Living with Scleroderma has many forms and a number of different symptoms that may present themselves singly or in combinations at various times throughout the course of the disease. Some symptoms develop with relative suddenness; others take years to develop. The exact course the disease may take is unpredictable, and the prognosis will vary from individual to individual. There may be periods of time when the person with scleroderma will be free of troubling symptoms and feel well. At other times, he or she may feel quite ill. Spontaneous improvements may occur. The skin, in particular, sometimes softens and becomes more pliable after a number of years. Spontaneous remissions, times when symptoms may actually disappear, may continue for long periods. The person with scleroderma should be cautious about attributing such improvements or remissions to a particular treatment, diet, or so-called “cure.” Scleroderma is a difficult disease to study because of its variable nature, its prolonged course, and the relatively small number of persons affected by it. Under these circumstances, it is difficult to conduct scientifically sound studies proving the value of a particular drug or treatment. Therefore, medical decisions are based on individual patient assessments – that weigh possible benefits against potential risks.

Scleroderma Society of Ontario

Keeping Things in Perspective

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Become Your Own Advocate – A Holistic Approach to Living with Scleroderma

When a person is first diagnosed with scleroderma, especially for those without access to specialized medical care or who live outside largely populated areas, he or she may never have met another with the same diagnosis. This feeling of ‘being alone’ often contributes to the emotional grief that a person with scleroderma may feel in light of their changing health and body. Stigma – experienced through the way that society has previously described scleroderma (by focusing largely on the losses) has contributed to misunderstandings about the abilities and needs of persons living with the disease. Although the losses for persons with scleroderma are real, it is important to think of oneself not as a patient (unless in the context of a physician’s office, hospital or clinic), but as a total person with a full life. Patient education research in persons with scleroderma has revealed that those who are most successful at learning how to manage their disease are also those who are most able to access and participate in appropriate medical care, live their life with a positive attitude, and learn as much as they can – about themselves and their disease. In essence, these people are their own advocate! An excellent article written by Cindy Mendelson and Janet Poole entitled, “Becoming your own advocate: Advice from women living with Scleroderma” (Disabil Rehabil. 2007 October 15; 29(19): 1492–1501) can be read at: www.ncbi.nlm.nih.gov/pmc/articles/PMC2768647/

What is Scleroderma?

Scleroderma (also called systemic sclerosis) is a chronic, multi-system autoimmune disease whereby the body’s immune system attacks its own tissues. Scleroderma can vary a great deal in terms of severity. Although scleroderma is often referred to as if it were a single disease, in fact, it is really a symptom of a group of diseases that involve the irregular growth of collagen. Collagen is a protein in connective tissue found in skin, tendons, ligaments, cartilage, bone, blood vessels, the digestive system and other internal organ surfaces. In some forms of scleroderma, hard, tight skin is the extent of this irregular collagen over-production process. In other forms, however, the problem goes much deeper, and may severely affect blood vessels and internal organs such as the heart, lungs, and kidneys. For many persons with the disease, they have few or minimal symptoms and are able to lead a “typical” life. For others, the disease is much more severe and causes disfiguring, disabling and life-threatening changes to the body. In all cases, scleroderma is a chronic, life-long health condition. At present there is no known cure, but as with other chronic illnesses there are ways people can control or manage its systems.

Scleroderma Society of Ontario

Living with Scleroderma

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Learning How to Cope with & Adapt to Change
Learning to recognize early symptoms of disease activity may lead to earlier detection and diagnosis of scleroderma and to prompt initiation of treatment. Some of the more promising medications in current use are slow-acting and the sooner treatment is begun, the better the results may be. If one has already been diagnosed as having scleroderma, it is especially important to watch for and report to the physician new or changed symptoms. Early treatment may prevent symptoms from worsening and may decrease the chance of permanent tissue or organ damage.

**Developing Personalized Care Plans**

While there is no proven cure for scleroderma, much can be done to prevent, minimize, or alleviate its effects and symptoms. The symptoms of scleroderma vary greatly from individual to individual; the manner in which each person responds to treatment also varies greatly; and there are many treatment options. It is important, therefore, that a physician experienced in the management of scleroderma work out an individually-tailored program to meet the specific needs of a person with this disease. Close cooperation with the physician will help him or her develop such a program.

**Physical Therapy & Exercise**

Physical therapists can help the person with scleroderma develop an appropriate program. Such a program may consist of "range of motion" exercises (important to help further minimize joint damage, skin ulcers and infection), paraffin wax baths, hydrotherapy or water therapy, strengthening exercises for muscle weakness, and gentle massage. These treatments can be carried out at various locations, including a hospital physical therapy department and in the home. The physician may recommend an exercise program involving activities such as stretching, walking, or swimming. Persons with scleroderma may find that their tolerance for activity and movement is below normal, so activities should be carried out in moderation, resting when tired. Individual exercises should be performed gently and with due care, and the exercise program should be built up gradually.

**Protecting the Joints**

To minimize further joint damage and to reduce the possibility of skin ulcers and infection it is important for persons with scleroderma to minimize pressure or stress on the joints by using them properly and maintaining their mobility and function by stretching and "range of motion" exercises. A variety of self-help aids and adaptive mechanical devices are available to help protect and to alleviate stress on the joints while carrying on the activities of daily living. Occupational therapists can demonstrate such devices and give further instruction on joint protection. To view a video presentation developed by Dr. Janet Poole, one of the world's leading experts Scleroderma Occupational Therapy, please visit the Scleroderma Society of Ontario's video library at: [www.sclerodermaontario.ca/Scleroderma-Video.html](http://www.sclerodermaontario.ca/Scleroderma-Video.html)

**Building Health & Community**

For a person with scleroderma, it is important that he or she participate actively in his or her own healthcare – and communicate cooperatively and effectively with the physician who is managing the disease. While the person with scleroderma and the physician are the focal point of the management "team" - many other persons and resources may be called upon to form a health and community support. Family and friends may provide emotional support for the person – to encourage the person with to follow the recommended treatment program, and assist in carrying out activities that he or she finds difficult. The health team begins with the physician, but may include many other health professionals such as medical specialists, nurses, physical and occupational therapists, and psychologists or others trained in counseling. Directories of community resources typically list a large number of voluntary and governmental agencies providing health, social, and rehabilitation services that may be of benefit to the person with scleroderma. Joining a Scleroderma Society of Ontario Support Group enables the person with Scleroderma to meet and to exchange information with others who experience similar issues, as well as to learn more about scleroderma. The extent of the health and support is limited only by the imagination and resourcefulness of those helping to create it.

**Taking Medications**

It is essential that the person with scleroderma take only those prescribed; read label warnings and follow instructions carefully as prescribed by the physician. Scleroderma symptoms vary from person to person, requiring different treatment. Some may benefit from certain drugs, while others may not. One should not be concerned if the physician prescribes different medications for different persons. Furthermore, individual tolerance for the drugs used in scleroderma varies greatly. The physician may find it necessary to adjust the medication program accordingly.

**Common-Sense Measures**

- Avoid over-fatigue by “taking it easy” and getting sufficient rest.
- “Know your own limits” does not mean you’re “lazy.”
- Learn to control and minimize stress.
- Eat well-balanced meals and maintain a sensible weight.
- Practice habits of good hygiene, especially of the skin, teeth, gums, and feet (this includes wearing cushioned and well-fitted shoes).
- If you currently smoke – QUIT! Seek support from your doctor to help you succeed.