

## Scleroderma Manitoba January 22 Support Group Summary

On Saturday, January 22, approximately 20 community members joined together on Zoom for small group discussions. After introducing ourselves, and a brief practice session with online breakout rooms, we separated into smaller groups to discuss different symptoms of scleroderma.

Approximately 20 participants were able to choose the topic of their choice by choosing a breakout room. Topics are shown below:

	Breakout Room 1	Breakout Room 2	Breakout Room 3	Breakout Room 4
Session 1	Fatigue	Reynaud's: Finger and Toe Sores	Lung Issues	Gastrointestinal Issues
<a href="#">Return to Main Session (brief wrap-up – 1 minute each facilitator)</a>				
Session 2	Fatigue	Reynaud's: Finger and Toe Sores	Pain and Stiffness	Gastrointestinal Issues
<a href="#">Return to Main Session (brief wrap-up – 1 minute each facilitator)</a>				

Meeting in a smaller group enabled us to share our experiences, ask questions, and compare coping strategies. After a 20-minute discussion, we reconvened in the “main meeting room” and the four facilitators gave a brief summary of the discussions. We then chose a different topic/symptom to discuss and held another 20-minute small group discussion group.

The groups came up with many coping strategies, some of these are summarized below:

Symptom	Observations   Coping Strategies   Ideas   Suggestions
<b>Fatigue</b>	<p>With scleroderma, a lot of time and energy is spent caring for yourself</p> <p>Importance of rest, taking a nap</p> <p>Don't try to “push through it”</p> <p>Take one day at a time</p> <p>Bank up energy. E.g., If you know you have a big event coming up, rest up (“bank up”) energy a couple of days prior</p> <p>It's not always clear how much energy you're going to have...you can wake in the morning and feel great but sometimes energy ebbs away</p> <p>Don't get down on yourself</p> <p>Be flexible in planning</p> <p>Try to manage expectations of yourself</p> <p>It can be hard to acknowledge your growing limitations over time</p> <p>It's okay to ask for help</p> <p>Sunshine and warmth helps!</p>

Symptom	Observations   Coping Strategies   Ideas   Suggestions
<b>Reynaud's</b>	<p>The importance of keeping our hands and feet warm. If necessary, wear gloves and/or mittens indoors as well as outdoors. It is beneficial if you keep the core of your body warm. Wearing gloves in stores is helpful.</p> <p>One person discussed using non-stick foam to protect open sore ulcerated areas. If you have open areas, using an antibiotic ointment such as Polysporin or Ozonol can be soothing.</p> <p>Be very careful when you are using a knife or sharp object as cuts or wounds are hard to heal due to poor circulation</p> <p>Wearing gloves when doing dishes helps to protect the hands from extreme temperatures.</p> <p>When driving or just outside, it is helpful to wear hand warmers in your mittens which can last for several hours.</p> <p>Some of the participants discussed taking a vasodilator such as Adalat but found them questionably helpful.</p>
<b>Lung Issues</b>	<p>Fatigue always accompanies breathing issues (comments mirrored fatigue breakout discussion)</p> <p>Comments about various Rx and side affects – names not noted</p> <p>Descriptions of various lung diagnostic tests at request of newly diagnosed group members</p>
<b>Gastrointestinal Issues / Reflux</b>	<p>To avoid choking: cut up your food smaller, eat slower, and drink water with your food</p> <p>To reduce Gastro reflux: use meds to minimize, raise the head of your bed, don't eat after supper, eat your largest meal earlier in the day</p>
<b>Pain and Stiffness</b>	<p>A lot of effort goes into explaining connective tissue disease/symptoms to uninformed allied health professionals (i.e., P.T.)</p> <p>Advice from a more informed PT: the goal is not necessarily doing ALL the reps, but the number of reps YOUR disease allows</p> <p>Scleroderma pain and stiffness often “passed off” as “only aging” by physicians of older scleroderma patients</p> <p>Managing expectations regarding the ability to exercise and the resulting aftereffects</p> <p>Sometimes the pain and stiffness makes patients feel like they are made of glass</p> <p>Mild exercise like walking or yoga helps to ease pain and stiffness</p> <p>CBD oil applied topically may provide pain relief</p>

Thank you to Linda Cassell, Linda Clark, Debbie Robitaille for facilitating some great discussions and Dianne Brydon for technical support that helped us all get into the breakout room we wanted.

Our next Support Group meeting is scheduled for Saturday, April 23<sup>rd</sup>, 10:30 am. Watch our website for more info and a registration link.

