



In Sync!®

**SUPPORT GROUP LEADER
REFERENCE GUIDE**

*Practical tips and guidance on
establishing and maintaining
a successful support group*








PMD Alliance

Parkinson & Movement Disorder Alliance





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PMD Alliance Programs for You and Your Support Group

WE ARE HERE FOR YOU. We know the importance of social connection – between you and your group members, between you and other group leaders, and between your group and PMD Alliance.



IN SYNC!® ONLINE WORKSHOPS

Stay connected with your peers without leaving home. Join in online, on the phone, or on your tablet to chat, to hear from experts addressing topics relevant to you and to share experiences with other group leaders.



IN SYNC!® SUPPORT GROUP LEADER WORKSHOPS

Support groups thrive when leaders feel confident, strong, and capable. That's why PMD Alliance offers its In Sync!® Support Group Leader Workshops. An event that brings group leaders together to learn from the experts and each other about managing their group activities, utilizing community resources, and supporting each other in this important work.



ENEWS AND EVENT NOTICES

As part of the In Sync!® Network, you will receive our general monthly newsletters via email, plus our *In Sync!® Insights* bi-monthly newsletter specially designed for support group leaders. We also send emails about upcoming events and online programs.



PMD ALLIANCE WEBSITE & NEURO LIFE ONLINE®

Explore www.PMDAlliance.org for resources and online activities for you, your group members, and your group meetings.



PMD ALLIANCE FACEBOOK

Visit the PMD Alliance Facebook page, then like us so you'll see what we're up to now and in the future. We also offer a private Facebook group for the Adult Children and Care Partners of people living with movement disorders.



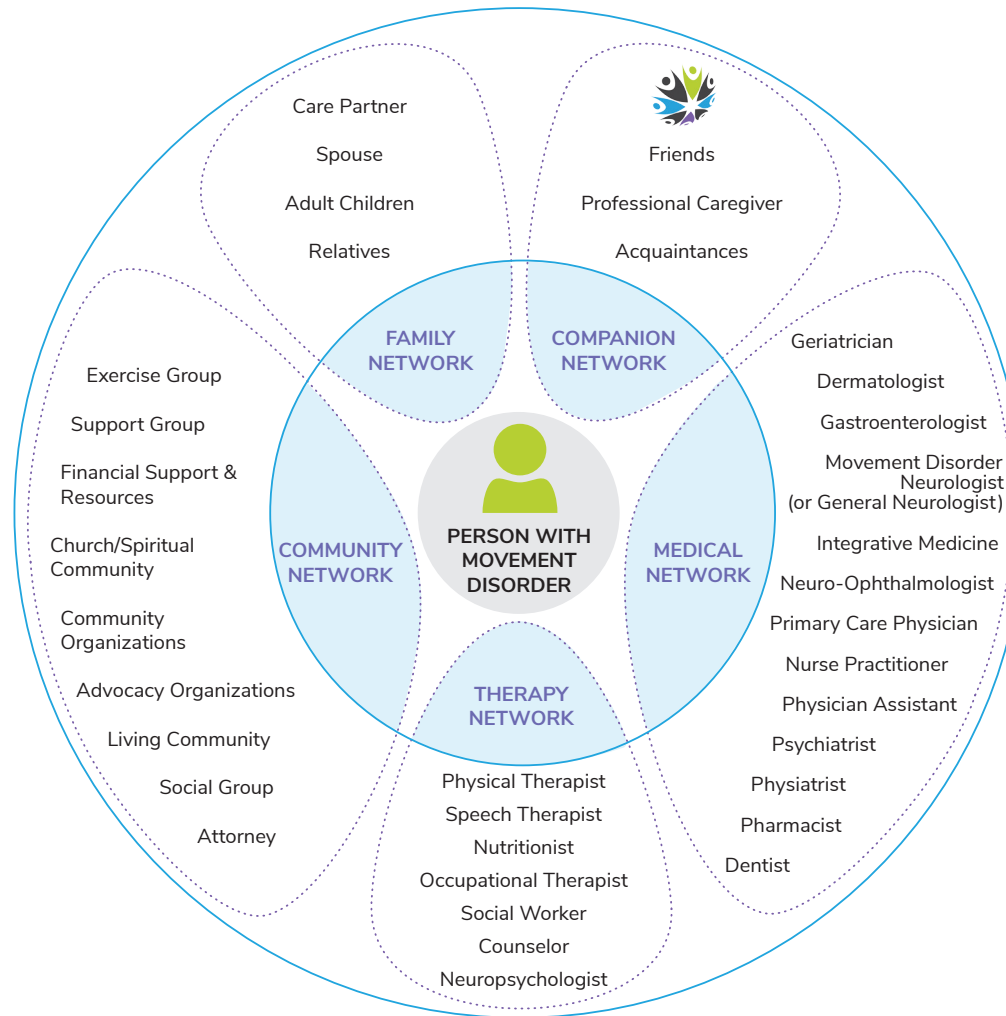
PMDALLIANCE YOUTUBE CHANNEL

Subscribe to our PMD Alliance YouTube Channel. View speakers on various topics at your convenience. Share videos with your group. Watch event clips to learn more about PMD Alliance programs. Go to www.youtube.com/pmdalliance to browse and subscribe to our channel.



Movement Disorder Care & Support Ecosystem[©]

Parkinson & Movement Disorder Alliance (PMD Alliance), a non-profit, independent organization, delivers high impact programs to the public, healthcare providers, and healthcare/residential facilities. With attention on the whole system, we re-ignite vitality, create resiliency and strengthen connections.



Who is likely to attend support group meetings?



- + Person living with a movement disorder
- + Accompanying care partners, family members, friends
- + Care partner alone
- + Many will be over 60 years old
- + Some will be over 80
- + Some will be in their 50s and some will be even younger
- + Some newly diagnosed in early stages
- + Some diagnosed decades ago, in various stages
- + Few in late stages (difficult to travel)

What does your group look like?

What do they want?



LEARN.

- + Medical information & procedures
 - + Medications
 - + Symptoms – Motor, Non-Motor, Cognition, Mood (Depression, Anxiety, Apathy)
 - + Research
 - + Hospitalization
 - + Medicare & other insurance
 - + Veterans' benefits & care
 - + Nutrition and diet
 - + Exercise
 - + Therapies – disease specific (BIG & LOUD, PWR!), speech, occupational, physical
 - + Complementary/holistic treatments – i.e. acupuncture, medical marijuana/ CBD, herbs, melatonin, supplements
 - + How others cope with various symptoms
-
-
-



LIVE.

- + Be recognized in the fullness of who they are, despite the disease
 - + Feel understood
 - + Spend time with family and friends
 - + Feel OK about their emotions
 - + Be accepted by friends and acquaintances
 - + Enjoy social activities
 - + Continue to travel
 - + Be out in the community
 - + Have reasons to be optimistic and hopeful
 - + Maintain daily activities
 - + Drive a car
 - + Enjoy the pleasures of sex/intimacy
 - + Continue to work
-
-
-



CONNECT.

- + Others with the disease
 - + Other care partners & family members
 - + Community organizations
 - + Medical specialists
 - + Healthcare resources & services
 - + Local Movement Disorder Ecosystem® professionals
 - + Daily care services
 - + Other veterans
 - + Exercise classes
 - + Respite services for care partners
 - + Yoga, dance, boxing, tai chi, etc.
 - + Elder law attorneys
 - + Insurance agencies – Medicare related
 - + Local / county / regional / state / federal programs
-
-
-

How do they feel?

(includes people living with movement disorders and care partners)



SAD

Ashamed
Depressed
Disappointed
Discouraged
Disheartened
Helpless
Hurt
Lonely
Numb



GLAD

Delighted
Eager
Encouraged
Excited
Happy
Inspired
Proud
Relieved
Thrilled



MAD

Agitated
Angry
Annoyed
Disgusted
Enraged
Frustrated
Furious
Impatient
Resentful



TIRED

Burned Out
Distracted
Exhausted
Fatigued
Hopeless
Indifferent
Lethargic
Restless
Weary



WORRIED

Alarmed
Anxious
Disturbed
Nervous
Overwhelmed
Shocked
Suspicious
Tense
Terrified
Wary



CONFUSED

Cautious
Doubtful
Hesitant
Puzzled
Rattled
Reluctant
Torn
Troubled
Uncomfortable
Unsettled
Unsure



CALM

Absorbed
Blissful
Comfortable
Content
Fulfilled
Loving
Peaceful
Relaxed
Secure
Serene



FRIENDLY

Appreciative
Grateful
Open
Receptive
Sensitive
Social
Tender
Trusting
Warm
Welcoming



EXCITED

Amazed
Curious
Energetic
Engaged
Exhilarated
Fascinated
Interested
Intrigued
Invigorated
Passionate



STRONG

Sure
Certain
Dynamic
Tenacious
Hardy
Secure
Empowered
Ambitious
Powerful
Confident
Determined

Speaker/Topic Possibilities



- + **AARP representative**
- + **Area Agency on Aging representative:** resources, services offered
- + **Assisted living, group homes, memory care:** what they do; who they serve; services, costs
- + **Audiologist:** the importance of hearing well for physical and psychological/social health
- + **Constipation:** symptom of PD; how to prevent; how to relieve
- + **DBS (Deep brain stimulation) manufacturer representative**
- + **Drug sales representative:** can sometimes bring a physician to speak
- + **Elder Law:** attorney speaking about legal issues related to aging
- + **Emergencies:** falls, going to the emergency room, creating an emergency kit
- + **Forgetfulness**
- + **Getting out of bed, getting up from the floor, reducing risk of falls:** physical/occupational therapist
- + **Home health:** temporary medical care in the home
- + **Hospice:** easing late stage symptoms and addressing end-of-life care
- + **Hospital:** MD, RN, dietitian, therapist, social worker, discharge planner, navigator
- + **Lack of motivation:** apathy as a symptom
- + **Long term planning:** financial options, lifestyle choices, care needs, legal situations
- + **Marijuana & derivative products**
- + **Medicaid / Medicare / Veterans' Benefits**
- + **Medicare expert:** during open enrollment
- + **Meditation instructor**
- + **Mood:** depression and anxiety as symptoms
- + **Movement Disorder Specialist and/or neurologist who sees many PD patients**
- + **Music / drumming / singing:** therapist/music teacher
- + **Neuro-psychiatrist:** clinical/medical
- + **News from the local hospital:** representative to discuss admissions changes, ER information, new MDs, new services, etc.
- + **Non-medical home care agencies:** help in the home with activities of daily living – dressing, bathing, shopping, light housework, companionship, eating, food preparation, etc.
- + **Nutrition & dietary:** food & medications interactions, food textures, weight loss
- + **Ophthalmologist:** how PD affects the eyes and vision

Remind guest speakers to answer the questions: **WHO, WHAT, WHERE, WHEN, WHY and HOW.** If they do not, leader should be sure this information is revealed.

When possible, consider including an experiential activity related to the meeting's topic. Always keep the safety of those attending in mind by cautioning everyone to only participate as they feel capable and confident.

TIPS

- + **Orthopedist:** arthritis, postural instability, back health, ambulation
- + **Pain specialist:** neuropathy, dystonia, internal pain, stress, postural
- + **Palliative care:** focused on comfort and quality of life
- + **PD-specific exercise therapies:** PWR, BIG & LOUD, dancing, Rock Steady boxing, personal training
- + **Pelvic floor (bowel/bladder) management**
- + **Pharmacist:** services, assistance, Medicare & Medicaid, Part D
- + **Psychologist:** social/behavioral
- + **Registered dietitian**
- + **Rehabilitation hospital:** how they are different from acute hospital and skilled nursing
- + **Relating to adult children in the family**

- + **Relating to young children in the family**
- + **Retirement community:** various choices and how they're structured, costs, services
- + **Senior Center/Recreation Center representative**
- + **Skilled Nursing facility:** care offered, how they are different from a hospital, Medicare regulations
- + **Sleep specialist:** PD related, sleep apnea, REM Sleep Behavior Disorder
- + **Social Worker:** overview of services
- + **Tai Chi (modified)**
- + **Therapists:** Physical, Occupational, Speech, Music, Dance, Psychological
- + **Urologist:** incontinence and sexual function
- + **Veterans Affairs representative:** VA benefits, services, procedures, including long term care

- + **What to expect when you go to the hospital**

- + **Word finding difficulty**

- + **Yoga teacher (modified)**

- + **Improv**

- + **Art Therapy**

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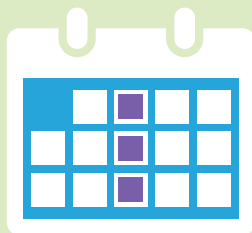
Group Discussion Topics (no speaker)

- + Birthdays / Birth City
- + Blessing / gratitude derived from living with the disease
- + Bucket List – what you’ve done and what you have yet to do
- + Watch/listen to a PMD Alliance video talk, then discuss (www.pmdalliance.org/video-archive)
- + Review a scientific article
- + Famous people you have met
- + Funny stories related to an experience with the disease
- + Devices that help make motor symptoms easier to cope with (spoons, plates, cups, pillows, etc.)
- + Professional accomplishments
- + Tips to stay safe at home (grab bars, railings, remove clutter, lighting, stairs, pets, flooring and rugs, etc.)
- + Symptoms – the most aggravating; ones that have disappeared
- + What you are most proud of
- + Your favorite travel experience
- + Looking back – before diagnosis, did you experience symptoms that you now know are part of the disease (i.e. depression, constipation, mood swings, loss of sense of smell, etc.)?
- + Last good book you read
- + Favorite food
- + What you do for fun
- + Hidden talent

+	_____
+	_____
+	_____
+	_____

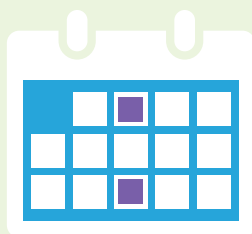
See our **Support Group Meeting Makers** for more ideas!

Meeting Frequency



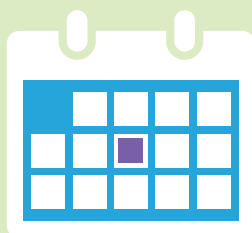
Weekly

Small, informal group, 1 hour – usually no speaker, everyone has time to talk



Bi-weekly

Small, informal group, 1 hour



Monthly

Any size group – 90 minutes – may include a speaker for part or all of the meeting.
Publicized to the public.

- + Everyone meets together for the entire meeting – person with disease & care partner
- + Meeting begins with everyone together, then separate into person with disease & care partner groups – separate groups must have adequate space and privacy
- + Can add social time afterwards



Special events

Scheduled outside of regular meeting times

- + Publicized to the public
- + May be in addition to or replace a regular meeting
- + May be in partnership with a community business or service (i.e. new assisted living residence, retirement community, healthcare service)

Meeting Locations & Logistics

When considering a meeting location, it's important that it have adequate and easily-accessible parking, easy entry and exit to the building, room between seats to accommodate walkers and wheelchairs, convenient access to a restroom, adequate lighting, and a generally safe environment to move in. Support groups meet in all kinds of places, generally free of charge.

As you set up for your meeting, keep in mind:

- ✓ Who is your meeting site contact person?
- ✓ How do you get into the room to set up? Do you need a key?
- ✓ Can you store any materials in the room between meetings?
- ✓ Where does everyone park?
- ✓ How will people know where to go? Simple signs may be useful.
- ✓ How do meeting attendees get into and out of the room?
- ✓ Is there space for wheelchairs and walkers to move between rows / tables?
- ✓ Tables to display materials
- ✓ Tables for refreshments
- ✓ Electrical outlets if you want to offer hot beverages
- ✓ Electrical outlets for a projector, PA system
- ✓ Screen or wall for projection
- ✓ Closest restrooms and drinking water
- ✓ Trash cans and trash management
- ✓ Who to contact in an emergency

- + Community center like YMCA or JCC
- + Church or synagogue
- + Retirement community / assisted living
- + Hospital
- + Senior center
- + School
- + Library
- + Dedicated room in a restaurant
- + Rehabilitation Center

Possible Meeting Locations



Seating options

When possible, choose the seating arrangement that allows people to see each other and a speaker without turning their chairs. Tables for everyone tend to be more comfortable but aren't required.

In a circle (no tables)

U or crescent (with tables)

Picnic tables (diagonal to speaker/screen/podium, with people seated on 2 table sides)

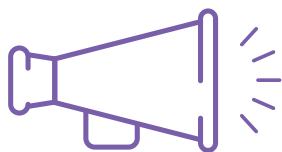
Classroom (rows with seating on one side of tables only)

Auditorium (chairs in rows)

Be sure to leave aisle room and space for people who use walkers and wheelchairs.

How can you improve your meeting space?

Publicity and Marketing



If you're beginning a new group, keep in mind that it takes time for people to hear about your meetings and plan to attend. Collecting email addresses is the easiest way for you to invite people to attend, send out quick reminders, and share information. Reach out to any community businesses and organizations that serve seniors. Ask them to include information about your meetings in their newsletters.

If possible, email notices can be sent out announcing each meeting. The first notice is timed about 10-12 days ahead of the meeting date. A second emailing of the same notice is helpful as a reminder 3-4 days before the meeting date.

Some groups also mail paper notices to people who don't use a computer or email. This practice is helpful, of course, but incurs expenses for postage, envelope, paper and copying.

When possible, flyers announcing the **Who, What, Where, When, Why** of the group's meetings will be most helpful. Be sure to include meeting day and time (i.e. 3rd Thursdays, 3-4:30 PM), along with a contact name, phone number, and/or email address.

It's helpful to periodically check that publicly posted flyers are still accurate and on view. They can be distributed and posted in:

- + Movement Disorder Specialist & Neurologist Offices
- + Therapist offices / gyms
- + Churches / synagogues
- + Senior centers
- + Libraries
- + Bulletin boards
- + Civic centers
- + Community colleges
- + Recreation centers
- + Hospitals
- + Nursing homes
- + Senior communities
- + Health fairs / street fairs
- + Rock Steady Boxing Centers
- + Community Newsletters

Sample Flyer

Parkinson's Support Group

Join us every month to connect with community and share your experience. All are welcome including people with Parkinson's, care partners, family members, and friends. We are here for you!

MEETING DETAILS:

WHEN:

WHERE:

WHO:

For more information or questions, please contact:

Download the fillable flyer here:





Newspapers, radio, television, and local publications

- + See example of a news release on the next page
- + Learn the deadlines your local newspaper and other publications use so you can submit your releases in a timely manner.
- + Always include the **Who, What, Where, When, Why** and **How** information at the beginning of your release.
- + Editors like factual, succinct writing.
- + Focus on the special aspect of your release to encourage publication – a locally known speaker, an expert who isn't usually available, an unusual topic for discussion, etc.
- + Invite a reporter to attend one of your meetings.
- + Learn about local calendars that will list your meetings – newspaper, hospital, library, community center, etc.
- + Notify local radio & TV stations about your meetings and special events.

Sample News Release



7739 E Broadway Blvd. 800-256-0966
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Tucson, AZ 85710 www.PMDAlliance.org

FOR IMMEDIATE RELEASE

June 2, 2020
1 page total

Contact: Jane Smith
800-555-0966 or JSmith@EmailHere.com

Focus on Care Partners of People with Parkinson Disease

At the June 9th meeting of the Verde Valley Parkinson Support Group, 3:00-4:30 PM, at Verde Valley Medical Center, Conference Room B, 269 S. Candy Lane, Cottonwood, Arizona, the meeting discussion will focus on care partners - their important role, how care takes a team effort, how it's not only care for the person with PD, but also helping people with PD to care for themselves.

The group discussion will be led by group co-facilitator Mary Lawson, and Pamela Cregger, Community Liaison and Home Health Specialist for Kindred at Home in Cottonwood. Cregger is highly regarded among her senior care and services peers and a popular speaker in the greater Prescott-Yavapai County area.

Pamela has spent most her career in the senior health industry with work in skilled nursing, assisted living, independent living environments, as well as in private duty caregiving and hospice. She knows well how care partners and families often struggle to balance caregiving responsibilities with the need to also take care of one's self.

As Pamela and her husband cared for a family member with a long-term illness, she experienced first-hand the many ups and downs of caregiving and now works diligently to help those seeking resources to prevent caregiver fatigue. Individuals with Parkinson disease, their families, care partners and friends are always invited to attend the Verde Valley Parkinson Support Group monthly meetings. The group meets the second Friday of every month, 3:00-4:30 PM, at the Verde Valley Medical Center, Conference Room B, 269 S. Candy Lane, Cottonwood, AZ. For more information, please contact group facilitator Jane Smith at 800-555-0966 or JSmith@EmailHere.com

###

Headline the most important aspect of the meeting.

Always put the date, time and location first so even if they cut the body of the article, this information is easy for the editor to find and use.

Tell me why I should attend.

Information about the speaker and why they're qualified to speak.

This information should be at the bottom of every news release.

General Meeting Rules

Group rules and guidelines enable a group to be a safe space for all attendees. It is important to have a few guidelines which are shared with all new members.

We recommend using this language with your group:

- 1.** This group maintains an environment of compassion and understanding, leaving judgment and criticism at the door. Our purpose in meeting is to provide everyone attending with a safe, kind and accepting space.
- 2.** We maintain confidentiality for all group members. It is expected that group members will not share personal stories and challenges shared by other people without the prior approval from that person.
- 3.** It is important that all people have an opportunity to talk. As a result, we ask that each person limit their sharing to 2-3 minutes until everyone has had an opportunity to talk.
- 4.** At no time shall anyone sell or market products or services. Speakers representing businesses/products are required to speak more broadly on a specific topic.

What are your group's general guidelines?

Roles and Activities That Can Be Assigned to Volunteers

In a small group, one or two people often take the lead and may rotate at leading meetings. Other than publicizing the meeting time, location, and keeping to a simple agenda, other activities are likely to develop as the group grows and becomes well established over time. Utilizing these roles within a group can help with sustainability and succession planning.



Which roles can be added within your group? Do you have members in mind who could fill these roles?

Responsibility Sign-Up Sheet

Responsibility	Description	Hours/Month	Term Length	Volunteer
Group Leader	Organize, coordinate with members, might facilitate	5-10	1 year	
Co-leader	Assists above	2-5	1 year	
Secretary (if app.)	Takes minutes; manages contact list if group has a list	2-5	1 year	
Program Speaker/Contact	Contact speakers as directed by members, recruit them, thanks them	4-5	1 year	
Librarian	Maintain and bring resources to meeting	1-2	6 months or 1 year	
Hospitality	Arrange for refreshments at monthly meetings, provide coffeepot and supplies	2-3	3-6 months	
Greeter	Greet new members at door, introduce them to members	1-4	3-6 months	
Contact Person(s)	Receive calls for group, information from ads, etc. Give info on location, time, etc.	1-4	6 months or 1 year	

*Adapted from "Sharing the Load: A Few Ideas for Recruiting Members for Group Tasks"; American Self-Help Clearinghouse, and the "Facilitating Self-Help Groups Manual for Self-Help Group Leaders, National Multiple Sclerosis Society."

Special Skills and Resources Survey

Name: _____ Date: _____

Spouse/Partner Name: _____

Member Since What Year: _____ City of Residence: _____

Phone: _____ Email: _____

What are your unique, personal qualities that could contribute to the success of the support group? (ex: organized, enthusiastic, warm and friendly, clear communicator)

What work and life experiences have you had that could potentially be helpful to the group? (ex: skill sets gained from former jobs or careers, other life experiences)

What are your special interests and hobbies? (ex: hiking, crafting, cooking, etc.)

What personal contacts do you have in your social circles who have skills or resources that could be drawn upon in order to help the group? (ex: friend is a caterer, journalist in my family, my neighbor has an event space for rent, etc.)

Name: _____ Type of Resource: _____

Phone Number and/or Email: _____

Name: _____ Type of Resource: _____

Phone Number and/or Email: _____

Name: _____ Type of Resource: _____

Phone Number and/or Email: _____

Costs and Expenses

It is important to remember that **you do not need to do anything more** than have a space for people to gather. PMD Alliance lists your group information on our website and refers people to your group when they inquire about support in your area. Please keep us informed of any changes to your support group listing.

Most groups require minimal funds to maintain ongoing operations. In general, PMD Alliance discourages forming a group that requires extensive funding as the need for funds can become challenging over time and burden the leader and group.

Possible Costs and Expenses

- + Initial flyers for distribution
- + Listing in local community calendar, if available
- + Informational materials
- + Equipment – projector, screen, PA speaker
- + Liability insurance
- + Paper and copying
- + Envelopes and postage
- + Meeting space rent
- + Food / beverages
- + Printer / supplies





Ongoing Group Operations

Groups may elect to collect money to support the basic costs of running a group, such as costs for copying, coffee, meeting space rent, etc. These donations are not tax deductible unless the group is affiliated with an organization with nonprofit status or has its own nonprofit status (IRS 501c3). There are significant startup and ongoing costs in securing and maintaining nonprofit status. Many groups elect to partner with an existing nonprofit organization if they envision significant fundraising. See **Special Fundraising Events** for more information.

Ways to collect petty cash include:

- + Donation basket at meetings
- + Donated food/beverages - potential sign-up sheet for members to bring each month
- + Ask for donations for specific expenses as needed

Special Fundraising Events



Groups that are interested in fundraising should consider the purpose of the money, potential funding sources, and all potential unintended consequences before engaging in that process. While fundraisers can be fun, here are some questions to ask prior to initiating fundraising projects:

1. Is there something easier to do that would raise the same amount of money?
2. Is the purpose to raise funds and/or to publicize/entertain/engage the people participating?
3. How sure are we that we'll cover expenses and still have funds left over?
4. Would it be more effective to have a fund drive and simply ask for donations?
5. Do we let people know they can donate to us in their loved one's name?
6. Would a special email request for donations work?
7. Do we ask for donations in our emails/newsletters?
8. Who's going to be the fundraising leader?
9. Who's going to organize everything?
10. Who's going to schedule / communicate with everyone else?
11. Are people fully committed to the work and time required?
12. Is it an event BY people impacted by the disease or FOR people impacted by the disease?
13. Are the people who want the event capable of creating and conducting it?
14. Is there support from outside the group?
15. Are we having fun yet?

Tips & Cautions

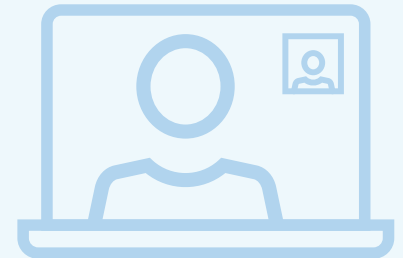
- + Repetition is good. People need to hear about your group and meetings often.
- + Every individual will take what they need from your meetings – information, encouragement, comfort, and fellowship. Topics revisited always offer new insights and give people a second chance to ask questions and discuss their situations.
- + Several organizations offer free literature and pamphlets on a variety of topics. Ask anyone who speaks to your group to bring information as well. It's a good idea to keep a plastic tub to hold printed materials so it's easy to set them out at meetings.
- + Weather conditions may create unsafe travel risks. It's especially helpful to email / call members when a meeting must be cancelled due to bad weather.
- + A sign or two directing people from the parking lot to your meeting location may be helpful.
- + Keep in mind that some care partners have their own physical and mental conditions that may make it difficult for them to move freely, hear or see well, or understand and remember what they've been told.
- + As your group grows, you're going to find that the same personalities that you knew in high school are represented by members of your group – the pessimist, the complainer, the go-getter, the cheerleader, the know-it-all, the chatterer, the shy one, the artist, and more.
- + Some senior products and services representatives will be interested in attending your meetings. Some individuals will attend to learn more about PD. Others will attend to exploit the meeting as a marketing opportunity. You may want to establish a policy that people attending as representatives of services or businesses are welcome but cannot discuss their product during meetings and/or solicit information about those attending the meeting.
- + If your group is small, the presence of sales and business representatives may be inappropriate and detract from the group dynamic. In those instances, you can explain that meetings are specifically for people with the disease, their care partners, and family members only.

- + If you have a speaker who represents a business, you'll find it beneficial to adopt a policy that speakers are welcome to leave their brochures and cards but cannot discuss their product/service during their talk. Instead, their topic should be educational and broader in scope than their particular business interest. Don't hesitate to tell them the name of the topic you'd like them to speak about.
- + If you are professionally associated with a business (i.e. marketing director of an assisted living community), your role is primarily to facilitate the meetings for the group members without emphasis on your work or your business. You'll find over time that people will associate you with your work and as they are interested, ask questions and seek information from you.
- + Food & beverages – some groups have members take turns bringing refreshments. Other groups don't offer food at meetings. It's up to you. Keep in mind that you'll need someone to coordinate the food and drinks, including providing cups, plates, napkins, set up and clean up.
- + Be aware that anecdotal information, while personal and often very interesting, is still just one person's story. Sharing experiences and information are major parts of every support group; however, it's important to suggest that group members do their own research before acting.
- + If it's too good to be true, it probably isn't true. People in support groups want relief and cures. Their hope and wishes can make them vulnerable to appeals by questionable advertising and sales representatives, as well as people who mean well but may not have the expertise they need to have an informed opinion. It's OK to express skepticism.

Considering Logistics of Your Meetings

How to Meet: A New World Since COVID

- + Meet in-person
- + Meet online on the Zoom platform (free access through PMD Alliance)
- + Combination of both - hybrid meeting or alternate in-person and Zoom meetings
- + If meeting in-person, determine COVID safety guidelines with your group



Please visit our In Sync Support Group Leaders resources page on our website to find a library of online trainings where you can learn how to run group meetings on Zoom.

Participate in trainings such as:

- + The “How-To” Guide for Hosting an Online Guest Speaker
- + Zoom on Smartphones Training
- + Basic Zoom Training for Support Group Leaders
- + Facilitating Breakout Rooms in Zoom

- + Advanced Features and Recent Updates on Zoom
- + PD&Me App Training for Support Group Leaders
- + I AM Poem Creative Writing Workshop for Group Leaders

Visit pmdalliance.org/support-group-leader
or scan the QR code to learn more.



Succession and Infrastructure

Group Lists

How do people stay informed? Where and how do they sign up for your group? Who maintains the list? How is it updated? Where is the list maintained? Who else can help?

Agenda & Program

What is your meeting structure and agenda? Do you have a template? Are there roles that group members can be assigned to share the responsibilities and deepen their commitment? Is that built into the program structure? What is the intention of the program? Who else can help?

Rules & Guidelines

Do you have a set of rules and guidelines for the group? How do you share this? Do you have a welcome paper that has the intention of the group, structure of the meeting and rules? Who else can help?

Marketing

Where do you market? How often do you market? Who develops the flyers or marketing? How do you market (email, flyers, etc)?

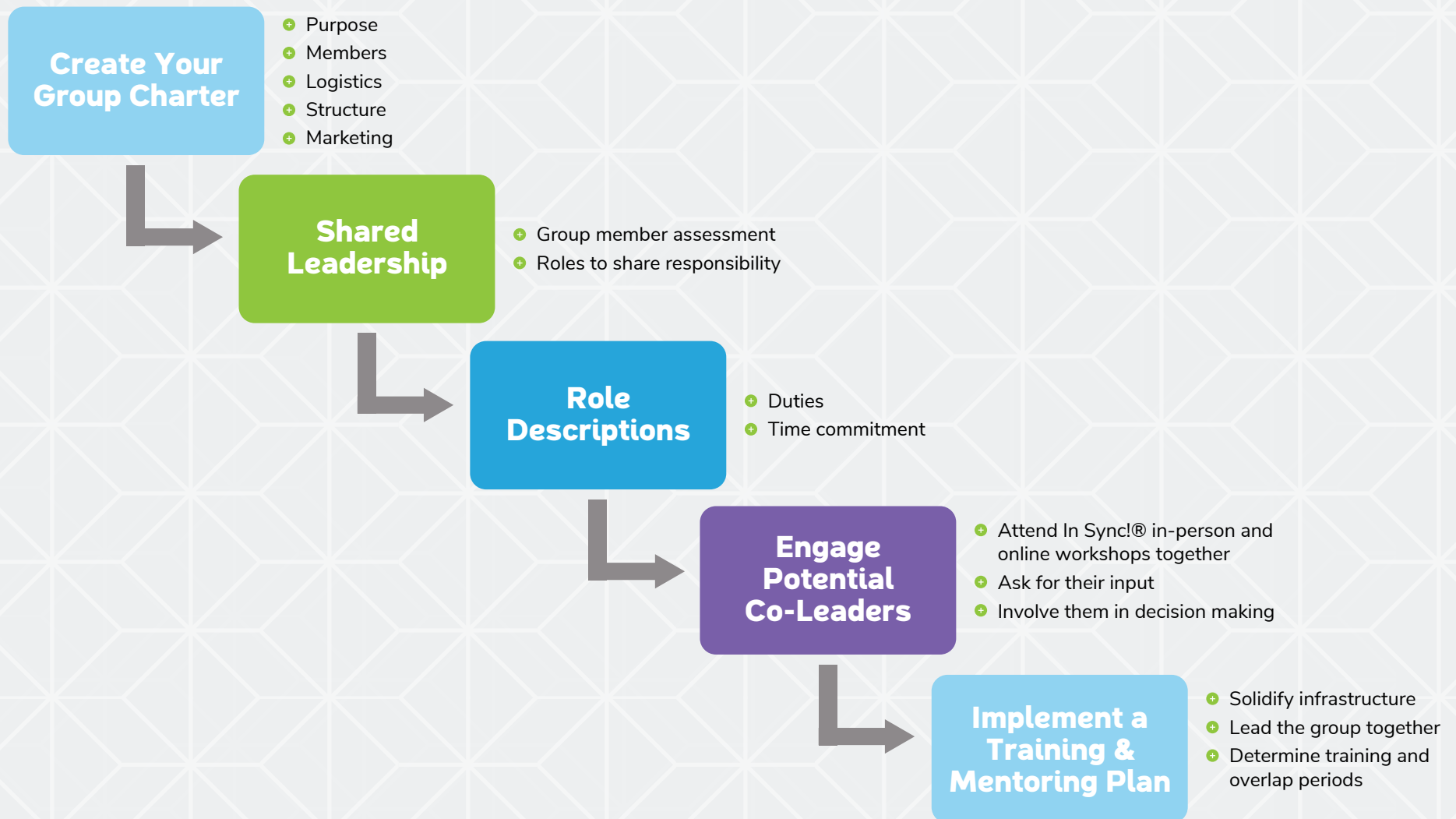
Meeting Location & Logistics

Where is your meeting held? When is your meeting held? How does the space get set up? Who helps set up the space?

Speaker Planning

Who invites speakers? Who confirms with speakers? When do they confirm with speakers? Is there a set of directions and guidelines given to speakers so you don't have to re-create each month? Do you have a calendar of topics for the year that you work off of so that you don't have to think about it each month?

Support Group Leader Succession Planning Guide™





PMD Alliance

Parkinson & Movement Disorder Alliance

First ***YOU***, then the disease.

Our Mission

Provide opportunities for people impacted by Parkinson's and other movement disorders to learn, live life more fully, and connect with others.

Offering conferences, events, and supportive programs designed to engage people impacted by movement disorders and their care partners in activities that enhance, enrich, and enliven their lives every day.

Hand-in-Hand with the Medical Community



A **PRIMARY CARE PHYSICIAN** is a physician who provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis.

A **NEUROLOGIST** is a physician specializing in neurology and trained to investigate, or diagnose and treat neurological disorders. Neurologists may also be involved in clinical research, clinical trials, and basic or translational research. While neurology is a non-surgical specialty, its corresponding surgical specialty is neurosurgery.

An **ADVANCED PRACTICE PROVIDER** is a medical provider (Physician Assistant or Nurse Practitioner) who is trained and educated similarly to physicians. They are trusted medical professionals who work hand-in-hand with physicians to create a seamless environment of care.

Hand-in-Hand with the Medical Community, cont.

NEUROLOGY is a branch of medicine dealing with disorders of the nervous system. Neurology deals with the diagnosis and treatment of all categories of conditions and disease involving the central and peripheral nervous system (and its subdivisions, the autonomic nervous system and the somatic nervous system), including their coverings, blood vessels, and all effector tissue, such as muscle. Neurological practice relies heavily on the field of neuroscience, which is the scientific study of the nervous system.

A **MOVEMENT DISORDER SPECIALIST** is a neurologist who has received advanced training and possesses specialized knowledge in the science, clinical evaluation and management of conditions that affect the control of movement, the basal ganglia, the cerebellum and their direct or indirect connections to the cortex, subcortex, brainstem and spinal cord. This field encompasses knowledge of the pathophysiology, pathology, diagnosis, and treatment of these disorders at a level that is significantly beyond the training and knowledge of a general neurologist.

People with **MOVEMENT DISORDERS** can experience involuntary movement such as tremor, abnormal posture, slowness, walking difficulty, and stiffness due to neurological conditions.

More than 30 different diseases are identified as neurological movement disorders. These disorders, which include Parkinson disease, Huntington's disease, essential tremor, and dystonia, range from mild to severe. While symptoms vary widely, the disorders are often progressive, increasing in severity over time. Nearly 40 million people in the U.S. have a movement disorder of some type. Most movement disorders are not curable, although treatment may slow or decrease symptoms.

Movement disorders are often induced by pathological changes within the brain. Often, the cause may not be known, although heredity and environment may play a role in some cases.

While many movement disorders are not life threatening, patients are significantly impacted in their ability to function well and live independently. Depression and other mental problems can coexist. In addition, abnormal posture or movement may result in severe pain.

Treatments include medications, botulinum toxin injections, occupational and physical therapy, and surgical procedures such as deep brain stimulation that are used to control motor symptoms.

Quick Facts About Movement Disorders

There are many types of movement disorders, including but not limited to Parkinson disease, Huntington's disease, Progressive Supranuclear Palsy, Dystonia, Tourette's, Multiple System Atrophy, and Essential Tremor.



42 million people in the United States have some form of a movement disorder.



A Movement Disorder Specialist (MDS) is a neurologist with advanced training specifically in movement disorders. It is recommended that every person with a movement disorder be seen by an MDS at least annually.



It is estimated more than one million Americans live with Parkinson disease, which is more than the combined number of people diagnosed with Multiple Sclerosis, Muscular Dystrophy, and Lou Gehrig's disease.



Approximately 60,000 Americans are diagnosed with Parkinson disease each year, and this number does not reflect the thousands of cases that go undiagnosed.



It is anticipated that the number of people impacted by movement disorders will increase dramatically between 2010 and 2050, with the highest increase being for dementia with Lewy bodies.*



Most people with a movement disorder have a family care partner who is directly involved in daily care, planning, and decision making.



*Projected numbers of people with movement disorders in the years 2030 and 2050. Bach JP1, Ziegler U, Deuschl G, Dodel R, Doblhammer-Reiter G.

Notes

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