

Vanderbilt Scleroderma Clinic

Scleroderma

Your Guide to Care



Welcome to the Vanderbilt Scleroderma Clinic



We're glad to be part of your care team. We'll guide you and answer your questions every step of the way.

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VanderbiltHealth.com (615) 322-5000

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Important contacts

Vanderbilt Scleroderma Clinic (615) 322-2386

Primary care provider _____

Phone _____

Insurance company _____

Phone _____

Pharmacy _____

Phone _____

My Health at Vanderbilt

If you haven't already done so, sign up for a My Health at Vanderbilt account.

► MyHealthAtVanderbilt.com

With your account, you can:

- schedule an appointment
- keep track of your appointments
- join an appointment wait list
- see test or lab results online
- pay your bill
- ask for prescription refills
- email your providers
- check your medical records.



Get the app

You can find the My Health at Vanderbilt app in Apple's app store and the Google Play store.

If you have any trouble, call our Help Desk at (615) 343-4357 (HELP).

About scleroderma

What is scleroderma?

It's an autoimmune disease. This means your own immune system attacks your skin and connective tissue (tough bands that hold your bones and muscles together) and causes them to harden. This makes it hard and painful to do even easy daily activities.

Will it go away?

There are a few ways to treat it, but it won't go away. It can sometimes be deadly. Our goal is to help you manage the disease.



What types of care will I need?

Depending on your symptoms, you may see many types of providers. These may include:

- pulmonologists (lungs)
- dermatologists (skin)
- gastroenterologists (belly, guts)
- and others.

There also will be times when we can't give you all the services, tests, and procedures you may need. When this happens, we may send you to other Vanderbilt clinics and providers. These may include:

- Pulmonary Clinic (lungs)
- Wound Care Clinic
- Pain Clinic
- The Sleep-Wake Center
- Dermatology (skin)
- Radiology (x-rays)
- Cardiology Clinic (heart)
- Pulmonary Lab (lungs)
- Pulmonary Rehabilitation (lungs)
- Occupational and Physical Therapy.

Do I need a primary care provider?

Yes. Our clinic only treats scleroderma and health problems that are directly related to it. For all other medical issues, you'll need to see a primary care provider.

If you do not have a primary care provider, you'll need to pick one as soon as you can. Try to find one who is near your home or where you work. You should also make sure they're covered by your health insurance.

Your clinic appointments

What will happen at my appointments?

A lot may happen during your visits, especially the first one. You may see one provider or a few different ones. It depends on how you feel and the problems you have that day.

Here are some things that may happen at your first visit.

Arrival

You should get here 30 minutes early. You'll need this time to park and check in. If you're late, it may affect other patients.

Once you're here, you'll check in at the main desk. We'll then take you back to an exam room.

Medical history

In the exam room, we'll check your vital signs, including your heart rate and blood pressure. We'll also go over your medical history and the reason for your visit.

Medicines

We'll go over your past and current medicines. Bring a list of all the medicines you take. Or you can bring the bottles they come in. We'll also check to see if you need any vaccines. You can ask any questions you may have about your medicines or vaccines at this time.

Tell us right away if you take any steroids. These can be very bad for your kidneys when you have scleroderma.

If you don't take any of your medicines because you have trouble paying for them, let us know.



Physical exam

Next, your provider will give you a physical exam. Take this chance to ask any questions you may have about your symptoms, your concerns, or anything else you want to know about scleroderma. Your provider will go over your

- treatment plan
- medicines
- any tests or procedures you need.

Your care instructions

Before you leave, we'll go over your home instructions. We'll also set up any follow-up tests or procedures that you need. We'll put all your instructions and appointments into an after-visit summary. You can read them in your My Health at Vanderbilt account.

If you need lab work or other tests, make sure the lab is in your insurance network. You don't want any surprise bills.

If you have any questions before you leave, be sure to ask us.



Is there anything I need to do before my appointment?

You're an important part of your care team. To help us give you the best care:

- bring any medical records, test results, and any other information we ask for.
- do any labs, tests, or procedures you need before your appointment so we can go over them with you.
- have someone come with you to each appointment. They can support you and help you remember everything we talk about.

If you would like us to refill your scleroderma medicines, make sure:

- you've come to all your appointments
- all your tests, procedures, and check-ups are up to date
- you ask for your refill at least 3 business days before your medicines run out.

When should I set up future appointments?

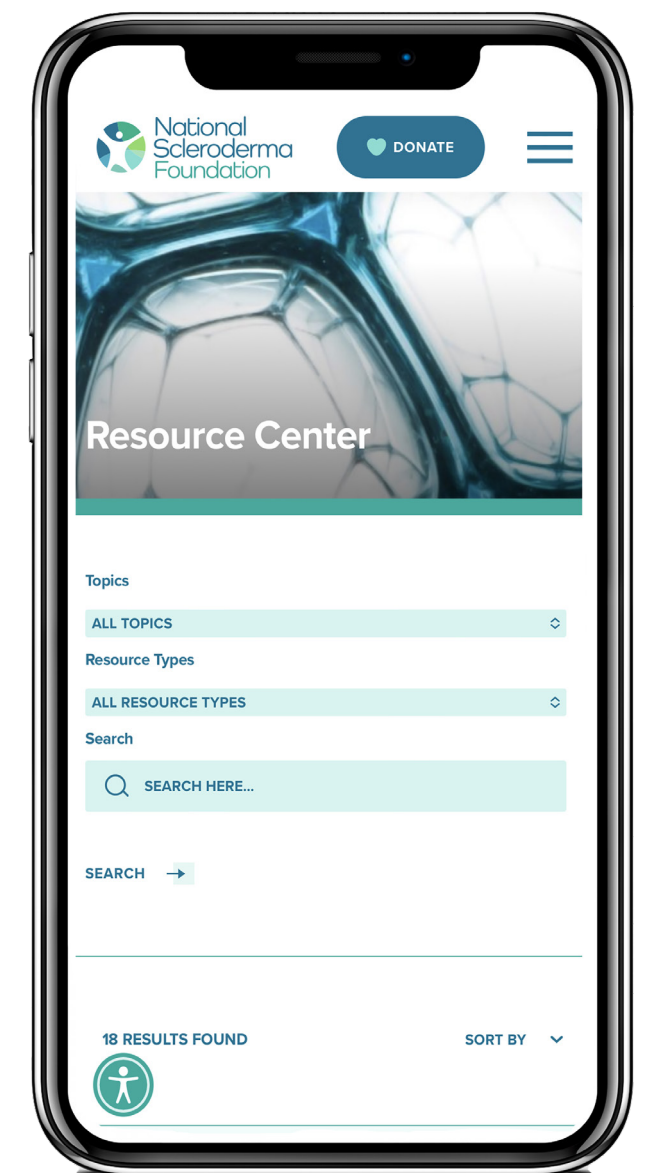
You can set up your appointments 3 to 12 months in advance. We know things may come up when you plan them that far ahead. If you need to change an appointment, tell us as soon as possible. And always tell us at least 24 hours before your scheduled appointment.

If your scleroderma caused a sudden problem, call us right away. If we need to see you, we may be able to fit you in that day.

If you have a medical emergency, call 911 or go to the closest emergency room.

Where can I learn more about scleroderma?

Visit Scleroderma.org and PubMed.gov. Keep in mind that not everything you read will apply to you. Never make any changes to your treatment plan unless your provider says it's OK.



Tests

What kinds of tests will I need?

We may do tests to help treat you and to learn what parts of your body are affected by your problem.

If we get results that aren't usually found with scleroderma, we may send you to your primary care provider or another specialist. It's possible that you'll have some health problems that aren't due to scleroderma.

Here are some of the most common tests and medicines we do for scleroderma patients.

Blood tests

Before or at your first visit, we'll do blood tests to check for autoantibodies. These are cells that attack your own body instead of infections. If we find these, we may do more tests.

If you take medicine that lowers your immune system's ability to fight, you'll need blood tests every 1 to 3 months. We'll always go over these

tests with you. If you've had these tests but haven't heard from us, call to make sure we got the test results.

Once a year, we'll also check your vitamin D, thyroid hormone levels, and a few other important things to watch for other problems.

Other tests

- An **echo** (echocardiogram) checks for high blood pressure in your lungs. You'll usually get this test once a year.
- An **EKG** (electrocardiogram) is a test for your heart. We usually do this test 3 times:
 - when you're first diagnosed
 - if you have swollen (inflamed) muscles
 - if you're on certain heart medicines.
- An **EMG** (electromyogram) or **NCS** (nerve conduction study) can help tell us if your nerves or muscles are inflamed.

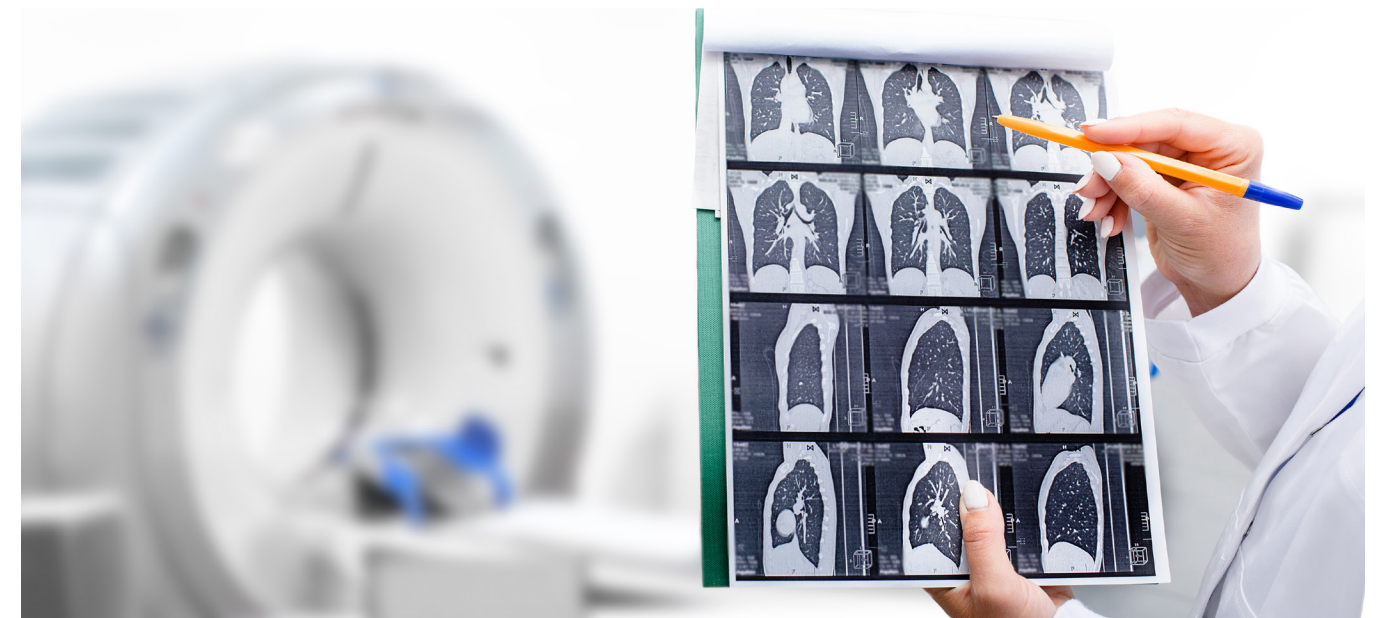


- A **PFT** (pulmonary function test) tells us how well your lungs work. You'll get this test at least once a year to look for damage in your lungs. You may also do this test if you have a change in how you breathe.
- A **hi-res CT scan** is like a more detailed x-ray. You may get one of these if:
 - you have an abnormal PFT
 - you have an abnormal lung exam
 - it's hard for you to breathe.

- An **ABI** (ankle-brachial index) checks to make sure your lower legs and feet get enough blood.
- A **joint ultrasound** helps us learn if your joint pain is caused by swelling or osteoarthritis.

Cancer screenings

If you take medicine that lowers your body's ability to fight germs, we need to make sure you've had all the cancer screenings and vaccines you need.



Care for your symptoms

Your treatment may help slow down your disease. But it's just as important to treat any symptoms you have. This will make it easier to get through your daily activities.

Scleroderma symptoms may come on fast. Or they may affect you for a long period of time. At your clinic visits, your providers will offer ways to help lasting symptoms. You need to do everything your providers suggest. This may include medicines, lifestyle changes, and keeping track of your symptoms.

It's also very important that you do not miss any clinic visits. You must come in for check-ups when your providers ask you to.

Here are some things related to scleroderma that you'll need to watch closely.

Blood pressure

The best way to track your blood pressure is to keep a log. We've added a sample log at the end of this section. Bring it with you to every clinic visit. Ask us how to manage high blood pressure if this is a problem for you. Do everything on this list to help manage your blood pressure.

- Check your blood pressure every day for the first month after you find out you have scleroderma. This will tell us what your usual results are.
- Only check your blood pressure when you're at rest.
- Do not have drinks with caffeine (coffee, cola).
- Do not smoke or use tobacco.
- Pee before you check your blood pressure.

If you have a sudden rise in your blood pressure that is 15 points higher than usual, or if it's higher than 150/90, check it again in 1 hour. If it's still high, call us right away so we can order lab tests.



Raynaud's syndrome

This is a problem that lowers blood flow to your fingers. It can also happen to your toes, ears, and nose. When it happens, your fingers turn white and then blue. When blood flow returns to normal, the area may turn red before it goes back to your normal color.



The main cause for this is when you've been out in the cold. But strong emotions can also bring it on. It can last from a few minutes to hours. You may also feel pain or tingling in your fingers.

If you have Raynaud's, you need to keep your body warm. You should:

- always keep extra clothes, a hat, and gloves with you
- put gloves on as soon as you feel your hands getting cold
- wear gloves when you handle ice or frozen food.

It's also important that you:

- exercise often
- do not smoke
- do not have drinks with caffeine
- try to keep your stress level low
- take breaks often when you use a computer
- use a backpack or shoulder bag instead of a handbag.

Wound care

People with scleroderma and Raynaud's may often get skin ulcers (open sores), especially on their fingers. The best way to keep this from happening is to take care of yourself.

But if you do get them, call us right away. Your provider needs to look at them. We may send you to the wound care clinic.

Treatment for skin ulcers includes:

- high-pressure (hyperbaric) oxygen therapy
- medicines
- skin creams
- surgery.

Skin ulcers heal best if you:

- keep them warm, moist, and covered in a bandage.
- take the medicines we give you to help your blood flow
- use any nitro creams we give you.



Lung disease

What is it?

Scleroderma patients may also have lung problems such as interstitial lung disease. This is a disease that causes scarring in your lungs. It doesn't go away. This can make it hard to breathe. It also makes it harder to get enough oxygen into your blood.

We usually treat lung disease with medicines. But you may also need pulmonary rehab and oxygen therapy.

Once a year, we'll check how well your lungs work. But if you ever have a change in how well you're able to breathe, tell us right away. We'll order more tests and set up a visit with a lung specialist.



How do you treat it?

Pulmonary rehab

This usually happens in an outpatient clinic. You'll do exercises to improve your energy levels and help you breathe better. Rehab may also:

- help you be able to exercise more
- improve your well-being
- make it easier to take part in social activities
- lead to fewer hospital stays
- help you have a better quality of life.

How long you have to do it depends on:

- your health
- how much you can do at each visit
- if you do all your exercises at home.

Oxygen therapy

Lung disease can cause low oxygen levels in your blood. When this happens, you may need oxygen therapy.

Oxygen therapy can help:

- lower your shortness of breath
- lower strain on your heart
- you sleep better
- you exercise more.

How do I get oxygen therapy?

You can use an oxygen tank or an oxygen concentrator. Talk to your provider to find out which is best for you.

Oxygen tank

This is the most common way to get oxygen therapy. The tank connects to a tube that goes under your nose or into a mask so you can breathe in the oxygen.



Oxygen concentrator

This is a machine that pulls the oxygen out of the air. It then sends pure oxygen through a tube for

you to breathe. If you decide to get one of these, make sure it can make all the oxygen you need.



Is there anything I need to do when I'm on oxygen?

- Do not smoke or use any kind of fire (matches, lighter, gas stove).
- Do not drink alcohol or take sleep medicine.
- Tell your electric company that you have electrical medical equipment in your home. If the power goes out, this will help make sure you're first in line to get it back.

Call your provider right away if you:

- feel a change in your breathing
- need more oxygen
- cough up yellow, green, brown, or bloody mucus
- have a fever or chills
- feel sick to your stomach.

If you feel very short of breath or have chest pain, call 911 to get to the nearest emergency room.

Physical and occupational therapy

With scleroderma, it's common to have weak muscles and trouble moving around. If this happens to you, we'll send you to physical or occupational therapy.

What is physical therapy?

A physical therapist (PT) is a provider who can help you move better. They'll give you stretches, exercises, and treatments that will make you stronger and more flexible. These may also help lower your pain.

What is occupational therapy?

An occupational therapist (OT) will help you do your regular things like bathing, chores, or job-related skills.

Where will I go for therapy?

You'll usually see your PT or OT in an outpatient clinic. But if you need to be in the hospital, they can see you there, too. How long you're in PT or OT will depend on a few things, including:

- your health
- how much and how hard you work at each visit
- if you do your exercises at home like your provider says.



Pharmacy services

You'll likely have at least one medicine for your scleroderma. If your insurance pays different amounts for in-network and out-of-network care, make sure to get your medicines at an in-network pharmacy.

If you'd like us to refill medicines that we've prescribed, you need to make sure you:

- come to all your appointments
- had all the check-ups, tests, and procedures you need
- ask for your refill at least 3 days before you run out of your medicine.

Vanderbilt has pharmacies in health centers all over the Nashville area. They're open a wide range of times and hours. This should make it easy for you to pick up your medicines after your visit.

Our pharmacies can:

- fill your new prescriptions
- refill your current medicines
- work with your provider on your medicine treatment plan
- get your prescriptions electronically
- give over-the-counter medicines
- offer online refill requests
- give specialty pharmacy services
- have good prices
- help you with billing and insurance questions
- help you if you can't pay for your medicines.



Mental health

Scleroderma is a physical illness. But it can also affect your mental health. Each person reacts in their own way after they find out they have it.

Here are some of the thoughts and feelings people with scleroderma often have.

You may have strong emotions

After you learn you have scleroderma, or when your symptoms get worse, you may feel:

- fear
- worry
- anger
- sadness
- relief
- overwhelmed
- like it can't be happening
- there's nothing you can do.

These feelings can come and go. At times you may feel like you're on an emotional roller coaster.

You may blame yourself

Your first thoughts may be “Why me?” or “What did I do wrong?” You may think you're being punished. Or this is your fault. Since there's no known cause of scleroderma, many people come up with their own ideas about why they have it.

You may feel like your disease defines you

It's important to remember that you're not a disease. You may need a lot of care and help from others now. But you're still the same person as before.

You may feel very sad

It's very common for people to grieve when they find out they've got scleroderma. You may also feel this same way when you can no longer do some things you used to be able to do. This is normal. It's OK to have those feelings.

You may feel drained

It can be very hard to take care of your illness every day. It drains you physically and mentally. You may be tempted to hide your feelings to help you get through the day. That can help sometimes. But it can also:

- make your symptoms worse
- raise your stress
- make you more upset about your life.

Try to find a pace that works best for you to get through your daily activities, thoughts, and feelings.

You may feel alone

It's common to feel alone after you find out you have a disease like scleroderma. You may not know anyone else who has it. You may not know anyone who has heard of it. And you also may not know where to turn for help.

How can I find help?

The Scleroderma Foundation (Scleroderma.org) has online support groups you can join. And there are other support groups and places to help you. They can help you find other people with scleroderma. They can also help you learn more about the disease.

Everyone goes through scleroderma in their own way. But when you hear how others have thought and felt about it, it may help. It may also answer questions in a way that only another person who has scleroderma can.



What can I do when I feel bad?

Here are things you can do when you feel bad or have bad thoughts:

- Be kind to yourself.
- Try not to judge yourself, your thoughts, or your emotions.
- Allow yourself to feel, explore, understand, and accept your thoughts and emotions.
- Write down your questions and concerns so you can talk with your providers about them.
- Talk to family or friends who listen and offer support.
- Do not try to do more physical and mental activities than you can handle each day.
- Get enough sleep.
- Get the emotional and mental help you need.

If you feel sad, hopeless, or helpless all the time, or if you feel like you want to hurt yourself or others, call 911 or go to a hospital emergency room right away.

Self-care

What is it?

Self-care is all the things you do to look after your health. This includes:

- body
- mind
- emotions
- spirit
- relationships
- work life.

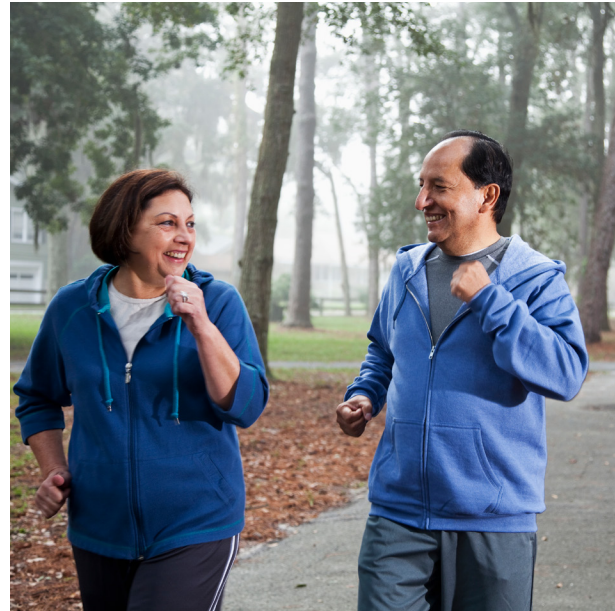
When you care for these things, it will help you find and keep balance in your life. The way to do it is different for everyone. You need to figure out what works best for you. And even though it can be hard to find that balance, the work you do to reach that goal will help you get healthy and do the things you need to do.

How do I do it?

Keep your body healthy

This can help keep the effects of scleroderma down and raise your energy. That will help you do everything you need to do each day. Things you can do are:

- lead a healthy lifestyle
- take your medicines as you're told
- get enough good sleep
- exercise often but within your limits
- eat a healthy diet as your provider has told you
- set goals for your care and reach them.



Keep your mind sharp

Good mental health can help you:

- pay attention
- improve memory
- make good decisions.

Here are some ways to do this.

- Take small breaks during the day.
- Make time to relax.
- Spend time with family and friends who are positive and support you.
- Stay away from work e-mail and phone messages outside of work hours.
- Take up a hobby.
- Use good problem-solving skills.
- If you have vacation time at work, use it.

Care for your emotions

Good emotional health will help you go through and handle all your feelings safely. Some ways to do this are:

- be aware of how you feel
- start a journal
- create and use your support system
- take deep breaths
- take walks often
- write down 3 things that are good in your life every day
- read a book
- listen to music.

Boost your spirit

Spiritual health affects how you see and live your day-to-day life. It's how you learn to love yourself no matter what. It also helps you connect to yourself and others again. To do this, you can:

- meditate
- do something nice for others every day
- try yoga
- use guided imagery
- laugh and sing out loud
- watch or read a story that makes you feel good
- interact with nature
- follow your gut
- live every moment to its fullest
- do not take anything for granted.



Keep healthy and supportive relationships

- Make your close relationships a priority in your life every day.
- Go to special events for your family and friends.
- Be open and honest with people who are important to you.
- Be present at home and with your family and friends.
- Do not work on the days you have off.

Keep a healthy work life

These things will help you keep a good work ethic and stay professional at work.

- Be at work on time and don't leave early.
- Learn new skills that will help you advance at work.
- Ask coworkers who have more experience to help you or look over your work when you're not sure about something.
- Keep proper boundaries.
- Read articles about your line of work.



Self-care plan

| | Overall balance | Things that might be in the way | Things I should not do | How it helps me |
|----------------------|-----------------|---------------------------------|------------------------|-----------------|
| Body | | | | |
| Mind | | | | |
| Emotions | | | | |
| Spirit | | | | |
| Relationships | | | | |
| Work | | | | |

Support groups

When you go to a scleroderma support group, you'll meet and talk with others who are going through many of the same issues you are. This may help you feel more in control and less alone.

These support groups are usually led by fellow scleroderma patients. The focus of each group may vary. But you can think of all of them as a safe space for you to share your thoughts and feelings without judgment. Support groups are where you can:

- learn more about the disease
- learn new coping skills
- get support

- lower stress, anxiety, and depression
- understand better what to expect with the disease
- get practical tips on how to live with it.

Check the National Scleroderma Foundation website at [Scleroderma.org](https://www.scleroderma.org) to find a support group or local chapter near you.



Second opinions

We know you may want a second opinion after you find out you've got scleroderma. It may change how you decide to treat it. If you decide you want one, we suggest you visit a certified scleroderma treatment center. You can find a list at [Scleroderma.org](https://www.scleroderma.org).

Also make sure to let us know you'd like a second opinion. We can send your medical

records before your visit. Because scleroderma is a complex disease, it's important they have your full medical history.

If you take part in any research or clinical trials with us, a second opinion may keep you from staying in the study or screening.



Advance care plan

What is it?

It's possible your illness could get so bad that you can no longer make your own decisions about your care. An advanced care plan tells your family and providers what type of care you wish to have.

It's a good idea to also choose a designated surrogate. This person will decide what type of care you'll get if you can't decide for yourself.

As you make your plan, think about your values and goals related to your scleroderma care. And after you've made your plan, make sure your family and care team know your wishes.

Here are some questions that may help you as you work on your advance care plan.

Values

- How do your values and things that are important to you relate to your healthcare?
- Do you have any beliefs that may affect your healthcare goals and wishes?
- Have you had any sick family or friends whose healthcare decisions were made for them? If so, think about what did or didn't work and how those things might affect your healthcare wishes.

Goals

- How well do you understand scleroderma and what it does to you?
- What are your worries about your future?
- What's important to you in your healthcare?

Wishes

- Are there conditions for which you would or would not want certain treatments?
- If you need advance care, where would you want it?
- Would you like to be an organ or tissue donor?

We've included a Goals of Care Plan worksheet at the end of this section. It'll help you figure out your healthcare goals and then tell your providers, family, and surrogate.

Do I need an advance directive?

We suggest you do. It states your wishes for your care if there's ever a time you can't do it yourself. It's important because you have the right to get the care you want no matter what.

An advance directive isn't the same as a living will. A living will is a legal paper, but it may only apply to terminal illnesses. It also may not include your healthcare wishes. An advance directive includes a living will section. It also gives you the chance to set up a surrogate or someone to make legal decisions for you.

Once you've set up your advance directive, make sure you to go through it and talk about it with your providers, family, and surrogate. You should also make sure they have a copy of it. Keep the original copy in a safe place.

You should look at your Goals of Care Plan and your advance directive at least once a year and if your health changes. Let us know if you have questions or need help with these.

Goals of Care Plan

Patient name: _____

Date: _____

Concerns

The main things I'd like to improve about my health are:

The main things that stop me from getting healthier are:

Symptoms

The main symptoms I wish to lower or get rid of are:

My treatment goals are:

What I'd like to happen

If I follow my plan, then:

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