

# What Is Scleroderma?

## *Fast Facts: An Easy-to-Read Series of Publications for the Public*

Scleroderma is a group of diseases that affect connective tissue in the body. This tissue supports your skin and internal organs. Scleroderma involves tissue that gets hard or thick. It can also cause swelling or pain in the muscles and joints.

Some types of scleroderma lead to hard, tight skin. Other types affect blood vessels and major organs (such as the heart, lungs, and kidneys).

### **What Causes Scleroderma?**

The cause is unknown. You can't catch it from other people. Doctors don't think it is passed through genes (from parent to child).

### **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 skin tissues. 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 the skin, tissues under it, blood vessels, and major organs.

### **Who Gets Scleroderma?**

Scleroderma is more common in women than men. Anyone can get it, even children.

Most localized types show up before age 40, and are more common in people of European descent than in African Americans.

Systemic types are more common in people aged 30 to 50 and are more common in African Americans than in people of European descent.

### **How Is Scleroderma Diagnosed?**

Doctors diagnose scleroderma using:

- Your medical history
- A physical exam

U.S. Department of Health  
and Human Services  
Public Health Service

National Institute of Arthritis  
and Musculoskeletal and  
Skin Diseases  
National Institutes of Health  
1 AMS Circle  
Bethesda, MD 20892-3675

Phone: 301-495-4484  
Toll free: 877-22-NIAMS  
TTY: 301-565-2966  
Fax: 301-718-6366  
Email: NIAMSinfo@mail.nih.gov  
Web site: www.niams.nih.gov



- Lab tests
- A skin biopsy

Scleroderma can be hard to diagnose. Other diseases can have similar symptoms. It is easier to diagnose if you have:

- Common symptoms
- Skin that gets thick fast.

### **How Is Scleroderma Treated?**

A rheumatologist (a doctor who treats arthritis and other diseases that cause swelling in the joints) may lead your health care team and refer you to other health experts for problems with:

- Skin
- Kidneys
- Heart
- Digestion
- Lungs
- Teeth
- Movement
- Speech.

Scleroderma has no cure. But symptoms and damage can be reduced. Below are some problems and treatments for systemic scleroderma. These problems don't happen with localized 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.

### **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.

### **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 eat 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**

Problems include:

- Some loss of lung function
- Severe lung disease
- Scarring of lung tissue
- High blood pressure in the artery that carries blood from the heart to the 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**

Problems include:

- Scarring and weakness
- Swelling of the heart muscle
- A heartbeat that isn't normal.

These problems can all be treated.

### **Kidney Problems**

Scleroderma can cause very high blood pressure and kidney failure in some people. Learn to 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.

### **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.

### **How Can Scleroderma Affect My Life?**

People with scleroderma may worry about the way their skin looks. They may have problems dressing, bathing, or handling basic daily tasks. Scleroderma can affect:

- The way you look
- How you feel about yourself
- How you take care of yourself
- Family relationships
- Sexual relations
- Having a baby.

### **What Can I Do?**

You and your doctors are partners in your treatment. Be sure to:

- Take your prescribed medicines
- Follow your doctor's advice
- Quickly report problems.

You can also:

- Learn about the disease
- Look for support from family and friends or a support group
- Get help for depression and other problems
- Learn coping skills.

### **What Research Is Being Done on Scleroderma?**

Current studies include:

- Research to understand the genes that might be involved in scleroderma
- Medicines to keep skin from getting thick and to treat kidney and lung problems
- Medicines to treat scleroderma and its various organ complications
- Ways to identify and diagnose scleroderma earlier and treat it sooner.

Research and new treatments are helping people with scleroderma feel better and stay active much longer than they did in the past.

### **For More Information About Scleroderma and Other Related Conditions:**

#### **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse**

National Institutes of Health  
1 AMS Circle  
Bethesda, MD 20892–3675  
Phone: 301–495–4484  
Toll free: 877–22–NIAMS (226–4267)  
TTY: 301–565–2966  
Fax: 301–718–6366  
Email: [NIAMSinfo@mail.nih.gov](mailto:NIAMSinfo@mail.nih.gov)  
Web site: [www.niams.nih.gov](http://www.niams.nih.gov)

The information in this fact sheet was summarized in easy-to-read format from information in a more detailed NIAMS publication. To order the Scleroderma Handout on Health full-text version, please contact NIAMS using the contact information above. To view the complete text or to order online, visit [www.niams.nih.gov](http://www.niams.nih.gov).

### **For Your Information**

This fact sheet may contain information about medications used to treat the health condition discussed here. When this fact sheet was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration at 888–INFO–FDA (toll free: 888–463–6332) or visit its Web site at [www.fda.gov](http://www.fda.gov).