LEARN TO LEAD

Effectively managing a support group
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Let’s Get Started

Defining what a scleroderma support group is.

In the book, It’s Not about the Coffee, by Howard Behar, he tells readers the importance of remembering that leadership begins with who you are, not with what you do. As a support group leader your role will be to lead with your heart, compassionately helping those whose lives have been touched by scleroderma.

A scleroderma support group can be composed of scleroderma patients, family members, friends or even those in the community seeking to learn more about the disease. More often than not, your group will have scleroderma 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 a scleroderma 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 surrounded by 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 self-worth.

Scleroderma support groups will be supplying accurate and updated information about the disease, current research and management techniques. This information will be supplied by the Michigan Chapter on a yearly basis and speakers can be located through local resources.

As a leader your role will be to affirm member’s 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 scleroderma 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 scleroderma treatment plan.
The Next Steps

Steps to starting a support group.

Starting a support group does not have to be a daunting task and the thought of it does not need to overwhelm you. Following these steps will help you begin to consider whether being a support group leader is right for you.

1. **Review your schedule** to determine whether you can devote three to four hours a month to the group. This timing will vary month to month and will be based on the amount of preparation work you desire to do, if you want the Michigan Chapter to create curriculum for you, if you want to have speakers at the meeting or how much follow up you do after each meeting.

2. **Determine if your health is adequate enough** to accommodate the coordination of meetings, working with the Michigan Chapter and helping to market and publicize the meetings.

3. **Evaluate your level of comfort with speaking in front of a group.** Are you able to lead and help facilitate open conversations or are you someone who prefers to remain silent in the back of the room while watching the others in the group participate?

4. **Know yourself and be true to who you are.** Consider how you handle your own chronic illness. Are you someone who believes in being inspiring, encouraging and uplifting? Support group leaders need to lead with a sense of inspiration, while accepting that you are also allowed to have a bad day.

5. **Contact Scleroderma Foundation Michigan Chapter** and let them know there is not a support group in your area and you are ready to lead! Make sure that there is not another support group within 40 miles of where you are considering locating your group.
Am I the right person to lead?

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 and unique
- 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
- Over all 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 when conflict arises among members
- Focusing on solution driven ideas as opposed to negative reactions to problem solving
- Giving members the tools they need to become the best advocates they can be in order to create treatment plans that will result in healthier lives
The Ten Principles of Leading

*It's Not about the Coffee by Howard Behar.*

I recommend that support group leaders take the time to read Howard Behar’s book, *It’s Not about the Coffee.* Howard is the founder of Starbucks Coffee shops; a very successful businessman who uses ten principles of leading to help keep himself grounded in life. These principles apply to all of our lives, no matter what we do. When reading the book, think about your role as a support group leader and how important it is to know yourself first and how you view yourself as a scleroderma patient, a caregiver or someone who possibly lost someone you loved to scleroderma. Looking inward to yourself will be a benefit as you take on the role of support group leader. It will help you be a more effective leader and role model to your membership.

In reading the book you will have the opportunity to consider why you are here right now, considering being a support group leader. What has brought you to this point in time? As a support group leader you will be thinking independently, helping your membership to build trust, you will learn that everyone in your group will bring value to the group, even that one member who may bring conflict or challenges to the group. Remember, that he or she is struggling too and have patience with this person, work with him or her and try to find the assets that he or she can bring to the group. As the leader of the group, others will follow suit when you look for the positive in each member.

As a support group leader you will learn to listen and to sometime 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 scleroderma 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 can make 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.
Practices of Leaders

*The Leadership Challenge* by James M. Kouzes and Barry Z. Posner.

All great leaders have qualities that have benefited their climb to success in life. In the book, *The Leadership Challenge*, another recommended read for support group leaders, you will learn what they call the five practices of exemplary leadership. They believe these practices contribute to the success of leaders. They define leadership not by personalities but by what an individual does. Again, an author is contributing the benefits of guiding others in the right direction.

As a support group leader you will be showcasing your leadership skills at every meeting. If you are negative and framing your disease as more of a burden to those in your meeting, this messaging will be received as such. Rather, if as the leader, you deliver the message that scleroderma has brought challenges into your life but you are facing them realistically and with a positive outlook; the group will be more receptive to your message. In this case, the difference in the messaging is vast.

You will be the vision for the group, the inspiration and the motivation. Your encouragement will provide the members of the group clarity and focus for how they face their own disease. Again, you don’t have to have all the answers. When you can’t answer a question, tell the group you will contact the chapter and seek out the answer. The chapter will contact our Medical Advisory Board and provide an accurate answer in a timely manner. Accuracy is important.

As a leader you are not a physician and no one is expecting you to be one. For your protection and the protection of the chapter, support group leaders are asked to not provide medical advice to the support group. Being a good leader means remaining in compliance at all times. If a member asks a medical question respond by saying, “That is a wonderful question to direct to your physician. Since every scleroderma patient is so unique it is difficult for me to answer your question accurately and I want you to have the best possible information you can obtain.”

Take a moment and read this book and see how it can enhance your role as a support group leader, as a volunteer or even as a scleroderma patient. Its principles apply to many aspects of daily life.
Working together

The benefits of working with Scleroderma Foundation.

The Michigan Chapter will provide each support group leader with supplies every year. Supplies are sent out in the fall, along with curriculum for every meeting and enough copies for all of your members.

If you would like brochures or materials, you can contact the chapter and request they be mailed to you. Quantities may be limited, but the chapter will work with each leader to assure all of your needs are met.

The chapter will include information about each support group on the chapter’s website. In the event that a meeting is cancelled or changed, it will be necessary to email staff and make them aware immediately. The chapter will work directly with the National Office to make any changes to their website.

The chapter will submit all annual plans and will work with every leader in the creation of these. No leader will be required to do this paperwork on their own. This will be done together with the chapter’s staff.

All support group leaders will have access to the current list of Scleroderma Foundation support groups as they are listed by state. This can be found on a private website, www.Scleroderma.org/InsideSF. Information about the organization, training materials and other pertinent documentation can be found at this site. Leaders will find information about the use of logos, fund raising information and guidelines on this site also.

The Michigan chapter does not allow for any support group leader to maintain or possess a private or public website of their own. This is a direct violation of our charter agreement with the National Office.
Figuring out the logistics

Making decisions about location and timing for the meetings.

Finding the right location for your support group does not have to be challenging or overwhelming. As the support group leader, you will work with chapter staff to determine the best location for your meetings. The goal is to not have meetings within twenty to thirty miles of each other.

Determine what day of the week will work best for your schedule. Review the chapter’s other support group schedules and make sure that your group will not be overlapping if you are in close proximity to another group. While it is nice to offer patients choices in support groups, we want to shy away from any form of competition for membership among groups.

Decide on the best time for your group, mornings, afternoons, or evenings. Consider what time will be the best draw for the membership of the chapter. To do this with accuracy, contact the chapter. 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 normally 1 ½ to 2 hours in length and will vary from group to group based on need and format. If your group is desiring 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.

With the location and the timing set, support group leaders can now focus on the location of the meeting. Either you can seek out a location or the chapter will also assist you with searching for where to hold the meetings. Community centers, hospitals, churches, senior centers, local medical office buildings that offer space to groups are all excellent examples of locations that offer a support group confidential and safe environment.

To secure space, support groups can either make the arrangements themselves or work with chapter staff to have someone in the office make the initial contact.

Once space has been secured—your paperwork has been turned into the chapter and been accepted by the national office, your information will be placed on the chapter website. Your support group will be official and recruitment will start!
Co-Leaders

The advantages of having more than one leader.

Scleroderma Foundation Michigan Chapter 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 scleroderma 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 group’s interest and helps the membership from growing bored or stale of a leader’s style. 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 because their membership is able to learn from their different teaching styles. Leaders can share the roles according to their own strengths, likes and experiences with scleroderma. 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 any computer or audio-visual obstacles 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 only enhance the experience for membership, as well as assure that in the event one leader has to step down the group will not be closed while seeking a new leader.
Structuring the meetings

Educational verses conversational meetings.

Scleroderma 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:

1. **Open discussion support group meetings:**
   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 scleroderma journey with those in the group. Leaders may begin the meeting checking in with membership to see how each person is doing. This starts off the conversation and opens the conversation up. It will usually lead to a more in-depth conversation among the group about scleroderma related issues.

2. **Educational support group meetings:**
   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 scleroderma related topic. A question and answer period is provided for the group. Handout materials are provided by the chapter to correlate with the speaker and topic.

3. **Combination support group meetings:**
   These meetings often do, but do not have to, have an agenda. 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 membership to discuss their current needs and issues pertaining to life with scleroderma. This format is the most popular for scleroderma 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, bring in their favorite snacks and treats and even do an off-site dinner or lunch once in a while for a bonding experience.
Protecting privacy

Confidentiality is essential.

What is confidentiality?

By definition, confidentiality means that what you are hearing within your support group is information that should not be shared or told to anyone outside of the group. Stories that are told by members may contain personal details that are not meant to be communicated to individuals that are not members of the group unless permission has been granted. This is all part of maintaining confidence among members in the group and is mandatory if you want your members to feel secure and comfortable in the environment you have created. The higher the level of confidentiality that the group is able to maintain, the more trust that will be built among the members and a bond will be established helping everyone desire to be at meetings.

What makes confidentiality so important?

The foundation of a support group is its members. At the core of that we find open communication and trust. By creating this type of environment, leaders can help their memberships establish a safe and secure relationship with each other which in turn allows for open discussions. The result of this can be lasting friendships, mutually satisfying bonding experiences and ultimately a sense of contentment and resolution with the state of an individual’s chronic illness.

What is the best way to establish confidentiality?

As a new support group leader it will be your role to help your group establish and maintain confidentiality at all times. It can be all too easy to void confidentiality and thus it takes practice and time, placing emphasis on this at every meeting to remind members of the importance of not sharing private details.

Best practice in regard to confidentiality is to open each meeting making a brief statement thanking all those present for remembering to maintain respect of the privacy of those in the group. This includes all conversations that take place during the meeting, any medical situations that may be discussed, and even personal funny stories that may be shared. The conversations that take place during your time together need to be respected unless again, permission has been granted to share. In the case where permission has been given to share details, make sure that it is made clear what the perimeters are and if there are any restrictions as to who information can and cannot be shared with.
Protecting privacy continued

Exceptions to the confidentiality rules:

As a support group leader it is essential that you report to the Michigan Chapter and Scleroderma Foundation National Office any suspected cases of child abuse or anytime you consider a child may be in danger. It is always worth having a conversation with staff if you have any concern regarding a situation. Do not hesitate to consult the chapter or the national office if you have concerns. It is better to reach out and allow us to intervene as opposed to later finding out that nothing was done and we could have helped.

If you have concern about one of the members of the support group being in danger or harming themselves, their caregiver or another individual, this is also considered a time when the confidentiality rule is void and as the leader of the group you will need to seek assistance from the chapter and the national office. We all take cases of depression seriously and the goal is to help individuals obtain the resources they need to obtain an effective treatment plan.
Marketing your meeting

Awareness of the product can make a real difference.

Scleroderma Foundation Michigan Chapter will work with you to help with the recruitment process for your support group. Together, we work to promote your group as a healthy alternative to searching the internet for information about scleroderma and overlapping autoimmune disease related symptoms.

The use of social media, the chapter’s website, and the national Scleroderma Foundation’s website, inclusion in local newspapers and in medical publications will be the main sources. Scleroderma Foundation Michigan Chapter encourages all support group leaders to network with local community groups, PTA’s, schools, hospitals, medical professionals, social services organizations, other nonprofits and educational groups.

The chapter will work with each leader to create marketing materials for the support group such as flyers, email templates, brochures, letters to the editor, public service announcements, and press releases.

All marketing needs to be approved by the chapter prior to submission for accuracy and compliancy requirements.
How to find the right speaker for your support group.

Finding the right speaker for your support group does not have to be a challenging task. The Michigan Chapter can assist you with the process or you can make the connection yourself. Every month you will be given a topic and materials that will complement the topic. If you desire to have a speaker address the topic, you can use community resources to locate one. You can also contact a local Speaker’s Bureau to request a speaker. Speakers Bureaus can be found at most hospitals in the state. Some hospitals have a public relations department or a health education department that will assist you with finding a speaker. By contacting the hospital directly you can determine the appropriate department to speak to.

Other possible speakers are:

- Pharmacist
- Nurse
- Emergency Response Worker
- EMT
- Yoga Instructor
- Hospice Groups (they do many talks, not just end of life issues)
- Disability
- Occupational Therapist
- Physical Therapist
- Researcher
- PAH Association
- American Autoimmune Related Diseases
- Raynaud’s Association’s
- Hyperbaric Chamber
- Wound Care Specialist
- Dentist
- Mindfulness Mediation Specialist
- Counselor/Therapist

Be creative when considering speakers and where to seek them. Your group will thrive when they feel they are obtaining accurate and updated information that benefits their everyday lives and helps them create a valuable treatment plan. They will want to return to the group finding it a safe and positive environment.
Curriculum

Focusing on topics that participants can relate to.

Support group meetings that are curriculum focused will receive all of their materials every year in the late fall from the Michigan Chapter. Materials will come directly to your home and will arrive via UPS or FEDEX. You will find handouts will be divided into folders that will be labeled or divided by rubber bands. You will also have a master sheet that will identify your master curriculum for the entire year.

Yearly you will receive all the supplies you will need for your support group. You are never expected to have out of pocket expenses as a leader. The Michigan Chapter asks that you do not make purchases with the intent of being reimbursed. We are unable to do this. In the event you are in need of something to make your support group run more effectively, simply contact the chapter via email and request the item and it will be provided if possible and sent to you.

Brochures, newsletters, envelopes, stamps and other materials may be limited if resources are low at the chapter, but every effort will be made to accommodate your request. The chapter does ask all leaders to allow at least two to three weeks for all requests when possible. This will provide the chapter enough time to obtain the items, make copies if needed and ship the item if needed.
Annual Plans

A national requirement that the chapter fulfills for all leaders.

Annual plans are defined as a support group leader’s master plan for the group. This document is submitted to the national office every year in the late fall. The Michigan chapter works with every support group leader to get this plan created and submitted. The chapter will create the yearly topics, submit them to the leaders for approval and then create your annual plans. Once each leader has approved their plans, the chapter will submit the plans to the national office. The national office uses these plans to advertise the information about each support group across the United States. The information will be displayed on the national website, www.scleroderma.org. This is why it is imperative that all of the information on the annual plan be accurate and be followed. In the event you cancel a meeting, move the location of your meeting, change the topic, or cancel a speaker, the chapter needs to be made aware of these deviations from your annual plan, so staff can make a change on the chapter’s website. This helps any potential individual who may be considering attending a meeting be made aware of any changes as soon as possible.
Getting donations

In-kind donations for your support group can come from local stores, friends and family.

Support group leaders sometimes desire to obtain in-kind donations from local sources. This is permissible and the chapter can assist in the process by providing suggestions, writing an introduction letter, or by providing the organization’s 501(c)3 paperwork.

In-kind donations are defined as contributions, other than cash, of goods or services that are provided to the chapter or to a support group. When an in-kind is made to a support group the chapter can provide a charitable donation letter. The support group can write a thank you showing their appreciation.

In-kind donations can be anything from a local bakery donating donuts and muffins for a support group, to an office supply store donating file folders and copy paper. Every donation helps a support group thrive and grow and will save the chapter’s overall budget. If you have a contact or connection that you think can make an in-kind donation, reach out and learn how you can work together. Never fear making a request for a donation, the worst someone can say is, “No, I am unable to help.” You then simply thank them and ask if there might be a better time to appeal for a contribution. This keeps the conversation going and provides you with information about your future relationship with the donor.
How to start off a meeting

The first few minutes really count.

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 scleroderma 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. That is boring and you will lose your membership fast! Have you ever been to a conference where the presenter had a long PowerPoint and all you did was glance ahead wishing they were at the last slide so you could go home? You don’t want your membership to have that kind of reaction. You want them to be excited about being at the meeting, they need to have a sense of purpose and an overall desire to achieve a goal.

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.

You want to make sure the members of the group are all actively participating in the discussion. If someone seems to be holding back, ask 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 has to participate when and if they are able to. Real empowerment will come from your ability to encourage members to move past their comfort zone.

Briefly remind the membership of the confidently rules, to turn their cell phones off or on mute and to respect each other when speaking. It is necessary to do this at every meeting. Introduce any new members to the group. Encourage positivity for the group and remind the members that scleroderma does not define them!
The awkward silence

**Silence does not mean failure.**

Silence may be golden when you are desiring a time out from the hectic pace that life can sometimes throw at us but as a support group leader, silence from your membership 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. It is fair to say, that some may want to grab the car keys and head for the parking lot, not looking back.

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 tool belt will make all the difference.

Most leaders might consider faking a sweet smile and moving forward with asking another question, selecting another topic or even answering the question as it applies to their own life. These are all excellent solutions and can be effective solutions. It is also perfectly acceptable to slowly pause, wait and allow the membership to think about the question or topic, and then to 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 achievements your group can make. 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.
Roles in the group

Identifying and managing personalities within the support group.

Research has shown that successful groups have one thing in common, they all have open dialogue and the membership respects each other. Members feel secure in their environment and they have built up a level of trust enabling them to speak freely to each other, knowing that confidentiality will be honored.

Support groups can experience difficulty and conflict when personality conflicts arise. Knowing common personality types in groups is helpful to leaders. It can benefit leaders to identify those in the group that fit into these categories and rather than fear them, use their qualities to provide growth for the group. Helping each member to contribute in constructive ways is the role of the support group leader. Working together as a group, conflicts can be overcome.

Support group leaders may notice that there are certain personality types that continue to surface in the group. This is common and very identifiable. Leaders may notice that a member likes to dominate conversation, always having answers or similar situations to relate to the group. This person may be driven to talk and overshare with the group. The focus may always be on this person in a negative way. As a leader, it will be your role to thoughtfully redirect this group and the attention to others in the group using open ended questions or by focusing on others in the group. If repeated focus continues to be on the frustrated person, you may have to privately have a conversation sharing your concerns that others in the group are able to share with equal timing being allowed. Explain what a valued member this person is and that you appreciate all he or she has to share but that it is important for everyone to feel valued.

The silent members are those who come to meetings and may be pleasant but do not openly share. It becomes easy to almost forget about their needs and to focus on those who are more vocal. As the leader, you may watch this person’s body language to determine their level of comfort within the group. Are certain topics causing distress? Does the body language provide any incite as to why the person is not opening up and sharing? Watch for any possible clues that might be picked up. Our bodies can tell a story about how we are feeling about the situation around us.

In every support group you will have someone who has a critical eye for everything that is discussed. This person may have a more negative personality and outlook on life. He or she may view life with a different lens and this type of personality can be toxic to a group if not managed properly. When working with an overly critical individual, presenting positive alternatives is a possible solution or even asking the person if they have ever considered a different solution is a good option.

Over sharers are those who want to tell the group about every detail in their scleroderma journey and their entire medical history. They will start from their birth and share their life story if you allow them to. From the first meeting to their last, you will know about every birth mark, every family member’s gall stone and even if their cat has been sick. They may appear to have no filter as to what they won’t tell the group. This person can be the hardest to problem solve for the group since he or she can scare newly diagnosed patients or family members who are looking for a positive resolve and searching for hope. As the support group leader you will need to consistently and lovingly redirect, redirect and redirect even more with this person or persons. Some groups can have more than one member who fits into this category. Since most members
Roles in the group continued

Identifying and managing personalities within the support group.

are dealing with a chronic illness and are coming to the support group to discuss health issues it will not be surprising to find that members want to discuss their own history. A good rule of thumb is to keep the agenda filled so that this is discouraged and unable to occur. Meetings where speakers are present, curriculum is available and goals are established in advance deter members from going off on personal story-telling that could involve their Aunt Milly’s recent colonoscopy, which then results in a thirty minute discussion of how poor Aunt Milly had to wait so long in the waiting room, had incredible gas after the procedure, was unable to meet her friends at Chili’s for dinner that evening as planned and then on top of all of that her cat got out and is now lost! While members of the group may have concern about Aunt Milly cat’s being missing, the relevance to scleroderma is lacking and especially for new members—could be the focal point for not returning next month. Most members are not looking for a coffee circle, they are looking for a scleroderma support group.

The last personality type that can be identified is the individual who knows everything and can problem solve everything for members in the group. As a leader this will be the easiest category to identify quickly. Normally within the first couple meetings this person will be out front and in the center of all of the discussion problem solving everything for everyone. There won’t be much that he or she can’t figure out or he or she has not experienced. Throw caution to the wind when allowing members in the group to accept medical advice. The role of the group is not to provide medical advice for each other but rather resources and support. Speakers can provide accurate information, what works for one scleroderma patient may not work for another. This is not a cookie cutter disease with treatment options that fit everyone. Reality is that patients need active advocates for themselves and they need to seek treatment plans based on their own needs.

Every support group will be unique and filled with members who come with distinctive life experiences, both personal and medical. These experiences will enrich the quality of the group and the role of the support group leader is to get to know the individuality of each member. Capitalize on their talents, skills, personality and gifts. Use their experiences to benefit the group in positive ways that will help them grow and achieve goals. Thinking creatively and with a different perspective than simply the fact that this is a support group where information is provide will open up a wealth of possibilities for your group and for support group leaders.
The keys to a successful meeting

Active listening, body language and the importance of eye contact.

Support group leaders will find that some meetings are more successful than others. Attendance for one meeting may be in double digits, while the next two meetings may see only two members in attendance leaving leadership feeling a sense of failure and questioning their purpose. No need to worry, this is the nature of support group leadership combined with managing a chronic illness and busy lifestyles. There is no reason to shake your head in frustration, rather celebrate the fact that you are touching the lives of those who are coming. You are making a significant difference in lives and they will be changed forever because of YOU! You are incredible and your role in their lives is something no one can undervalue. The Michigan Chapter appreciates you, the time you are giving and the fact that you are sharing your talents with those who are affected by scleroderma.

Here are some keys to making your support group meeting a success.

- Start each meeting on time.
- End each meeting on time.
- Allow each member time to share openly.
- Respect confidentiality of all members at all times.
- Follow the agenda and topics that have been established for the meeting.
- Resolve any conflicts immediately and notify the chapter.
- Read body language of members.
- Use active listening skills.
- Maintain good eye contact.
- Follow your gut instincts regarding the focus of the meeting.
The parking lot concept

Parking ideas, thoughts and concepts in the parking lot can make for more productive meetings.

During support group meetings you may find members diverting topics off to subjects that either have nothing to do with scleroderma or simply are not relevant to the focus and theme of the meeting. One easy way to handle this with grace and finesse is the, “parking lot” concept. This concept can be a rescue technique for leaders to pull out of your bag of tricks when you find meetings are trailing off into area of unchartered territory or into conversations that may not be as productive as you desire them to be. A good way to bring the discussion back where a support group leader would like it to be is to say, “Let’s place this discussion into the parking lot and we can circle back to it if we have time at the end of the meeting or at a future meeting if the members all agree it is worth discussing further. I know it is sounds promising but right now I would like to continue with the material we have planned for today.”

Using the parking lot concept will help ease the membership back into dialogue that is more appropriate, or scleroderma related, and bring the focus full circle exactly where you would like it to be. You can either keep track by writing these parking lot topics down on paper or by having one of the members keep a journal of reserved topics. These can be then be used to fill extra time at the end of meetings or during luncheon meetings when the emphasis is more social and less educational.
The never ending meeting

All good things must come to an end.

Support group leaders will find that meeting time will go by very quickly. It will be important to manage the schedule of the meetings well in order to end on time, something that leaders will desire to do in order to maintain the respect of the membership. Meetings that consistently start late and run over in time may have attendance issues.

Fifteen minutes before the closing of the meeting begin the wrap up of the meeting. Start by directing the membership with a summary statement as to the content of the meeting, what has been the main focus of the group or even asking for input from two or three members as to the highlights of the meeting.

One wrap up technique leaders can use is the check in technique. Going around to the membership, ask an open ended question to the membership about how each individual is feeling about his or her experience at the meeting. This mini evaluation can provide you with a quick assessment as to how your membership viewed the meeting. Leaders can also ask for feedback on what part of the meeting members found to be beneficial and what aspect of the meeting were found to be least valuable.

Leaders will want to end the meetings assured that all situations have been neutralized and all members feel positive about their experience within the group. If conflict had arisen during the meeting, make a point to ask those members involved to remain after the meeting to have a private discussion. Do not hold up the meeting to resolve.

Always end the meeting on a positive and uplifting note. Smile, be enthusiastic. Leaders may desire to use an app for a 5 or 10 minute Mindfulness Meditation to end the session on a relaxing note. Encourage members to journal, do a 10-10-10 routine of 10 minutes of journaling/pray/mediation a day, 10 minutes of some type of exercise, even chair exercise and 10 minutes of laughter. Giving members some form of an assignment is a great way to keep them engaged.
How to keep the conversation going after the meeting.

Maintaining a connect with membership 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 receive an updated health status. When membership is larger than five members a communication chain can be created to take the strain off of leadership and share the responsibility among all members. Each member then becomes responsible for connecting with only one person in between meetings and checking on health status, if the member requires a ride to future meetings or what resources the group can supply for the member.

Members like to feel they are valued and an important part of a group. Sharing the responsibility, checking in on each other and showing compassion to membership provides a stronger relationship with a true sense of worth. This in turn can help membership feel a sense of urgency for coming to meetings.
Addressing problem areas

What to do when something goes wrong.

Wherever two or more are gathered, you may have obstacles to overcome! This is just human nature and part of life and as a support group leader you role will be to facilitate a group that is cohesive and collaborative in nature. Leaders who have 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.

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 brainstorming.

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 has to 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 voluntarily and must be done only one a member feel safe and secure in the environment.

Most leaders will experience at least one or two members who enjoy being the focus of attention, the one person who makes the claims to have experienced everything medically and physically scleroderma related and the one who has all the right answers and enjoys monopolizing the conversation during the majority of the meeting. These individuals will be the ones who also like to over share 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 or member for sharing their opinion, thank them for wanting to provide information and resources and then gently ask other members what their experiences have been. Leaders can also use the parking lot technique when possible to table a topic or when conversations are heading in a direction that is not productive. Leaders want to provide positive feedback always to members for those who share and are able to contribute to open dialogue.
Addressing problem areas continues

What to do when something goes wrong.

Whenever possible leaders should establish group rules as to having one member speak at a time and even the length of share time per meeting per member. This can help with those members who want to come to a meeting and overshare every medical experience they have encountered, believing that it requires the attention of the group when in fact it may not.

From time to time groups may have a member with a strong or overpowering personality. For those members who are reserved and less willing to share or newly diagnosed, this can certainly be intimidating especially if one member is being graphic with medical details and causing alarm to others who are disease progressed. The overall goal of a support goal is to provide coping skills and teach problem solving skills, not to have anyone go home feeling overwhelm or panicked about the future. Encouraging a positive attitude, a mindfulness of not focusing on the negative and looking at the promising areas of life.
When you don’t have the answer

Finding the answers and information to member’s questions.

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. Relax! It is not a problem, the Michigan Chapter and the National Office are here to help and will be the ones you can come to when you need resources, answers and solutions. We both have your back and are just a phone call or email away every day of the week. Email is the easiest way to reach someone quickest for answers, especially the Michigan Chapter. Staff is available seven days a week and willing to provide you with resources. Patient services are our priority and we strive to meet their needs. Reach out and ask and if we are unable to locate resources or answer your question, we will reach out to the National Office and get their expertise. Never feel as if you are alone.

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. Remain confident with our answers will help membership feel safe and confident. Leaders can use these phases 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).

- I have wondered the same thing many times and would like to do some research about this, reach out to the Michigan Chapter and those who have the answers we are looking for and I am confident I can obtain the answer and email everyone by (provide a two week timeframe).
Avoiding burnout

Knowing your limitations and respecting yourself.

Burnout is something that all support group leaders need to be mindful of allowing to happen. Burnout is defined as an exhaustion mentally and physically, usually experienced with some form of fatigue. Support group leaders can suffer from burnout and not realize it at first, thinking it is scleroderma related symptoms for those who are also patients or caregivers or even job related stress.

Symptoms often associated with burnout:

- Lack of energy and motivation
- Difficulty with sleeping
- Undesirable attitude
- Frustrated easily and often for no reason
- Unable to focus or concentrate
- Sad and depressed
- Lack of enjoyment in activities
- Short temper
- Exhaustion
- Muscle fatigue

How to manage burnout:

- Set boundaries for yourself
- Know your limitations
- Learn to say no without accepting or placing guilt on yourself
- Don’t over schedule and overcommit
- Exercise
- Manage stress
- Take time away from the support group
- Make down time a daily ritual not a luxury in your life
- Stop trying to be a people pleaser
- Ask for help when you need it
- Accept help when it is offered
- Learn how to focus on not being a perfectionist
- Change unrealistic expectations
- Engage in daily positive and encouraging self-talk
Responsibilities of the leader

Communicating with Scleroderma Foundation Michigan Chapter.

Support group leaders are responsible to lead the support group meetings in a professional and confidential manner at the scheduled time. If for any reason leaders have to cancel a meeting, it is the responsibility of the leader to email the Michigan Chapter in advance of the cancellation to advise the staff so we are able to make the change on the chapter website. Remember, we advertise these meetings and the community refers to the website for accurate and updated information. It is important and a goal of the chapter to maintain accurate and updated information on our website and we appreciate our leader’s help in achieving that goal.

Yearly, the National Office requires every leader to submit an annual plan, detailing dates of meetings, location, and topics. This plan will also include any speaker’s names. This requires advance planning. The chapter will work with leaders and will create all the topic materials and annual plans for leaders. Leaders will be required to sign off on the plans prior to them being submitted to the National Office to assure accuracy. This is a compliancy issue and for this reason, when leaders receive this email the chapter asks that leaders make this a priority to responding and approving the annual plan. Make correction, changes or deletions immediately and return to the chapter within two days.

Leaders are required to maintain accurate attendance records for all meetings. This is a compliancy issue and a legal issue. The chapter is legally obligated and responsible for every person that attends a meeting. We need accurate attendance records. These can be emailed or mailed via standard United Stated postal mail services to the chapter. If you are using the post office to mail them, please retain a copy for your records in case they get lost.

If leaders need additional supplies or items for the group email is the best way to request these items. Email staff and if the items are available, they will be mailed or available for pick up within one business day. If the item or items are not available, it may take additional days for purchasing and then shipping. The chapter does not expect leaders to have out of pocket expenses for support group costs.

The office number is (248) 595-8526 or email staff at ldyas@scleroderma-mi.org. Scleroderma Foundation Michigan Chapter – 23999 Telegraph- Southfield, MI 48033
Scleroderma related topics

Discussion topics for consideration in support groups.

A good meeting begins with a topic that will be interesting and keep membership engaged. Not every topic will be of interested to every member in the group. Some members will enjoy one meeting more than others. This is just the nature of a support group. This is not a reflection of leadership. Do not take it personally, it can cause burnout if leaders try to please membership every meeting. It is just not possible since membership will be at different disease stages.

Possible topics for meetings

- Scleroderma 101 for the newly diagnosed patient
- PAH and how it can effect scleroderma
- How to ask for help
- Coping techniques
- Disability and what to do when they tell you no
- How to manage wound care properly
- Dental treatments
- Accepting the loss and grief and learning to turn it into something positive
- Mindfulness meditation and how to incorporate it into your daily life
- Alternative techniques for pain management
- How to organize your medical records
- A disease does not define you
- The hospital, the medical system and learning how to figure it all out
- Music and art therapy and the benefits of using them
- How to use the Internet correctly to find resources
- Making your emotions work for you, not against you
- Scleroderma and the work force
- Sleeping and scleroderma
- Exercise and the positive impact it can have on your life
- It is time to leave the work force: Accepting the decision and learning to face the challenge with a positive attitude
- Challenges with your caregiver
- Learning to communicate effectively with the world around you
- Intimacy and a chronic disease
- Fatigue and overcoming it before it overcomes me
- Talking to family about scleroderma
- Lung involvement and scleroderma
- Keeping your kidneys happy means the rest of your organs are happy
- Transplants and knowing when the time is right
- Clinical trials and figuring out if they are safe or right for you
- Resources and scleroderma
- Finding the new normal in your life
Opening ended questions

The many benefits of open ended questions.

Leaders will find that when effectively conducting support group meetings, the use of open-ended questions can help the flow of conversation. Open-ended questions are beneficial in obtaining specific information about a person or a situation. They can be helpful in determining in depth facts and details. They are used to keep conversations flowing and aiding the membership in actively participating.

Examples of open ended questions

- What scleroderma symptom do you have the hardest time managing?
- What is your fondest pre-scleroderma memory?
- Where do you see yourself in one year?
- What one goal do you have for yourself for 20XX?
- What one thing can you change today to lead a more positive life?
- Who is the one person in your life that you can be honest with and what makes this person someone you trust?
- What is your favorite hobby?
- What is your best scleroderma tip?
- What is your favorite scleroderma nutritionally sound recipe?
- If you met a newly diagnosed patient today, what would you tell them about scleroderma?
- If you could change one thing about the way you reacted to your diagnosis, what would you do?
- How has intimacy changed since your diagnosis?

Leaders will see that open-ended questions will require longer and more in depth answers from membership. This will spark conversations providing the opportunity for membership to offer tips, solutions and help the membership problem solve situations. Resources will be provided and bonding begins to takes place. When correctly executed, open ended questions can be an effective tool to be used at meetings to keep building the engagement rate.
Expressing emotions

Effectively dealing with emotions during a support group meeting.

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 scleroderma and the often overlapping diseases. During support group meetings leaders may have members of the group that become overwhelmed with emotion, everything from sadness, grief, anger, to 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 the Michigan Chapter. If you are a scleroderma patient or a caregiver or you have lost a loved one to scleroderma 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 membership 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, contact the chapter and speak to staff for direction in this area immediately. Do not wait, we are here to help.

When someone in the group is displaying emotion 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, leaders can ask an open ended question to the member, reframe the question that was asked that directly affected the member or even say, “I can see how that topic has caused you significant discomfort. 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 of the member and allows him or her the opportunity to compose.
Expressing emotions continued

Effectively dealing with emotions during a support group meeting.

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 the chapter and we will address the issue.

Using good active 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, you do not. 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.

If a member is having difficulty breathing during a meeting do not hesitate to contact medical personnel.
When to refer

Knowing when to refer someone to the chapter or to a professional.

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 Michigan Chapter be contacted so the Chapter can intervene and 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 scleroderma and move toward managing symptoms. Leaders should be looking for continued patterns of severe or traumatic displays of stressful symptoms.

The Chapter will work with the member to obtain the needed referral after determining if the member has had an extended period of depression, usually over 45 days with no relief of symptoms and the symptoms are interfering with the normal day to day activities of life.

Symptoms of clinical or major depression include the following:

- Difficulty with sleep or change in sleep patterns
- Anxiety
- Guilt
- Loss of interests in areas that previous were of interest
- Mood swings
- Sadness and overall feeling of hopelessness
- Fatigue
- Changes in eating habits
- Frustration
- Irritability
- Anger
- Social isolation
- Crying without reason or explanation
- Inability to focus
- Weight loss or weight gain
- Thoughts of suicide
- Repeatedly going over thoughts in your head

As a support group leader your role is facilitate the referral process of the member to the Michigan Chapter only. Leaders are not responsible for making referrals to mental health professionals.
I am not a doctor

Not giving medical advice is key in a support group.

Two key elements of running a support group are confidentiality and assuring that no one is offering medical advice to the membership or endorsing products. For obvious legal reasons, leaders and other members of the group are asked to not offer each other medical advice to each other. It is acceptable to say, “As a scleroderma patient this treatment has worked for me but I would recommend that you first check with your physician who is treating you and ask if this is something that might work for you since every case is so unique.” This will prevent any misunderstandings that any one treatment is the answer for every patient.

Support group leaders should also be cautioned to not bring any speaker to a group that is wanting to have the Chapter endorse a product, clinical trial or treatment that has not been approved by the National Office. The Chapter is legally responsible and is unable to authorize this type of behavior. The Chapter must maintain our Charter with the National Office and has to be in compliance at all times, meaning leaders who endorse, promote or bring speakers that have not been approved to a support group will be removed from their volunteer position.

This compliancy rule is for the protection of not only the Chapter but also all leaders. If leaders would like to have a speakers bring a product line to a meeting that could benefit the scleroderma community, email the contact information and all pertinent information regarding the product to Chapter staff in advance of the meeting so that staff can review the materials, contact the requested speaker and seek the approval of the National Office. The Chapter will make every effort to gain approval for the speaker and as long as the product line is seen as one that is beneficial for member, approval should be granted. Approval can take up to 45 days so it is advisable to plan ahead.
Stepping down

Steps to close your support group and knowing when the time is right to step down as a leader.

Support group leaders will find one day it is time to move on and step down from the position of leadership. This will be a difficult and possibly overwhelming decision but a necessary one. The decision can be made for many different reasons. For some who are scleroderma patients, the reason to step down might be due to health reasons. For a caregiver it might be the increased demands of a loved one. For someone who has lost a loved one to scleroderma, it might just be time for a leader to begin to focus on a new project. Whatever the reason a leader has for stepping down from the support group, here are some things to consider.

1. Carefully consider whether this is the right time for you to step down.
2. Ask yourself if you no longer enjoy leading.
3. Are you no longer motivated to attend the meetings?
4. Are the meetings requiring too much of your time?
5. Do you still get pleasure from leading?
6. Are there activities in your life that you are neglecting because of your leadership position?
7. Is your health declining or at risk of failing because of your leadership position?
8. Write down the benefits of staying on in a leadership position, versus the benefits of stepping down as a leader and evaluate both lists to determine which one has more weight.
9. Are there any alternative choices you could make such as getting a co-leader if you do not already have one? (Contact the Chapter for assistance in doing this.)
10. Should you take a short break from leadership or is it better for you to step down completely?
11. If you step down as the leader, will you still remain as one of the members?
12. Is there another member in the group who might be interested in serving as the leader?

Leaders will need to work with the Michigan Chapter once the decision has been made to step down. The Chapter will assist in locating another leader or in closing the group.
Check list

Outline for support group leaders to follow

Facilitating A Support Group

Opening the meeting
__Prepared yourself
__Prepared 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
__Close the meeting by:
  • Making a summary statement
  • Asking for comments/questions
  • Reminding members of next meeting
  • Requesting volunteers, if necessary
  • Giving a final greeting
  • Making final notes

Don't cry over the past, it's gone.
Don't stress about the future, it hasn't arrived.
Live in the present and make it beautiful.
Check list continued

Outline for support group leaders to follow

Additional suggestions

__You have looked over the tips on keeping your support group going.
__You know when to use empathy and compassion.
__You know when to use assertive caring.
__You know the four steps to assertive caring:
  • Showing that you understand the member's dilemma
  • Setting limits
  • Suggesting alternatives
  • Getting the member's agreement on the alternative
Support group facilitator agreement

Form must be completed and return to SFMC. (Return only signature page)

Responsibilities of the Scleroderma Foundation include:
- Provide training and/or training materials for support group facilitators.
- Provide brochures and other literature.
- Advertise locations and times of meetings in newsletter and online.
- Visit the support group when necessary.
- Assist facilitator with finding speakers, volunteers and venues for meetings.
- Be available as needed to respond to questions and concerns that may arise.

Responsibilities as a Support Group Facilitator:
- Participate in trainings offered by the Chapter or National Office.
- Follow all Scleroderma Foundation policies.
- Have sign-in sheets and materials available at each meeting.
- Maintain a sharing and supportive group environment.
- Inform Chapter or National Office in advance regarding any conflict of interest.
- Work closely with the Chapter or National Office.
- Provide current updates on meeting times, location, speakers, etc.
- Encourage members to obtain medical information from medical professionals.
- Preserve the importance of confidentiality during and after meetings.
- Maintain a nondenominational group open to anyone regardless of religious beliefs.

Restrictions for Support Group Leaders:
- Leaders are not permitted to maintain a website for the support group or a site that advertises Chapter or National activities outside of the website maintained by the Foundation.
- Leaders are not permitted to raise or maintain funds without the explicit approval of the Chapter or the National Office. Failure to do this may jeopardize the Foundation’s tax-exempt status with the U.S. Internal Revenue Service and state tax authorities. The Michigan Chapter will be out of compliance if leader is found to be engaging in this type of activity.
- Leaders should never promote or endorse treatment options.
Support group leaders are not permitted to solicit or allow others to solicit group members.

The Michigan Chapter is committed to working with support group leaders to make your leadership experience a positive one. With open communication, total transparency and by maintaining continued compliancy, we are all assured the membership will benefit from an educational, informative, safe and secure environment. We thank you in advance for your dedication to promoting the three-fold mission of Scleroderma Foundation of support, education and research. There is no cure for scleroderma but together, we CAN, change that!

Signature required:

I ________________________, have read and understand the material outlined in the Support Group Leader Manual and in this volunteer agreement.

Signed: ____________________________________________________________
Support group leader signature

Printed name: _________________________________________________________
Support group leader printed name

Date __________________________

Signed: _____________________________________________________________
Chapter representative signature

Printed name: _________________________________________________________
Chapter representative printed name

Date __________________________
Support group leader application

Form must be completed and return to SFMC.

Name: ______________________________________________________________________________________

Address: _____________________________________________________________________________________

City: _________________________________________________________________________________________

State: _________________________ Zip: ___________________________

Telephone: __________________________________________________________________________________

Work: _______________________________________________________________________________________

Email: ______________________________________________________________________________________

How did you hear about the Scleroderma Foundation? ________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

Are you or have you ever been a health professional? ________________________________________________

_____________________________________________________________________________________________

If yes, what type? __________________________________________________________

Please list any relevant education or course work. ___________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

What is your present profession/major activity? ______________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________
Leader application continued

Form must be completed and return to SFMC.

What type of volunteer activities have you been involved in? ________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

If you were to state one philosophy by which you live, what would it be? ______________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Briefly describe why you would like to be a support group leader: ______________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Briefly describe your thoughts as to what an ideal support group meeting would be: ___________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Thank you for your time and support!
Public disclosure form

Form must be completed and return to SFMC.

The following information will be made public and listed on Scleroderma Foundation’s national website, as well as, the Michigan Chapter’s website. Please make sure you print legibly and that the information is accurate.

Support Group Leader First Name: __________________________________________________________

Support Group Leader Last Name: __________________________________________________________

Best Phone Number for Contact: __________________________________________________________

Email: ________________________________________________________________________________

Address: ______________________________________________________________________________

City: _________________________________________________________________________________

State: ________________________________________________________________________________

Zip: __________________________________________________________________________________

Signature: _____________________________________________________________________________

Date: ________________________________

Please return this form to the Scleroderma Foundation Michigan Chapter:
23999 Telegraph
Southfield, MI 48033
(248) 595-8526
ldyas@scleroderma-mi.org