

*Become active in your
Parkinson's community
Start a Support Group*

PARKINSON'S SUPPORT GROUP STARTUP GUIDE



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Introduction/Mission

A. Mission of a support group

To increase awareness of PD, to Educate and Comfort, provide support, information, and hope for affected persons and their families.

B. Dedication

This guide is dedicated to all the support group leaders past and present who have the courage and vision to embrace the challenge of helping others.

C. Disclaimer

A support group is a good resource. However, neither changes to medication nor treatment plans should be undertaken without first discussing them with your physician.

Part One

Starting a Support Group

A. What is a Support Group?

- A support group is a voluntary gathering of people who share common experiences, situations or problems related to living with Parkinson's disease.
- They offer each other emotional and practical support and reduce the sense of isolation that is associated with PD diseases.
- Remember group leaders are not professionals and all group members are there as participants.
- Support groups include discussions on topics of interest and sharing of information, resources and experiences.
- It's okay to just listen in on a support group; each person has their own comfort level about sharing with others.

B. What Skills Does a Volunteer Need to Be a Support Group Leader?

- Compassion
- Continuing commitment
- Time
- Ability to relate and to work with others
- Organizational skills

Part One - *(Continued)*

Starting a Support Group

C. What Are the Benefits of Being a Support Group Leader?

- A sense of helping others
- Getting support for yourself from the group.
- Personal growth
- An added circle of friends

D. Expectations of Support Group Leaders and How Parkinson's Helps

- Many prospective leaders become discouraged at the idea that too much will be expected of them by both PARKINSON'S and group's members. In actuality, PARKINSON'S has very few firm requirements of support groups and support group leaders.
- PFNWO would like to support group leaders and their groups to:
- Meet regularly, preferably monthly, but the leader and the group decide what is best.
- Decide if meetings will be for patients, caregivers, or both.
- Stay in contact with group members, preferably by email, to increase a sense of connection.
- Possess a basic knowledge of Parkinson's Disease with a willingness to learn more.
- Let PFNWO know if more educational materials are needed for group meetings.

Part One - *(Continued)*

Starting a Support Group

- Make the sign-in list provided by PFNWO available to group members so they can be.
- Added to the database and receive regular updates.
- Let PFNWO know if attendance is low or if help is needed with any other aspect of running the group.
- PFNWO will help support group leaders and their groups by:
 - Promoting the group to locals in the area contained in the organization's database via email, while also listing the group on the website and bi-monthly newsletter.
- Supplying the group and leader with educational materials on PD and any other information that may be useful to the group.
- Listing the group in all the informational packets that are sent out weekly to patients, families, and healthcare providers.
- Communicating with leaders regularly via email on topics of interest that can be shared with the group
- Providing annual Facilitator Meetings to allow leaders to ask questions and share ideas

Part Two

The First Meeting

A. Where to Hold the First Meeting

- The meeting place can often determine when the group meets because some facilities are Available only at certain times. It will be important to find a meeting place that accommodates wheelchairs and walkers. There are many places that offer free meeting space such as churches, synagogues, libraries, community centers and hospitals. Be sure to mention that PFNWO is a nonprofit organization and the support group is a free service to the community.
- Questions to consider when deciding on a space for your group:
 - Is there a cost to use the space? If so, is there a nonprofit discount?
 - When is the room available?
 - Are tables and chairs provided?
 - Who is responsible for set up and putting chairs and tables back in their original order
 - How many people does the room hold?
 - What kind of parking is available?
 - Is it free?
 - If not free, can they offer a discount, parking passes, or validation?

Part Two - *(Continued)*

The First Meeting

- Are bathrooms located near the room?
- Are they handicap accessible?
- Can refreshments be brought into the room?
- Provide nametags.
- Arrange chairs so that attendees can see each other, either in a circle or in a u-shape it's hard to share when you feel like you have to strain to see people.
- Introduce yourself and welcome attendees, state the group's purpose and goals, and share your own experience first which will encourage others to share their own experiences.
- At the beginning of every meeting, remind members that what's discussed during the meetings is confidential.
- Ask everyone to say their names and to share a little about themselves keep in mind that not everyone is immediately ready share personal information, and reassure people that listening and interjecting when comfortable is also perfectly acceptable.
- Allow plenty of time for introductions, patients may have difficulty speaking, so patience will be appreciated.
- Make sure to tell people about future meetings and encourage them to come back.

Part Two - *(Continued)*

The First Meeting

- Some groups invite guest speakers and you can ask your group if they would be interested in having a speaker at times if someone is identified or a topic comes up that people would like to hear more, ask group members for help in finding and arranging a speaker.
- Discuss refreshments ask the group if they would like refreshments at the meeting members can agree to bring their own, share responsibility of bringing on alternating weeks, or the leader can take a small donation at each meeting to fund the cost of refreshments - they might also decide that refreshments are not important.
- Create a roster of attendees that includes the caregiver's name, the patient's name, mailing address, phone and e-mail - have people indicate if they'd like to receive any communications with other members or from the group leader.
- PFNWO will promote your group, but there are also some things that you and your group members can do to spread the word.
- Contacting local neurologists or other healthcare providers that you and/or group members are familiar with can increase visibility.
- Local Parkinson's support groups often have members with atypical parkinsonism contacting their group leaders is a good thing to do, as many leaders appreciate knowing of other groups for patients.
- Sharing responsibilities with other group members allows people to be come more involved and more invested. Ask for volunteers to help with advertising, refreshments, finding a local speaker, or any other needs of the group.

Part Three

Meeting Activities

A. Discussion Topics

- Whether you're looking for a speaker or just a way to get people in the group to start talking, having some possible topics to bring up can be of help. Some recommendations of current group leaders include:
- Community Resources: Day Care, Home Health Care
- Respite Care
- Staying active despite the disease
- Learning to ask for help
- Laughter and Humor
- How to avoid becoming isolated
- Help for behavior problems
- Communicating effectively with your physician
- Stress Management
- When to take the car keys away
- Levels of loss as the disease progress
- How to talk with your loved one about their disease
- What its like to get the diagnosis
- Preserving self-esteem
- Coping with holidays and special family events
- Travelling with a person with PD
- Changing roles and responsibilities for PD caregivers
- Managing time away from your loved one
- Improving communication
- Changing sexuality
- Normal and abnormal ageing
- Home Emergencies: What to do when the unexpected happens
- Research Updates
- The nursing home decision
- Long Distance Caregiving

Part Three - *(Continued)*

Meeting Activities

- Parent-Adult Child Relationships
- Personal Growth in spite of PD
- How to talk to family and friends about the diagnosis
- Disability: What benefits are available and how to apply
- How to cope with lack of sleep
- What is hospice and how can it help
- The leader has a role in making sure the discussions are flowing and that a group's members feel respected and heard.
- Here are some tips in facilitating discussions:
 - Listen closely to what people are saying
 - Don't answer all the questions yourself
 - If someone is monopolizing the conversation, carefully mention that it is important to hear from others by saying something like, "That's good, Joe - let's see what others have to say"
 - Look for similarities of experience if someone mentions an important fact or issue, ask others if they've experienced it too.
 - Help clarify a question or point being made, if it is not clear.
 - If someone gets off track, tactfully bring it back to the discussion, by saying something like "that's a great point, however, let's get back to the main subject," or offering to address their topic at another time.
 - Be patient when those with the disease are talking paraphrase what you thought you heard so they can acknowledge that you understood them, and don't forget to use family members to help interpret, if needed
 - Clarify facts from opinions when someone shares something controversial, you can express that it is their opinion and may not be a proven fact yet, or you can ask the person for the source of their information – an alternative strategy is to offer to check with PFNWO for further clarification and then report your findings back to the group at the next meeting

Parkinson's Support Group Member Information

Patient Name: _____

Address: _____

City: _____

State: _____ Zip: _____

Email Address: _____

Phone: _____

Cell Phone: _____

Privacy:

Welcome to the Parkinson's Support Group. Please complete the following questionnaire so we may include you in our distribution list for future support group meetings. This information will remain strictly confidential within the Parkinson's organization and will not be sold to or shared with any other entity.