

Self-Help Group Meeting Topic & Conversation Guide

Self-help groups often benefit from focusing meetings on specific topics or utilizing conversation starters. This guide provides suggested meeting ideas, topics, and discussion questions to support informational and supportive group meetings.

Begin all meetings utilizing the <u>Community Disclaimer for Peer Connections Participation</u> to set the foundation for group conversation sharing and <u>risk management</u>. Additional <u>Society Policy</u> resources available on the Peer Connections Volunteer website are helpful resources for navigating tricky topics including religion & inclusivity, medicine sharing and medical advice.

It can be helpful to approach the task of "running" a meeting if you are prepared with questions and topics that can stimulate discussion. Remember that the purpose is to help individuals reflect on and share their unique experiences. It's important to remember that group members' thoughts and comments are not right or wrong; they reflect individual beliefs, coping methods, and circumstances.

Relationships with Family and Friends

- Who has been most/least supportive to me in helping me deal with my MS? What have they done or said that has helped or not helped me? When someone is not supportive or helpful, how have I responded?
- How did my loved ones react to my MS diagnosis? How did it differ from what I expected or from what I wanted? Have I been able to shape people's reactions to me? How?
- How do I maintain my relationship with my partner when/if my needs change?
- Who is the easiest person to talk to about MS? Why? Who is the hardest person to talk to about MS? Why?
- How do people react when they learn that I have MS?
- What do children/grandchildren need to know about MS?
- How has MS affected my role as a parent?
- Managing family and friends who learn about a treatment and want me to try it.
- Communicating my feelings and needs.
- Helping my friends and family to understand.

Taking Care of Yourself

- How and when to ask for help.
- Saying "no" without guilt.
- Managing specific challenging MS symptoms (i.e. bowel and bladder, cognition, intimacy)
- What challenges related specifically to MS have I experienced and overcome?
- What challenges have I not handled as well and why not?
- Handling exacerbations and coping with the unpredictability of MS.
- How do I promote "wellness" in all areas of my life?

Personal Feelings

- How did I feel when I first learned that I (or another family member) had MS?
- How do I respond to any stigma I have experienced due to my MS?
- How do I cope with any fear I have as a result of my diagnosis?

Managing Life Changes

- Generally, how has my life changed? What new values and priorities do I have now that I did not have before?
- To what degree have I learned to accept my MS and what has helped me to do this?
- Tips & tricks that I have found helpful in my everyday life.
- Have I considered using assistive devices?
- Dealing with invisible symptoms and educating family and friends.
- What positive experiences have occurred as a result of having MS?

Physician/Professional Relationships

- What are my relationships with my doctor, neurologists and other medical professionals?
- What can I tell my doctor to support my best treatment? What is important to communicate?
- Do I get angry with my doctor and/or care team? About what? How do I handle these emotions?

Employment

- How has MS changed my <u>employment</u> situation?
- Should I disclose my MS at work?
- Asking for reasonable accommodations at work.

National MS Society Resources

- The Society provides a variety of toolkits that are arranged as bundles of educational materials about a specific topic. These topics and tools can be used to lead discussions within your group. You can access these materials on the Peer Connection Volunteers webpage <u>here.</u>
- Utilize <u>on-demand educational content</u> including Society virtual programs & webinars (either during a live presentation or via recording) can provide education via professional speakers on a variety of topics.
- Review the <u>Guest Speakers for Self-Help Groups</u> resource for additional ideas on bringing educational content into your group.

Additional Suggestions:

- Celebrate birthdays and personal successes of members.
- Discuss group successes and/or concerns.
- Book club: discuss a book you have all agreed to read.
- <u>Travel</u> and vacationing with MS.
- Advocate for change in your community together
- Utilize a guest speaker to learn more about a topic or community resource.



Social Activities Outside of the Traditional Group Meeting Setting

Spending time together outside of meetings can be as important to the development of the group as the meetings themselves. Remember to check the <u>accessibility</u> of locations and follow all <u>risk</u> <u>management</u> guidelines to ensure a safe and fun group outing. Remember to check the <u>accessibility</u> of locations and follow all <u>risk management</u> guidelines to ensure a safe and fun group outing. Talk to your staff partner about potential reimbursement for social activities.

- Picnics
- Lunch or dinner at local restaurants
- Crafting activities
- Wellness activities
 - Any type of physical exercise requires a waiver form. Connect with your staff partner to discuss considerations, risk management and waivers.
- Holiday gift exchange and/or meal together
- Plan a trip to the movies, history museum, art center, sporting event, etc.
- Attend a National MS Society educational program together.
- <u>Volunteer</u> together for the National MS Society or elsewhere in your community.
- Form a team for a local Walk MS[®] event or create a Walk Your Way event.

