

**LUPUS**  
**ONTARIO**  
Life Without Lupus



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***Support Group Manual***

***Revised September 2020***

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## Guidelines

The following guidelines not only help to create a safe place for a productive and enjoyable meeting, but they help to eliminate the kind of habits that quickly dissolve a group. We recommend that you review these guidelines at the beginning of every meeting.

- Our support group focuses on problems and feelings in regard to a diagnosis of lupus. We understand that we are all here to better understand our own feelings about lupus and to support each other as we learn to continue to have fulfilling lives.
- Confidentiality is a top priority. Nothing said in this room will leave this room, nor will people be pressed to share more information than they are comfortable with here or after the meeting.
- We provide support by listening carefully, sharing our own stories, and relating our own problem-solving experiences. We are sensitive to each person's stage in the acceptance process.
- We each speak from our own experiences and respect the experiences of others.
- We are supportive rather than confrontational. Anyone who is uncomfortable may make this known to the facilitator. Everyone will be given the chance to speak. In addition, each person is asked to be conscious of the amount of time they are using to allow others to speak. No one person is permitted to monopolize the conversation.
- We are considerate of the group and do not have side discussions. Each person's remarks are important to the whole group.
- Speak from your own experience; use the word "I" not "you" when speaking to other members.
- Stay in the here and now; share what you are dealing with today or this week. Bring past history to the present.
- Share feelings about 'experience, strength and hope'.
- Feelings are neither right nor wrong. We accept one another unconditionally. No shaming or blaming.
- No fixing – avoid offering suggestions or methods for fixing another person's problems, allowing individuals to experience their pain without your interference. Each member grows as he/she expresses him/herself and listens to others. No discussion of what someone else has shared. No advice.
- In absolutely no circumstances are you allowed to conduct a meeting in private residences, including, meeting rooms (i.e. community room).

## **Facilitator Guidelines**

The facilitator will intervene when the guidelines are not followed and redirect the discussion.

Our main concern is to create a supportive atmosphere for all group participants. Thank you for helping to support the family feeling we have at our support meetings.

**Equal time:** when running a group, be sure that each person has a chance to speak. While there may certainly be times when a member needs extra attention, it's important to prevent members from continuously dominating the conversation. To ensure that everyone gets equal time, we recommend that you use a timer to keep members on track. Do not allow cross talk, criticism and advice giving, or 'fixing' of anyone.

**Positive focus:** put the attention on what works. Look for and acknowledge a member's strengths. Keep complaining and whining to a minimum – one minute or less (we all need to do it sometimes).

**Honor the group:** check in regularly to be sure that all members are satisfied with how the meetings are run. Be willing to tell the truth gracefully. You might check in at the end of each meeting – or, every other meeting.

**Time limited sharing:** please raise your hand or type in the chat section so the facilitator knows you wish to speak before sharing and limit your sharing to 3 – 5 minutes allowing everyone in the group to share once before you share again. For maximum benefit everyone is encouraged to share. No one should feel pressured to share but may 'pass'. The group should keep to the agreed upon meeting times.

Read the Confidentiality Policy to new members and have new members sign the Confidentiality Agreement once per calendar year. If is an online group meeting, please have them sign the form and email it to the facilitator or to Lupus Ontario.

- ***In absolutely no circumstances are you allowed to conduct a meeting in private residences, including, meeting rooms (i.e. community room within building).***
- ***Please keep a copy of this document on the table or in visible reach for the regular group members and the new members.***

### **What is a Facilitator?**

A facilitator is a person who assists a group with accomplishing its goals for the meeting. For example, if a group has decided to discuss the fear many have with lupus, then a facilitator will assist group members with doing this. He/she can use a variety of tools and techniques suitable for the group to help his/her with this job.

As a general rule, a facilitator does not control the group. This is, the facilitator does not decide the content of the meeting, assume the role of expert, make the decisions, or shoulder the burden of failure. Instead, the facilitators way of working with the group guarantees that all members take responsibility and share in the tasks. In fact, the facilitator is not the only one who can facilitate a meeting. When the facilitator is

doing the job well, it works in a way that allows all members to use facilitation skills.

In some groups, facilitators who are also group members, participate in decision-making, exercises, and all other aspects of the group. Your group should discuss how much the facilitator will be a participant in the group.

## **The Role of a Facilitator**

The role of the facilitator is to get the group to respond to its own thing, knowing when to turn the questions back to the group, really understanding the role to keep the group going – not to go overboard, not to be therapist, not to try to do everything.

This is good advice for anyone beginning to learn facilitation skills and for anyone who has been facilitating for some time.

As you facilitate a group you must be aware of the meeting in two ways. One is the content of the meeting; the theme or subject the group is dealing with. The other is what is called the process, or how the group members interact or communicate with each other.

An example of process and content used at a Network facilitator training session is explained below:

Someone is discussing upcoming tests, and her fear associated with this. Others are initially quiet, or reassuring. Then two members begin to dominate with anger at the medical system. This shifts to wide involvement among members of the group.

The content of the discussion is tests, reassurance, and the medical system. Process of the discussion was empathy, contagion of fear, hunting that fear through re-assurance, expressing fear through anger, diverting from original focus.

An awareness of the meeting in these two areas requires that a facilitator take on certain roles. I have included a list of some of these roles. This list is by no means complete and nor does it mean that a facilitator will do everything on this list. Lists are helpful for those of us who just need to get an idea of what it is we are supposed to do.

1. Plan the meeting and prepare the agenda. If the agenda was discussed at the prior meeting, then the task is easy. If there is no pre-planned agenda, the facilitator assists the group with developing one.
2. Follow the agenda and keep the discussion focused. If the group sways off topic, then the facilitator draws attention to this and asks the group if they would like to continue with this discussion or get back to the topic of discussion.
3. Help the group make agreements or guidelines. Many groups usually make agreements during the first few meetings. However, guidelines can be changed, added to, or altered at any time. Making group agreements can be an ongoing process.
4. Make sure group structure and guidelines are followed. Once the group has

decided on a structure, agreements and guidelines, then the facilitator ensures members are upholding their agreements.

5. Ensure that everyone understands what the group is discussing and why the discussion is taking place. This clarity is especially important at the beginning of all groups and gets things started on the right track.
6. Facilitate discussion through questioning. Stimulating discussion and encouraging communication is critical for any group.
7. Ensure that everyone has an opportunity to participate in the discussion equally. This means checking in with silent members, ensuring some members are not dominating the group, or using exercises like 'rounds' to encourage participation.
8. Encourage the group to take responsibility for the meetings.
9. Convey that everyone is responsible for the group, what happens in the group and should also share in facilitating it.
10. Encourage members to share experiences.
11. Encourage members to support one another.
12. Encourage members to share resources.
13. Help move the group through difficult experiences.
14. Give every member a chance to voice their own opinion without interruption.

### **Tips to Avoid Controlling the Group:**

When eyes seem to focus on you a lot of the time, and the majority of the conversation is directed to you, there is a problem. Three easy steps can help you from setting this situation up in a group:

1. Always wait before responding so there is time for group members to react. If support is the response needed, sometimes members need a bit of time before they can offer it.
2. If no response is forthcoming, attempt to draw out by asking questions that cannot be answered 'yes' or 'no' such as what he/she is needing from others. Or you can try linking their experience to others' in the group. I.e.) "Mary, didn't you have a similar experience..."
3. If no support is forthcoming you need to provide it. Support will soon follow from other members.

## **Roles in a Support Group**

### **Facilitator:**

At each meeting an individual is responsible for;

- a) Starting and ending the meeting on time.
- b) Keeping the conversation going.
- c) Ensuring no one person monopolizes conversation.
- d) Ensure everyone who wants to, has a chance to talk.
- e) Consider an online meeting using the Lupus Ontario zoom account during bad weather or winter months. Check with your group to see if they would like this option. Contact the office if you need a zoom meeting set up.

### **Greeter:**

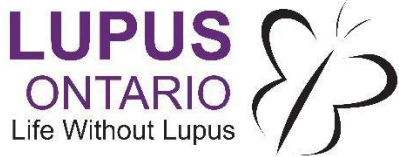
An individual who welcomes members. This person meets new members at the door and helps them feel part of the group.

### **Phone/Email Contact:**

A person who calls or emails members to remind them of the meeting. The phone/email contact may be responsible for speaking to potential new members and providing them with information about the group.

### **Secretary:**

Some groups take notes. This information should only be about topics of discussion or group activities. A group never writes down personal or confidential information shared in the group.



**HARASSMENT POLICY ACKNOWLEDGEMENT**

I, the undersigned, \_\_\_\_\_  
(Name of Facilitator, printed)

acknowledge that I have received the documents titled “*Attendant Policy*”, “*Harassment Policy*”, “*Confidentiality Policy*”, “*Illegal Activity Policy*”, and “*Anti-Discrimination Policy*” for Lupus Ontario.

By virtue of my signature below, I confirm that I have read, understood and agree that I will be held responsible for the information contained in these policies.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

-----

-----

Address

\_\_\_\_\_  
Witness



## **Support Group**

### **Harassment Policy**

#### **POLICY:**

The \_\_\_\_\_ support group is committed to the establishment of an environment in which all persons with lupus or their support network have the opportunity to participate and contribute to their maximum potential.

Lupus Ontario and its support groups do not tolerate any form of harassment and undertake to protect all persons with lupus and their support network from harassment by support group members, staff/volunteers of Lupus Ontario, with whom they may have contact during the course of their involvement.

#### **DEFINITION OF HARASSMENT:**

Harassment takes many forms, but can generally be defined as behavior including comments and/or conduct which is insulting, intimidating, humiliating, hurtful, malicious, degrading or otherwise offensive to an individual or groups of individuals or which creates an uncomfortable environment.

#### **Harassment may include:**

- Written or verbal abuse or threats.
- Sexually oriented comments.
- Racial or ethnic slurs.
- Ought to be known to be unwelcome or unwelcome remarks, jokes, innuendos, or taunting about a person's body, attire, age, marital status, ethnic or racial origin, religion, etc.
- Displaying of sexually explicit, racist or other offensive or derogatory material
- Sexual, racial, ethnic or religious graffiti.
- Practical jokes which cause awkwardness or embarrassment, endanger an individual's safety, or negatively impact participation in the support group, or lower self-esteem in others.
- Ought to be known to be unwelcome or unwelcome sexual remarks, invitations or requests whether indirect or explicit, or intimidation.
- Leering (suggestive staring), or other obscene or offensive gestures.
- Condescension, paternalism or patronizing behaviors which undermines self- respect or adversely affects work performance or working conditions.
- Physical contact such as touching, kissing, patting, pinching etc. that would reasonably be considered offensive.
- Vandalism.
- Physical assault.

Failure on the part of the support group to comply with this policy may result in dissolution of the support group.

## Support Group

### Confidentiality Policy

#### **POLICY:**

Confidential information is any fact about another person, which if shared with others could pose distress or hardship to that person or their family. No one from the group, including the Facilitator, shall recognize, acknowledge or introduce women/men they casually run into between meetings as either being from the group or is living with lupus.

During the course of this support group meeting you will become aware of participants names and personal information. As a member of this group it is your responsibility to ensure that this information is not shared outside of the group meeting or with anyone who is not a member of this support group.

#### **A BREACH IN CONFIDENTIALITY**

- Takes away the person's right to the privacy that was agreed to.
- Gives group members the message that the group may not be a safe place in which to learn and to share experiences and information.
- Breaks the circle of group trust and loyalty and keeps discussion at a less meaningful and superficial level.
- Can have a negative long-term impact on important things such as family relationships, employment, insurance benefits etc.

#### **DISCUSSING CONFIDENTIALITY GUIDELINES WITH YOUR GROUP**

- Not everyone in your group will have the same understanding of Confidentiality as it applies to the group.
- Have a group discussion concerning Confidentiality at least once a year to review and reinforce Guidelines.
- This will also encourage and promote trust in the group.
- Have each person share what Group Confidentiality means to them and give an example of this.
- Capture what you can on paper to share with new members during the next 12 months.

Failure to comply with this confidentiality policy may result in an individual being asked to leave the group.

I \_\_\_\_\_ agree to the conditions of the above confidentiality policy and will, to the best of my ability keep names and personal information about group members in strictest confidence.

DATE \_\_\_\_\_

## **What Are Support Groups?**

Support groups have a lot of names. Sometimes they are called self- help groups, mutual aid groups, or just plain old 'support groups'.

They usually arise where people have not found the information or support they need when they are going through a hard time. What makes them unique is that they are controlled by group members and not outside 'experts'.

Depending on the group members and their goals, support groups can focus on emotional support, practical suggestions, health education, information sharing, and/or advocacy.

The strength of a support group is not in helping group members, but in empowering them to help themselves. It is going through our own struggles and finding our own way, with the support of our peers, people who have had a similar experience.

*"A support group member spent one of its meetings talking about what the group meant to them. One woman talked about how scared she was starting new medications and doctors' appointments, about all the fears and questions she had had. Then she talked about, realizing in the group, that she's not alone, feeling other people reaching out, sharing concerns, answering questions...and about how the group supported her through a really rough time."*

### **Beliefs underlying support:**

- Sharing our stories can help us heal and help others to heal
- People can learn about themselves and their reality in a group setting
- Discovering what we have in common helps us
- Both giving and receiving support helps us
- Groups help us explore the links between our personal struggles – what's inside us – and social structures – our environment, our society, and the world outside us.

### **Support Groups Are:**

- Voluntary
- Run by and for participants
- Co-operative
- Welcoming to the diversity of those living with Lupus

### **Ideally, all members of Support Groups:**

- Respect each other
- Share power, responsibility, and decision making and planning
- Have equal opportunities to participate and influence the group
- Encourage people to use their own resources
- Reinforce successes and positive change
- Validate feelings, experiences, and strengths

- Are free to draw on the strength of the group when needed, and to extend strength to others whenever possible
- Are optimistic about the possibilities of change and growth.

## **Benefits of Support Groups:**

People who have taken part in support groups say that because of this they:

- Know more about lupus are more able to cope with the illness and with medical procedures.
- Have a better perspective on the illness.
- Are more aware of themselves and their needs.
- Are more able to talk about lupus and are more able to talk generally, with family and friends.
- Feel better about themselves.
- Are less isolated.
- Are more socially active.

*“The beauty of a support group is that you don’t have to explain anything”, says one woman. Many people with lupus feel they must shield family and friends from what they’re going through, how scared or angry they might be. In a support group, ‘you don’t have to protect anyone. They’re there to support you.’”*

In Support Groups, many find they can tell their ‘whole story’ in an honest and direct way. Other people help them clarify their problems and think through solutions. They find out about lupus resources like books, organizations, tapes etc. they have a chance to see how others have coped with similar problems, and gain inspiration. They become a caring and sharing community.

Important notes about the benefits of support groups;

Everyone comes with a different idea about what they will get out of the group, what benefits it will bring. It is important to talk about expectations and clarify as a group the purpose of coming together.

The good things about Support Groups, the true benefits, do not just ‘happen’. A group becomes what its members make it. Each of the members is responsible for the group’s successes and for overcoming its problems.

## **Understanding Support As Per The Self Help Model**

### **Support is Not:**

1. **Advising**– telling someone what to do, how to do it and what they should have done instead. For example, you should have left your partner last year when you had the chance because you will never be able to leave now. Sometimes advising can be based on what has been helpful for yourself and/or what has been helpful for friends. However, this may not be possible or helpful for a group member. You need to explore options with members, let them be in control of which options they choose if any, and provide them with the support they need to carry out their plans.

2. **Assuring** – telling another group member that there is nothing to worry about and that everything will be O.K. Sometimes this meets our own desire for everything to be O.K. We know that what we want to do is to offer some comfort. However, you are not a mind reader and cannot control the future. The best thing to do is to validate his/her feelings and his/her reality as he/she expresses them.
3. **Assessing** – telling a group member about him/her self, his/her situation, and what will happen with her/him. What you are doing is evaluating and judging this person. This may sound
  - a. like; “you are in denial because you cannot face up to the fact that you have lupus, you need to face this and get on with the rest of your life or you will never get well.” Although you think you are helping this group member to deal with lupus by
  - b. helping them face the reality, you may be pushing them away from the support group. Assessing does not allow him/her to cope the way he/she needs to.
4. **Fixing and Rescuing** – this means finding solutions to the group members problems and/or even doing the work to fix these problems. We may be trying to make things better and easier for them. Again, this is taking control of their life away from them. We all know that people can and will take care of themselves. Again, the best thing to do is to listen and be there with them. Help the group member to explore what is happening. You cannot explore this with them if you change it or fix it.

### **Support is:**

1. **Active Listening** – this is paying full attention to another person as they communicate and express themselves. It's more than just listening to the words. It is 'being there' with him/her. Involve yourself in what this group member is saying; try to understand their reality the way he/she means it. Watch body language, gestures, facial expressions, and changes in their emotions. To help improve your active listening skills, it is important to not be thinking about how you will respond to her while he/she is talking. Active listening depends on the Listener giving the Speaker his/her full attention.
2. **Asking** them what they need from other group members and being respectful of that. Never assume you know what they need.
3. **Validating** their feelings, strengths, and experiences.
4. **Giving them space** to express feelings fully and freely.
5. **Being yourself** – not pretending to be someone you are not.

## **Support and Cultural Sensitivity:**

Some people say that differences between group members do not matter, especially if they all have the same illness (lupus). But often differences do matter. For instance, cultural groups each have their own:

- Understanding and beliefs about illness, why disease happens, how people who are ill are supposed to behave, how significant certain physical symptoms are and what they mean.
- Ideas about how to be healthy and what to do about disease, whose advice and treatment to seek, who to make decisions with and how to make those decisions.
- Attitudes about the body.
- Ways of communicating, including standards about which issues are acceptable and unacceptable to talk about, and who it may be OK or not OK to talk about with them.
- Ways of responding to loss, ways of grieving.
- Support systems and networks and way of caring where responsibilities are often defined in terms of family and community position.

If we are supporting a group member, we are supporting 'all' of him/her. Although their experience differs from yours, you shall accept and support their ways of experiences. We are also trying to understand and support the group members in the ways they experience being different from ours.

Cultural Sensitivity "means not making assumptions about the meaning of what someone says or does. It means being aware of assumptions and judgments we are making, and treating others with the same kind of respect one expects to be treated with."

## **Starting A Group In Your Community**

(For those of you who already facilitate a group. Please read on, you may find some useful hints and helpful tips).

Lupus support groups have started and developed in many different ways.

There is not one 'right path' to take. The ways groups start and develop are as different as the group members involved in them.

One piece of advice that comes from many, many people who have started a support group: "Don't do it alone!" if you decide to take some steps towards starting a support group for people with lupus, consider beginning with creating an 'organizing group'.

Members of the organizing group plan and arrange. They identify the steps that will help the group achieve its goals. They decide as a group how the steps can be taken, and who will do what tasks by when. Then they carry out the tasks. The organizing group can be as few as two people, but it helps to have 4 or 5.

Holding a Community Meeting, and doing some networking before the meeting, connecting with other health and wellness interests in your community are tasks that can be taken on by the organizing group.

Make sure you get a mailing address, phone number and email address from people who call, so you can send them information about upcoming meetings and events. Let them know that the mailing list is confidential and will only be used by your group. Ask them to call Lupus Ontario for more information.

## **Building a Framework**

The framework of 'structure' that a group needs depends on the size of the group, the kind and number of activities members want to take on, the amount of support they can gather, and their resources, financial and in terms of energy.

If your group is just starting and the single activity you want to do is a support group, you don't need much of a framework at all. Often in groups like this, people might decide at each meeting who will take care of what for the next meeting.

You met as a group for the first couple of times, and then you were asking, what are we going to do? How should we keep it going? But sometimes all it needs is actually meeting as a group and talking...you know how people are; you don't have to have any major plan. It just happens. Often it does 'just happen' – this is one of the great things about support groups. But if your group wants to take on a number of different activities, more of a framework might help you accomplish your task. Please contact Lupus Ontario if you wish to take on more activities and speak with the Lupus Ontario about facilitating a peer support group.

## **USEFUL TOOLS - Guidelines and Agreements**

Guidelines are important for all groups. Members need to have a clear understanding of the group's 'norms', how the group behaves, in order to know what to expect from the group. All members should have an opportunity to discuss any guidelines they may need to feel comfortable in a group. For example, a woman who has experienced a hearing loss in one ear may ask that members speak clearly and directly to her. A man may have vision loss and therefore requires handouts to be in minimum 14 and preferably 16 point font size or larger. Another member may need to request the support of another member if he/she is upset and needs to leave the room. Guidelines are usually made at the beginning of group but can also be made at any time during a group's span.

Most groups make verbal agreements with each other. It is a good idea to keep a record of agreed on group guidelines for new members. (Please provide a copy of all group guidelines if you make any changes that differ from this Support Group Manual to Lupus Ontario info@lupusontario.org).

### **Examples of Guidelines Used in Groups:**

Meet once a month for two hours (7-9) every second Monday of every month. Sometimes a group will meet every second month due to geography or seasonal weather and transportation issues.

Room will be available for ½ hour after group has formally ended for socializing time.

This group will begin on time and end on time. We ask that all members arrive on time. Start and stop time will depend on the members and on the contract Lupus Ontario has with the company the space is rented from.

To keep this a comfortable space for all, all members have agreed to be open to being educated and challenged around racism, homophobia, etc.

Members are supported in discussing issues at their own pace.

If someone wants to leave the group or come for just one meeting, this is their choice, but we ask that he/she let other members know so we are able to say good – bye.

No smoking in the room, there will be a break.

All discussions outside group, about the group, are brought back to the group. This guideline encourages members to resolve these issues in group. Chances are other members may feel the same way or have the same concerns.

When a member is talking, this member has the floor and we give this person the space he/she needs to express themselves.

We will not judge, ridicule, or criticize, or interrupt other members.

If you need to leave the room while the meeting is in session, just let the group members know you are leaving. If you want someone to go with you, ask.

## **Check-In**

Check-in is a tool many groups use at the beginning of their meetings to allow everyone to get acquainted and to get a sense of what to expect from each other. After the agenda has been reviewed, each member has an opportunity to 'check-in' with the group. The time is hers to use as she wants. For example, she can let the group know how she is feeling today, inform members of some important events in her life, let members know what she needs today, and request additional time later in the meeting to discuss a particular issue or concern.

Check-in is just that and therefore is usually brief. Your group may want to agree on a time limit for check-in because sometimes it can take up all the group time. If your group has decided to organize its meetings this way; then all members should be fine with this arrangement. However, if your group has agreed on an agenda for the meeting that gets ignored, many members may become frustrated and not want to return for the next meeting.

## **Check-out**

All meetings should provide an opportunity for the group to conclude a meeting. Like check-in, each member will be given time to close.

The facilitator can use check-out for a variety of reasons. He/she may summarize the meeting, discuss what he/she would like to see at the next meeting, explain what he/she got out of the meeting, express how he/she is feeling about the meeting, let other members know he/she is needing someone to talk with after closing, share music, poetry, reading materials, etc. many groups use check-out to ensure members leave on a positive note. Groups can also use closing time to discuss the agenda and plan for the next meeting. Whatever your group decides to do during closing, leave enough time to do it in.







## **Running Effective Groups**

After the group has reached the point where it has established a schedule, much of the organizational work of the facilitator has been accomplished. A support group has been created; there is a core set of members ensuring healthy attendance, new members continue to arrive bringing additional points of view and a dedicated volunteer team shares the work load. At this point the facilitator's primary responsibilities change to executing the plan. In most situations this will involve managing meetings and checking with members concerning the status of their responsibilities.

Be flexible, there are numerous situations that may cause changes to the schedule, often at the last minute (cancellations, weather, change in venue, illness etc.). Do not worry. Your members will understand that there are circumstances that cannot be anticipated nor controlled. The best way to handle a late change or cancellation is to simply introduce a discussion topic that the group has not dealt with or one that is of particular interest. In cases where the schedule needs to be updated to accommodate to change the necessary arrangements need to be documented and communicated.

Keep a watch on attendance. If you find that it is dropping over 2 – 3 consecutive meetings, contact some people who have not returned to determine why. You may have to begin another promotional program. If attendance is regularly above a manageable number, start thinking about strategies to split the group during the discussions.

## **As Your Group Matures**

Over a long period of time (3+ years) a support group matures, attendance levels and few new members join (if they do they are often not supported adequately). Subjects have evolved from dealing with the unknowns of lupus to ones of discussing specific therapies, advocacy initiatives and meetings become more social in nature. Strong friendships have developed and the group has grown assured of one another's support and encouragement.

It is important to continue to evaluate the more mature group to determine if it is still providing 'support' (therapy) for the members.

### **The facilitator should check for the following:**

- Do members give and receive support on a regular basis?
- Do "older" members help our newcomers?
- Is the group achieving all of its goals?
- Do members look forward to the next meeting?

The yearly planning sessions are extremely important events for the mature group. Members need to be more creative in selecting the activities undertaken, taking the opportunity to investigate different types of topics or themes of discussion over the period of time that the group has remained together they have most likely discussed the basics at least 2-3 times. Exciting new prospects exist; they just need to be carefully examined and members open to the challenge.

The members often become more active, taking on programs in support 'of the cause' and are enthusiastic about supporting initiatives outside the group.

### **Initiatives that a group will undertake over time often include;**

- Fundraising in support of lupus and Lupus Ontario.
- Community Outreach.
- Volunteering for Lupus Ontario.
- Support of advocacy programs.
- Educating and informing health care professionals and the general public about lupus and its effects.
- Involvement in community events such as fun fairs or health fairs.
- Social Media Campaign.
- Newsletter.
- Education Workshops for members, Lupus Education Days, Etc.
- Email monitor for online support group.
- Online support group co-facilitator.
- AGM (Annual General Meeting) committee.
- Service Club Presentations about lupus. (PowerPoint and worksheets available).

### **Typical Support Group Issues**

#### **SKILL DEVELOPMENT**

Successfully facilitating a support group requires three key skills: Organization, Active Listening and Communication. Most people possess the basic ability and should feel confident in accepting the role with the understanding that they will easily gain 'expertise' through experience in a surprisingly short time.

#### **Organization**

- Need to manage a yearly schedule.
- Prepare for individual meetings (compile supporting material, handouts, etc.).
- Ensure that group confidentiality is maintained.
- Know how best to delegate group tasks.
- Follow-up with member volunteers to ensure tasks are being completed.
- Prepare and follow a meeting agenda.
- Instill a sense of rigor into group practices.
- Liaise with Lupus Ontario.

#### **Active Listening:**

- Watch out for myths, stereotypes or out of date information (*courteously but firmly correct inaccuracies - for example; "No, that is not correct. I am not a medical person so I can't tell you the whole story but do talk to your doctor, pharmacist or nurse about this."*).
- Monitor the amount of information exchanged (*listen to determine if people*

*have exhausted a subject, do they want more information or do they want to move on to something else). Suggest topics to the Support and Education Committee.*

- Remark when there is too much negativity (*refocus the group from negative to positive*).
- Allow adequate time for everyone to speak up (*especially with people with lupus, allow polite pauses before starting to talk or changing the subject*).

### **Communication**

- Present a Confident Demeanor – must be reliable and honest.
- Tactful – able to respectfully deal with conflict and difficult people.
- Speak loudly and clearly.
- Make eye contact with everyone when addressing the group.
- Try not to single people out.
- Be cheerful.
- Ask open ended questions.
- Methodically ask questions to help people express their opinions in a clear manner (*Why was that important to you? Can you give us an example?*).
- When explaining a position or opinion restating what someone has said illustrates that you are listening and offers the opportunity to clear up any misunderstanding.
- Paraphrase or sum up at the end of a discussion period.

## **DEALING WITH PEOPLE**

Any time more than five people meet as a group, personality traits of the individuals will influence how everyone relates to one another. As a facilitator (you) need to recognize some of the more diverse behaviours individuals exhibit in order to make sure everyone has an opportunity to contribute during information sessions.

### **The Person Who Won't Stop Talking**

- Be firm, thank them for their opinions but then pleasantly tell them it is time to move on to someone else.
- Frequently remind the group that time is limited and that everyone should have a chance to speak.
- If someone goes too deeply into problems that are beyond the group's scope or is of no general interest, ask the group if they have any suggestions, and then move on. Also, refer them to Lupus Ontario who can help connect them with local psychological support services.

### **The Person Who Seldom or Never Speaks Out**

- Be respectful, there are people who wish to attend and learn simply by listening (*no one should be centered out or made to feel that they must contribute*).
- If an opportunity arises to speak with the person in private, try to determine if that person's needs are being addressed and what may make his or her experience more comfortable.
- With time and familiarity, people will begin to speak more frequently, voicing opinions on topics they feel strongly about.
- When contributing to the conversation, help protect the person from the more dominant characters who sometimes interrupt.

## **The Person Who Always Complains**

- Try recommending that every criticism or complaint be accompanied by a positive suggestion.
- Ask the person or the group for a suggestion of what would make things better.
- Schedule a time during each meeting for every member to share something positive.
- Remember – keep the complaining and the whining to under a minute, we all have to vent, but it should not be the topic of conversation.

## **DEALING WITH INFORMATION NEEDS**

One of the principal reasons people participate in a support group is to obtain as much information as possible. To support this requirement, the facilitator (you) needs to plan to have various types of information available for meetings. One or two 'news' items are always appreciated and can lead to some interesting conversations.

### **Types of Information that people often request**

- Medications and current treatment options.
- Research (*types, progress, where, what to expect, etc.*).
- Information about your local Member Organization (Lupus Ontario).
- Exercise (*programs, types, best options, etc.*).
- Conferences, Education Sessions (*where, when how much.*)
- Best sources of information.

*\*(Please contact Lupus Ontario for your information)*

## **INCONSISTENT ATTENDANCE**

Attendance can vary greatly for a number of valid reasons. Do not be offended by members who do not return, it should not be interpreted as a criticism of your efforts.

### **Reasons Why People May Not Return or Miss a Meeting**

- Some people are simply not "group people".
- Health reasons.
- Weather.
- Some find that the format is not for them.
- Time and/or location are not convenient (*cannot accommodate everyone.*)
- They may feel that they do not fit in.
- Young onset people may prefer a younger group.
- Belief that they can no longer be helped.

## **MEDICAL INFORMATION EXCHANGE**

People attending support groups enjoy sharing information of a medical or personal nature; it is often used as a barometer to help individuals judge where they are with the progression of the disease or how different specialists prescribe treatments. While interesting and informative, the facilitator (you) needs to make people aware of the dangers of adopting a course of action based on what was discussed at meetings without consulting their specialist.

### **Pitfalls to Avoid Concerning Medical Information**

- Watch out for situations that demand professional help or counselling (*don't feel bad about having to tell someone that you or the group cannot help them, advise the person where/how they can get professional services*). Develop a list of resources for your area.

- Lupus is a disease of a thousand faces, no two people will have the same experiences (*the group can listen but remember you cannot really put yourself in another's shoes*).
- The group should not tell another person what to do. (*as a facilitator you should encourage the group to act as a sounding board and listen to each person problems; think of possible solutions and assess the advantages/disadvantages of a particular action*).

## **EXERCISE**

The importance of movement and exercise for people with lupus cannot be emphasized enough. Research has proven that quality of life is greatly improved for those who adopt a regular exercise routine. The exact type of exercise does not matter as long as it is safe for the person, doable and fun. The best exercises are those that enhance flexibility, strength, coordination, posture and/or balance.

Many support groups incorporate exercise time within their meetings to promote its value and expose members to the various types to help them make a decision as to what may be best for them. Discuss the possibility of exercise time with your group; understand that doing so will likely take away from either discussion or break time so a compromise will have to be made.

## **REMAINING OBJECTIVE**

It is important that the facilitator be seen as part of the group, not someone who is an outsider whose primary purpose is to make arrangements and set the agenda. Often when an individual assumes a leadership role it is easy to become overly concerned about logistics and his or her focus is directed more towards running an effective meeting. To avoid having the facilitator become overburdened and leave time to relax and become involved during discussions, tasks associated with group operations should be shared with the members.

Sharing responsibilities helps people attain a strong sense of ownership with the group knowing they are contributing towards an activity that they value. With a greater number of people involved, decision making becomes more inclusive and appropriate for the entire group.

### **Actively Solicit Help in Running the Group**

- Work as part of a volunteer committee (*it is important that the group know the facilitator is a member of the group, not the president, not a teacher, and not an expert*).
- Assign tasks as early as possible (*distributing work lets everyone feel they have ownership and prevents burn-out*).
- Find tasks for all those who want to be involved from the outset.
- Avoid guilt trips, don't let any participant (including yourself) take on more than they can reasonably deliver.
- Use education materials developed by Lupus Ontario (Contact Lupus Ontario at [info@lupusontario.org](mailto:info@lupusontario.org)).

## **COMMON COMPLAINTS ABOUT SUPPORT GROUPS**

Perceptions of how well the group is being run are very powerful; too many negative experiences and people will begin to question the value of returning. Be aware of

damaging practices or policies that most would find annoying. Ask a few trusted members to evaluate your performance occasionally and make the hard changes necessary to eliminate what was identified as poor work or practices. During the yearly planning session ask all members if they believe a change in facilitator and/or format is required.

### **Some Concerns That People Have Expressed About Support Groups**

- Inconsistent intervals between meetings.
- Meetings are too negative; complaint sessions with little constructive discussion.
- Poorly planned meetings; no specific topic, speaker, lack of agenda, etc.
- Controlling facilitator; uses meetings to address personal agenda.
- Ineffective leadership; no adherence to yearly schedule or agenda.
- Splinter groups form and hold side discussions during meetings.
- Meetings are over programmed; little time for discussions or personal sharing.
- Meeting topics may be upsetting or inappropriate.
- Lack of trust among members; people not respectful of each other's feelings.
- People don't feel involved; they are not consulted or provided with the chance to help.

### **Let us Talk Meeting Rooms And Checklists**

#### **CONSIDER FOR MEETING ROOMS;**

- Churches, Synagogues or Mosques.
- Municipal Community Centres.
- Recreation Centres.
- Hospitals.
- Public libraries.
- Apartment or condominium community rooms.
- YMCA/YWCA.
- Senior Centres.
- Long term care facilities.
- Local malls often have a community room.
- At your local Member Organization (i.e. Lupus Ontario).
- Grocery Store Community Rooms.
- Cooking School.
- Service Club Centre (Kiwanis, Lions, Knights of Columbus, etc.)
- Some Places rent space at a reduced price to non-profit groups.

#### **MEETING SITE CHECKLIST**

- Is there a cost?
- When is the room available?
- Is a flip chart available?
- Does it have a white/blackboard?
- Are tables and comfortable study chairs provided? Will they be set up for you?
- How many people will the room hold?
- Can the doors be closed for privacy?



- Can the room be rearranged easily to accommodate different activities?
- Is it quiet, can people be heard across the room when speaking in a low voice?
- How many steps are involved, inside and outside?
- Is there an elevator? (*if room is located off the main floor*)
- Is parking safe and convenient?
- Is there a charge for parking?
- Is there a good drop off place at the door nearest the meeting room?
- Is it accessible by public transit?
- Is the entire building including bathrooms, accessible to walkers and wheelchairs?
- Are the bathrooms located near the meeting room and on the same floor?
- Is the room adequately heated and air conditioned?
- Is there a telephone accessible at all times? Does the facilitator have a cell phone?
- Is there a secure place for people to hang their coats?
- Who is the contact person and how can they be reached during off hours?
- Is liability insurance required?

### **IF NECESSARY**

- Is there a kitchen available?
- Is a coffee maker and/or kettle made available?
- Is there a storage closet where the group can store supplies or literature?
- Is audio visual equipment available? (*overhead projector and screen or white wall, VCR, DVD player, internet connection*)?

### **LIST OF MEETING NEEDS**

- Name tags (*reusable type or “peel & stick” – if using reusable type, collect them after each meeting as people often do not remember to bring them to the next meeting*).
- Flip Chart.
- Markers.
- Masking tape.
- Pens.
- Paper.
- Chalk and eraser (*if using blackboard*).

### **MEMBERS LIST**

- Name.
- Preferred method of contact, Phone number, E-Mail, Address, Cell Phone.
- Other information as required.

NOTE: List is to remain confidential and not shared with the members. This is a legal requirement under the bylaws.

### **LUPUS ONTARIO’S REFERENCE MATERIALS AND LIBRARY**

- Materials supplied by Lupus Ontario.
- Books.
- Articles.

- Website information.
- Education PowerPoints and Handouts.

## **What's On The Agenda?**

### **Agenda Examples**

#### **Example one:**

Set up room 15 to 20 minutes in advance, so it is ready for early arrivals and if there is a speaker, prepare any necessary equipment.

- Introductions (10-20 minutes): everyone is invited to give his or her name and a short comment on their experience with lupus or on the subject that will be discussed at this meeting – NOTE: *Some groups may wish to dispense with introductions after a period of time; if new people arrive it is recommended that everyone introduce themselves*).
- Business (*no more than 10 minutes*): Review any important decisions made at the previous meeting, verbal reports from any volunteer committees and any news from Lupus Ontario.
- Exercise Break (8-10 minutes): Simple routines from a sitting or standing position that is led by a member of the group (*explain the value of each exercise*).
- Main Topic (20-45 minutes): Including question time.
- Refreshments and Informal Discussion/Conversation (15-20 minutes).
- Conclusion (5-10 minutes): Facilitator (you) provides brief summary, restating a few of the main points – reminds the group about the next meeting's topic and invites comments from members.

#### **Example Two**

Set up room 15 to 20 minutes in advance, so it is ready for early arrivals and if there is a speaker, prepare any necessary equipment.

- Social Time (20 Minutes): Meeting begins informally, allowing people to meet independently as an 'ice breaker'.
- Introductions (10-20 minutes): everyone is invited to give name and short comment on their experience with lupus or on the subject that will be discussed at this meeting. NOTE: *Some groups may wish to dispense with introductions after a period of time; if new people arrive it is recommended that everyone introduce themselves*).
- Main Topic (20-45 minutes): including question time.
- Refreshments and Informal Discussion/Conversation (15-20 minutes).
- Conclusion (5-10 minutes): Facilitator (you) provides brief summary, restating a few of the main points – reminds the group about the next meeting's topic and invites comments from members.

## **MEETING SUGGESTIONS**

### **About Lupus**

- What is lupus? (*demographics, what is happening*).
- Diagnosis of lupus (*signs and symptoms*).
- Lupus medications (*how they work, effects*).
- Lupus research updates (*what is the most recent news, what can we expect*).
- Myths.

- Discussions based on a recent conference.
- Lupus as a chronic illness (*how will the progression of the disease affect me*).

### **Living with Lupus**

- Stages of lupus (*loss, grief, denial, anger, and growth*).
- The importance of exercise in maintaining health.
- Diet and Lupus.
- Tips for daily living (*sharing coping strategies*).
- Getting around more safely and comfortably.
- Managing with poor handwriting and keyboarding skills.
- Memory and cognitive issues related with Lupus Ontario Communicating better.
- Sleep problems with Lupus Ontario Intimacy and sexuality and Lupus Ontario Lupus and the work environment.
- Hobbies and crafts (*share activities we enjoy and participate in*).
- How lupus affects the family.
- Using adaptive equipment.
- Driving and community mobility with Lupus Ontario Handling emergencies.
- Stress management and relaxation.
- Sheared expectations sessions.
- Emotional well-being (*how to feel good about yourself and your condition*).
- Physical well-being (*how to feel healthy and vital*).
- Humour – the lighter side of Lupus Ontario.
- Gender perspective about living with Lupus Ontario helping your family and friends understand your condition.
- Bring and brag ego booster (*we are more than just someone with lupus – tell us about your accomplishments*).

### **Health Care and Community Resources**

- The ‘pros’ and ‘cons’ of home care.
- What you need to know about nursing homes.
- How best to deal with health care professionals (*Neurologist, Rheumatologist, Physician, Pharmacist*).
- Lupus Ontario information session.
- Adult day care.
- Transportation and other resources for those living with Lupus.
- Accessible dining, recreation and travel options.
- Lupus Ontario – (*what services do they provide, how can I help/contribute*).
- ADP Presentation by Lupus Ontario.
- Power of Attorney for Personal Care by Lupus Ontario.

### **Social Ideas**

- Summer Barbeque.
- Pot Luck session.
- Meeting where everyone plays games.
- Attend a conference as a group.
- Lupus luau – in custom.
- Attend a movie.
- Meet at a member’s home for tea, dinner, or special event.
- Plan and attend a “Walk for Lupus” Event. (email: [info@lupusontario.org](mailto:info@lupusontario.org))

## **List of Potential Speakers**

- Rheumatologist.
- Neurologist.
- Family doctor who has lupus patients.
- Nurse Specialist.
- Social Worker.
- Psychologist or Psychiatrist.
- Physical therapist, Massage Therapist, Osteopath or Chiropractor.
- Occupational Therapist.
- Pharmacist.
- Nutritionist, Dietician, or Naturopath.
- Exercise Physiologist.
- Tai Chi, Qi Gong or Yoga instructor.
- Health educator.
- Life Skills Coach.
- Recreation Therapist.
- Attorney.
- Hospital Chaplain.
- Specialist from a local medical equipment company.
- Travel agent.
- Dancing or music instructor.
- Member of a neighboring Lupus support group *\*(someone who has experienced hip replacement, has lived with SLE for a long time, someone involved in a study, someone involved in research or someone who has a unique story to share).*
- Someone from Lupus Ontario.
- Gastroenterologists.
- Internists.
- Firefighter.
- Police officer.
- Dentist or dental hygienist.
- Ophthalmologist or Optometrist.
- Acupuncturist.
- Art Therapist, Garden Therapist, etc.
- Natural or Organic Skin Care Products manufacturer or retailer.
- Chronic pain specialist.

## **Working With Speakers**

You can maximize the value of a speaker by following some simple guidelines that promote information exchange between the support group and the individual invited to speak. The more each presenter knows about lupus and the group, the better prepared that person will be.

## **At the time of Agreement**

- Confirm the time, date, location, and topic (*ensure that there are no misinterpretations*)
- Include with the confirmation letter your best Lupus booklet/pamphlet and any pertinent newspaper clippings or newsletter. Maybe reports which you would like the person to respond to
- Request some background information on the speaker to use for publicity purposes and for an introduction

## **Two Weeks Before the Meeting**

- Send the speaker a reminder, along with a copy of the meeting announcement and/or press release.
- Include some information about the group: length of time together, age range, number of people with lupus.
- Ask if the speaker will need any special equipment; projector, projector screen, laptop, video, flip chart, etc.
- Provide a list of five to ten questions that the group would like to have addressed.
- Reconfirm the time and format: (*30-minute talk with 15 min. for questions*)
- Ask for permission to take photos or tape record the presentation and make sure to get this in writing, hardcopy or email.
- Ask if the speaker will make available copies of his or her presentation
- Make sure the speaker has good directions and a telephone number to call.

## **With the Group**

- Determine who will introduce the speaker at the meeting.
- Post the name of the speaker in a prominent area.
- Decide if they will be giving the speaker an appropriate gift (*a small box of chocolates, Lupus Ontario wristband, hoodie, hat, snowflake etc.*).
- \$10 gift card

## **At the Meeting**

- The speaker is introduced.
- Following the presentation, the facilitator (you) lets everyone know what time is remaining for questions and that it will be monitored (*tell people you may need to limit the amount of questions*).
- The speaker should be thanked and invited to stay and meet with people informally.
- If the speaker needs to leave at a certain time, someone should escort him or her to the door of the building.

## **Speaker Invitation Letter Example**

Date:

Topic:

Dear (Speaker),

Lupus Ontario's Support Group in (municipal location) is a peer support group designed to provide education and support to patients and families affected by lupus, as well as to other interested individuals. We do this by holding regular, often monthly meetings, where we often invite professionals to discuss their area of expertise and entertain questions from those in attendance. Our members appreciate an open time for discussion, exchange of information and coping strategies. Our group is about (# years) old and with membership of about (##) people. We normally have about (##) members attending our meetings.

We are currently planning our calendar for next year and we would like you to consider being a speaker for our group meeting on (date) and (time). If this date is not convenient, an alternate date can be arranged. The topic of discussion that we would like you to address is (topic). We ask our speakers to make their presentation about (## minutes) in length and allow an additional (## minutes) to answer questions.

As the Facilitator of the group, I will be calling you within the next two weeks to discuss this proposal with you. We hope you will consider our request. As individuals with lupus, we are very anxious to hear from knowledgeable and concerned professionals. We look forward to meeting you soon.

Sincerely,

(Name and Title) Lupus Ontario  
(Name of Group)  
(Phone Number)  
(Group email address or  
info@lupusontario.org)  
www.lupusontario.org

## **THE FUNNY PAGES**

### **Some Ideas For Icebreakers**

Icebreakers are used at the beginning of meetings and are intended to acquaint people with each other and to put them at ease. Icebreakers can also be used after a break just to 'perk' people up – especially if there's been a bit of tension. However, it may not be the best method to resolve tension and as the facilitator, you'll be the best judge of how to handle such a situation.

There are many icebreaker games around and you can search the internet to find some that may be appropriate for your group. Keep in mind that many of these games are intended more for professional meetings but they can be adjusted for our purposes. Here are just a few examples of icebreakers you may wish to try:

### **Two True, One False:**

Go around the group and everyone has to say two true statements about themselves and one false one. The rest of the group has to guess which one is false. You may be surprised. You can learn some truly interesting things about each other.

### **Marooned**

You are marooned on an island. What five items (or any number depending on the size of the team) would you have brought with you if you knew there was a chance that you might be stranded. There are only five items per team – not per individual. Have each group write their items on a flip chart and discuss/defend their choice with the whole group. You can make this a serious exercise by having strictly survival items needed or more fun by having teams pick outrageous but useful items to be stranded with.

### **Who Done That?**

Prior to the meeting, make a list of 10, 15, or 20 items (depending on the size of your group and the time you allot for the icebreaker) relating to work, volunteering or home life. Ensure there is plenty of space below each item (3 or 4 lines) and then make enough copies for each person. Give each person a copy of the list and have them find someone who can sign one of the lines. Specify a certain amount of time for the task. If you like, give a gag prize to the first one completed or to the person who has the most names on their list when the time ends. Make sure when you're creating the list, you're selecting items that are realistic to your group members. Some items to think about are WHO: - has seen 10 movies this year? WHO: enjoys hiking? WHO: belongs to a social club (i.e. card group, coffee club, etc.).

### **Finish the Sentence**

Go around the room and have each person complete one of these sentences (or something similar): The best job I ever had was... The best trip I've been on .... This is a good game to put everyone at ease because it informs the group about some of the best things that have happened to an individual. If you felt the group was ready to move on to a more serious topic, you can by shift to a new subject by asking a leading question such as: "I came to the group because..." Anyone who doesn't want to answer the question shouldn't be pressured to do so.

## Introduce Humour

Humour has many uses; to entertain, to help someone relax and feel at ease, to distract from problems even if only of a short time. Sometimes meetings may become intense and humour is a way of breaking the mood – as long as you don't make light of the individual's feelings or the situation they face. While you or some members of your group may have great spontaneous humour, it's important to recognize the tone of the moment and keep the meeting on track without straying too far from the discussion at hand.

Using humour for your support groups can be a difficult and somewhat daunting task so it's best to be prepared. Here are some ideas you might incorporate occasionally into a meeting or as a regular ingredient of your meetings.

- Common Current Events – What's funny in the world today?
- The Literary World – Interject humorous poetry, quotes or short pieces of prose during your meetings.
- Creating a Top Ten List – Humour from a structured outline.
- Home Project – make a list of items – i.e. Campbell's Soup, Lysol, Kitty Litter, Motor Oil, etc. write each item on a piece of paper and fold each one. Place them in a box and have each member pick one. With the item they chose, have them design a funny ad at home – next meeting, they can present it at the beginning of the meeting or after a serious discussion (please use your discretion).
- Leaving them with a Bang – Leaving your group laughing at the end of a meeting can sometimes be a great relief.

*“A merry heart doeth good like a medicine; but  
a broken spirit drieth the bone.”*

*William Shakespeare*

Let your group know that laughter is important to their health and well-being. Laughter may make you physically weak, but it can make you strong in an emotional sense. That's why it's important to strengthen your sense of humour so you can see the funny side of things you can't change, especially those that cause stress. Laughter releases endorphins and enkephalins and these hormones make you feel fantastic. Laughter is the best medicine in the world.



## **Facilitators Office Duties And Procedures**

It is important that all Facilitators complete monthly reports and documentation. After each session, you are required to fill out the expense report, the LOA1 Support Group Meetings form, attached signed (by all members and new members as they join) the Acknowledgement form, Harassment Policy and the Confidentiality Policy. Please attach any completed Support Group Evaluation Reports. You, as the Facilitator, decide when a Support Group Evaluation Report (SGER) should be completed. Please attach any new information that has been introduced to the group. Please make sure to document any new activities, new members and new ideas.

All documentation must be mailed/faxed/emailed to the Lupus Ontario office each month – please provide by your next meeting. All your files must be up to date prior to your next meeting. If faxing or emailing the documentation is easier, please do so, however, the original must be mailed as soon as you can.

### **EXPENSE REPORT**

It is crucial that the expense report be completed exactly as described. This eliminates the Accountant having to decipher all receipts, which in turn delays your cheque or direct deposit. Please follow the instructions attached to the Expense report. Included with the expense report – please staple all your receipts to a blank piece of paper with a short explanation of said costs. You may fax or email your expense report to the office; however, the original should be mailed as soon as possible. Please write (Copy sent by fax or email) on the documentation to avoid duplication. Email to [admin@lupusontario.org](mailto:admin@lupusontario.org).

### **SUPPORT GROUP AGENDA'S**

It is important to send a copy of your Support Group Agendas to the chairperson of the Support and Education Committee. I would like to have all activities recorded/documented. This should be mailed or emailed to the chairperson every three months. It is important that Lupus Ontario keeps track of all Support Groups and makes sure we are all on the same page. This will also give us an opportunity to share new ideas – perhaps something you are doing in your Support Group can benefit another Facilitator in another Support Group. Timely reporting also allows the Support and Education Committee to include your group in the monthly reports to the Board of Directors.

Thank you.

## Appendix A – Online Support Groups

There are some additional skills and software needed to run an online support group.

### Software

Lupus Ontario is currently using Zoom for video communications. You can download the software for free at [zoom.us](https://zoom.us). The chairperson of the Support and Education Committee has access to the Lupus Ontario Zoom account. Send your meeting dates and times to the chairperson and he/she will set up the meetings in zoom and email you a registration URL or link. Each meeting will have its own “meeting id” number. When a person registers, zoom sends them a meeting link.

People join the meetings from a computer, cell phone, tablet or other device. In all cases they login with their unique meeting link. Invitations include both links and call in phone numbers.

From time to time, Zoom changes the security settings in the software. This has happened more frequently during the pandemic with so many more people using zoom meetings. Sometimes that will mean a meeting’s information has to be edited. There is then an option to send the changes to all people who are registered for that meeting.

There are many FAQs and help topics on <https://support.zoom.us/hc/en-us/articles/206175806>

### Using Zoom

When Lupus Ontario sets up an online support group, the support group facilitator or a member of the Support and Education Committee will act as the “host” for the meeting. Ideally, the facilitator is host and another member of the support group acts as the chat monitor. The chat monitor keeps an eye on the questions and comments that people type into the chat box and informs the facilitator of anything that needs a response, or that needs to be mentioned to the rest of the group.

You submit the dates, times and registration URLs for your support group meetings to the chairperson who sends them to the person updating the Support Page on the Lupus Ontario website. When a person clicks on the meeting date it links to the registration URL for that meeting. Check the support page and verify that your group information is correct at [lupusontario.org/support/](https://lupusontario.org/support/)

In Zoom, the *host* is the person running the meeting. This person can control mute, share screen, chat, raise hand, and other functions.

The *chat monitor* is a person you choose in your group to look at the messages being typed into the chat box and telling you the facilitator about anything that needs to be dealt with. It is good to have more than one person to take turns doing this task so that everyone can enjoy the meetings without always having a job to do. The chat monitor will need to practice with you during a short meeting with just the 2 of you prior to the support group meeting so that they are confident with the job.

## **How Lupus Ontario Sets Up Zoom Meetings for Support Groups**

There are several options in the various levels of zoom paid accounts. For support groups, we use the following options when setting up support group meetings.

- **Registration Required:** To maintain confidentiality and to prevent hackers and mischief makers from attending a meeting, the person setting up the meeting in zoom checks this box. When a person clicks on the registration URL, the zoom software creates a link that is unique to that person which is connected to their email address. Zoom automatically sends them an email with their unique link to the actual meeting. For this reason it is important that people do not forward their personal link to anyone else. You can forward the registration URL but not your personal link. You will need to explain this to your group members. You still need to get a signed copy of the confidentiality form/statement from each member of your group once per calendar year and forward the PDFs of the forms to the chairperson of the Support and Education Committee.
- **Enable join before host:** This feature allows the group members to login before the start time with their unique, individual link. This helps avoid system crashes with a whole group of people trying to login to the same meeting within a 5 minute period. You can advise the group members to try to login 5 or 10 minutes before the start time. This also gives them time to reconnect if they have any internet issues.
- **Mute participants on entry:** This keeps background noise to a minimum before the meeting starts. As with conference calls, any dog barking, children talking, tv, radio or other noises can interrupt the person who is speaking making it impossible for anyone to hear. It is helpful to ask group members to mute their microphone when someone else is speaking. The facilitator, as host, can also mute people individually or as a group. Respect for each other's time to talk is essential for an online meeting to work.

### **Within a meeting:**

- *Participants* on the zoom floating menu bar lets you see all the participants who have joined the meeting and you can move the participants to another part of your screen if you are using screen share. You have a choice to also open the *chat* and move it under the participant's box.
- *Reactions* allows you to have non-verbal feedback beyond typing in the chat box. See <https://support.zoom.us/hc/en-us/articles/115001286183-Nonverbal-feedback-during-meetings>.
- *Audio, Video, Sharing* has many features on using different settings within the zoom meeting. See <https://support.zoom.us/hc/en-us/categories/201137166>.

### **Meeting Names or Topics**

On the support page and in newsletters, you will see standard names for the different groups. For example, Provincial Online Lupus Support Group, Durham Online Lupus Support Group, Youth Online Lupus Support Group, Ottawa Online Lupus Support Group, etc.

If there is an educational webinar, the name or topic will always start with the word

Webinar followed by a very short abbreviation of the topic. A more detailed description of the topic would be included in the body of the email with the zoom invitation.

### **Internet Issues**

Some people may have problems with garbled audio or scrambled video. Often this is due to the internet account band width, connection speed or type of internet access. If people get the message, “your internet connection is unstable,” it is usually a result of not enough band width and simply turning off the video will solve this for many people. Other people may have to leave the meeting and rejoin to solve this.

We recommend the use of a noise cancelling headset for online meetings. It dramatically cuts down background noise and interruptions to all who are trying to listen and participate.

There are good ones available for \$21 at Staples and other office supply companies. Ask people ahead of time to use a noise cancelling headset whenever possible out of respect for all group members.

### **Share Screen**

This Zoom option is used to share documents with your group on the screen. You open the document you want to share before the meeting. It can be a pdf, MS Word document, spreadsheet, handout, PowerPoint or other document.

As host you can move around the document the same as if it was just you on your own computer but the group members can also see it. This is also useful for sharing something on a website where you have the website open and share screen in order to show the group members the information you want them to see. You can screen share [lupusontario.org/support/](http://lupusontario.org/support/) and [lupusontario.org/education/](http://lupusontario.org/education/) and guide them around these pages.

This can be used to show a guest speaker’s presentation or handout. Shared documents are visible to the members even when they have their own video turned off. Share screen does not usually cause any problem with internet band width.

You can also use this feature for guest speakers and presentations.

### **Zoom For Speakers and Webinars**

As host for a guest speaker or webinar there are several steps that should be included.

- Welcome everyone.
- Introduce yourself, your position or role for the webinar (facilitator, etc.).
- Introduce your chat monitor.
- Remind participants about confidentiality
- Inform them that the webinar is being recorded (if it is being recorded).
- If there is a handout, tell them where it will be posted or who to email for a copy.

- Give them some pointers on how to use Zoom, how to turn off video to conserve band width if they get the message that their internet connection is unstable, to try leaving the meeting and reconnecting or try a different device, how to turn their microphone on or off.
- Tell them that they will be muted during the presentation so that everyone can hear the presentation and that they can unmute during the question and answer part of the webinar. Ask them to stay muted during the presentation out of respect for all participants.
- Explain how to open the chat box and tell them they can type questions into the chat box during the presentation.
- Introduce the speaker.
- When the presentation part is finished, tell them how long the Q&A session will be, for example, 20 minutes, or 30 minutes. Read appropriate questions from the chat box out loud for the speaker to answer.
- Wrap up.
- Thank the speaker.
- Close the meeting for all.