



Parkinson Association
of Northern California

Creating Local Support Groups

A STARTUP GUIDE TO CREATING A LOCAL SUPPORT GROUP

PARKINSON ASSOCIATION OF NORTHERN CALIFORNIA

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INTRODUCTION

Don't underestimate the power of a Support Group. Attendees find it helpful to tell their stories, get advice from experts, and share resources to help them. Parkinson's can make People with Parkinson's (PwP) and their care partners feel isolated. Support Group can help them see and feel they are not alone. It's a powerful, healing feeling when you realize there are others willing to share in your journey.

Support Groups rely on the experience and support of the members more than the knowledge of experts. A good Support Group won't replace your doctors but will compliment them nicely. The mission of a Support Group is to increase awareness of PD, to educate and comfort, and to provide support, information and hope for affected PwP and their families.

CONTENTS

Introduction.....	2
Qualities of a Successful Support Group Leader	4
Planning a Support Group Meeting	4
So, Are you Ready to Start?.....	4
Typical Characteristics.....	4
Typical Skills.....	5
Why Should YOU Become a Support Group Leader?	5
Helpful Considerations	6
Finding a Meeting Location	6
Finding a Helper or Three.....	6
Picking a Meeting Day and Time	6
Promote Your Group	6
It's Your Very First Meeting!	7
Materials	7
Decisions as a Group	7
Relationship to PANC	7
Type of Meeting	7
Mailing List	8
Refreshments	8
Donations	8
After the First Meeting.....	8
AND NOW, THE REST OF THE STORY.....	8
About PANC	9
Finally	9
Additional Resources.....	10

QUALITIES OF A SUCCESSFUL SUPPORT GROUP LEADER

It helps to understand what it takes to be a member of a group in order to be a leader. Some basic understanding of how people behave in groups, the natural progression of group development and how to encourage the group's growth is important, but not definitive. Some effective facilitators have picked up their skills through books on group leadership or have taken a workshop to help them gain these skills. However, many learned by being a part of a group – any group – and saw how the group leader did things they liked and didn't. Therefore, some of the qualities of a successful support group leader are:

- **Connected.** If possible, the Support Group facilitator should have some Parkinson's background. We have facilitators who are patients themselves, care partners, and members of the exercise community.
- **Organized.** It's important for the facilitator to be organized. They should arrive early for meetings, respond to inquiries in a timely manner, and have materials ready or available.
- **Focused.** You don't have to run meetings like boot camp. But don't let things get out of control. Attendees can be quickly turned off if the meetings become too chaotic or inconsistent.

PLANNING A SUPPORT GROUP MEETING

There is no one right way to run a Support Group. Every group will have its own way of doing things depending on your personality and the members of the group. You should be open to suggestions from the attendees. As a group, within reason, let everyone decide how it should be run.

Other considerations include location, duration, and frequency. Again, nothing is written in stone. Shake it up with 30-minute coffee talks, 60-minute meetings, an activity with time to chat as a group. Remember, sometimes the best therapy is just having someone else there to listen, talk to, or hang out with.

SO, ARE YOU READY TO START?

If you are thinking about starting a Support Group make an honest assessment of your readiness. If you feel up to the challenge and can commit to it for at least a year, GO FOR IT! Let's take a look at YOU.

Typical Characteristics

Are you the type of person who is openminded? The characteristics of a Support Group Leader include:

- **Open-Minded.** Everybody is different. Different experiences, issues, perspectives. The ability to recognize that and use it in a positive way is priceless.
- **Self-Aware.** Being able to identify your own strengths and weaknesses, even going as far

as self-reflecting and continued personal growth allows people to adapt to change, improve upon themselves, and strengthen those around them.

- **Compassion.** Having the ability to express empathy and regulate your emotions is a good way to connect with people and create lasting bonds.

Typical Skills

The skills most common in a Support Group Leader are:

- **Good listener.** Hearing something and listening to someone are not the same. Do you hear them, or are you listening to them?
- **Conflict resolution.** People don't always see eye to eye. Keeping discussion from becoming debates and erupting into arguments is easier than you think. "I think you both make excellent points, but for now I think we should ..."
- **Planning.** Think of it as having some friends over for something informal. You need space, enough seats, maybe ask people to bring some drinks or snacks, and start and end on time.
- **Resource management.** Some Support Groups have members who contribute locations, refreshments, pens and paper, etc. Make sure the things are respected and people recognized and thanked.

WHY SHOULD YOU BECOME A SUPPORT GROUP LEADER?

People start and run Support Groups for many reasons. If you are thinking of starting, or getting involved in one, ask yourself what you want to get out of it. Some reasons are:

- "I need support"
- "I want to help PwP find support"
- "I want to learn more about Parkinson's"
- "I want to share what I already know about Parkinson's"
- "I want to give back to the community"
- "I want to be a part of something meaningful"

Keep in mind, attendees may have different expectations than you or others. During the first few meetings, continue to ask what the attendees want. What are their goals and objectives for the group? Keep a list so you can ask the group informally, or write them down for everyone to see and go over them each meeting. It is good to see if they are the same or if they have changed as the attendees interact and the group forms its own dynamics.

HELPFUL CONSIDERATIONS

Finding a Meeting Location

If possible, it's best to find a place where you can meet for free. If not, you may need to ask the attendees for a little financial support (more on that later). Some ideas are churches, assisted living facilities, senior centers, restaurants, and community centers.

Make sure you find a place with:

- Consistent availability
- Ample parking – especially handicap accessible
- Enough room for your group –
- Accessible - wheelchair accessible, bathroom accessible
- Amenities such as coat room, chairs, tables, wifi, trash cans, white boards, etc.

Finding a Helper or Three

This may not seem necessary for your first meeting, but you will rest easier if you have someone you can have step in and run the meeting if you can't for some reason. Overtime you may need to be in two, three, or four places at once. Having volunteers, an assistant Support Group leader, Greeters, etc. will not only let you focus on the meeting itself, but your group will appreciate the team effort.

Picking a Meeting Day and Time

Once you find a location that works, decide what day and time you would want to meet. Make sure the location you picked is available. Most Support Groups meet once a month, but that can be decided at the first meeting. PANC has a list of potential speakers that you may contact to attend either in person or virtually.

Promote Your Group

The PANC website and our quarterly newsletter, *Parkinson PATH*, lists every Support Group connected with PANC. People can see the location, time, date, and who to contact. Even in this world of modern technology, word of mouth is the easiest and most effective way to promote your group. If your location has a publication, signage, marquee, or message board, ask if you can put a notice up. Some local newspapers will donate ad or announcement space to Support Groups.

If you are willing, try visiting nearby doctors' offices that help PwP and ask if you can put up a flyer (PANC will gladly assist you). Contact local assisted living facilities to see if they have PwP living there. If they can't disclose that information, ask if you can post a flyer in the event someone could use the support.

IT'S YOUR VERY FIRST MEETING!

Congratulations! But first: **Breath!** Everyone is going to have a great time. It may be awkward at first, but don't let that stop you. Break the ice with a big smile, a warm welcome, and tell them what to do next – even if you're not 100% sure. Try saying, "We're in this room over here" or "Enjoy some refreshments while we wait." This will also help you remember.

The **NUMBER ONE** thing to say: "Hi, my name is _____. Thank you for coming."

Materials

Pen, paper, hand sanitizer, and disposable masks are a good idea – and most people have extras lying around home. It also helps to have a list for people to put their contact info on. If they are hesitant, smile and simply put a check mark or something to keep a head count. Name tags are useful so attendees get to know one another. A good practice is to introduce new people and ask them to tell a little about themselves. At this meeting it will start with you and everyone should be asked to do the same.

Decisions as a Group

During this first meeting there are things that should be discussed by the group, such as relationship to PANC, types of meetings to hold, refreshments or not, and donations.

Relationship to PANC

What type of relationship does your Support Group want to have with PANC? As an affiliate member (basic services) or do you want to operate as a mini 501c3?

Type of Meeting

There are many types of meetings. Successful models include:

- **Discussion Group.** Some groups meet to have open discussion between the attendees on a variety of problems, share information, or ask questions they have. If you decide to have open discussion meetings you might come to the meetings prepared to ask one or two questions and let people just talk. Have some conversation starters or topics, even a personal account, ready. End it with: "Has that ever happened to any of you?" or "What did you do?"
- **Speaker Meeting.** Some groups meet to hear from speakers on topics or needs that relate to Parkinson's. If you decide to have speakers poll the attendees to see what their needs/wants are. The way to keep them involved is to have speakers pertinent to their interests. Make sure you allow enough time at the end of any presentation for questions that will come up during the speaker's presentation. We are in the process of developing a list of available speakers
- **Combo Discussion/Speaker.** Some groups do a combination of the two alternating between speakers and open discussion meetings. How your group is set up should be a consideration of the attendees. Find out what their needs are and set up your group accordingly.

- **PwP and/or Care partner Meeting.** Some groups prefer to have everyone in one place hearing the same discussions and hearing the same speakers. Others prefer to have the PwP in one place and the care partners in another. Some want presentations together and discussions separate. This depends on what your group is comfortable with so ask them.

Mailing List

You need to circulate a clipboard at every meeting to get attendees phone numbers, emailing addresses, and home mailing addresses if wanted. This way you can communicate with the attendees before meetings to tell them when the next meeting is and what will be happening. This way you can also keep a current roster of all the attendees of your group.

Refreshments

Refreshments may be served at each meeting, but this should be a group decision so no one feels forced to participate. A sign-up sheet may be used to get people to volunteer to bring refreshments.

Donations

If you find a need to ask the attendees for a small donation to cover mailings, supplies, etc., they can donate cash that you can hold on to or submit to PANC in your Support Group's name and this will be held for your use only in a separate banking account for only your group's use. We recommend keeping no more than \$500. When you need to use your money you just need to contact the PANC office with our check request form. Donations made directly to PANC-only qualify for tax receipts and acknowledgment letters sent to donors.

AFTER THE FIRST MEETING

Get in touch with everyone who attended the meeting and thank them for their participation and let them know again when the next meeting will be. This is where the sign-up sheet comes in handy.

AND NOW, THE REST OF THE STORY...

Once the group is moving along you can ask for volunteers to head up different parts of your group. Some groups have volunteers for emails, speakers, refreshments, name tags, library, etc. Your group may not start with all these tasks, but as you grow you may find the need to have more people on your team to share. One of the key people you need to find to help you is a backup facilitator in case you can't make a meeting.

Sound overwhelming? It can be, but we are here to help you be successful. If your first meeting is you and one other person, THAT IS A SUCCESS! After all, you wanted to help someone and YOU ARE. Over time attendance will increase and decrease, but eventually people will become regulars, floaters, and occasional attendees. But what really matters is someone found the support they needed, including yourself.

ABOUT PANC

The Parkinson Association of Northern California is a community benefit, nonprofit organization that serves the PD community of Northern California. One of our goals is to make Support Groups available in areas that are currently underserved is one of our important goals.

PANC provides all Support Groups with the following:

- **Group promotion.** PANC will post your group's information on our website, social media, and in our newsletter.
- **Support Group Support.** PANC hosts an annual workshop where all facilitators are invited to learn and share best practices from other Support Groups.

Depending on the relationship chosen for your Support Group PANC also provides:

- **Legal infrastructure.** The legal infrastructure for the group to act as a nonprofit
- **Accounting support.** The groups accounting for donations including tax prep.
- **Insurance.** General Liability insurance for group meetings.

FINALLY

If any questions come not covered in this guide, please call (916) 357-6641 or email panc@panctoday.org.

ADDITIONAL RESOURCES