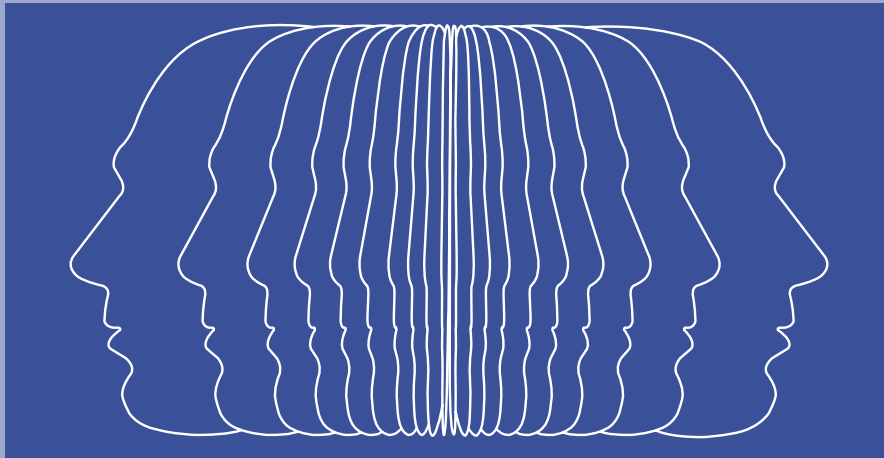


Looking Forward



Moving Ahead!



SUPPORT GROUP LEADERS MANUAL

National Parkinson Foundation

*This manual is dedicated to the memory of
Sidney Dorros
author, educator and advocate
whose courageous message of
“accomodation without surrender”
is what PD support groups are all about*

The Mission of the National Parkinson Foundation is:

- **To find the cause of and the cure for Parkinson disease and related neurological disorders through research.**
- **To educate general medical practitioners to detect the early warning signs of Parkinson disease.**
- **To educate patients, their caregivers, and the general public.**
- **To improve the quality of the life for both patients and caregivers.**

The National Parkinson Foundation is a non-profit organization, supported by membership contributions. We provide direct answers to patients and their families on problems relating to Parkinson's. May we solicit your consideration for a contribution to our foundation? To send your contribution, or to ask for detailed information, please call or write.

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Welcome!

The **National Parkinson Foundation** is very pleased to offer this manual to you and your support group. We salute your commitment to help yourself and others to meet the challenge of really **living** with Parkinson's disease.

At this point, you may have many questions:

"I would like to start a Parkinson's support group. Where do I begin?"

"We just started our PD support group. Do you have any ideas for our next meeting?"

"Our support group has been meeting for several years, and we seem to be running out of steam. What should we do now?"

This manual will suggest some answers to these and other questions we have heard from PD support group leaders across the country. Your shared experiences provide a wealth of practical wisdom and well-honed skills. It is our privilege to share this treasury with **you!**





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INTRODUCTION

A support group?

“No, thanks. That’s not for me.”

Does this sound familiar? Perhaps it was your own reaction when someone first suggested that you join, or start, a Parkinson’s support group. The idea of a “support group” may have made you uneasy. You may have objected to the idea of sharing your problems with others. And who needs other people’s problems?

However, a PD support group is not a problem exchange: Nor is it a place to go in order to feel more burdened – or blessed. Let us be clear from the start about what a PD support group is not:

A PD support group is **not** a therapy group.

A PD support group is **not** a “12-step” program.

A PD support group is **not** a substitute for medical treatment or health counseling.

A PD support group is **not** a replacement for family and friends, or other close relationships.

This is not to deny the need for family or personal counseling and other professional supports. And, although the support group cannot provide those things, it can be a resource for finding them.

Hopefully, the above has already eased your mind somewhat. Your role as support group leader or member is not as “heavy” as you might have thought!

So what is a PD support group?

- A PD support group is a **self-help** group. It is run **by** and **for** people who have in common a particular challenge or life situation willing to talk freely and to trust openly in the good Will of the other group members.
- A PD support group is a place to be **yourself**. The most difficult “step” is walking in the door. The “program” is about making yourself and others feel welcome and accepted. It means knowing that your privacy and confidentiality will be respected.



- A PD support group is a source of **information**. Its members are a treasury of practical experience! They are also great collectors of articles, newsletters, books and other information about PD – who enjoy sharing them with others.
- A PD support group is an **added** circle of **friends**. Here is the place to talk; laugh and cry about life with PD – with people who will listen, laugh and cry, too. [This can save much “wear and tear” on family and other relationships!]

To summarize, a PD support group is an informal, self-managed organization of persons with Parkinson’s and their caregivers whose purpose is to **share information** and **offer mutual support** in a spirit of self-acceptance. It is also a place where other family members and friends can feel welcome and supported.

Another way of saying it is that, in a support group, persons with PD, and their caregivers become **“prosumers.”** To be a prosumer is to be both needed and empowered, in a most meaningful way. It means being not only a better equipped **consumer** of medical services and products, but also a uniquely qualified **provider** of practical, real- life wisdom to others.

No one is an **“expert”** – but everyone has experience to share!

Finally, each PD support group is as unique as its membership. The interests and capabilities of support group members vary greatly, and may change over time. It is not “sameness” that counts, or meeting some standard. Rather, it is making the most of what each group has to offer to its members at any given time. This is the role of the support group leader.

Who is a support group leader? Read on!



GETTING STARTED

How does a PD support group get started?

Each PD support group has its own story, including how it got started. Some of the common scenarios are:

- A lone caregiver realizes the need to talk to others in her situation. She puts her telephone number in the church bulletin and the local paper asking other PD caregivers to contact her. They arrange to meet for coffee at one of their homes, and agree to make it a weekly event.
- A Parkinson's couple contacts their local hospital, looking for a support group. They find groups and programs for everything but PD. So they ask the hospital's community relations department for "equal time" and space, and some help with publicity. Soon they have a monthly meeting going – with refreshments – courtesy of the hospital!
- A social worker (or a nurse or health educator or therapist) realizes how helpful a PD support group would be to his clients. He gets a lot of support for the idea from both clients and colleagues. So he makes arrangements to work late on the first Tuesday of each month to get the group started and to serve as its facilitator.
- A city-based NPF Center of Excellence sees the need for a PD support group in the outlying rural community. They cull their patient data base and identify patients in a certain area. Patients in that area receive a letter from the Center, inviting them to a meeting on a Sunday afternoon at a local senior center. The PD Center provides a staff member to lead the meeting and to explore the idea of starting a group.

A PD support group can be started by anyone – patient, caregiver or health professional – who sees the need and is willing and able to act on it. If one is willing, but not able, he or she may succeed in getting someone else to pick up the ball. However, it is very important to give that person ongoing input and support, by attending the meetings and encouraging others to attend as regularly as possible.



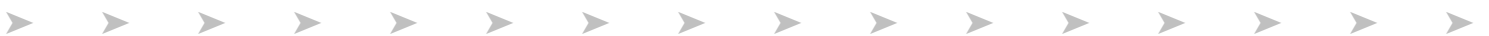
The organizer need not (and perhaps should not) lead all of the discussions. Another member may be a very able facilitator, or a local health professional may be willing to do so.

Why should I start a PD support group?

Of course, the only one who can answer this question is you, with input, perhaps, from your spouse or other family members.

Here are a few things to consider:

- ▶ **Starting a support group takes time and energy.**
However, it can also save time (looking for information and resources) and give you energy (the support of others).
- ▶ **Starting a support group requires organization.**
However, it doesn't take a whole lot. It means being able to handle a yearly calendar, sign-up sheet, and mailing or telephone list with some skill, and knowing when to delegate even these basic tasks to others.
- ▶ **Starting a support group is an ongoing commitment.**
However, it can be made in time-limited terms. You might agree to lead the group for one year, with the understanding that someone else will "step in" at that time. That someone else should know who he or she is, and be working closely with you in order to get ready to lead.
- ▶ **Starting a support group is not a one-person job.**
However, it is usually up to one energetic, well-organized ("visionary") type of person to get the group going and keep them inspired. Beyond that, the success of the group is up to the group, and each member should have a "job" to do, no matter how small.
- ▶ **Starting a support group may change your life.**
However, the change will be gradual- and positive! You will no longer be able to be "anonymous" about your own PD or your connection to it. In fact, you will find yourself becoming an unavoidable (even if unlikely) PD advocate in your hospital or community. Now you have really started something!



Where should we meet? When? How often?

Right after “should I start a support group?” The next two questions to answer are when and where to meet. The two are closely linked, and depend, first of all, on your own availability:

- If you have PD, are you working? If so, you may look toward evening or weekend meetings. If you are not working, keep in mind that others may be.
- If you have PD, when is your own best time of day (or evening)? When are you most likely to be “on” – and to have the most energy to spare?
- If you are a caregiver, what is the best slot in your already stressful schedule? Will your PD partner come with you to the meetings? If so, you need a time that will allow both of you to eat, dress and drive there safely.
- If you are a caregiver, how can you simplify your life on meeting days? Perhaps this is a good “excuse” to order out and avoid the kitchen altogether.
- If you are a health professional, is there time available during your work day? Most likely not – meaning a commitment to one evening or weekend time a month. Do you have one or more of those already? If so, it might be time to re-group.

Most older people with PD would probably say that they prefer a day time meeting, in order to avoid driving at night. Also, there are more transportation options during daytime hours, particularly on weekdays. However, a weekday meeting will leave out most PD persons and caregivers who are employed.

Some groups have solved this by alternating daytime and evening meetings. Another option is to hold evening meetings in the spring and summer months (when there is more daylight); daytime meetings in fall and winter. Some groups do not meet at all in the coldest winter months.

Weekends are another possibility, with Sunday afternoons being the most popular. When looking at weekends it is important to consider the religious differences within the group, especially when it comes to Sabbath observances.

Some groups manage to combine all of the above by holding regular meetings on weekdays (or nights) and one or two “rap sessions” a year on Saturday mornings or Sunday afternoons.



Any mid-day gathering allows the possibility of having a brown bag lunch. The “hospitality committee” supplies beverages and one or two people bring desserts to share. Eating together makes the meeting a special event, and creates a warmer and more social atmosphere.

No matter what the meeting schedule, planning ahead is important. So is consistency – it helps to have a regular pattern of meeting times. The support groups who do best with attendance are those who publish a yearly or six-month schedule of meeting times and topics and stick to it.

In terms of how often to meet monthly meetings seem to be the most popular. Monthly meetings are far enough apart to be not too taxing – yet close enough together to allow people to get to know each other. Some groups have smaller, weekly gatherings of those who are seeking extra support, or a chance to exercise or socialize.

Where to meet? To some extent, this will be related to when you meet. Certain facilities (such as churches) are available only at certain times. Hospital meeting space seems to be in great demand these days – its availability may also be limited. Also, some persons with PD and their partners would rather avoid yet another hospital contact and its inescapable association with illness.

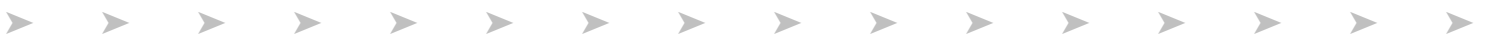
Perhaps what is most important is finding a meeting place that offers “psychological” comfort as well as the necessary physical accommodations. Finding such a place may require a bit of looking, but it is well worth it.

Here we some places to start:

- Hospitals
- YM or YWHA’s
- Senior centers
- Public libraries
- Churches or synagogues
- Rehabilitation centers
- Senior housing communities
- Community room at local malls

Then there are the more “unusual” meeting places: one group near Philadelphia meets at a funeral home! Don’t laugh – the owners offer a beautiful downstairs meeting room and coffee free of charge.

In fact, all of the places listed above should be available free of charge. Some groups offer a donation at the end of the year to help cover maintenance costs.



Checklist for meeting sites

- Is there a cost?
- When is the room available?
- Are tables and chairs provided? Will they be set up for you?
- How many people will the room hold, if some are in wheelchairs?
- How many steps are involved -inside and outside? Is there an elevator?
- Is the parking safe and convenient? Is there a good “drop-off” place at the door nearest to the meeting room?
- Is the entire building including bathrooms, accessible to walkers and wheelchairs?
- Are the bathrooms located near the meeting room and on the same floor?
- Is the room adequately heated and/or air-conditioned?
- How will you gain access to the building especially on nights and weekends? Will there be staff around?
- Is there a telephone accessible at all times?
- Who is the contact person and how can he or she be reached during off hours?
- Is liability insurance required? (Many facilities have their own.)

Optional items:

- Is there a kitchen available? Coffee pot?
- What audio-visual equipment is available?
- Is there a portable (hand-held) microphone?
- Is there a closet where the group can store supplies and literature?
- Would the facility be willing to help your group to advertise its presence there?

How do we get people to attend?

Getting people to come to your first meeting may not be as difficult as you think. The challenge is getting them to keep coming back!

Most groups start out with a small number – maybe only five or six people. What brings them to your first meeting? Probably a personal contact with someone like yourself or a staff member at the local PD Center. Then there are those brave souls who respond to flyers and newspaper notices. Local advertising is a good place to begin!

- Most newspapers accept public service announcements (PSAs) free of charge. They will require that you send it in writing, and at least two weeks in advance. Be sure to include the name and telephone number of a contact person.
- Radio stations also accept PSAs.
- Most supermarkets, libraries, senior centers and senior residential communities have bulletin boards where meeting notices can be posted.
- Don't forget your doctors' offices – all of them! Doctors' waiting rooms are great places for small posters and/or flyers. They will have greater "staying power" if you obtain permission (of course) and ensure that any printed items fit neatly into the literature rack.

Each notice, regardless of where it appears, should include a person's name (at least a first name), telephone number, and when to call. The "telephone contact" should be prepared to extend a warm welcome to prospective members, and to provide all of the information they need for the first meeting, including directions. The contact person should also keep a list of each person who calls, including addresses and phone numbers.

The initial telephone contact is very important. It may be the deciding factor as to whether someone attends the meeting or not.

However, no matter how warm the conversation, there are some persons who will choose not to attend. Don't take it personally. They simply aren't ready. However, they may agree to be on your mailing list "just in case."



What should we do at the first meeting?

The first meeting will probably be a small gathering of five to ten people. Regardless of the number, a great deal can be accomplished.

This meeting (and every meeting) should begin with introductions. Usually each person introduces himself or herself. This allows each person to decide his or her own comfort level with respect to how much they wish to share with the group. You might ask each person to respond to the question, “What brings you to this meeting?”

This is also a good time to remind the group of the importance of two things: careful listening, and confidentiality. Nothing that is shared, nor the identities of group members, should be revealed outside of the group, for any reason.

When the group gets a little larger, first time attendees should be welcomed “officially,” and given a little more time to introduce themselves. Many groups have a “buddy system” that pairs newcomers with “old timers” for the first several months.

Seating arrangements are very important. Arrange the chairs so that people can make eye contact comfortably.

Make sure that each person has a chance to speak. Some persons with PD speak more slowly, or more softly, than others. It is OK for you (or a caregiver) to assist, but not to speak for that person. Make sure that each person is heard. It helps if the leader repeats each name as you go around, with a statement like, “We’re glad you’re here, Mary!”

[Many PD support groups employ a hand-held microphone, which is passed around to each person as he or she speaks. This lessens the embarrassment of “soft spoken” members, and ensures that everyone can hear what is being said.]

Speaking of names – most of us have trouble with them! Have a supply of name tags on hand and use them at each meeting. Everyone will thank you for it! Note: First names are usually sufficient, and may even be preferred by some members.



Then what happens?

- The leader should welcome everyone once again and state what got him or her interested in starting a PD support group. Then he or she should provide an update on the availability of meeting times and places.
- Attendees should state preferences about meeting times, and may know of some other possible places.
- A list of discussion topics should be developed along with ideas on how to approach them. These might include: PD medications (invite a physician); coping with PD (try a video); or a “rap session” (draw up questions). Try to come out of the first meeting with three meeting ideas.
- Each meeting could be “assigned” to a different member to arrange (the speaker, the video, or the questions). The support group leader serves as the’ back-up.
- The group should decide about refreshments, based on the facilities available. Most groups rotate the job of bringing the “goodies.”
- A complete listing of everyone’s name, address and telephone number should be obtained. Many groups give out the list to members, so they can be in touch between meetings. Each person should give his or her permission to be listed, and the list should not be shared outside the group.

[Note: For reasons of confidentiality, some members may prefer that “Parkinson’s” not appear on the outside of any mailings they receive from the group.]

- The next meeting date and time should be set, if known. If not, the group should decide on how everyone will be informed of the next meeting.

After the first meeting, the organizers or core-group should remain to discuss how it went. Did people seem comfortable? Did everyone get a chance to participate? Did one or more persons talk too much at the expense of others? This is a good time to decide what, if anything, you will do differently at the next meeting to make things go even better.



KEEP IT GOING

Who's doing what?

Every group needs a leader. But the leader cannot – in fact, should not, do it all. This may seem the simplest way to go, especially at first, but it is a sure road to leader “burnout.” It is easy to forget that PD support group leaders are subject to the same challenges as the rest of the group, including fatigue, changing symptoms, and the unpredictably of life with PD.

The leader can preserve his or her own energies – and the life of the group – by filling a few basic “jobs” within the group. This can be done as early as the first or second meeting:

- **Co-leader(s):** One or two other persons who share the job of planning and leading the meetings especially in the leader’s absence. Everybody needs a “back-up!”
- **Secretary:** Keeps the membership list up-to-date, including addresses and phone numbers. Prepares and sends meeting notices (if this is done). Handles the group’s correspondence (e.g., thank you notes to guest speakers). Keeper of the name tags!
- **Hospitality:** Makes arrangements for refreshments for each meeting. Ensures that there are coffee and tea supplies and paper products as well as a pitcher of water and cups. Also manages the sign-up sheet for “goodies.”
The Hospitality committee also serves as “greeters” – especially for new members. When any member misses a meeting or two, it is nice to have someone there to say, “*Your were missed!*”
- **Telephone contact(s):** The person(s) whose names and phone numbers are listed in air public announcements. Also, they serve as a “telephone tree” when members need to be contacted by phone.
- **Publicity:** Makes sure that the meeting announcement gets to the local papers and explores other possible sources of publicity, including local hospitals, physician’s offices, churches and senior centers.



These five basic tasks are usually enough to keep things going for the first few months. However, as the group increases in size, you may find a need for the following:

- **In-Home/Outreach:** Visits homebound or hospitalized members either in person or by telephone; brings or sends materials from meetings.
- **Treasurer:** Opens a bank account for the group to keep member contributions and memorials. Most groups have a very modest “treasury” which they use to pay for postage, photocopying, book purchases, subscriptions, or to send flowers.
- **Librarian:** Keeps PD books, videos, newsletters and other materials in a box and brings it to each meeting for members use. Keeps a sign out list for items that are borrowed .
- **Historian:** Keeps a scrapbook of the group’s activities, including photographs, clippings and other souvenirs. It helps if this person is good with a camera!

Many groups have a **Planning Committee** who meet two or three times a year to plan the year’s agenda. Key members of this committee are: Co-Leaders, Secretary, Treasurer, Publicity persons, and of course, any other interested persons.

Some members may hesitate to take on a “job.” They may feel that, due to PD or other circumstances, they do not wish to make such a commitment. Of course, no one should be pressured into taking on a title. However, the hesitant may be encouraged to serve if: 1) each job has a one-year limit, and 2) each position has a “buddy,” or back-up person assigned to it.

Health professionals who start PD support groups or become involved with them may find it difficult to avoid (or resist) the leadership role. It may be necessary for the professional to “lead” at first; But the sooner he or she can delegate the above tasks – and assume an advisory or consultant role, the better. This supportive (“on tap but not on top”) role promotes self-help and gives the group its own sense of power and purpose.



Planning ahead: What is our agenda?

Many PD support groups spend the first few months simply discussing common concerns and giving members a chance to get to know one another. Eventually, however, the need for expert or at least outside information becomes apparent. That is when many groups decide to plan a yearly agenda, or meeting schedule, so that they can cover several bases educational, supportive and social.

Out of a 12-month period, your group may meet eight to 12 times. This will depend on local weather patterns and the preferences of the members. Many groups avoid difficult winter months, or especially “slow” summer months. In any event, these are probably not the best months to schedule important guest speakers.

A full yearly agenda might look like this:

September	Welcome back meeting Parkinson’s Update by a local neurologist or nurse specialist
October	“Rap session:” open or guided discussion about living with PD; may separate into PD and caregiver groups
November	Another guest speaker on coping with PD and/or accessing local resources
December	<i>Holiday party</i>
January	Review a new video or book on PD as a group; write to the author or publisher!
February	Video with speaker on exercise and PD; everyone participate!
March	Speaker on couple and/or family issues in PD (e.g. sexuality); may be combined with a rap session

April	Speaker on medications and/or nutrition and PD; i.e., neurologist, nurse, specialist, pharmacist, dietician
May	Mini walk-a-thon/ bike ride, bake sale or health fair activity – to raise awareness and research funds for PD
June	Arrange a local trip or have an indoor travelogue with a local travel-agent who arranges trips for disabled persons
July	Family picnic or day at the beach, lake or other relaxing spot
August	Take a month off and arrange a postcard exchange instead!

Of course, each group's agenda will be different, and will depend on the availability of speakers and sites. The general idea is to have several educational topics, with at least a few "rap sessions" scheduled in between. One or two social or public awareness activities should fit naturally at certain times of the year.

To the extent that you can, it is a good idea to publish your calendar in advance. This can be very helpful to members who like to "plan ahead" – or who need a tool to entice reluctant spouses or other family members to attend.

Advance planning will also make it easier to obtain speakers. As soon as the speaker has agreed, ask your group secretary to confirm the date and time in writing. About two weeks before the date, contact the speaker again with some information about the group and a list of five to ten questions the group would like him or her to answer. This serves as a reminder for busy professionals, helps them to prepare their remarks, and ensures that they will be "on target."



Suggested topics for Parkinson's support group meetings

About Parkinson's

- Is PD a "Family Disease?"
- Diagnosis of PD: Signs and Symptoms
- PD Medications: Current and Forthcoming
- PD Research Update: Are We Moving Toward a Cure?

Living with PD

- PD as a Chronic Illness
- Changes of PD: Loss, Grief and Growth
- Can Exercise Make a Difference in PD?
- What is the Role of Diet in PD?
- Tips for Activities of Daily Living
- Getting Around: More Safely, More Smoothly
- Speech and Swallowing and PD
- Handwriting and Computer Skills
- Memory and Communication skills
- Sleep Problems and PD
- Intimacy and Sexuality and PD
- PD in the Work Environment
- Creativity and PD: Hobbies and Crafts
- How PD Affects Children and Grandchildren
- The PD Consumer: Using Adaptive Equipment
- Driving and Community Mobility with PD
- Long-Term Care and-Financial Planning
- Handling Emergencies
- Stress Management, Relaxation and/or Massage

For the Caregiver

- What is Self-Care?
- Caring Smarter – Not Harder
- Planning Your Own Future



Getting Children and Other Family Members Involved
Building Your Own Support Network

Health Care and Community Resources

The “Ins and outs” of home care
What You Need to Know about Nursing Homes
Long-Term Care Communities
Adult Day Care: Is It For Us?
Transportation and Other Resources for Aging in Our County
Accessible Dining, Recreation and Travel Options

Possible Speakers for PD Support Group Meetings

- Neurologist
- Nurse specialist
- Social worker
- Psychologist
- Physical therapist
- Occupational therapist
- Speech pathologist
- Pharmacist
- Dietician
- Exercise physiologist
- Health educator
- Recreation therapist
- Attorney
- Hospital or nursing home chaplain
- Adult day care or nursing home administrator
- Representative from county office on aging
- Owner of a local medical equipment company
- Travel agent
- Speaker from local museum or historical site



- Dancing or music instructor
- A local artist
- Member of a neighboring PD support group
- One of your own members – who has had a recent publication, art show or travel adventure

Working with speakers

Some speakers are better than others -but almost all have something to offer to your group. To get that “something” here is a speaker preparation checklist:

- Confirm the time, date, location and topic in writing as soon as the speaker agrees.
- Include with the confirmation letter your best PD booklet (or one that pertains to the topic); and any relevant newspaper clippings to which you would like him or her to respond.
- Request some background information on the speaker to use for publicity purposes, and to introduce him or her.

Two weeks before the meeting:

- Send the speaker a reminder note (“We’re looking forward to seeing you on ...”) along with a copy of the meeting announcement and/or press release.
- Include some information about your group: the size, age range, number of patients and caregivers.
- Ask if he or she will need video equipment, a slide projector or flip chart.
- Provide a list of five to ten questions that the group would like to have addressed.
- Reconfirm the time and format (e.g., a 30-minute talk with 15 minutes for questions and answers).
- Ask for permission to take photos and/or tape record the presentation (if you plan to do so).
- Finally, make sure he or she has good directions – and a telephone number to call in case of any last minute problems.



Determine who will introduce the speaker at the meeting. This person should be prepared with the speaker's background information. If a blackboard or flip chart is available, it is helpful to write the speaker's name on it in large letters.

Encourage the speaker to use the microphone so that everyone can hear. [Group members may use the mike later to ask questions.]

The group leader or introducer should keep track of the time and provide a warm thank you on behalf of the group at the end of the presentation. If time has been allowed for questions and answers, let everyone know what the time limit is and stick to it. (You may have to set a limit of one question per person). If the speaker needs to leave at a certain time, someone should escort him or her to the door promptly. After all, you may want him or her to come back again!

The group leader can assist the speaker during the question and answer period by:

- Ensuring that each person gets a chance to ask a question.
- Adding some helpful background to the question, such " as, "This came up at our last meeting, because...".
- Offering to ask the question for group members for whom voice volume is a problem (if a hand microphone is not available).

PD support groups have found that most speakers are available at no charge. Some groups offer to pay for travel expenses, or offer a small token of thanks (a group T-shirt or a new PD paperback). Medical professionals may receive sponsorship from pharmaceutical companies, who may also offer to provide literature and refreshments. (Your regional PD Center or local neurologist's office can give you the names of the PD pharmaceutical representatives in your area.)

Finally, it is a good idea to place your speakers on your mailing list, thus keeping them informed of your activities. They may have persons with PD to refer to your group or they may want to attend a future meeting for their own benefit.

Working with the Media

Now that you have a full-agenda planned, including some good speakers, how will you let people know about it? Your members, or course, can do "word of mouth" publicity. But what about the rest of your community?

In addition to the publicity suggestions offered in the previous section, there are these:



- Use a particular speaker, or topic, as a “draw.” Include a short, descriptive paragraph in the press release you send to the local media, in addition to the usual meeting announcement.
- A meeting topic stated in the form of a question (vs. a straight phrase) may be more enticing; i.e., “Is Parkinson’s Disease Inherited?” versus, “Heredity and Parkinson’s.”
- The speaker may have media contacts that you can use; e.g.” the public relations department of his or her hospital or organization.
- Make sure that every meeting flyer and other piece of publicity displays the words “Parkinson’s disease” clearly, and includes a brief description of the condition. You never know on whose desk, or in whose home, that piece will wind up nor how much (or how little) the recipient knows about PD.
- Don’t be shy about making follow-up phone calls to media contacts, nor about learning and using their names. Be courteous and brief – but remember that you are doing them a favor by helping them to learn more about a neurologic condition that affects more than a million Americans.
- Don’t become discouraged. Remember that media and public relations people are bombarded with press releases on a daily basis. They may become distracted and you may be displaced – by a “bigger” story. That’s OK – they’ll remember you next time.

Keeping attendance up – when the group is “down”

Even the most upbeat PD support group can have its “down” times. This may be due to any number of factors, including:

- Sudden illness or death of a regular member (may be a PD member or a caregiver)
- Absence of the support group leader (due to PD stressors, family or work demands)
- Loss of the support group leader (due to a new job, relocation or “burnout”)
- Gradual loss of membership as PD takes its toll on general health, personal mobility and caregivers’ well-being



- Lapse in meetings due to weather availability of meeting space or turnover in leadership

What should you do?

First, realize that is OK for the group to “take a rest.” Those who live with PD are familiar with that piece of wisdom!

Many PD support groups have “rested” for months at a time, only to come back stronger, and with renewed membership.

Whether you choose to take a break or not, the following ideas may help your group to rejuvenate:

- Ask each member to volunteer to call a missing member and invite him or her back. If he or she cannot attend, offer to visit. Ask if the members would like to send a tape recorded message or photo back to the group.
- Renew your publicity efforts via the local newspapers and local hospitals. Do they know that you are still here?
- Organize a lunch outing to a favorite local restaurant. Ask for a large, quiet table or private room where you can enjoy one another’s company and hear each other talk. Ask everyone to bring recent family or vacation photos.
- Visit a neighboring PD support group. You will probably find that they have similar difficulties and you may get a few good ideas.
- Ask for help from your regional PD Center – they may be able to send a support group facilitator as a “consultant” to listen and make suggestions.
- Get a speaker who can address issues of loss – such as a social worker, psychologist or clergy person. Talk to the speaker ahead of time about what has been going on in your group, as well as your own concerns.

Of course, none of these suggestions can make everything right, nor restore your group to the “way it was. Change is a reality in the life of every group, just as it is in the lives of individuals. Allow your group to change, along with the changing energies and experiences of its members. Acknowledge the “down” times and encourage the group to talk about them. And finally, don’t be afraid to rest and “re-group!”



SPECIAL ISSUES

Affiliations: local and national

PD support groups may exist alone or in a “network” of groups that is affiliated with a regional Parkinson’s center. Each of the **National Parkinson Foundation** Centers of Excellence has its own network of support groups.

Although it is not necessary to affiliate with a PD Center, or even with one of the national organizations, it can be extremely helpful. A PD Center can provide speakers, updates on research and treatment, and assistance in helping your group to get started. Your Center can also put you in touch with other PD support groups in your area, and serve as an important source for referring new members to your group.

The **National Parkinson Foundation** keeps a computerized directory of PD support groups throughout the United States and abroad. NPF would like to have your group on its list for the purpose of referring prospective members – or even PD travelers – to your next meeting.

NPF also is a valuable resource for PD literature, which is available in quantity for your group. The latest in research, treatment and coping strategies can be found in NPF’s quarterly Parkinson Report, at no cost to you or your members.

Other PD organizations are also sources of information and ideas. They vary in terms of what they require from their support group affiliates, including by-laws and annual dues. It is hoped that one day all of the national PD organizations will be able to “join forces,” in order to conserve resources and to command a stronger voice.

Your role in research

Yes! Your support group has a role in Parkinson’s research, if you choose to pursue it, by:

- Inviting a local PD researcher to speak to your group about current studies.
- Recruiting research participants from your group (and within your community) based on the needs of local researchers.



- Volunteering to participate as a group (or a sub-group) in any survey-type studies being done at your local Center (e.g., on personality, hereditary factors, caregiver stress).
- Suggesting to your PD Center or local college or university a research study in which your group is especially interested and would like to participate (e.g. physical therapy students maybe interested in measuring the effects of home exercise on PD).
- Letting the National Institutes of Health and Congress know that you are watching their PD research efforts with great interest – and requesting periodic updates.
- Getting on as many mailing lists as you can related to PD, aging or caregiver research. There is a lot going on out there!

But most important get complete Information on any research project you are considering, particularly if it involves PD medications or a change in your treatment. Check it out with your physician or local PD Center.

You want evidence that all of the standards for sound and ethical research have been met, including a human subjects review by the sponsoring institution. You also want assurance that the privacy and confidentiality of your members will be a prime concern.

At some point, a researcher or student may request a copy of your mailing list to conduct a survey, or for recruitment purposes. You may need to inform the researcher that the mailing list belongs to the group and cannot be shared without the entire group's approval. If you do not wish to release your list, you may choose to mail the researcher's materials yourself, with the researcher reimbursing you for postage (including return postage).



Consumer advocacy and public awareness

Persons with PD and their care partners are consumers of many things, including medications, adaptive equipment, and mobility aids (such as walkers and wheelchairs). They are also consumers of the “good things” in life – such as sports events, musical entertainment, fine dining, good books and bargain matinees.

This is serious patron power!

Your group can empower one another to expect the best (in value and service) from the public marketplace. You can also “educate” your local entrepreneurs. Here are a few suggestions:

- Invite your local pharmacist to speak candidly to your group about prescription drugs.
- Contact your local pharmaceutical representative (through your PD Center or doctor) and invite him or her to attend a meeting.
- Invite the owner of a local medical equipment company to speak to your group. Ask him or her to bring demonstration or sample items.
- Write complimentary letters to establishments (restaurants, theatres) in which group members feel especially comfortable and welcome.
- Write “constructive” letters to establishments which are not as accessible or amenable as they could be. Make specific and realistic suggestions.
- Request a speaker from your local Chamber of Commerce. At the same time, inquire about upcoming health fairs or consumer awareness events in which your group might participate.

The idea is for your group to be “out there,” letting your community know of your presence. Let it be known that your concerns apply not just to those who live with PD – but to hundreds of thousands of medically and physically challenged persons throughout the country.



Fundraising: How, why, for whom?

Fundraising may be the last thing you as a PD support group leader want to think about. You may feel that you have your hands full as it is, and/or you may feel uncomfortable about “asking people for money.”

First of all, fundraising is an option, not a requirement, for PD support groups. It is just one way of contributing to the work of your local PD Center, or to the research effort nationwide.

Funds are always needed for PD research, much of which is not subsidized by public or private funding.

Many support groups organize and participate in a local fundraiser to promote Parkinson’s Awareness Month (April). This does not mean that your event must be in April (you may prefer to wait for warmer or less rainy weather). However, you may choose to start your local publicity in April in order to take advantage of national Parkinson’s Awareness Month publicity and materials.

What are some of the most popular events to raise awareness and funds for PD research? Here are just a few:

- PD “walk-a-thons” (a Mall or a simple mile-route will do – its visibility that counts!)
- PD bike-a-thons, swim-a-thons, golf-a-thons, dance-a-thons – again, it’s not Olympic endurance but public exposure that counts!)
- PD raffles – of almost anything legal (a good way to get wide participation)
- PD bake or craft sales – a PD pamphlet goes out with each item sold!
- PD T-shirt button or bumper sticker sales – appeal to people of all ages

The idea is to keep it simple, low-cost and fun. The amount of money collected does not matter. What does matter is how-much participation and public awareness you can muster on behalf of your own group and PD families throughout the country.



MEETING GUIDES

This section includes six support group meeting “guides” that may be used alone or supplemented with a speaker or videotape.

These guides may be especially helpful when the group is small in number, as the main idea is to get the members to share with one another. These can also be used to generate questions for a forthcoming speaker:

- A. What is Parkinson’s?
- B. Diagnosis and Treatment of Parkinson’s
- C. Nutrition and Parkinson’s
- D. You and your Doctor
- E. Coping with Parkinson’s
- F. For Care Partners Only

The “Suggested Reading” list at the end of this section includes several sources of information on these topics. Also, there are many educational videotapes now available which can be used alone or as discussion starters. For more information, call the **National Parkinson Foundation** at 1-800-327-4545.

Let us know what has worked for you !



Topic A

WHAT IS PARKINSON'S?

Introduction

“Parkinson’s” may mean something different for each member of our group. Each member has his or her own symptoms, sources of information and personal understanding of the condition.

One of the most important things our support group can do is to try to arrive at a common understanding of what Parkinson’s is, allowing for the fact that each one of us will experience it differently.

Discussion questions

1. What does the word “Parkinson’s” mean to you?
How did you feel when you first heard it?
2. About how many Americans have Parkinson’s?
At what age is Parkinson’s most likely to develop?
3. Why was Parkinson’s first called the “shaking palsy?”
What are the other symptoms of Parkinson’s?
4. How does the brain control movement?
What happens when dopamine is in short supply?
5. Do we know the cause of PD – that is, what causes
the early death of the brain’s dopamine-producing cells?
What are some of the current “theories?”
6. Can drugs, toxins or germs cause Parkinson-
like illness? If so, which ones?
7. How is Parkinson’s most likely to affect your daily life
and activities? Are all of these changes unavoidable?
8. What is the best way to describe Parkinson’s to a
friend, co-worker or family member?

Suggested Speakers

Neurologist, nurse, or health educator who works with Parkinson’s; an informal panel of patients and caregivers

Your ideas



Topic B

DIAGNOSIS AND TREATMENT OF PD

Introduction

“Each of us has our own “story” about how we (and our doctors) arrived at the diagnosis of PD. For some, the diagnosis was made almost immediately. For others, it may have taken quite a while.

Likewise, each person is on a different treatment route. Those with PD, vary in their symptoms, and doctors differ in their approaches to treatment. This can be confusing at times.

Discussion questions

1. Is there a “test” for PD?
If not, how does the doctor diagnose PD?
2. Is it important to start treating PD right away?
Why do some doctors wait to start PD medication?
3. What types of medication are available for PD?
How does each one help to restore the brain’s dopamine balance – thus reducing the symptoms of PD?
4. What should I look for when I take, PD medications?
What are the good effects – and the side effects – that I can expect?
5. Why is it important to take PD medications on a daily schedule? Should I keep a “log” – and what should I write in it?
6. What role does physical, occupational, or speech therapy have in the treatment of PD?
7. What are the surgical treatments for PD – and who is most likely to benefit from them?
8. How can I make the most of my own PD treatment – and become more involved in the plan?

Suggested Speakers

Neurologist, nurse, pharmacist who works with Parkinson’s

Your ideas



Topic C

NUTRITION AND PD

Introduction

Nutrition plays a role – whether positive or negative – in every condition. Parkinson’s is no exception. A healthy , well-balanced diet supports our general well-being and gives us the strength to keep going.

Some people with PD have found that by limiting their protein intake – and /or postponing it until later in the day, they get a better result from their PD medications. This type of diet requires careful meal planning and should be done with the guidance of a doctor, nurse or dietician.

Discussion questions

1. What is a “normal, healthy” diet for an adult?
Is it possible to control fat, sodium and calories (if necessary) – and still be able to eat?
2. How much protein do I need?
What are the best – and tastiest – protein sources for me?
3. What are carbohydrates? Which foods are they in?
Are some carbohydrates better for me than others?
4. How does the “low protein” diet work?
How would it fit into my (our) eating routine?
5. What about eating out? Will I be able to stick to the diet on those days?
6. How will know if the diet is doing any good?
What effects should I be looking for?
7. How much fluid should I take in during the day?
8. What is the effect of diet and fluid intake on constipation – a common complaint of those with PD?

Suggested Speakers

Registered dietician, nurse or health educator who works with Parkinson’s

Your ideas



Topic D

YOU AND YOUR DOCTOR

Introduction

The doctor-patient relationship is key in any chronic illness, and this includes Parkinson's. Through changing symptoms and medication trials, through an the ups and downs of PD, the doctor-patient relationship can and should be a constant.

This is not to say that doctor and patient will always agree nor that it is easy to find the "right" doctor. But it is to say that the search is well worth it.

Discussion questions

1. Can my family doctor treat my Parkinson's?
How will I know when or if I need a neurologist?
2. What can I expect from a neurologist?
What questions should I ask him or her?
3. What is the best way to get my questions answered?
Should I write them down or not?
4. What does the doctor need to hear from me?
How can I give the most accurate picture of my symptoms?
Which daily activities are most important?
5. Should care partners be present in the exam room
and/or the doctor's office? Why or why not?
6. How should I handle questions or difficulties
between visits?
7. How do I keep my family doctor up-to-date on my PD?
8. What do I look for in a doctor – and how do I
know when I have found it?

Suggested Speakers

Neurologist, PD patient and/or caregiver, or all together

Your ideas



Topic E

COPING WITH PARKINSON'S

Introduction

Coping with PD, like any other chronic illness, is a matter of personal resources, experience and style. No two persons will “cope” the same way. However, there is some common wisdom to be found among all those who live and cope with PD. Let's hear from our own group.

Discussion questions

1. What has changed since your diagnosis of PD?
What has changed because of it?
2. What do you tell yourself about your condition?
What do you tell others?
3. What is the most difficult thing to cope with?
What is the easiest (for you)?
4. What do you worry about most?
How and with whom do you share your worries?
5. Who helps you to cope – and how do they do it?
6. What thoughts or actions help you to cope – and why do they work for you?
7. What practical advice would you give to someone who is newly diagnosed with PD? To his or her care partner?
8. Why is “cope” the step between “mope” and “hope?”

Suggested Speakers

PD patients and care partner; social worker, nurse or psychologist who works with PD

Your ideas



Topic F

FOR CARE PARTNERS ONLY

Introduction

“Care partners” are those who help the person with PD in whatever ways are needed at the time. As we know, these needs can change from day to day, even from moment to moment. A care partner may be a spouse, a family member, a friend or neighbor.

Many prefer the term “care partner” to “caregiver” or “caretaker” because the word partner connotes a mutual relationship. As we have learned, often it is the care partner who needs the help!

Discussion questions

1. 1. When did I first realize my role as a care partner?
How did it make me feel?
2. What is the worst part of PD – from a care partner’s point of view? What is the best part?
3. What are my greatest worries as a care partner?
How or with whom do I share them ?
4. How do I know when to help, my partner – and when to let him or her do things alone?
5. Should we talk with the doctor together, or separately? How will I know when to do either?
6. How am I different – physically or mentally – since becoming a care partner?
7. What are a care partner’s typical feelings through the course of a day? Which ones do I feel guilty about?
8. If I could change one thing about our PD “partnership? it would be?

Suggested Speakers

PD care partner(s); social worker or psychologist who works with PD

Your ideas



EXERCISE!

Everyone knows that “exercise” is a good thing for those with Parkinson’s – and that is good for the care partner, too! But doing exercise – that is another thing.

Many PD support groups encourage their members to exercise by having a 20-30 minute “warm- up” before each meeting. Each member leads his or her favorite exercise or a new exercise he or she just learned. *[Care partners sometimes take this opportunity to have their own mini-meeting in another area.]*

Music helps many persons with PD to move – so why not exercise to music? One side of a favorite audiotape is all you need to get you through a simple workout.

The exact order or type of exercise does not matter so much, as long as the exercises are safe, doable and fun. They should be exercises that enhance flexibility, strength, coordination, posture and/or balance. A local physical, occupational or movement therapist may give you some suggestions. Or you may want to try one of the Parkinson’s exercise videotapes now available.

Parkinson’s exercises (with illustrations) may also be found in any number of PD booklets. You can easily obtain copies of the booklets for every one, or photocopy the exercises for everyone to take home. The idea is to exercise every day – then come to the meeting and brag about it!

A sample Parkinson’s exercise routine is outlined below.

Sample Exercise Routine

Relaxation and deep breathing (5- 10 minutes)

Have everyone sit comfortably. Make the room as quiet as possible and dim the lights somewhat. A tape of ocean sounds or quiet music may be helpful.

Ask everyone to close his or her eyes. Begin to breathe deeply and slowly, and concentrate on the breathing sounds. Inhale through the nose, let your stomach expand, and slowly exhale through the mouth.



Stretching (15-20 minutes)

“With eyes open, and sitting up straight, begin a head-to-toe body stretch. Stretch arms, hands, fingers, legs, and feet gently and purposefully. Do several sighs and shoulder shrugs. Breathe in and out on each stretch.

Don’t forget the face, lips and tongue! Make as many “funny faces” as you can think of, using all of your facial, eye and mouth muscles.

Do one last “cat” stretch, take another deep, cleansing breath.

Coordination and balance (5-10 minutes)

Pick a seated game that everyone likes: tossing a bean bag or beach ball, balloon “volleyball” or another favorite. Play it to music!

Or try a sit-down or simple line dance to one of the group member’s favorite tunes. Why not sing along?!

Challenge each member to come up with an activity to teach the group next time.

*At all times, the emphasis is on fun and full participation.
Let everyone leave feeling good!*









NATIONAL PARKINSON FOUNDATION CENTERS OF EXCELLENCE

Alexian Neuroscience Institute*
Chicago, Illinois

Baylor College of Medicine*
Houston, Texas

**Beijing Institute of Functional Neurosurgery
Xuanwu Hospital**
Beijing, China

**Beijing Institute of Pharmacology and Toxicology
Chinese Academy of Military Medical Sciences**
Beijing, China

Beth Israel Medical Center*
New York, New York

Biomedical Research Institute of New Mexico
Albuquerque, New Mexico

Centro Neurológico Hospital Francés*
Buenos Aires, Argentina

Chang Gung Medical College
Taipei, Taiwan

**Clinical Neuroscience Center
William Beaumont Hospital**
Southfield, Michigan

Colorado Neurological Institute*
Movement Disorders Center
Englewood, Colorado

Federation de Neurologie*
Hôpital de la Salpêtrière
Paris, France

Groningen University Hospital
Groningen, The Netherlands

Johns Hopkins University School of Medicine*
Baltimore, Maryland

Juntendo University School of Medicine*
Tokyo, Japan

Kings College
London, England

Kings County Hospital (SUNY) Health Science*
Brooklyn, New York

Kuakini Medical Center*
Honolulu, Hawaii

Markham Stouffville Hospital*
Toronto, Ontario, Canada

**Massachusetts General Hospital*
A Harvard Medical School Affiliate**
Boston, Massachusetts

Medical College of Georgia*
Augusta, Georgia

Muhammad Ali Research Center*
Phoenix, Arizona

Neurologic Associates
Palo Heights, Illinois

**National Institute of Neurological Disorder & Stroke*
National Institutes of Health**
Bethesda, Maryland

Nevada Neurological Consultants*
Las Vegas, Nevada

Northwestern University*
Chicago, Illinois

Oregon Health and Science University*
Portland, Oregon

**Parkinson Education
Society of Puget Sound**
Olympia, Washington

**Pennsylvania Hospital*
University of Pennsylvania**
Philadelphia, Pennsylvania

Rabin Medical Center, Sackler School of Medicine
Tel Aviv University
Tel Aviv, Israel

Segawa Neurologic Clinic for Children
Tokyo, Japan

Sinai Samaritan Medical Center*
Wisconsin Parkinson Association
Milwaukee, Wisconsin

Southern Illinois University School of Medicine**
Springfield, Illinois

Struthers Parkinson's Center*
Minneapolis, Minnesota

Technion*
Israel Institute of Technology
Haifa, Israel

Tel Aviv Sourasky Medical Center*
Tel Aviv, Israel

Texas A & M University Health Science Center
Temple, Texas

The California Neuroscience Institute
Oxnard, California

The Ohio State University Medical Center
Columbus, Ohio

The Parkinson's Center*
Newport Beach, California

University of British Columbia*
Pacific Parkinson's Research Centre
Vancouver, British Columbia, Canada

University of California San Francisco*
School of Medicine
San Francisco, California
University of California, San Diego
The Salk Institute
San Diego, California

University of Kansas Medical Center*
Kansas City, Kansas

University of Miami School of Medicine*
Miami, Florida

University of Navarra
Pamplona, Spain

University of Pittsburgh*
Pittsburgh, Pennsylvania

University of Rochester*
Medical Center
Rochester, New York

University of Southern California*
Los Angeles, California

University of Toronto*
Toronto, Ontario, Canada

University of Würzburg*
Würzburg, Germany

Vanderbilt University*
Nashville, Tennessee

Yale University School of Medicine
New Haven, Connecticut



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