

# Living with Parkinson's Starting a Support Group



The Parkinson's Disease Foundation® (PDF®) would like to thank you for your interest in starting a Parkinson's disease (PD) support group in your area. Support groups are a wonderful source of information and social and emotional support for people with Parkinson's, their care partners and family members.

Although PDF does not sponsor any groups, we are always happy to support facilitators in any way that we can. The following includes some ideas that may be helpful as well as referrals for other sources of information for your group.

- 1 Although emotional support and sharing are a vital part of the PD and care partner experience, many people with Parkinson's may not attend a traditional "support" group. You may wish to call your group a "PD education" or "PD advocacy" group.
- 2 Consider making your first meeting a general information session on Parkinson's disease. If possible, invite a movement disorder specialist or neurologist specializing in PD to give an overview of the current treatment options and answer questions. If this type of professional is not available, consider showing a video such as PDF's "Diagnosis Parkinson's Disease: You Are Not Alone" or a DVD of one of our *PD ExpertBriefings*. This will give your group members information about PD and can serve as a discussion-starter for the rest of the meeting.
- 3 Set a regular time and place for your meetings. Most PD groups meet once or twice each month. Although it may be less convenient for the facilitator, a weekend meeting allows those who may still be working an opportunity to attend and does not force others to drive at night. Possible meeting sites include libraries, senior centers, community centers, churches, synagogues and hospital conference rooms.
- 4 Maintain contact information for all of your members and remind everyone approximately a week before each meeting of the date, time and topic. You may wish to do this with a postcard, a single page newsletter with some additional information on PD, or through a telephone tree. These regular reminders may help improve attendance at meetings.
- 5 Publicize your group regularly. Two weeks before your meeting date, send an announcement via fax or email to your local newspaper for their community section. Include the date, time, place and topic of the meeting as well as the name and contact information for

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the facilitator. Also consider sending regular announcements to your local hospital, area neurologists, churches, synagogues, community centers and senior centers.

- 6 It is usually a good idea to have a specific topic or speaker for at least the first four meetings to get the group going and build rapport among members. Suggested topics include: non-motor symptoms of PD, exercise, sleep, depression and/or anxiety, assistive devices to make life easier, the Lee Silverman Voice Treatment® program for PD, and managing constipation. Suggestions for speakers include a physical therapist, an occupational therapist, the local caregiver specialist (contact your Area Agency on Aging to find out who serves your community) or a representative from Social Security/Medicare/Medicaid. The official presentation may only last 30 minutes, but will serve as a jumping off point for group discussion.
- 7 Don't get discouraged. It can take six to 12 months to build attendance, and many groups begin with only three to six regularly-attending members.
- 8 PDF keeps an unpublished listing of Parkinson's support groups to share with callers to its National HelpLine. If you would like to add your group to this list, so PDF can refer callers from your community to your group, contact PDF's HelpLine at (800) 457-6676 or [info@pdf.org](mailto:info@pdf.org).

Thank you for your interest in starting a Parkinson's disease group. Although there is definitely work involved in starting and running a group like this, other facilitators have told us that they receive more from their group members than they ever give to them. Our very best wishes for success!

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice.  
This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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