SCLERODERMA & RAYNAUD'S UK

UNDERSTANDING SCLERODERMA

WE ARE DEDICATED TO IMPROVING THE LIVES
OF PEOPLE AFFECTED BY SCLERODERMA AND RAYNAUD'S

WHAT'S INSIDE

ABOUT THIS INFORMATION

Scleroderma is a complex condition, which affects people in different ways. There's a lot to take in, so this information gives an overview.

It's written for adults with scleroderma. It's also useful for family and friends.

This guide is backed up by reliable sources and evidence. It's been reviewed by healthcare professionals and people who are living with scleroderma. You'll also find some real-life stories.

When you've got a rare condition like scleroderma, you have to become something of an expert yourself. That way, you can make informed choices about your treatment. This guide can get you started, and we're here to give you more details and support along the way.

ABOUT SCLERODERMA

Scleroderma occurs when your body produces too much collagen, which is a strong, fibre-like protein. Collagen is useful because it provides a kind of scaffolding to support the skin and the body's connective tissues.

When you have scleroderma, extra collagen builds up. This can make your skin stiff, tight, thick or scarred. For some people, this build-up affects the blood vessels, joints and muscles, and internal organs.

We don't fully understand what causes scleroderma but we're looking for answers. You can learn more on page 8.

Different types

There are two basic types of scleroderma:

- **LOCALISED** which only affects your skin
- **SYSTEMIC** where other parts of your body are involved

These main categories are divided up further into more specific types. You'll find more details on page 11.

> **SRUK has helped me so much. I no longer feel like a person with a disability with no confidence.**
> Hannah

Scleroderma is…

- ☑ linked to your immune system
- ☑ sometimes difficult to diagnose
- ☑ variable from mild to severe

Scleroderma is not…

- ☒ contagious
- ☒ confirmed with a single test
- ☒ the same for everyone

Managing scleroderma

We’re still looking for a cure. But the treatments we have today can improve your symptoms and quality of life. Treatment also aims to protect your body from further damage.

And you can help yourself stay as well as possible, by following a healthy lifestyle and looking after your skin. It’s ideal if you can work alongside your healthcare team to make a treatment plan, keep an eye on how it’s working, and make changes when needed.

Living with scleroderma isn’t always easy, and it can bring on some strong emotions at times. There’s lots of support available when you need it, from your doctors, nurses, therapists, family and friends, and the SRUK community.

Learning about scleroderma also puts the power in your hands, so you can get the most out of life and meet it on your own terms.

> **When I received my diagnosis of scleroderma, I didn’t realise what the disease meant for me and my health. Trusted information was key to helping me understand what this diagnosis meant.**
>
> Lorraine

SYMPTOMS OF SCLERODERMA

Everyone's experience of scleroderma is different. It depends on what type you have, how severe it is, and what parts of your body are affected.

Skin changes

For most people, scleroderma causes problems with the skin. These symptoms can include:

- patches of thick, hard skin that may become discoloured
- itching
- tight skin that makes it harder to move your joints
- hard lumps under your skin (calcinosis)
- tiny blood vessels (spider veins) appearing just beneath your skin, called telangiectasia

You can develop painful sores on your fingers and toes, called digital ulcers. These must be treated right away to protect the tissue and prevent an infection.

Skin changes can affect your appearance. If it's bothering you, do speak to someone like your doctor, nurse or therapist because they can help. Or you can contact us any time at SRUK for information and support.

Raynaud's and scleroderma

Alongside scleroderma, it's common to have a condition called Raynaud's.

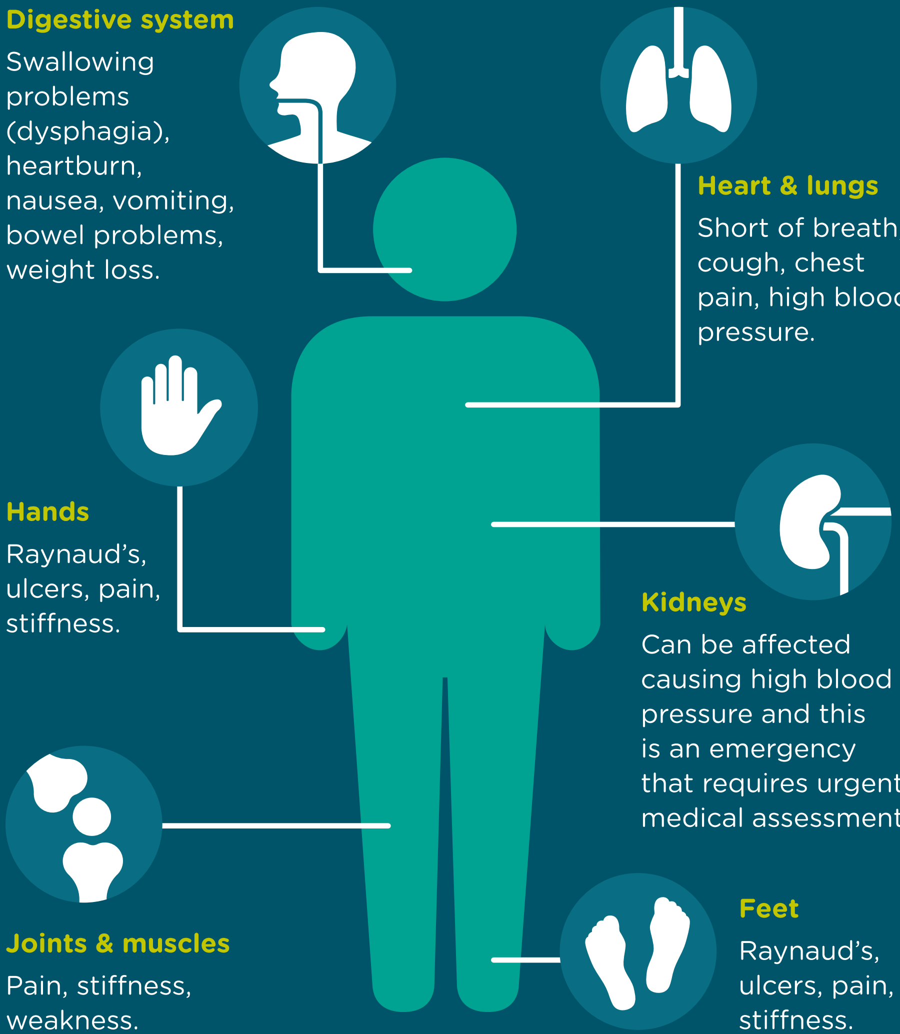
People with Raynaud's are sensitive to temperature changes or cold, and this can set off tingling, discomfort or pain, usually in the hands and feet. Your fingers or toes might turn from white, to blue, to red. Stress and anxiety are sometimes a trigger.

We have lots of information on Raynaud's, so visit our website or call the helpline if you want to know more.

0800 311 2756
www.sruk.co.uk

Other symptoms

Some types of scleroderma can affect other parts of the body beyond the skin, causing the symptoms you see in the diagram.



Digestive system

Swallowing problems (dysphagia), heartburn, nausea, vomiting, bowel problems, weight loss.

Heart & lungs

Short of breath, cough, chest pain, high blood pressure.

Hands

Raynaud's, ulcers, pain, stiffness.

Kidneys

Can be affected causing high blood pressure and this is an emergency that requires urgent medical assessment.

Joints & muscles

Pain, stiffness, weakness.

Feet

Raynaud's, ulcers, pain, stiffness.

Pain and severe tiredness (fatigue) can get you down, but there are practical ways to manage these symptoms (see page 16).

CAUSES AND OUTLOOK

We don't completely understand what causes scleroderma. But it's thought to be an autoimmune disease. This means your immune system, which usually fights off infections, goes wrong and starts attacking the tissues in your body.

With scleroderma, this leads the body to create too much collagen. As a result, the skin and sometimes the blood vessels and other parts of the body stiffen up, in a process called fibrosis.

Genetic links

Several genes that control your immune system have been linked to scleroderma, but we need to learn more through research.

In a few cases, scleroderma may occur in more than one member of a family. However, this is very rare and scientists haven't found a clear pattern.

In some cases scleroderma may be triggered by exposure to a certain chemical and you may be asked about possible environmental exposure.

What will happen?

Everyone is different so it's not possible to predict exactly how your condition will develop. Partly, it depends on what type of scleroderma you have. Some people have less severe symptoms that settle over time. Others progress quickly and, sadly, their condition is very disabling or even life-threatening.

The best thing to do is talk to your doctor about your individual situation. They won't have all the answers but they'll do their best to give you an honest picture.

Living with uncertainty is hard. We are always here for you at SRUK, to offer understanding and support during difficult times.

Up to

19,000

people living with scleroderma

Up to

1,000

people are diagnosed each year

80%

of scleroderma patients are female

– People with scleroderma, UK

> **I have always experienced Raynaud's, so symptoms such as cold and blue hands have been present throughout my life. I didn't know that Raynaud's could be a sign of something until I was diagnosed with scleroderma.**
>
> Alex

HOW SCLERODERMA IS DIAGNOSED

One of the frustrating things about scleroderma is that getting a diagnosis is not always straightforward.

Because it's a rare disease, it's possible your GP has never seen a case before. And many other conditions can have similar symptoms. If they suspect scleroderma, your GP should refer you promptly to a specialist clinic.

Unfortunately, there's not a test that can tell, on its own, whether you have scleroderma or not. Your specialist team must put together lots of different information to confirm that you have the condition.

They also need to determine what type of scleroderma you have, and find out which parts of your body are being affected. They will check your heart, lungs, digestive system kidneys and muscles, as well as your skin.

Examinations and tests

At your hospital appointment, your specialist team will ask you some questions and you'll be examined by a doctor. They'll take an especially close look at your skin.

> **It is difficult to pinpoint when it all began, as the changes happened very slowly. Looking back, I think I had the first signs in my mid-forties with Raynaud's… when I started to get ulcerated fingers that were incredibly sore, this led to a diagnosis of limited cutaneous systemic sclerosis.**
>
> Michael

Over time, you'll probably have several tests, which might include:

- blood tests
- blood pressure check
- tests for Raynaud's in your hands
- testing a sample of your skin (biopsy)
- breathing tests (pulmonary function tests)
- x-rays
- ultrasound scan of your heart (echocardiogram)
- ECG heart test (electrocardiogram)
- CT scan (computed tomography)
- endoscopy (looking at your digestive system with a scope)

You might not have all of these tests, or you might have others that aren't listed here.

Which type?

There are different types of scleroderma. They are based on your skin changes, and which parts of your body are affected.

LOCALISED SCLERODERMA (ALSO CALLED MORPHOEA) Only the skin is affected.	**MORPHOEA PATCHES (PLAQUES)** Affected skin appears in circles or patches.
	LINEAR MORPHOEA Affected skin runs in a line.
SYSTEMIC SCLERODERMA Can also affect your organs.	**LIMITED CUTANEOUS** Comes on gradually; affects only some areas of your skin, generally the hands and telangiectasia on the face; organs may also be affected, particularly the lungs in the form of pulmonary hypertension.
	DIFFUSE CUTANEOUS Comes on suddenly; commonly affects more of the skin than limited cutaneous; the organs are also commonly affected, often the heart and lungs through fibrosis.

TREATMENTS FOR SCLERODERMA

We don't have a cure yet for scleroderma. But treatment aims to manage your symptoms, and to limit damage to your tissues and organs.

It will also be tailored to your individual needs, depending on what type of scleroderma you have and how it is affecting your body.

Your treatment should also follow a clear plan that has been agreed between you and your doctor. This plan should reflect your goals and wishes as far as possible.

We've invested

£10 million

in research, including studies on understanding the disease process and complications of scleroderma, finding better treatments and managing scleroderma in children.

Holistic care

Because scleroderma is a rare condition, and treatment can be complex, your care should be managed by a specialist team.

This team will ideally have people from different health professions, who can give you support and bring their skills to different aspects of your care.

RHEUMATOLOGIST OR DERMATOLOGIST

Specialist doctor. Diagnosis, medication, scleroderma care.

OTHER SPECIALIST DOCTORS

You might have care from specialists in surgery or heart, lung or kidney medicine.

GP

Your usual doctor continues to care for everyday medical problems.

SPECIALIST NURSE

Has extra training. Helps you manage your condition, gives advice and a listening ear.

PHYSIOTHERAPIST

Helps you stay active and mobile with exercise, helps manage pain and symptoms.

OCCUPATIONAL THERAPIST

Offers practical solutions for everyday living, helps you stay independent.

SPEECH THERAPIST

Can help with swallowing problems.

DIETICIAN

Helps you follow a nutritious diet and keep a healthy weight.

DENTIST

Can provide extra care if scleroderma is affecting your oral health.

Treatment options

While they're not the entire answer, medicines might play an important role in your treatment.

Many different medicines are used to manage scleroderma, so it helps to think about them in groups, based on what aspects of the condition they work on. There are medicines that aim to:

- regulate your immune system
- ease skin symptoms
- help with Raynaud's and finger ulcers
- protect your heart, lungs and kidneys
- help with digestive problems
- help with sexual problems

Some of the most commonly used drugs are named in the glossary, starting on page 20.

Everyone's experience is different, but all medicines can have side effects. Your doctor will talk you through the risks and benefits. Your team is also there to adjust your medicines or manage side effects if they do happen.

Non-drug treatments are also important. These can include physiotherapy, occupational therapy and in some cases surgery. There are treatments to improve the appearance of your skin, and ways to cover up problem areas with cosmetics if you want to.

In a few severe cases, a procedure called autologous haematopoietic stem cell transplant (ASCT) may be considered. This involves giving very powerful drugs to suppress the immune system and can have a high risk of life-threatening infection. As with any treatment option, the team on our helpline can tell you more about ASCT.

> **I take eight different medications regularly to treat my condition.**
>
> Michael

LIVING WELL WITH SCLERODERMA

Treatments for scleroderma will work best when you play an active role alongside your healthcare team. It takes time and persistence, but you should feel the benefits if you can:

- Learn about your medicines and how to take them.
- Talk to your doctor about medication side effects. They might be able to change your prescription or help you feel more comfortable.
- Keep up with the exercises recommended by your physiotherapist, and ask for advice if they're too hard or not working for you.

Many people also find that keeping warm helps with symptoms if you have Raynaud's. Visit our website or call our helpline to get our handy hints.

Skin care

Routine skin care is essential when you have scleroderma. Keep your skin well moisturised: products with lanolin are especially recommended.

Try to avoid harsh, deodorised soaps. Instead, go for non-soap cleansers.

If you're bothered by the appearance of telangiectasia (clumps of tiny, broken blood vessels), you can learn to cover the area with specialist make-up, called skin camouflage. Our helpline can put you in touch with these services.

Some people try laser or pulsed light treatments for telangiectasia. When you have scleroderma, these are usually performed by a dermatologist in a specialised clinic.

Healthy lifestyle

Like anyone else, a healthy lifestyle will help you feel your best.

If you smoke, be kind to yourself and stop. This will help your blood pressure and your circulation. There are free stop smoking services to advise and support you, and treatments to get you through the cravings. Ask for details at your GP surgery.

Digestion problems are common with systemic scleroderma. Some people have trouble swallowing, or lose too much weight. A dietician can help a lot, so ask your doctor or nurse for a referral if you are struggling. You'll also find nutrition tips on the SRUK website.

Regular exercise is good for your heart, lungs and muscles, and can help keep you supple. Even if you don't feel up to something strenuous, every little bit helps. Try something you enjoy so you're more likely to stick to it.

Staying hopeful

It's not the same for everyone, but sometimes scleroderma can be very hard to accept.

Researchers are looking for new treatments or even a cure – often with support from SRUK – and we think this is a reason to be hopeful. You can read more on the next page.

Meanwhile, we are here to help at SRUK if you need a listening ear. You can join our community, too, and talk to other people who will understand because they are living with scleroderma, too.

> **SRUK has helped me so much. I no longer feel like a person with a disability with no confidence.**
> Hannah

RESEARCH AND NEW DEVELOPMENTS

We don't have all the answers yet, but researchers around the world are looking for better treatments, ways to improve care, and ultimately, a cure for scleroderma.

As you'd expect, much of current research aims to find the causes, and test possible medicines for scleroderma. Stem cell transplantation is another active area of research.

But there's also research on many other aspects of care, such as:

- better diagnostic tests
- treatment with gut microbes or probiotics
- support groups and online learning
- feelings about appearance
- music therapy
- types of exercise

We've invested £10 million in research, including studies on understanding the disease process and complications of scleroderma, finding better treatments and managing scleroderma in children.

Taking part in research

We need medical research studies, also called clinical trials, to find safe and effective new treatments for scleroderma.

Your healthcare team might invite you to join a clinical trial. They will explain the possible risks and benefits, and answer all your questions.

It's up to you whether you participate or not. Your decision will not affect your care, so don't ever feel pressured.

If you want to know about current studies, you can visit the central register at www.clinicaltrials.gov and search for 'scleroderma'.

Thank you to our clinical reviewers

We would like to thank Professor Ariane Herrick from Salford Royal NHS Trust, Professor Chris Denton from Royal Free NHS Hospital Foundation Trust and Professor David Scott for their expert guidance and input.

GLOSSARY OF MEDICINES

Many different medicines are used to treat scleroderma and the list here introduces some of the most common ones. Your doctor's recommendations will be based on the type of scleroderma you have and how it is affecting your body.

You can read more detailed information about many of these medicines on our website at **www.sruk.co.uk**. This list is not exhaustive and several of these drugs do go by other names.

OFF-LABEL PRESCRIBING

Medicines are regulated by government authorities. They approve medicines for specific uses based on clinical trials. For rare diseases like scleroderma few trials are available and so it is usual for doctors to use their expert judgement to prescribe a medicine for other uses. This is called off-label prescribing. Some of the medicines listed here are prescribed off-label for scleroderma.

AMBRISENTAN

Sometimes called Volibris (brand name). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs).

ANGIOTENSIN-CONVERTING ENZYME INHIBITORS

Sometimes called ACE inhibitors, various brand names. To treat serious kidney problems.

AZATHIOPRINE

Sometimes called AZA (abbreviation), Imuran (brand name). Suppresses your immune system, sometimes used to treat lung and skin symptoms.

BOSENTAN

Sometimes called Stayveer, Tracleer (brand names). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs), digital ulcers (sores on your fingers or toes).

CALCIUM CHANNEL BLOCKERS

Medicines in this group go by several names. They relax and open your blood vessels. For treating Raynaud's and digital ulcers (sores on your fingers or toes). You can read more on our website.

CYCLOPHOSPHAMIDE

Sometimes called CYC (abbreviation), Cytoxan (brand name). Suppresses your immune system, particularly to treat lung and skin symptoms.

EPOPROSTENOL

Sometimes called Flolan, Veletri (brand names). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs), Raynaud's, digital ulcers (sores on your fingers or toes).

ILOPROST

Sometimes called Ventavis (brand name). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs), Raynaud's, digital ulcers (sores on your fingers or toes).

MACITENTAN

Sometimes called Opsumit (brand name). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs).

METHOTREXATE

Sometimes called MTX (abbreviation), Jylamvo, Maxtrex, Methofill, Metoject, Nordimet, Zlatal (brand names). Suppresses your immune system, especially to treat problems with skin and joints.

MYCOPHENOLATE MOFETIL

Sometimes called MMF (abbreviation), CellCept, Ceptava, Myfenax, Myfortic (brand names). Suppresses your immune system, particularly to treat lung and skin symptoms. You can read more information from NICE at www.nice.org.uk

PROTON PUMP INHIBITORS

Sometimes called PPIs, various brand names. For treating reflux (indigestion or 'heartburn' symptoms).

RIOCIGUAT

Sometimes called Adempas (brand name). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs).

SILDENAFIL

Also known as Viagra, Granpidam, Revatio (brand names). For lung problems, severe Raynaud's, finger ulcers. You can read more information from NICE about sildenafil for ulcers on your fingers and toes, at www.nhs.nice.org

TADALAFIL

Sometimes called Adcirca, Talmanco (brand names). For pulmonary arterial hypertension (PAH, high blood pressure in the lungs).

HOW SRUK CAN HELP

We are the only UK charity dedicated to improving the lives of people affected by scleroderma and Raynaud's. We exist to improve awareness and understanding of these conditions, to support those affected, and ultimately to find a cure.

We understand that being diagnosed with a condition can be a scary and uncertain time. But don't worry we're here for you, every step of the way.

We offer expert information

We provide trusted, reliable and evidence based information on scleroderma and Raynaud's.

We want you to be able to learn more about your condition, feel confident in working with your health professionals and receive the right care for you.

You can access our information through our website **www.sruk.co.uk** or by calling **020 7000 1925**.

> **SRUK helps me put my mind at rest, and I know that I am lucky to have been diagnosed recently rather than 20 years ago, as I have access to provisions and information.**
>
> Ninder

Access to support services

Our online community is a friendly space where you can exchange advice, information and support with others who are affected by scleroderma and Raynaud's. Many of our community members are people who are living with the conditions themselves, but friends, family and partners are also welcome.

We can connect you with your local scleroderma and Raynaud's support group, so you can meet others living with these conditions.

We can help you find a specialist centre to make sure you are getting access to the best care and latest treatment.

You can connect with our helpline to talk about your condition and receive further support. Our helpline operates 365 days a year from 9am–7pm: **0800 311 2756**.

To find out more and receive all the latest information join our community on social media and start building a network of supportive friends today:

@WeAreSRUK **/WeAreSRUK** **/WeAreSRUK**

Research

We fund scientific and medical research to better understand the causes and progression of the conditions. Enabling us to find better treatments as we work towards a cure.

Our community is at the heart of our research programme. We are committed to addressing your needs to improve life in the here and now, alongside focussing on our long-term aim of discovering a cure.

Through our investment in research we have increased life expectancy for people living with scleroderma and have brought more treatments into clinics.

HOW TO GET INVOLVED

The work of the charity is funded entirely through donations, fundraising and memberships. We would like to ask you to support our work so we can continue to improve lives.

Become a member

Being a member of SRUK is a great way to receive all the latest information on the work of the charity and advancements in treatment and research. Membership entitles you to:

- four issues of our magazine received quarterly
- priority booking for all patient educational events
- regular member-only discounts in the shop, where you will find beneficial products for the conditions
- invitations to sign up for observation and/or product trials we may be running throughout the year, with key product partners and market research partners

Visit our website to find out more **www.sruk.co.uk/membership** or call our team on **020 7000 1925**

Donate to us

Donating will help support the life-changing work of Scleroderma and Raynaud's UK. There are many ways to donate including one off or monthly donations, leaving a gift to us in your Will or nominating us as Charity of the Year at your company.

Make a donation today by texting SRUK05 £5 to 70070

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