



# **NTM Info & Research Support Group Leader Guide**

Research - Education - Patient Support

CREATING A NATIONAL NETWORK OF  
SUPPORT FOR PATIENTS AND LOVED ONES



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**“IT IS ONE OF THE MOST BEAUTIFUL COMPENSATIONS OF THIS LIFE THAT NO ONE CAN SERIOUSLY HELP ANOTHER WITHOUT HELPING THEMSELVES”.**

**-CHARLES DUDLEY WARNER 1873**

NTM can be a scary journey where one may feel alone, that others (including medical practitioners) often don't understand what the person with NTM is going through (being told, for example, that “you don't look sick”), or what the caregiver is experiencing (not knowing how to respond, hesitation to mention their own concerns). Support groups are a valuable resource in helping one another through this journey.

Living with a chronic illness can be emotionally, physically and financially draining. It often takes a person and his or her loved ones out of what was previously their comfort zone and everyday life. In addition, for many with NTM, the expression “you can't judge a book by its cover” clearly applies. Often, the patient's outward appearance gives no indication of what is occurring on the inside. In this way, the disease may be “invisible” to others, and its seriousness not understood. Further, because NTM is an invisible illness, too often friends and others may tell the person with NTM that he or she does not look sick, or that he or she looks great. While such statements may not be intended to hurt, those with NTM may be left with a feeling of not being believed and this can lead to changes in self-image and self-esteem, and feelings of loneliness and isolation.

Support groups are extremely important when someone is facing a chronic illness. For those NTM patients who have been newly diagnosed, support groups put them in contact with other patients who may be experiencing similar symptoms and can offer support to them.

**SUPPORT GROUP LEADERS PLAY A VITAL ROLE WHEN SOMEONE IS FACING A CHRONIC ILLNESS.**

**NTMIR IS GRATEFUL TO THESE LEADERS WHO HAVE VOLUNTEERED THEIR TIME TO HELP OTHERS.**

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# Introduction

## **PARTNERING WITH NTM INFO & RESEARCH, INC. (NTMIR)**

NTMir is a not-for-profit 501(c)(3) organization formed on behalf of patients with pulmonary nontuberculous mycobacterial (NTM) disease for the purpose of patient support, medical education, research and advocacy.

NTMir serves patients and physicians concerned with NTM. As a national organization, we can advance a broad agenda. Our voice is that of the patients and physicians who comprise our collective constituency.

NTMir evolved from [www.ntminfo.org](http://www.ntminfo.org). This website was developed by Fern Leitman, an NTM patient, and her husband Philip. Fern was referred to Dr. Michael Iseman at National Jewish Health in Denver, where surgery and treatment therapies succeeded in stabilizing her condition. During return visits Fern and Philip met many patients from different parts of the country, most of whom had experienced delayed diagnoses, were frightened and were often unfamiliar with many aspects of NTM disease. The website was developed to help those and other patients.

In an unanticipated response, the website generated over two million hits during its initial period. People logged on from 22 countries, the United States government and major institutions. There was a need to develop an organization that could speak for patients and the physicians trying to help them. NTMir is that organization.

NTMir is primarily funded through donations from patients and their families and friends. We receive no public funding. We have no membership fee or dues. We provide support to patients and facilitation to the NTM research community. Occasionally we ask that support group leaders reach out to their group members, and ask they assist with public outreach and/or help us by participating in fundraising projects to the extent they are comfortable doing so.

## **THE BENEFITS OF WORKING WITH NTMIR**

- Support Group members will be kept up to date with important and accurate information about upcoming events.
- NTMir will list your group area, name and e-mail address on the NTMir website and on NTMir's social media including our Facebook page, Twitter and Instagram, as well as have it placed on the sites of National Jewish Health in Denver, CO, ([www.nationaljewish.org](http://www.nationaljewish.org)), University of Texas Health Center at Tyler ([www.maclungdisease.org](http://www.maclungdisease.org)), and Insmad's AboutNTM.com.
- NTMir will facilitate virtual support group meetings.
- We will send you a supply of the NTMir pamphlet, "Insight, A Patient's Perspective".
- We can send pre-printed labels with your contact information that can be placed inside the pamphlets you distribute.
- We will introduce you by e-mail to the other group leaders so you can contact them for advice and friendship.
- We will post your meeting dates on our website calendar and Facebook page.



# SUPPORT GROUPS

# 101



# Support Groups 101

The purpose of a support group is to provide a safe environment where people affected by NTM and related lung diseases can mutually support one another by sharing their thoughts, ideas, concerns, questions, information and coping strategies in a non-judgmental and caring atmosphere. Support groups offer people with NTM an opportunity to meet face-to-face with others who are experiencing similar challenges, as well as to hear presentations by health professionals on topics of interest. Through the sharing of knowledge, feelings, and experiences, those with NTM and their caregivers learn from each other and take comfort in knowing they are not alone. They are member-focused and patient-driven.

## **DEFINING WHAT AN NTM SUPPORT GROUP IS**

An NTM support group can be composed of NTM patients, family members, friends or even those in the community seeking to learn more about the disease and related lung diseases such as bronchiectasis. Your group will have NTM patients who are seeking to learn more about the disease and how they can better cope with the many challenges that come with a chronic illness.

There are tremendous benefits of an NTM support group and as the leader and facilitator of the group you will want to convey those benefits every time your group meets. Members of your group will find that being active in a support group can provide them with a decreased sense of isolation. When members are able to interact with others who share in like experiences, it affords the opportunity to validate feelings and allows a supportive and safe environment.

Feelings of loss, anger, sadness, anxiety, and depression can be openly and freely expressed in this environment, and as the leader, your role will be to encourage a nurturing and compassionate response. The overall goal is to always direct members in an optimistic and uplifting manner to make healthy and constructive choices that will reflect effective coping skills.

Support group members often grow to share a bond with each other that even family members and caregivers may not be able to duplicate. Members share resources and life experiences. They teach each other how to successfully manage obstacles that they face. Working together strategically to problem-solve, members feel a sense of accomplishment which can decrease stress levels and increase self-esteem and optimism.



NTM support groups will supply accurate and updated information about the disease, current research, and management techniques. This information will be supplied by NTMir on a regular basis and speakers can be located through local resources.

As a leader your role will be to affirm members' feelings, to encourage openness and honesty, and to help members feel safe and protected in the environment. Your ability to remain upbeat and enthusiastic will set the tone for the entire group.

On those days when you are feeling the effects of your own NTM symptoms if you are a patient, it is perfectly acceptable to be honest with those in the group and to frankly share your limitations, setting an example of what to do on the days when the disease is harder to manage. Being an example to those in your group will also help you to better manage your NTM treatment plan.

## **A SUPPORT GROUP CAN PROVIDE MANY BENEFITS**

- A place to exchange information, support, and friendship with others whose lives are affected by NTM and related lung diseases.
- A forum for sharing practical tips and strategies for coping with the many changes connected with the disease.
- A place to express feelings and be reassured that these feelings are normal and expected.
- An opportunity to decrease feelings of isolation and loneliness.
- A place to find a positive outlook on things without being misunderstood.
- The chance to regain some control in the face of a disease that cannot be controlled.
- A place to find a sense of hope.
- A place to access the most current information about NTM research, therapies, news and events.

## **WHY DO PEOPLE JOIN A SUPPORT GROUP?**

Patients and caregivers often feel like they are alone. Therefore, a Support Group can act like a family, where members feel supported, cared for, and accepted for who they are.

- **Empathy:** People outside a Support Group may not understand the experiences of people who have NTM, or their caregivers. They may even dismiss their feelings. In a Support Group people are heard and understood.
- **Safety:** Inside a Support Group, people often feel protected and safe to express their feelings, whether positive or negative. A Support Group offers a place to be vulnerable and to be one's self.
- **Reducing Isolation:** Support Groups develop a sense of community through shared feelings and experiences. People feel connected with one another which can assist them in addressing their personal concerns and their need to ask questions.
- **Humor:** People feel comfortable to have a good laugh and rejuvenate through inspiring, and often comical stories that are shared between members.
- **Answers.** People need answers.



**AM I  
THE RIGHT  
PERSON  
FOR THE**

**JOB?**



# Am I the Right Person for the Job?

## WHAT MAKES A GOOD SUPPORT GROUP LEADER?

At NTMir, we believe it is a person who cares about others, a person who “gets it”, and a person who has the ability to listen, and help others in dealing with an awful, often debilitating disease still awaiting a cure.

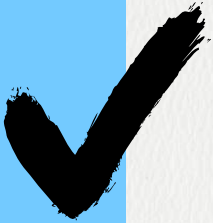
## DECIDING IF YOU ARE READY AND ABLE TO BECOME A SUPPORT GROUP LEADER

As you are deciding whether to become a support group leader you may be wondering whether this is a role you are qualified for and whether you have what it takes to lead a group. These are normal feelings to have and questions to be asking yourself. Effective leaders all seem to have some common qualities and characteristics that they share. Key characteristics of an effective leader are often associated with the following:

- Ability to separate personal needs from those of others
- Comfortable with emotions
- Desire to help others
- Possesses a positive attitude
- Respectful of others' opinions even if they are different
- Able to manage conflict
- Willing to share inspiring conversation
- Desire to work toward the goal of keeping the group focused positively
- Aspiration to reaffirm members feelings
- Overall emphasis on wanting to make a difference without wanting power
- Capability to actively listen to members in the group
- Effectively posing questions in a non-threatening manner
- Affirmatively motivating the members of the group in a supportive manner
- Constructively providing feedback



KEY  
CHARACTERISTICS  
OF EFFECTIVE  
**SUPPORT  
GROUP**



**LEADERS**



# Key Characteristics of Effective Support Group Leaders

## **UNDERSTAND GROUP BEHAVIOR AND LEADERSHIP ROLES.**

It is helpful to understand what it takes to be a member of a group as well as a leader. Some basic understanding of how people behave in groups, the natural progression of group development and how to encourage the group's growth is important. Many effective facilitators have picked up their skills through books on group leadership or have taken a workshop to help them gain these skills.

Leading an effective group begins with a commitment to three basic assumptions: each member can contribute to the group, each member is the ultimate authority on his/her needs and what will work for him/her, and communications need to be open and honest to promote positive group experiences.

## **CAPABLE OF RECOGNIZING AND CONTROLLING THEIR PERSONAL VIEWS.**

The effective leader is able to separate their personal needs from those of the group or member needs. Those having their own agenda or "axe to grind" can end up promoting their views and opinions over the groups. It is necessary at times, for the leader to step out of their role for the purpose of expressing personal needs and opinions.

## **WILLING TO WORK TOWARD THE GROUP'S GOALS.**

The effective leader is enthusiastic about the goals of the group and is quite willing to work for their accomplishment. They see themselves as part of a team and are emotionally and physically committed to the team's success. They actively and creatively look for ways to give members the opportunity to participate in the process of setting and carrying out the goals of the group.

## **POSSESS THE ABILITY TO INITIATE ACTIVITY.**

Every leader seeks to develop shared responsibility and leadership for the group. They refrain from identifying the group as "my group" or its members as "my people." There will, however, be occasions when no one else is capable, ready, or willing to do what needs to be done. In these instances, the facilitator must be prepared to get the ball rolling.

## **COMFORTABLE WITH THE EXPRESSION OF EMOTION, TENSION, AND CONFLICT.**

There is no escaping the fact that emotion, tension, and conflict are likely to arise in a support group. It is important that you are comfortable with this, not only as it occurs in others, but in yourself as well. You need to expect that conflict within the group will appear and that criticism will be directed towards you as the facilitator. Learn to look at criticism objectively and try to avoid taking it personally. Facilitators know basic communication skills and are willing to look at their own behavior to see when they need to make changes.

## **COMMITTED TO THE WELFARE OF THE GROUP AND ALL ITS MEMBERS.**

The commitment lies with the group - how to make it succeed, how to meet needs, etc. This will sometimes require a willingness to look at the big picture and serve as visionary for the group. A good leader will focus upon building a sense of community, group cohesiveness and consensus decision making within the group.

## **VALUE AND RESPECT EACH MEMBER AS AN INDIVIDUAL.**

Members are seen as equals, deserving mutual respect and consideration for the values they hold as individuals. Instead of thinking of the participants as “manpower” to get things done, facilitators see each person as an individual who is a potential teacher; having a reservoir of knowledge and experience from which others may benefit.

## **EMPHASIZE THE POSITIVE ASPECTS OF THE SUPPORT GROUP.**

It can be easy to get caught up in the problems and to view life from a depressed perspective. In an effective support group, negative emotions are addressed, but do not become the main focus. People are allowed to have their feelings without hasty problem solving, while still being guided to their strengths and away from a victim focus.

## **ENCOURAGE MEMBERS TO IDENTIFY/EVALUATE ALTERNATIVES FOR THEMSELVES.**

The effective facilitator does not decide what is right for the members. Each member is encouraged to examine problem solving strategies and potential solutions for themselves. Leaders provide a process by which members explore options and alternatives and they offer their support as the members carry out this process and arrive at their respective choices.



**SUPPORT  
GROUP LEADER  
ROLES AND**

**RESPONSIBILITIES**



# Support Group Leader Roles and Responsibilities

As a Support Group leader, you will have a significant effect on the other group members. Leaders use communication, vision, esteem, and personal enthusiasm to motivate and encourage members to feel excited and passionate about their role as patient or caregiver. As a support group leader, you will learn to listen and to sometimes listen to what is not being said. Follow your inner gut—that may mean doing follow up when you think it is warranted. If someone appears to be having a troubled day in the group but is not able to share and open up, make a follow up call the day after the meeting or send an email to the member to let him or her know you are thinking about them and hoping that they are feeling more positive.

People want to know that someone is supporting them, especially on the days when NTM is challenging them. Be that support person and the one who reaches out just to say, “I am here and I understand.” You don’t have to have all the answers. You don’t have to fix the problem. You just need to show this person you are there and you care. Even that gesture makes a significant difference.

As a support group leader, you want to lead by example and with your heart. Be genuine, honest, and empathetic when leading. Focus on the needs of the group and in turn you will see that the positive attitude will help you better manage your treatment plan and health.

## KEY ROLES AND RESPONSIBILITIES INCLUDE:

- Maintain a safe, friendly, and warm environment that encourages mutual support and an opportunity to participate.
- Facilitate balanced discussion - lead the discussion, but do not dominate it.
- Be an active listener. EFFECTIVE LISTENING!
- Implement the ground rules and mediate any conflicts that arise.
- Maintain confidentiality.
- Begin meetings on time and facilitate items on the monthly meeting agenda.
- Make use of up-to-date and accurate information obtained from **NTMir**.
- Maintain group attendance records.
- Be honest - if you don't know an answer to a question, say so, but commit to finding out.
- Recognize when a member's concerns are beyond the group's ability to help and be willing to suggest alternative resources such as **NTMir**.
- **Have fun.**





**EFFECTIVE**



**LISTENING**



# Effective Listening

A way of showing concern for group members, and that fosters cohesive bonds, commitment, and trust, effective listening tends to reduce occurrences of interpersonal conflict while increasing the likelihood that when conflicts do emerge, they will be resolved with a solution favorable to all involved. In addition, by truly listening to the people in the group, leaders will understand the reasons for the behavior and personality of each member. This allows leaders to be more effective at motivating them, to be sensitive to and meet the need for encouragement, and to quickly recognize when the individual is experiencing difficulty in the group.

Effective listening is actively assimilating the information provided by a speaker, showing interest, and providing them with feedback so that he or she knows the message was received. Effective listeners show speakers that they have been heard and understood. Active listening techniques aid in listening effectively:

**Reflecting back words, thoughts and feelings:** Reflect back the words, thoughts and feelings of the group, while subtly emphasizing their own words (e.g. “It sounds as if you’re saying you want to change the way you’ve been handling this issue?” or “It sound like you are very disappointed.”)

**Respond with affirmations:** Validate the speaker by responding with affirmations. Not only does this boost the speaker’s self-esteem, but it also helps them feel understood and stay positive (e.g. “It seems like you handled that well.” or “It sounds like you were effectively assertive. I remember you’ve previously said that was something you found difficult.”)

**Clarification:** Help the speaker clarify their thoughts and messages by reiterating what they said and asking clarifying questions using their own words.

**Summarizing:** Every so often, leaders should paraphrase what the speaker has said to ensure there is a clear understanding of their message. This also helps other members of the group follow along.

**Eye contact:** Without staring, maintain eye contact with the speaker to indicate active listening and interest in what is being shared. Be especially mindful of maintaining eye contact if other members of the group are being distracting. For example, leaders should not break eye contact to look at another member entering or exiting the room or to repeatedly look at a watch or phone while someone is speaking. Group members tend to become distracted if the leader appears distracted.

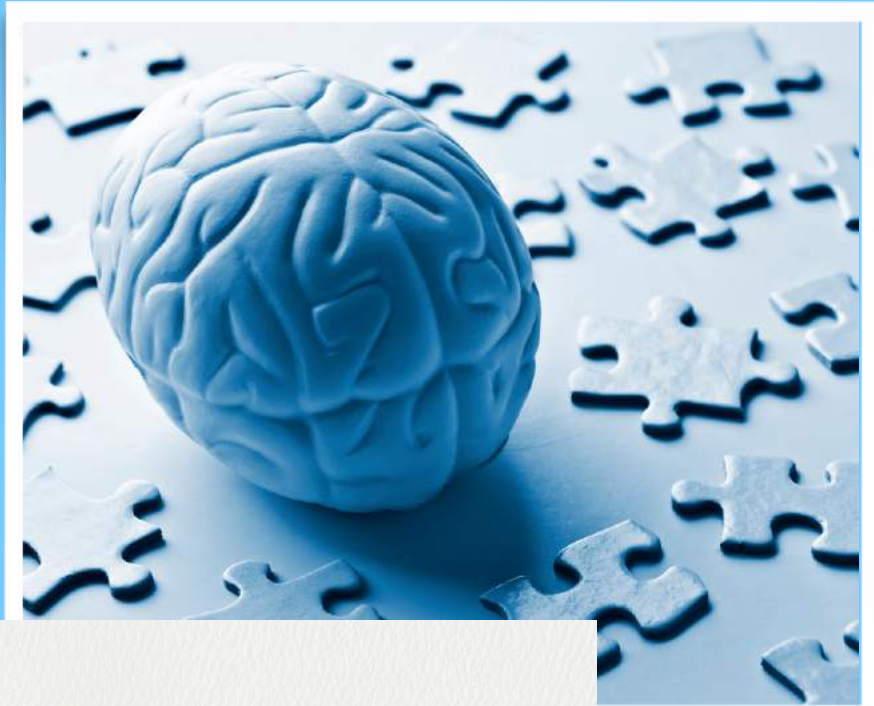
**Positive facial expressions:** Judgmental expressions like head shaking and frowning need to be avoided. Instead, encouraging and empathetic facial expressions like smiling and looks of empathy should be given. These are positive ways of responding naturally to the group.

**Slight Gestures:** Using physical expressions of listening, like nodding the head, lets the speaker know they are being heard and understood.

**Body posture:** Leaning slightly towards the speaker and keeping arms unfolded in an open body posture further demonstrates interest and receptiveness.

## HEARING VS. LISTENING

HEARING	LISTENING
IMPLIES PERCEIVING SOUND	UNDERSTANDING INFORMATION WITH INVOLVEMENT OF MIND AND BODY
IS A PASSIVE PROCESS	IS AN ACTIVE PROCESS
INVOLVES EFFORTLESS ACTIVITY	REQUIRES CONSCIOUS EFFORTS, CONCENTRATION, AND INTEREST



**CRITICAL**



**MANDATES**



# Critical Mandates

Confidentiality is of primary importance for support groups, and we strongly suggest that this be carried forward as a policy in all group activities. Information that might individually identify a group member should not be released outside the group. This expectation should be stated at the beginning of each meeting, along with any other expectation for that particular meeting (e.g., meeting format). A good rule of thumb is: “What goes on in the meeting stays in the meeting.” News releases about a group activity that includes a picture or name should be done only with a signed news release permission form signed by the competent adult.

Record keeping is another important aspect of support group operation. As a general comment, it is suggested that the local group establish and maintain a folder on the group itself, containing information relating to the group’s formation, meeting locations, meeting dates and general topic areas. This folder also might include a list of resources, membership, and other information to provide a history of the group and its operation that can be shared with future group leaders and members. As with other documents that have individually identifiable information, this material should be maintained in such a manner as to protect the individual’s confidentiality. While it is unclear how often this might occur, such safeguards help to protect the person against inappropriate contacts by pharmaceuticals or other similar entities.

**Medical Advice:** The third mandate is not to give medical advice to another group member. Encourage group members to consult with their personal medical practitioners on questions about the person’s specific medical condition. While group leaders/members may share their personal experience with medical care, this is not, nor should it be a substitute for advice from a medical professional. Group leaders should NOT suggest treating this condition using alternative therapies (instead of antibiotics) that have not been proven.



**CO-**



**LEADERS**



# Co-Leaders

**NTMir** suggests that all groups have more than one support group leader. The reasons for this are plentiful and overall beneficial to both the membership and the leaders.

Running and managing a support group can be time consuming and with more than one leader, the roles and responsibilities can be divided and shared. For those leaders who are also NTM patients, this is advantageous because if one leader is having a challenging day, one of the other leaders can pick up and manage the group. Everyone has obstacles to overcome when facing a chronic illness and rather than assume as a support group leader you will never need help, it is best to work together in a team approach.

Co-facilitation keeps the groups interest. With more than one leader, membership has the benefit of multiple personalities from which to learn from and this will keep the group thriving longer. Support groups that are managed by more than one leader often find they are more successful. Leaders can share the roles according to their own strengths, likes and experiences with NTM. This makes for a much richer experience for the group.

When a group has more than one leader it makes it easier for one leader to focus on the educational component, while the other can center in on the body language of the membership. By watching body gestures the second leader can often redirect the conversation as needed to maintain a good flow in the meeting. Managing the agenda based on the needs of the group is the most effective way to lead a group.

Two leaders can also better handle the logistical needs of the group, the environment needs of the location and help with computer or audio-visual issues that may arise during the meeting.

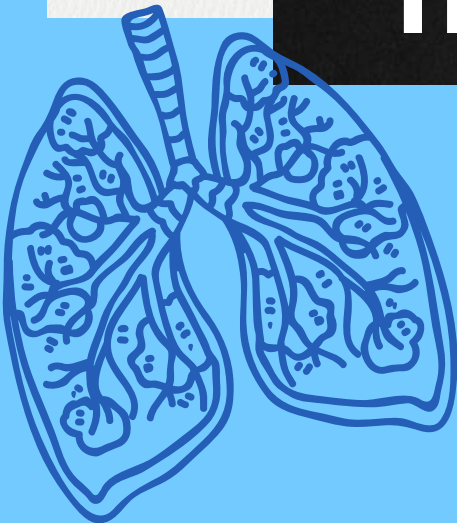
Collaborating on support groups will also provide leaders with creative ideas, added resources and strategic efforts. Having a more team approach to leadership will also assure that in the event one leader has to step down, the group will not be closed while seeking a new leader.



**GETTING  
STARTED**



**THE LOGISTICS**





# Getting Started – The Logistics

Certainly, this issue has been complicated by a pandemic that forced us to keep physically distant from one another, but thankfully, technology has cleared the way for us to continue meeting and NTMir is happy to help facilitate this.

If you have your own paid Zoom or other online meeting account that you would prefer to use, you should feel free to do so, but please do not feel obligated to do this. While you will need to set up your own account to use platforms such as Zoom, a free account will allow you to attend meetings and NTMir will gladly schedule your support group meetings on their Zoom accounts. Once your meeting is scheduled, we send you the information so you can send it on to your group members. Any calendar listings for the meetings will have a contact listed so someone may contact the group leader for meeting information, but we will never publicly post the meeting link on the internet. NTMir will also show you the basics of managing your own Zoom meeting and acting as host, and if you prefer, we are happy to stay on to help facilitate technical issues as well as answer questions that your support group members may have for us.

Eventually, we will be able to be together in person again. When that day comes, finding the right location for your support group does not have to be challenging or overwhelming. Here are some helpful suggestions for locating a meeting space:

- Community organizations or agencies such as hospitals, community mental health centers, Red Cross, Salvation Army, Rotary, YMCA or YWCA, Lions, Kiwanis Clubs, or senior citizens centers will sometimes provide space free of charge for Support Group meetings.
- Your local library or daycare centers and schools, banks, municipal town hall or community college are other facilities where Support Groups hold meetings.
- Hospitals are another option. Contact the community relations department or the social services department to request a meeting place or contact the American Lung Association if you have a branch nearby. You can also speak with your physician if they work at a local hospital and ask if they would be able to help find meeting space there for your meetings.

- Places of worship are a common public meeting place for Support Groups. They are usually cooperative in providing space. You and members of your core group can contact a religious leader and request a room for your meeting. The personal connection is the best and could mean no charge initially or a minimal charge or donation. However, be alert to the possibility that some members or potential members of different faiths may not feel comfortable with a faith-based location.
- Private homes are generally not appropriate meeting locations. Most homes do not meet the requirements of the Americans with Disabilities Act. In addition, the homeowner and his or her insurance company will be responsible for any injuries that occur in the home. So, think twice about using a private home for your meeting.

When inquiring about a meeting place for your group, be sure to communicate that your group is affiliated with a voluntary non-profit organization that provides a service to the public free of charge. Be clear on the specific nights/days that you would like your meetings to take place, how long they will be, and who will be responsible for opening and closing the facility. Take a few minutes to touch base with the receptionist, community service staff, building security or maintenance staff, letting them know who you are. Such attention to detail will serve you and your group well!

### **IN ADDITION TO FULL ACCESSIBILITY, TRY TO FIND SPACE THAT**

- Is conveniently located and easy to find
- Has plenty of parking or easy access to public transportation
- Is well-lit and safe
- Is air-conditioned/appropriately heated
- Is clean
- Is cheerful and welcoming
- Has comfortable seating
- Has a flexible room set-up
- Has a kitchen or place to serve refreshments
- Has an accessible restroom(s)
- Has liability insurance

## TIMING

Determine what day of the week will work best for your schedule. Decide on the best time for your group, mornings, afternoons, or evenings. Consider what time will be the best draw for the membership. Many patients do not like to be on the roads late at night, so refrain from scheduling your meetings later than 7:00 p.m.

Meetings are typically 1½ to 2 hours in length and will vary from group to group based on need and format. If your group would like to have speakers at the meetings, you might want to have a two-hour format so that the first hour can be devoted to the speaker and the second hour could be focused on a more open format. This type of a support group can address most needs.

Some groups have started with a couple of people in a local restaurant. You don't need a lot of people to have a support group. Some of the smaller groups get together for coffee at a local café or have monthly lunch dates at a restaurant. Your group is whatever works for your members. The ultimate decision is up to the group.

At the first meeting you can discuss meeting times and frequency of meetings. It will be easier to remember meeting times if held at a regular day and time and when most can attend.

## MARKETING YOUR MEETING

NTMir will work with you to help with the recruitment process for your support group.

The use of social media, NTMir's website, inclusion in local newspapers and in medical publications will be the main sources. NTMir encourages all support group leaders to network with their own healthcare providers, local community groups, PTA's, schools, hospitals, other medical professionals, social services organizations, other non-profits, and educational groups.

NTMir will work with each leader to create marketing materials for the support group such fliers, email templates, brochures, letters to the editor, public service announcements, and other materials that may be helpful.

**TELL YOUR FAMILY AND FRIENDS ABOUT YOUR SUPPORT GROUP. SHARE YOUR PASSION. THEY'LL GET EXCITED ALONG WITH YOU. INVITE FAMILY AND FRIENDS TO YOUR MEETINGS. SHARE THE PAMPHLET WITH THEM. IT IS A WONDERFUL WAY TO HELP THEM UNDERSTAND MORE ABOUT THIS DISEASE.**



# SUPPORT GROUP MEETING



# FORMATS



# Support Group Meeting Formats

NTM support groups can be structured in a few different ways. As the leader of a group it will be your role to determine which design will work best for your membership. Here are the different types of support groups:

## DISCUSSION

These meetings generally have no formal agenda or formal format. The focus is conversational by nature. Membership attend the meetings with the intent to share their personal journey with those in the group. Leaders may begin the meeting checking in with membership to see how each person is doing. This starts the conversation and opens the conversation up. It will usually lead to a more in-depth conversation among the group about NTM related issues.

To prompt discussion, select one or more related discussion questions and invite the members to express their thoughts, opinions, and ideas. This can be planned ahead of time, from meeting to meeting, to ensure that the leader has gathered accurate and up-to-date information from **NTMir**. As the leader, you may also invite members to begin the discussion with any concerns that they may have on their mind.

The best way to avoid the quiet members of the group to be left out of the discussion is to adopt the round-robin approach and a policy where only one person speaks at a time. Some groups use a variation on a First Nations custom of passing the "talking stick". Only the person in possession of the talking stick is allowed to speak.

## EDUCATIONAL

These meetings generally will have a more structured format and may or may not even have an agenda. Leaders may opt to have speakers attend the meeting to provide educational information about a specific NTM related topic.

## COMBINATION

One half of the meeting is structured with a speaker, a question and answer period and the second part of the meeting is planned with a more conversational and open format. This allows for the members to discuss their current needs and issues pertaining to life with NTM. This format is the most popular for NTM support groups since it offers versatility. This multi-layered system will keep the meeting interesting to different learning styles.

Whichever style you may select for your group, know that it is critical that it must work for your membership. Keeping your membership engaged and interested is the main priority. Challenge yourself to change up the format every once in a while! Change can be exciting, and it might invigorate the membership. Consider having different members lead the group, ask your members if they would like to have some snacks and treats, and even do an off-site dinner or lunch occasionally for a bonding experience. Having bottled water on hand usually goes over well with group members.



**FINDING  
GUEST**

**SPEAKERS**



# Finding Guest Speakers

Tap the experience and contacts of your group members because a member's personal knowledge of a speaker is usually a good reference. Also, a potential speaker may be more likely to respond to someone he or she knows personally. Does someone in your group know of a local professional (e.g. a physician, therapist, lawyer, or another) who is knowledgeable and can be approached?

Professional associations (of psychologists, social workers, nurses, doctors, county medical society, others)– for local speakers on subjects such as stress management, a specific type of therapy, medications, choosing a good therapist/advisor, etc.

Government agencies – Social Security Administration, Division of Vocational Rehabilitation, etc.

Local social service and government agencies and hospitals– sometimes they already have lists/brochures of possible speakers; contact the public/community relations department.

Speakers Bureaus.

Lawyers–especially those specializing in discrimination law, financial planning, insurance, and disability law.

Consider using a pre-recorded or "canceled" speaker (e.g. tape a radio interview show (25 minutes long or less), conference presentation, portion of a TV program, etc.).

Integrative health providers– meditation, yoga, or other practices that may be helpful to patients and caregivers.

Representatives from another NTM Support Group– to speak about their group's best meetings, discussions, speakers, and other successful activities they have had.

NTM industry representatives. (We recommend checking with NTMir for vetting.)





**SUGGESTED  
SUPPORT  
GROUP**



**MEETING TOPICS**



# Suggested Support Group Meeting Topics

What is your group interested in learning about or discussing? Think about what your group members are interested in and develop meeting plans accordingly. You could conduct a "formal survey," or you could just look for ideas through a conversation among the group.

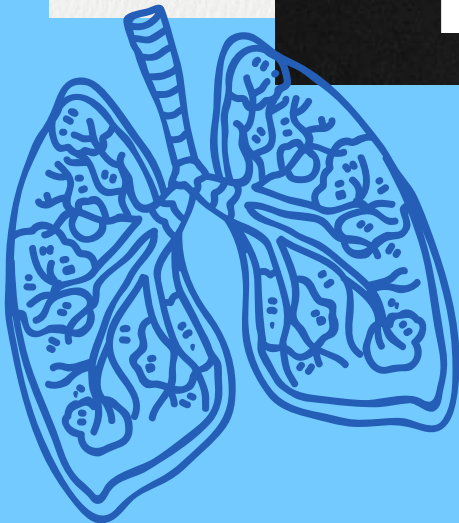
- Get to know one another better— each member speaks about their major concerns about NTM or each answers a question or talks on a topic of concern such as managing relationships through the prism of NTM.
- Medications— issues and questions – include a pulmonologist or pharmacist as an expert. Avoid misinformation on this important topic.
- The latest research on NTM and related lung diseases.
- Depression— symptoms, where to find help, and managing depression symptoms.
- Work and NTM – Strategies for managing work, communicating with your boss and coworkers about NTM, finding a new job— What to share or not share about NTM.
- Talking with your friends, family, and co-workers about NTM.
- Arranging your life to minimize NTM issues – Living Well with NTM.
- Healthful living – Exercise and nutrition – how to maximize your health through best dietary and exercise practices.
- Making a difference for NTM – participating in fundraising, advocacy, sharing your story.
- Activities to do with an individual living with NTM and related lung diseases.
- Important information to document for your family physician.
- Self-care for caregivers.
- Travel considerations with NTM.
- Have group members share their own meeting topics.

Discussions can lead to finding physicians who successfully treat NTM patients. Out of that came a list of those doctors that were shared by group members and submitted to NTMir to be listed on their website.



**READY,  
SET, GO -**

**THE MEETING**



# Ready, Set, Go – The Meeting

Setting the tone for your support group meeting will begin from the first few minutes you start off the meeting. Many leaders underestimate the power of those first ten minutes, and it is critical that you capture the intensity of the group so you can move the meeting forward in the right direction.

Engagement is the overall goal for every support group meeting. As the leader of the group, you will want every member of the group to leave feeling they have been an active participant. You will also want your membership to feel you have adequately provided them with information that directly relates to their lives and is applicable to NTM or what they are dealing with in their current struggles.

A good way to start off the meeting is to briefly inform the group of the overall goal of the meeting. This does not mean to read off the agenda. Consider the first few minutes, your way of informing the group of the format of your time together. If you have a more relaxed type of support group this can still work, simply summarize how you plan to move forward with the discussion or what the topic will be.

Next, engage and excite the membership. Maybe use a group activity or an open-ended question session. This is a great ice breaker for groups and a wonderful way to start conversations. If you have a new member at the meeting, ask them to introduce themselves and give everyone a little background information about themselves and their patient experience.

You want to make sure the members of the group are all actively participating in the discussion. If someone seems to be holding back, try asking the member an open-ended question or ask the person if they have had a similar experience they would like to share. Engagement is important for members to feel valued even if it is their first meeting. It is a good way for them to build trust and start to feel secure in the environment. Remember to never force or pressure anyone to share if they are not comfortable. Everyone should participate when and if they are able to. With a virtual meeting, it becomes a little more complicated, and people will occasionally speak over each other by accident; everyone will get used to this and to making sure others have the chance to chime in. As group leader, you can also call on members one by one to speak – this works in virtual or face-to-face formats.

Briefly remind the membership of the confidentiality rules, to turn their cell phones off or put on silent mode and to respect each other when speaking. It is necessary to do this at every meeting. If the meeting is a virtual meeting, you will likely have to remind a few people to mute themselves when they are not speaking, and this is something you will be able to do as well as the meeting host.

Real empowerment will come from your ability to encourage members to move past their comfort zone. Encourage positivity for the group and remind the members that NTM does not define them!

## **PREPARE FOR THE MEETING**

Make sure you have contact information for everyone who attends, including their email. Have name tags and markers available for everyone and be sure to have an attendance list for everyone to sign.

Consider making a packet of information for each patient:

- NTMir Pamphlet: NTMir can do contact labels for you to put inside the pamphlet
- Questions to Ask Your Doctor
- Doctor Visit Notes Form
- Send a meeting reminder
- For in-person meetings: Ask people not to use fragrances, suggest they bring water
- Tell them it will be friendly and informal
- Remind them to have a pen and paper in case they want to take notes

## **THE GROUND RULES FOR DISCUSSION**

- Everyone will have a chance to talk; no one should dominate the discussion.
- Only one person will talk at a time, uninterrupted, while others listen and refrain from side conversations.
- At times of sharing, everyone will have the right to pass. Silence is okay.
- Feeling upset or sad is allowed; tears are acceptable.
- Respect one another's differences.
- Keep other members' identities and issues confidential; refrain from discussing other members situations outside the group environment.

## **SAMPLE AGENDAS**

An agenda is a list of topics that will be covered during a meeting. It is a guide for both the leader and members. Most meetings last two hours. Here are some typical agenda items:

## **CHECK-IN AND ICEBREAKERS (SUGGESTED TIME, 5-10 MINUTES)**

New members may be introduced at this time. The idea is to begin the meeting on a positive note. Each member responds to a particular question and speaks in turn. No one comments or interrupts. Always give permission to pass. Groups sometimes ask an open-minded question here, such as, “How did your week go”, be aware this type of question has no limits on airtime and can eat up most of the meeting. We suggest that if you use the check-in, you restrict airtime to 2-3 minutes so as not to use all of the meeting time. Check-in time can also be used to go over the group’s guidelines. Here are some other examples:

- Do check-ins make sure everyone has signed in.
- Leader can briefly ask how they are each doing as they arrive.
- Group members share something good or exciting that has happened to them since the last time they were together.
- Group members state one feeling word that describes their emotions at the moment.
- Support leader begins meetings with a positive quote. For example: “I don’t fear tomorrow because I’ve lived through yesterday and I love today”; “Today is the first day of the rest of your life”; “We don’t get any dress rehearsals!”

## **REVITALIZATION (SUGGESTED TIME, 5 MINUTES)**

These are short, energetic games that revitalize the group. You can use yoga, dancing (e.g., the Macarena), charades, etc. These can be used at the beginning of the meeting or just after a break to perk members up.

## **BUSINESS (SUGGESTED TIME, 20 MINUTES)**

Who is facilitating, time keeping, taking notes to type up for the group? Update on last meeting? Unfinished business? Go over today’s agenda – any changes?

## **TODAY’S PROGRAM (SUGGESTED, 30-45 MINUTES)**

Groups use a variety of tools or a combination at each meeting. Some examples are: discussions, visiting speakers, videos, activities that inform members and help build their confidence, advocacy activities, public education, education of the membership through attendance at workshops and conferences, socializing, fundraising, problem solving sessions to share and / or develop coping strategies, fun night, etc.

## **SPECIAL EVENTS & FUNDRAISING**

Support groups play a unique role by providing an invaluable service to patients and families and by raising awareness of NTM. Support groups often create an annual fundraising event. Even something very small helps further the programs and research NTMir is able to do.

## **WORKING WITH SPEAKERS**

Speakers are usually available at no charge, and it is important to thank speakers by sending a “thank-you” card within a week of their visit. All speakers have something to offer. However, the difference between a well-prepared presentation and a presentation that misses the mark is often due to the communication between the speaker and the person who invited the speaker. The following checklist has been developed to assist you in communication your expectations to a speaker. Confirm the time, date, location, and topic in writing as soon as the speaker agrees to make the presentation.

## **TWO WEEKS BEFORE THE MEETING**

- Send the speaker a reminder, i.e., “We’re looking forward to seeing you on...”, along with a copy of the meeting announcement and/or press release.
- Reconfirm the time and format (e.g., a 30-minute talk with 15 minutes for questions and answers).
- Provide information about your group size, age range.
- Ask the speaker if they will need video equipment, a slide projector, or a flip chart.
- Provide a list of five to ten questions the group would like to have addressed.
- Ask permission to take photos and/or tape-record the presentation.
- Make sure the speaker has good directions and a telephone number to call in case of any last-minute problems.
- Four weeks prior to meeting ask your participants to send questions two weeks prior to meeting. Select only “general” questions to share with the speaker.
- Send speaker questions sent in advance by participants, this allows the speaker to prepare his/her response in advance.
- Request some background information on the speaker to use for publicity purposes and for introductions.
- Determine in advance who will introduce the speaker at the meeting. Be prepared with the speaker’s background information. If a blackboard or flip chart is available, it is helpful to write the speaker’s name on it in large letters. Encourage the speaker to use the microphone, if available and necessary, so everyone can hear.
- Keep track of the time and provide a warm thank you on behalf of the group at the end of the presentation.

## **ASSISTING SPEAKERS DURING QUESTION AND ANSWER PERIODS**

- If time has been allotted for questions and answers, let everyone know what the time limit is and stick to it.
- Ensure that each person gets a chance to ask a question (you may need to set a limit of one question per person depending on the number of persons attending).
- Add helpful background to the question, such as, “This came up at our last meeting, because...”
- Offer to ask questions for group members for whom voice clarity is a problem
- If the speaker needs to leave at a certain time, someone should escort him or her to the door promptly. After all, you may want that speaker to come back again!
- Depending on the meeting venue and the number of people, there may be a request for using a cordless microphone that is passed around. Some group members experience hearing loss as a side effect of medications. Please remember to have antimicrobial wipes or alcohol wipes on hand to wipe down the microphone between users.

Finally, it is customary to place your speakers on your mailing list, thus keeping them informed of your activities. They could know people with NTM to refer to your group or they may want to attend a future meeting for their own benefit.

At every meeting, the Support Group Leader has two important roles:

## **MAKING PEOPLE FEEL WELCOMED**

- If the meeting is in person, arrange the chairs and table before people arrive, preferably in a u-shape, so that people can make eye contact. Remember any necessary social distancing guidelines.
- If the meeting is virtual, the first five minutes or so of the meeting can be spent welcoming people and letting them chat and catch up a little before starting the formal meeting.
- Remember the goal is to make the meeting a safe space for sharing. Open with introductions. Ask everyone to introduce himself or herself and say maybe one or two sentences about who they are, their diagnosis and for how long. At future meetings, you will want to repeat this question to new members only. Keep introductions short and light so anyone who is shy or uncertain won't feel intimidated. Start it off by introducing yourself to set the tone and pace.
- For in-person meetings, make name tags for everyone. Most of us have trouble remembering names. Name tags will lessen the embarrassment of having to ask someone's name several times. We recommend using a sharpie as a regular pen might be difficult to see from a distance.



- If you have not set future meeting times and dates, consider surveying the initial participants to determine the best date and times.
- Let participants know how everyone will be informed of the next meeting. Groups typically use email. However not everyone will have access to email so, select the co-leader or support group member to contact those who do not have email access. We have found that the most effective way of communicating with group members is to develop a group email list. For those few who are not on email, request an email of a close relative or friend who can receive the information, then transmit to the person. Other groups may have a snail mail list. Be sure you get a phone number for each group member in case you ever need to follow up with any of them or check in on them.
- Create a roster of attendees and/or have a sign in sheet. Have them identify as patients, caregivers, family, etc. and ask for contact information. You may ask if they would like to share this information with the group so that they can communicate with each other outside of the Support Group meetings.
- For online/virtual meetings, write down names of attendees and a detail or two of their background. You might want to designate someone to take down these notes.

## **FACILITATE THE DISCUSSION**

- It is your responsibility to manage the time. Start and end the meetings on time. Share the agenda with the members and remind them of the timing. Express to the group that you want to be respectful of everyone's time so it is important to stick to the agenda and schedule.
- Lay the ground rules. At the beginning of every meeting, remind members that anything discussed during the meetings is confidential. Encourage everyone to participate in the Group and to respect the views of others.
- As the Leader, it is up to you to make sure that no single person monopolizes the conversation and that everyone feels it is a safe place to participate. Remind them that everyone should have a chance to speak during the meeting.
- Remember your own role: lead the discussion, do not dominate it; be an active listener, but do not give advice or provide counseling.
- Be prepared for active involvement. Facilitating a Support Group means you must be ready to deal with real conversations, interruptions, questions and answers from various members of the Group.
- Be honest – if you don't know the answer, say so, but commit to trying to find it. You have an excellent resource in other group leaders, who may forward the question to their own group members to see if they have an answer.
- Look for similarities of experience – if someone mentions an important fact or issue, ask others if they have experienced it too.

## AFTER THE MEETING

- The agenda for your first meeting might be dedicated to discussing what members hope to get from the support group, the format they prefer for the meetings (open discussion, speakers, etc.) and the topics they would like to discuss. But every meeting should have time on the agenda for feedback, idea sharing and offering opportunities for the members of the group to get involved in promoting the group and planning for future meetings.
- Discuss how you feel about the first meeting with other organizers immediately after the meeting. What went well? What did not? Don't be hard on yourself about the things that do not go well; use the experience to plan things differently for next time. Take pride in all the work and look forward to more success in the future.
- Bring closure to the meeting. Here are some suggestions for ending a meeting:
  - Provide a 10 to 15-minute notification before discussion is scheduled to end.
  - Invite members to make any final comments.
  - Have the group share how they feel the meeting has helped them.
  - Encourage new attendees to try out the group for a few meetings before deciding whether it is right for them or not.
  - Make mention of any literature or materials that are available for the group.
  - Briefly summarize what has happened at the meeting and any conclusions or consensuses the group has reached.
  - Announce location date and time of next meeting.
  - Conclude the meeting by expressing appreciation to the group for their presence and participation.
  - Encourage members to support one another in between meetings and to reach out when needed.
  - While not required, a written summary can be helpful sent out after the meeting. The group leader or one of the members may do this.

## REMEMBER TO RE-EVALUATE PERIODICALLY

- Re-evaluating how the Group is working periodically is a good idea. Be sure that the programs, meeting time and frequency continue to match the needs of Group members. Here are some yardsticks to measure what your Group has accomplished:
  - Do members give and receive support on a regular basis?
  - Do long time members help newcomers?
  - Are members leaving the Group?
  - Accept that your Group needs to be flexible and adaptable to meet its members' changing needs. Build review and change into the way you run it as well as making special efforts to check on what you're doing. Be proud of your achievements!

## CONNECTING AFTER THE MEETING

- Maintaining a connection with members in between meetings can be the difference between members being engaged and not being active participants. Leaders can send out e-mails or make calls to members who miss meetings to check in. When membership is larger than five, a communication chain can be created to take the strain off leadership and share the responsibility.
- Members like to feel they are valued and an important part of the group. Sharing the responsibility, checking in on each other and showing compassion to members provides stronger relationship with a true sense of worth. This can also help members feel a sense of urgency for coming to meetings.

## MEETING CHECKLIST

### OPENING THE MEETING

- Prepare yourself
- Prepare the room
- Start the meeting on time and in a friendly manner
- Give preliminary introductions/information
- Encourage members to listen to each other
- Encourage members to give support to one another
- Encourage members to talk about themselves
- Offer support
- Help members solve problems by:
  - Clarifying the problem
  - Talking about alternatives
  - Choosing which option to take
  - Offering help

### CLOSING THE MEETING

- Make a summary statement
- Ask for comments/questions
- Remind members of next meeting
- Request volunteers, if necessary
- Give a final greeting
- Make final notes
- Lights, Clean Up, Lock Up
- In the case of a virtual meeting, end the meeting for everyone



**TIPS FOR  
MAKING YOUR  
SUPPORT  
GROUP THE**

**MOST EFFECTIVE**



# Tips for Making Your Support Group the Most Effective

Giving advice is a common occurrence among Support Group members. Although most advice is given with good intentions, it sometimes can be ineffective, and perhaps even aggravate the problem. When addressing concerns related to NTM, it is important to remember, that each individual's journey is unique and what works for one caregiver, may not work for another. Rather than giving advice, group members may assist one another by using being solution focused which invites the individual to explore various options. The steps are as follows:

## **DEFINE THE SITUATION**

Often times a group member may think their problem is one thing, when it actually isn't. It is very important to explore what may be contributing to the problem, before clearly defining the situation. Sharing diagnosis and treatments gives other patients questions to ask their own healthcare provider.

## **BRAINSTORM SOLUTIONS**

Invite Support Group members to come up with a list of things that might work to overcome the challenge. A key suggestion which should always be included is to seek professional advice from a physician.

We believe an important strength of a support group is that it remains adaptable, that as a person with NTM needs change so might the person's participation in the group. The informality allows the group to remain welcoming to those with NTM and others affected by this disease.

At the same time, it is important to keep in mind that the support group is not intended to, nor implied to be a substitute for professional medical advice, or to be used for medical diagnosis or treatment. The support group can serve, however, as a valuable resource, as it can offer education and support to NTM patients, families, and caregivers, and can provide information about future events and activities.

Each group should identify its own focus area, and this may change at various times. Your group may wish to focus solely on supporting those with NTM and their caregivers, to help one another deal with the quirks and difficulties of this disease. It may help to host information sessions on NTM, or social activities.

Support groups have the opportunity to help not only those affected by this disease, but also to inform and educate others, including medical practitioners about the impacts of NTM on those affected. Your group may begin with one purpose but will have the flexibility to adapt based on the changing interests of its members. This can also help members feel a sense of urgency for coming to meetings.

## **WAYS TO KEEP MEETINGS UPBEAT**

Here are some ideas to help your group members focus on sharing positive experiences, insights, and information – and avoid the risk of having a meeting that has people going home feeling worse than before they came.

- Explain that an important purpose of your group meetings is to help all members to recognize and share their strengths, successes and hopes, not just their problems.
- Help your members share their good experiences by reminding them to contribute their insights, quotes, information on helpful resources or literature they have used, or any practical coping techniques that work for them. For example, you could build this into the structure of your meetings by regularly starting them with introductions and a brief “go-around” where each member briefly answers a question that draws out a positive experience (e.g. “Describe the best things you have done or that have happened to you since the last meeting.”)
- Share good news gathered from outside of the group related to NTM (e.g. new research, helpful magazine articles, news from **NTMir** or other organizations.)
- To help keep the discussion upbeat, encourage members to share their strengths, skills, insights, successes (however small) and their hopes.
- Make members aware of the real health benefits of helping others. One of the best ways to take your mind off your own issues is to help give other members feedback, whether it be to summarize the progress of others and the group or to give a helpful nod of understanding when a member is sharing.

## **WAYS TO ENCOURAGE YOUR SUPPORT GROUP MEMBERS TO PARTICIPATE**

One of the primary purposes of a Support Group is to provide an environment where people with similar life situations can meet with one another and help one another address their questions and concerns in a supportive, caring, and non-judgmental atmosphere.

- Invite new members to attend the Support Group meetings.
- Help members feel comfortable and get to know one another.
- Participate in the discussions.
- Promote positive comments and new viewpoints.
- Listen attentively.
- Notice shy people in the group and encourage them to contribute their thoughts.
- Offer to make reminder calls or send reminder emails to each member on a monthly basis.
- For in-person meetings, provide some refreshments for the group members to share. This may be as simple as providing bottled water. Query your group members to find out what they would prefer.



**OVER-  
COMING**

**CHALLENGES**



# Overcoming Challenges

The reality is that as a Support Group leader you will face challenges. This section will address some of the common challenging situations and provide suggestions on how to respond.

## **DISEASE PROGRESSION**

Support Groups typically have a mix of people at various stages of NTM. The needs of a person caring for a loved one who has been recently diagnosed are often very different from a person whose loved one's disease has advanced. Acknowledge that each person in the group has different needs and that all needs are valid and can be addressed. Also encourage those who are reluctant to speak up in the meeting, to talk with you, the leader, after the meeting has concluded.

## **ATTENDANCE**

A group is defined as two or more individuals. Ups and downs in attendance are normal. Group members' lives are very busy. If numbers are low, you may wish to discuss the scheduled time and location. Reminder phone calls or emails made or sent out each month, as a friendly reminder of the upcoming Support Group meeting, are helpful to promote regular attendance. Encourage group members to recruit others who may benefit from the mutual support of a Support Group meeting. (See "What to do if your Support Group meetings are Losing Steam" on page 32.)

## **DEATH**

Due to the nature of the relationships built between Support Group members, the loss of a loved one, or a member themselves, can be incredibly emotional. Acknowledging the loss at the time of death via email or a phone call to group members, will prevent any surprises at the next meeting. Invite the participants to offer their support - send flowers, cards, etc.

## **PREVENTING BURNOUT**

No matter the dedication and sense of commitment one may have, there is always the risk of experiencing "burnout". For example, you have been leading the support group for a long time and you are just plain tired! To be an effective source of support for others, you must first take care of yourself. Some steps that can address this are further delegation of responsibilities, turning over some duties to the group co-leader, and stepping back and taking a break.



## WHAT TO DO IF YOUR SUPPORT GROUP MEETINGS ARE LOSING STEAM

- Invite a guest to speak about NTM and/or specific topics the group is interested in.
- Arrange to have the group preview a video and discuss it afterward. NTMir can provide information regarding upcoming webinars, online presentations, and educational videos related to NTM and related diseases.
- Arrange for a special demonstration of a particular skill or coping strategy. Arrange it so that group members can practice these skills during the meeting.
- Change the pace of the meeting. Have at least one “Social Only” meeting per year where having fun is the only goal - holiday party, a potluck dinner. Virtual meetings can be a social hour as well!
- Participate in a fundraising event with NTMir as a team. Visit NTMir’s website for a list of ideas. While fundraising is NOT the reason for a support group’s existence, it can be an empowering group activity.
- Always ask the members of the group what they would like to do for a change of pace and include their participation as much as possible when planning the structure for a particular meeting.





**COMMON**

**PITFALLS**



# Common Pitfalls

## WHAT TO DO WHEN SOMETHING GOES WRONG

Wherever two or more are gathered, whether in person or online, you may have obstacles to overcome. This is human nature and part of life and as a support group leader your role will be to facilitate a group that is cohesive and collaborative in nature. Leaders who have a positive attitude and bring an optimistic and encouraging perspective to meetings will see the membership reflect that same tone. Leaders who bring a more negative and pessimistic tone to meetings, will see that their membership may follow the lead and take on a less desirable attitude.

## DISAGREEMENTS

Leaders may see members who disagree about things. Disagreements are not always seen as an impediment, rather they can be viewed as a healthy way to build relationships and conversations within the support group. When membership is disagreeing, it is important to respect the difference of opinion and allow each member involved in the discussion to explain his or her point of view. As a group, it is an outstanding opportunity for members to provide solution-based conversations that can spark problem solving and brain storming.

## THE TIMID

For those in the membership who are quiet, or who chose to retreat during open dialogue, leaders will need to be creative and respectfully inspire the member to participate. This should be done cautiously and to the level of comfort the individual feels. No member should ever feel pressured to speak or share. Involvement in all support group activities is voluntary and must be done only once a member feels safe and secure in the environment.

## THE BIG PERSONALITY

Most leaders will experience at least one or two members who enjoy being the focus of attention, someone who claims to have experienced everything medically and physically NTM-related, someone who has all the right answers, or someone who enjoys monopolizing the conversation during the majority of the meeting. These individuals will often be the ones who also like to overshare about their personal experiences with the group. For leaders, these types of participants can be the most challenging to manage in a group. The goal is to always respect each member, while managing the needs and overall spirit and objectives of the support group. This can be a challenge when one or two members have different views and want to express them openly, causing conflict in a group. The best way to handle this is praise the member for sharing their opinion, thank them for wanting to provide information and resources, then gently ask other members what their experiences have been. Leaders want to provide positive feedback to members who share and are able to contribute to open dialogue.

You may have a member with a strong or over overpowering personality. For those members who are reserved and less willing to share or are newly diagnosed, this can be intimidating, especially if one member is sharing graphic medical details and causing alarm for others who are disease progressed. The overall support goal is to provide coping skills and teach problem solving skills, not to have anyone go home feeling overwhelmed about the future. Encourage a positive attitude!

## MANAGING DISRUPTIVE MEMBERS

Support group leaders must utilize a balanced combination of control and benevolence. This assertive compassion involves keeping the focus on the disruption itself, instead of the member(s) causing the disruption. It allows the leader to directly address problems with the group without insulting or offending members.

- Initially, leaders may want to simply pose the correction to the entire group without singling out specific members. When a member is often late to meetings, casually remind the group how important punctuality is to maximize the benefit of the group for every member.
- When a member is monopolizing the discussion or frequently interrupts others, give the floor back to the original speaker (e.g. “I’d like to go back to Ann for a minute. I don’t think she was finished talking. We want everyone to have equal opportunity to share.”)
- When someone brings up inappropriate subjects that are offensive in nature or otherwise incendiary (e.g. “It doesn’t seem like this is an appropriate discussion for this group, so we are going to move on. For those who would like to continue this conversation, feel free to do so after the meeting.”)
- When triggering language is being used (e.g. “I recognize this is a meaningful topic for people to be able to talk about and I am also sensitive to the fact that it may pose a trigger to some. Please be considerate when choosing your words and avoid being overly detailed in your descriptions.”)
- When a member continuously digresses to irrelevant topics, redirect the focus to the purpose of the meeting (e.g. “How does that relate to recovery and what we’ve been talking about today?”)

Leaders must be able to determine if disruptions can effectively be addressed to the entire group or if speaking to the member in private outside of the meeting is better. Individuals that become combative or unresponsive to feedback and correction may need to be excused from the meeting. Sometimes a quick break is sufficient to allow for de-escalation and the individual may be able to return to being a positive, contributing member of the group. During this break, when leaders take the disruptive person aside privately, they must firmly, but politely, state how their behavior is affecting the group.

## **THE AWKWARD SILENCE**

Silence does not mean failure. Silence may be golden when you wish for a time out from the hectic pace that life can sometimes throw at us but as a support group leader, silence from your members can cause your stomach to churn and butterflies to fly around in your gut. No support leader wants to have no response when he or she poses a question or starts a conversation. Fear not! Silence is not an overall bad thing and can in fact be used as an effective tool for your group. As a leader you need to be prepared that this might happen and if it does, having the right tools in your toolbox will make all the difference.

Consider smiling and moving forward with asking another question, selecting another topic or even answering the question as it applies to your own life. These are all excellent solutions and can be effective. It is also perfectly acceptable to pause, wait and allow the members to think about the question or topic, and then say, “I can tell this is a difficult area for all of us, any idea why it is so hard to talk about?” Leaders can then select one member, use their first name and ask with reflection, “So and so, what experience have you had with this topic?” This open-ended question might be met with a negative response resulting in the topic going nowhere, but it also may produce the best conversation the group has ever had.

Taking the chance is the first step you as the leader can make in leading your group to finding out the depth of what your group can accomplish. There are no limitations unless you create them, there are only possibilities!

Using silence as a benefit will produce growth for your support group and enable the membership to build a deeper level of trust and confidence in themselves.

## **WHEN YOU DON'T HAVE THE ANSWERS**

There will be times as a leader when a member of the support group may ask for information that you do have, may ask a question you do not have an answer for or may want a resource that you cannot provide. Take a deep breath! It is not a problem and NTMir is here to help and will be the ones you can come to when you need resources, answers, and solutions. We have your back and are just a phone call or email away. Patient services are our priority, and we strive to meet their needs. Reach out and ask; if we are unable to answer your question, we will help you locate resources that can.

When you are in the group, here are a few suggestions as to how you can approach not having answers. Leaders want to project a professional manner even when you may not have answers. Leaders can use these phrases to help membership feel at ease even when no information can be provided immediately:

- I am able to provide you with some information about that excellent question at this time but I would like to research it more and get back to everyone within (provide a timeframe), to give you more information.
- Let me be sure I completely understand what it is that you are asking and looking for before I answer. (This allows you some time before you answer to gather more information.)
- I am personally not an expert on that topic, but I do have excellent resources that can provide us with the answers you are looking for. I will connect with them and get the answer to your question and email everyone within (provide timeframe).

## EMOTIONAL MOMENTS

Coping with a chronic disease can be difficult and often means overcoming obstacles and challenges. No one provides a manual for how an individual will manage the many emotions that accompany NTM and the often-overlapping diseases. During support group meetings leaders may have members of the group that become overwhelmed with emotions including sadness, grief, anger, frustration and even guilt. These are all very normal and healthy emotions and leaders should be prepared to respect when a member is displaying emotion.

As a leader if you know that emotion is something you have difficulty dealing with, it is a good idea to talk to staff at NTMir. If you are an NTM patient or a caregiver or you have lost to loved one to NTM you may feel a sense of your own emotions bubbling up as you hear others sharing and expressing emotion. This can be challenging as you try to lead and control and understand your own feelings. The best way to handle this is to be honest with members when this happens. Acknowledge that you struggle with this same issue or that this specific topic may be something that you are sensitive to. Leaders are humans with emotions and feelings and it is perfectly normal and acceptable to express them as long as you are able to control them and not let them get in the way of being a leader at every meeting. If you find that emotionally you are unable to lead, rely on a co-leader or another member of the group.

When someone in the group is displaying emotion, here are some coping steps:

- The first step is to remain calm.
- If the emotion is crying, allow the member to cry. Do not say, “It is ok to cry.” The person does not want your permission to cry and often when someone hears these words they will feel badly about their actions and stop immediately and try to compose themselves.
- Sit quietly for a few minutes and allow the member a chance to release the emotion freely. Crying is a way of releasing tension and emotion from our bodies and our system.
- Leaders should not immediately go to the member and offer a hug or act of touch. For some members, this act may be foreign or uncomfortable, for others, it may be welcomed. As a leader, unless you know the member personally and you are familiar with what actions the member is comfortable with, be cautious about what forms of touch you offer.

- Using a soft tone, ask an open-ended question or say, “I can see how that topic has upset you. I am sorry, but I am glad to see that you felt safe enough to share your emotion with us. I too, have felt this way and it is helpful to let it out. Has anyone else ever felt this same way?” This will open up the conversation and help others offer similar situations, providing the member with relief that he or she is not alone. It also takes the focus off the member and allows him or her the opportunity to compose.
- When a member is expressing anger or possibly even becomes overly frustrated, agitated, or aggressive during a meeting, leaders need to use reframing techniques to keep the focus on positive aspects and more optimistic things. As a leader you should never feel concerned for your safety or the safety of the membership. If you have a member who you have concerns about his or her behavior, contact NTMir and we will address the issue.

Using effective listening will be the best tool you can utilize when a member is experiencing a crisis or is expressing emotion. Listen closely to determine what the member is saying before you speak. Use compassion and genuine empathy when speaking. Be cautious not to minimize or patronize a member. Even if you have had a similar situation, do not express that you understand what the member is going through. Everyone has a different reaction to situations. Sometimes a member just wants another person to listen to them, they are not looking for anyone to have an answer, just a good ear. Respect how the member is feeling, allow them to own their feelings. Provide an adequate amount of time for the member to grieve or express emotion before moving on with the meeting.

## **MENTAL HEALTH**

Support group leaders may notice that a member is experiencing periods of sadness, grief, and loss. A member may come to meetings expressing emotions of being depressed or not even be able to voice the exact emotion he or she is feeling. In cases where a leader has any concern about a member’s mental health, how he or she is coping with life, or if a leader ever has a concern whether a member may do harm to him or herself or another individual, it is mandatory that the leader make a professional referral on behalf of the member. Most patients and even caregivers will have moments in their lives when they have difficulty accepting their diagnosis or the diagnosis of a loved one. For some patients, it may take weeks, months, or even up to a year to accept the initial diagnosis of NTM and move toward managing symptoms. Leaders should be looking for continued patterns of severe or traumatic displays of stressful symptoms.



**TIPS FOR  
KEEPING  
YOUR**

**SANITY**





# Tips for Keeping Your Sanity

- Keep meetings positive and encouraging. The number one reason people give for not wanting to go to a support group is the perception that it's just a bunch of people getting together to whine and complain. While members need to be able to bring up problems, you always need to bring the focus back to finding solutions. Don't allow the meeting to degenerate into an anger or self-pity session. When a problem is presented encourage other members to come up with positive ways to deal with it.
- Be a better listener than you are a talker. People need to be able to share their problems with someone who understands what they are going through. Just as you may sometimes need support from the group, so do they.
- Remember that you set the tone for the meeting. We all have bad days and bad moods but try not to let yours show in front of the group. While you might acknowledge that it's been a rough day, put on a smile and forge ahead with the meeting or ask a co-leader or another member to lead that day.
- Develop your own personal support system. Find one or two trusted friends with whom you are comfortable sharing your personal struggles. You need individuals in your life who will celebrate with you on good days and comfort you on bad days.
- Connect with other support group leaders. Whether you meet in person, talk on the phone or by virtual meeting platforms, or communicate through e-mail it helps to develop relationships with other support group leaders. You can exchange meeting ideas, share strategies, troubleshoot programs, and encourage one another during those times when you wonder whether it's worth it all.
- Set limits and stick to them. It's easy to have your life hijacked by a few group members who want your attention and will call at all hours. Set up boundaries and decide which days and times are best for you and announce at the meeting that those are the only times you will be available.
- Encourage members to use the buddy system. Everyone needs someone to talk to, someone to commiserate with them. But you cannot be that person for every member of the group. Urge them to find someone in the group with whom they could exchange phone numbers and agree to be a mutual support system
- Be on the lookout for other potential leaders. When you find a group member who seems to have leadership qualities, consider training him or her to back you up in case you are unable to attend a meeting. Even if you have a co-leader, it is a good idea to have someone in training just in case.

It's easy to fall into a pattern of doing everything yourself. Ask for help when you need it.



**SELF-**

**CARE**



# Self-Care

Managing the wellbeing of a Support Group starts with managing the wellbeing of its leader. This must be every leader's first priority. One of the building blocks of self-care is self-awareness. Successful Support Group Leaders are aware that their own situations and experiences may impact their facilitating. This is particularly true for leaders whose personal health conditions, or the health conditions of a loved one, can influence their responses. There may be times when a leader needs to remove themselves from the role of leader to take care of themselves. If the physical or emotional energy it takes to facilitate the group becomes detrimental to the leader's wellbeing, then they need to be prepared to pass that responsibility to the co-leader or another designee.

## EMOTION REGULATION

This is a broad set of skills and abilities that help keep the emotional system healthy and functioning. Good emotion regulation includes the ability to:

- Recognize that you are having an emotional response.
- Understand what the emotional response is.
- Accept your emotional responses rather than reject them or react to them with fear.
- Access strategies that allow you to reduce the intensity of the emotion when needed.
- Engage in goal-directed behavior when upset.
- Control impulsive behaviors when upset.

By practicing these techniques, leaders will be better equipped to handle the challenges of being emotionally involved and impacted. Maintaining a healthy emotional life is important to overall health and sustaining effectiveness as a leader.

Emotion Regulation is only one of many facets of good self-care. Physical, intellectual, social, and spiritual health are also parts of individual wellness. They entail:

- Getting proper exercise.
- Maintaining balanced nutrition.
- Having sufficient quantity and quality of sleep.
- Receiving preventative and ongoing medical and dental care.
- Staying home and resting when ill.
- Engaging in creative activities or learning new things.
- Having and utilizing a strong social network consisting of healthy relationships.
- Resources for support and stress relief.
- Forgiveness of self and others.
- Understanding personal beliefs, values, and ethics to guide decision-making and overall approach to life.

Some leaders may encounter personal barriers to self-care. These often stem from unhealthy attitudes, habits, and beliefs. They often feel overwhelmed.

With its multiple components, self-care can seem like an astronomical task. It may feel as if it is too complex or simply too massive of an undertaking. Developing a self-care plan and gradually implementing it will help leaders adjust and adopt self-care into everyday life.

## TIME MANAGEMENT

- Living in a fast-paced and often demanding society, packed with medical appointments, meetings, housekeeping and home improvement projects, and parenting leaves little time to stop and relax. Despite tight schedules, leaders must find time to do the things that will get and keep them well. Activities for self-care do not have to be time consuming or done all at once. They can be done in small increments of time spread throughout the day. It is much more beneficial to practice self-care as a preventative measure rather than as a reactive response.
- Minimizing the Importance – The perceived value of self-care plays a major role in the leader’s development and implementation of an effective self-care plan. Many people engage in self-care activities only when they feel they need to.
- When leaders develop a habit of taking care of themselves, it also provides an example for group members to follow.
- Guilt – Particularly for individuals with low self-esteem, focusing on the self is viewed as selfishness. They feel guilty about taking time for themselves. On the contrary, self-care is the best thing leaders can do to help another person. When the leader is at their best, both they and the group will benefit. The reverse is also true. When the leader is not well, it diminishes their ability to facilitate effectively and help the group.
- Resources – It is a widely believed myth that self-care is too expensive because the activities always cost a lot of money. In actuality, the opposite is true. There are countless things people can do to take care of themselves that cost very little or even nothing at all. Nature walks, naps and meditation are just a few examples of self-care activities that are either free or inexpensive. Additionally, it may be helpful to set aside a small budget for other activities that do have a cost associated with them.
- The consequences of self-neglect can be enormous. They range from wearisome stress that erodes health to burnout so debilitating that leaders are forced to walk away from their position or from the group entirely. For the sake of the leader, and the group, self-care is both fundamental and indispensable.



# RESOURCES



# Resources

## ONLINE RESOURCES

- [www.ntminfo.org](http://www.ntminfo.org) NTM Info & Research (NTMir) patient support forum, NTM disease information, press releases, activities of the organization, calendar of support group meetings
- [AboutNTM.com](http://AboutNTM.com): A comprehensive website from Insmmed Pharmaceuticals.
- [www.maclungdisease.org](http://www.maclungdisease.org) University of Texas Health Center at Tyler patient support forum, NTM disease information, UTHCT patient services
- [www.nationaljewish.org](http://www.nationaljewish.org) National Jewish Health in Denver, NTM disease information, NJH patient services

## MAJOR MEDICAL INSTITUTIONS TREATING NTM

- National Jewish Medical and Research Center, Denver CO
- University of Texas Health Center at Tyler TX
- Mayo Clinic, Rochester MN
- National Institutes of Health, Bethesda MD
- OHSU – Oregon Health & Sciences University, Portland, OR
- UCSD – University of California San Diego, La Jolla, CA
- NYU – New York University, NY, NY
- Georgetown University Hospital, Washington, DC
- University of Miami, Miami, FL
- Johns Hopkins Medical Institute, Baltimore, MD

**NTMIR PROVIDES A PHYSICIAN REFERRAL  
LIST ON ITS WEBSITE AT  
[WWW.NTMINFO.ORG](http://WWW.NTMINFO.ORG).**



# Notes

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