ways to move. Parkinson’s damages part of the brain, and exercise aids your brain in discovering new nerve cell connections. This process is called neuroplasticity, which can be thought of as disconnecting the old wires in the brain and redirecting new wires to make different pathways.
- » In addition to possibly slowing the progression of Parkinson’s, exercise can help you live well with Parkinson’s right away. It helps reduce motor symptoms such as rigidity, stiffness, slowness, and postural instability, and it has also been shown to reduce tremor in people with Parkinson’s. It can positively impact gait, balance, and functional mobility, as well as fine motor skills.
- » Exercise has been shown to reduce non-motor symptoms of Parkinson’s, including sleep problems, constipation, digestion, depression, fatigue, and cognitive decline.
- » Exercise not only minimizes daytime fatigue and sleepiness but can also help you sleep more soundly at night.
- » Before starting or increasing the intensity of an exercise program, be sure to have a conversation with your healthcare professional about anything specific to your symptoms and health that you should be aware of as you exercise.



## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » Why “x” is the best exercise for Parkinson’s
- » How much aerobic exercise, and at what intensity, is the ideal amount
- » The impacts of low-intensity exercise compared to high-intensity
- » Exercise’s impacts on symptoms
- » How to begin an exercise routine if you don’t see yourself as “an exerciser”



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## EXERCISE



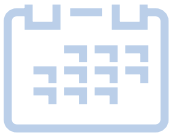
### Reflection Activity

Think about a form of joyful movement that you loved as a child. Was it jumping rope? Ballet? Tennis, swimming, or hiking? How long has it been since you exercised in this way? Are there opportunities to build this activity into your routine to make your exercise plan more fun?



### Call to Action

Invite your participants to get the go-ahead from their physicians and then explore options for group exercises classes in their community or online. (If they're looking for a free online class where they can move and connect with other people living with Parkinson's, point them to [this growing list of offerings](#).) Encourage them to attend at least one class per week for the next month and keep a diary of how they feel, physically and mentally, before and after each class. Then invite them to share their feedback at the month's end and note any victories they experienced.



### Next Steps

If you plan to meet with this group again, set the date and time for your next meeting, and choose the next *Every Victory Counts* topic, webinar, book, essay, or podcast to study. If your group will only be meeting once, thank everyone for their participation.



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# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## EMOTIONAL HEALTH

Designed to complement the sixth edition of the *Every Victory Counts* manual while also being useful on its own, this discussion guide will help you facilitate a group discussion about emotional health and Parkinson's.

### 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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**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?" or "I'd love to hear [name of 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 emotional health and Parkinson's.

- » What did our reading/viewing/listening teach you about emotional health and Parkinson's that you didn't already know?
- » Have you noticed any impacts on your emotional health following your Parkinson's diagnosis? If so, would you like to share them?
- » Have you ever been part of a group counseling session? If so, what was the experience like?
- » Have you ever worked with a counselor one-on-one? If so, are you still seeing this professional? How did you find them? What value did they bring to your situation?
- » Is shame or embarrassment something you've experienced since your Parkinson's diagnosis? If so, are there strategies you've found that can help you manage this emotion?
- » Is spiritual practice a part of your life? If so, how would you describe its impacts on your well-being?
- » Did you learn about any emotional wellness practices in our reading/viewing/listening that you're excited to try? What are they?
- » How was this reading/webinar/podcast the same or different from other media you have seen, read, or heard about emotional health and 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

- » Parkinson's impacts your whole self. Therefore, attending to your emotional health is just as important as taking care of your physical and mental health.
- » What was once a philosophical discussion is now an emerging area of healthcare called mind-body medicine. Specialists who practice mind-body medicine share the belief that thoughts and emotions influence healing and well-being. Rather than viewing the brain and body as separate entities, this philosophy views them as linked together to form each person's unique existence.
- » How you think affects how you feel, and how you feel affects how you think. Your mind, therefore, can have a positive effect on your body.

- » Spending time in the sun can be particularly beneficial to people living with Parkinson's who experience symptoms like depression, apathy, poor sleep, pain, and fatigue because it helps the body produce serotonin.
- » Absorbing sunlight also encourages your body to produce beta-endorphins. These hormones cause a feeling of well-being, strengthen your immune system, relieve pain, increase alertness, reduce depression, and more.
- » As Florence Williams details in her book *The Nature Fix*, being outdoors in natural spaces makes us happier, healthier, more creative, more empathetic, and more apt to engage with the world and each other.
- » Evidence shows that giving back can reduce stress while improving happiness and mood. In 2020, the Cleveland Clinic reported that health benefits associated with giving back include lower blood pressure, increased self-esteem, less depression, lower stress levels, longer life, and greater happiness and satisfaction.
- » Giving back also allows you to put your struggles and worries in perspective, which can boost your feelings of gratitude and optimism. A 2017 study from Cambridge University underscores this idea, finding that participants in a three-week study who engaged more by helping others (as opposed to sharing and receiving support for their problems) felt decreased levels of depression and increased feelings of gratitude.
- » Counseling can be helpful even before things become overwhelming. Trying to manage your symptoms, avoid complications, and live with a chronic disease can drain both you and your family or care partner. Support, knowledge, understanding of available resources, and knowing where you can turn for help are some of the best defenses to avoid feeling overwhelmed and burned out.
- » Your culture, upbringing, values, and religious or spiritual beliefs directly affect your health and well-being. For some, spiritual solace is their most significant source of guidance and support.



## POTENTIAL POINTS OF CONTENTION AND DISAGREEMENT

- » The power of certain religious or spiritual beliefs to help someone overcome challenges
- » The strength of the connection between mind and body
- » The benefits of counseling compared to medications for managing emotional health



# EVERY VICTORY COUNTS® DISCUSSION GUIDE

## EMOTIONAL HEALTH



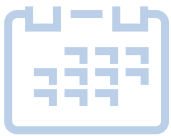
### Reflection Activity

Think about what activities bring you joy, meaning, and a sense of calm. Is it enjoying a cup of coffee first thing in the morning? Taking a walk in a city park? Singing with the choir at church? Watching birds at a feeder? Hearing the sound of your grandchildren's laughter? When was the last time you savored that activity, being fully mindful of the present moment? How can you remind yourself to cherish that moment in the moment next time? How can you create more of these moments?



### Call to Action

Even short periods outdoors can bring countless benefits. According to the World Health Organization, getting just 15 minutes a day of natural sunlight can reduce stress and anxiety and may help you sleep better at night. Create for yourself a one-week challenge to spend at least 15 minutes outdoors every day for the next week. If you're looking to boost the benefits even more, get moving while you're soaking up the sun. Meet a friend for a walk. Pick up trash. Tend a garden. Volunteer. Take notes about how your sleep, mood, pain levels, and other Parkinson's symptoms are affected by the time outside. (NOTE: People with Parkinson's are at greater risk for developing melanoma. If you plan on being outside for a while, be sure to apply sunscreen once the rays have touched your skin for 15-20 minutes.)



### Next Steps

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# 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.



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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 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.



# EVERY VICTORY COUNTS® CARE PARTNERS DISCUSSION GUIDE

## 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.



**Choose a media format and create a schedule.** Does your group want to discuss the care partner experience following a Parkinson's diagnosis 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.) 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?" 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



# EVERY VICTORY COUNTS® CARE PARTNERS DISCUSSION GUIDE

## 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.



### 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

## MANAGING THE COMPLICATIONS OF PARKINSON'S

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 being a Parkinson's care partner for a person experiencing complications.



### 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 for a person experiencing complications 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.) 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.

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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.



#### Explore More

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