Living with Scleroderma
What Do I Need to Know?

Scleroderma (skler-row-der-muh):

Sclero means hard and derma means skin. Scleroderma causes your skin and muscles to become hard and tight.¹ This happens when your body makes too much collagen (kol-a-jen). This is a protein your muscles and skin need in small amounts.² But, too much of it can cause problems.

There are different types of scleroderma. One type hurts only the skin. Some types can also hurt the organs in your body, like your stomach and kidneys.

Having scleroderma can be tough. You may feel like it’s changed your life. Your scleroderma may not be the same as someone else’s.

There may be days when you feel in control of it. There may be other days when you are tired of it or don’t want to think about it.

Knowing the facts can help. Learning as much as you can about scleroderma will help you take better care of yourself and know what to do when problems happen. It gives you a chance to fight back and stay well. You are the best person to take care of yourself.

Keep reading to learn more about scleroderma. Even if you know a lot about it already, you may learn something new.

In this article you will learn:
- What scleroderma is and why treatment matters
- What causes scleroderma and what the signs are
- Who gets this and how
- What to expect and how to make a plan that works for you

Living with Scleroderma

There is good news. There are many things that you can use to help you cope with your scleroderma. It may be hard to know what to expect.

Here are some things to think about as you learn how to live with your scleroderma.

Did You Know?

Both men and women can have scleroderma but women have it more often. There are about 300,000 people in the US who have scleroderma. There could be more people who have it. Scleroderma can be hard to find since it can look like so many other things when skin is not affected.¹
Coping with the News

Your first thought may be to get online or go to the library and read as much as you can about scleroderma. What you find may be pretty bleak. But remember every person is different. And not everyone has all the problems that scleroderma can cause.

One of the most important steps to take is to arrange your healthcare team. You may need a team of doctors to help you feel best. While having the facts about scleroderma can be stressful, it will help you make a plan. This may help you feel that you have more control over what happens and how your scleroderma will be treated.

You may start by thinking about other stressful things you’ve had in life. How did you handle those things? How did that feel? What did you do first? These things may help you think about how to deal with this news.

Making Decisions

People make decisions in different ways. You may need to talk to family and friends before deciding on something. You may want to be alone and think through your thoughts. You don’t have to have all the answers today.

Yet, it is a good idea to start thinking about things that you may need to do.

Here is a list of questions to ask yourself that may be helpful as you start thinking about your treatment plan.

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<tr>
<th>What Do I Need to Think About?</th>
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<tr>
<td><strong>Questions to Ask Now?</strong></td>
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<tr>
<td>Do I have my healthcare team ready?</td>
</tr>
<tr>
<td>Have I made a plan for my scleroderma with my doctors?</td>
</tr>
<tr>
<td>Do I know how often to see my doctor and when to call for a problem?</td>
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</table>

How Is Scleroderma Found?

**Blood tests:** People who have a disease like scleroderma, will make more antibodies in their blood than other people because of inflammation (in-fluh-may-shun).²

The most common blood test is called the ANA, which is short for antinuclear (an-tih-new-klee-ur) antibody (an-tih-bah-dee). ANA is found in about 9 out of 10 people with scleroderma and can show whether it has hurt your body.³

**Skin or tissue biopsy:** These tests are used to look for signs of disease.² They can help confirm scleroderma if your skin is tight or thick.²

Your doctor also can look for clumps of collagen under your skin.³ This is a common sign of scleroderma.

**X-rays:** This can show if scleroderma has hurt your lungs.³ Many people with scleroderma will have lung problems.

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Managing Symptoms

Your scleroderma signs and problems may be different from the next person and may change from day to day. You should talk to your doctor about what to expect and when to call the doctor. Here are some questions you may want to ask.

<table>
<thead>
<tr>
<th>Questions I Should Ask My Doctor</th>
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<tbody>
<tr>
<td>What are the most common problems with scleroderma?</td>
</tr>
<tr>
<td>When should I call your office for a new sign or problem?</td>
</tr>
<tr>
<td>What can I do at home to help ease the signs I have of scleroderma?</td>
</tr>
<tr>
<td>Do you have any other ideas that I should think about?</td>
</tr>
</tbody>
</table>

What Is an Autoimmune Disease?

**Autoimmune Disease**

Scleroderma is an “auto-immune” disease. Your body’s immune system protects you from disease and infection.

Think of it as the body’s defense or security system. It watches for anything that doesn’t belong in the body (like germs) and then attacks it until it leaves. This is how you get well when you’re sick.

When you have an autoimmune disease, the immune system mistakes parts of your body as being sick when they aren’t. It then begins to attack the healthy body part. This can cause damage to that area of the body. For scleroderma, it causes your body to make and store too much collagen.

Scleroderma is a chronic (kron-ik) disease. It is also an autoimmune disease. This means your immune system isn’t working right.

With an autoimmune disease, the immune system starts to attack itself and kills healthy parts of your body.4,5 This causes inflammation, or swelling, at the site of the attack.

With scleroderma, this inflammation causes your body to make and store too much collagen.4 The extra collagen keeps your skin and body from working as they should.4

This is a key part of scleroderma and is also the reason scleroderma is known as an inflammatory (in-flam-uh-tor-e) disease.4

Scleroderma can attack almost any part of your body.
What Are the Types of Scleroderma?

The word scleroderma is a general word. There are several types of scleroderma:

- **Localized** (low-kul-ized) **scleroderma**: This type only affects skin and the muscles right below your skin. For many people this type of scleroderma can be mild and the symptoms may get better.

- **Systemic** (sis-tim-ick) **scleroderma**: This type of scleroderma can hurt your skin and the organs, tissue, and blood vessels in your body. There are different types of systemic scleroderma:
  1. **Limited scleroderma** is the less severe form. It affects the fingers and face. Limited scleroderma usually does not cause damage to your organs.
  2. **Diffuse scleroderma** affects more areas of the skin compared to the limited type. Skin of the arms, legs, and trunk might be involved. It can affect major organs in your body, including the lungs and kidneys.

The signs of the disease are different from person to person. There are some common signs that may happen more often, like muscle and joint pain or dry mouth.

What Causes Scleroderma?¹

There is not a clear answer to this question. Most studies suggest that scleroderma is not passed down in families. Studies have found that there is not one single gene that causes scleroderma, but genes may play a role.

Some research has found that other things may cause it, like:
- Viruses and
- Chemicals

These are sometimes called **environmental** (in-vy-ron-men-tul) factors.

These are things you may come in contact with in the world. It is also thought that hormones may play a role. The link is not clear, but women do get scleroderma much more often than men.

Research is still being done to find out what causes scleroderma and why. Some studies suggest that people who get scleroderma have an immune system that does not work well before they get sick.
Who Gets Scleroderma?

You are not alone.

Studies suggest that more than 300,000 people in the US are living with scleroderma. Women get scleroderma more often than men. But many men also get scleroderma.

African American and Native American men and women who get scleroderma can have worse symptoms than others.

It’s hard to know just how many people have it in the US. The signs of it are not the same for each person and that often makes it hard to find and track. There may be many people living with scleroderma who do not know they have it.

How Is It Treated?

You will see a doctor called a rheumatologist (rhee-uh-muh-tuh-loh-jist) to make a plan just for you. The goals of your plan may include:

- treating the inflammation that scleroderma causes
- slowing down your immune system
- helping with problems like joint pain or feeling tired
- keeping scleroderma from hurting your body

Treating your scleroderma will be a team effort. It may take some time to find the right medicine and you may have more than one medicine.

You may also have more than one doctor helping with your care. Besides your rheumatologist, you may see other doctors who will help take care of other parts of your body.

For example, you may see a gastroenterologist (gas-tro-in-tur-all-oh-jist) for problems with your stomach. You may have heart burn or problems with your bowels. It will be helpful for you to stay in touch with your team. This means letting them know of any change in your signs or problems from scleroderma.

The medicine that you use to care for your scleroderma will depend on the type of problem you have. Scleroderma can cause many different problems. It will be important to tell your doctor about all of the problems you are having. This will help your doctor make a complete treatment plan for you.

Make sure you show the list of medicine you take to each of your doctors when you talk to them about treatment.
What about Other Treatments?

You may decide to check out other choices for treatment. These things can help you feel more relaxed and lower pain, like massage or aromatherapy. You may have more energy.

Talk to your doctor about what you can expect from these choices and whether they can help. Never make a change without talking to your doctor first.

What Can I Expect Now?

Knowing that you have scleroderma can have a huge impact on your life. You may feel many things in the weeks after learning about this. You may feel relief to know what is wrong, since scleroderma can be hard to find. Your feelings can range from anger to sadness.

It is a good idea to get those feelings out in the open, talk about them, tell your friends and family how you feel, and get help if you need it.

Depression is very common in people who have chronic illness. It is ok to take time to grieve and figure things out.

Scleroderma can cause some changes in the way you think or act because of the disease itself. These are not the same for each person. They can happen whether you feel depressed or not.

It’s a good idea to talk to your doctor, your spouse, or family member about how you feel. Let them help you work through your feelings.

Part of living well with your scleroderma is having a plan in place to deal with the signs you may have from time to time. You also need to know when your sign of scleroderma needs treatment by your doctor. Taking good care of yourself can help you stay well and take the best care of your body.
<table>
<thead>
<tr>
<th>What Is It?</th>
<th>What Does It Mean?</th>
<th>Can I Fix It?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raynaud’s</td>
<td>About 9 out of 10 people with scleroderma have this. This happens when blood</td>
<td>Yes, you can. Try these tips:</td>
</tr>
<tr>
<td>(ray-nose)</td>
<td>vessels narrow (the fingers and toes turn blue and lose feeling) because of cool</td>
<td>• Wear gloves.</td>
</tr>
<tr>
<td>Attacks</td>
<td>weather or stress.</td>
<td>• Don’t smoke. This causes blood vessels to get even smaller.</td>
</tr>
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<td></td>
<td></td>
<td>• Talk to your doctor about medicine to help keep you from having an attack.</td>
</tr>
<tr>
<td>Joint and Muscle</td>
<td>Hard skin and weak muscles can cause the joints to get stiff. A joint is the</td>
<td>Yes, there are things you can do to help:</td>
</tr>
<tr>
<td>Pain</td>
<td>place where your arms, legs, feet and hands bend. They may be hard to move or</td>
<td>• Ask your doctor about seeing a therapist to get help with stretching</td>
</tr>
<tr>
<td></td>
<td>very sore when moved. You may have muscle pain near the joint, too. You may</td>
<td>exercises to keep joints loose.</td>
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<tr>
<td></td>
<td>notice some swelling.</td>
<td>• Try to exercise if you can. This will help keep your muscles strong and</td>
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<tr>
<td></td>
<td></td>
<td>may lessen pain.</td>
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<td></td>
<td></td>
<td>• Learn new ways to do old things. If it hurts to hold your coffee cup in the</td>
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<td></td>
<td></td>
<td>morning, try using a straw.</td>
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<td></td>
<td></td>
<td>• Ask your doctor whether you could try an over-the-counter medicine to help</td>
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<tr>
<td></td>
<td></td>
<td>with pain.</td>
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</table>
## Living With Scleroderma Each Day

<table>
<thead>
<tr>
<th>What Is It?</th>
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</tr>
</thead>
</table>
| **Skin Problems** | When too much collagen builds up in your skin it can keep your skin from making sweat and oil. This can cause hard, tight, dry skin. You may have itchy skin. | Yes, there are things you can do to help your skin.  
- Use oil-based creams after you bathe and before bed.  
- Use a humidifier in your room. This will help keep the air from being too dry.  
- Don’t take hot baths or showers. This dries skin.  
- Exercise as much as you can. This helps blood move better to the skin. |
| **Dry mouth** | When skin around the face gets tight it can be hard to open your mouth.  
Scleroderma may also limit the amount of saliva or spit you have in your mouth.  
This can cause damage to your teeth and bad breath. | Yes, there are things you can do at home to help.  
- Brush and floss your teeth each day if you can. Your dentist may give you a special toothbrush to make caring for your teeth easier.  
- See your dentist often. Ask your dentist how often you need to come in for a check-up.  
- Tell your dentist about any sores or loose teeth right away.  
- Drink water and chew sugarless gum. This can help keep your mouth wet. |
## Living With Scleroderma Each Day

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</table>
| **Stomach Problems** | Scleroderma can hurt the stomach and the muscles that your body uses to move your food. You may have:  
  - Heartburn  
  - Trouble swallowing  
  - Feeling full after a few bites  
  - Diarrhea *(die-uh-ree-uh)* or constipation *(con-stuh-pay-shun)* | Yes, you can do things to help.  
  - Eat smaller meals and eat them more often.  
  - To keep from getting heartburn, don’t lie down or bend over for 2 hours after eating.  
  - Don’t eat late at night and try not to eat things that can cause heartburn, like:  
    - Alcohol  
    - Chocolate  
    - Spicy food  
    - Caffeine  
  - Eat moist, soft foods and chew them well if you have trouble swallowing. Talk to your doctor about what else you can do to help. |
| **Lung Problems** | Scleroderma can hurt the lungs and may cause lung disease. | Yes, you can. Watch for these signs:  
  - Feeling very tired  
  - Feeling short of breath  
  - Having trouble breathing  
  - Swollen or puffy feet  
  These could be signs that your scleroderma has hurt your lungs. Be sure to tell your doctor right away if you have any of these things.  
  Have your lungs checked often by your doctor. Ask your doctor how often you should be seen.  
  Get the flu shot each year. This will lower your chance for other lung problems from the flu virus or pneumonia. |
## Living With Scleroderma Each Day

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<tbody>
<tr>
<td>Heart Problems</td>
<td>Many people with scleroderma will have weak heart muscles or scarring from scleroderma. The repeat inflammation over time can scar the tissues in the heart or make them weak.</td>
<td>Yes, these can be treated by your doctor.</td>
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<tr>
<td></td>
<td></td>
<td>Tell your doctor if you:</td>
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<tr>
<td></td>
<td></td>
<td>• Feel short of breath</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Have chest pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Feel like your heart is beating fast</td>
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<tr>
<td>Kidney problems</td>
<td>About 1 out of 10 people with scleroderma will have a very bad problem with their kidneys. Many more will have high blood pressure, which can lead to kidney problems.</td>
<td>Yes, you can do something to stop this before it starts.</td>
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<tr>
<td></td>
<td></td>
<td>• Check your blood pressure. Talk to your doctor about how often you should check your blood pressure.</td>
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<td></td>
<td></td>
<td>• Be sure to tell your doctor if you have had kidney problems before.</td>
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<td></td>
<td></td>
<td>• If you take medicine for your kidneys, do not miss a dose.</td>
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### Infections and Scleroderma

Having scleroderma gives you a higher chance for getting infections. This is because of scleroderma itself and the medicines you take to treat it.

Know the signs of infection and check with your doctor for any signs that are new or worse than before. The signs of infection can be:

- Fever
- Redness or swelling
- Body aches
- Pain
- Cough
- Sore throat
- A high fever (over 100 degrees)

Get medical help as soon as possible if you have the signs of an infection.
# Other Signs of Scleroderma That Need Treatment Fast

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>Chest pain or cough¹</td>
<td>Inflammation from scleroderma can hurt the tissue around your heart and lungs, and the muscles in your heart.</td>
<td>Tell your doctor right away if you have any of these symptoms. Talk to your doctor about ways to lower your chance for heart disease.</td>
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<tr>
<td>Swelling of hands and feet¹</td>
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<tr>
<td>Fever or chills¹</td>
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<tr>
<td>Skin that does not get color back after a Raynaud’s attack¹</td>
<td>There is a chance that you could lose the blood flow in your fingers or toes and have damage after an attack.</td>
<td>Tell your doctor right away if you have a Raynaud’s attack and your skin does not get color back after an hour or two.</td>
</tr>
<tr>
<td>Trouble breathing²</td>
<td>Scleroderma can scar the lining of the lungs and cause problems.</td>
<td>Tell your doctor right away if you have any of these signs.</td>
</tr>
<tr>
<td>Trouble doing exercise²</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling very tired²</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble opening your mouth²</td>
<td>Tight skin from scleroderma can keep you from opening your mouth. This can make caring for your teeth very hard.</td>
<td>Tell your doctor if you feel that your mouth is hard to open. Your doctor may send you to a therapist for tips on stretching the muscles near your mouth.</td>
</tr>
<tr>
<td>Bad diarrhea⁷</td>
<td>When muscles in the stomach get weak, it can cause problems.</td>
<td>If you have a change in your bowels, talk to your doctor. This needs treatment sometimes.</td>
</tr>
<tr>
<td>Stool that smells bad and looks oily</td>
<td>If your intestines (in-tes-tins) can’t move your food through, it could cause these problems.</td>
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<td>Constipation</td>
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</table>
# What Else Can I Do to Help My Scleroderma?

Put a check beside any of the things you think you can do in the list below.

<table>
<thead>
<tr>
<th>Learn more. Try to learn as much as you can about scleroderma. What makes it better? How can you stay well? Does diet help?</th>
<th>See your doctor often. Your doctor can help you track your scleroderma over time. Are you staying well? Are you the same? Do you have new signs? You can help by keeping track of your signs. Tell your doctor about any change, no matter how small.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t be afraid to ask questions. Always ask at least these three questions: 1. What is my main problem? 2. What can I do about it? 3. Why is it important for me?</td>
<td>Take care of yourself. Follow your doctor’s orders. Take your medicine the right way. Try to eat a good diet and stay as active as you can.</td>
</tr>
<tr>
<td>Keep track of your medicine. Keep a list of all the medicines you take. Take it with you to your doctor’s visit. You can also put your medicines in a brown bag and take them with you for each visit.</td>
<td>Have a health-support friend. Have a family member or friend go with you to each doctor’s visit. They can help you keep up with your doctor’s plan, listen to what your doctor tells you, and give you support when you need it.</td>
</tr>
</tbody>
</table>

Save this list and come back to it. See if you can check off all the boxes!

There is hope for your scleroderma. There are many choices and help for the problems that you must deal with each day. More than ever, research is being done to learn more about this disease.

Now is the time to get started. Talk to your Accordant nurse honestly about your fears. Don’t be afraid to ask questions of your doctor. You have the power to make this work for you. There is no goal you can’t reach if you are willing to work for it.

**Now it’s Your Turn!**

What other questions do you have after reading this? This was a lot to take in. You may have to put this down and come back to it. It might be helpful to keep this in a place where you can reach it easily. Share this with family and friends who have questions about your scleroderma.

When you are ready, let’s use the next page to make a list of questions for your doctor.
Questions I Can Ask My Doctor or Accordant Nurse

(Write in other questions you have here. Here is an example. Check off each question after you’ve asked your doctor.)

What is the most important thing I should know about SCLERODERMA?

My Notes

My Action Plan

Now it’s time to get started. What will you start doing now to help take care of scleroderma? You have the power to take care of your own health. Let’s get started today. Use the box below to think about what you can do.

Put a check beside each item and take this with you the next time you visit your doctor. Write in other steps you can take that your doctor tells you about.

<table>
<thead>
<tr>
<th>Action Items</th>
<th>I will do this...</th>
<th>I might do this...</th>
<th>I will think about doing this...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write down all the medicine I have taken in the last 3 months (even things I bought at the drug store, like aspirin).</td>
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<tr>
<td>Write down a list of my doctors.</td>
<td></td>
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<tr>
<td>Write down any questions I have about scleroderma.</td>
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<tr>
<td>Write down whether I have any new health problems or have been to the hospital in the last 3 months.</td>
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</tbody>
</table>
**Important Things to Remember**

- Talk to your Accordant nurse about scleroderma.
- Learn as much as you can about scleroderma.
- Take your list of questions with you to each doctor’s visit.
- Take your medicine with you each time you go to the doctor.
- Don’t be afraid to ask your doctor questions.

**Want to Learn More Now?**

Call your Accordant Health Management Nurse or go online to www.Accordant.com today!

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**References**