ARTHRITIS NATIONAL RESEARCH FOUNDATION®

FACT SHEET

What is Scleroderma?

Scleroderma is an autoimmune disease where the immune system attacks your skin and other connective tissues. These tissues are tendons and cartilage that protect and support your body. Scleroderma can change how your skin looks, creating patches of hard or discolored skin or scars. There are 2 main types of scleroderma based on which parts of the body it affects:

1) **Localized scleroderma** only affects the skin.
2) **Systemic scleroderma** affects the skin and other parts of the body. This is also called systemic sclerosis.

What are the symptoms?

Symptoms of localized scleroderma include:

- Patches of thick, hard, shiny skin. Patches may be yellow, red, or appear in stripes or ovals
- Patches of darker or lighter skin
- Stiff joints

Symptoms of systemic scleroderma include:

- Small lumps of calcium under the skin, which may ooze
- Raynauds phenomenon (where fingers turn blue-purple, white, or red, usually due to cold or stress)
- Stomach problems, such as acid reflux, bloating, constipation, or diarrhea
- Thick, tight skin on hands and fingers
- Small red spots on hands or face
- Sores on fingers or toes
- Hair loss

You may be at risk for organ damage if you have systemic scleroderma. This damage can lead to problems with your lungs, heart, kidney, and reproductive organs.

What causes Scleroderma?

You are more likely to develop scleroderma if a family member has scleroderma or other autoimmune diseases that affect connective tissue (such as lupus). However, you may have no family history of scleroderma and still develop the disease.

Scientists are still learning what other factors may increase the risk of scleroderma. They think certain chemicals, infections, or hormones may increase the risk.

Who has Scleroderma?

Scleroderma is estimated to affect around 100,000 people in the United States.

Anyone can get scleroderma. But some people have a higher risk of having it.

- **Women** are 4 times more likely to have scleroderma than men. However, men may have worse symptoms and a higher risk of dying from the disease.
- Scleroderma is most often diagnosed in people **ages 30 - 50.**
- **Black** people are more likely to have systemic scleroderma than other racial and ethnic groups. Symptoms may appear when they are younger, and symptoms may be in more organs beyond the skin. Localized scleroderma is more common in **White** people than other racial and ethnic groups.

How do you know if you have Scleroderma?

Scleroderma can be hard to diagnose because it looks like other diseases. Doctors use many tests to diagnose scleroderma.

- Doctors use a physical exam and scans to check for abnormal patches of skin.
- They may also remove a small piece of skin to test it in the lab. This is called a skin biopsy.
- Doctors may run tests to check for autoantibodies. Autoantibodies are molecules that attack healthy cells by mistake.

Scleroderma

How do you manage Scleroderma?

Scleroderma has no cure, but treatments can help you feel better and reduce organ damage. Physical or occupational therapy can make moving easier and less painful.

You may also make lifestyle choices to be more comfortable, such as:

- Wearing layers to keep warm
- Wearing lotions and sunscreen
- Avoiding harsh chemicals to make the skin feel better
- Exercising to improve blood circulation (how well your blood moves through your body)
- Eating small meals often to help digest food

What treatments are used for Scleroderma?

Treatments for scleroderma typically do not stop or fix the skin thickening. However, treatments can help with other symptoms. Here are the treatment types, treatment names, and common uses used for scleroderma:

Treatment type	Treatment names	Common uses
Nonsteroidal anti-inflammatory drugs (NSAIDs)	Ibuprofen, naproxen	Reduce inflammation and relieve fever, painful joints, and swelling
Steroids (also called corticosteroids)	Prednisone	Reduce inflammation and pain. These are different from steroids used to improve athletic performance
Immunosuppressives	Mycophenolate mofetil and methotrexate, cyclophosphamide or IVIg, nintedanib, tocilizumab,	Reduce skin scarring
Blood pressure treatments	Nifedipine, losartan, phosphodiesterase-5 (PED-5) inhibitors	Open blood vessels to improve blood flow to fingers and toes
Acid reflux treatment	Omeprazole and famotidine	Reduce the amount of acid in the stomach

Talk with your doctor about which treatment is right for you. They can recommend a treatment based on your symptoms and health history.

Will there be more treatments in the future?

Scientists are looking for more scleroderma treatments. Some treatments are in clinical trials to treat organs that might be affected by systemic scleroderma. Some of these treatments also reduce thickened, scarred skin.

Questions?

Talk to your rheumatologist for more information about diagnosing and managing scleroderma.