



# PATIENT FACT SHEET

## Scleroderma



### CONDITION DESCRIPTION

**Scleroderma is a chronic autoimmune disease that affects skin and internal organs.** It is classified as either being localized (only involving some parts of the skin) or systemic (involving the skin and other internal organs). The systemic form can be further divided into limited or diffuse disease, depending on how much of the skin is involved. Scleroderma results from the immune system attacking the body, causing inflammation and tissues changes. It often leads to skin tightening and thickening, and may affect the heart, lungs, kidneys, blood vessels or intestines.

Scleroderma is rare. It affects mostly women between the ages of 30 and 50. Children may get a juvenile form of scleroderma. Twins and relatives of people with scleroderma or other connective tissue diseases like lupus may be at slightly higher risk for it.

Diagnosis includes a physical exam to look for common signs, imaging tests and blood tests for certain markers called autoantibodies. While there is no cure for scleroderma, there are treatments to help manage symptoms and improve quality of life.



### SIGNS/ SYMPTOMS

**Scleroderma symptoms may range from minor to life-threatening.** An early, common sign of scleroderma is color changes to the fingers, called Raynaud's phenomenon. Fingers or toes may look red, white or blue, especially during cold weather. Digits may be swollen, numb, painful or develop ulcers.

The number of symptoms a patient can have varies widely. In addition to Raynaud's phenomenon, patients

can have scarring of the internal organs including the heart, lungs, blood vessels, gastrointestinal tract and kidneys. Not every patient experiences all of these symptoms. Depending on what organ is involved, patients can experience different symptoms including high blood pressure, difficulty swallowing, bloating, constipation, weight loss, shortness of breath and joint pain.



### COMMON TREATMENTS

**Scleroderma treatments mainly alleviate symptoms, but do not reverse the course of the disease.** To ease Raynaud's, blood pressure medications called calcium channel blockers or PDE-5 inhibitors, like sildenafil (Viagra) and tadalafil (Cialis), can improve circulation. Antacids and proton pump inhibitors (omeprazole) can ease heartburn.

For muscle pain and weakness, intravenous immunoglobulin (IVIg) and/or immunosuppressants, such as mycophenolate, may help. Physical or occupational therapies are important

to help patients maintain joint and skin flexibility and preserve function.

Mycophenolate is the most common medication used to treat patients with scleroderma who develop scarring of the lungs (known as interstitial lung disease). Treatments for another serious lung complication (pulmonary arterial hypertension) open constricted blood vessels to ease high blood pressure.



### CARE/ MANAGEMENT TIPS

**Patients with Raynaud's phenomenon should keep their bodies warm with layered clothing, boots and gloves in cold weather.** It is more important to warm the core of the body (torso), as well as the hands and feet. Hand warmers and mittens are helpful for patients when they know they will be out in the cold (or in the frozen food aisle). Protect fingers and toes from activities that could injure skin.

People with digestive problems might change their diet to prevent heartburn. Eating several smaller meals, instead of three large ones, as well as not eating right before bed, can also help with heartburn.

Keep skin well moisturized. Use caution during daily tasks like gardening, cooking or even opening mail to avoid skin cuts. Regular exercise and physical therapy may keep joints flexible.

Because scleroderma is a chronic disease, depression or mood problems are possible. Seek support from family or friends, patient groups, or if needed, mental health treatment from a psychologist. It is important to remember that it is possible for patients with scleroderma to lead long, fulfilling lives.

Updated March 2019 by Christopher Mecoli, MD, and reviewed by the American College of Rheumatology Committee on Communications and Marketing. This information is provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnosis and treatment of a medical or health condition.