CONDITION

Scleroderma

Scleroderma is an autoimmune condition that hardens skin and may affect blood vessels and internal organs.

WHAT IT IS
Skin-hardening autoimmune condition, sometimes affecting internal organs

BODY SYSTEM
Skin, blood vessels, digestive tract, lungs, heart, and kidneys

MAIN SYMPTOMS
Tight skin, Raynaud's attacks, joint stiffness, heartburn

WHAT CAUSES IT
Immune and blood-vessel changes; exact cause unknown

HOW IT IS DIAGNOSED
Clinical exam, antibody tests, nailfold capillaroscopy, sometimes biopsy

MAIN TREATMENT
Symptom control, immune-modifying medicines, therapy, and organ monitoring

CAN IT BE CURED?
No - treatments control, but cannot eliminate

IS IT AN EMERGENCY?
Sometimes - sudden breathlessness or severe headache needs emergency care

LONG-TERM OUTLOOK
Often manageable; organ involvement shapes long-term health

Overview

Scleroderma is a long-term condition that causes areas of skin to become thick, tight, or hard. The name means "hard skin." It is linked to changes in the immune system, small blood vessels, and collagen, a protein that supports skin and other tissues.

There are two main forms.

Localized scleroderma affects the skin and sometimes the tissue beneath it. Patches may be oval-shaped, known as morphea, or form a line along an arm, leg, or the face. Localized scleroderma usually does not affect internal organs.

Systemic sclerosis can affect the skin, blood vessels, digestive tract, lungs, heart, or kidneys. It is often divided into limited and diffuse forms, based mainly on how much skin is involved.

These labels can help estimate which complications need closer monitoring, but they do not predict exactly what will happen to one person.

Some people have mild, mainly skin-related symptoms. Others develop organ involvement that requires regular testing and treatment. Early assessment matters because some internal changes can begin before they cause obvious symptoms.

Scleroderma is not contagious. It cannot be passed between people through touch, coughing, food, or sex.

Symptoms

Symptoms differ between localized scleroderma and systemic sclerosis. They may develop slowly, and not everyone has every symptom.

Skin changes can include:

Many people with systemic sclerosis have Raynaud's phenomenon . Fingers or toes change colour, often becoming white, blue, and then red, in response to cold or stress. They may feel numb, painful, or tingly. Reduced blood flow can sometimes cause sores on the fingertips.

Digestive symptoms may include heartburn, trouble swallowing, bloating, constipation, diarrhoea, or feeling full after a small meal. These can occur when tightening or abnormal movement affects the digestive tract.

Joint stiffness, muscle weakness, tiredness, and reduced hand movement are also possible.

Lung involvement may cause breathlessness, a dry cough, or reduced exercise ability. Possible causes include scarring of lung tissue, called interstitial lung disease, or high pressure in the blood vessels of the lungs, called pulmonary arterial hypertension.

Heart or kidney involvement may initially cause few symptoms. This is why routine blood pressure checks, blood tests, breathing tests, and heart assessments can be important even when you feel well.

- Swollen or puffy fingers, followed by tighter or thicker skin
- Shiny skin or reduced skin folds
- Itching, tenderness, or changes in skin colour
- Reduced movement when skin tightens over a joint
- Small visible blood vessels called telangiectasias
- Firm calcium deposits under the skin, called calcinosis

Causes and risk factors

The exact cause of scleroderma is unknown. It appears to involve three connected changes:

Genes may affect susceptibility, but scleroderma is not usually inherited in a simple, predictable pattern. Having a relative with the condition does not mean you will develop it.

Hormones and environmental exposures may contribute in some people. Certain workplace exposures and a small number of medicines or chemicals can cause scleroderma-like changes, but most people cannot identify a specific trigger.

Systemic sclerosis is more often diagnosed in women than men. It can begin at any age, although it most often starts in adulthood. Localized scleroderma can also occur in children.

Stress, diet, or personal behaviour do not cause scleroderma.

- The immune system becomes overactive
- Small blood vessels are damaged or work abnormally
- The body produces too much collagen, causing tissue to thicken or scar

Diagnosis

There is no single test that confirms every form of scleroderma. Diagnosis is based on the pattern of symptoms, a skin and joint examination, and tests chosen for the suspected form.

Blood tests can look for antinuclear antibodies and more specific antibodies associated with systemic sclerosis. These results may support the diagnosis and help estimate which complications need monitoring. A positive antibody test alone does not prove that you have scleroderma.

Nailfold capillaroscopy uses a microscope or magnifying device to examine tiny blood vessels at the base of the fingernails. Certain changes can support a diagnosis of systemic sclerosis, particularly in someone with Raynaud's phenomenon.

A skin biopsy, which removes a small skin sample, is sometimes used when the diagnosis is uncertain. It is not always necessary.

If systemic sclerosis is suspected, assessment may also include:

These tests help identify organ involvement and provide a starting point for future comparisons.

- Lung function tests

- A chest CT scan when lung involvement is suspected
- An echocardiogram, which uses ultrasound to examine the heart
- Blood pressure, urine, and kidney blood tests
- An electrocardiogram to check heart rhythm
- Digestive tests when swallowing or severe reflux is a concern

Treatment and management

There is currently no treatment that removes scleroderma completely. Care focuses on controlling inflammation or immune activity when appropriate, protecting circulation, preserving movement, relieving symptoms, and detecting organ problems early.

Treatment is tailored to the form of scleroderma and the parts of the body affected.

For localized scleroderma, treatment may include medicated skin creams, ultraviolet light therapy, or medicines that reduce immune activity. Physiotherapy can help when a patch crosses a joint or limits movement. Some inactive patches mainly need observation and skin care.

For systemic sclerosis, treatment may include:

Kidney crisis is treated urgently with blood-pressure-lowering medicine. Corticosteroids like prednisone or hydrocortisone are used cautiously in systemic sclerosis because higher exposure has been associated with an increased risk of this complication. Do not stop a prescribed steroid suddenly; discuss concerns with the prescriber.

Keeping your whole body warm, wearing gloves in cold places, and avoiding smoking or vaping nicotine may reduce Raynaud's attacks. Moisturizer can help dry or itchy skin. Gentle stretching may support hand and joint movement.

Regular monitoring is part of treatment, even if symptoms are stable. The schedule is based on your form of scleroderma, antibody results, previous tests, and any organ involvement.

- Medicines that improve blood flow for Raynaud's symptoms or fingertip sores
- Acid-reducing medicines and other treatments for reflux or digestive symptoms
- Immune-modifying medicines for progressive skin or lung involvement
- Treatments aimed at high pressure in the lung arteries
- Physiotherapy or occupational therapy to maintain movement and hand function
- Pain management and treatment for itching or dry skin

Complications

Localized scleroderma can leave areas of darker or lighter skin. Deeper or linear patches may affect growth, muscles, joints, or facial structures, particularly when they begin during childhood.

Systemic sclerosis can affect several organs. Possible complications include:

Not everyone develops these problems. Screening aims to find changes early, when treatment and closer monitoring may help.

Mood, sleep, relationships, work, and body image can also be affected. Emotional and practical support are valid parts of care, not separate from the physical condition.

- Painful fingertip ulcers, infection, or tissue damage from poor circulation
- Persistent reflux, swallowing difficulty, or reduced absorption of nutrients
- Interstitial lung disease, in which lung tissue becomes inflamed or scarred
- Pulmonary arterial hypertension, or high pressure in lung blood vessels
- Abnormal heart rhythms, heart muscle scarring, or inflammation around the heart
- Scleroderma renal crisis, with a rapid rise in blood pressure and kidney injury

Prevention

There is no proven way to prevent scleroderma because its exact cause is unknown. Genetic susceptibility cannot be changed, and most people have no avoidable trigger.

If you already have systemic sclerosis, some steps may reduce symptoms or complications. These include avoiding nicotine, protecting your hands and feet from cold, taking prescribed treatment, and attending recommended monitoring.

Good blood pressure awareness is especially important. If you have been asked to measure it at home, follow the instructions given by your healthcare team and report readings outside your agreed range.

Sun protection may help limit contrast between affected and unaffected skin, but it does not prevent the underlying condition.

Living with it and what to expect

Scleroderma usually changes over months or years rather than from day to day. The course is

different for localized and systemic forms.

Localized patches may enlarge or new patches may appear during an active period. They can then become inactive, although colour changes, skin tightness, or reduced movement may remain. Children with deeper or linear patches may need follow-up as they grow.

In systemic sclerosis, skin thickening may progress for a time and later stabilize or soften. Raynaud's symptoms and digestive problems may continue even if the skin improves. Internal organ involvement can develop at a different pace from visible skin changes.

Many people continue working, exercising, caring for family, and taking part in usual activities. Adaptations may be needed for hand stiffness, tiredness, temperature sensitivity, or medical appointments. Occupational therapy can suggest tools and techniques for dressing, cooking, work, and hand protection.

Regular activity within your ability can support strength, movement, and heart and lung health. If breathlessness, pain, or fatigue is limiting activity, ask for advice rather than pushing through a major change in symptoms.

Keep routine appointments even when you feel well. Monitoring may detect changes in lung function, heart pressure, blood pressure, or kidney function before they become severe.

When to get medical help

Arrange a routine medical appointment if you develop persistent skin hardening, puffy fingers, repeated Raynaud's attacks, unexplained fingertip sores, or ongoing trouble swallowing. These symptoms have several possible causes and need proper assessment rather than self-diagnosis.

If you have diagnosed scleroderma, contact your healthcare team promptly about new or worsening breathlessness, cough, swelling, reduced exercise ability, fingertip ulcers, muscle weakness, or digestive symptoms. These usually need timely review but are not automatically emergencies.

Seek urgent or emergency care for:

These symptoms may indicate a serious circulation, lung, heart, kidney, or digestive complication.

- Sudden severe breathlessness, chest pain, fainting, or blue-grey lips
- A severe new headache, vision changes, confusion, or a sudden major blood pressure rise
- Markedly reduced urine, especially with headache or high blood pressure

- A finger or toe becoming persistently pale, blue, black, cold, or severely painful
- Vomiting blood, black stools, or heavy rectal bleeding

Common questions

Is scleroderma the same as systemic sclerosis?

Scleroderma is a broad name covering localized skin forms and systemic sclerosis. Systemic sclerosis is the form that can affect internal organs as well as the skin.

Can scleroderma go away?

There is no complete cure. Localized patches can become inactive, and skin thickening in systemic sclerosis may stabilize or soften. Lasting skin changes or other symptoms may remain.

Does scleroderma always affect internal organs?

No. Localized scleroderma usually stays in the skin and nearby tissues. Systemic sclerosis can affect internal organs, but the organs involved and severity differ from person to person.

Is Raynaud's phenomenon always a sign of scleroderma?

No. Raynaud's is common and often occurs by itself. It is more concerning when it begins later in life or occurs with puffy fingers, skin tightening, fingertip sores, or abnormal nailfold blood vessels.

Can I exercise with scleroderma?

Many people can and do exercise. Walking, strength work, stretching, and hand exercises may help maintain function. The right level should reflect your joint, heart, and lung health, especially if you have breathlessness or chest symptoms.

Can scleroderma be passed to my children?

It is not usually inherited directly. Genes can influence susceptibility, but most children of people with scleroderma do not develop the condition.

Sources

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