Parkinson's Foundation

PART ONE

A GUIDE For Support Group Leaders

Starting a Support Group for people impacted by Parkinson's Disease.

2024 Edition

Parkinson.org

1.800.4PD.INFO (1-800-473-4636)

Parkinson's Foundation

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Foreword: We thank the support

The Parkinson's Foundation would like to thank group leaders from across the U.S. who took time to review this much-needed Support Group Guide. Your input and direction is much appreciated. Most importantly, thank you for the limitless care and dedication you bring to the Parkinson's community.

Part One: Introduction

About the Parkinson's Foundation

The Parkinson's Foundation makes life better for people with Parkinson's by improving and advancing research towards a cure. In everything we do, we build on the energy, experience, and passion of our global Parkinson's community.

The challenges of living with Parkinson's disease (PD), improving care, and hoping for a cure can seem overwhelming. No individual or group can do it alone. We are the Parkinson's Foundation. A community. An alliance. A movement. Where people living with Parkinson's, families, caregivers, scientists, advocates, donors and volunteers join forces to improve lives and advance research toward a cure.

About This Guide

If you are reading this, the chances are you share the Parkinson's Foundation mission to make life better for people with PD. There is no right way to start, organize and facilitate a support group. We offer this guide to help first-time support leaders navigate logistics of starting a new group. This guide can also serve as a reference for veteran group leaders looking to improve or adjust how they work with an existing group.

How the Parkinson's Foundation assists support group leaders

The Parkinson's Foundation has many resources available to help you successfully start and maintain a support group. Please see Appendices A & B for a list of programs and resources. The Parkinson's Foundation actively responds to our community's needs so check **Parkinson.org** regularly for new programs and updates or stay in touch through our Helpline at 1.800.4PD.INFO (1-800-473-4636). They will be an invaluable resource for you and the individuals who attend your group.

Once your group is established, take advantage of having your group details and contact information listed on the appropriate Parkinson's Foundation Chapter webpage. To visit your chapter webpage, go to **Parkinson.org/Chapters**.

The Parkinson's Foundations Chapters:

- California
- Carolinas
- Florida
- Georgia
- Great Lakes
- Gulf Coast
- Heartland
- Mid-Atlantic
- Midwest
- Minnesota and Dakotas
- New England
- New York
- New Jersey and Pennsylvania
- Pacific Northwest
- Rocky Mountain
- South Central
- Southwest
- Tennessee and Kentucky

Part Two:
Starting a Group

Support Group Basics

This information can help you focus on group members expectations and group dynamics. In addition, this information will hopefully provide you with a bit of comfort that facilitating a support group is something you can do.

Use the following guidelines to guide your planning:

A PD support group is:

- A self-help group, generally informal but will utilize helpful group rules.
- A source of information, education and resources.
- A group where anyone with PD or anyone impacted by PD will feel accepted, be respected, and feel comfortable attending.
- Most importantly, your PD group will be a supportive community, a place for people to connect and know that he or she is not alone in living with PD.

A PD support group is NOT:

- A therapy group
- A 12-step program
- A substitute for mental health counseling

Suggestion:

One person having total responsibility for a support group is a plan bound to fail. It is expected that you are excited, motivated and passionate about creating this needed group. However, whether you have PD or not, you need to consider your own health and responsibilities.

Share responsibility. Have others in the group help with these responsibilities:

- Regularly communicating with the group
- Scheduling guest speakers
- Getting to the location early to turn on the coffee maker and set up the chairs
- Staying to put the chairs away, unplug and clean the coffee maker, etc.
- Is the decision-maker if group should be cancelled because of inclement weather
- Keep a list of email addresses and phone numbers
- A variety of other tasks

If you do not have anyone identified as a potential co-leader ahead of time, it is a priority once the group is up and running. Keep an eye out for a co-partner.

If you are unable to identify anyone as a potential group co-leader, how about asking for someone to help with individual tasks? In other words, delegate and share the workload. A wonderful output from getting more people involved is that you are giving them an opportunity to feel ownership of the group. Consider creating a steering committee. Tasks and responsibilities can easily be parsed out to ensure the smooth operation of the support group.

Getting Started

Whatever your motivation is to start a PD support group, your desire to help build a community of support for people with PD is fantastic. Thank you for being part of our community of support!

The "let's get started" phase can be overwhelming. Perhaps you have already started to ask yourself many questions about how and where to start.

Here is one strategy you might find helpful.

> “Breaking down a big task into smaller parts can greatly increase productivity and make things much more manageable.”

You can use this guide as an outline that you can adjust as you see fit. If it helps, start a spreadsheet, use a Google doc, or a pad of paper to map out your *To Do* list. Many agree that building and launching a support group requires one to be organized. Consider how you want to organize the work.

Who will attend this group?

There are different types of support groups when it comes to PD. It's common to have an open group where anyone can attend, whether it is a person with Parkinson's disease, care partner, family or friend.

For others, there is a focus on a specific population within Parkinson's disease, such as a group for care partners, those with Young Onset PD or even a single-gender group. These groups are generally open and on-going as well.

Whatever you determine the need is or what your resources can support, the following information is applicable across the board for whatever group you have in mind.

Where?

Disclaimer:

The section below discusses in-person meetings without addressing health-related concerns related to a pandemic. The Parkinson's Foundation cannot make any recommendations about whether you should or should not meet in person. The information below discusses support group meetings in a pandemic-free environment. You'll find a brief discussion below of virtual group meetings.

It is important to visit a potential meeting space. The location can make or break your group. You can easily rule out any possibilities that are not physically accessible. If a person with PD who uses a cane, walker or wheelchair, cannot enter the building, this is not a good fit.

Some typical spaces used for support groups:

- ✓ Public libraries
- ✓ Some non-profits have space available, including YMCA's
- ✓ Hospitals
- ✓ Community living centers
- ✓ Houses of worship (remember accessibility requirements for older buildings)
- ✓ Community recreation centers
- ✓ Town halls
- ✓ Senior centers
- ✓ Senior living facility or nursing home

Each community is unique, so consider what other possibilities could exist in yours. Talk to people, let them know what you are looking for. Let others spread the word to help you secure a solid, consistent location.

Important factors to consider:

- How easy or difficult is the parking: paved, flat, lighted, near the entrance to building?
- Are any meeting rooms in your area that are free of charge?
- Consider group member's comfort such as A/C and access to bathrooms.
- Do you need/want access to a coffee maker or water?
- How will you handle the supplies necessary to have beverages?
- Is there any technology available — a computer, screen or projector? Lots of groups improvise with this and make it work, bringing their own computer or screen. Ultimately, it is up to you to decide how much of a priority this is for you and the group. A microphone may be one item that is essential, particularly when you have a speaker.

Weighing Options:

A nursing home or senior living facility might be eager to provide free meeting space, maybe even provide refreshments. It is encouraged you tread lightly: think about someone who has just been diagnosed with Parkinson's — some may feel uncomfortable with the idea of "seeing too far into their future." Weigh the pros and cons for each possible location.

When?

It is fairly customary that this type of support group meets once a month, but find the frequency that works for your group. Consider that more than once a month could possibly fatigue all involved and require more planning while less than once a month can limit the group's ability to build relationships. Factor in your energy level and availability, etc. Having a consistent day of the month (i.e., the second Tuesday of each month) helps people to remember when the group meets. You also might want to avoid Mondays as they tend to be national holidays.

An even bigger consideration is time of day — will your group meet in the morning, afternoon, evening? It is important to note that there is no one right time. Perhaps a daytime meeting excludes a person with PD who is working. Make the best decision that works for you as the leader and any feedback you have received from potential participants. Establishing a regular time and place will help your group expand as more people become aware of its existence.

Format and Length

Format

There are numerous formats you may choose to use for your group, the best advice is to stay flexible. You may start out with a formal meeting agenda and decide that you want to change things up and make things less formal. Listen to what your group members tell you! Do they need a stretch break half-way through? Do you want to have a speaker or presentation at each meeting? Does the group only want open discussion time or to have a particular topic to discuss at each meeting?

To help "break the ice" at the start of each meeting, particularly if you have a new member in attendance, introductions are a great technique. Not only does everyone get a chance to say something, but it also helps members remember names, relationships, etc.

A short exercise while seated may energize attendees at the start or in the middle of the group. A volunteer from a local gym may be interested in facilitating the movement break. Music is a great compliment and support for any movement break.

Length

How long are meetings? It is a generally accepted practice for a support group to meet for no more than 90 minutes. It also may be helpful to take a break halfway through the meeting (see movement break suggestion in the previous section). You could also consider breaking after a speaker finishes his/her presentation, for refreshments and rest room break.

Suggestion:

Your success as a group leader increases dramatically when you remain flexible and responsive. Rules and boundaries are important but need to be balanced by what your group members want and need.

Parkinson's Education and Hosting Speakers

Support groups can address a variety of needs. One common need for the Parkinson's community is disease education. Learning more about Parkinson's can include basic and specific disease information, treatment options, medications, research and more. Reach out to local Parkinson's experts and ask them to speak!

Where to start? Ask your group members for their suggestions and topic recommendations. You will then have a strategy to determine what speakers best match the group needs.

Popular support group speakers can include:

- Doctors and movement disorder specialists are the most requested.
- Specialists from neurology practices: physical, occupational and speech therapists.
- Dieticians, pharmacists and mental health professionals experienced in Parkinson's.
- Local human service providers from a college or university.
- Fitness professionals with Parkinson's experience.
- Local VA hospital or outpatient program Parkinson's expert.

Promoting/Advertising Your Group

The information in this Guide is only helpful if you have people who need and want to attend your group. Promoting and advertising is essential for a successful support group. Word of mouth can certainly help but it is typically not enough. Consider creating an inexpensive flyer or letter announcing the group, starting date, location and contact person. If you have a speaker scheduled be sure to include that information and topic as well.

Suggestions for promoting your group:

- Neurologist offices (get to know the office staff — they can be a great resource)
- Primary care clinics
- Hospitals
- Senior centers
- Local newspapers and TV stations
- Office for the Aging (typically county-based)
- Non-profits serving senior citizens
- Community library or coffee shop
- If you are located near a Center of Excellence or Comprehensive Care Center, reach out regarding promotion or to request a speaker (see Global Care Network listings in Appendix B)

What about social media? Social media can be helpful in raising awareness of your new group. Do you have a Facebook page, Twitter handle or Instagram account? Social media can be especially helpful for reaching younger people with Parkinson's and their care partners — even adult or adolescent children of people with Parkinson's. Managing a social media page could be a great volunteer role for a group member.

It is likely that you will start to develop an email distribution list of group members or possible group members. An email group can be used as a tool to remind people of upcoming meetings, announcements or resources in your community.

As time goes on, you may want to consider developing a website or Facebook group. Search the Internet for ideas of how other support groups use them, their formats, contact information and more.

Suggestion:

Setting up and maintaining the group email list is a great volunteer role for a group member. Setting up a website could be a great task with the right volunteer. Remember to ask for help! Someone's grandchild, friend or neighbor might want to contribute to your group by volunteering for one of these roles.

Remember that not everyone in your group may use email. Phone communication is still the primary way some may communicate. Building a phone tree is a great volunteer opportunity.

Part Three:
Facilitating a Group

Facilitating a Support Group

Just as no two people with Parkinson's disease are the same, no two support group leaders are the same in how they lead or facilitate. Using your uniqueness coupled with some simple guidelines should result in a support group that is extremely successful.

Essential qualities for a support group facilitator include:

- Knowledge of or **willingness to learn about PD** and its impact on people.
- Ability to **separate your personal needs** from the group's needs.
- Comfort with the **expression of emotions.**
- **Sense of humor** and ability to laugh at yourself (a must have).
- **Flexibility** — able to adjust to what the group needs vs a "set agenda."
- A **non-judgmental attitude.**
- Ability to **respectfully redirect** and keep discussion flowing.
- Comfort with **silence.**
- Lead members may need **to repeat or rephrase comments** from those who have soft voices or challenges expressing themselves.

You do not have to be an expert in PD to lead a support group. Facilitating means understanding the goals of the meeting and providing the resources to meet them. This requires ensuring everyone is involved — sometimes that just means being okay if the quiet ones want to remain quiet.

If you like structure, use an agenda. It is strongly encouraged to ask the group what they would like to include in the meeting agenda. While you oversee and facilitate the group, members need to be invested and willing to participate. The latter will not happen if people are being told what to do and how to do it.

Your goal is to engage the attendees. If someone stops paying attention ask yourself: Do I need to slow down, clarify, take time for people to stretch or have a movement break?

How you come across is important. For example, are you speaking too fast, asking too many questions at once? Make eye contact with members as you go, smile, and breathe. At the beginning of each group, having members introduce themselves (with time limits) is a strategy to get immediate engagement and gives you an opportunity to catch your breath.

Suggestion:

Some people with PD speak with a soft voice, which can be difficult for people to hear in a large group or large room. How can you make this work for everyone?

- It may help to mention at the start of each meeting that if someone is speaking too quietly, it's okay for members to kindly remind them to "speak up" or "project" their voice. If this is a common problem, consider bringing in a Speech Language Pathologist as a future speaker!
- Remember that some PD medications cause side effects such as sleepiness. This is not a reflection of your facilitation skills.
- Use person-first language — it is encouraged that you to refer to people with the disease as "a person with Parkinson's" rather than a "Parkinson's patient." This recognizes that a person is not defined by a diagnosis.

Virtual group meetings

Virtual support groups were fairly uncommon until the pandemic in 2020. Many support groups adapted to virtual meetings until it was safe to meet in person again. However, some are now permanently hosted online, or offer an online option. Virtual groups can be convenient, as it allows people to join regardless of location and accessibility. Here are pros and cons to a virtual support group:

Pros:

- People with PD can attend meeting from comfort and safety of own home.
- Virtual groups provide a way to engage and stay connected.
- Group meeting likely not to be cancelled due to inclement weather.
- Some people who could not get to a physical meeting space may be able to participate virtually.
- Virtual support groups exponentially grow the opportunities for people to be part of a support group where no group exists in a certain area.

Cons:

- Not everyone has access to the tools needed or affordable, dependable internet service.
- Too many people trying to speak at once.
- If someone is unable to mute their mic, the group may hear a lot of background noise.
- Online meetings need to have proper security to protect integrity of group.
- Can be emotionally challenging to adjust to virtual world; people can miss meeting in person.

Platforms – most people have now heard about virtual meetings, most often using Zoom. There are other options you can explore such as Google Meet.

Suggestion:

Helping your group host virtual meetings can be a great volunteer opportunity for a college or high school student connected to a group member.

What's Next?

The Parkinson's Foundation will publish a second part of the Support Group Leader Guide focusing on maintaining a support group. Visit **Parkinson.org/SupportGroups** for more information on Foundation resources and to find other support groups in your area. We thank you for reading this Guide and hope it offers you what you need to get a support group started!

APPENDIX A: Parkinson's Foundation Resources

All Parkinson's Foundation resources are available free of charge. Fact sheets, books and more can be downloaded from **Parkinson.org**. Physical copies can be requested from your local Parkinson's Foundation Chapter or by contacting our Helpline at 1-800-4PD-INFO (1-800-473-4636). Support group leaders may request sample copies and resources order forms to keep on hand and share with group members — contact your local Chapter or Helpline to learn more.

HELPLINE

The Helpline, 1-800-4PD-INFO (1-800-473-4636), provides information in English and Spanish to people with Parkinson's, their families, friends and healthcare providers. Connect with a compassionate, trained Helpline information specialist to get current information about PD, referrals to healthcare professionals, community resources and a wide variety of free publications. The Helpline is open from Monday to Friday. You can also email the Helpline at **Helpline@Parkinson.org**.

ONLINE RESOURCES

Parkinson.org is the go-to source for people with Parkinson's, their care partners and loved ones. Here you will find blog articles, podcast episodes, upcoming and archived events and digital resources, and ways to get involved in the Parkinson's community.

- PD Conversations is a place to ask your Parkinson's questions, connect with others and be a part of a network of support: **PDConversations.org**.
- Comprehensive PD library, including user-friendly books, fact sheets and worksheets. Resources are available in English and Spanish: **Parkinson.org/Library**.
- "In Your Area" feature to find your local PD center, Parkinson's Foundation Chapter, or wellness programs: **Parkinson.org/Search**.
- Our blog features articles about the latest in Parkinson's research, care and treatments. Visit **Parkinson.org/Blog**.

HOSPITAL SAFETY

Research has found that three out of four people with Parkinson's do not receive medications on time when hospitalized. When this occurs two out of three will experience unnecessary complications. The Hospital Safety Guide includes tools to help people with Parkinson's get the best possible care during a hospital stay. There are easy ways to get these resources:

- Download the free printable resources
- Order or download the Hospital Safety Guide

Learn more at **Parkinson.org/HospitalSafety**.

PARKINSON'S FOUNDATION CHAPTERS

Through our local Chapter network, staff help connect the community to local resources and services. Our Chapters also educate the community about PD and raise awareness and funds through activities such as Moving Day walks and educational programs. To find programs and events near you, visit **Parkinson.org/Events** or contact our **Helpline** at **1-800-4PD-INFO (1-800-473-4636)** or **Helpline@Parkinson.org**.

PD HEALTH @ HOME

Join us weekly for interactive virtual events focused on exercise, mental health and key Parkinson's topics. To learn more, visit **Parkinson.org/PDHealth**.

VIDEOS

Utilize our educational videos to educate your group and generate discussion. Videos range from a few minutes to an hour and cover a wide range of PD topics. More than 200 videos can be viewed at **Parkinson.org/Videos**.

SOCIAL MEDIA

For the latest in Parkinson's news, resources, articles, and events follow us on Facebook, Instagram, Twitter and more. **Facebook.com/ParkinsonDotOrg**. Remember to follow your Parkinson's Foundation Chapter on Facebook, too!

PUBLICATIONS

Parkinson's Foundation publications focus on issues critical to people with Parkinson's. People with PD, loved ones and healthcare professionals consider our comprehensive educational materials essential reading for information about PD. Our resources range from introductory content to more in-depth material on important topics. Find available publications at **Parkinson.org/Library** or order them at **Parkinson.org/Store**.

Books

Visit **Parkinson.org/Library** to download our educational books. Select books are available in print and can be ordered online, through our Helpline, purchased to read on an e-reader through Amazon or listened to as an audiobook.

Pro Tip:

Consider starting a Parkinson's book club as part of your support group. All members can read the same book and discuss it during a meeting. You can break up the book into sections or focus on chapters that are of special interest to get into a detailed discussion. For many topics, this can also help reduce stigma about some lesser talked about Parkinson's symptoms.

Fact Sheets

Visit **Parkinson.org/FactSheets** to read and download fact sheets about PD symptoms, experiences and treatments. Many are available in Spanish and some are available in Mandarin! Fact sheets can be a great launch pad for discussion during a group meeting. If you have a resources table, consider printing some to display and distribute.

PODCAST

The Parkinson's Foundation podcast, *Substantial Matters: Life and Science of Parkinson's* focuses on treatments and techniques that can help you live a better life now, as well as the research that can bring a better tomorrow. Episodes are 15 minutes or less, so you can listen to them together at a meeting or assign "homework" to group members. Subscribe wherever you listen to podcasts or listen now at **Parkinson.org/Podcast**.

APPENDIX B: Parkinson's Foundation Global Care Network

The Parkinson's Foundation Global Care Network creates opportunities for people with PD to access high-quality care while also providing health professionals the chance to advance and share their knowledge.

Our aim is to ensure that all people with PD have access to equitable and quality care —getting what they need, where and when they need it. This is essential to ensuring that all people with PD can live their best lives.

The Global Care Network includes:

- **Parkinson's Foundation Center of Excellence.** A medical center with a specialized team of neurologists, movement disorder specialists, physical and occupational therapists, mental health professionals and others who are up to date on the latest Parkinson's medications, therapies and research to provide the best care.

  Centers of Excellence around the world deliver care to more than 100,000 people with Parkinson's and create a community of healthcare professionals dedicated to Parkinson's care.

- **Parkinson's Foundation Comprehensive Care Center.** A medical facility with specialized, multi-disciplinary teams that provide evidence-based PD care. Comprehensive Care Centers meet the same criteria as Centers of Excellence, but participation in clinical research is not a requirement.
- **Parkinson's Foundation Community Partners in Parkinson's Care.** A program designed to educate and prepare care staff to provide optimal care for people living with Parkinson's disease living in care communities.

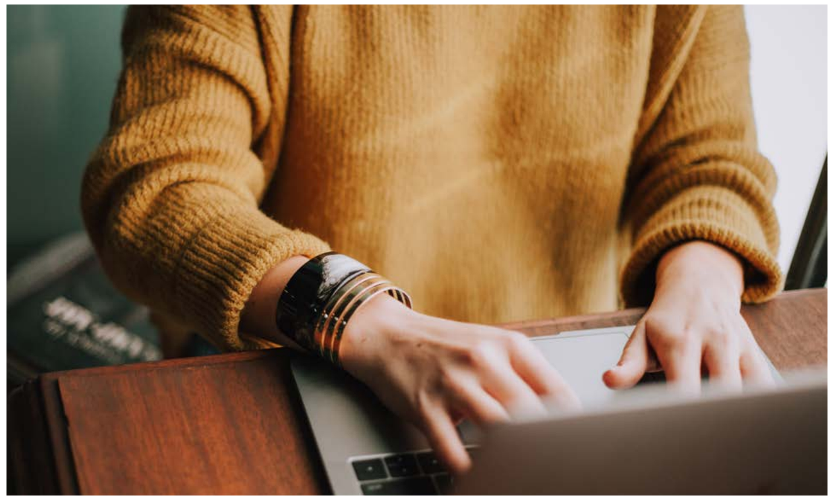
Visit **Parkinson.org/GlobalCareNetwork** to learn more and find locations near you.

ABOUT THE PARKINSON'S FOUNDATION

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community. Visit **Parkinson.org** to learn more.

YOUR FEEDBACK MATTERS!

We want to know what you think of our publications and programs. Please take a few moments to fill out our online feedback form. Your answers will be used to improve our resources and will benefit people with Parkinson's, caregivers, families and others in the Parkinson's community. Thank you for your help. Visit **Parkinson.org/Feedback**.



YOUR GENEROSITY MAKES THIS PUBLICATION POSSIBLE.

The Parkinson's Foundation is proud to provide this guide and other educational materials at no cost to people around the globe. If you found this book helpful, please consider a donation so that we may continue to make life better for people with Parkinson's through research, expert care and education initiatives. Thank you for your support.

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