Points To Remember About Scleroderma

- Scleroderma causes thick, hard patches of skin.
- Symptoms of scleroderma vary a lot, depending on the type of disease you have.
- There is no cure for scleroderma, but you can reduce damage from the disease with proper treatment.
- Since some types of scleroderma can cause serious damage to your internal organs, it is important to monitor your health and let your doctor know if you notice any new symptoms.

What is scleroderma?

Scleroderma is the name for a group of diseases that cause patches of tight, hard skin. Some forms of scleroderma can also damage your blood vessels and internal organs.

Who gets scleroderma?

Anyone can get scleroderma, but it is more common in adults and women.

Some types of scleroderma are more common in different groups. Most localized types show up before age 40. They are also more common in people of European descent. Systemic types are more common in people ages 30 to 50 and in African Americans.

What are the types of scleroderma?

Scleroderma’s main types are localized and systemic. Localized means the disease affects only certain parts of the body. Systemic means it can affect the whole body.

The localized type often affects only your skin. It does not harm major organs. It may get better or go away without help. But it can be severe in some people and can leave skin damage.

The systemic type affects your skin, tissues under it, blood vessels, and major organs.
What are the symptoms of scleroderma?

Scleroderma causes your tissues to get hard and thick. Depending on what type of scleroderma you have, you may find that your skin gets hard and tight, or you may have problems with your blood vessels and major organs, such as your heart, lungs, and kidneys.

What causes scleroderma?

Doctors don’t know what causes scleroderma, but they do know you can’t catch it from other people. It is probably an autoimmune disease, which means your immune system is attacking your own body.

Is there a test for scleroderma?

Scleroderma can be hard to diagnose, since other diseases have similar symptoms. To figure out if you have scleroderma, your doctor may ask questions about your health and symptoms and do a physical exam. Your doctor may also do some lab tests and take a sample of your skin to look at under a microscope.

How is scleroderma treated?

The treatment for scleroderma depends on what part of your body it is affecting. Your doctor may recommend stretching exercises for your joints, creams for your skin, dietary changes, or treatments to make the red patches on your skin less apparent. Scleroderma has no cure, but symptoms and damage can be reduced.

Who treats scleroderma?

Several types of health care professionals may treat you, including:

- Rheumatologists, who treat diseases of the bones, joints, and muscles.
- Internists, who diagnose and treat adults.
- Dermatologists, who treat skin problems.
- Orthopaedists, who who treat and perform surgery for bone and joint diseases.
- Pulmonologists, who treat lung problems.

Living with scleroderma

You can take an active part in treating your scleroderma. Be sure to take your medications as prescribed, keep your physical therapy appointments, and call your doctor if you notice new
symptoms. Here are some ways to take care of your skin:

- **Skin problems.** With scleroderma, collagen builds up in the skin. Too much of it can make your skin dry and stiff. To help, you can:
  - Use oil-based creams and lotions after every bath.
  - Use sunscreen.
  - Use a humidifier at home.
  - Avoid hot baths or showers.
  - Avoid strong soaps, cleaners, and chemicals. Wear rubber gloves if you have to use those products.
  - Exercise regularly.

- **Cosmetic problems.** Scleroderma can damage your skin and change how it looks. These skin changes can affect your self-image. Ways to fix skin damage include:
  - Lasers that take away red spots on the hands and face.
  - Plastic surgery in areas where the disease is not active.

If you have systemic scleroderma, the disease may affect other parts of your body, besides just your skin. Here are some common treatments and things to watch for if you have systemic scleroderma:

- **Raynaud’s phenomenon.** Most people with scleroderma have Raynaud’s phenomenon. It can affect the fingers, feet, and hands. It makes them change color if you are too cold or anxious. To help, you can:
  - Not smoke.
  - Dress warm, and keep hands and feet warm.
  - Do exercises that relax the body.
  - Ask about medicines that open small blood vessels and help with blood flow.
  - Ask about medicines that treat skin sores and ulcers.

- **Stiff, painful joints.** Stiffness and pain come from hard skin around joints and joint swelling. To help, you can:
  - Do stretching exercises that help with joint motion.
  - Exercise regularly (swimming is best).
  - Take medicine to help ease pain or swelling. Ask your doctor which are the best for you to take.
  - Learn to do daily tasks in ways that put less stress on the joints.

- **Dry mouth and dental problems.** If you have tight skin on your face, you may have trouble
caring for your teeth. Dry mouth speeds up tooth decay. Harm to tissues in the mouth can loosen teeth. To avoid problems:
  ○ Brush and floss your teeth each day.
  ○ Have frequent dental checkups.
  ○ See your dentist if you have mouth sores, mouth pain, or loose teeth.
  ○ Ask your dentist about special rinses and toothpastes.
  ○ Learn ways to keep your mouth and face flexible.
  ○ Keep your mouth moist. You can drink lots of water or suck on ice chips. You can also chew gum or suck on hard candy that has no sugar added.
  ○ Avoid mouthwash that has alcohol.
  ○ If dry mouth still bothers you, ask your doctor about helpful medicines.

• Gastrointestinal problems. Digestive problems can include heartburn, trouble swallowing, feeling full as soon as you start eating, diarrhea, constipation, and gas. To help, you can:
  ○ Eat small, frequent meals.
  ○ Stand or sit for 1 to 3 hours after eating.
  ○ Use blocks to raise the head of your bed.
  ○ Avoid late-night meals, spicy or fatty foods, alcohol, and caffeine.
  ○ Eat moist, soft foods, and chew them well.
  ○ Ask your doctor about medicines for diarrhea, constipation, and heartburn.

• Lung damage. Lung problems with systemic scleroderma can include loss of lung function, severe lung disease, lung tissue scarring, and high blood pressure in the artery that carries blood from your heart to your lungs. Watch for signs of lung disease, such as:
  ○ Fatigue
  ○ Shortness of breath
  ○ Problems with breathing
  ○ Swollen feet.
  ○ As soon as your skin starts to thicken, see your doctor. Get regular flu and pneumonia shots.

• Heart problems. Systemic scleroderma can sometimes cause scarring and weakness in your heart, as well as swelling of the heart muscle and a heartbeat that isn't normal. These problems can all be treated with help from your doctor.

• Kidney problems. Scleroderma can cause very high blood pressure and kidney failure in some people. Talk to your doctor about what symptoms to look for so you can spot problems right away. You should:
  ○ Check your blood pressure often.
Check your blood pressure if you have new symptoms.
Call your doctor if your blood pressure is higher than normal.
Take the medicines your doctor prescribes.

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.

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