



## About Scleroderma

Scleroderma, or systemic sclerosis, is a chronic, connective tissue disease generally classified as an autoimmune rheumatic disease. The disease stems from the over-production of collagen (a connective tissue) in the body that creates hardening (sclerosis) of the skin (derma) and internal organs such as the lungs, kidneys, heart and gastrointestinal tract.

The word “scleroderma” comes from two Greek words, “sclero” meaning hard and “derma” meaning skin. Skin hardening is one of the most visible manifestations of the disease. The disease has been called progressive systemic sclerosis. However, the use of the term has been discouraged since scleroderma is not necessarily progressive. The disease can take several forms and varies for each patient.

## Frequently Asked Questions

Here are some of the most frequently asked questions about scleroderma to help you better understand the disease:

### **Q: *Is scleroderma contagious?***

A: Scleroderma is not contagious. It also is not an infection or cancer.

### **Q: *How serious is scleroderma?***

A: Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the affects of scleroderma can range from mild to life-threatening. The severity depends on which parts of the body are affected, and to what extent in which they are affected. A mild case can become more serious if not properly treated. Early and proper diagnosis and treatment by qualified doctors may minimize scleroderma symptoms and lessen the chance for irreversible damage.

### **Q: *How is scleroderma diagnosed?***

A: The diagnostic process may require a consultation with a rheumatologist (someone who specializes in conditions such as arthritis) or dermatologist (a doctor who specializes in the skin), and a blood study or other specialized tests depending on which organs are affected.

### **Q: *Who develops scleroderma, and when?***

A: There are an estimated 80,000 to 100,000 in the U.S. who have the systemic form of scleroderma. If those patients who also have Raynaud’s and one symptom of scleroderma were to be counted, the figure would rise to around 150,000 people. Also, there are many more people with the localized form of the disease. The international incident rate is unknown. However, cases have been reported around the world. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult, and there may be many misdiagnosed or undiagnosed cases, as well.

Localized scleroderma is more often seen in children. Systemic scleroderma is more common in adults.

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Overall, female patients outnumber male patients about 4-to-1, and the average age of diagnosis is in the 40s.

Factors other than sex such as race and ethnicity may influence the risk of getting scleroderma, the age of onset and the pattern or severity of internal organ involvement. The reasons for this are unclear. Although scleroderma is not directly inherited, some scientists believe there is a slight predisposition to it in families with a history of rheumatic diseases.

While scleroderma can develop in every age group, the onset is most often between the ages of 25 and 55. Still, symptoms, onset age and other factors vary for each patient. Many patients are alarmed when he or she reads medical information that contradicts their own experience. He or she often concludes that what is happening to them is not supposed to happen. There are many exceptions to the rules in scleroderma, perhaps more so than any other disease. Each case is different, and information should be discussed with your own doctor.

**Q: What causes scleroderma?**

A: The exact cause or causes of scleroderma are unknown. Scientists and researchers are working hard to find the cause. It is known that scleroderma involves overproduction of collagen.

**Q: Is scleroderma genetic?**

A: Most patients do not have relatives with scleroderma and their children do not get the disease. Research indicates that there is a susceptibility gene, which raises the likelihood of getting scleroderma, but by itself does not cause the disease.

**Q: What is the treatment for scleroderma?**

A: Currently, there is no cure for scleroderma, but there are treatments available. Some are directed at particular symptoms such as heartburn, which can be controlled by medications called proton pump inhibitors or medications that improve the motions of the bowel. Some treatments are directed at decreasing activity in the immune system. Some people with a mild form of the disease may not need any medication. Occasionally, people can go off treatment when their scleroderma is not active. Because there is so much variation from one person to the next, treatments vary for each patient.

**For more information about scleroderma, visit [www.scleroderma.org](http://www.scleroderma.org) or call (800) 722-HOPE (4673).**