

Systemic Sclerosis & You

What is it?



Systemic sclerosis is a rare disease that's also known as scleroderma. It is a long-term (chronic) autoimmune disease. For some reason the immune system gets confused and starts to attack the skin and underlying tissues. This causes a build-up of fibrous scar tissue that makes the skin feel thick and hard.

There are two forms of systemic sclerosis. They are called limited and diffuse. In the limited form, the skin on the arms from the elbows down, on the legs from the knees down, and on the face and neck may be affected. Often only the skin of the fingers and the face and neck are affected. In the diffuse form, skin involvement is more widespread and can affect the lower arms and legs as well as the trunk, back, thighs and upper arms.

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RheumInfo.com is a free educational website where you can learn more about systemic sclerosis and treatments for the disease. The website is operated by Dr. Andy Thompson, a rheumatologist.

What is it going to do to me?



When the skin tightens it can take on a shiny appearance. In some people, changes in skin pigment can give the skin a "salt and pepper" appearance. Tightening of skin on the face can cause loss of wrinkles. When the skin tightens around the mouth it can make it difficult to properly open your mouth. A rash consisting of tiny little red dots may appear on the palms, fingers and around the mouth.

Systemic sclerosis can affect the swallowing tube and other parts of the digestive tract. This can cause significant heartburn. Almost all people with systemic sclerosis have "Raynaud's Phenomenon". This causes the fingers and sometimes the toes to turn white in the cold. Many people with systemic sclerosis can have inflamed and swollen joints. Other parts of the body can sometimes be affected including the lungs, heart, and kidneys. As with many autoimmune diseases, fatigue is a very common complaint in people with systemic sclerosis.

Life expectancy in people with systemic sclerosis depends on the extent and severity of internal organ involvement. Life expectancy has improved a lot due to better treatment, supportive care, and better nutrition.

What can I do about it?



Being diagnosed with a chronic disease like systemic sclerosis can be frightening. The first thing is don't panic. Most people have the milder or limited form of the disease. The most important thing if you have systemic sclerosis is to see your doctor who should refer you to a rheumatologist. A rheumatologist is a specialist doctor who is an expert in treating various forms of arthritis and rheumatic diseases such as systemic sclerosis.

Because systemic sclerosis can be very different for different people, your treatment plan will be tailored just for you. There are effective treatments available that can help relieve the symptoms that bother you. Although they do not cure the disease, treatments can make living with systemic sclerosis more comfortable.

Medications may be prescribed depending on the extent of your disease and your specific symptoms. They can help relieve symptoms of Raynaud's, heartburn, and swollen and inflamed joints. In more severe disease with lung, kidney or heart involvement, immune suppressing medications may be used.

Physical or occupational therapy to improve function with aids, splints, etc. is important for many patients. Preventive strategies also play an important role in managing systemic sclerosis.

Here are some other recommendations on what you should do:

- **Learn as much as you can about the disease**
- **Attend your medical appointments regularly**
- **Get your tests such as blood tests done as suggested**
- **Learn about the medications used to treat systemic sclerosis**