



SCLERODERMA QUEBEC'S SUPPORT GROUPS

Violet Konrad, Support group leader for Estrie and trainer of support group leaders
Edouard Lebeau, Support group leader for Estrie
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Scleroderma Quebec's Support Groups meet in person or on Zoom for mutual support with the challenges of living with scleroderma. These groups are composed of people living with scleroderma and may also include spouses or other natural caregivers. They are led by one or more trained leaders who have taken a course specifically designed to equip them to facilitate the groups and to share pertinent information about living with scleroderma. The leaders are volunteers within the Scleroderma Quebec organization and most are themselves living with scleroderma. The well-prepared, warm, and welcoming meetings include pertinent information for coping with scleroderma. Members feel free to share their experience of living with scleroderma with others who understand from within. Many members feel that belonging to a support group has changed their lives for the better.

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WHY JOIN A SCLERODERMA SUPPORT GROUP?

FOR COMMUNITY

Many people living with scleroderma feel alone because their condition is not well known or understood. Joining a group of people who have this disease and are willing to share the tricks of the trade for living better with symptoms can give a real sense of well-being and community. Madone Coulombe has been a part of a support group for close to ten years. She writes:

"I believe that medical appointments are not sufficient for really understanding the complexity of this disease. Through sharing with people living with scleroderma I recognize myself, and it makes me realize that I am not alone in living with these sometimes difficult symptoms that are so hard to explain to those who do not have this disease."

Support group members are good listeners for each other. They have personal knowledge of the disease, and they are very supportive of one another.

FOR INFORMATION

Although one of the important rules in support groups is to not give medical advice but rather to refer one another to medical professionals, members can and do share their experiences. Often another person's experience can be a valuable source of information, hope, and inspiration.

Various themes are discussed and information is shared from reputable sources including among other topics:

nutrition with scleroderma, bone health, mindfulness, pain management, dental health, digestive issues, skin health, managing anxiety, getting the most from your medical appointments, communicating about your disease with family members and others, becoming an expert on your own health and keeping a personal health record, coping with changes in appearance, accepting your limits and learning to live the best you can with them, living with Raynaud's syndrome, managing energy, how to promote better sleep habits, travelling with scleroderma, and many many more subjects.

Members can suggest subjects that are important to them and bring their questions and concerns to meetings. They can also contact Scleroderma Quebec or leaders directly, with topics that they would like to see addressed.

FOR CONFIDENTIALITY

Support groups are safe, caring, and confidential places to share about life with scleroderma. Confidentiality is an important value in these support groups. Anything said in a group remains confidential. Meetings are not recorded. The commitment to confidentiality is explained and reviewed at the first meeting of a new year and new members are introduced to this and other important rules that help the groups maintain a positive, caring, and confidential space.

FOR FUN

The goal of each support leader is that the meetings will bring a smile and maybe a laugh to the members. Meetings may include Christmas parties, humour, costumes, and silliness. As we know, "Laughter is the best medicine." Some groups have picnics or other activities just for the fun of it. In the groups, you may be asked to talk about and share about your hobbies, travel experiences, pets, favourite memories, etc.

WHAT SUPPORT GROUPS ARE NOT?

Support groups are not led by medical professionals. They do not diagnose or treat individuals. They do not provide therapy.

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WHO ARE SUPPORT GROUPS FOR?

FOR THE RECENTLY DIAGNOSED

Support groups can be very valuable for people who have been diagnosed recently. They will be reassured that members have full and active lives even after many years of living with the disease. They will find compassionate listeners who understand the distress of a scleroderma diagnosis, and they will gain more understanding of their disease and learn where to look for pertinent information.

FOR ANYONE WITH SCLERODERMA

No matter how long a person has lived with scleroderma there may be new challenges or symptoms. Anyone living with scleroderma, no matter the length of time, will find a community to support them. Being able to give support and share experiences with the more recently diagnosed can be a very positive experience. You may benefit from a support group but the support group will also benefit from your presence and your experiences.

FOR ANYONE SUPPORTING SOMEONE WITH SCLERODERMA

Spouses and family members can also feel alone and overwhelmed by their role in supporting a person with scleroderma. Joining a support group can give them valuable information and support.

FOR MEN WITH SCLERODERMA

There are more women than men living with scleroderma. Groups are open to both men and women but tend to have many more women members. To offer men with scleroderma their own space, we have a men's group. Please see the list of groups and meetings on the Scleroderma Quebec website for contact information, dates, and times.



FOR YOUNG PEOPLE WITH SCLERODERMA

Scleroderma affects people of all ages, from children to seniors. Young people with scleroderma feel doubly alone. Not only do they have a rare disease, but they are also a minority of the people living with the disease. As well, fewer young people have chronic conditions. To give young people living with scleroderma a place to share their experiences and form a community with their peer group, we propose meetings specifically for young people between the ages of about 14 to 40. Again, please see the list of groups and meetings on the Scleroderma Quebec website for contact information, dates, and times. Young people are also cordially invited to all other Scleroderma Quebec support groups.

FOR ENGLISH SPEAKERS

Up until recently, all our support groups have been in the French language. We are very happy to now have a Zoom support group in English that meets once a month. It is open to anglophones and to bilingual members who prefer the afternoon time slot. Scleroderma Quebec is very attentive to the needs of English-speaking members. The website is bilingual, the various publications are translated and available in English, and our magazine, *Le Bulletin*, has an English version available online, by request. You can contact the association in English for any enquiries or support.

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WHAT ARE MEETINGS LIKE?

IN-PERSON MEETINGS

In-person meetings can be occasional or regular. They could be held in a restaurant, a community hall or at a member's home. They usually last about two hours. They could have a guest speaker or be a time of discussion around a theme, or a freer less-structured discussion. Usually, there would be a snack time. All in-person meetings are announced on the Scleroderma Quebec website with contact information, dates and times and details about the location. You are welcome to visit in-person meetings in different regions of Quebec. If you would like to attend an in-person meeting and there is not one announced for your region, you could contact the support group leader in your area and express your interest. That could be the spark that helps get one organized.

ZOOM MEETINGS

Like in-person meetings, Zoom meetings can be occasional or regular. They can have special guests and free or structured discussions. Many groups hold meetings once a month or every six weeks, for example. Zoom meetings usually last a maximum of ninety minutes. Because they are online, you are not limited to your geographical region. You can attend a Zoom meeting organized by a leader who lives anywhere in the province. You will want to choose a Zoom group that meets at a time and on a day that suits your schedule. Again, please see the list of groups and meetings on the Scleroderma Quebec website for contact information, dates, and times. You can try out more than one group to find the group that suits your needs best.

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WHAT DO I NEED TO JOIN A ZOOM MEETING?

To join a Zoom meeting, you will need a computer, tablet or cell phone with a camera and microphone. After you contact the leader of the support group, they will send you a link to the meeting by email. To attend the meeting, you will need to click on the link in the email. **If you are unfamiliar with this technology, please tell the leader that you would appreciate some help** in becoming proficient. They will be more than happy to do a practice Zoom with you in preparation for your meeting. For those who do not have Internet, it is still possible to join a Zoom meeting by telephone but that would incur long-distance charges if you do not have a long-distance phone plan. .

WHEN DO SUPPORT GROUPS MEET?

Most support groups meet from September through May or June. Some meet once a month, others every six weeks and some meet occasionally. Generally, there are no meetings in the summer. Before the pandemic, most groups stopped for the winter months because of road conditions and concerns about Raynaud's syndrome. Now, with the possibility of Zoom meetings, many groups meet throughout the winter via Zoom. Some groups meet in the morning, and others in the afternoon or evening. Most groups meet on weekdays but there are occasional meetings on weekends. For more details, check the Scleroderma Quebec website.



HOW DO I JOIN A SUPPORT GROUP?

The first step for joining a support group is to contact Scleroderma Quebec at 514 990 6789 or by email at info@sclerodermie.ca. They will refer you to a leader who will help you find the right group for you. Alternatively, you can go to the list of meetings posted on the first page of the Scleroderma Quebec website, and find the contact information for the group you are interested in. Then you can contact the leader of the group directly by phone or email. Usually, they will set up a time for a phone call or Zoom to get to know you better and answer your questions about their group.

If you are planning on attending an in-person meeting and the place and time are available on the website, it is still a good idea to contact the leader to let them know you are planning to attend. If there is a last-minute change in plans, they will be able to contact you and let you know about any changes.

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HOW CAN I BECOME A LEADER OF A SUPPORT GROUP?

Scleroderma Quebec is always recruiting support group leaders for both in-person and Zoom groups. Many leaders find that this volunteer commitment contributes to their own well-being as they find valorization in supporting others and using their talents of organization and compassionate caring. Scleroderma Quebec provides a training course for leaders developed by SPIN, a detailed guidebook, and a support committee. It is very important to the association that leaders feel affirmed and supported in their volunteer work.

If becoming a leader interests you, first contact Scleroderma Quebec to communicate your interest. Second, join an existing support group to learn how groups function by being a part of a group. Finally, apply formally to Scleroderma Quebec to go through the selection process. Many groups have co-leaders so even when you become a leader you will be supported by your co-leader.

THANK YOU

Many thanks to all the volunteer leaders who have pioneered the Scleroderma Quebec support groups over the last thirty or so years. Sincere thanks to Scleroderma Quebec and the professionals and volunteers working for the association who make these groups possible by providing the structure within which the groups can thrive. Special thanks to SPIN and Brett Thombs for developing the SPIN-SSLED program that equips leaders to develop healthy support groups.

IN CONCLUSION

Joining a support group can be a real help to many people living with scleroderma. Sharing with others with the same condition reduces the feeling of isolation. Groups offer a safe, positive, and confidential space to share concerns and learn more about coping with the disease. Often members experience increased hope and resilience. Leaders are well-trained and supported under the supervision of Scleroderma Quebec. There are well-defined guidelines for group members which help maintain the quality of the interactions. If you are interested do not hesitate to contact Scleroderma Quebec by phone at **514 990 6789** or by email at **info@sclerodermie.ca** or contact a support group leader for more information. We are looking forward to hearing from you.



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www.en.sclerodermie.ca

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