

Irritants such as detergents and certain perfumed toiletries can worsen the damage to the skin while some soaps, creams and bath oils can help keep the skin supple and moist. This requires a degree of experiment to find the products that suit you.

Some patients will experience dry eyes and dry mouth symptoms known as Sicca Syndrome. If the mouth is dry, check that medication is not the cause. There are a number of treatments such as artificial saliva, chewing gum and mouthwashes however these are not always effective. If the eyes are a problem, try Liquifilm® for mild symptoms; use every 30 minutes initially then reduce usage until eyes feel comfortable. For severely dry eyes, use viscotears or gel tears which can be used three times a day.

### Social and psychological aspects of scleroderma

No less important are the social and psychological aspects of the disease. This involves many of the health care team that are looking after you. There are often lots of things that can be done to help people cope at home despite their disabilities. A range of aids might help you do the things you can't manage. The "hidden problem" is often the emotional aspect of having a condition like scleroderma. It is difficult to emphasise enough how important it is to treat this part of the disease.

**Be positive:** There is a lot of support available both from professionals (medication, counselling and other psychological support) and other people affected by scleroderma (patient support organisations). A positive outlook is important. Open discussions can help family and friends understand the physical problems and feelings you are experiencing. Often this can help them to help you when you need it most.

The disease can change the way you look to some degree, but it does not have to change who you are!



The **Scleroderma Society** supports people with scleroderma and their families by providing:

- educational literature
- a telephone helpline
- a comprehensive website & forum
- a newsletter with research information
- member contact
- informal group meetings
- an annual conference

We also work to promote awareness of scleroderma among the medical profession and general public in order to improve early diagnosis and prognosis. We fund medical & scientific research in the UK and are a founder member of FESCA (Federation of European Scleroderma Associations), working to forward the cause of people with scleroderma throughout Europe.

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## Scleroderma: Not Just Hard Skin

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# Scleroderma: Not Just Hard Skin

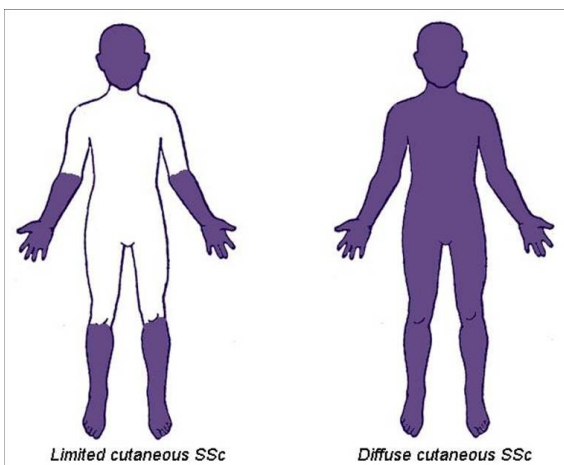
## What is Scleroderma?

Scleroderma is one of the more uncommon of the connective tissue diseases. These diseases affect the connective tissue of the joints, tendons, muscles, skin, blood vessels, heart, lungs, and many other organs. Although it is a chronic illness, proper treatment and management can make it possible for people with scleroderma to lead full and productive lives.

## How Many Kinds of Scleroderma Are There?

Scleroderma is an umbrella term used to indicate a spectrum of disorders. There are two main types of scleroderma— localised and systemic. Often medical professionals use the term “scleroderma” when they talk about systemic sclerosis. Localised scleroderma (see Localised scleroderma leaflet) only affects the skin and sometimes the underlying soft tissues, while systemic sclerosis may affect the internal organs.

With systemic sclerosis, distinction can be made between the limited and diffuse form based upon the extent of skin involvement. In the limited cutaneous systemic sclerosis, skin thickening does not extend above the knees and elbows while in the diffuse cutaneous systemic sclerosis, it can affect the whole body. The face is usually affected in both forms of the disease.



The internal organs, including the blood vessels, digestive system, lungs, heart, kidneys, muscles and joints may become involved.

Systemic sclerosis varies from person to person. People with the illness may have one or more parts of the body affected to different degrees. Systemic sclerosis should not be confused with multiple sclerosis. There is no connection between the two diseases.

## Who Gets Systemic Sclerosis?

The disease affects four times more women than men. The illness usually starts between the ages of 25 and 50 but it can affect children and the elderly.

## What Causes Systemic Sclerosis?

The cause of scleroderma is still unknown. It is not contagious, so you can't catch it from someone or give it to anybody else. It is believed that people with scleroderma have a genetic predisposition for the illness and often environmental factors act as triggers for the disease onset. Most people with systemic sclerosis will not have other family members with the condition.

There are three aspects of the disease processes— small blood vessel damage, autoimmune inflammation and tissue scarring (fibrosis). The blood vessel damage leads to Raynaud's phenomenon and may cause ulcers. The immune system is your body's natural defence against illness. Unfortunately, it can sometimes be defective and attack the healthy body as is the case in scleroderma. We also know that the tissue cells of people who have scleroderma produce too much of a protein called collagen, which may result in scar tissue development in the skin or internal organs.

## How Does Systemic Sclerosis Start?

One of the early problems people with systemic sclerosis get is sensitivity to cold. This is called Raynaud's phenomenon and it affects most people with the condition at some point. Raynaud's phenomenon occurs when the blood vessels overreact to cold, causing the fingers and toes to turn white, blue and then go red when warmed up. This causes numbness and tingling, and sometimes even pain.

Swelling and puffiness of the hands and feet is also a common early feature. The fingers may look and feel swollen, making the skin lose its normal lines and look shiny.

## How Does Systemic Sclerosis Develop?

Most people with systemic sclerosis have some thickening and hardening of the skin; especially of the hands, arms and face. The joints can tighten into a bent position due to tightening of the skin or tendons. It can also cause joint inflammation with symptoms of pain, stiffness, swelling, warmth and tenderness. You may also get tired very quickly and the muscles may be weak. Ulcers are not uncommon and some people may develop calcium deposits in various parts of the body (calcinosis).

The illness may also affect the tissue of the internal organs. For example, if the digestive system is involved, the muscles in the gullet may become weak leading to difficulties in swallowing. Heartburn can also be a frequent problem. Sometimes the middle and lower bowel are affected and this affects bowel motion. The lungs, heart and kidneys can also be affected.

The limited subset of systemic sclerosis is more common than the diffuse. The disease outcome and organ complications can vary between patients from extremely mild to severe.

## What Can Be Done to Help?

Although at the moment there is no proven cure for scleroderma, there are multiple treatments for the different aspects of the disease. Medications (including tablets, infusions and creams) are too numerous to mention here. Special exercise programs have proved very useful in the treatment of scleroderma by keeping the skin flexible, maintaining better blood flow, and keeping the joints supple. Social and psychological support is also very important.

## Take sensible preventive action

It is sensible to keep skin healthy to prevent cracking, peeling, and ulcerating. This can be done by regular moisturising. A good blood supply is essential and can be helped by keeping warm. The head, hands and feet are often the worst affected areas and should be covered up when in the cold. Hats, thermal clothing, hand warmers, electrically heated gloves/socks and many others can help this and stopping smoking is very important.