

UNDERSTANDING RAYNAUD'S



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

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ABOUT THIS INFORMATION

Each person has their own individual experience of Raynaud's. The symptoms can be mild, severe or anything in between, and no one is affected in exactly the same way.

It does help to hear about the experiences of other people with Raynaud's though, and to learn about the condition. This information gives an overview. It explains what Raynaud's is, how it's diagnosed and treated, and ways to help yourself.

It's written for individuals with Raynaud's, and it's useful for family and friends too.

This guide is backed up by reliable sources and evidence. It's been reviewed by healthcare professionals and people who are living with Raynaud's.

If you need more details and support, get in touch with us at SRUK - we're here to help.

Words in **bold** are explained in the glossary at the end.

ABOUT RAYNAUD'S

Clearing up the jargon is a good place to start. You may hear different names for this condition, which is sometimes called:

- **RAYNAUD'S DISEASE**
- **RAYNAUD'S SYNDROME**
- **RAYNAUD'S PHENOMENON** (this is the term recommended in latest guidelines for health professionals).

For simplicity, we call it Raynaud's. The condition is named after the doctor who first described it, Maurice Raynaud.

Two types

There are two types of Raynaud's: primary and secondary.

Primary Raynaud's occurs on its own and is not linked to any other condition. We don't fully understand what causes it, although scientists are working to find out.

Secondary Raynaud's happens because of a medical condition. It can also be caused by certain medications. Read more about the causes on page 9.

Both types are more common in women and may start before the age of 30. Sometimes it runs in the family.

What happens during a Raynaud's attack

When we're exposed to cold, some of our blood vessels, such as those in the fingers, get narrower. This is a normal response to help the body's core stay warm. In primary Raynaud's, this reaction is exaggerated, causing poor blood flow to the affected part of the body.

During an attack, both types cause similar symptoms, which typically include colour changes, pain and numbness. The symptoms affect specific parts of the body, and it's most common in the hands and feet. It can also affect other parts of the body like the lips, nose and ears. There's more information about symptoms starting on page 6.

Raynaud's can be uncomfortable and get in the way of daily life sometimes, but generally the symptoms are manageable. As much as you can, it helps to avoid the main symptom triggers, which are:

- exposure to cold
- being stressed

This is important for both types of Raynaud's, and so is keeping warm, taking good care of your skin, and stopping smoking. Exercise also helps with stress and can boost your circulation. You can read more about managing Raynaud's as part of your lifestyle, starting on page 12.

A few people with secondary Raynaud's go on to develop a connective tissue condition called **scleroderma**, also known as **systemic sclerosis**. You can learn more about the warning signs to be aware of, on page 8.

With secondary Raynaud's, you may need more support and possibly medical treatment to manage this form of the condition. For example, secondary Raynaud's can cause severe circulation problems like finger ulcers.

Primary Raynaud's

- is not linked to another condition
- may have milder symptoms and does not cause damage to the skin
- may mostly be managed with practical steps

Secondary Raynaud's

- is linked to another condition
- may have more severe symptoms like finger ulcers
- may need medical treatment

What to expect

We are still looking for a cure, but practical steps and medical treatment, if needed, can improve your symptoms and quality of life.

Everyone's experience of Raynaud's is different, and individuals may feel differently about it day to day.

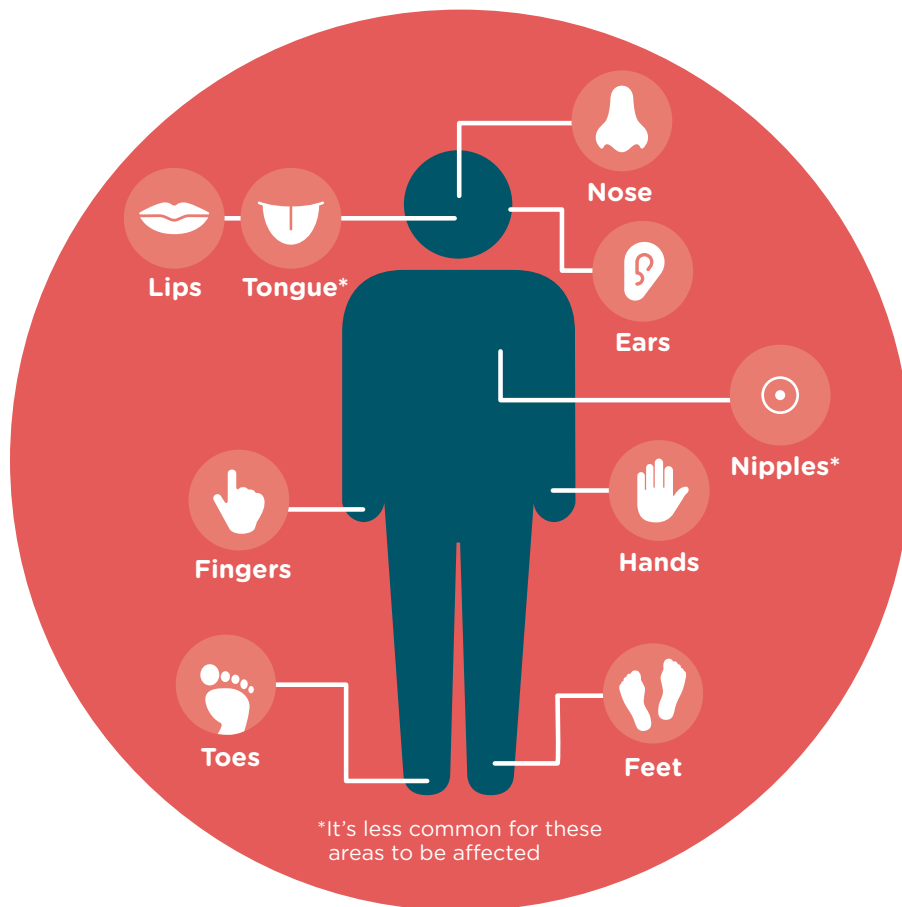
Raynaud's can be difficult to cope with but the good news is that you can take measures to help yourself manage the symptoms. You can also rely on support from our helpline and community at SRUK.



SYMPTOMS OF RAYNAUD'S

People with Raynaud's are sensitive to temperature changes or cold, which can set off the symptoms. Stress is sometimes a trigger.

Most of the time, Raynaud's affects the hands and feet, but Raynaud's symptoms can also appear in other areas (see the diagram below).



Raynaud's symptoms may include:

- cold fingers and toes
- colour changes in your skin, often from white, to blue, to red
- numbness
- tingling
- pain

At the end of the attack, there can be a stinging or throbbing pain when the area warms up.

The symptoms aren't constant – they come and go. An attack can be as short as a few minutes or it may last for hours. Some people have long gaps between attacks while others may have one or more attacks every day.

How symptoms happen

Raynaud's symptoms happen when your body's normal reaction to cold is too strong.

Here's how it works. When it's cold, your body's top priority is to keep the essential organs, such as the heart and kidneys, warm by temporarily increasing blood **circulation** to your core organs.

Your body does this by narrowing the small blood vessels (**arterioles**) that deliver oxygen-carrying blood to your extremities, like your hands and feet. This squeezing action is called **vasospasm**.

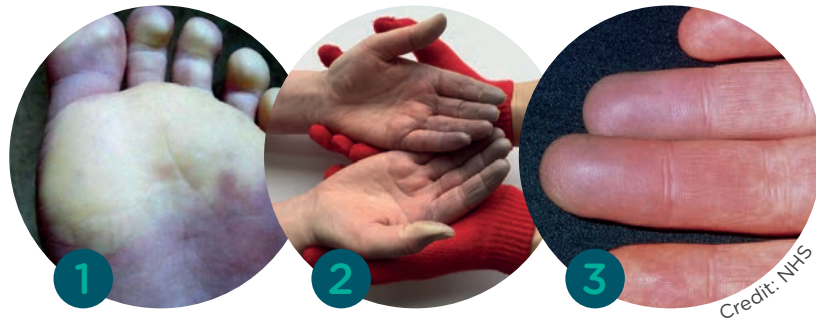
The problem is, with Raynaud's, this system goes into overdrive and too much oxygen-rich blood is kept away from some parts of your body. This temporary lack of blood flow is what causes your symptoms. If you have Raynaud's, stress can cause the same reaction.



10 million

People in the UK are affected by Raynaud's

Colour changes with Raynaud's



- 1 Your skin goes white when the blood supply gets cut off to the skin.
- 2 It turns blue when the blood trapped in the skin loses its oxygen (**cyanosis**).
- 3 The area turns red when blood flow returns to normal.

Not everyone with Raynaud's has all of these colour changes.

Signs of another problem

Raynaud's can be the first symptom of a potentially serious condition called **scleroderma**. Other symptoms that might suggest scleroderma include swollen fingers, heartburn (**reflux**) and breathing problems.

It's important to see your GP if you also have these symptoms, or if they start to appear. Your GP can refer you for tests, to find out whether you have an underlying condition that needs treatment.

CAUSES AND OUTLOOK

We don't know what causes primary Raynaud's. The medical term for an unknown cause is **idiopathic**.

In some people, Raynaud's is the first sign of an underlying problem. Around 1 in 10 people with primary Raynaud's have or go on to develop an **autoimmune** condition (see below). So if your symptoms get worse or you develop new ones, it's important to see your GP and get it checked out.

Secondary Raynaud's always has an underlying cause. It's sometimes a symptom of other conditions such as:

- **Scleroderma**
- **Lupus**
- **Sjogren's syndrome**

These are all **autoimmune** conditions where the body's immune system, which is meant to protect you against infections, mistakenly attacks your connective tissues.

Other medical conditions can also cause Raynaud's. So can various drugs, exposure to certain chemicals and the use of vibrating tools.

Complications

Primary Raynaud's can definitely affect your daily life but it doesn't cause complications.

With secondary Raynaud's, repeated, severe attacks can damage the tissues that have been starved of blood flow. This can cause painful sores on the fingers and sometimes the toes (digital ulcers).

The ulcers can be very painful and affect daily tasks. They can take a long time to heal, and they can get infected, so it's important to get treatment quickly. You'll find a fact sheet about digital ulcers on our website.

www.sruk.org.uk

HOW RAYNAUD'S IS DIAGNOSED

Your GP can advise whether you have Raynaud's. If you have symptoms, it's always worth getting things checked out. That's because your GP can give you advice on managing the condition, and help you find out if there could be an underlying cause.

When you go to see your GP, they will examine the affected area. They'll also ask some questions, which may include:

- what your symptoms are
- whether someone in your family has Raynaud's
- if you smoke
- what you do for work, sport or hobbies

They will consider your overall medical history, because various medical conditions can cause Raynaud's. So can different medicines.

It's also likely that you'll be offered some blood tests (see table) and some of these can be done at your GP surgery.

If your GP is unsure whether it's Raynaud's, or if they suspect an underlying cause, they should refer you to a specialist (usually a rheumatologist) for more tests.

A key test performed by your GP involves looking for autoantibodies. These are tiny proteins and high levels of these can suggest an autoimmune disease like scleroderma.

A specialist consultant will do a test called **capillaroscopy**, where the doctor looks at your fingernails under a microscope. This allows them to see your **capillaries**, which are the tiniest blood vessels. They can become damaged in conditions like scleroderma.

Blood tests you might have:

ABBREVIATION	FULL NAME	WHAT IT LOOKS FOR
ANA	Antinuclear antibody	A positive test may suggest an autoimmune condition (not always). Can show whether more tests are needed.
ESR	Erythrocyte sedimentation rate	This can be higher when there's inflammation (also goes up as we get older). Can show whether more tests are needed for an autoimmune condition.
FBC	Full blood count	This is a general test that tells your doctor a lot about your overall health. It can sometimes show whether more tests are needed.
TSH	Thyroid function	If your thyroid gland is underactive, it can result in cold fingers.



SRUK's information sheets have been useful for William's teachers as they are aware of his condition and what they need to do for him.

Cheryl

LIVING WELL WITH RAYNAUD'S

While scientists keep looking for a cure, making some straightforward, practical adjustments can help with Raynaud's symptoms.

For many people, lifestyle changes are all that's needed.

But don't blame yourself if this doesn't always work. Sometimes an attack can't be prevented, and some people do need extra medical help to treat Raynaud's, especially if it's more severe.

Raynaud's affects everyone's quality of life at least to some degree, and it can be hard to live with. So go easy on yourself if you feel fed up, and do ask for help.



Staying warm

It's also vital to stay warm when you have Raynaud's. Here are some tips:

- avoid sudden changes of temperature when you can
- try and keep your body warm, especially your hands and feet (to the point of feeling mildly uncomfortable, for example to the point you would normally take off a layer of clothing)
- dress in thin, loose layers for maximum warmth. This gives you flexibility too, because you can peel the layers off if you get too hot, or pile them on when it's chilly
- wear gloves and long, warm socks when it's cold
- try hand-warmers and thermal insoles

In addition to the weather, other exposures to cold can set off symptoms. It might be something simple like walking through the cold aisle in the supermarket, or reaching into your freezer. Think about situations where this could happen so you can be prepared in advance.



For more tips on staying warm, including when you're active outdoors, visit our website at www.sruk.co.uk

You'll also find advice on managing at work when you have Raynaud's.

Smoking and Raynaud's

If you smoke, stopping is one of the best things you can do to help with Raynaud's. That's because it restricts the blood flow to the skin.

There's lots of support available to help you stop smoking, so talk to your GP. Your pharmacist can also help. You can search for stop smoking services at www.nhs.uk or call our helpline for more details.

Be sure to tell professionals you have Raynaud's, so they can make suitable recommendations for you. Nicotine replacement therapies are thought to be better for you than smoking, but the nicotine will still encourage the blood vessels to narrow and you should try to come off treatment completely once you have successfully managed to stop smoking.

Managing stress

Stress can also bring on Raynaud's symptoms. We don't have strong evidence on what works best for Raynaud's, but it makes sense to try and reduce stress in your life.

Some ways to manage stress include pacing yourself, being aware when you're taking on too much, and making it a priority to get enough sleep.

Some people find that meditation, mindfulness, yoga or relaxation therapy helps them feel better.

Regular exercise and a healthy diet can help you deal with stress, which is good news because these measures could potentially help Raynaud's.

Caring for your skin

Anyone with Raynaud's will benefit from good skin care habits, so keep your skin clean and dry, use a moisturiser regularly, and treat any cracks or grazes promptly.

For people with secondary Raynaud's there's a risk of developing painful sores, called digital ulcers, on your fingers or toes. It's important to get treatment quickly, so see your doctor if you develop a sore like this, which doesn't go away.

For more information about digital ulcers, please visit www.sruk.co.uk/raynauds/managing-raynauds/

Complementary therapies

When drug treatments don't work, or if they don't want to take medication, some people try complementary therapies.

Various therapies have been studied for Raynaud's, including acupuncture, biofeedback, low-energy laser, herbs, vitamins and other nutritional supplements.

However, there's no strong scientific proof that they work. If you do want to try a therapy, check your practitioner is qualified and chat with your GP before you start.



“

We do a lot of walking, so I layer up with warm clothes and this helps a lot... exercise itself helps hugely.

Chloe

TREATMENTS FOR RAYNAUD'S

We don't have a cure for Raynaud's yet, but treatment aims to manage symptoms.

Self-care is a very important part of your treatment. Please see page 12 for everyday ways to manage Raynaud's.

Your GP can help by explaining the condition and suggesting practical ways to avoid and manage Raynaud's attacks.

Drug treatment

If everyday changes alone aren't helping, your doctor may offer you treatment with a medicine.

Often, the first medicine that is tried is nifedipine. This medicine is classified as a **calcium channel blocker**. It works by relaxing your blood vessels, thus improving circulation.

Side effects can happen with any drug, but not everyone experiences them. Some of the side effects for nifedipine include dizziness, flushing, headache, swollen hands and feet, feeling or being sick, constipation, rash or a fast heartbeat.

The headache is a sign that the blood vessels are being opened up and is not worrying.

The headache often disappears after a few days of treatment as the brain adjusts to the new blood pressure within the skull. You may need to take an occasional painkiller such as paracetamol during the first few days of treatment to help manage headaches, as your body gets used to the blood vessels being opened up.

Dizziness, flushing, light-headedness and fast heartbeat are also caused by the blood vessels being opened up. These symptoms may persist with continued treatment, so sometimes people need a lower dose, or their doctor advises them to stop taking nifedipine.

There are other drug treatments that your doctor might recommend to open up the blood vessels. Below is a list of the drug classes, and an example of a specific medicine for each one:

- angiotensin receptor blockers (losartan)
- antidepressants (fluoxetine)
- alpha blockers (prazosin)
- phosphodiesterase inhibitors (sildenafil)
- iloprost infusion

Further options

You should be referred to a specialist if this treatment does not work, or if your GP suspects secondary Raynaud's.

A specialist might recommend other drug treatments to try or, rarely, surgery.

With secondary Raynaud's, good management of your other condition may also help with the Raynaud's symptoms.

You'll find more details about treatment options on our website, or call our help line.

0800 311 2756
www.sruk.org.uk

RESEARCH AND NEW DEVELOPMENTS

There's still a lot to learn, which is why we fund research to make life better for people with Raynaud's and a related condition, scleroderma.

In addition, we help people with Raynaud's join clinical trials and other research studies if they want to (see below).

And we spread the news, communicating the latest findings at events that bring the research community together.

Around the world, some current and recent studies have been looking at:

- better diagnosis
- food supplements and nutrition
- new medicines
- improved surgical techniques
- non-drug treatments such as electrical stimulation

This means there are plenty of reasons to be hopeful. You can keep up-to-date with the latest research news on our website at www.sruk.co.uk/research



You can do your part by giving the patient's perspective on social media. On Twitter and Facebook, you'll find us [@WeAreSRUK](https://twitter.com/WeAreSRUK). Use [#SRUKResearch](https://twitter.com/WeAreSRUK) to tell us what you think about research.

Taking part in research

Your healthcare team might invite you to join a study. 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 in the UK and abroad, you can visit the central register at www.clinicaltrials.gov and search for 'Raynaud's'.

Thank you to our clinical reviewers

We would like to thank Dr John Pauling from the Royal National Hospital for Rheumatic Diseases, Dr Michael Hughes from the Salford Royal NHS Foundation Trust and Professor David Scott for their expert guidance and input.

GLOSSARY OF TERMS

Antibody

A protein made by your blood, normally as part of your immune response to a germ. Some blood tests for Raynaud's look at various antibodies.

Arterioles

The small branches of your blood vessels that carry oxygen to the tissues.

Autoimmune disorder

When your immune system, which normally fights off infections, mistakenly attacks your own tissues.

Calcium channel blocker

A type of drug (class) used to treat Raynaud's. One example is nifedipine.

Capillaroscopy

A test where the doctor examines the tiny blood vessels at the base of your fingernails, through a magnifier or microscope.

Capillary

The tiniest blood vessels, with walls that are only one cell thick. They are the link between your arterial circulation, which carries oxygen and nourishment to your tissues and the venous circulation, which carries away carbon dioxide and wastes.

Cyanosis

When your skin is blue because the blood in that area does not have enough oxygen.

Idiopathic

A symptom or condition that has an unknown cause.

Lupus

Full name systemic lupus erythematosus (SLE). An autoimmune, connective tissue condition, sometimes associated with Raynaud's.

Reflux (also called acid reflux)

Full name gastro-oesophageal reflux disease (GORD). Heartburn symptoms caused by stomach acid leaking up into your gullet. Can be a symptom of scleroderma.

Scleroderma (also known as systemic sclerosis)

An autoimmune, connective tissue condition with skin thickening, very commonly associated with Raynaud's.

Sjogren's syndrome

An autoimmune, connective tissue condition, often with dry eyes and mouth, sometimes associated with Raynaud's.

Systemic sclerosis

Another name for scleroderma.

Vasospasm

When a blood vessel squeezes and becomes narrower, reducing the blood flow.

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. We are here to help you every step of the way and reduce that worry.

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 gave me the chance to make friends with people who really understood my situation, extending my support network. It also helped my parents understand my condition.

Connor

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 call 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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