



# Supporting LGBTQ+ People with Parkinson's:

## A Guide for LGBTQ+ Community Centers and Health Centers



The Parkinson's Foundation estimates that close to 100,000 LGBTQ+ people in the U.S. are living with **Parkinson's disease (PD)**. Parkinson's, a degenerative neurological disorder, requires early diagnosis and consistent treatment. As trusted voices in communities across America, LGBTQ+ Community Centers and Health Centers are able to make a significant impact on the lives of community members living with and affected by Parkinson's.

The **Parkinson's Foundation** and **SAGE** co-created this guide to highlight things you can do right now to support LGBTQ+ people living with PD in your community. To learn more about Parkinson's, visit [Parkinson.org](https://www.parkinson.org).

According to data from the Census Bureau's Household Pulse Survey,  approximately 10% of adults in the U.S. identify as members of the LGBTQ+ community. Given that approximately 1 million people are living with Parkinson's in the U.S., we estimate that about 10%, or 100,000 people with PD, are part of the LGBTQ+ community.

### Advocate for Community Members to Talk to their Doctors

**Fact:** As LGBTQ+ Community and Health Centers are well aware, LGBTQ+ people may often purposely delay interactions with healthcare professionals as the result of past trauma within the medical establishment. For a person living with Parkinson's, receiving a diagnosis and related treatment early on can have significant benefits resulting in positive health outcomes and a better quality of life.

**What you can do:** Share information about the **10 early signs of Parkinson's disease** and encourage LGBTQ+ community members to seek the care they deserve without delay.



## Facilitate Support Groups for People with Parkinson's and Care Partners

**Fact:** Depression and anxiety are the number one factors impacting the overall health of people living with Parkinson's. Managing a life with Parkinson's, both for the person with PD and their care partners, can be an **isolating** experience. This is especially true for LGBTQ+ people with Parkinson's who may feel uncomfortable at PD support groups that do not explicitly welcome those who identify as LGBTQ+.

**What you can do:** **Facilitate a support group** for LGBTQ+ people affected by PD to help community members build their support network and maintain their emotional health.

## Read and Share the Parkinson's Foundation's Digital Resource Care Package

**Fact:** The Parkinson's Foundation offers a variety of **free resources** for people living with PD, care partners, and healthcare professionals. In partnership with SAGE, the Parkinson's Foundation created a Digital Resource Care Package with information tailored to the LGBTQ+ PD community including:

- *10 Early Signs Brochure*
- *About Parkinson's Disease fact sheet*
- *Key Questions For Your Doctor's Visit Fact Sheet*
- *5 Steps to Live Better Today with Parkinson's Disease Brochure*
- *A Guide for Support Group Leaders Brochure*

**What you can do:** Read the Care Package, [attached here](#), and share the resources with your colleagues and community members. To order materials for your center at no cost, call or email the **Parkinson's Foundation Helpline** at 1-800-4PD-INFO (473-4636) or [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org).

## Connect with Your Local Parkinson's Foundation Chapter

**Fact:** We know that local support is critical to living well with PD. The Parkinson's Foundation has chapters around the country that are ready to connect with and support LGBTQ+ community members.

**What you can do:** Invite **your local Parkinson's Foundation chapter** to table at a Health Resource Fair or your community's Pride event.



For more information about Parkinson's disease visit [Parkinson.org](http://Parkinson.org) or call the Parkinson's Foundation Helpline at **1-800-4PD-INFO (473-4636)**.



To learn more about SAGE, visit [sageusa.org](http://sageusa.org) or call the SAGE LGBTQ+ Elder Hotline at **877-360-LGBT(5428)**.



## **Digital Resource Care Package**

- **10 Early Signs Brochure**
- **About Parkinson's Disease Fact Sheet**
- **Key Questions For Your Doctor's Visit Fact Sheet**
- **5 Steps to Live Better Today with Parkinson's Disease Brochure**
- **A Guide for Support Group Leaders Brochure**

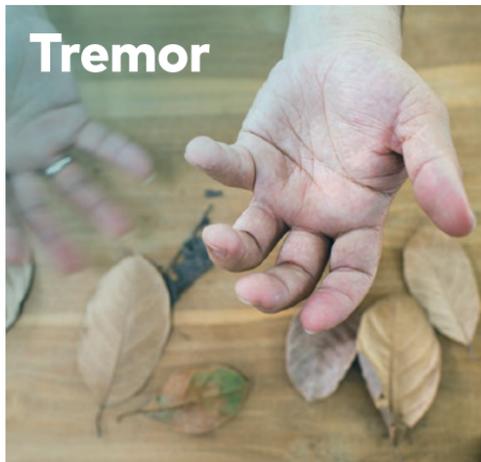
# 10 Early Signs of Parkinson's Disease



It can be hard to tell if you or a loved one has Parkinson's disease (PD). PD is a neurodegenerative disorder that predominately affects dopamine-producing ("dopaminergic") neurons in a specific area of the brain called the substantia nigra. Symptoms generally develop slowly over years and the progression of symptoms is often different from one person to another due to the diversity of the disease.

**What follows is a list of 10 early signs of Parkinson's disease.**

No single one of these signs means you should worry about having PD, but if you have more than one sign, you should consider making an appointment to talk to your doctor.



## Tremor

Have you noticed a slight shaking or tremor in your finger, thumb, hand or chin? A tremor, while at rest, is a common early sign of PD.

**WHAT IS NORMAL?**  
Shaking can be normal after lots of exercise, if you are stressed or if you have been injured. Shaking could also be caused by a medicine you take.



## Small Handwriting

Has your handwriting gotten much smaller than it was in the past? You may notice that your letter sizes are smaller and the words are crowded together. A change in handwriting may be a sign of PD called micrographia.

**WHAT IS NORMAL?**  
Sometimes writing can change as you get older, if you have stiff hands or fingers or poor vision.



## Constipation

Do you have trouble moving your bowels without straining every day? Straining to move your bowels can be an early sign of PD and you should talk to your doctor.

**WHAT IS NORMAL?**  
If you do not have enough water or fiber in your diet, it can cause problems in the bathroom. Also, some medicines, especially those used for pain, will cause constipation. If there is no other reason such as diet or medicine that would cause you to have trouble moving your bowels, you should speak with your doctor.



## Loss of Smell

Have you noticed you no longer smell certain foods very well? If you seem to have more trouble smelling foods like bananas, dill pickles or licorice, you should ask your doctor about PD.

**WHAT IS NORMAL?**  
Your sense of smell can be changed by a cold, flu or a stuffy nose, but it should come back when you are better.



## Trouble Sleeping

Do you thrash around in bed or act out dreams when you are asleep? Sometimes your spouse will notice or will want to move to another bed. Sudden movements during sleep may be a sign of PD.

**WHAT IS NORMAL?**  
It is normal for everyone to have a night when they 'toss and turn' instead of sleeping. Similarly, quick jerks of the body when falling asleep or when in lighter sleep are common and often normal.



## Dizziness or Fainting

Do you notice that you often feel dizzy when you go from sitting down to standing up? Feeling dizzy or fainting can be a sign of low blood pressure and can be linked to PD.

**WHAT IS NORMAL?**  
Everyone has had a time when they stood up and felt dizzy, but if it happens on a regular basis you should see your doctor.



## Stooping or Hunching Over

Are you not standing up as straight as you used to? If you or your family or friends notice that you seem to be stooping, leaning or slouching when you stand, it could be a sign of PD.

**WHAT IS NORMAL?**  
If you have pain from an injury or if you are sick, it might cause you to stand crookedly. Also, a problem with your bones can make you hunch over.



## Trouble Moving or Walking

Do you feel stiff in your body, arms or legs? Have others noticed that one or both of your arms doesn't swing like it used to when you walk? Sometimes stiffness goes away as you move. If it does not, it can be a sign of PD. An early sign might be stiffness or pain in your shoulder or hips. People sometimes say their feet seem "stuck to the floor."

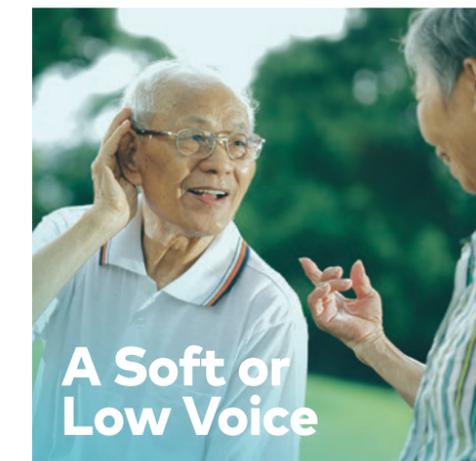
**WHAT IS NORMAL?**  
If you have injured your arm or shoulder, you may not be able to use it as well until it is healed, or another illness like arthritis might cause the same symptom.



## Masked Face

Have you been told that you have a serious, depressed or mad look on your face, even when you are not in a bad mood? This is often called facial masking. If so, you should ask your doctor about PD.

**WHAT IS NORMAL?**  
Some medicines can cause you to have the same type of serious or staring look, but you would go back to the way you were after you stopped the medication.



## A Soft or Low Voice

Have other people told you that your voice is very soft or that you sound hoarse? If there has been a change in your voice you should see your doctor about whether it could be PD. Sometimes you might think other people are losing their hearing, when really you are speaking more softly.

**WHAT IS NORMAL?**  
A chest cold or other virus can cause your voice to sound different, but you should go back to sounding the same when you get over your cough or cold.

## What can you do if you have PD?

It is possible to have a great quality of life with PD. It is essential to work with your doctor and follow recommended therapies in order to successfully treat symptoms.

- Develop a plan with your doctor to stay healthy. This might include:
  - A referral to a neurologist, a doctor who specializes in the brain, or a Movement Disorder Specialist, a neurologist with additional training in PD
  - Care from an occupational therapist, physical therapist and/or speech therapist
  - Meeting with a medical social worker to talk about how Parkinson's will affect your life
- Start a regular exercise program to help manage symptoms and maintain well-being.
- Talk with family and friends who can provide you with the support you need.

## The Parkinson's Foundation is here to help.

Contact the Parkinson's Foundation Helpline for answers to your questions in either English or Spanish. Staffed by Parkinson's disease information specialists, the Helpline is free and here to support you—and your loved ones—in any way possible, including:

- Current information about Parkinson's
- Emotional support
- Referrals to health care professionals and community resources

A wide variety of free publications are also available. To order, call or email our Helpline: **1.800.4PD.INFO (1.800.473.4636) / Helpline@Parkinson.org**.

Not ready to talk to someone about PD?

Visit **Parkinson.org** for reliable information.

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200 SE 1<sup>ST</sup> STREET, SUITE 800  
MIAMI, FLORIDA 33131

1359 BROADWAY, SUITE 1509  
NEW YORK, NEW YORK 10018

HELPLINE:  
800.4PD.INFO (473.4636)  
HELPLINE@PARKINSON.ORG

PARKINSON.ORG

# About Parkinson's Disease



## What is Parkinson's disease?

Parkinson's disease (PD) is a progressive neurological disorder that affects predominately dopamine-producing neurons in a specific area of the brain called substantia nigra.

## How common is PD?

Nearly one million Americans and 10 million people worldwide live with PD, with approximately 60,000 people in the U.S. diagnosed with Parkinson's each year. It is the second most common neurodegenerative condition after Alzheimer's. The number of people with PD will increase substantially in the next 20 years due to the aging of the population.

## What are the symptoms of Parkinson's?

Parkinson's disease can vary from one person to the next. There are many symptoms associated with Parkinson's, but no one will develop all possible symptoms. However, there are four cardinal features of the disease which are often considered when making a diagnosis. Note that not all four need not be present to make the diagnosis. These include:

- Tremor, mainly at rest and described as pill rolling tremor in hands
- Slowness of movements (called bradykinesia)
- Limb rigidity (stiffness)
- Gait (walking) and balance problems

In addition to movement-related (motor) symptoms, Parkinson's symptoms may be unrelated to movement (non-motor), such as apathy, anxiety, depression, constipation, sleep disorders, loss of sense of smell and cognitive impairment.

## Who does Parkinson's affect?

Getting older is the biggest risk factor for Parkinson's with most people diagnosed in their 60s. In some cases, people can develop PD before the age of 50, known as Young Onset PD. About 4% of people with PD are diagnosed under the age of 50. Men are 1.5 times more likely to have Parkinson's than women.

We do not know exactly what causes Parkinson's, but scientists believe that a combination of genetic and environmental factors are the cause. Genetics cause about 10% to 15% of all Parkinson's. In the other 85 to 90 percent of cases, the cause is unknown.

## How is Parkinson's diagnosed?

There is no diagnostic test for PD. Physicians rely on a combination of clinical exams and tests evaluating symptoms. Often, a Parkinson's diagnosis is first made by a primary care physician or general neurologist. Many people seek an additional opinion from a movement disorder specialist, a neurologist with experience and specific training in the assessment and treatment of PD.

## How is Parkinson's treated?

It is possible to have a good to great quality of life with Parkinson's. Treatment for each person with PD is based on his or her symptoms, and may include medication and, later, surgical therapy. There are many medications available to treat Parkinson's symptoms, although none yet that reverse the effects of the disease. Other treatments include lifestyle modifications, like getting more rest and exercise.

Palliative care is an additional option for people with Parkinson's and their loved ones. Often mistaken with end-of-life care, palliative care address social, spiritual and emotional needs to better care for the person with Parkinson's and their loved ones in all stages of the disease. Learn more about palliative care by visiting [Parkinson.org/PalliativeCare](http://Parkinson.org/PalliativeCare).

## 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.**

### Aware in Care Kit

This hospitalization kit contains information on the importance of medication for people with PD during emergency or planned hospital visits. Visit [Parkinson.org/AwareinCare](http://Parkinson.org/AwareinCare) for more information, to download information or to order the kit.

### Newly Diagnosed Kit

A Parkinson's diagnosis can be overwhelming — the Newly Diagnosed kit was created to help those newly diagnosed figure out next steps and learn Parkinson's basics. Visit [Parkinson.org/NewlyDiagnosed](http://Parkinson.org/NewlyDiagnosed) to order the kit.

### Frequently Asked Questions

composed of questions asked by people with Parkinson's and loved ones. To download or order your own copy of this book, visit [Parkinson.org/Library](http://Parkinson.org/Library).



# Key Questions For Your Doctor's Visit

**Below is a list of recommended questions to help you prepare for your upcoming doctor's visit. Based on your personal priorities, think ahead of time about what questions you want to discuss with your doctor.**

1. How quickly does Parkinson's disease usually progress and what will change over time?
2. How is Parkinson's treated? Are there ways I can slow the progression of my Parkinson's?
3. What test(s) or tools did you use to determine my diagnosis?
4. How often should I make appointments, and should I expect to see you or another staff member at each visit?
5. What other specialists or healthcare professionals should help me manage my care?
6. What symptoms or side effects should I report immediately?
7. How and when should I take my medication? Should I take the medicine before, with, or between meals?
8. What are the potential side effects of medication? Is there anything I can do to avoid or manage the side effects that I might experience?
9. Besides taking medications, what else can I do to manage my Parkinson's disease? Are there specific therapies, exercises, or lifestyle changes that can help?
10. Are there any clinical trials I could participate in?

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**Get more of your questions answered today:**

**Parkinson.org/NewlyDiagnosed**  
**Helpline 1.800.4PD.INFO (473.4636)**

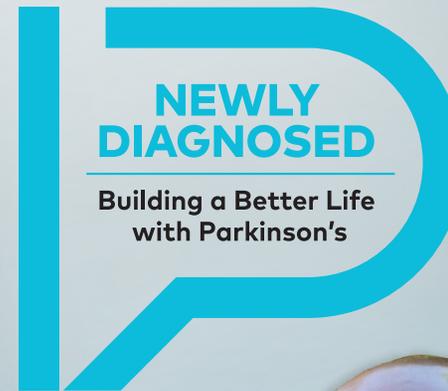
# You are not alone.

You have control in how you handle and manage Parkinson's. The Parkinson's Foundation is here for you, every step of the way.

**Questions? Call our Helpline:**  
**1.800.4PD.INFO (473.4636)**

Staffed by Parkinson's disease information specialists speaking both English and Spanish, the Helpline is free and here to support you — and your loved ones — in any way possible, including:

- Current information about Parkinson's
- Referrals to healthcare professionals
- A wide variety of free publications
- Emotional support
- Community resources



**5 STEPS**  
to Live Better Today  
with Parkinson's Disease



**When you are first diagnosed with Parkinson's, it can be overwhelming. Take time to understand how the disease can impact you physically and how it can impact your mood and emotions.**

**These 5 steps — in any order that works for you — will help get you started on your journey to living well with Parkinson's.**



**1 Think about what is most important to you**

Based on what's important to you, determine your personal goals and priorities. This will help you create an action plan to continue doing the things you love and care about most.

“The mind is not separate from the body. It directly affects the quality of life for people with PD and their care partners.”

– **Gretchen**, person with Parkinson's diagnosed 2017

**2 Find someone you can talk to**

“We now have a whole network of people who understand. It may be hard at first, but connect with other people who are living with PD. You'll be glad you did.”

– **Karen**, care partner, husband diagnosed 2002

When you're ready, we encourage you to talk to someone, whether that is calling our Helpline, **1.800.4PD.INFO (473.4636)** to ask questions, or reaching out to a family member or friend, or another person with Parkinson's. Don't isolate yourself, you are not alone.

**3 Create healthy habits**

Choosing healthy foods may help your medications work better and improve your energy. Getting enough sleep can help your body and brain recharge. Small changes can make a big difference and creating a healthy routine may help you feel better. Learn from others through our online community, **Parkinson.org/NewlyDiagnosed**.

**4 Be active in whatever way works best for you**

“Take a walk. Climb those stairs. Keep moving. Find activity everywhere you go.”

– **Dave**, person with Parkinson's diagnosed 2004

It's a fact: exercise can improve your quality of life. Visit our website, **Parkinson.org/NewlyDiagnosed**, to learn about the importance of exercise and find a Moving Day event near you. Get up, get out there, get active.

**5 Find a doctor who is an expert in Parkinson's disease**

Call our Helpline to find expert care in your area. Look for a neurologist who treats people with Parkinson's, and when possible, a movement disorder specialist.

“Go to the best specialist you can find. Talk with others for recommendations. Don't settle.”

– **Andréé**, person with Parkinson's diagnosed 2007

 **What's one step you can take NOW that will help you the most?**

PART ONE

# A **GUIDE** For **Support** Group **Leaders**

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



**2021 Edition**  
Parkinson.org  
1.800.4PD.INFO (473-4636)

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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.

**Courtney Malburg, BSW**  
Professional Education

**Nancy Nealon, LMSW**  
Community Engagement

# 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.



## The Parkinson's Foundations chapters:

- California
- Carolinas
- Florida
- Georgia
- Greater Illinois
- Greater Texas
- Gulf Coast
- Heartland
- Mid-Atlantic
- Minnesota and Dakotas
- New England
- New York and New Jersey
- Pacific Northwest
- Rocky Mountain
- Southwest
- Tennessee and Kentucky

*Chapters as of Spring 2021*

## 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](https://www.parkinson.org) regularly for new programs and updates or stay in touch through our Helpline at 1.800.4PD.INFO (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](https://www.parkinson.org/Chapters)



# 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.



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.

## 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. ”



## 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.

**Part Two:**  
**Starting a Group**

**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.

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.

**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



**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.

**Possible places and people to share your announcement:**

- 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, reach out regarding promotion or to request a speaker (see Center of Excellence listing 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](https://www.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](https://www.parkinson.org). Physical copies can be requested from your local Parkinson's Foundation Chapter or by contacting our Helpline at 1-800-4PD-INFO (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 (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](mailto:Helpline@parkinson.org).

### ONLINE RESOURCES

[Parkinson.org](https://www.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](https://www.parkinson.org/PDConversations.org)
- Comprehensive PD library, including user-friendly books, fact sheets and worksheets. Resources are available in English and Spanish: [Parkinson.org/Library](https://www.parkinson.org/Library)
- "In Your Area" feature to find your local PD center, Parkinson's Foundation Chapter, or wellness programs: [Parkinson.org/Search](https://www.parkinson.org/Search)
- Our blog features articles about the latest in Parkinson's research, care and treatments. Visit [Parkinson.org/Blog](https://www.parkinson.org/Blog)



## AWARE IN CARE

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 Aware in Care kit includes tools to help people with Parkinson's get the best possible care during a hospital stay. There are three easy ways to get these resources:

- Download the free printable resources
- Order the free Aware in Care Packet
- Order the full Aware in Care Kit, free with an \$8 shipping charge

Learn more at [Parkinson.org/AwareInCare](https://Parkinson.org/AwareInCare).

## PARKINSON'S FOUNDATION CHAPTERS

The Parkinson's Foundation has Chapters and staff in cities around the country that offer educational information, support groups, wellness classes, symposia and other resources. To find programs and events near you, visit [Parkinson.org/search](https://Parkinson.org/search) or contact our Helpline at 1-800-4PD-INFO (473-4636) or [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org).

## PARKINSON'S EXPERT BRIEFINGS

Expert Briefings Online Webinars are available for on-demand viewing. Sign up for future Expert Briefings and attend as a support group meeting: [Parkinson.org/ExpertBriefings](https://Parkinson.org/ExpertBriefings)



## 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](https://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](https://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 all our available publications at [Parkinson.org/Library](https://Parkinson.org/Library) or order them at [Parkinson.org/Store](https://Parkinson.org/Store).

### Books

Visit [Parkinson.org/Library](https://Parkinson.org/Library) to download our educational books. All books are available in

print and can be ordered online through our Helpline or purchased to read on an e-reader through Amazon.

### 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](https://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](https://Parkinson.org/Podcast).

# APPENDIX B: Parkinson's Centers of Excellence

A Parkinson's Foundation Center of Excellence is 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.

- **AZ** - Barrow Neurological Institute
- **CA** - Keck School of Medicine of University of Southern California
- **CA** - University of California, San Francisco
- **CA** - Altman Clinical Translational Research Institute University of California, San Diego
- **CA** - Movement Disorder Center
- **CO** - University of Colorado Movement Disorders Center
- **DC** - Georgetown University Hospital
- **FL** - University of Florida Center for Movement Disorders and Neurorestoration
- **FL** - Miller School of Medicine, University of Miami
- **FL** - University of South Florida Parkinson's Disease and Movement Disorders Center
- **GA** - Medical College of Georgia, Augusta University
- **GA** - Emory University
- **IA** - University of Iowa
- **IL** - Northwestern University Movement Disorders Center
- **IL** - Rush University Medical Center
- **IN** - Indiana University School of Medicine
- **KS** - University of Kansas Medical Center
- **MD** - Johns Hopkins Parkinson's Disease & Movement Disorders Center
- **MA** - Massachusetts General Hospital
- **MA** - Beth Israel Deaconess Medical Center
- **MN** - Struthers Parkinson's Center
- **NY** - Mount Sinai Beth Israel
- **NY** - Columbia University Department of Neurology
- **NY** - Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at NYU Langone Medical Center
- **NY** - University of Rochester Medical Center
- **NC** - Duke Health Movement Disorders Center
- **NC** - University of North Carolina at Chapel Hill School of Medicine
- **OH** - Cleveland Clinic Ohio
- **OR** - Oregon Health & Science University Parkinson Center
- **PA** - University of Pennsylvania Movement Disorder Center
- **PA** - Jefferson Health's Comprehensive Parkinson's Disease & Movement Disorder Center
- **SC** - Medical University of South Carolina
- **TN** - Vanderbilt University Medical Center
- **TX** - Baylor College of Medicine

## 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](https://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](https://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.

**Donate online:** [Parkinson.org/Donate](https://Parkinson.org/Donate)  
**Donate by mail:** Parkinson's Foundation 200 SE 1st St, Suite 800 Miami, FL 33131  
**Donate by phone:** 1-800-4PD-INFO (473-4636)  
**Tax ID:** 13-1866796

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Parkinson.org  
1.800.4PD.INFO (473-4636)