

# SUPPORT GROUPS

## YOUR PERSONAL HEALTH SUPPORT NETWORK

Taking an active role in managing your own health care is important in achieving your optimal wellness level. It is equally important to cooperate and communicate effectively with your primary care physician who is managing your illness. While these two - you and your doctor - are the focal points of your health management team, many other people and resources can form part of your health and support network:

Family and friends can provide emotional support, encouraging you and assisting with activities of daily living that you find more difficult

Other health professionals such as medical specialists, nurses, physical and occupational therapists, psychologists, massage therapists, etc. may form part of your treatment team

Community resources (voluntary and government agencies) offer health, social and rehabilitation services that may benefit a person with scleroderma

Scleroderma support groups will enable you to meet and exchange information with others who have scleroderma

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## BENEFITS OF SUPPORT GROUPS

One of the biggest advantages of a support group is that you'll meet other people who feel like you do. This can improve your mood and make you feel less alone.

Being in a support group can help you to learn successful tips about coping as well as managing daily choices and challenges.

Problem-solving with your fellow group members may also remind you that you also have knowledge and experience to share. That can prompt you to remember to apply these skills in your own life.

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## AM I A CANDIDATE?

Support groups can help anyone who needs emotional support, feels isolated or feels that the other people in their lives don't fully understand their struggle with scleroderma.

Peer-led support groups do not replace individual/group therapy or professional counselling, but can be a cost-effective and helpful tool to complement more formal treatment.

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## JOINING A GROUP - WHAT TO EXPECT

You may be uncomfortable at first sharing your concerns with strangers; however, the fact that the others in the group are facing similar challenges may help you to open up and discuss your feelings. Everything that takes place during the support group will be kept confidential.

Usually a support group is led by a member who has had some training or experience in facilitating group discussions. Unlike group therapy, peer self-help groups are usually not led by a professional therapist (such as a nurse, psychologist or social worker). These groups are not a substitute for more formal professional counselling.

You may get helpful ideas from other members, but don't take their opinions and comments more seriously than those of your doctors and health care team. Always keep your primary care physician informed of new therapies or lifestyle changes.

While groups share a common goal of providing mutual emotional support, all groups are different. Groups vary in size, frequency and format of meetings. Some groups may arrange community activities or guest speakers while others may be more informally organized.

If you have concerns about how your group is doing, you may want to speak privately to the facilitator who leads it to share your feedback, or you may want to find another group or other form of personal support that better suits your needs.

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## SCLERODERMA CANADA SUPPORT GROUPS

Scleroderma support groups exist across Canada. To find a support group in your area, contact the regional division where you live.

Check <http://www.scleroderma.ca>  
for the most updated information or contact the SC Office at 1-866-279-0632 or [info@scleroderma.ca](mailto:info@scleroderma.ca)

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## STARTING A SUPPORT GROUP

If there is no group near you and you are interested in starting one, the following questions can help you decide whether being a support group leader is a good fit for you:

### Do you have the time?

Review your schedule and see if realistically you can put aside time to prepare for and run meetings.

### How are you feeling?

Determine if your health is adequate at this time to take on this added commitment.

### Are you comfortable leading?

Consider your ability to organize, speak in front of groups and facilitate conversations.

### How do you approach your own illness?

Support group leaders need to lead with an overall sense of hope and encouragement, focusing on positive solutions vs. negative reactions.

Scleroderma Canada can provide funding, tools and training resources to support you as you support others.  
Please contact us!