



**PARKINSON
ASSOCIATION
OF THE ROCKIES**

PAR SUPPORT GROUP FACILITATORS GUIDE

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ABOUT PAR

Mission

PAR connects and empowers People with Parkinson's to thrive through educating, creating awareness, promoting research, and supporting those with the disease, their families, and the Colorado and Wyoming communities.

Vision

To provide the care that counts on the way to a cure for the Colorado and Wyoming Parkinson's communities.

Staff

- ❖ CEO: Responsible for leading, directing, and guiding the organization toward achieving its mission, strategic goals, and long-term sustainability. Plays a critical role in shaping the organization's vision, strategy, and overall impact on the community.
- ❖ LCSW Patient and Family Services Director: Licensed clinical social worker on staff. Is the direct contact for the Information and Referral Helpline (303-861-1810). Does free assessments to ensure comprehensive treatment and care. Any questions about insurance, hospitals, doctors, assisted livings, or any type of resource.
- ❖ Program Coordinator: Plans educational programs (Chat with the Parkinson's Pro, e3 Conference, Care Partner Summit, PD 101) and oversees support groups. You will be working very closely with the PC.
- ❖ Exercise Coordinator: Oversees and manages weekly exercise classes. Coordinates with exercise instructors and gym locations for new exercise classes.
- ❖ Community Outreach for NoCo & WY: Oversees support groups and plans educational programs in NoCo & WY. Connects with local community organizations. If your support group is in the NoCo or WY area, you will be working very closely with this position.
- ❖ Director of Development: Responsible for planning, implementing, and overseeing strategies to secure funding, cultivate donor relationships, and drive

the organization's financial sustainability. Plays a pivotal role in ensuring the organization's mission and programs and supported through effective fundraising efforts.

- ❖ Special Events Coordinator: Plans fundraising events (Play fore Par, Vitality 5K, Evening of Empowerment, and other 3rd party) and is the volunteer coordinator.
- ❖ Marketing Specialist: Creates and publishes biweekly e-newsletter and Parkinson Voice, the physical newsletter published by PAR twice a year. Creates all marketing materials for all programs and manages social media pages. If you want to promote the support group, please contact the PC or Marketing Specialist. We will work with you to create marketing materials that have appropriate branding.
- ❖ Database Coordinator: Manages organization's database systems, ensures data accuracy, maintains data integrity, and provides support to different departments that rely on up-to-date data.
- ❖ Administrative Assistant: Provides vital support to the operation of the organization by performing a range of administrative and clerical tasks. Essential in ensuring daily operations run smoothly. Manages PAR's Equipment Loan Program.

Marketing

Branding consistency is important especially because PAR is a local, independent non-profit and all our programs and services are free. Your donations make a difference in the Colorado and Wyoming Parkinson's communities. PAR has no association with any other Parkinson's organizations.

All social media usernames are @PARockies. PAR has Instagram, Facebook, Twitter, and Youtube. The logo will be the profile picture for all the accounts.

Marketing materials that are available to support groups include: include support group spotlight on PAR's biweekly e-newsletter and brochure inserts (as needed). The brochure inserts have information about the support groups and exercise classes in the area. Support group members can place brochures and their inserts in community

centers, rec centers, doctor's offices (with permission), grocery stores, libraries, or any other public areas to promote the support group. If you want any extra marketing materials, contact the PC. If needed, PC will set up a meeting with the Marketing Specialist and Support Group Facilitator to discuss marketing needs.

PAR can always mail you or when the PC or CEO visits the support group, they can drop off materials like brochures, pens, notepads, and newsletters.

Refer to the appendix to view PAR logos, colors, and fonts.

Programs & Services

- Education Programs

Need to register for all educational programs. The link to register can be found on the PAR website.

○ Care Partner Summit

- PAR's annual conference is exclusively for Care Partners of People with Parkinson's. This conference is designed with Care Partners in mind by hosting social workers, psychiatrists, neurologists, palliative care physicians, and others to present on Care Partner-related topics.
- Hosted in the beginning or middle of November on a Saturday. The location is at the Hyatt Aurora-Denver Conference Center from 10am-1pm
- Option to attend in person or livestream.

○ Chat with the Parkinson's Pro

- This educational series provides topic-based seminars from experts in the field of Parkinson's for the Denver Metro Area and satellite communities in Colorado and Wyoming. PAR offers the opportunity for these communities to learn and engage with nurses, neurologists, lawyers, rehabilitation specialists, psychologists, and more.

- Usually scheduled for Saturday mornings but can differ depending on the availability of the presenter.
- E3 Conference: Educate, Empower, Energize
 - PAR's annual conference (since 2012) that brings together individuals with Parkinson's, their Care Partners, family members, and professionals who work with the Parkinson's community to provide them with tools and resources for living vibrant and healthy lives.
 - The conference is hosted on a Saturday in September. The location is Hyatt Regency Denver Tech Center from 9:45-2:00 pm.
 - Over 30 vendors, energize breaks, and educational sessions depending on the theme of the conference.
- Parkinson's 101 for the Newly Diagnosed
 - 3-part educational series that occurs in the spring and the fall. Each session is 2 hours long, usually on Wednesdays from 4-6 pm. The first session is an overview of PD presented by a Movement Disorder Specialist (MDS), the second session is focused on medications and treatments presented by a MDS, and the third session is Building your Team and the Importance of Exercise by a physical therapist. This series is hosted in the Denver Metro Area. Can attend in person or virtually.
- Webinars
 - Educational programs that are held virtually. These can range on a variety of topics including Medicare, Medicaid, Nutrition, DBS, and more.
- Parkinson's 101 presentations to institutions, senior living facilities, clinics, and more.
 - There is a presentation that the CEO can provide to the community that gives an overview of Parkinson's and an overview of programs offered by PAR.
 - There is another presentation given by the Patient and Family Services Director that can train healthcare staff on how to recognize

symptoms and be able to mitigate symptoms and pain for the People with Parkinson's.

- *Equipment Loan Program*

- All equipment is stored in the PAR's office on Colorado Blvd and Louisiana Ave. There is some equipment available in Glenwood Springs and Fort Collins.
- The goal of this program is to provide equipment to members when they want to test drive a piece of equipment before they make a purchase or loan equipment while they are working with their insurance provider to acquire their own.
- All equipment is for short term loan of 2-month loan with possibly 30-day extension for U-Step walkers, 4-wheel walkers, transfer chairs, manual wheelchairs, and walking canes.

- *Exercise Classes*

- Exercise is the one thing proven to slow the progression of Parkinson's Disease. Every type of class that is offered has a virtual option to attend.
- You must register for exercise classes on Wellness Living. The PAR website redirects you to Wellness Living. Refer to the Appendix to find how to sign up for a PAR exercise class.
- There will be a Liability form that is electronically signed. Then there will be a Medical Consent Form that has to be signed by their physician.
- As of June 2023, there are over 80 weekly exercise classes occurring in Colorado and Wyoming
 - Yoga for PD
 - Pilates for PD
 - High Intensity Exercise
 - PAR for the Course Exercise (Balance & Strength Classes)
 - Power Punch Parkinson's
 - HIIT & Circuit Classes
 - PWR! Moves Classes
 - Dance Classes: Tango for PD, Rhythm & Grave, Dance for PD®
 - Singing/Music/Voice Classes: Tremble Clefs, LOUD for Life

- Tai Chi & Qi Gong
- Water Aerobics for PD
- Step and Connect
- *Free Case Assessments*
 - Cari Friedman, Licensed Clinical Social Worker, provides individualized evaluations of care needs through free assessments. You and your family will receive help in working through the diagnosis, identifying resources tailored to meet your specific needs and more. Cari works closely with the patients' team of healthcare providers to ensure all aspects of the disease are addressed with care.
- *Information and Referral Helpline*
 - This helpline is available to answer immediate questions concerning the many aspects of Parkinson's. The helpline is staffed by Cari Friedman, LCSW and is accessible for People with Parkinson's and Care Partners.

How SG Facilitators Collab with PAR

- ❖ Support the goals of PAR in local communities with an emphasis on providing information, support, and resources for People with Parkinson's and their families.
- ❖ Ensure all public notices for the group contain the group information, PAR logo, and a reference to the group being hosted by PAR.
- ❖ Provide Program Coordinator with updated support group member lists, including addresses, phone numbers, and email addresses.

OVERVIEW OF SUPPORT GROUPS

What is a Support Group?

- ❖ A place for People with Parkinson's to be themselves and share tips and experiences with others going through a similar experience.
- ❖ A source of information which includes PAR educational materials and community resources.
- ❖ A place to confidentially share, learn, and help others.

A Support Group is not...

- ❖ A professional counseling or therapy group. If the facilitator perceives that a person needs more help than a support group can provide, the facilitator can talk to that person privately and suggest that they contact PAR's LCSW Patient and Family Services Director. The facilitator must not provide individual referrals, the Director can do that.
- ❖ A substitute for medical treatment or health counseling. Support group members can talk amongst themselves about the medications they are taking and how they feel. The facilitator must not give medical advice. If they are interested in learning more about medications, refer to the support group speaker list and contact a professional to speak to the group.
- ❖ For everybody. The idea of a support group may make some people uncomfortable. Some people prefer different types of support at different times in their lives, depending on a variety of factors. One may not want to share their health problems with others, and listening to other people's problems may be too stressful. A newly diagnosed individual may not be ready to attend a support group.

Why are Support Groups important?

- ❖ Even though Parkinson's is different for everyone, people find comfort in the understanding and empathy inherent in support groups. It provides a sense of relief to support group members which helps establish community.
- ❖ Support group members can help others develop new insights about how to live and thrive with Parkinson's.
- ❖ Support group members can help each other understand that coping is not a single behavior, but a collection of many strategies and behaviors that develop over time.
- ❖ Support groups allow members to accept their diagnoses in a way that makes sense to them.
- ❖ Support groups allow members to take small steps which make adjusting to living with Parkinson's easier. Small, steady changes with validation from peers is beneficial to improving quality of life.

Goals of Support Groups

- ❖ Provide an accepting and safe learning environment so that support group members can express their feelings and concerns and develop appropriate skills to cope with chronic illness.
- ❖ Provide comfort and reassurance to those who feel alone in their diagnosis.
- ❖ Provide current and accurate information about Parkinson's and related issues.
- ❖ Help group members come to terms of living with Parkinson's and gain confidence in learning to cope.
- ❖ Encourage group members to share their health issues, including any change or worsening of symptoms and disease management concerns, with their doctors and other members of their healthcare team.
- ❖ Assist group members, through guided and effective group interaction, in adjusting to changes in lifestyle that can help them cope and better manage living with PD.
- ❖ Provide a positive social support system where a peer support network can develop.
- ❖ Sharing
- ❖ Information and Education
- ❖ Peer Support and Friendship

Different Types of Support Groups

❖ Care Partners

Care Partner groups are intended for the spouses, family members, friends, healthcare professionals, or others who act as primary caregivers for a Person with Parkinson's. The group offers a platform for Care Partners to discuss their roles, concerns, and difficulties they face while providing support and assistance to their loved ones with PD. Sharing experiences, learning about resources, and gaining emotional support and coping strategies from other Care Partners.

Challenges Care Partners face:

- Managing the physical and emotional demands of being a Care Partner which can be exhausting and emotionally draining.

- Adapting to changes in their loved one's physical and cognitive functioning over time.
- Balancing their own needs and well-being with the needs of the Person with PD
- Dealing with feelings of helplessness, frustration, and guilt, particularly when symptoms worsen
- Deciding when to find respite, palliative, or hospice care to move Person with PD to an assisted living or memory care facility.

❖ **Deep Brain Stimulation (DBS)**

Tailored for individuals who have undergone or are considering DBS surgery as a treatment for PD. Members can discuss their experiences with DBS, share post-surgery recovery tips, and provide guidance to those considering this treatment option. This group can offer invaluable insights into managing life with DBS and coping with any challenges that arise. *For more information on DBS, go to program topics*

Challenges DBS recipients face:

- Coping with the initial recovery period after the surgery, which can involve temporary side effects and adjustments to the stimulation settings.
- Managing expectations for symptom improvement and understanding that DBS is not a cure but a treatment to alleviate certain symptoms.
- Adapting to lifestyle changes and learning how to use the DBS devices effectively.

❖ **General and Inclusive**

These groups are open to anyone affected by Parkinson's, including Care Partners, family members, friends, loved ones, and interested individuals. This group provides a broad platform for people to connect, share experiences, exchange resources, and offer mutual support.

Challenges General Support Group members face:

- Addressing the varying needs and experiences of members. This can vary on date of diagnosis, symptoms present, reaction to medications, family, and community support, and more.
- Ensuring an inclusive and supportive environment for all members, regardless of age, gender, or background.
- Managing group dynamics and facilitating effective communication among members with diverse perspectives.

❖ **MSA/PSP/CBD**

These groups are specific to certain Parkinson's-related disorders: Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), and Corticobasal Degeneration (CBD). These disorders share some clinical features with Parkinson's. These support groups provide a space for individuals affected by these conditions to discuss their unique challenges, access condition-specific resources, and find solace in connecting with others who understand their struggles.

Multiple System Atrophy (MSA)

- A rare and progressive neurological disorder that affects various systems in the brain and the body. It is characterized by the degeneration of nerve cells in specific areas of the brain for regulating involuntary functions, movement, and autonomic function. The primary symptoms can be categorized into 2 main subtypes:
 - **MSA with predominant Parkinsonism (MSA-P)**: This subtype presents with symptoms like Parkinson's, such as bradykinesia (slowness of movement), rigidity, postural instability, and tremors. However, the response to typical Parkinson's medications is generally limited in MSA-P.
 - **MSA with predominant cerebellar ataxia (MSA-C)**: This subtype exhibits symptoms resembling cerebellar dysfunction, including difficulties with coordination, balance, and walking. Speech and swallowing problems may also occur.

Progressive Supranuclear Palsy (PSP)

- Rare and progressive neurodegenerative disorder characterized by the accumulation of abnormal tau protein in certain areas of the brain, leading to cell damage and cell death. PSP affects movement control, balance, and cognitive function. Treatment focuses on managing symptoms and improving quality of life.

Symptoms

- Difficulty in moving the eyes upward and downward voluntarily, leading to a distinctive “downward stare” appearance.
- Balance and gait disturbances, leading to frequent falls.
- Rigidity and bradykinesia like Parkinson’s but typically with poor response to levodopa, the primary medication for Parkinson’s.
- Speech and swallowing difficulties
- Cognitive impairment, including problems with memory, attention, and problem-solving.

Corticobasal Degeneration (CBD)

- Rare neurodegenerative disorder characterized by the progressive degeneration of nerve cells in specific areas of the brain, including the cerebral cortex and basal ganglia. Affects both movement and cognitive function.

Symptoms

- Asymmetric motor symptoms, such as limb rigidity, tremors, and apraxia (difficulty performing purposeful movements).
- Cognitive changes, including problems with memory, language, and executive functions.
- *Alien limb phenomenon*: where a limb may appear to move involuntarily or contrary to the individual’s intention.

Challenges:

- Coping with the progressive nature of these condition, which can lead to more rapid and severe disability compared to Parkinson’s.
- Navigating the complexities of managing less common Parkinson’s disorders, which may have fewer treatment options and resources available.

- Dealing with the emotional impact of a diagnosis that may have a more limited life expectancy and uncertain progression.

❖ **Parkinsonism**

- Umbrella term that refers to conditions with similar, movement-related effects. These conditions present a combination of motor symptoms such as bradykinesia, rigidity, resting tremors, and postural instability. However, Parkinsonism can be caused by various underlying conditions, and not all cases are due to Parkinson's.

Lewy Body Dementia

- One of the common causes of Parkinsonism is the presence of abnormal protein deposits called Lewy Bodies in the brain. Lewy bodies are aggregates of alpha synuclein protein that accumulate in nerve cells and interfere with their normal functioning. Parkinson's is characterized by the presence of Lewy Bodies in specific brain regions, particularly in the substantia nigra, a region involved in motor control.
- LBD is a progressive neurodegenerative disorder and one of the most common causes of Parkinsonism. It is closely related to both Parkinson's and dementia and is characterized by the presence of Lewy Bodies in various brain regions, including the cerebral cortex.
 - **Dementia with Lewy Bodies (DLB):** Primarily presents cognitive impairments, such as problems with memory, attention, and executive functions. Individuals may also experience Parkinsonian motor symptoms, visual hallucinations, and fluctuations in alertness and attention.
 - **Parkinson's Disease Dementia (PDD):** Characterized by Parkinson's motor symptoms along with the development of cognitive decline and dementia over time. Typically occurs in individuals who have had Parkinson's for several years before cognitive symptoms appear.
- Both DLB and PDD are part of the spectrum of Lewy Body Dementia and their clinical symptoms can overlap. The distinction between DLB and

PDD is primarily based on the timing of cognitive symptoms relative to motor symptoms.

❖ **Recently Diagnosed**

- A flexible term used to describe the early stages of a Parkinson's diagnosis. For this purpose, recently diagnosed will be considered 0-5 years.

❖ **Spouses that lost their Person with Parkinson's**

❖ **Veterans**

- For some veterans, developing Parkinson's can be associated with exposure to Agent Orange or other herbicides. Veterans with PD who were exposed to certain herbicides during their service may be eligible for disability compensation and healthcare. There is a large community of Vietnam veterans who have PD.
- This group would be able to discuss challenges specific to veterans like navigating the Department of Veteran Affairs (VA) healthcare system, accessing benefits, disability claims, and specialized support.

❖ **Women**

- Women tend to have different experiences with symptoms, treatment responses, and emotional challenges due to biological and hormonal factors.
- Women have different societal roles and are often primary caregivers in families. Women experience different gender biases in healthcare or public perceptions of PD.

❖ **Young Onset**

- Typically, under the age of 65 years old. Usually are working full time or part time, raising children, paying off a mortgage, some aren't working at all, applying for SSDI, and other challenges face this community.
- Important to have a group separate for this community to be able to relate better. If in a group with older Parkinson's folks, it may be overwhelming to see the progression of the disease.

STARTING A SUPPORT GROUP

Considerations

- ❖ Starting a support group that is consistent and active takes time and energy. If you have Parkinson's, it is important to be aware of how you are feeling physically, mentally, and emotionally. Ask yourself if taking on the responsibility of a support group might add to the stress of Parkinson's. If you are a healthcare professional, ask yourself if you can volunteer your time during the date and time of the support group. Don't overbook yourself. This is why having a committee of 2-3 people to assist you is important to meet the demands of organizing and running an effective support group. This makes the support group experience more enjoyable and prevents burnout. Effectively delegating tasks is important. Not all of this must fall on you.
- ❖ Starting a support group can have many positive effects and can change your life. You may find yourself becoming a Parkinson's advocate in your community. There are always other ways to volunteer with PAR.

Different Ways Support Groups get Started.

- ❖ A Person with Parkinson's, Care Partner, or healthcare professional who sees the need for a support group and is willing and able to take on the responsibility can plan, organize, and implement a support group with the Program Coordinator of PAR. Some scenarios include:
 - A Person with Parkinson's contacts PAR looking for a support group but learns that there are none in the area. That person then expresses an interest in starting a support group.
 - A Care Partner contacts PAR looking for a Care Partner only support group but learns that there are none in the area. The Care Partner then expresses an interest in starting a support group.
 - The Person with Parkinson's and Care Partner decide to facilitate the group together.

- A healthcare professional, such as a social worker, nurse, mental health professional, rehabilitation specialists, realizes that a Parkinson's support group would be beneficial in the community and contacts PAR for information about starting a support group.
- Program Coordinator meets with a healthcare professional, Person with Parkinson's, or Care Partner and asks if they want to facilitate a support group in certain area.
- ❖ Collaborate with Program Coordinator on time, date, and location.
- ❖ If no space in the area is willing to donate the space for the support group, PAR can pay for any location fee.

Meeting Location

- ❖ You will work with the Program Coordinator to determine a meeting location, time, and frequency.
- ❖ Examples of support group locations
 - Hospital meeting rooms
 - Community or senior centers
 - Assisted living facilities.
 - Public libraries
 - Churches
 - Recreation centers
 - Virtual (Zoom)
- ❖ Considerations when looking at a potential meeting space:
 - Is there a parking lot close to the entrance? Do people have to pay to park?
 - Are the building entrances, exits, bathrooms, and meeting space easily accessible, handicapped-accessible, and well lit? Is there an elevator?
 - How large is the room? Will it accommodate wheelchairs? Will the room ensure privacy for the group?
 - Is the room quiet, or will the noise from other building activities and the surrounding area be disturbing?

- Is the room adequately ventilated, heated, and/or air-conditioned for year-round comfort?
- Does the location set up the room for the meeting or do you need to arrive before the meeting time to set up?
- Are there any security issues?
- Can you bring refreshments and snacks?
- Would the facility be willing to advertise the group to their community?
- Is there a security deposit or requirement for liability insurance?
- ❖ All locations should have a projector, projection screen, and audiovisual equipment. One should be able to plug in a laptop with HDMI cable to show videos and presentations.
- ❖ Be sure to visit the potential meeting place before deciding to use it. The location must be accessible. Have access to an elevator or be located on the first floor. Easy entrance to building, no steps or wheelchair ramp option.

Meeting Time

- ❖ The facilitator should be aware of their availability as well as the availability of support group members. The facilitator can ask participants at the first meeting about convenient meeting times. The day of the week and time of day are important factors.
- ❖ Considerations
 - Certain routines and commitments such as work, school, and/or childcare may preclude daytime participation for some members, especially during the work week. Young Onset support groups may have to meet on weekends. Folks that are retired tend to meet during the weekday in the morning or early afternoon. If booking a weekend, it is important to consider religious observations within the group, especially when it comes to Sabbath observances.
 - Late evening meeting times are not recommended because Parkinson's medications seem to tire out folks at the end of the day. As well as safety and public transportation issues like driving at night.

- A support group meeting initially is an hour. As the support group becomes more comfortable, it can be 1.5-2 hours, depending on if there is a speaker.

Meeting Frequency

- ❖ How often a support group meets is an important consideration. Most support groups meet monthly. Some groups meet more often by planning social outings like walks in the park, coffee, attending an exercise class. Example: Meet on the 1st Thursday of the month at 11:30 am. Well-attended support groups have consistent meeting times and should share a yearly or 6-month schedule of meeting times and topics.

Marketing

- ❖ PAR can help by promoting the support group on social media, our biweekly e-newsletter, print newsletter, and at our exercise classes.
- ❖ Print brochure inserts with information on the support group and exercise classes in the area. Then these brochure inserts can be placed around town (churches, libraries, community centers, supermarkets, senior facilities, etc).

First Meeting

- ❖ Have PAR materials (brochures, newsletters, notepads, pens, educational resources) on a table. Make sure to let everyone know PAR is the organization that hosts the support groups and provides free services for the Parkinson's community.
- ❖ Introductions
 - Name and where you're from
 - How long have you been diagnosed/How long have you been a Care Partner?
 - Are you seeing a neurologist or movement disorder specialist?
 - Most troubling symptoms now
 - Make sure to write notes about what symptoms are troubling everyone. This can be good discussion topics for future meetings.

- ❖ After introductions, ask the support group members what they want from this group.
 - Do they want to split the second half of the group into Care Partners and PWP?
 - Do they want to meet for longer than an hour?
 - Do they only want to discuss or are they interested in hosting speakers as well?
 - What do they want out of the group?

SUPPORT GROUP MEETINGS

Before the Meeting

- ❖ Communicate the meeting details well in advance including date, time, location, and the itinerary/agenda (any topics or guest speakers). Email is the best communication. PAR's PC shares resources in their monthly email to support group facilitators. Make sure to send resources at the end of each meeting. If a speaker is presenting, share any materials related to the topic so support group members can come prepared with questions.
- ❖ Facilitators can help the meeting get off to a good start by being prepared. Have a good understanding of the meeting itinerary and topic(s). Develop a few questions that reflect this topic to use in initiating group discussions. Use open-ended questions that will draw out thoughts and feelings rather than questions leading to a simple yes or no response.
- ❖ The facilitators should arrive at the meeting location before the meeting is scheduled to make sure that the room is open, clean, and well-lit, and that the temperature is comfortable. If a speaker is presenting, make sure they arrive early to make sure that the Audio-visual equipment is working properly.
- ❖ Seating in the room (usually in a circle or facing the projector if there's a speaker) should be arranged by the facilitators or meeting location staff.
- ❖ If you would like to bring materials for everyone to have a name tag, that may be beneficial in helping support group members remember names easily.

- ❖ Support Group Meeting Sign-in Sheet and Support Group New Member Registration Forms should be easily accessible and appropriate education materials neatly arranged on a table. You can always ask PAR PC or other staff members to be sent PAR marketing materials or education materials. (See Appendix)

Planning an Agenda

- ❖ One of the most common formats of an annual agenda is that on the even months a guest speaker presents and on the odd months, discussions are shared amongst the group.
- ❖ Meeting agenda can vary depending on the size and length of support group.
- ❖ Sample 2-month agenda:
 - January
 - Theme of discussion: Coping Strategies for Everyday Challenges
 - Welcome and Introductions (10 mins)
 - Coping with Motor Symptoms Discussion (30 mins)
 - Break out Groups: Care Partners and People with Parkinson's (20 mins)
 - Reflection, Announcements, Resources, Closing (10 mins)
 - February
 - Program Topic: Medical Updates and Treatment Options
 - Welcome and Introductions (10 mins)
 - Guest Speaker: Medical Advances in PD Treatments (40 mins)
 - Q&A Session (20 mins)
 - Members share their experiences with different treatments and therapies (20 mins)
 - Thank Guest Speaker, Reflection, Announcements, Resources, Closing (10 mins)
 - Continuing this alternating pattern of discussion-focused meetings and guest speakers throughout the year. Adjust the themes and topics based on support group member's feedback. This approach ensures a well-rounded

and engaging experience for members while addressing practical coping strategies and staying informed.

- ❖ Program Ideas and Topics (See Appendix)

During the Meeting

- ❖ As support group facilitators, you should introduce yourself, extend a warm welcome to the group, and share what your role is as facilitators.
- ❖ Ask everyone if they're comfortable with the temperature of the room and/or can see the screen for the presentation.
- ❖ Going around the room, allow each person to introduce themselves. Members may want to share when they were diagnosed or have been caring for someone with Parkinson's. They can share what brought them to the group and what they hope to gain from the group.
- ❖ If the group is more accustomed to each other, the facilitators may ask members to share how they have been doing since the last meeting (highs and lows of the month). Each support group member will interact at their own pace, so the facilitators should be accommodating towards people who may not want to share personal information right away.

Symptoms that may affect the group process.

- ❖ **Bradykinesia (Slowness of movement)**
 - Group members may arrive late for meetings.
 - It may take some people a long time to communicate their message.
- ❖ **Rigidity**
 - A person may have reduced facial expression and a reduction in body language that we rely on for feedback in conversations.
 - Stooped posture and reduced body language make the person appear bored or sad when they are actually very interested and engaged in the conversation.
 - It can be helpful to ask more questions to get verbal information to compensate for reduced body language.
- ❖ **Speech Difficulties**

- Speech can be much softer, and it may be difficult for the person to articulate clearly. Hosting a meeting in a room with a microphone is beneficial.
- Poor posture can accentuate communication difficulties if the voice is being projected downward.
- Discuss with the person how they would like the group to help them communicate. Helpful tips include:
 - Encourage them to pretend that they are trying to speak from another room.
 - Start the meeting with some voice exercise.
 - Encourage the group to support them in their efforts and give supportive feedback when their communication is heard.

❖ **Cognitive Changes**

- Executive brain functioning may be affected. This means that task initiation, problem solving, prioritizing, and planning may be impaired.
- The ability to be attentive and to concentrate may be impaired.
- They may have “word-finding” difficulty in the middle of a sentence.
- Some may have difficulty multi-tasking.
- Allow more time for everyone in the group to think and process information.
- Cognitive challenges can affect memory, attention, and processing speed.

❖ **Fatigue**

- Can lead to decreased participation, shorter attention spans, and reduced engagement in activities.

❖ **Emotional Changes**

- Depending on life situations and unexpected changes, members can be at higher risk for anxiety, depression, and apathy.

❖ **Medication Fluctuations/Off-Periods**

- Changes in medication levels might impact members’ energy levels, motor and non-motor symptoms, and overall ability to actively participate.
- During off-periods when medication is less effective, members might experience worsened symptoms.

❖ Sleep Issues

- Can lead to reduced energy levels and increased irritability.

❖ Timing of Medications

- Be prepared to expect alarms during the meeting. Do not ask for all phones to be silenced.

❖ Mobility Issues

- Can impact members' ability to move around the meeting space, affecting their physical participation.

Social Gatherings

- ❖ Hold an informal gathering at a restaurant to celebrate a special occasion.
- ❖ Some groups like to meet at a coffee shop once a month in addition to the regular meeting.
- ❖ Consider having a BBQ or potluck at a park during the summer.
- ❖ For November and December, consider hosting a holiday party. This can be potluck style as well.
- ❖ During the spring, summer, and fall plan a time to walk in a park as a group.

Support Group Rules

- ❖ Group members will respect and listen carefully to all members, accept feelings, not engage in side conversations, and not be judgmental.
- ❖ Group members are here to express their own experiences, rather than those of someone else who is not present.
- ❖ Emotions are a healthy part of coping. Group members are encouraged to reveal as much or as little as they wish about their journey with Parkinson's.
- ❖ If a person has expressed a need or concern, allow the group to support them before expressing your own need or concern. After the meeting, you can always provide them with any other resources or support needed.
- ❖ It is important that each member's differing needs and values are respected, and the group remains a safe place where people can be themselves.

ROLE OF SUPPORT GROUP FACILITATORS

What makes an Effective Facilitator?

- ❖ An effective support group facilitator plays a vital role in creating a safe, welcoming, and productive environment for members.
- ❖ Key qualities and skills:
 - Dependable
 - Reliable
 - Patience.
 - Empathy for People with Parkinson's and Care Partners
 - Able to listen in a non-judgmental manner.
 - Clear and concise communication that helps convey information and discussions effectively.
 - Adapt to changing dynamics of group and addressing unexpected situations including discussions, activities, or agenda.
 - Ability to mediate conflicts and guide members towards respectful resolutions.
 - Facilitators should understand Parkinson's to address common questions and concerns.
 - Maintain confidentiality and respect members' privacy.

Choosing Co-Facilitators

- ❖ The most effective way to find co-facilitators is to look for a person from within the group. If there is someone who has shown an interest in helping or an individual that you think would be a good facilitator, talk with the person privately.
- ❖ If you do not have someone in mind to be co-facilitators, but you need some help, ask the group during a meeting.

Working with Co-Facilitators

- ❖ When facilitators work together, they can assist each other during difficult times. Absence from the group, and lack of time and energy in organizing responsibilities can be compensated for by the second facilitator. If the

facilitators foster joint relationships among group members, the support group will benefit from the co-facilitator's relationship.

- ❖ It is important to spend considerable time and effort communicating with each other. When the group members perceive a healthy mutual respect and honest communication between the facilitators, they will respond in the same manner with each other.
- ❖ Schedule regular meetings for facilitators to discuss upcoming agendas, share insights, and address any challenges. Discuss previous meetings highlights.
- ❖ Clearly define each facilitator's roles and responsibilities. This can include leading discussions, organizing guest speakers, managing logistics, and sending out communications.
- ❖ Be adaptable and open to each other's suggestions and feedback.

Reaching out to Potential Speakers

- ❖ Either use PAR's Support Group Speaker List or any recommendation from support group members or yourself. Make sure the presenter isn't trying to sell any product or business. The objective of hosting a guest speaker is to inform and educate support group members.
- ❖ PAR's speaker list will have the preferred method of communication for the guest speaker. Be respectful when reaching out. Make sure that you give the guest speaker multiple dates a couple of months in advance. A lot of these Parkinson's professionals are very busy and need time to schedule presentations and meetings.

Providing Support: Member hasn't shown up at too many meetings.

- ❖ There are many reasons why people may stop attending a support group. It is not unusual for some members to come and go depending on their circumstances.
 - One or two sessions might be enough for some individuals.
 - A change in health status (improved health or deteriorating health) or other circumstances.

- They may be physically unable to attend a support group due to symptoms.
- After attending some meetings, a member may become overwhelmed and may need some time to reflect on their situation before coming back to the group.
- Support groups are not for everyone.
- ❖ Reach out through email or phone number. If they aren't responsive, let PAR PC or Director of Family and Patient Services know so we can reach out to them as well. Make sure to not overwhelm the Person or Care Partner with too many messages.

Providing Support: Death of SG Member

- ❖ Let the PAR staff know so we may send a letter to the family.
- ❖ Inform the members about the passing of a member in a sensitive manner.
- ❖ At the next meeting, begin by acknowledging the loss and creating a safe space for members to share their feelings and memories. Offer a moment of silence if appropriate.
- ❖ Encourage members to express their grief however they are most comfortable.
- ❖ Make it clear that the group is a safe space for processing grief and that everyone's feelings are valid.
- ❖ Discuss healthy coping strategies for dealing with grief such as seeking support from loved ones, seeking professional help if needed, and engaging in self-care.
- ❖ Provide information about grief counseling, bereavement support, and resources that members can access outside the group.
- ❖ Be mindful of shifts in group dynamics, some members might withdraw temporarily while others might become more engaged in seeking and offering support.

When to Intervene

- ❖ Intervention skills:
 - Practice "permission based" interventions. For example, "May I offer an alternative?" or "May I offer a few suggestions?"

- Keep interventions brief and to the point.
 - Focus on behaviors, and not individual personalities.
 - Intervene with respect and empathy.
 - Encourage balanced participation by gently involving quieter participants and moderating dominating ones.
 - Be flexible in your interventions, adjusting your approach based on the group's dynamics, needs, and comfort levels.
- ❖ An intervention is *valid* when it:
- Protects the purpose of the support group.
 - Helps address conflict.
 - Helps the group process move forward.
 - Encourages all members to participate and express thoughts and feelings appropriately.
 - When a member is consistently disrupting the flow of the meeting by monopolizing the conversation or engaging in inappropriate behavior
- ❖ An intervention is *invalid* when it:
- Is not relevant to the situation at hand.
 - Is used for the purpose of sounding superior and showing one's expertise to the group.
 - Encourages behaviors that move the group away from constructive interaction.
- ❖ Avoid intervening too frequently, as it can stifle organic conversations and discourage members from sharing openly.

Encouraging Positive Interactions

- ❖ Start each meeting with a warm welcome and a brief overview of the meeting's goals and agenda.
- ❖ Express the importance of creating a safe, non-judgmental space where members can openly share and support each other.
- ❖ Encourage members to listen attentively when others are speaking, without interrupting or judging.

- ❖ Model active listening by maintaining eye contact, nodding, and responding empathetically to member's comments.
- ❖ Validate members' experiences and emotions, even if their perspectives differ. Acknowledge that there's no one "right" way to experience Parkinson's.
- ❖ If a conversation becomes negative or unproductive, gently redirect it toward more constructive topics or solutions.
- ❖ Encourage members to celebrate their small victories and achievements, no matter how seemingly insignificant. Positive reinforcement boosts morale.
- ❖ Support Care Partners and their own unique journey. Emphasize that it is important to take care of yourself.
- ❖ Regularly express gratitude for the mutual support and shared understanding within the group.

Responsibilities

- ❖ The support group facilitator is there to guide the group, stimulate discussion, manage the group dynamics, and encourage interaction.
- ❖ Coordinates speakers (use speaker list as reference)
- ❖ Send meeting notes and reminders to email list.
- ❖ Maintain consistent communication with Program Coordinator about any updates or changes with time or location of group.
- ❖ Plan and facilitate support group meetings.
 - Plan itinerary in December for the upcoming year. This is to ensure that speakers are reserved.
- ❖ Set up a meeting room. Use AV equipment to show presentations and videos.
- ❖ The facilitator works with the group to:
 - Develop a facilitation committee of 2-3 people sharing responsibilities. Ask for help with tasks like room setup, coffee, snacks, planning social events. This committee is beneficial so in case there is an emergency with the SG facilitator, committee member(s) can step up.

Confidentiality & Privacy Statement

- ❖ Participation in the support group is confidential. Don't share any information or support group members' names outside of the group.

- ❖ A list of group members should only be accessed by the support group facilitator and PAR's Program Coordinator. An attendance list should be sent to the Program Coordinator monthly. This list should have a first and last name and an email address.
- ❖ At the end of the year, the group list should be shared with the Program Coordinator. The list will include the name, phone number, address, and email of support group members. This information will be safely secured in PAR's database to be able to share information on upcoming events and other resources. Support group members must give their permission for this information.
- ❖ Data relating to support group members will not be traded, sold, or otherwise shared by PAR or by the support group facilitator.
- ❖ Support group members may choose to exchange names, phone numbers, and/or email addresses among themselves. It should be made clear that no one is required to do so and that no exchange of information should be given to anyone outside the group. This policy is especially important for those who have not shared their diagnosis with others (friends, employers, family, etc.).

What if I move or decide not to facilitate the group anymore?

- ❖ Inform PAR's PC 3 months before departure to give ample time for the transition process.
- ❖ If you work with co-facilitators, initiate an open conversation about your transition and how to proceed. Discuss who may be a potential co-facilitator.
- ❖ Notify support group members about your departure during a meeting. Assure them that the group will continue and that you're working to ensure a smooth transition. Ask if anyone wants to form a committee or become a co-facilitator.
- ❖ Create a document containing essential information such as meeting agendas, contact details, topics group is interested in, and resources. Share this with the new facilitator and PAR's PC.
- ❖ While the departure might bring changes, the support group's essence remains in the connections and community that members have built. Your thoughtful transition ensures that the group's mission of providing support and

understanding to People with Parkinson's and the Care Partners continue effectively.

Code of Conduct

- ❖ Facilitators will conduct themselves with integrity, honesty, and professionalism upholding the values of empathy, respect, and dignity.
- ❖ Facilitators will create an inclusive environment that welcomes and respects members regardless of their background, beliefs, or experiences.
- ❖ Facilitators will maintain the confidentiality of members' personal information and discussion, ensuring that what is shared within the group remains private.
- ❖ Facilitators will communicate respectfully, listening actively to members and valuing their perspectives.
- ❖ Facilitators will approach discussions without judgment, creating a safe space where members feel comfortable sharing their thoughts and feelings.
- ❖ Facilitators will encourage equal participation among all group members, ensuring that no individual dominates discussions.
- ❖ Facilitators will address conflicts and disagreements in a respectful and constructive manner, seeking resolution while maintaining the group's well-being.



SUPPORT GROUP FACILITATOR AGREEMENT

I agree to uphold and abide by the Support Group Facilitator Code of Conduct during my tenure as support group facilitator for Parkinson Association of the Rockies. I understand the importance of creating a safe and supportive environment for members and am committed to adhering to the ethical standards outlined in the Code of Conduct.

I understand that my volunteer role involves active listening, promoting respectful communication, and fostering inclusivity. I will maintain members' confidentiality and handle sensitive information with care. If conflicts arise, I will address them in a professional and constructive manner. If anyone is severely struggling with mental health issues, I will contact PAR's Director of Family and Patient Services.

I am committed to my ongoing development as a facilitator and will seek opportunities to enhance my knowledge and skills to better serve the support group members. I acknowledge that I am representing Parkinson Association of the Rockies and will conduct myself in a manner that upholds the organization's mission and vision.

Signature

Date

PAR Staff Member

PICKING PROGRAM TOPICS

TOPICS OF INTEREST

Please circle your level of interest for each subject listed. If you have any suggestions for topics, please list it below.

Parkinson's Information

Overview	Not Interested	A Little Interested	Interested	Very Interested
Common Difficulties with PD	Not Interested	A Little Interested	Interested	Very Interested
Balance/Walking Problems	Not Interested	A Little Interested	Interested	Very Interested
Sleep Disorders	Not Interested	A Little Interested	Interested	Very Interested
Rigidity/Flexibility/Tremors	Not Interested	A Little Interested	Interested	Very Interested
Slowness/Mobility/Agility	Not Interested	A Little Interested	Interested	Very Interested
Fatigue	Not Interested	A Little Interested	Interested	Very Interested
Anxiety/Apathy/Depression	Not Interested	A Little Interested	Interested	Very Interested
Memory/Cognitive Problems	Not Interested	A Little Interested	Interested	Very Interested
Swallowing/Voice Difficulties	Not Interested	A Little Interested	Interested	Very Interested
Ongoing Research Studies	Not Interested	A Little Interested	Interested	Very Interested

Alternative Medicine and Therapies

Massage Therapy	Not Interested	A Little Interested	Interested	Very Interested
Acupuncture	Not Interested	A Little Interested	Interested	Very Interested
Chiropractic	Not Interested	A Little Interested	Interested	Very Interested
Diet and Nutrition	Not Interested	A Little Interested	Interested	Very Interested

Other Issues

Care Partners Concerns	Not Interested	A Little Interested	Interested	Very Interested
Increased Communication	Not Interested	A Little Interested	Interested	Very Interested
Stresses and Failures	Not Interested	A Little Interested	Interested	Very Interested
Elder Care Attorneys	Not Interested	A Little Interested	Interested	Very Interested

Other Suggestions:

Facilitators: _____

Location: _____ Date: _____

[illegible]

RESOURCES

- Make sure to acquire or create a list of resources in your local area. Transportation, in-home care, assisted livings, senior centers, recreation centers, mental health providers, movement disorder specialists, etc.

PAR

- [PAR Youtube Channel](#)
- [PAR website](#)
- [PAR Color Scheme](#)
- [PAR Fonts](#)
- [PAR Social Media Hashtags](#)
- [PAR Support Group Speaker Questionnaire](#)
- [Doctor's Visit Worksheet](#)
- [Parkinson's 101 for the Newly Diagnosed Educational Packet](#)
- *PAR's PC will send the most updated Support Group Speaker List on their monthly email to support group facilitators
- [University of Colorado – Movement Disorder Clinic](#)
- [CurePSP Foundation](#)
- [PSP and CBD Foundation](#)
- [Multiple System Atrophy Coalition](#)
- [Defeat MSA Coalition](#)
- [International Essential Tremor Foundation](#)
- [National Organization for Rare Disorders](#)
- [Parkinsonism](#)
- [Lewy Body Dementia Association](#)
- [Veteran Affairs](#)
- [Road Map for Aging](#)
- Parkinson's National Organizations
 - [American Parkinson's Disease Association](#)
 - Online Education Resources for a variety of communities
 - Research
 - [Michael J Fox Foundation](#)
 - Online Education Resources for a variety of communities
 - Research
 - Advocacy (legislation)

- [Davis Phinney Foundation](#)
 - [Support Group Discussion Questions](#)
 - Online Education Resources for a variety of communities
 - Research
- [Parkinson's Foundation](#)
 - [Aware and Care Kit](#)
 - Online Education Resources for a variety of communities
 - Research
- [PD Active](#)
 - Online exercise classes
 - Online support groups
 - Online Education Resources for a variety of communities
- [PMD Alliance](#)
 - Online support groups
 - Online Education Resources for a variety of communities
- [Deep Brain Stimulation](#)
 - [Abbott](#)
 - [Boston Scientific](#)
 - [Medtronic](#)