

Support Group Guide



FOR NEW AND EXPERIENCED
SUPPORT GROUP FACILITATORS

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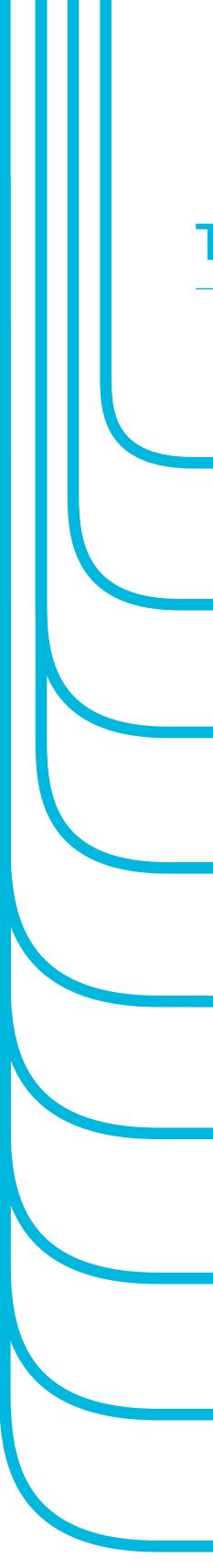
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ABOUT THE PARKINSON'S FOUNDATION

The Parkinson's Foundation makes life better for people with Parkinson's through expert care and research. We provide support, education and free resources through our toll-free Helpline (1-800-473-4636), Chapters, Centers of Excellence and affiliated support groups.

ABOUT THIS GUIDE

You share our mission to make life better for people affected by Parkinson's, so we offer this manual to answer some of your questions about starting and maintaining a Parkinson's support group. We collaborated with our Chapters and experienced support group leaders, drawing on their wealth of practical wisdom to address many of the questions we've heard from current and potential support group facilitators around the country.

COLLABORATING WITH THE PARKINSON'S FOUNDATION

We are here to support you and your group members, so we hope this guide is only one of many resources you will find useful. See Appendices A and B for lists of programs and resources.

Let us know about your group! Call our Helpline at 1-800-4PD-INFO (473-4636). Our PD Information Specialists can take your group information, including contact information, so we may refer local callers

to you. The Helpline is open from 9am to 6pm ET and is staffed by Parkinson's specialists who will answer your questions, fulfill your resource requests and provide up-to-date PD information, referrals to local resources and more.

In addition, we offer a support group "starter kit" with sample materials and order forms for your members. Contact the Helpline to get your starter kit, which includes the following resources:

- 2 sets of our Parkinson's educational book series
- 2 *Aware in Care* kits
- Helpline postcards (25)
- *Aware in Care* postcards (1 pack of 25)
- Resources order forms (5)

Your support group members should also contact the Helpline individually or visit our website, www.parkinson.org, to order materials for themselves and their loved ones.

If there is a Parkinson's Foundation Chapter in your area (visit our website to find out: www.parkinson.org/search), the Chapter can offer additional information and resources, such as speaker recommendations and inclusion in Chapter support group listings.

HELPLINE



The Parkinson's Foundation Helpline, 1-800-4PD-INFO (473-4636), provides information (in English and Spanish) to people with Parkinson's disease (PD), their families, friends, and healthcare providers. Connect with a compassionate, trained PD information specialist to get current information about PD. You can also email the Helpline at any time: helpline@parkinson.org.

I GET MORE THAN I GIVE

Mary's first experience with a Parkinson's support group was as a member of a care partner group. Mary and her husband, Karl, lived with Parkinson's for many years.

"The support group was important to me. The people there just got it. I didn't have to explain things to them – they were living with the same challenges that I was living with. We helped and supported each other in so many ways. Some of us continue to meet even though our husbands have passed away. We share how it has been since our husbands passed away and how we are creating new lives," said Mary.

After Karl passed away Mary was asked by her local Parkinson's center, a Parkinson's Foundation Center of Excellence, to start and facilitate a support group in an area that had no group for care partners. "I didn't have any training in how to facilitate a support group, but I got so much from being a member of a support group that I said I would do it," she said.

"We have eight to twelve members that come consistently. It is a mixed group made up of care partners that are at different stages of living with Parkinson's. The spouse of a newly diagnosed person may or may not want to hear about what the spouse in a later stage is going through. Then again, sometimes the spouse living in the early stage wants to know what is coming so that they can prepare. It's an individual thing. Sometimes a member comes to meetings, then they don't show up for a while, and they come back when they are ready.

"I feel comfortable being a facilitator. I make sure we have a place to meet and I bring coffee and snacks. I keep a roster of the members and make sure I ask for permission to share names, phone numbers and emails with others in the group. I also tell them they

can call any time for advice. One member has volunteered to call everyone in between meetings to see how people are doing and remind them of the upcoming meeting. I am there every time – I am a constant from meeting to meeting.

"We mostly talk amongst ourselves at our meetings. Sometimes I bring in a speaker. Sometimes I bring in a handout that I found on a website or in a magazine. Sometimes I buy a book to share and let people check it out if they want to read it. But it is mostly about getting together. About 75% of the time is spent on sharing information and tips about how to handle things. 25% of the time is spent on emotional stuff. We laugh a lot. Someone always has a funny story about what their spouse did since the last meeting.

"Sometimes I think I need more instruction on how to facilitate the group. But we seem to be able to fill an hour and a half just going around the circle and sharing what is on our minds. Sometimes someone will dominate the group, and I have to divert the conversation so that everyone has a chance to talk. But that doesn't happen often. Sometimes someone will not want to share, and I have to respect that and let them know I am there to talk later, one-on-one if they would like.

"Facilitating the support group is an upper for me. It gives me energy. I see people sharing and remember how important a care partner support group was to me. The reason for the meeting is to get the courage and strength to keep going. I get more from the group than I give."

CHAPTER 1: INTRODUCTION

If you are reading this manual, it means you are considering starting a Parkinson's disease (PD) support group or taking over the facilitator's role, or you need ideas for maintaining or re-energizing your group. You've come to the right place! Although it will require some work and dedication on your part, leading a support group may be one of the most satisfying things you will ever do.

To start, let's make sure we're on the same page about what a PD support group is and is not. It's NOT a problem exchange or place where people go to feel either more burdened or more blessed. A PD support group also isn't a therapy group, a "12-step" program, a substitute for medical treatment or health counseling or a replacement for family and friends or other close relationships.

A personal support network, as well as professional support, such as counseling, are still beneficial for support group members (and facilitators, too!). Although the support group cannot provide or replace those things, it can be a resource for finding them.

Now that we know what a PD support group isn't, let's look at what it is:

- A self-help group: Members share a particular challenge or life situation and are willing to talk freely and to trust openly in the goodwill of the other group members.
- A place where people with PD and their care partners can be themselves: The most difficult step is walking in the door. The program is about making members feel welcome and accepted. It creates a sense of belonging. It means knowing that member privacy and confidentiality will be respected.

- A source of information: Its members and guest speakers are a treasury of knowledge and practical experience!
- A place to connect with others, empathize with one another's situations, learn and exchange coping skills and empower one another.
- A motivational tool: Members, and the group itself, can help cultivate self-esteem, inspiration, personal growth and hope for the future.
- A reminder to members that they are not alone: Here is a place where members feel understood and accepted. A support group is an added circle of friends, where members can talk, laugh and cry about life with PD — with people who will listen, laugh and cry, too. Support group members have reported feeling better after attending meetings and that meetings have increased their confidence in dealing with PD.

To summarize, a PD support group is an informal, self-managed organization of persons with Parkinson's and their care partners – sometimes together, sometimes separate – whose purpose is to educate about the disease, 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." This 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.

Living with Parkinson's every day makes all members of a support group experts in their own right, and everyone has experience to share!

CHAPTER 2: GETTING STARTED

HOW DOES A PD SUPPORT GROUP GET STARTED?

A PD support group can be started by anyone — a person with Parkinson's, care partner, 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 important to give the leader ongoing input and support by attending the meetings and encouraging others to attend as regularly as possible.

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

- 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 lone care partner 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 care partners to contact her. They arrange to meet for coffee at one of their homes, and agree to make it a weekly event.
- An assisted living facility notices that they have several residents with Parkinson's disease, so they want to start offering services for people with PD, including a support group. It is staffed by an employee of the facility, even though she has no particular Parkinson's experience.
- 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 serve as its facilitator.

- A city-based Parkinson's Foundation Center of Excellence sees the need for a PD support group in the outlying rural community. They compile their patient database 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.

We hope this manual will provide guidance and ideas for anyone in the position of starting and maintaining a support group!

I want to be around people that do things. I don't want to be around people anymore that judge or talk about what people do. I want to be around people that dream and support and do things.

- Amy Poehler

WHAT DOES IT TAKE TO START A PD SUPPORT GROUP?

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.** For example, 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 these tasks to others (see page 26).
- **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. Make sure your successor is in place with enough time to work closely with you for a while to learn the process and get ready to lead.
- **Starting a support group is not a one-person job.** Frequently a particularly energetic, well-organized ("visionary") person gets the group going and keeps everyone inspired. Beyond that, the success of the group is up to the group members, and everyone should have a job to do (see page 26).
- **Starting a support group may change your life.** Don't worry; the change will be gradual and positive! If you are a person with PD or a care partner, you will no longer be able to be anonymous about your diagnosis or your connection to PD. In fact, you will find yourself becoming a PD advocate in

your hospital or community. Now you have really started something!

WHEN SHOULD WE MEET? HOW OFTEN? WHERE?

These questions are usually the ones asked after, "Should I start a support group?" When, where and how often are closely linked, and the answers depend, first of all, on your own availability. Let's start with when...

WHEN

- 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? When are you most likely to be "on" and have the most energy to spare?
- If you are a care partner, 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, without rushing.
- If you are a care partner, how can you simplify your life on meeting days? For example, perhaps this is a good excuse to order take-out for the night.

Most older people with PD prefer a daytime meeting, 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 people with PD and care partners who are employed. Although this could pose certain challenges, there are ways to compromise and make sure everyone can be included:

- Some groups have alternate daytime and evening meetings.
- Another option is to hold evening meetings in the spring and summer months when

there is more daylight, and daytime meetings in fall and winter.

- Some groups do not meet at all in the coldest winter months. This, of course, depends on where you live!
- 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.

Meeting during the day allows the possibility of a brown bag lunch. Eating together can make the meeting feel like a special event and create a warmer and more social atmosphere. When you send your meeting announcement and reminder, make sure to specify the time you will meet for lunch (and that each person should bring their own food) and the time the content of the meeting will begin. Some people may want to join for both, while some people may only want or be able to join for the official meeting portion.

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 six-month or yearly schedule of meeting times and topics and stick to it.

HOW OFTEN

Monthly meetings are the most popular. Monthly meetings are far enough apart to not be too taxing, yet close enough together to allow people to get to know each other. The important thing is that the group meets regularly: for example, the third Thursday of every month at 1pm.

There may be additional meetings, such as a presentation on current research and clinical

trials once a quarter. Some groups also have smaller, weekly gatherings of people who are seeking extra support or a chance to exercise or socialize. Once your group gets up and running, you can ask members if they'd like to arrange some of these extra activities. Or they might happen naturally, with members who live near each other or who become particularly close making their own plans to meet up outside formal group times.

WHERE

Support group members have shared with us the importance of making connections within the group. A safe and comfortable environment plays a vital role in helping to facilitate these connections. There are many factors that impact how comfortable people feel about interacting with each other and participating actively in the group. The location of your meeting will play an important role in creating a comfortable environment.

To some extent, where you meet will be related to when you meet. Certain facilities, such as churches and hospitals, are available only at certain times. Indeed, hospital meeting spaces seem to be in great demand these days, so availability may be limited. Also, some persons with PD and their partners would rather avoid yet another hospital contact and its inescapable association with illness.

Many places should be available free of charge, though some groups offer a donation at the end of the year to help cover maintenance costs. Here are some places to start your search for a location to host your group:

- Hospitals
- YMCAs or Jewish Community Centers
- Senior centers
- Public libraries
- Churches or synagogues

- Rehabilitation centers
- Senior housing communities
- Community centers

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. Another group used the city council chambers for their monthly meetings.

An important consideration when choosing a location (if you have multiple options) is the accessibility of the space. In this context, accessibility has many meanings:

- Is the meeting site near the center of town, or close to a majority of people? If the site is too far away, you might lose some participants. In fact, maybe this is a reason you're starting your own group! If you have a small number of people with whom you've discussed starting your group, check with them about convenience. If most of you agree on a location, there are likely others in your area who will be grateful that you started a group nearby.
- Does the meeting site comply with the Americans with Disabilities Act (ramps, etc.)?
- Is there adequate parking? In urban areas, parking can be difficult and expensive. Is the site accessible via public transportation?
- Does the meeting room offer some flexibility as the group grows? You may start out with only a few members, but over time your numbers will probably increase.

Checklist for meeting sites

- When is the room available?
- Is there a cost?
- Are tables and chairs provided? Will they be set up for you?
- How many people will the room hold? What if some people are in wheelchairs?
- Are there steps (inside and outside)? Is there an elevator?
- Is the room quiet?
- 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?
- 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?
- Is food permitted in the meeting room?
- 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?

Knowledge is power, community is strength and positive attitude is everything.

— Lance Armstrong

HOW DO WE GET PEOPLE TO ATTEND?

Getting people to come to your first meeting may not be as difficult as you think. Most groups start out with a small number — maybe 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!

- It helps if you can announce the new group at a larger Parkinson's seminar, conference, or educational event. Some attendees will definitely be interested in coming to the new group!
- Most newspapers accept public service announcements (PSAs) free of charge. Make sure you ask how far in advance the announcement needs to be submitted, and be sure to include the name and telephone number of a contact person. The paper may also be interested in writing an article about Parkinson's and the new support group.
- These days, newspapers also have online events calendars. Post your group on local newspaper websites and on other free online calendars, such as [Eventbrite.com](https://www.eventbrite.com).
- Radio stations also accept PSAs.
- Bring flyers or business cards to local events like health fairs, street fairs, farmers' markets or anything else that is community-oriented and open to the public.
- Most supermarkets, libraries, churches and synagogues, senior centers and senior residential communities have bulletin boards where meeting notices can be posted. Remember to ask permission before posting anything.

- Don't forget your doctors' offices — all of them! Doctors' waiting rooms are great places for small posters and/or flyers. Ask for permission to post, and try to make sure that any printed items fit neatly into the literature rack.

Each notice, regardless of where it appears, should include a contact person's name (at least a first name), email address and telephone number and when to call. The contact should be prepared to extend a warm welcome to prospective members, explain how the group works and who attends and get some basic information about the caller to see if they're a good fit. For example, a recently diagnosed individual might not want to attend a support group with people who've had PD for 10+ years. If it is decided that the person would like to attend, the group contact should be able to provide all the information they need for the first meeting, including directions.

If the initial contact is via email, try to obtain the person's telephone number. An initial telephone contact may be the deciding factor as to whether someone attends the meeting or not. No matter how warm the conversation, there are some people who will choose not to attend. Don't take it personally. They simply aren't ready. However, it is important for the contact person to keep a list of each person who calls, including addresses, phone numbers and email addresses if available. These names should be added to the contact list that you use to send announcements, updates and reminders to the group (see Appendix E for a sample group contact list). Even if someone decides not to attend a meeting, they may agree to be on your mailing list, so make sure to ask.

IT'S A GOOD WAY TO GIVE BACK

Tom volunteered to be a Parkinson's support group facilitator when he asked his church to form a new group for people who were in the early stages of the disease. The support group that he had been attending was more for people that were in the advanced stages of the disease. Tom wanted a group for people like him, people who were doing OK and just needed more information. So Tom started a new group together with the church nurse.

"Mary and I announced the formation of the new PD support group at a seminar held at my church on how to live with Parkinson's. There were about 100 people at the seminar and 20 of those people showed up for the kickoff of a new support group the next week. We average 15 to 22 people each meeting. Three or four people have dropped out, but that's due to the fact that it was just getting too hard for them physically to get to the meetings. But new people show up, too, usually because they hear from someone that it is a good group to go to for Parkinson's information and support.

"I have a dual role," said Tom. "I am a co-facilitator and a member. Mary takes care of the logistics – setting up the room, getting the coffee ready, sending out the notices and getting speakers to come talk at our meetings. My role is to draw people out to participate in the discussions.

I make sure that no one takes the group off track by dominating the discussion or changing the topic to something completely different from what the group agreed to discuss. But I have to admit, the group is so good at monitoring itself, I don't have to step in very often. If someone starts to take the group off track, another member finds a way to steer it back.

"We usually have a speaker for about 45 minutes. After the speaker we may or may not break into two groups – those who have Parkinson's and those who are care partners. The group decides whether they want to split up after the speaker.

"If we don't have a speaker, I will introduce a question or topic. Often times all I have to do is ask 'What would you do if.....?' We learn from each other – what medications are out there, how they are working for someone, referrals to doctors who specialize in Parkinson's and other useful information.

"I also tried something different for one of our summer meetings. I changed things up by inviting everyone to my house for a barbecue, and it went over very well. It was more social, with a little discussion about Parkinson's. It was relaxed and everyone joined in the games, like throwing bean bags at a target.

"I have also started a coffee group for people with Parkinson's that meets every week in between the regular group meeting. It's informal; about six people show up. It's about fifty percent informational and fifty percent sharing. A couple of people that don't want to come to the 'official' support group meetings come to the coffee group. I guess they still need some support but don't feel comfortable in the regular meeting.

"Everyone in our group knows they are not alone in this journey. We all share our experience of living with Parkinson's. The group is a place to get both information and support from people who know how disease changes your daily life. I have fun being the facilitator AND being part of the group. Its feels good to share my experience and it's a good way to give back."

CHAPTER 3:

HOW TO FACILITATE A GROUP MEETING: BUILDING A COMFORTABLE ENVIRONMENT

Just because you started the group does not mean you have to facilitate each meeting. By getting the group up and running, you – perhaps with a team – have taken on the responsibility of organization and planning for the group overall, but there also needs to be someone in charge of moving through the agenda and effectively meting the goals of each individual gathering – this person is the facilitator.

Chapter 4 covers planning and walks you through a meeting from start to finish. But here we review the process skills that good meeting leaders need to have. These skills can help with planning, developing new leaders, resolving conflicts and keeping good communication in your support group. They'll also come in handy in your everyday life!

QUALITIES OF A FACILITATOR

Your job as a PD support group facilitator is not to be a medical or mental health professional. You don't need a PhD or years of training to be a successful support group facilitator. The most important "skill" a facilitator needs to have is the ability to provide a place where people living with PD can come together to get information, share their experiences and support each other – to be with others that know what it is to live with the disease.

After that, there are some models that can be used to start a support group and structure and facilitate the meeting. There are techniques that can be learned to manage group dynamics. These things are shared throughout this guide.

In the Parkinson's Foundation network of support groups, many facilitators are volunteer lay people with PD and/or a family member. These people draw on their personal and professional experiences, skills and passion to lead their groups. It also helps to have the following qualities:

- Knowledge of or willingness to learn about PD and its impact on people
- Comfort with the expression of emotions
- Ability to separate personal needs and group needs
- Strong listening skills
- A sense of humor
- Non-judgmental attitude
- Ability to redirect and facilitate discussion

DO I HAVE TO BE AN EXPERT ON PARKINSON'S TO BE A SUPPORT GROUP FACILITATOR?

You do not have to be a PD expert or have experience living with Parkinson's disease to be a good facilitator. This allows you to be just as open as the group members to new information and learning about PD. It is important to share with the group what kind of background and knowledge you have about Parkinson's so they understand your level of expertise and understanding.

CAN ANYONE LEARN TO FACILITATE A MEETING?

Yes, to a degree. Being a good facilitator is both a skill and an art. It is a skill in that people can learn certain techniques and improve their ability with practice. It is an art in that some people just have more of a knack for it than others.

To put it another way, facilitating means:

- Understanding the goals of the meeting and the organization
- Keeping the group moving forward through the agenda
- Involving everyone in the meeting, including drawing out the quiet participants and controlling the domineering ones
- Making sure that decisions are made democratically
- Fostering connections between group members

HOW DO YOU FACILITATE?

Every person that facilitates a support meeting comes with their set of skills, their unique experience living with Parkinson's, and a different amount of information about PD. Every support group is different, whether it is the process they use to discuss living with PD, the composition of the group or the expectations they have of the group meetings. Therefore, all facilitators fulfill their role in different way. In fact, they may start facilitation in a certain way and then modify it as the group evolves and the facilitator tries different things.

Regardless of the differences mentioned above, a good facilitator wants to make sure that the group process is sound, that everyone is engaged and that the experience is the best it can be for all participants. There are several things that are helpful to consider as you try to build a safe and comfortable environment:

FACILITATOR SKILLS AND TIPS

Here are a few more points to remember that will help to maximize your role as a facilitator:

1. Don't memorize a script.

Reference and stick to your agenda, but be flexible and natural. If people sense that you are reading memorized lines, they might feel like they are being talked down to and won't respond freely.

2. Watch the group's body language

Are people shifting in their seats? Are they bored? Tired? Confused? If folks seem restless or in a haze, you may need to take a break, or speed up or slow down the pace of the meeting. If you see confused looks on too many faces, stop and check in with the group. Make sure that everyone knows what you are discussing and where you are in the agenda, and resolve any confusion as needed.

TIP: Remember that Parkinson's medications can make people drowsy. Some people will tell you that they fall asleep as soon as they sit down to watch TV. If a member falls asleep, it may have nothing to do with the quality of your leadership.

3. Always check back with the group.

Be careful about deciding where the meeting should go. Check back after each major part of the process to see if there are questions and make sure that everyone understands and agrees with decisions that were made.

4. Summarize and pause.

When you finish a point or a part of the meeting process, sum up what was done and decided, and pause for questions and comments before moving on. Learn to "feel out" how long to pause – too short, and people don't really have time to ask questions; too long, and folks will start to get uncomfortable from the silence.

5. Be aware of your own behavior.

If you feel nervous or are losing control, take a break to calm down. Watch that you're not repeating yourself, saying "ah" between each word, or speaking too fast. Pay attention to your voice and physical manner: Are you standing too close to folks so they feel intimidated? Are you making eye contact so people feel engaged? How you act makes an impact on how participants feel.

6. Occupy your hands.

Hold onto a marker, chalk or the back of a chair. Don't play with the change in your pocket!

7. Watch your speech.

Be careful you are not offending or alienating anyone in the group. Use swear words at your own risk!

8. Use body language.

Body language can be a great tool to control the dynamics in the room. Moving up close to a shy, quiet participant and asking them to speak may make them feel more willing, because they can look at you instead of the big group and feel less intimidated. Also, walking around engages people in the process. Don't just stand in front of the room for the entire meeting.

TIP: Many facilitators sit in the circle as part of the group. This allows you to be more a part of the group than an authoritarian presence.

9. Don't talk to the newsprint, blackboard or walls; they can't talk back!

Always wait until you have stopped writing and are facing the group to talk.

**DEALING WITH DISRUPTERS:
PREVENTIONS AND INTERVENTIONS**

How do you protect folks who are worried their ideas will be attacked or mocked? How do you hold back the big talkers who tend to dominate while still making them feel good about their participation?

One option is to establish some ground rules. Not all groups have them, but developing ground rules together can help group members feel invested in the group, physically and emotionally safe, and respected.

TIP: If you are going to establish ground rules, it is best to have only a few key rules. You want to make sure people feel comfortable without feeling burdened. It helps to put the guidelines in writing and to revisit them when a new member joins the group. Common examples of ground rules include the following:

- Any personal information shared must be kept confidential by all members of the group unless someone is a danger to themselves or others.
- One person speaks at a time. Carefully listen to what other people are saying, and raise your hand if you want to speak.
- Respect each other: No mocking, criticizing or attacking another person or his or her ideas.
- Allow everyone who wants to the chance to speak.

Rather than setting these guidelines yourself and imposing them on the group, you can develop ground rules as part of one meeting's agenda. Here is a process you might use:

Don't be ashamed of your story. It will inspire others.

- Begin by telling folks that you want to set up some ground rules, so everyone knows what to expect at each meeting and can hold each other accountable. Put a blank sheet of paper on the wall (or easel, or chalkboard – whatever you have) with the heading "Ground Rules."
- Ask for suggestions from the group. If no one says anything, start by suggesting one yourself. That usually gets people going.
- Before writing anything down, check in with the whole group: "Sue suggested raising our hands if we have something to say. Is that O.K. with everyone?"
- Once you have gotten 5 or 6 good rules up, check to see if there are any final suggestions. If there is overlap, see how you might rephrase or consolidate so that you have a few, clear guidelines.
- When you are finished, ask the group if they agree with these ground rules and are willing to follow them. Make sure you get folks to say "Yes" out loud. It makes a difference!

Even if you establish ground rules, you might have one or more "disrupters" in the group: people who try to dominate, keep going off the agenda, have side conversations with the person sitting next to them, or folks who think they are always right and ridicule or attack others' ideas. Along with the above tips on facilitation, there are some things you can do both to prevent disruption before it occurs and to stop it when it's happening in the meeting.

TRY THESE "PREVENTIONS" WHEN YOU SET UP YOUR MEETING TO AVOID DISRUPTION BEFORE IT OCCURS:

- 1. Find out the group's expectations.**
Uncover at the start what participants think they are meeting for. When you find out, be clear about what will and won't be covered in this meeting. Make plans for how to cover issues that won't be dealt with: Write them down and agree to deal with them at the end of the meeting, or have the group agree on a follow-up meeting to address unresolved issues.

There are lots of ways to find out what the group's expectations of the meeting are. Try asking everyone to finish this sentence: "I want to leave here today knowing..." You don't want people sitting through the meeting feeling angry that they're in the wrong place and no one bothered to ask them what they wanted to achieve here. These folks may act out their frustration during the meeting and become your biggest disrupters.

- 2. Get agreement on the agenda, ground rules and outcomes.**

In other words, agree on the process. These process agreements create a sense of shared accountability and ownership of the meeting, joint responsibility for how the meeting is run, and group investment in whether the outcomes and goals are achieved.

- 3. Listen carefully.**

Don't just pretend. Listen closely to understand a point someone is making. If you are summarizing, always asking the person if you understood their idea correctly.

4. Show respect for experience.

We can't say it enough. Encourage folks to share strategies, stories from their life experiences and lessons they've learned. Value the experience and wisdom in the room.

5. Stay in your facilitator role.

You cannot be an effective facilitator and a participant at the same time. When you cross the line, you risk alienating participants, causing resentment, and losing control of the meeting. It is helpful to offer strategies, resources, and ideas for the group to work with, but NOT opinions.

In fact, all participants should refrain from giving opinions on other people's situations. Remind group members to draw from personal experience when sharing. For example, instead of saying, "You shouldn't have done that!" try, "When it happened to me, I did this..."

TIP: As the facilitator, you should correct erroneous statements from group members. An example might be someone telling the group that she knows coconut oil cures PD because her friend saw it on the internet.

6. Don't be defensive.

If you are attacked or criticized, take a "mental step" backwards before responding. Once you become defensive, you risk losing the group's respect and trust, which might cause members to feel they can't be honest with you.

7. Engage "power players."

These people can turn your meeting into a nightmare if they don't feel that their influence and role are acknowledged and respected. If possible, give them acknowledgment up front at the start of the meeting. Try giving them roles to play during the meeting. For example, you might need a sounding board during breaks to check in with about how the meeting is going.

TRY THESE "INTERVENTIONS" WHEN DISRUPTION IS HAPPENING DURING THE MEETING:

1. Use the agenda and ground rules.

If someone keeps straying from the agenda, has side conversations through the whole meeting or verbally attacks others: Go back to the agenda and ground rules and remind folks of the agreements made at the beginning of the meeting.

2. Have the group decide.

If reminding people of the ground rules doesn't help and someone continues to dominate the meeting, refuses to stick to the agenda, keeps bringing up the same point again and again or challenges how you are handling the meeting, throw it back to the group and ask them how they feel about that person's participation. Let the group support you.

3. Be honest: Say what's going on.

If someone is trying to intimidate you, if you feel upset or undermined or if you need to pull the group behind you, it's better to say what's going on than try to cover it up. Everyone will be aware of the dynamic in the room. The group will get behind you if you are honest and up front about the situation.

4. Use humor.

If there is a lot of tension in the room, if you have people at the meeting who didn't want to be there, or if folks are scared/shy about participating, try a humorous comment or a joke. Humor almost always lightens the mood. It's one of the best tension-relievers we have.

5. Accept or legitimize the point or deal.

If there is someone who keeps expressing doubts about the group's ability to accomplish anything, is bitter and puts down others' suggestions, keeps bringing up the same point over and over or seems to have power issues, try one or more of these approaches:

- Make it clear that you hear how important the issue is to them: "That's a great point, and I think others will agree it is critical."
- Make a bargain to deal with their issue for a short period of time: "O.K., let's address your issue for 5 minutes. Then we ought to move on."
- Agree to defer the issue to the end of the meeting, or set up a committee to explore it further.

6. Use body language.

If side conversations keep occurring, if quiet people need to participate or if attention needs to be re-focused, use body language. Move closer to conversers, or to the quiet ones. Make eye contact with them to get their attention and convey your intent.

7. Take a break.

If less confrontational tactics haven't worked and someone keeps verbally attacking or cutting off others, or otherwise distracting and interrupting the group, it's time to take a break. Invite the disruptive person outside the room and politely but firmly state your feelings about how disruptive their behavior is to the group. Make it clear that the disruption needs to end. At the same time, try to find out what's going on, and see if there are other ways to address that person's concerns.

8. Confront in the room.

If all else has failed, and you're sure the group will support you and it won't create backlash,

confront the disruptive person politely but firmly in the room. Tell the person explicitly that the disruption needs to stop now. Use body language to encourage other group members to support you. This is absolutely the last resort when action must be taken and no alternatives remain!

HOW DO I KNOW IF I AM AN EFFECTIVE GROUP FACILITATOR?

There are several signs of an effective facilitator:

- Does the discussion flow? Does everyone seem to be engaged in the conversation?
- Do other group members ask questions of each other and help facilitate the conversation?
- Do people keep coming back to the meeting month after month?
- Do people recommend the group and/or bring others with them?

There are many reasons why a member is quiet during a meeting or stops attending (either for a period of time or permanently). But you can tell when people are comfortable and engaged. You can also ask the group members if their time together is meeting their needs. It doesn't need to be a personal comment on how you are doing as the facilitator. Just ask the members what parts of the meeting benefit them the most and how they would modify the meeting to make it better.

Acknowledging the good you have in your life is the foundation for all abundance.

– Eckhart Tolle

CHAPTER 4: THE FIRST MEETING

There are several ways to kick off your support group. To attract a crowd, you may decide to offer a general overview of Parkinson's given by a local neurologist or other Parkinson's professional, such as a speech-language pathologist or physical therapist. If you live near a Parkinson's Foundation Chapter office or Center of Excellence, those entities can suggest or even supply you with a speaker. After the presentation, you can let the audience know that a new Parkinson's support group will be starting next month and ask anyone who is interested to sign up with their contact information.

If you don't have access to a qualified speaker or choose not to go this route, it is perfectly acceptable to start with a small group of interested persons. Use the guidelines under the "How to Get People to Attend" section on page 10 to attract your initial members. The first meeting will probably be a small gathering. Don't be discouraged. It can take several months to grow a group. Regardless of the number of participants, you can accomplish a lot at your first meeting.

In fact, at your first meeting – really, the first few meetings – you will establish the group: introduce yourself and your ideas and goals, and ask potential members their expectations for the group. You may suggest a "trial period" to see how things go, especially if you are not sure you will have consistent turnout or if you are nervous about taking on this responsibility. There are several considerations that you should discuss with group members, so everyone is on the same page:

- **Length of meetings:** How long should each meeting last? You'll want at least an hour, most likely one and a half to two hours, to have ample time for discussion.

Depending on the structure and frequency of meetings, you may want to add more time. For example, the group can meet for an hour and a half with some social time afterwards. A mixed group of people with PD and their care partners might meet together for an hour and then break into two groups for the second hour. The group can have a speaker for the first 45 minutes and break into smaller groups for the second 45 minutes.

- **Frequency of meetings:** How often should we meet? Most groups meet monthly, so that's a good place to start. This is a question you may want to revisit after a while. You may also add other types of meetings more frequently later on, such as an exercise group or a social group outside of regular meeting times.
- **Structure of meetings:** What will be the format of each meeting? This does not have to be the same for every meeting, and you will likely want to mix it up over time. But it is helpful to get a sense of what members are most interested in. Here are some support group formats:
 - » Extended turns—Each member takes a turn to share what's on their mind related to a particular topic
 - » Discussion—The facilitator specifies a topic and comes prepared with some questions to get the ball rolling; discussion can also be based on a book, article, webinar or other material
 - » Educational speaker/presentation—An invited guest presents, followed by Q&A
 - » Care and share—Members share openly, no particular order or topic

- **Reminders/cancellation plan:** Reminders are key to having successful group attendance. How will you inform everyone about important updates or if the meeting is cancelled? It is helpful for the group leader or other member to maintain a contact list for all members. There are several efficient and low-cost ways to share reminders:
 - » Email reminders
 - » Telephone tree for reminder calls
 - » Buddy calling system
- **Member roles:** Who will be responsible for various tasks within the group? It might be best to wait until the group gets to know each other before assigning roles, but it is a good thing to mention at your first meeting. Let everyone know that they should expect to play a part in maintaining and growing the group. (See page 26 for a list of roles that group members can take on.)

LOGISTICS AND ROOM ARRANGEMENTS

What may seem like small details – how people sit, whether they are hungry and whether they can hear – can make or break your meeting process. As a facilitator, the logistics of the meeting should be of great concern to you, whether you're responsible for them or not. Some things to consider are as follows:

- **Chairs and chair arrangements:** You might be limited in choice of chair type by what is available in your venue, but remember that people with PD can have trouble getting out of chairs, especially those that don't have arms. When it comes to arranging the chairs, a circle is ideal. Or you can set up around a table, if one is available and the size is right. This

format allows everyone to see each other and encourages discussion, equality, and familiarity. Podiums and lecture-style seating can feel intimidating and formal.

- **Sign-in sheet:** Make sure you have a piece of paper with headings for name, email and phone number to collect contact information as people arrive. It is best to have a table or at least a clipboard for people to write on. You can have the sign-in sheet at the entrance to the meeting, or pass it around.
- **Refreshments:** If you're having refreshments, who is bringing them? Do you need outlets for coffee pots? Can you set things up so folks can get food without disrupting the meeting? Who's cleaning up afterwards?
- **Microphones and audiovisual equipment:** Do you need a microphone? Some PD support groups have successfully used microphones to lessen any embarrassment for soft-spoken members. Can someone set up and test the equipment before you start?
- **Places to hang newsprint:** You may be using a lot of newsprint or other board space during your meeting. Can you use tape without damaging the walls? Is an easel available? Is there enough space so that you can keep important material visible instead of removing it?

THE MEETING PROCESS

In the last chapter we reviewed some facilitation tips and skills. But you're probably wondering, "What do I actually do to keep us moving through our meeting agenda?" Here are the basic steps:

1. Start the meeting on time.

Few of us start our meetings on time. The result? Those who come on time feel cheated that they rushed to get there! Do your best to start on time – no more than five minutes late – and thank everyone who came on time. When latecomers straggle in, don't stop your process. Acknowledge them, but wait until after a break or another appropriate time to have them introduce themselves.

2. Welcome everyone.

Personally welcome everyone who comes. Have people sign in and fill out a nametag. Especially for the first few meetings, have a supply of nametags on hand.

TIP: First names are usually sufficient, and may even be preferred by some members. If attendance is low, don't worry or complain. Thank the people who are there, and tell everyone to invite a friend to the next meeting!

3. Make introductions.

First, introduce yourself. Give people some background on you: your connection to Parkinson's, why you wanted to start this group. Credibility doesn't mean you have a social work degree or 15 years of facilitation experience, but potential group members will want to know why you are doing the facilitation and what has led you to this role.

Once you've introduced yourself, everyone else in the group should have a chance to speak. There are lots of ways for people to introduce themselves other than just their names. One option is to ask an introductory question(s) at the beginning of each meeting. This is called an "icebreaker." Icebreakers can:

- Break down feelings of unfamiliarity and shyness.
- Help people open up.
- Build a sense of being part of a team.

- Create outreach opportunities.
- Help share participants' skills and experiences.
- Remind people they are more than just their disease.

For the first meeting, information about attendees' experience with Parkinson's are most relevant, and there are plenty of options:

- What brings you to this meeting?
- What do you want to know about Parkinson's disease?
- What do you want to know about how to live well with Parkinson's?

As your group continues, you can ask questions that get more in depth into life with Parkinson's. For example:

- What is one Parkinson's-related challenge you have overcome since the last meeting?
- What is one area of PD research you're particularly interested in?

These questions will not only give you insight into your group members, but may also help you identify topics for future meetings.

Some days you might want to ask questions that have nothing to do with Parkinson's:

- What is/was your occupation?
- What do you do for fun?
- What is your favorite food?
- What is the last good book you read?
- What is your hidden talent?

Regardless of the subject matter, opening questions are a great way to help new and old members learn something new about each other at every meeting.

Make sure that each person is heard. Some people with PD speak more slowly or softly than others. It is OK for you (or a care partner) to assist, but do not speak for that person. It helps if the facilitator repeats each name as you go around, with a statement like, "We're glad you're here, Mary!"

TIP: Many PD support groups pass around a hand-held microphone 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.

4. Review the agenda and objectives for the first meeting.

It is important to have an agenda for the first meeting to keep the meeting on track and make best use of everyone's time. A sample first meeting agenda might include the following:

- Welcome everybody and do introductions.
 - Discuss expectations and goals.
 - Develop ground rules.
 - Brainstorm future meeting topics along with ideas on how to approach them.
- For example:
- » Managing the motor symptoms of PD – invite a movement disorders specialist or general neurologist
 - » Managing depression and anxiety in PD – watch an archived webinar from the Parkinson's Foundation and discuss
 - » Tips for living your best life with PD – members share their best ideas
- Vote on one of the brainstormed topics to be the focus of the next meeting.
 - Thank everyone, announce date and time of next meeting and adjourn.

There are plenty of other decisions to be made to get a group up and running, but not everything can be addressed at the first meeting. It is a good strategy to cover at

least one logistical item at each meeting. For example, if the group votes on "Managing depression and anxiety" as the topic for the next meeting, before you watch the webinar, include on the agenda a discussion of whether the group will have a kitty. Some groups have a voluntary \$1-2 donation per member per meeting. The funds can be used for meeting operations such as postage, photocopying, book purchases and subscriptions; to make annual donations to a Parkinson's-specific charity; or to send flowers

5. Encourage participation and foster connections.

This is one of your main jobs as a facilitator. It's up to you to get those who need to listen and those who ought to speak to do so. Encourage people to share their experiences and ideas and urge people with relevant background information to share it at appropriate times. Making interpersonal connections is important; it fosters a true feeling of support. One way to facilitate connections is to invite people to respond to others' stories or questions. You can ask, "Who can relate to what was just shared?" Or, "Does anyone have a similar experience to share?"

6. Stick to the agenda.

Groups have a tendency to wander off topic, sometimes without knowing it. If you notice the discussion wandering, bring it to the group's attention: "That's an interesting issue. Let's get back to the original discussion and bookmark that topic for another time."

7. Seek commitments.

Getting commitments for future involvement is often a meeting goal. You want members to feel invested in the group, and also to ease the burden on you, the facilitator. Ask members what they would be willing to do to help the group succeed. If someone is involved in an exercise program, would that person be willing to lead a 5-10 minute session at the start of each meeting? Would a member be

willing to invite his or her neurologist to speak to the group? Don't try to remember all the commitments – write down the names, skills and connections, then make sure to use them.

Many groups create a buddy system for members. This might be based on geography or similarity of life stage or experience. It can be helpful to pair a newer member with an "old timer" for a few months.

8. Avoid detailed decision-making.

Sometimes groups get so wrapped up in debating a small issue – e.g., the color of napkins – that they lose sight of the real issues they are facing. Especially in the first meeting, don't try to cover too much or get too far into the weeds. In future meetings you will assign roles and create committees; many decisions can wait until someone (or a small group) is designated to address them.

9. Bring closure to each item.

Just like we tend to go off topic and get in the weeds, many groups discuss things for much longer than they need to unless a facilitator helps people recognize that they're basically in agreement. Summarize a consensus position, or ask someone in the group to summarize the points of agreement, and then move forward. If one or two people disagree, state the situation as clearly as you can: "Tom and Levonia have other feelings on this matter, but everyone else is heading in this direction. Perhaps we can move on for now, in the direction that most of the group wants, and Tom and Levonia can get back to us with suggestions on how to accommodate their concerns." You may even suggest taking a break so Tom and Levonia can come up with some options.

Some groups feel strongly about reaching consensus on issues before moving ahead. If your group is one of them, be sure to read a good article or book on consensus decision-

making. Many groups find that voting is a fine way to make decisions. A good rule of thumb is that a vote must pass by a two-thirds majority for it to be a valid decision. For most groups to work well, they should seek consensus where possible, but take votes when needed to move things along.

10. Respect everyone's rights

The facilitator makes sure everyone is comfortable and engaged. This means encouraging quiet folks to speak while keeping dominant people from monopolizing the meeting or ridiculing the ideas of others.

Sometimes, people dominate a discussion because they are passionate about an issue and have a lot to say. One way to channel their interest is to suggest that they consider serving on a committee or task force on that issue. Other people, however, talk to hear themselves talk. If someone like that shows up at your meeting, review chapter 3 for tips on dealing with "disrupters."

11. Be flexible.

Sometimes issues will arise that take up much more time than you planned for. Something may come up in discussion that no one had thought of before, or that resonates so strongly with the group that everyone wants to share their thoughts on it. In this case, you may run over time or have to alter your agenda. It is ok to follow the energy of the group as long as you do not have an invited guest.

12. Summarize the meeting results and needed follow-ups.

Before ending the meeting, summarize the key decisions and points that were made, as well as any follow-up actions that were agreed on and need to take place. Remind folks how much good work was done and how effective the meeting was. Refer back to the objectives or outcomes to show how much you accomplished.

13. Thank participants.

Take a minute to thank people who prepared things for the meeting, set up the room, brought refreshments, or did any work towards making the meeting happen. Thank all of the participants for their input and energy and for making the meeting a success.

14. Close the meeting.

Just as people appreciate a meeting that starts on time, they appreciate a meeting that ends on time! Before everyone leaves, remind them to fill out the sign-in sheet so you have their names and contact information to notify them about the next meeting. Some groups share the contact list among members, so people can keep in touch between meetings. You can add a field to the sign-in sheet that says, "You may share my information with others in the group," and people can write "yes" or "no." Make sure everyone understands that the list should not be shared outside the group.

A nice way to close a meeting is to go around the room and have people say one word that describes how they are feeling now that all of this discussion has taken place. You'll usually get answers from "exhausted" to "energized!" If it's been a good meeting, even the "exhausted" folks will linger, chatting with others before leaving.

AFTER THE FIRST MEETING

Reflect on what you just accomplished: 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 think about what, if anything, you will do differently at the next meeting to make things go even better.

TIP: For reasons of confidentiality, some members may prefer that "Parkinson's" not appear on the outside of any mailings they receive from the group.

There are going to be times when you learn more about the world you're entering and feel defeated when you see the gap between the ideal and the reality... But that's something we'll all face. The people that face those obstacles and overcome them are people whose dreams come true.

- Tsugumi Ohba

NOT KNOWING ABOUT PARKINSON'S WORKED IN MY FAVOR

Libby is a registered nurse that has worked in long-term care facilities for her entire career, but she did not have any special background or training in Parkinson's disease. So when she took over the role of facilitator of a PD support group, she was honest with the group that she had a lot to learn about the disease. "The group enjoys teaching me about PD. The lack of knowledge about the illness has worked in my favor.

"The support group meets in the long-term care facility that I work at. We have about 10 to 12 people in the group. I kick off the meeting and keep it on track. We meet for an hour and then we have a half hour for coffee. I come with a question of the day, usually a question about living with PD. This warms people up. They always have things to add and the discussion just happens.

"It's a mixed group of people. Some members have Parkinson's disease, some are care partners. Some people come alone, but it's mostly couples. Several times a year we split up into groups, one made up of people with the disease and the other for care partners.

"I think it is important to let them talk about what's going on – especially the care partners. They don't always feel comfortable talking candidly in front of their spouse who has PD.

"The group is also mixed in regards to the stages of Parkinson's that people are in. The members in the later stages are resources for those who are in the beginning stages. The more experienced group helps the others solve the challenges that come with living with disease. They all share their

experience and information – like where to go to find neurologists and medical professionals that really understand PD. I thought the people in the later stages would scare those just beginning their PD journey, but that is not the case."

Libby sees her primary role as coming up with programs that are meaningful. "A facilitator needs to be inquisitive about PD and willing to learn more about the disease by reading and looking at websites. The members always want information on medications and clinical trials. They love having speakers. I found someone to talk about physical therapy. The group has requested speakers on pharmacology and ophthalmology. It can be hard to find medical professionals with knowledge and experience in PD, especially in a rural area like ours. I have a collection of books they can check out. I have a list of volunteer groups that can provide help and resources.

"A good facilitator needs to be perceptive and knowledgeable about group dynamics. I have one couple that tends to take over the conversation. When this happens, I watch others in the group to see if their attention has wandered. You can't be afraid of interrupting and getting things back on track. You also need to draw people out and get them to participate in the conversation. This can be tricky because you also want to be respectful of a person that does not want to share. A facilitator needs a personality that is assertive and gentle at the same time.

"I didn't know what I was getting into when I started. I see the residents and their families struggle. But I feel that I am helping in some way for people who need support. I find being a facilitator is very fulfilling."

CHAPTER 5: KEEPING IT GOING

ROLES AND RESPONSIBILITIES

The support group facilitator has many roles and responsibilities:

- Handle meeting logistics (make arrangements for meeting room, etc.)
- Facilitate group processes and draw out everyone's participation in the discussion
- Encourage group participants to provide assistance and emotional support to one another
- Obtain speakers on issues of interest and communicate with speakers
- Assist group participants in finding community resources
- Develop an emergency plan

TIP: If you have questions or concerns about any of these responsibilities, the Parkinson's Foundation has answers for you. Contact your local Parkinson's Foundation Chapter or the Helpline at 1-800-4PD-INFO (473-4636).

The leader cannot, and should not, do it all. It may seem simplest at first to shoulder all the responsibility for group functions, but it is a sure road to burnout. You can preserve your energy — and the life of the group — by filling a few basic jobs. Whether you are a person with Parkinson's, care partner or healthcare professional, you need support!

Starting as early as the first or second meeting, we recommend facilitators find ways to share responsibilities with others in the group. This brings group members together and promotes ownership and cohesion within the group.

TIP: Depending on the size of your group, you may fill only some of the roles below. These are suggestions, and you must decide what is right for your group.

- **Co-leader(s):** One or two other group members who share the job of planning and leading the meetings, especially in the leader's absence. Everybody needs a backup!
- **Telephone contact(s):** The person(s) whose name(s) and phone number(s) is listed in public announcements.
- **Secretary:** Keeps the membership list up-to-date, including addresses, emails and phone numbers. Prepares and sends meeting announcements (if this is done). Handles the group's correspondence (e.g., thank you notes to guest speakers).
- **Hospitality committee:** It is helpful to have at least a couple people for this committee, as there are many aspects to being a good host!
 - » Members of the hospitality committee serve as greeters: have everyone fill out a nametag and sign the sign-in sheet when they arrive. Greeters are particularly encouraging for new members and people who have been away from the group for a while. If you couldn't make the last meeting or two, it is nice to have someone there to say, "You were missed!"
 - » Depending on the meeting location and needs, this group also makes arrangements for refreshments for each meeting, including food and beverage as well as plates, cups, utensils, etc. You might seek donations from local restaurants or markets, or you might maintain a sign-up sheet for a different group member to bring snacks each meeting.

- » The hospitality committee can also be in charge of arranging chairs in the appropriate format if they're not already set up in a circle. Ask all group members to put their chairs back at the end of the meeting if a different set-up is needed.
- **Publicity person/committee:** Makes sure that the meeting announcement gets to the local papers, hospitals, physician's offices, churches, senior centers and other possible venues for outreach.

If your group increases in size, you may find a need for additional roles, such as the ones below. Again, these are only suggestions, and you and your members will decide what is needed and how much responsibility people can take on.

- **Outreach coordinator:** Works to recruit new members, connecting with local doctors' offices, churches, community/senior centers, etc., to let others know about the group. Can also visit homebound or hospitalized members either in person or by telephone and bring or send materials from meetings.
- **Treasurer:** Opens a bank account for the group to keep member contributions and memorials. The treasurer can also work with the co-leaders and hospitality committee to secure sponsorship from pharmaceutical companies and local businesses and with event chairs on fundraising if your group decides to do this.
- **Librarian:** Keeps PD books, videos, newsletters and other materials in order and available for members to use, and maintains a sign-out list for items that are borrowed. Depending on where your meetings are held, there might be a space on-site for you to store materials. Otherwise they will need to be brought home after each meeting.

- **Historian:** Keeps a scrapbook of the group's activities, including photographs, newspaper clippings and other souvenirs; it helps if this person is good with a camera!
- **Social coordinator:** Organizes social activities for group members outside regular meeting times.

Due to PD or other circumstances, some group members may hesitate to commit to a job. No one should be pressured into taking on a title. However, it can be helpful to have a buddy system in place for each role, where two people work together, or one person is the primary and one person is the backup. Parkinson's is unpredictable, so it might make people more comfortable taking on a role if they know there is another person to help. Another option that might decrease someone's hesitation is to put "term limits" on the jobs – for example, one year. People may choose to keep their roles for longer, but they only commit to a year at a time, so they can reevaluate their situation as needed.

Many groups have a **planning committee** that meets two or three times a year to plan the year's agenda. Key members of this committee are the co-leaders, secretary, treasurer and publicity committee, though it is nice to welcome anyone who is interested in participating.

TIP: 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 tasks and assume an advisory or consultant role, the better. This supportive role ("on tap but not on top") 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.

Over a 12-month period, your group will meet several times, with the total number of meetings depending on local weather patterns and the preferences of the members. Many groups avoid difficult winter months or especially slow summer months. It helps to know the schedule in advance to determine best times to invite speakers and plan particular activities.

TIP: A full year agenda should include a mix of educational and socialization events. This might mean you alternate – one month with a speaker presentation, one month with a bingo night – or you might stick with regular educational events and add social activities outside regular meeting times.

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 "Care and Share" sessions scheduled in between. "Care and Share" sessions are as important as the educational meetings, as they help build connections and strengthen bonds among group members. (See page 20, "The Meeting Process," for tips on how to foster connections among members). One or two social or public awareness activities should fit naturally at certain times of the year. For example, April is National Parkinson's Awareness month, an ideal time for your group to plan an outreach activity

in your community.

To the extent that you can, it is a good idea to publish your calendar in advance. This can be helpful to members who like to plan ahead or who need a tool to entice reluctant spouses or other family members to attend. Importantly, advance planning will also make it easier to obtain speakers. See the section "Working with Speakers" on page 30 for more information.

Here is a sample calendar for a year of PD support group meetings:

September - Parkinson's update by a local neurologist or nurse specialist

October - "Care and Share" session: open discussion about living with PD; may separate into PD and caregiver groups

November - Guest speaker on coping with PD and/or accessing local resources (November is National Family Caregivers Month)

December - Holiday party

January - Choose one of the archived webinars on www.parkinson.org/webinars to view as a group, with discussion to follow

February - Video with speaker on exercise and PD; everyone participates!

March - Speaker on couple and/or family issues in PD (e.g., sexuality); may be combined with a "Care and Share" session

April - Walk-a-thon, bike ride, bake sale or health fair to raise awareness and research funds for PD (April is National Parkinson's Awareness Month); find out when your local Moving Day® A Walk for Parkinson's, is (www.movingdaywalk.org) and get involved with Parkinson's Champions (www.parkinson.org/champions)

May - Speaker on medications and/or nutrition and PD; e.g., neurologist, nurse, pharmacist, dietician

June - Local excursion or indoor travelogue with a travel agent who arranges trips for people with disabilities

July - Group picnic or day at the park

August - Take a month off and arrange a postcard or email exchange instead!

HERE ARE SOME TOPIC IDEAS TO GET YOU STARTED (AND KEEP YOU GOING!*):

About Parkinson's

- Beyond medications: Parkinson's treatment options
- Is Parkinson's a family disease?
- Parkinson's medications: What's available and what's on the horizon?
- Parkinson's research update

Living with Parkinson's

- Changes and adaptation: Loss, grief, and growth
- Creativity and PD: Hobbies and crafts
- Dealing with the diagnosis
- Driving and community: Getting around with PD
- Exercise as medicine
- Handwriting and computer skills
- Help! Being prepared for an emergency
- Intimacy and sexuality
- Long-term care and financial planning
- Memory and communication skills
- Mobility: Getting around safely and smoothly
- PD as a chronic illness: Living your best life
- PD in the workplace What is the role of diet in PD?
- Sleep problems
- Speech and swallowing

- Stress management, relaxation and/or massage Talking to children (and grandchildren) about PD
- The PD consumer: Using adaptive equipment
- Thinking and behavior changes
- Tips and tools for activities of daily living

TIP: Depending on the length of your meetings, you might combine some of the topics above into a symposium-style event, or organize a series. For example, a "Taboo Topics" series that addresses issues that people are sometimes shy about discussing, such as thinking and behavior changes, intimacy and sexuality and long-term care and financial planning; or a series for people with young-onset PD that covers Parkinson's in the workplace and talking to children about PD.

For the Care Partner

- Building your support network
- Caring smarter, not harder
- Dealing with non-motor symptoms of PD
- Getting children and other family members involved Planning your own future
- Transitions in care
- What is self-care?

Healthcare and Community Resources

- Accessible dining, recreation and travel options
- Adult day care: Is it for us?
- Aging in our county: Transportation and other resources
- The "ins and outs" of home care
- What you need to know about assisted living facilities, Continuum of Care retirement communities, and nursing homes

*See Appendices C and D for meeting guides.

WORKING WITH SPEAKERS

Speaker presentations are a popular part of support group meetings: They share their expertise as it applies to Parkinson's, and members get to ask questions of the "expert." It's typical to have the speaker talk for about 30-45 minutes and then open it up for discussion, either with the entire group or split up into smaller groups. It is not necessary to have a speaker at every meeting, but here are some tips for working with speakers when you do.

PD support groups have found that most speakers are available at no charge, though some groups offer to pay for travel expenses or offer a small token of thanks (a group T-shirt or a gift card). If a potential speaker asks for a stipend, do your research. Make sure they are well-known and well-respected, and discuss with the group whether the fee is worth it.

Some medical professionals receive sponsorship from pharmaceutical companies to give disease state presentations at support groups and events. For example, a company that produces a medication for people who experience an unexpected or inconvenient "off" episode likely works with doctors who will give talks to support groups about managing "off" time. These presentations can be educational for your group, and the pharmaceutical company may even offer to provide literature and refreshments. (Your regional Center of Excellence or local neurologist's office can give you the names of the PD pharmaceutical representatives in your area.) You'll want to make sure that the speaker understands you are interested in information about the disease, not a sales pitch for a particular drug or product.

Here is a speaker preparation checklist:

Speaker invitation

Regardless of whether you are inviting someone you know or someone you've never worked with before, and whether you ask in person or via email, it is helpful to provide the following information to a potential speaker:

- The topic you would like the speaker to present and the length of the presentation (e.g., 30-minute presentation followed by 15-minute Q&A)
- The date, time, and location of your meeting; it can be helpful to inform the speaker of your ongoing schedule. If he or she has a conflict with the proposed date, he might be able to present at a different meeting in the future.
- The average size of your group
- Some basic information about your members, such as age range and makeup of the group (how many patients and care partners)

Once the speaker responds

If the speaker declines:

- Thank him or her.
- Let him or her know that the invitation is open if she would like to speak to the group in the future.

If the speaker accepts:

- Confirm the date, time, location and topic in writing as soon as the speaker agrees.
- Request a brief biography and photo to use for publicity purposes, and to introduce him or her on the day of the meeting.
- Add the speaker's name and title of presentation to your events calendar, if you have one.
- Ask if the speaker will share information about this event in particular, and your support group in general, with his or

her patients. Then mail or deliver your support group flyer, calendar and/or other promotional materials.

- Let the speaker know what, if any, A/V equipment is available. If you do not have the ability for the speaker to show a PowerPoint presentation, make this clear, as many presenters rely on slides for their talks. Some speakers have their own laptop computers and LCD projectors if there aren't any available at your venue, so this might be an option.

Two weeks before the meeting

- Send the speaker a reminder (e.g., "We're looking forward to seeing you on...") along with a copy of the meeting announcement.
- Remind the speaker about the extent of the audience's knowledge and any specific items you'd like him or her to address within the agreed upon topic area. Practical tips are greatly valued by support group members.
- 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 record the presentation (if you plan to do so).
- Let the speaker know he or she can bring materials or handouts for group members.
- Make sure he or she has good directions and a contact person to call in case of any last-minute issues. Also make sure you have the speaker's day-of-event contact number.
- Determine who will introduce the speaker at the meeting. This person should be prepared with the speaker's background information.

Day of meeting

- Whoever has been communicating with the speaker should greet him or her on arrival and provide a nametag.
- If a blackboard or flip chart is available, it is helpful to write the speaker's name on it in large letters.
- If the speaker will be presenting with slides, load the presentation onto the computer and test it before the meeting begins.
- Before the meeting starts, ask the speaker whether he or she prefers to field questions as they come up or to take all questions at the end of the presentation. Many speakers prefer to take questions as they arise so their answers are in context.
- Encourage the speaker to use the microphone so that everyone can hear. Group members may use the mic later to ask questions.
- 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; "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 handheld microphone is not available).
- Someone should keep track of the time, particularly after the presentation for the Q&A. 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!
- Provide a warm thank you on behalf of the group at the end of the presentation.

- Give the speaker support group flyers or other promotional material to distribute at his or her clinic.

TIP: Make sure your group members understand that these speakers/occasions are not personal consultations. The presentations and any answers given during the Q&A session should not replace their doctor visits, and they should not use up the group's time for specific, personal needs and questions.

After the meeting

- Send a personalized thank you note to the speaker.
- Place speakers on your group 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.

Possible speakers for PD support group meetings

- Adult day care or nursing home administrator
- Attorney
- Dance or music instructor
- Dietician
- Exercise physiologist
- Group fitness professional
- Health educator
- Hospital or nursing home chaplain
- Local artist or author
- Member of a neighboring PD support group
- Neurologist/movement disorders specialist
- Nurse specialist
- Occupational therapist
- Owner of a local medical equipment company
- Pharmacist
- Pharmaceutical representative

- Physical therapist
- Psychologist or other mental health counselor
- Recreation therapist
- Representative from Area Agency on Aging or County Office on Aging
- Social worker
- Speaker from local museum or historical site
- Speech-language pathologist
- Tax specialist
- Travel

Advantages to having in-house speakers

In addition to all the external speakers listed above, consider your members, both people with Parkinson's and care partners, as potential speakers. Parkinson's does not define you. Your group members likely have personal or professional experience that will be valuable to the group. Maybe someone had a recent publication, art show or travel adventure they could share. Or maybe a member who is coping with depression or some other aspect of PD would like to guide a discussion. This allows group members to get to know each other from a different perspective. And because participants are already familiar with each other, members may have to explain themselves less when asking the speaker questions. Finally, coming in as a speaker can boost confidence in the group member giving the presentation.

MARKETING YOUR SUPPORT GROUP

Now that you have a full year's agenda planned, including some good speakers, how will you let people know about it? Your members, of course, can do word-of-mouth publicity. But what about the rest of your community? Your publicity committee should spearhead these efforts.

Here are some marketing suggestions to build on those offered in the section "How do we get people to attend?" on page 10:

- If you have a speaker or topic you think people will be particularly interested in, use that as a "draw." Include a short, descriptive paragraph along with the usual meeting announcement.
- A meeting topic stated in the form of a question may be more enticing than a simple statement; for example, use "Is Parkinson's Disease Inherited?" instead of "Heredity and Parkinson's."
- The speaker may have media contacts that you can use. For example, the public relations department at his or her hospital or organization maybe be willing to send an email announcement to their listserv or network about the speaker's presentation or post on social media.
- Make sure that every meeting flyer and other piece of publicity includes the words "Parkinson's disease." You never know on whose desk, or in whose home, that piece will wind up – even if that person does not have PD, he or she may know someone who does!
- Start a social media page for your group. People frequently turn to Facebook for local events and information, so it is good to post your meeting schedule there, as well as contact information and any other group basics. New people can find your group this way, and members may use it to connect in between meetings.
- Collect motivational personal stories from participants to showcase in your communications – print newsletters, emails, web pages, social media, etc. These can be anonymous if people do not want to share their names or photos.
- Research other Parkinson's-specific programs at local hospitals and ask them to share your group with their lists. Also ask if they can include your flyer in their waiting room.

- Reach out to local hospitals, rehabilitation centers and allied health practices that might have patients with Parkinson's. Ask if they can include your flyer in their waiting room.
- If you have a small budget, consider placing a quarter page ad in a newspaper or community circular.

Don't forget:

- Ask your current participants to share with their networks, such as book clubs or community service organizations. Word of mouth is still one of the strongest marketing tools.
- Let your local Parkinson's Foundation Chapter and/or Center of Excellence know about your group and your schedule. They might be able to share information about your group on their website or social media, or in a newsletter.

Working with media

- Learn and use the names of media contacts at your local newspapers and other news outlets, and don't be shy about making follow-up phone calls. Be courteous and brief—you are doing them a favor by helping them to learn more about a neurologic condition that affects more than a million Americans. There are many aspects of PD and lots of research going on. Parkinson's could be a topic they want to cover and return to, and they can use you as a source for quotes and information.
- If you don't hear back, don't be discouraged. Remember that media and public relations professionals are bombarded with story leads on a daily basis. They may become distracted, and you may be displaced by a "bigger" story. But with periodic, friendly reminders, they might agree to cover Parkinson's and include your group in an upcoming story.

ISSUES THAT MAY AFFECT THE GROUP PROCESS

Every PD support group will have some challenges for the facilitator, but there are no issues that you can't handle with some common sense and basic information. Remember, a support group is a place for people to come together and support each other on their Parkinson's journey.

PD SYMPTOMS THAT MAY AFFECT GROUP PARTICIPATION

Thinking changes

- Some people experience slowness of thought, so it might take them longer to think about how they want to respond to discussion content.
- Some people have "word-finding" difficulty in the middle of a sentence.
- The ability to concentrate may be impaired.

TIPS:

- Do not rush through meeting content. Allow time for people to think, process and respond.
- Concisely summarize content occasionally to make sure everyone is on the same page.
- As a discussion topic is coming to a close, pause and ask if anyone else has something to say.

Speech impairment

- Speech can be much softer.
- Some people have difficulty articulating and enunciating words.

TIPS:

- Encourage the person to speak loudly and concisely.
- Encourage good posture: with stopped posture, the voice is projected downward.

- Encourage the group to support soft-spoken members in their efforts and give positive feedback when their communication is heard.

Rigidity

- A person may have reduced facial expression, making them appear bored or upset when they are not.
- Stiffness can reduce the body language that we rely on for feedback in conversations.

TIPS:

- Ask questions so that verbal information can compensate for reduced body language.
- Periodically check in with the group to see how everyone is feeling.

WHAT IF A MEMBER COMES TO THE MEETING WITH THE NEW "CURE" OR MEDICATION FOR PARKINSON'S?

Be cautious. Let the member share their information and how they think it has worked for them, but explain that each person's Parkinson's is unique in terms of symptoms, tolerance of medications and other health problems. Ask if there is any research to support the use of that treatment. Everyone should check with their medical professional to get more information and see if it might work for them. If you know something to be medically inaccurate, correct it.

You can also redirect the conversation by saying, "That's interesting, let's talk about it later during the break." Or you can make the discussion more inclusive by saying, "That exercise routine sounds great. What exercises have others found helpful?" The facilitator's job is to bring the conversation back to the entire group and the topic of the meeting.

DECLINING HEALTH OF A MEMBER

The progressive and unpredictable nature of Parkinson's is often a cause for anxiety, and one of the most challenging events faced by a support group for people with Parkinson's is the serious decline or death of a participant. An effective way to deal with the initial shock is to allow time for everyone to talk about what the loss means to them. Some will have been closer to the person than others and may, understandably, have a more intense reaction.

Many times a group will effectively process the loss and move on. In other situations, the loss may cause the group to deflate and lose energy. Read on for tips on how to re-engage and re-energize your group.

KEEPING ATTENDANCE UP – WHEN THE GROUP IS "DOWN"

Even the most upbeat PD support group can have its down times. There are many possible factors:

- 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 it is OK for the group to take a break. 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 revive your group:

- Ask each member to call a member who's been away for a while and invite him or her back. If he or she cannot attend, offer to visit.
- Renew your publicity efforts in local newspapers and local hospitals. Do they know that you are still here?
- Extend your outreach – have you tried all the marketing tactics outlined on pages 32-33? Have you advertised online?
- Plan a social gathering outside the regular meeting time to reconnect with each other beyond Parkinson's. For example, 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 (or think of another topic to generate discussion).
- Visit a neighboring PD support group. See how their meeting runs and talk to their members and leadership. You will probably find that they have similar difficulties, and you may get a few good ideas.
- 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.

TIP: If you live in a state with a local Parkinson's Foundation Chapter, contact them for ideas on revitalizing your group. Not in a state with a chapter? Call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636). Our PD Information Specialists can brainstorm ideas and make suggestions. Some of them are long-time support group facilitators themselves.

EVALUATION

Periodically, you – probably working with your planning committee – should revisit many of the same areas you considered when you were first starting your group. Ask yourselves, and possibly your group members, some questions to assess whether the group is on the right track and continues to meet everyone's goals.

- **Group size:**
 - » Is the group too big? Consider splitting into homogeneous sub-groups. For example, individuals who are all in early stages of the disease can meet together to discuss similar issues they might be facing. Research has shown that homogenous groups are more participant-friendly than mixed groups. Care partners may form their own groups, too.
 - » Is the group too small? Call on your publicity committee to step up their efforts. Has your group become complacent about advertising itself and welcoming new members? See page 33 for outreach ideas. You might make marketing a topic on an upcoming meeting agenda, so the whole group can brainstorm.
- **Sub-groups:** Even if the group is not too big, you might want to have a separate group for care partners. Both people with Parkinson's and caregivers are able to speak more freely and ask more candid questions when their loved ones are not in the room. If you do not have enough people to support completely separate groups for people with Parkinson's and care partners, you may do the first half of the meeting together (for example, everyone listens to a neurologist presentation with Q&A), then split into small groups for further discussion.

- **Group dynamic:** Is everyone comfortable speaking up? Do certain people dominate the group? Revisit the section "Dealing with Disrupters" on page 15.
- **Location:** Is it convenient? How far do participants travel on average to get there? How do they get there: do they drive themselves, have someone else drive them, take public transportation or another option? Is there parking? All of these factors influence how likely people are to come back.
- **Time/frequency:** How often are meetings held, and at what time? If your group starts with many people who are still working, but evolves to a group where people have mostly retired, you might shift the day or time of your meetings.

These suggestions likely won't solve every issue, but they may help reestablish your group, or lead to something new. 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!

Be *strong*,
Be *fearless*,
Be *beautiful*.

And believe that anything is possible
when you have the right people
there to support you.

- Misty Copeland

CHAPTER 6:

SPECIAL GROUPS: YOUNG ONSET, NEWLY DIAGNOSED AND CARE PARTNERS

YOUNG ONSET

There are two challenges in starting and running a group for people with young-onset Parkinson's disease (YOPD). The first one is defining what "young onset" means. Medically, it refers to someone diagnosed with PD before age 40, but for support group purposes it probably has more to do with life stage than age. As a group, young onset folks generally still have school-age children at home (if they have children), are working and may or may not have some responsibilities for caring for their own aging parents. As an example, a woman diagnosed at age 50 with two children ages 10 and 7 has more in common with a 40-year-old woman with elementary school age children than another 50-year-old woman whose children are grown and has grandchildren. Often anyone diagnosed under the age of 60 believes they have young-onset PD. It is important when facilitating a YOPD group to screen participants carefully and make sure they are a good match for other members.

The second problem when running a YOPD group is how long does someone remain in the group? There are YOPD groups who still bill themselves as such even though their members have had the disease for 20+ years, and they are in their 60s and 70s. Members of these groups maintain that they will always be young onset patients and have different experiences than people diagnosed later in life. But imagine what it is like for a newly diagnosed 48-year-old to walk into one of these groups. If members do not want to transition into a regular Parkinson's support group, it is better to ask them to rename

their group to something like "Young Onset: Diagnosed Five Years or More" to give new members a better idea of the group's actual make-up.

Meeting topics for YOPD groups include everything that regular PD groups would talk about, with some additions:

1. How long do I stay on the job? (Weighing your desire and ability to continue working with the chance of foregoing employer benefits like short- and long-term disability if you are laid off)
2. Filing for Social Security Disability (what to expect)
3. Talking to your children about Parkinson's disease
4. Keeping your relationships strong
5. Disclosing your diagnosis to your employer and asking for accommodations
6. Financial planning now and for the future

TIP: "Young onset" has more to do with the life stage of the person than his or her chronological age.

NEWLY DIAGNOSED

These groups are often time-limited and stress education about Parkinson's disease and how to live well with it. Often, they are sponsored by a movement disorders clinic or Chapter with access to healthcare professionals from different disciplines who treat Parkinson's. These groups meet for four, six, eight or twelve weeks, and then members are encouraged to join regular, ongoing groups. New groups often start several times a year, and topics may include the following:

- What is Parkinson's disease?
- Medications
- Physical therapy and exercise
- Speech and swallowing
- More than a movement disorder – depression and anxiety
- The patient role in managing PD

CARE PARTNERS

Parkinson's care partners need a place to share their experiences, but it can be hard to get a group started and keep it going. By the time care partners realize they need a group of their own, it may not be safe to leave the person with Parkinson's home alone. Arranging for someone to care for the person with Parkinson's while the care partner attends a meeting can seem like one more stressor in an already over-stressed life.

If you are considering starting a care partners only group, you might want to hold it at the same time and place that a Parkinson's exercise program is taking place. Or, if you already hold a regular support group meeting, you might decide to break the group into people with Parkinson's and care partners once every quarter. Both groups will still need a facilitator. If there is another Parkinson's support group in the area, that facilitator may be willing to help. You may also be able to reach out to a former care partner member of your group whose loved one with Parkinson's has passed away. After sufficient time has gone by, many former care partners are happy to give back to a group that meant so much to them in the past.

TIP: If you can break your group apart, you will find that both the care partners and the people with Parkinson's are much more forthcoming when they aren't together.

Was it you or I who stumbled first? It does not matter. The one of us who finds the strength to get up first, must help the other.

- Vera Nazarian

I LIKE A LITTLE STRUCTURE

Teresa started going to a caregiver support group. She tried the group two times and she ran out in tears both times. "My husband had been diagnosed with Parkinson's disease, but things were still pretty good. The support group was made up of caregivers in the 'advanced' stage of their loved one's disease. They didn't need a lot more information – they could have taught a course on PD with all they knew about the disease from living with it. They needed the support and companionship of others trying to get through the day with grace and a little humor.

"The group I needed was one that was exploring the implications of their partner's PD. What impact is PD going to have on our lives as caregivers? I knew that I needed to prepare for the surprises and changes PD was going to give me as I dealt with my new caregiver role. I wasn't in denial, but I also did not need to deal with hard and emotional stuff before its time.

"I tried another support group, this time it was an 'intermediate' group that couples attended together. This group gave me great information. But it was focused on the person with PD, and I did not think it was a place where I could ask the questions I needed to ask as a care partner.

"Finally I decided to create a new group or a sub-group with the other care partners in our mixed group who felt the same way. We met once a month and rotated the location from one home to another. I guess it was successful. The group grew too big to meet in a home. Also, no one was a trained facilitator, so it was more of a social group than a support group. We found a social worker who facilitated PD support groups and moved the meeting to the Parkinson's center.

"I wanted to meet with care partners who were in the same situation and stage that I was in. I wanted to talk about how to handle self-pity and family dynamics. I needed to talk about how my husband and I could still feel intimate given his physical changes. I needed to know when to help my husband when he struggled to do something and when to just let him do it in his own way. I needed suggestions on how to handle a new situation that would come up."

Along the way, Teresa went through a facilitator training for another kind of program that held support groups for patients and their families. "I learned a process that seems to work, where everyone could get their needs met. First every person does a quick two to three-minute introduction and check-in: everyone gives their name and the name of the loved one with PD, when they were diagnosed and how they are doing right now. Then you go back and ask the members whether anyone has a simple, straight-forward question that the group can give input on or help solve right then. After that you get into the 'hot potatoes,' the intense stuff.

"I go to a support group to be with people who are facing the same challenges of living with PD as I am. I am finding that there is a growing distance between my old, dear friends and me. I don't have the same life that I used to, especially as I have to stay closer to my husband Jorge to keep him safe and because he needs more help. I have a new life, a different life that my old friends don't understand.

"What I need from a support group right now is information, support and connections. I want to discuss issues that relate to my life as it is now. I need to leave with a lighter mood and a sense of hope that I will be able to handle what is coming."

CHAPTER 7:

WELCOMING NEW MEMBERS TO THE SUPPORT GROUP

Some people will be uncomfortable with the thought of coming to a PD support group. They don't know what to expect or whether it will meet their needs. Some of them may be newly diagnosed with PD and may be experiencing depression or anxiety about their future. New members may feel intimidated upon realizing that some members of the group have known each other for a long time already and have built a rapport. Others have many questions about coping with PD, but they may feel uneasy about sharing their problems or listening to the challenges of others. People might feel overwhelmed upon seeing members with more advanced symptoms of PD. They may think, "So this is what my future looks like?" In short, new members face a lot of challenges when they first join a support group.

You can provide your contact information, including a phone number, so that people can call ahead of time to ask questions about the group. This contact information should be on the flyers, on websites listing the group and meeting times, in the local newspaper, etc. You can tell the potential members about your group – who is in it, what topics are discussed, why you believe people come to the meetings. You can also ask them questions about what they are looking for, so you can see if the group is a good fit for them.

TIP: Many Parkinson's specialists suggest that their patients wait until they have learned more about the disease and integrated it into their concept of self before joining a support group, unless it is a

newly diagnosed group. This is why a phone conversation with prospective members before they attend the first meeting is so important.

Here are some suggestions to help your group reach out to newer members:

1. Make a personal connection!

Create a buddy system pairing seasoned, veteran members of the group with newer members. Have them exchange contact information, and encourage the seasoned members to call the newer members outside of the meeting and answer any questions they may have.

2. Consider creating a sub-group that is more geared to the needs of newly diagnosed members.

Recently diagnosed people might be overwhelmed at first by seeing others struggle with more advanced symptoms of PD. If you have enough people, consider breaking the group into two: one group for those who have had Parkinson's for a while, and another for newer members just beginning their Parkinson's journey. If you do this, think about a timeline for when people are no longer "recently diagnosed" and should transition into the regular group.

3. Bring in outside speakers.

Try to find a counselor, psychologist or social worker who can speak to the adjustments and adaptations that need to be made throughout a life

with Parkinson's. This can help recently diagnosed people come to terms with their diagnosis, but will also provide useful strategies for all members as they cope with different aspects of the disease.

4. Share resources

Books, fact sheets, videos and articles can provide information and help answer questions people may have on a range of Parkinson's topics (see the end of this manual for references).

5. Use "Care and Share" sessions strategically.

When new people come to a meeting, plan to devote at least part of the group time to a "Care and Share" session to help them get to know older members. Share experiences of coping with PD and encourage everyone to stay positive!

6. Use icebreakers.

Use the icebreakers described on page 21 to help newer members get to know the rest of the group and to help everyone feel comfortable enough to share their questions and concerns with the group.

7. Share personal experiences related to coping with depression or anxiety.

Depression and anxiety are common in people with PD. This is not just a reaction to the diagnosis, but a symptom of the disease itself. Some of the same chemical changes in the brain that lead to Parkinson's also lead to these mood disorders. If you think a newer member might be struggling with depression, or if you notice mood changes in any long-time members, put a discussion of depression and anxiety on an upcoming agenda, with a speaker or as a "Care and Share" session.

You can ask the group if anyone is willing to share their personal experiences, or create a buddy system. You might reach out to other facilitators to see if any of their group members may be willing to do the same.

8. Encourage new members to be patient.

It takes time for newer members to get to know the group and build relationships. Keep encouraging newer members to stick with the group and to not give in to feelings of discouragement. Group members have shared with us that once these initial feelings gradually dissipated, they ended up learning a lot and highly valued the contributions of the group.

9. Acknowledge their feelings.

Acknowledge and validate any negative feelings that newer members may be experiencing. Share with them your own negative experiences as a new support group member or as a newly diagnosed patient or care partner, and turn it to the positive by sharing how you coped.

10. Sing praises of your group.

Brainstorm as a group the many benefits of attending a PD support group, both in the short and long term. For example, 1) not feeling alone, 2) feeling better after meetings, 3) being able to talk to friends who understand and accept you, 4) being inspired by the group and gaining empathy for the person with PD, and 5) boosting confidence in your ability to cope with PD. Share these benefits and personal testimonials with the whole group: new members who might have been tempted to stop attending may feel encouraged, and older members might feel re-energized.

11. Brainstorm as a group.

Devote part of a group meeting to brainstorming strategies to reach out to newer members. This will help create ownership and a shared sense of responsibility for recruiting new members and maintaining the group. If there is a core group of members who are especially interested in welcoming new folks, form a committee that shares responsibility for making new members feel welcome and comfortable with the group.

Another brainstorm idea that can be a good discussion topic for part of a meeting is what helped you the most when you were newly diagnosed, as well as what did not help you when you were newly diagnosed. This can be a satisfying exercise to help people vent, but also take away constructive and practical strategies for how to speak with people in their lives and communities about PD.

New members are important to your group. It is beneficial to have new perspectives every once in a while. If your numbers have decreased or energy is lagging, bringing in a few new members can reinvigorate the group and help you draw in even more new members. Furthermore, people recently diagnosed with PD are the future of your group! Along with their care partners, they may have many healthy years to participate.

Mentor and nurture the newer members of your group – it is time well spent. Create a welcoming environment, and people will want to keep coming back.

No person,
trying to take
responsibility
for her or
his identity,
should have
to be so alone.
There must be
those among
whom we can
sit down and
weep, and still
be counted as
warriors.

- Adrienne Rich

CHAPTER 8: EXERCISE

Everyone knows that exercise is good for people with Parkinson's, and care partners. But actually doing exercise can sometimes be a hurdle (pun intended!).

Many PD support groups encourage their members to exercise by having a 20- to 30- minute "warmup" 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 people with PD to move — so why not exercise to music? You only need a few songs 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.

Parkinson's exercises (with images) can be found in the book *Fitness Counts*. Get a sample copy for your group by calling the toll-free Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636). The idea is to exercise every day — then come to the meeting and brag about it!

The Parkinson's Foundation holds our signature event, Moving Day®, A Walk for Parkinson's, in cities throughout the country. Your support group may choose to form a team to raise funds and awareness as well as participate and get moving. You can find a listing of Moving Day events at www.movingdaywalk.org.

Each person holds so much power within themselves that needs to be let out. Sometimes they just need a little nudge, a little direction, a little support, and the greatest things can happen.

— Pete Carroll

CHAPTER 9: SPECIAL ISSUES

USING THE INTERNET

The widespread use of the internet has brought both benefits and challenges to Parkinson's support groups. Email provides an easy and inexpensive way to communicate with group members. In addition to regular meeting announcements, facilitators often send out breaking news, opportunities to participate in research, announcements of exercise or other types of PD-specific programs in the area, links for webinars and pretty much everything else that may be of interest to the group.

The Internet can be a great resource for health information. Unfortunately, it can also be a source of false or misleading information, so it is wise to be cautious when using the internet to access information important to your health. There are three key questions to consider when evaluating information online (or in print):

- Who said it? Who is responsible for the site? Is it the government, a university or a well-known health related organization? Is it a manufacturer of a drug or another product? And what is the purpose of the site? The site should have a link titled "About" that states the purpose of the site or the organization. Is the purpose to promote or sell a product, or to educate? All of this information should be easy to find.
- When did they say it? Is the information current? Does the information include the date that it was published or updated?
- How did they know? Is the information on the site documented? Are there references for medical facts and figures?

Guidelines to help you evaluate health information can be found on the following

sites: www.trustortrash.org and www.cancer.gov/about-cancer/managing-care/using-trusted-resources. For information on Parkinson's disease, your first stop should be www.parkinson.org!

YOUR ROLE IN RESEARCH

There is a lot we still don't know about people and their health. Different forms of medical research help us learn more. Studies that involve people – human subjects – are called clinical studies. At some point, you or someone in your group may be asked to volunteer for such a study. Clinical trials aim to test new interventions – this could be a drug, surgery or therapy like exercise or diet guidelines – to make sure they are effective and safe. Researchers need people with Parkinson's to participate in studies, so they can figure out how different interventions work on different populations, depending on age, how long you've had PD and many other factors. Your participation might help you get a new treatment before it is available to the public, and you will also be contributing to the body of knowledge on Parkinson's for other people with the disease now and in the future.

However, there are also risks that you should clearly understand. It is important to get complete information on any research project members are considering, particularly if it involves PD medications or a change in treatment. Members should check it out with their physician before agreeing to participate.

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.

EVALUATING RESEARCH REPORTS

New drugs and other treatments for PD often garner attention in the popular press, and headlines can send people searching for a new drug. Often, a closer look reveals that the new medication is only in the early stages of research and years away from becoming an available treatment. Taking some time to review the research can help determine the best way to use the new information. Following are some questions to ask when evaluating clinical studies of new medications and treatments for PD.

- What is the source of the information? Where was it published? It may have been published in a reliable medical journal, at a scientific conference, in a magazine or by another source. Check with a member of your healthcare team to determine if the source is reputable.
- How many people participated in the study? In general, the higher the numbers, the more reliable the results.
- How was the study designed? There are several basic study designs, and some are considered better than others.
 - » Placebo-controlled studies are those that use a study drug and a placebo, which is a pill or other treatment without any medicine in it.
 - » Single-blind, placebo-controlled studies are those in which the study participant OR the researcher evaluating the participant's response knows if the person is receiving the actual study drug or placebo. The other party does not know, making them "blind."
 - » Double-blind, placebo-controlled studies are those in which neither the

study participant nor the researcher know if the participant is receiving the study drug or placebo. Double-blinded studies are thought to be the most valid study design, though they are not always possible.

Here are some ways for you and your support group to get involved in research if you choose to:

- Invite a local PD researcher to speak to your group about current studies.
- Become a research advocate through our **Parkinson's Advocates in Research (PAIR) Program**. These in-person trainings give people impacted by PD the knowledge and skills to partner with scientists and health professionals and collaborate with research institutions. Learn more and apply for a PAIR Learning Institute at www.parkinson.org/pair.
- Help recruit research participants from your group (and within your community) based on the needs of local researchers.
- Volunteer 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).
- Suggest 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 may be interested in measuring the effects of home exercise on PD).
 - » Let the National Institutes of Health and Congress know that you are watching their PD research efforts with great interest — and request periodic updates. You can also look up NIH-funded clinical trials at www.clinicaltrials.gov.

- Get on as many mailing lists as you can related to PD, aging or caregiver research. There is a lot going on out there! Here are a few to get you started:
 - » Parkinson's Foundation:
www.parkinson.org
 - » Parkinson's Life: www.parkinsonslife.eu
 - » Next Avenue: www.nextavenue.org
 - » National Alliance for Caregiving:
www.caregiving.org

At some point, a researcher or student may request a copy of your mailing list to conduct a survey or for recruitment purposes. You should 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). Many researchers now use an email announcement of their study with the appropriate contact information. This allows you to inform your group of opportunities without breaching confidentiality.

CONSUMER ADVOCACY AND PUBLIC AWARENESS

Persons with PD and their care partners are consumers of many things, including medications, adaptive equipment (e.g., commode chair, tub bench, etc.), and mobility aids (such as canes, walkers and wheelchairs). They are also consumers like anyone else; people with Parkinson's and care partners like 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 to your group about prescription drugs.
- Contact your local pharmaceutical representatives (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.
- 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.
- Write letters to and reviews of businesses that are accommodating for people with Parkinson's, as well as those that are not as accessible or amenable as they could be. Many people read online reviews of restaurants and other businesses when making their choices: Yelp and Google are two good places to start. Compliment establishments in which group members feel especially comfortable and welcome, and provide constructive feedback with specific and realistic suggestions for businesses that are not PD-friendly.

The idea is to spread the word about your group and raise awareness about PD in the broader community. 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

If your group is not sponsored by a hospital or other local organization, you will likely need to collect a nominal fee from members to help support the operations of the group. This can be done as a collection at regular meetings. Beyond that, fundraising is an option, not a requirement, for PD support groups. But it is one way you can contribute to the work of your local PD center or to research and educational efforts nationwide.

As a PD support group leader, your hands are already quite full. If your group decides to do a fundraiser, you might ask for a volunteer to be the event or overall group fundraising chair. Some people do not feel comfortable asking for money, and that's ok. Not everyone in your group has to participate. But there are many options for how and for whom you raise money that might appeal to all members of your group.

TIP: With personal appeals, you will likely be most successful if you share at least some aspect of your connection to the cause you are fundraising for – in this case, Parkinson's.

Why fundraise, and for whom?

Funds are always needed for PD research, much of which is not subsidized by public or private funding. The Parkinson's Foundation is conducting the *Parkinson's Outcomes Project*, the largest-ever clinical study of Parkinson's, with more than 10,000 participants enrolled. We make the data available to researchers who want to study particular aspects of living well with Parkinson's, from depression to the benefits of expert care to what is special about people who have had PD for over 20 years

and much more.

In addition to our research efforts, the Parkinson's Foundation makes all our education and support resources – from our comprehensive educational book series to our toll-free Helpline to this manual – available free of charge to people impacted by PD around the U.S. We could not do this without the support of thousands of individuals like you and your support group members.

Your group can decide together what you are most passionate about supporting, and direct your funds there. Whether you choose to support the Parkinson's Foundation, your local PD center or another organization, you will be helping people impacted by Parkinson's in your own community and beyond.

How to fundraise

Fundraisers can take place at any time of year, but many support groups organize or participate in local fundraisers in April to promote National Parkinson's Awareness Month. Many news outlets cover Parkinson's during this time, so it is a good opportunity to simultaneously do some promotion for your group.

Here are some of the most popular events to raise awareness and funds for PD:

- Create a Moving Day® A Walk for Parkinson's, team – our signature event takes place in more than 40 cities across the country every year. Get moving to beat Parkinson's! www.movingdaywalk.org
- If there is no Moving Day in your area, you can organize your own walk-a-thon. A mall or a simple mile route will do – it's visibility that counts!

- Join Parkinson's Champions – This community fundraising program allows anyone who wants to organize an event to raise funds and awareness for PD. You take the lead in planning your own event, so feel free to get creative! Below are some Parkinson's Champions events that have been planned in the past.

www.parkinson.org/champions

- » Bike-a-thons, swim-a-thons, golf-a-thons, dance-a-thons — it's not Olympic endurance, but public exposure that counts!
- » Raffles or silent auctions — get local businesses or individuals to donate items, and host a reception to do the drawing.
- » Bake or craft sales — include a PD pamphlet with each item sold. "Pancakes for Parkinson's" is a particularly popular (and alliterative) event.
- » T-shirt, button or bumper sticker sales — make sure to offer merchandise for people of all ages.

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

Strong people don't put others down... They lift them up.

-Michael P. Watson

APPENDIX A: PARKINSON'S FOUNDATION RESOURCES

**Also available in Spanish*

All Parkinson's Foundation resources are available free of charge. Written materials can be downloaded from our website, www.parkinson.org, or 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, also by contacting your local Chapter or the Helpline.

HELPLINE*

The Helpline, 1-800-4PD-INFO (473-4636), provides information (in English and Spanish) to people with Parkinson's disease (PD), their families, friends and healthcare providers. Connect with a compassionate, trained PD information specialist to get current information about PD, referrals to healthcare professionals, emotional support, community resources and a wide variety of free publications. The Helpline is open from 9am to 6pm ET. You can also email the Helpline at any time: helpline@parkinson.org.

ONLINE RESOURCES*

Parkinson.org is the go-to source for information about PD for people with Parkinson's, their caregivers, family and friends. Articles, videos, fact sheets and more help people understand the disease, find resources, connect with providers and get involved with the Parkinson's community.

- "Ask the Doctor" forums and open forums for newly diagnosed individuals, caregivers and people with young-onset PD: forum.parkinson.org
- Comprehensive PD library, including books, fact sheets, videos and webcasts and newsletters: www.parkinson.org/library
- "In Your Area" feature to find your local PD center, Parkinson's Foundation Chapter or wellness programs: www.parkinson.org/search
- *Parkinson's Today* blog with articles from healthcare professionals, researchers, people affected by Parkinson's, Parkinson's Foundation staff and others: www.parkinson.org/blog

AWARE IN CARE*

The Aware in Care kit has tools and information to help people with Parkinson's get the best possible care during a hospital stay. The kit includes a Parkinson's disease ID bracelet, medical alert card, hospital action plan and several other items to empower the person with Parkinson's and educate hospital staff during a planned or emergency hospital visit. Learn more at:

www.parkinson.org/awareincare.

PUBLICATIONS*

Parkinson's Foundation publications focus on issues critical to people with Parkinson's. People with PD, families and professionals alike consider our comprehensive educational materials essential reading for information about PD, ranging from introductory content to more in-depth material on important topics that can be reread many times over.

Books

You may want to start a Parkinson's book club as part of your support group. All members can order a book, read it individually and discuss it as part of a meeting. Depending on how often you meet, you can break up the book into sections, or focus on chapters that are of special interest to get into a detailed discussion. The books can also serve as a launching point for a "Care and Share" session. For example, if members are interested in mood issues, you might read a section from *Mood: A Mind Guide to Parkinson's*, then a member who has worked with a therapist can share his or her experiences. For many topics, this can also help reduce stigma about some lesser-talked about Parkinson's symptoms. All the books are available for order and download at www.parkinson.org/books.

Fact Sheets

Fact sheets can also be a great launch pad for discussion. If you have a resources table at your support group, you might want to print some of the fact sheets to display and for members to take if they're interested. Visit www.parkinson.org/factsheets to read and download dozens of fact sheets on almost any aspect of PD you can imagine. If there is an additional topic you think we should consider, please let us know at www.parkinson.org/feedback!

Newsletters

- *Parkinson Report* is a hard-copy newsletter that comes out three times per year. It contains articles written by Parkinson's researchers, medical practitioners and caregivers, as well as contributions from Parkinson's Foundation staff. To get your copy, visit www.parkinson.org/parkinsonreport
- *Parkinson's Today* is a monthly e-newsletter that includes the latest research, tips and ways to help the Parkinson's community. To be added to our mailing list, visit www.parkinson.org, scroll to the bottom of the page and enter your email address in the "Sign Up" field.

PODCAST

Podcasts are an increasingly popular format for people to get news, stories and other information. In 2017 the Parkinson's Foundation launched a podcast series called *Substantial Matters: Life and Science of Parkinson's*. New episodes come out every two weeks and focus on the treatments and techniques that can help you live a better life now, as well as the research that can bring a better tomorrow. The podcasts are short (15 minutes or less), so you can listen to them together at a meeting, or assign "homework" to group members: listen to an episode, and be prepared to discuss. You can subscribe on iTunes, TuneIn or wherever you listen to podcasts, or listen directly or download the episodes at www.parkinson.org/podcast.

PARKINSON'S EXPERT BRIEFINGS

If your meetings are at least an hour and a half and you have the appropriate A/V equipment available, you can watch a Parkinson's Expert Briefing together and discuss it. All webinars are about an hour long and are available for viewing at www.parkinson.org/webinars.

VIDEOS

If you don't want to spend a full hour but still would like to use a video to educate your group and generate discussion, check out our video library. Videos range from a few minutes to an hour long and cover a wide range of PD topics. More than 200 videos can be viewed at

www.parkinson.org/videos.

SOCIAL MEDIA

The Parkinson's Foundation has a large presence on social media, particularly Facebook. News, resources, articles and events are posted daily, many of which might be interesting and relevant to your group members:

www.facebook.com/parkinsondotorg

If there is a Parkinson's Foundation Chapter in your area, check out their local Facebook page, too.

PD SELF-EFFICACY LEARNING FORUM (PD SELF)

This program helps people develop a personalized health management approach to living with Parkinson's. The lessons from the nine-module course cover skills that will be useful for an individual's own PD journey but can also be shared with support group members. People diagnosed with PD within the past three years may be eligible to participate in one of our pilot programs. If you have been living with Parkinson's for more than three years, learn more about our PD SELF leader training at www.parkinson.org/pdself.

Life is 10% what happens to us and 90% how we react to it.

APPENDIX B: PARKINSON'S FOUNDATION CHAPTERS AND CENTERS OF EXCELLENCE

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 www.parkinson.org/search or contact our Helpline at 1-800-4PD-INFO (473-4636) or helpline@parkinson.org.

We also have Centers of Excellence around the world that deliver care to more than 100,000 people with Parkinson's; create a community of healthcare professionals dedicated to Parkinson's care; and work to advance a comprehensive approach to care that addresses the whole person and full range of symptoms. Here is a list of our national and international centers, with contact information for appointment scheduling.

US CENTERS

- AZ** Muhammad Ali Parkinson Center at Barrow Neurological Institute (Phoenix)
kristina.watts@dignityhealth.org
602-406-6262
- CA** University of California, San Diego Movement Disorder Center (La Jolla)
allau@ucsd.edu | 858-822-5873

- CA** University of California, San Francisco Parkinson Disease Clinic and Research Center (San Francisco)
aaron.daley@ucsf.edu | 415-476-9276
- CA** University of Southern California Parkinson's Disease and Movement Disorder Center (Los Angeles)
kara.barton@med.usc.edu
323-442-5710
- CA** Parkinson's Institute and Clinical Center (Sunnyvale)
avalencia@parkinsonsinstitute.org
408-542-5691
- DC** Georgetown University Hospital (Washington, DC)
hhh102@gunet.georgetown.edu
202-444-2333
- FL** University of Miami Parkinson's Disease and Movement Disorders Center (Miami)
arussell@med.miami.edu
305-243-6732
- FL** University of Florida Parkinson's Disease and Movement Disorders Center (Gainesville)
amanda.fessenden@neurology.ufl.edu
352-294-5400
- FL** University of South Florida Parkinson's Disease and Movement Disorders Center (Tampa)
ktehan@health.usf.edu | 813-396-0751
- GA** Medical College of Georgia, Augusta University (Augusta)
ktuckey@augusta.edu | 706-721-2798
- GA** Jean & Paul Amos Parkinson's Disease & Movement Disorders Program at Emory University (Atlanta)
tammyjo.best@emoryhealthcare.org
404-712-6990

IL	Northwestern University Parkinson's Disease and Movement Disorders Center (Chicago) ppalment@nm.org 312-695-7950	NY	Mount Sinai Beth Israel Medical Center (New York) jmiravite@chpnet.org 212-844-6134
KS	University of Kansas Medical Center (Kansas City) klyons@kumc.edu 913-588-6782	NY	University of Rochester Medical Center (Rochester) amy_cheshire@urmc.rochester.edu 585-341-7500
MA	Beth Israel Deaconess Medical Center (Boston) asilver2@bidmc.harvard.edu 617-667-9885	OR	Oregon Health & Science University Parkinson Center (Portland) mannli@ohsu.edu 503-494-5620
MA	Massachusetts General Hospital (Boston) cparow@partners.org 617-726-5532	PA	University of Pennsylvania Parkinson's Disease and Movement Disorder Center (Philadelphia) sreichwein@pahosp.com 215-829-7273
MD	Johns Hopkins Parkinson's Disease and Movement Disorders Center (Baltimore) rdunlop@jhmi.edu 410-955-8795	TN	Vanderbilt University Medical Center (Nashville) kelly.b.arney@vanderbilt.edu 615-936-5517
MN	Struthers Parkinson's Center (Golden Valley) joan.gardner@parknicollet.com 952-993-5495	TX	Baylor College of Medicine (Houston) chunter@bcm.edu 713-798-3951
NC	Duke University Movement Disorders Center (Durham) kendra.channer@duke.edu 919-613-5266	INTERNATIONAL CENTERS	
NC	University of North Carolina at Chapel Hill School of Medicine (Chapel Hill) jshurer@neurology.unc.edu 919-595-9683	AUSTRALIA Victorian Comprehensive Parkinson Program (Cheltenham, Victoria) emma.flanagan@monashhealth.org 613-9265-1526	
NY	The Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at New York University Langone Medical Center (New York) parkinsons@nyumc.org 646-501-9241	CANADA Morton & Gloria Shulman Movement Disorders Centre, Toronto Western Hospital (Toronto, Ontario) lhatton@uhnresearch.ca 416-603-6422	
		University of British Columbia Pacific Parkinson's Research Centre (Vancouver, British Columbia) agnes.kwok@ubc.ca 604-822-7721	

**University of Calgary (Calgary,
Alberta)**

karen.hunka@ahs.ca | 403-944-4364

**McGill Movement Disorder Clinic
(Montreal, Quebec)**

nellie.pilla@muhc.mcgill.ca
514-398-4691

**University of Alberta
(Edmonton, Alberta)**

charlene.heavener@albertahealthservices.ca
780-407-5465

**University of Western Ontario, London
Health Sciences Centre
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daina.white@lhsc.on.ca | 519-663-3814

GERMANY

The Phillips University
(Marburg, Hessen)
siepe1@med.uni-marburg.de
49-6421-28-66278

ISRAEL

Tel Aviv Sourasky Medical Center
(Tel Aviv)
adil@tlvmc.gov.il | 972-3-6974912

NETHERLANDS

Nijmegen Parkinson Center
(Nijmegen)
milou.vanrijswijk@radboudumc.nl
31-24-3615202

SINGAPORE

Singapore National Neuroscience
Institute (Singapore)
tay.kay.yaw@singhealth.com.sg
65-63577095

TAIWAN

Taiwan University Hospital Center for
Parkinson & Movement Disorders
(Taipei)

irenelu1020@gmail.com
886-2-2312-3456 ext 66052

UNITED KINGDOM

Derby Hospitals NHS Foundation Trust
and The University of Nottingham
(Derby)
lisa.brown8@nhs.net
44-133-234-0131

UNITED KINGDOM

Kings College Hospital (London)
a.rizos@nhs.net | 44-203-299-8336

I may not
always be
there with
you, but I
will always
be there for
you.

APPENDIX C:

MEETING GUIDES FOR PEOPLE WITH PARKINSON'S AND MIXED SUPPORT GROUPS

This section includes several support group meeting guides that may be used alone or in combination with a speaker presentation or webinar. These guides may be especially helpful if your group is small, as the main idea is to get the members to share with one another. These can also be used to generate questions for an upcoming speaker:

- What Is Parkinson's? (page 57)
- Diagnosis and Treatment of Parkinson's (page 58)
- Nutrition and Parkinson's (page 59)
- You and Your Doctor (page 60)
- Coping with Parkinson's (page 61)
- *Aware in Care – PD and Hospitalization* (page 62)

In addition to these guides, the books, fact sheets, podcasts, videos and webinars listed in Appendix A can all be used as the basis for a meeting. You can have group members read a book (or a few chapters) or watch a webinar in advance of the meeting and come ready to discuss; you can watch a video as a group and ask people to share their experiences on that topic; or a piece of literature or video can set the stage for a speaker presentation. The possibilities are endless!

Let us know what has worked for you.

WHAT IS PARKINSON'S?

Relevant resource

The book *Parkinson's Disease: What You and Your Family Should Know* is a good resource for this topic. Find it at www.parkinson.org/books.

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. At what age is Parkinson's most likely to develop? How old were you when you were diagnosed? Thinking back, how old were you when symptoms first began?
3. What are the 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. How is Parkinson's most likely to affect your daily life and activities?
Are all of these changes unavoidable?
7. 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:

DIAGNOSIS AND TREATMENT OF PD

Relevant resource

The PD Expert Briefing "Diagnosis PD, Now What? Managing the First Few Years with Parkinson's" is good resources for this topic. Find it under "Past Expert Briefings" at www.parkinson.org/expertbriefings.

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 are the good effects — and the side effects — that I can expect?
5. Why is it important to take PD medications on a regular schedule? Should I keep a "log"? What should I write in it?
6. What role do physical, occupational and 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:

NUTRITION AND PD

Relevant resources

The fact sheets "Parkinson's Nutrition" and "Constipation in PD" are good resources for this topic. Find them at www.parkinson.org/library.

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 wellbeing 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 dietitian.

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 foods I like, and be satiated?
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 if I go to a restaurant?
6. How will I 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. Could changes in my diet help me better manage my constipation problems?

Suggested speakers

Registered dietitian, nurse or health educator who works with Parkinson's

Your ideas:

YOU AND YOUR DOCTOR

Relevant resources

The following videos from the "Managing Parkinson's Mid-Stride" playlist are good resources for this topic. Find them at www.parkinson.org/videos.

- Your Neurologist and You: How to Prepare for Your Parkinson's Visit
- Your Neurologist and You: Find a Doctor You Trust
- Your Neurologist and You: What to Bring to Your Parkinson's Visit
- Your Neurologist and You: Involving Your Care Partner

Introduction

The doctor-patient relationship is key in any chronic illness, including Parkinson's. It is important to find healthcare providers you trust – both your Parkinson's specialist(s) and your primary care doctor. Parkinson's progresses, so symptoms will change and you will need to adjust medications and dosing. Through these 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, or that it is easy to find the "right" doctor. But the search is well worth it and can make a real difference in your confidence managing your own health.

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?
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:

COPING WITH PARKINSON'S

Relevant resource

The section "Emotional Well-Being" on www.parkinson.org is a good resource for this topic. Find it in the "Living with Parkinson's" section under "Managing Parkinson's."

Introduction

Coping with PD, like any chronic illness, is a matter of personal resources, experience and style. No two people will cope the same way. However, there is some common wisdom to be found among all those who live and cope with PD day to day. 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 cope — and how do they do it?
6. What thoughts or actions help you cope — and why do they work for you?
7. What practical advice would you give to someone who is newly diagnosed with PD, or to his or her care partner?
8. Why is "cope" the step between "mope" and "hope?"

Suggested speakers

Person with PD and care partner; social worker or psychologist who works with PD; chaplain

TIP: This might be a good time to invite a person with Parkinson's from another group to lead the discussion.

Your ideas:

PD AND HOSPITALIZATION

Relevant resource

The *Aware in Care* kit is a must-have resource for this topic. Learn more and order yours at www.parkinson.org/awareincare.

Introduction

Did you know that three out of four people with Parkinson's disease do not receive their medications on time when staying in the hospital? People with Parkinson's visit hospitals more often, and, combined with the great importance of the timing and dosing of Parkinson's medications, face greater risks in the hospital than their age-matched peers.

This is why the Parkinson's Foundation launched the *Aware in Care* initiative in 2011. The program aims to help people with Parkinson's get the best care possible during a hospital stay.

To protect, prepare and empower people with Parkinson's and their care partners before, during and after a hospital visit, the Parkinson's Foundation developed the free *Aware in Care* kit with tools and information to share with hospital staff during a planned or emergency hospital stay.

Both a webinar and a PowerPoint presentation on the *Aware in Care* program are available at www.awareincare.org. You may request a sample kit and ordering cards for your group by calling the Helpline at 1-800-4PD-INFO (473-4636) or contacting your local Parkinson's Foundation chapter.

Discussion questions

1. Why are people with Parkinson's more susceptible to challenges during a hospital stay?
2. What kinds of challenges do people with Parkinson's face during a hospital stay?
3. What are the underlying causes for these challenges?
4. Have any of you been hospitalized and what was your experience?

Suggested speakers:

Doctor or nurse; person with Parkinson's and care partner

Your ideas:

APPENDIX D:

MEETING GUIDES FOR CARE PARTNERS ONLY

While care partners will have a lot to say about any of the topics in the meeting guides above, care partners also have their own distinct needs. If your group has enough people, it is a good idea to split the group – if not for every meeting, then every once in a while – to give people with Parkinson's and care partners time to ask questions and discuss life with Parkinson's independently of one another.

The meeting guides here will help you dive into the care partner experience:

- What Does It Mean to Be a Care Partner? (page 64)
- The Caregiver Experience (page 65)

WHAT DOES IT MEAN TO BE A CARE PARTNER?

Relevant resource

The book *Caring & Coping* is a good resource for this topic. Find it at www.parkinson.org/books.

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, family member, friend or neighbor.

Many prefer the term "care partner" to "caregiver" or "caretaker" because the word partner connotes a mutual relationship. Indeed, the care partner also needs support.

Discussion questions

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?
6. How am I different — physically or mentally — since becoming a care partner?
7. What are a care partner's typical feelings throughout the course of a day?
When do I feel guilty?
8. If I could change one thing about our PD "partnership," what would it be?

Suggested speakers

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

Your ideas:

THE CAREGIVER EXPERIENCE

This workshop was developed by Susan Gangsei, MBA, MAIR, an author, speaker, marketing professional and caregiver advocate. She was a family caregiver for her husband, who was diagnosed with Parkinson's in 2000 and passed away in 2013. She was a steering committee member and facilitated this workshop at the 2016 National Parkinson Foundation Caregiver Summit.

Introduction

Being a caregiver for someone with Parkinson's disease is a unique experience. It can be scary, exhausting and isolating. It can also be humorous, endearing and a time to grow closer to your partner. Caring for a person with Parkinson's can bring out strength you didn't realize you had. The journey can teach you about yourself and others. In this workshop, participants will share experiences, reminiscences and advice. You will write four notes to Marge, a hypothetical care partner, offering insights about living with someone with Parkinson's. By sharing your personal journey, you will find company and support from others traveling the same road.

Notes to Marge

- What makes me angry, scared or sad is ...
- I found it funny and endearing when
- What I have learned about myself is ...
- An unexpected gift I have received is ...

Workshop instructions

- Break into small groups (no more than 6 people) based on which "Dear Marge" scenario you most relate to (see page 63) – relatively new to PD, or mid- or later-stage.
- Each person fills out the four notes to Marge for themselves. (10 minutes)
- Each person at the table shares their "What I learned about myself" note with others. (10 minutes – if there is extra time, share and discuss another note)
- Each group picks a person to read one representative postcard of "What I learned about myself" with the rest of the groups.

Materials needed

- Copies of the two Marge scenarios (so that people can read the scenarios again to refresh their memories of the details if needed)
- Copies of the "Dear Marge" prompts
- Paper and pens for people to write their notes to Marge

Marge scenarios

Marge in the middle

A few years ago, Marge and her husband, Andy, found out that he has Parkinson's disease. It hasn't been too bad for either of them, but now she can see Andy is having a harder time physically. He's shaking more, especially when he is rushed or nervous. He struggles to move with grace. Falls are becoming more frequent due to his "freezing," especially when he tries to start walking or wants to turn around. But when they allow for extra time, Andy can do most everything he wants to do. Marge and Andy call this slower pace "Parkinson's time."

Recently Andy retired. He could no longer hide his PD at work. His voice has become weaker and it was harder to communicate with coworkers and customers. His shaking made people nervous, and Andy does not have the physical stamina he once had.

So now he is taking continuing education classes at the local university. Andy enjoys taking afternoon naps and walking the dog, and he does small things around the house. One of these is laundry. Marge appreciates this, but she has to hide any delicate clothes because Andy will DRY (to the bone) everything in sight.

Marge continues with her life. She likes her job, and she can go to work without worrying about Andy. The only thing that has changed is that she doesn't take on extra assignments anymore or volunteer for anything that requires travel. Marge knows that her company no longer considers her for promotions or added responsibility, but that's OK. She enjoys spending more time with Andy.

Bit by bit Marge is taking on more at home. She is picking up tasks that were once Andy's. If something needs to get fixed around the house, Marge fixes it or finds someone to do it. She now pays all the bills and keeps track of financial matters. Marge schedules all Andy's doctor appointments and goes with him, partly to make sure that the doctor has an accurate idea of what is going on and partly to ask questions that she has. Marge is thinking that it is time to get their will updated and do some estate planning.

Marge knows that Andy's Parkinson's has changed their lives. But so far, with some adjustments, they still make everything work, and they are even planning their dream vacation.

Marge beyond the middle

Marge no longer leaves her husband, Andy, alone, at least not for too long. Andy is using a walker now and frequently needs help getting up from a chair. Medications have to be administered at exactly the right time and coordinated with his meals. Every so often Andy will wake up during the night with hallucinations or terrible leg cramps. He can't turn over in bed on his own and, if he needs to use the bathroom during the night, he needs help getting in and out of bed.

Andy forgets to turn things off, like the water faucet, and he is having difficulty figuring out the "next step" when he wants to get something done. Any place her husband has to go, Marge has to take him there and make sure the "mission" is accomplished. If Andy wants to get something done at home, like taking out the trash or walking the dog, Marge needs to be there to help. Marge's day leaves her exhausted. She would love a good night's sleep!

Marge decided to retire from her job. Her company couldn't be as flexible as she needed and she was tired of having two full-time jobs, one at work and one at home. But Marge found a day program that Andy can go to a few days a week. He seems to enjoy it, and Marge likes having time during the day to herself. She uses that time to have lunch with friends, get her hair done and go to water aerobics.

Several good things have happened. Marge and Andy's kids have really stepped up. One day a week their daughter comes and stays for a day and night to help out and give Marge a break, including a good night's sleep. Their son is doing all the chores around the house. This really helps, and it is good to see the kids on a regular basis.

As Marge and Andy spend more time together, Marge is finding out that Andy has not lost his great sense of humor. It is amazing what they can find to joke about. And even though it takes a bit more effort, they try to get out and enjoy something every day, even if it is going to the Dairy Queen for an ice cream cone.

Marge has a growing awareness of how strong she has become and that she is able to do things she never thought she could do. Marge takes care of everything around the house and makes all the plans and arrangements. She has taken charge of their finances and is doing a good job of managing their resources. She met with a lawyer and thought through all the things she needed to decide to update their wills and documents. She even does the taxes now.

Marge's life is centered on Andy and his Parkinson's. Marge is aware that her life as she knew it and the partner she married have changed – things are different. They still have fun together, but they do it in different ways than before. And Marge is discovering what is really important to her.

Dear Marge,

What makes me angry, scared or sad is...

Dear Marge,

I found it funny and endearing when...

Dear Marge,

What I have learned about myself is...

Dear Marge,

The unexpected gift I have received is...

PARKINSON'S SUPPORT GROUP CONTACT LIST

Please provide us with your contact details below. This list will be used to distribute information about group activities and relevant resources and will not be shared.

Acknowledgements:

Paula Wiener, MSW, LCSW, a Parkinson's Foundation Senior PD Information Specialist and long-time support group facilitator, contributed to the writing and review of this guide.

Thank you to all support group leaders for the work you do for people affected by Parkinson's! Your commitment helps us fulfill our mission to make life better for people with Parkinson's.

The stories in this guide – "I Get More Than I Give," "It's a Good Way to Give Back," "Not Knowing About Parkinson's Worked in My Favor," and "I Like a Little Structure" – were all written by Susan Gangsei, MBA, MAIR, who also created the "Dear Marge" workshop for caregivers. Susan is the author of *The Light in the Middle of the Tunnel: Harrowing but Hopeful Stories of Parkinson's Family Caregivers* and *Stuck With It, Not In It: Redefining Life with Parkinson's Disease*, both available on Amazon.com.

Happiness cannot be traveled to, owned, earned, worn or consumed. Happiness is the spiritual experience of living every minute with love, grace and gratitude.

– Denis Waitley

This guide has been made possible in part through generous support from:





Never believe that
a few caring people can't
change the world.

For, indeed, that's
all who ever have.

– Margaret Mead

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