Frequently Asked Questions (FAQ)

Q. What causes Scleroderma?
A. Scleroderma is not contagious; you cannot catch it from someone, nor can you give it to another person. The cause of scleroderma is currently unknown. There does not seem to be evidence that Scleroderma is hereditary although, research is being conducted that indicates there are other factors that may trigger scleroderma in people who are predisposed. There is also some research suggesting viral and bacterial infections may start the development of the disease.

Some environmental factors are now known to be possible important triggers for the development of a scleroderma like condition. Some workers in the PVC (Plastics) industry using polyvinyl chlorides have developed a scleroderma like condition. Substances such as silica, and epoxy resins may also cause a condition which has the features of scleroderma. Contaminated rapeseed oil, sold as olive oil in Spain in the early 1980's resulted in many people dying of a condition called Toxic Oil Syndrome. Some of the survivors of this condition went on to develop a scleroderma type illness. Scleroderma caused by these environmental factors appears to respond better to treatment than scleroderma from an unknown cause. It is important to recognise that for most people with scleroderma, the cause is unknown, and that environmental factors may not be involved at all. (Reference: http://www.sclerodermansw.org/scleroderma.htm)

Doctors have traditionally believed that it simply occurs naturally and cannot be cured, but a growing number of experts suspect an autoimmune response to environmental toxins. There is a good deal of evidence that silicone implants or occupational exposure to silica can cause the disease, and patients with autoimmune disorders such as scleroderma sometimes dramatically improve when their silicone implants are removed. The chemical polyvinyl chloride (PVC) has also been linked to a form of scleroderma. Exposure to PVC may be occupational, or through a variety of ordinary items like car interiors, water pipes, plastic food wrappers, and carpets. Everyday exposure levels may be enough to induce multiple chemical sensitivity syndrome in
some.

Solvents such as those found in typewriter correction fluid, paint removers, and other products have also been linked to scleroderma. Many scleroderma cases benefit from specific and individualized nutritional support that activates the release of toxins through liver-produced bile. Most traditional detoxification methods fail as toxins are backed up into the brain, skin, and kidneys causing the condition to worsen. (Reference: http://www.wellsphere.com/general-medicine-article/scleroderma/796564)

Q. Is there such a thing as worker’s Scleroderma?
A. Yes. Ontario’s Workplace Safety and Insurance Board recognizes scleroderma resulting from occupational exposure to silica dust as an occupational disease pursuant to subsection 2(1) of the Workplace Safety and Insurance Act. According to the guidelines, the following is persuasive evidence that a worker’s scleroderma is due to the nature of the employment:

- the scleroderma, as defined below, is diagnosed by a licensed internist or rheumatologist, and
- the worker was exposed to substantial levels of silica dust in the employment before the diagnosis of scleroderma is made.

The level of exposure to silica dust is considered "substantial" when it is continuous and long-term, or when it is of short duration but intense.

Scleroderma has been observed among workers occupationally exposed to silica dust for cumulative periods ranging from as few as 3 years to as many as 43 years. Case reports indicate that workers diagnosed with scleroderma have been exposed to extremely high levels of silica dust. Such exposure is exemplified by mining, or sandblasting in an enclosed space.

Occupational settings and processes that may expose workers to substantial levels of silica dust are:

- hardrock mining
- sandblasting

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Q. How serious is Scleroderma?
A. Currently, Scleroderma is classified as a chronic disease with no known cure. The diagnosis of any chronic disease is considered serious. Scleroderma has a wide range of symptoms which are specific to each patient making it difficult to generalize how serious this disease is. The seriousness will depend a great deal on what parts of the body are affected and to what extent. Proper diagnosis, monitoring, and treatment by physicians can minimize symptoms of scleroderma and lessen the chance of irreversible damage.

Q. Is Scleroderma inherited?
A. Scleroderma is not considered a hereditary disease. However, some families are more affected by autoimmune disorders than others. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic diseases. Although scleroderma is not thought to be an inherited disease, there may perhaps be a link between its onset and those who come from families with a history of rheumatic diseases. African Americans and Native Americans generally have more severe scleroderma than Caucasians. These findings suggest a hereditary (genetic) component to scleroderma and other autoimmune disorders. Environmental factors could also put people at risk for

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scleroderma. For example, men exposed to silica appear to have a higher risk for developing sclerosis and certain drugs are capable of causing a sclerosis-like reaction.

**Family History.** A family history is the strongest risk factor for scleroderma, but even among family members, the risk is very low (less than 1%).

**Genetics.** Genetic factors appear to play a role in triggering the disease, but most cases are unlikely to be inherited. Preliminary research suggests that patients with certain gene variations may be more susceptible to scleroderma than those who do not carry these variations.

**Ethnicity.** Limited data on risk by ethnic group in the United States suggests that the risk from highest to lowest is the following: Choctaw Native Americans (highest), African-Americans, Hispanics, Caucasians, Japanese Americans.


**Q. Why should I be monitoring my blood pressure regularly if I have systemic Scleroderma?**

A. Regular self-monitoring of blood pressure is crucial in newly diagnosed people. Increases in blood pressure signify the onset of hypertension. Hypertension requires rapid action by medical professionals as it may indicate renal crisis. Renal crisis is a medical emergency and considered one of the most life threatening complication of Scleroderma. Renal crisis is the onset of high blood pressure, kidney failure, and increased levels of urea and renin in the blood. People recently diagnosed with Diffuse Scleroderma are at a much higher risk of developing renal crisis compared to those with Limited Scleroderma. Rapid diagnosis and therapy are the keys to overcoming renal crisis.

**Q. How do I cope with Scleroderma?**

A. Although there is a single disease called scleroderma, one person’s symptoms and course may look very different from another’s. Similarly, people do many different things to cope and live as well as possible with scleroderma, and some strategies may work well for one person and not for another. Generally, however, many of the steps that people with scleroderma take to cope successfully fall into three areas:
(1) **Obtaining accurate information on scleroderma and developing relationships with knowledgeable and caring healthcare professionals in order to get the best possible care within the medical system.** Often when people learn that they may have scleroderma or when they are faced with new or frightening symptoms, they seek information. The internet is a valuable resource, but much of the information available on the internet has not been reviewed by people with expertise in scleroderma. As a result, the accuracy of this information varies quite a bit. Good sources of information are websites of established and reputable scleroderma societies, such as the Scleroderma Society of Ontario, the Scleroderma Society of Canada, Sclérodernie Québec, or the Scleroderma Foundation in the United States. The Johns Hopkins Scleroderma Center has an outstanding patient-oriented website ([http://www.hopkinsscleroderma.org/](http://www.hopkinsscleroderma.org/)), and other major university-based scleroderma treatment and research centers around the world often provide sound and useful information. Beyond the internet, there are a number of books that people with scleroderma and people close to them have found to be helpful in understanding and coping with the disease and its effects:

- Living a Healthy Life with Chronic Conditions, 3rd edition, by Kate Lorig, RN, DrPH et al. (2006). Bull Publishing Company.

(2) **Developing and/or maintaining a good support network.** Good support can take on many forms and some forms of support may work better for some things than others. Some people rely upon family members and friends, whereas others may look to support from other people living with scleroderma, perhaps in the form of a support group. Other people may seek professional supports, such as psychologists or therapists, or religious/spiritual support. Many people rely upon several different kinds of support. The key thing is to have people available for both practical and emotional support.

(3) **Staying as active and involved as possible.** There will be times when scleroderma may make it difficult to be as involved as you would like to be in activities that you enjoy, social and otherwise. Although staying active and involved may require making adaptations to usual
activities or seeking alternative activities, the physical and emotional benefits make it worth the effort. (Reference: Dr. Brett Thombs, PhD, Assistant Professor, Department of Psychiatry, McGill University / Jewish General Hospital, Montreal).

**Q. Does Scleroderma cause depression?**

A. It is important to distinguish clinical depression from the sadness and other emotional distress that often go along with living with a disease like scleroderma. Clinical depression is characterized by a low or sad mood most of the day, almost every day, or the loss of interest in all, or most activities, along with a number of other emotional and physical symptoms. Compared to approximately 5% of people in the general population who have depression at any given time, the rate may be as high as 15% or so among people with diseases like scleroderma. When symptoms of depression are present that make it difficult to cope with living with scleroderma or any other aspect of daily life, it is a good idea to consult with a health care provider. Although most people with scleroderma do not have depression, many experience other forms of emotional distress, such as bouts of sadness, frustration, and anxiety or worry related to living with the condition. While these may or may not constitute clinical depression, people who experience significant distress may benefit from professional support. Others may find different kinds of support useful, such as from family, friend, or others living with scleroderma. Staying active, both physically and socially, is also helpful for many people. (Reference: Dr. Brett Thombs, PhD, Assistant Professor, Department of Psychiatry, McGill University / Jewish General Hospital, Montreal).

**Q. Is there any hope for a cure for Scleroderma?**

A. Absolutely. There have been huge advances in the treatment of symptoms of Scleroderma in the last decade. Survival rates amongst those diagnosed are much improved as well as patient’s quality of life. Fortunately, Scleroderma research has become a very popular field in the last decade and there are many promising studies being conducted at this time.
Q. Will smoking make my Scleroderma symptoms worse?
A. Yes! Smoking is not a healthy choice for anyone, but for those suffering from Scleroderma; smoking can have a large impact on their respiratory, vascular and gastrointestinal tracts. Stopping smoking is the number one thing you can do to lessen your symptoms and improve your longevity. Lung problems can be very severe with Scleroderma patients, smoking drastically complicates these problems. Smoking constricts blood vessels and can have a large impact on Raynauds symptoms. Smoking also makes your mouth dry which can worsen the symptoms of Sjorgens syndrome.

Q. How do I prevent / deal with digital ulcerations?
A. Digital ulcers are skin sores that most often occur on your fingers, but are also reported on toes and joints. These ulcers are extremely painful and are difficult to heal. They occur because there is limited circulation to these areas. Ulcers often start as a cut that doesn’t get enough blood to heal properly. Preventing and healing ulcers can be difficult. Strategies that have proven effective include

- Keep your hands protected - this helps avoid getting ulcers in the first place and helps aid in healing current ulcers. This means wear protective gloves while cleaning or doing activities that can injure hands. Keep your hands moisturized – this will help keep them from cracking and possibly producing an ulcer. Keeping ulcers moisturized will help in healing. Use non perfumed lotions as perfumes can be drying to hands. A humidifier is useful in dry environments. Keep your hands warm - this will help to prevent new ulcers and heal existing ones. Wear protective clothing in cold environments to keep hands warm, wearing multiple thin layers is better than one bulky layer. Keep ulcers infection free – wash hands often remembering to moisturize after. If an infection does occur antibiotics will likely be needed.
- Keep the blood flowing to your fingers – with or without an ulcer. Do not wear tight clothing that will limit blood flow and may cause friction on your ulcer. Avoid putting pressure on your ulcer in your everyday activities, this may be challenging and you will likely have to experiment with using other fingers to perform your regular tasks. Lastly

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try to encourage blood flow to accelerate the ulcer healing by massaging fingers and exercising hands.

Q. What can I do to manage Raynaud’s in the winter months?
A. Raynaud’s phenomenon occurs when the blood vessels in the fingers and toes contract (close up) excessively following exposure to cold. The resulting reduction in blood flow causes fingers (and toes) to become blue or white in colour. When severe there is pain and numbness as well. Raynaud’s is brought on by a cold environment or stress. Avoiding the cold or protecting yourself from the cold should be priorities for managing Raynaud’s in the winter. Wear multiple thin layers of clothing opposed to one bulky layer. Ensure that layers are not too tight so they do not restrict circulation. Raynaud’s can also be triggered by stress. Stress restricts blood flow and thus makes Raynaud’s worse; working on reducing stress should be a goal for those suffering from Raynaud’s.

Q. I am having trouble sleeping is this normal?
A. It is estimated that approximately 30% of the general population complains of sleep problems with about 10% reporting problems that affect their ability to function. There has not been very much research on sleep in scleroderma, but there is reason to believe that sleep problems may be much more common among people with scleroderma when compared to the general population. A recent survey of more than 400 Canadians with scleroderma found that 76% of those surveyed reported difficulty sleeping at least some of the time and 59% said that poor sleep affected their ability to function at least moderately. Many studies have found that older people and women, particularly in the postmenopausal years, have difficulty with sleep and that sleep can be affected by cigarette smoking, alcohol and coffee consumption, and many prescription medications. Depression, anxiety, and worry have also been linked to poor sleep. For many people living with scleroderma, pain can play a major role in sleep problems. Gastrointestinal problems, including heartburn, can also be uncomfortable and painful, making sleep difficult. Given the importance of sleep, it is important to let your health care provider know
Q. Should I feel so tired all the time?
A. Everybody gets tired from time to time. Fatigue from scleroderma, however, is different from normal tiredness in that it is often not related to physical exertion and not helped by getting enough rest. For many people, fatigue from scleroderma is debilitating and impacts the ability to go about daily activities more than any other symptom of the disease. Of the more than 400 Canadians with scleroderma surveyed in the recent Scleroderma Society of Canada/Canadian Scleroderma Research Group survey, almost 90% said that they experienced fatigue at least some of the time, and more than 70% said that it had a moderate to severe impact on their ability to carry out normal daily activities. Many factors contribute to the fatigue experienced by people who have scleroderma, and there is no easy remedy. There are some things, however, that can be done to reduce the impact of fatigue. Light, consistent exercise, for example, that does not go beyond reasonable limitations, can help keep the body strong and boost energy. Similarly, eating a nutritional diet and maintaining a healthy weight can help combat fatigue. Other things that can be done include being sure to get enough rest, pacing oneself through the course of the day to avoid overexertion, and managing stress. (Reference: Dr. Brett Thombs, PhD, Assistant Professor, Department of Psychiatry, McGill University / Jewish General Hospital, Montreal).

Q. Why do people with scleroderma get heartburn and difficulty swallowing?
A. Heartburn in Scleroderma patients is caused by the dysfunction of the valve that separates the stomach and the esophagus. This allows stomach acid to flow backwards up the esophagus causing heartburn. Abnormal contractions of the esophagus also occur so acid is not cleared properly and may result in difficulty swallowing. Strategies for coping with heartburn include using over the counter medications that neutralize or reduce stomach acids, elevating the head of your bed, eating smaller meals, and avoiding foods that cause heartburn are also

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good coping strategies. Chewing food well, eating slowly, as well as drinking fluids with meals can also help with heartburn.

Q. Why do my hands hurt and feel stiff? What can I do?
A. People with Scleroderma have thickened and tight skin, this can lead to stiffness and reduced motion of the joints in affected areas. Some studies have shown that those with Scleroderma may benefit by range of motion exercises, where the fingers, hands and wrists are stretched daily to keep them moving and mobile. Other studies have found connective tissue massage with joint manipulation can also be effective in combating stiffness.

Q. Is erectile dysfunction related to Scleroderma?
A. Males with Scleroderma suffer more frequently from erectile dysfunction compared to the general population. Treatment for men with Scleroderma can be a challenge as there is limited research. Doctors are first likely to rule out any other potential causes of the erectile dysfunction besides Scleroderma.

Q. My mouth is so dry what can I do?
A. Dry mouth, also called Sjogren’s Syndrome, can be a real nuisance to those affected. Staying hydrated by constantly sipping beverages can help. Sucking on hard candy or chewing gum such as Wrigley’s Excel Mist may also help. Avoiding foods that dehydrate the mouth and body such as alcohol, caffeine, or salty foods can keep it from getting worse. Sometimes the mouth is so dry that it becomes difficult to swallow, in which case drinking liquids while eating may also help.