

HOW TO LEAD A PARKINSON'S DYSKINESIA SUPPORT GROUP

A GUIDE FOR FACILITATORS



DAVIS PHINNEY
Foundation For Parkinson's

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Whether you have Parkinson's dyskinesia or are the care partner of someone who does, leading a support group on this important topic allows you to both teach and learn about the common symptom and help others navigate its challenges. Here, we share ways to build your own knowledge base about Parkinson's dyskinesia, discussion questions for your support group, and ideas for taking the conversation one step further.

Getting Started



Step One: Brush up on the differences between dyskinesia and tremor by reading [this article](#), which defines the terms and explains how treatments vary depending on the diagnosis.



Step Two: Read the article "[When Parkinson's Dyskinesia Feels Embarrassing](#)" to learn what advice you can share with your group about managing dyskinesia while shopping, dining in public, getting dressed, and more.



Step Three: [Watch this webinar](#) and hear Dr. Irene Malaty and three panelists share medical information and real-life stories about managing and treating Parkinson's dyskinesia.



Step Four: Lead the discussion. Plan for an hour-long support group conversation, making sure the discussion is interactive and engaging. Below are some questions to keep the conversation flowing.

DISCUSSION QUESTIONS

1. How long have you (or your person with Parkinson's) experienced Parkinson's dyskinesia?
2. Did you and/or your care team have any difficulties in determining if your abnormal movements were dyskinesia or tremor?
3. For those of you who have Parkinson's dyskinesia, do you notice it increasing during times of intense emotions? Is there a certain trigger that you're aware of that makes your dyskinesia worse?
4. Do you plan your daily schedule around times when you know your dyskinesia might be at its peak?
5. Are there ever times when your dyskinesia is embarrassing? If so, do you have advice for managing those feelings?
6. Does exercise affect your dyskinesia?
7. Have you made any changes to your diet that have helped lessen your dyskinesia?
8. Have you altered your medications to treat your dyskinesia?
9. For those of you who have had deep brain stimulation (DBS), how has it affected your dyskinesia?
10. What advice would you give to someone who has only recently begun experiencing Parkinson's dyskinesia?

Next Steps

Ready to host a second group discussion? Want to pass along questions with your group members that they can talk about with their care partners? Eager to give members ideas to think about after the discussion? Here are some additional questions and prompts to inspire individual reflection or to frame your next group conversation about Parkinson's dyskinesia.

1. If you know your dyskinesia increases when you are experiencing stress, what [techniques](#) can you use to minimize common stressors in your life?
2. Has your dyskinesia become more bothersome over time? If so, what [complementary therapies](#) can you try that might help ease the symptoms? (Because Parkinson's changes over time, your medications and dosages will change over time as well. Be sure to tell your doctor if your symptoms are getting worse and ask if there are new treatments that might help.)
3. If you feel embarrassed by your dyskinesia in public, what are some strategies that will help you manage these feelings?
4. What additional resources can you find to help you learn more about managing Parkinson's dyskinesia?

Additional Resources

[Impact of dyskinesia on activities of daily living in Parkinson's disease: Results from pooled phase 3 ADS-5102 clinical trials](#)

[What are the issues facing Parkinson's disease patients at ten years of disease and beyond?](#)

[Symptoms Worksheets for Self-Assessment and Doctor's Visits](#)

Want more practical articles like this?

Much more can be found in our Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action. Request your free copy of the Every Victory Counts manual by clicking the button below.

Request your complimentary copy of the new Every Victory Counts manual at www.EveryVictoryCounts.com.

Tell us what you think about this guide. Contact us at blog@dpf.org to share your thoughts.



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