

WHAT TYPE OF ACCOMMODATIONS AT WORK OR SCHOOL WILL HELP PROVIDE BETTER SUPPORT?

FATIGUE/LOW ENERGY

– not enough energy to perform daily tasks because of disease symptoms & medication side-effects (drowsiness).

Possible Solutions: Part-time hours, rest breaks, job sharing. For school assignments, consider 'quality' vs. 'quantity' of homework completion.

SUSTAINING CONCENTRATION

– restlessness, GI symptoms, pain in muscles, stiff joints.

Possible Solutions: Break large projects into smaller tasks, allow brief but more frequent breaks (to stretch, walk around, get fresh air, go to the bathroom, eat small snacks, drink water). Assign tasks one at a time, provide written instructions.

ENVIRONMENT

– cold temperatures (less than 68°C), physical vibration can trigger changes in a person's vascular system which leads to permanent nerve and blood vessel damage in the hands, feet, arms and legs.

Possible Solutions: Keep environment warm by raising temperature (consider the use of portable heaters); avoid exposure to cold/damp environments such as air conditioning units or drafty windows. Control measures to protect against hand-arm or wholebody vibration from power tools or heavy equipment may include:

- 1) Covering handles with resilient wrapping layer to provide thermal and vibration isolation - especially for steel handles,
- 2) Wearing full fingered, "anti-vibration" gloves meeting the requirements of ISO Standards 10819:1996,
- 3) Using a suspended seat containing a vibration-damping mechanism adjustable to the driver's weight,
- 4) Driving with dynamically balanced vehicle wheels and tires with a low vibration tread pattern.

SCLERODERMA IS A CHRONIC ILLNESS

Scleroderma is a chronic illness. The cause of scleroderma is unknown and currently there is no cure. The symptoms of scleroderma vary greatly from individual to individual, and the effects of scleroderma may range from mild to severe. The seriousness of the illness will depend on what parts of the body are affected and the extent to which they are affected. Some people experience tight skin, swollen fingers, Raynaud's phenomenon and extreme fatigue. Others may have no outer skin affected and instead the disease may cause serious damage to internal organs and internal connective tissue involving the kidneys, lungs, digestive tract, vascular system, and the heart. Although medical treatments are available to help minimize the symptoms of scleroderma, prompt diagnosis and proper treatment of patients by physicians qualified in the scleroderma care is required.

To learn more how you might better support persons living with scleroderma, please contact:

TOLL FREE: 1-888-776-7776
www.sclerodermaontario.ca



Scleroderma Society of Ontario

Many new patients find it helpful to seek support from people living with scleroderma as it provides the opportunity to build connections with others who are learning to manage the variety of issues that affect their daily lives. Contact the Scleroderma Society of Ontario to find out where your nearest Scleroderma Support Group is located or how you can go about starting a Scleroderma Support Group in your community.

Supporting Persons with SCLERODERMA at Home, Work & School



(for illustration purposes only)

What Should I Know?



Scleroderma Society of Ontario

WHAT IS SCLERODERMA?

Scleroderma is a chronic, multi-symptom autoimmune disease whereby the body's immune system attacks its own tissues. The normal role of the immune system is to provide protection from invaders such as viruses. In autoimmune disorders, the ability to distinguish foreign from self is compromised. As immune cells attack the body's own tissue, inflammation and damage result. Scleroderma can vary a great deal in terms of severity. For some, it is a mild condition; for others it can be life-threatening. There are medications to slow down disease progression and help with symptoms, but as of yet, **there is no cure for scleroderma.**

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 forms the cellular matrix of connective tissue found in skin, tendons, ligaments, cartilage, bone, blood vessels, the gut 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.

WHAT CAUSES SCLERODERMA?

The cause of scleroderma is unknown. However, we do understand a great deal about the biological processes involved. In **localized scleroderma**, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In **systemic sclerosis**, there are three processes at work: **vascular disease**, **fibrosis** (which is an overproduction of collagen) and **autoimmunity** (or immune system dysfunction) which leads to **inflammation.**

DOES SCLERODERMA IMPACT QUALITY OF LIFE?

When Scleroderma is in an active phase, many different symptoms can affect the body. The most common of these symptoms is **fatigue, low energy, and difficulty sleeping, extreme sensitivity to cold temperatures (Raynaud's phenomenon).** Sleep is often disturbed by a combination of physical and/or physiological symptoms such as: **pain, skin itching,** internal organ dysfunction (e.g. **shortness of breath** from heart or lung failure or **heartburn** from gastrointestinal reflux), **anxiety** and **fear** of the illness and **depression.** The lack of sleep can cause daytime symptoms, especially fatigue, muscle and joint pain, to be more intense.



WHO GETS SCLERODERMA?

Scientists are certain that **scleroderma is not contagious, not infectious, and not cancerous.** Studies of twins also suggest that **scleroderma is not inherited.**

Although scleroderma is more common in women, with an average age of disease onset around 40 years, scleroderma also occurs in men and children, from infants to the elderly. It affects people of all races and ethnic groups.

HOW CAN I OFFER SUPPORT?

Take time to understand how scleroderma affects the person you care about. Do not prejudge or assume that the person is "unmotivated" or "lazy". Often people with scleroderma look well, but the symptoms of chronic fatigue, pain, and issues that affect self-esteem and psychological well-being, or the effects of medication, can affect a person's ability to perform daily tasks at home, work or school in a usual manner.

Ask what support the person you care about who has scleroderma may need. She or he is the expert on what specific accommodations will make a difference.

Often the type and level of support needed by persons with scleroderma will fluctuate as the disease itself will fluctuate and there will be times when the person may have extended periods where they do not need or want any special consideration. Let each person's ability to cope with scleroderma and their daily tasks at home, work or at school, not the clinical diagnosis, be your guide.

"Remember, persons with scleroderma are persons first."

