Points To Remember About Scleroderma

- Scleroderma is an autoimmune connective tissue and rheumatic disease that causes inflammation in the skin and other areas of the body. This inflammation leads to patches of tight, hard skin.
- Scleroderma can affect just one area of the body, or it can affect many systems in the body.
- Your treatment depends on the type of scleroderma you have, your symptoms, and which tissues and organs are affected. Treatment can include medications and physical and occupational therapy.
- You can do many things to help live with scleroderma, such as wear warm clothing, avoid cold or wet environments, wear sunscreen when outside, and reach out to loved ones, online or community support groups, and your health care team for support.

What is scleroderma?

Scleroderma is an autoimmune connective tissue and rheumatic disease that causes inflammation in the skin and other areas of the body. This inflammation leads to patches of tight, hard skin. Scleroderma involves many systems in your body. A connective tissue disease is one that affects tissues such as skin, tendons, and cartilage.

There are two major types of scleroderma:

- Localized scleroderma only affects the skin and the structures directly under the skin.
- Systemic scleroderma, also called systemic sclerosis, affects many systems in the body. This is the more serious type of scleroderma and can damage your blood vessels and internal organs, such as the heart, lungs, and kidneys.

Who gets scleroderma?

Anyone can get scleroderma; however, some groups have a higher risk of developing the disease. The following factors may affect your risk.

- **Sex.** Scleroderma is more common in women than in men.
• **Age.** The disease usually appears between the ages of 30 and 50.

• **Race.** Scleroderma can affect people of all races and ethnic groups, but the disease can affect African Americans more severely.

What are the types of scleroderma?

There are two types of scleroderma:

• Localized scleroderma affects the skin and tissues below it.

• Systemic scleroderma, sometimes called systemic sclerosis, affects your skin, tissues, blood vessels, and major organs.

What are the symptoms of scleroderma?

The symptoms of scleroderma are different for each person, depending on the type of scleroderma you have.

Localized scleroderma typically causes patches of thick, hard skin in one of two patterns:

• Patches in firm, oval shapes that stay in one area or spread to other areas of skin.

• Lines of thickened or different colored skin that run down your arm, leg, and, rarely, on the forehead.

Systemic scleroderma, also known as systemic sclerosis, may come on quickly or slowly and may also cause problems with your internal organs in addition to the skin. Many people with this type of scleroderma feel overly tired (fatigue).

What causes scleroderma?

Doctors do not know the exact cause of scleroderma, but they think that several factors may play a part in causing the disease:

• **Genetic makeup.** Genes can increase the chance for certain people to develop scleroderma and play a role determining the type of scleroderma they have. While the disease is not passed from parent to child, you are more likely to develop scleroderma if a close relative has it.

• **Environment.** Exposure to things in the environment, such as viruses or chemicals, may trigger scleroderma.

• **Immune system changes.** When your immune system changes, it can trigger cells to make too much collagen in the body. Too much collagen causes patches of tight, hard skin.

• **Hormones.** Hormonal differences between women and men might play a part in the disease.
Is there a test for scleroderma?

There is no single test for scleroderma; your doctor may:

- Ask about your medical history.
- Ask about your current and past symptoms.
- Perform a physical exam.
- Order lab tests.

How is scleroderma treated?

Your treatment depends on the type of scleroderma you have, your symptoms, and which tissues and organs are affected. Treatment can help control the symptoms and limit damage.

Your doctor may recommend:

- Medications to help decrease swelling, manage pain, control other symptoms, and prevent complications that may arise.
- Physical or occupational therapy to help with pain, improve muscle strength, and teach ways to help with daily living, such as brushing your teeth.
- Regular dental care because scleroderma can make your mouth dry and damage connective tissues in your mouth, speeding up tooth decay and causing your teeth to become loose.

Who treats scleroderma?

Most people will see a rheumatologist for scleroderma treatment. A rheumatologist is a doctor who specializes in rheumatic diseases such as arthritis and other inflammatory or autoimmune disorders. Dermatologists, who specialize in conditions of the skin, hair, and nails, may play an important role in treating the disease.

Because scleroderma can affect many different organs and organ systems, you may have several different doctors providing your care, including:

- Cardiologists, who specialize in treating diseases of the heart and blood vessels.
- Dental providers, who can treat complications from the thickening of tissues of the mouth and face.
- Gastroenterologists, who treat digestive problems.
- Mental health professionals, who provide counseling and treat mental health disorders such as depression and anxiety.
- Nephrologists, who treat kidney disease.
- Occupational therapists, who teach how to safely perform activities of daily living.
• Orthopaedists, who treat and perform surgery for bone and joint diseases or injuries.
• Primary care providers, including physicians, nurse practitioners, and physician assistants.
• Physical therapists, who teach ways to build muscle strength.
• Pulmonologists, who treat lung disease and problems.
• Speech-language pathologists, who specialize in the treatment of speech and communication disorders.

Living with scleroderma

Living with the disease may be hard. To help, try to take an active part in treating your scleroderma. The following tips and suggestions may help.

• Keep warm. Dress in layers, wear gloves and socks, and avoid cold rooms and weather when possible.
• Try to avoid cold or wet environments that may trigger symptoms.
• If you smoke, quit.
• Put on sunscreen before you go outdoors.
• Use moisturizers on your skin to help lessen stiffness.
• Use humidifiers to moisten the air in your home in colder winter climates.
• Avoid hot baths and showers, as hot water dries the skin.
• Avoid harsh soaps and household cleaners. Wear rubber gloves if you use such products.
• Exercise regularly.
• Visit the dentist regularly for check-ups.
• Reach out to online and community support groups.
• Talk to your family and friends to help them understand the disease.
• Talk to a mental health professional for help with coping with a chronic illness.
• Talk with your doctor about any symptoms you may have, and follow your doctor’s directions.

For more info

U.S. Food and Drug Administration
Toll free: 888-INFO-FDA (888-463-6332)
Website: https://www.fda.gov

Drugs@FDA at https://www.accessdata.fda.gov/scripts/cder/daf. Drugs@FDA is a searchable catalog of FDA-approved drug products.

Genetic and Rare Diseases Information Center
Website: https://rarediseases.info.nih.gov/diseases/10308/scleroderma

Genetics Home Reference
Website: https://ghr.nlm.nih.gov/condition/systemic-scleroderma

Centers for Disease Control and Prevention, National Center for Health Statistics
Website: https://www.cdc.gov/nchs

American Academy of Dermatology
Website: https://www.aad.org

American College of Rheumatology
Website: https://www.rheumatology.org

Scleroderma Foundation
Website: https://www.scleroderma.org

Scleroderma Research Foundation
Website: https://www.srfcure.org

Arthritis Foundation
Website: https://www.arthritis.org

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- Asian Language Health Information
- Spanish Language Health Information