



Hamilton Scleroderma Group
 50 Charlton Ave E, Room F336-1
 Est 2010

Introduction: After receiving a scleroderma diagnosis, it's crucial to rely on credible resources. Reach out to medical offices and patient organizations for accurate information tailored to your needs. Hold off on internet searches until we provide you with a list of reputable websites. Instead, focus on building a support network. Connect with healthcare professionals, patient groups, and learn about scleroderma through reliable sources. Your diagnosis is the beginning of a journey, and whilst the effects of this disease will be unique to you, you are not alone as many patients share symptoms and have a similar concern. With the right information and support, you can navigate your journey more effectively.

Standard of care testing:

Test required	Pulmonary Function Test (PFT)	Echocardiogram (Echo)	CT (computed tomography)	Blood work for specific immune testing
Explanation of the testing	This is performed to assess how the disease may be affecting your lungs. This simple and painless test measures various aspects of lung function, such as capacity and efficiency. Systemic sclerosis can lead to lung scarring, making breathing more difficult. The test helps doctors monitor and manage respiratory complications early on. The results guide doctors in suggesting medications and interventions to maintain optimal lung function, contributing to an improved quality of life	An echocardiogram, or "echo," is a straightforward heart test. Pressing a probe on your chest over the chambers and valves of your heart, it uses sound waves to create detailed images, helping doctors assess how the disease may be impacting the heart. Systemic sclerosis can lead to heart-related complications, and the echo allows for early detection and management of issues, contributing to better overall care and improved quality of life.	Systemic sclerosis can lead to lung complications, including scarring and inflammation. If you have shortness of breath or changes in the PFTs, a chest CT (computed tomography) scan is often performed to examine the lungs. This imaging test provides detailed pictures of the lungs and surrounding structures. This helps doctors assess the presence and extent of these changes, identify abnormalities, and guide treatment decisions.	Typically, this is done in a special lab at the hospital and this is not testing that can be done in the community. Some of this testing is sent to another province and can only be ordered by specialists like a rheumatologist
Test timing	usually every 6 -12 months	usually once a year	usually done as a baseline and not required ongoing unless areas are identified that need to be routinely monitored	Usually done once when you are first diagnosed

Self-help measures: To stay warm, consider using heated gloves; ensure they provide warmth all the way to the fingertips. If you have private insurance, consider requesting a letter from your treating physician. This letter can support your claim for reimbursement, especially if your plan includes a health spending account. If you do not have private insurance, keep the receipt and talk to your accountant as you may be able to claim as a medical expense on your tax return.



Hamilton Scleroderma Group
50 Charlton Ave E, Room F336-1
Est 2010

For digital ulcers: Consider exploring over-the-counter options like Vitamin E ointment and Manuka honey for potential relief. Additionally, if you're dealing with non-healing ulcers, you may want to discuss the possibility of a prescription for Tadalafil cream with your healthcare provider. There are multiple medications that are usually suggested to help heal ulcers. Talk to your doctor about these.

For research purposes: Engaging in research projects can empower patients, making them active participants in their medical care. To explore such opportunities, consult your treating respiratory or rheumatology specialist to inquire about studies you may qualify for. Additionally, you can search online for research opportunities at <https://www.canadiansclerodermaresearchgroup.org/>.

Patient Partnerships and Connections: Scleroderma Canada and Ontario are great patient support organizations. You can explore available support groups in your area. They regularly organize social mixers, providing a great opportunity to connect with others. To learn more, I suggest visiting their website and checking their social media accounts for additional information. Joining such groups can offer valuable support and insights.

Online resources:

Scleroderma Canada: <https://www.scleroderma.ca/> **Scleroderma Ontario:** <https://www.hardword.ca/>

** Their social media accounts can be found on Facebook as well as Instagram, this is the best way to stay up-to-date with information.*

Additional thoughts: Starting your own medical file is a wise step, and obtaining copies of testing and clinic notes can be invaluable. Keep a binder, and write notes yourself or as a caregiver to write notes during appointments. While the medical community is generally collaborative, having your records on hand is especially helpful during initial visits with new healthcare professionals.

KNOW YOUR BLOOD PRESSURE. INVEST IN A BP MACHINE! For certain subtypes of SSc, there is an increased risk of the kidneys being affected by the disease. This is called Scleroderma Renal Crisis and usually presents with no symptoms, but raised BP, and can lead to irreversible kidney damage if not treated early. Regular blood pressure monitoring is crucial. Check your blood pressure three times a week to detect any signs of Scleroderma Renal Crisis (SRC). Understand your usual blood pressure range and seek emergency care if you observe a persistent increase of 20 points or more over three consecutive measurements within 24 to 48 hours. Tell the ER docs that you have scleroderma and may be at risk of SRC, and that they should check your CBC, Creatinine and urine for signs of hemolysis and kidney damage,

Reliable websites:

<https://rheuminfo.com/> great resource to look at medications and layman's terms/explanations. Developed by Dr. Andy Thompson (Rheumatology).

<https://www.thombsresearchteam.ca/spin> research-based website with lots of self-help modules related to scleroderma patients.

<https://arthritis.ca/> for patients with overlap diagnosis of any arthritic conditions.

Additional Resources:

"Supporting a loved one with Scleroderma" By Dr. Danielle Rice *education resource developed with Scleroderma Canada

"The First Year of Scleroderma" By. Karen Gottesman

March 2024

Created by Stephanie Densmore-Farnworth

Information verified by Dr. Maggie Larché