

Thank you for downloading the Raynaud's Information Pack

Raynaud's and Scleroderma affects millions of us in the UK, yet so many people remain undiagnosed or deal with the impact alone. We're calling on everyone affected to unite and create a world where there is much greater awareness and understanding of the two conditions and their impact, a world where diagnosis happens earlier and much better treatment and care is available to everyone who is affected. Together, we can create a better world for people with Scleroderma and Raynaud's.

In this pack you will find information on:

- The Signs and Symptoms of Raynaud's
- The Difference Between Primary and Secondary Raynaud's
- Managing The Condition At Home
- Medical Treatments Available
- The Link Between Raynaud's and Scleroderma Explained
- Who We Are and What We Do

The Signs and Symptoms of Raynaud's

Early signs of Raynaud's are when you are subjected to extreme reactions to the cold or any slight change in temperature, the extremities change colour and can be extremely painful.

Initially one or two fingers may turn white and feel numb. This can occur occasionally or regularly with all the fingers eventually becoming involved. It can be concerning at first, especially if the fingers then change to a bluish colour followed by bright red.

These symptoms are a normal a part of the condition, it is also worth noting not all symptoms are the same for any two people, but in all accounts, when the circulation returns, the usual colour of your hands/ feet is restored.

Top Five Signs of Raynaud's

1. Cold fingers and toes
2. Colour changes in the skin in response to temperature changes or stress
3. Colour changes in the affected area to white, then blue and then red
4. Numbness, tingling or pain in the fingers and toes
5. Stinging or throbbing pain upon warming or stress relief

These symptoms can last for minutes, or even up to several hours.

If you are experiencing the symptoms and they are extreme or frequent then it is worth making an appointment with a GP to explore your symptoms further. If these colour changes are occurring in the hands and possibly in the feet, nose, ears, lips, tongue or in the nipples (usually noticed during breastfeeding), a diagnosis of Raynaud's is likely to be given.

Your GP can do a simple blood test to establish if you have Raynaud's and whether it is the primary or secondary form of the condition.

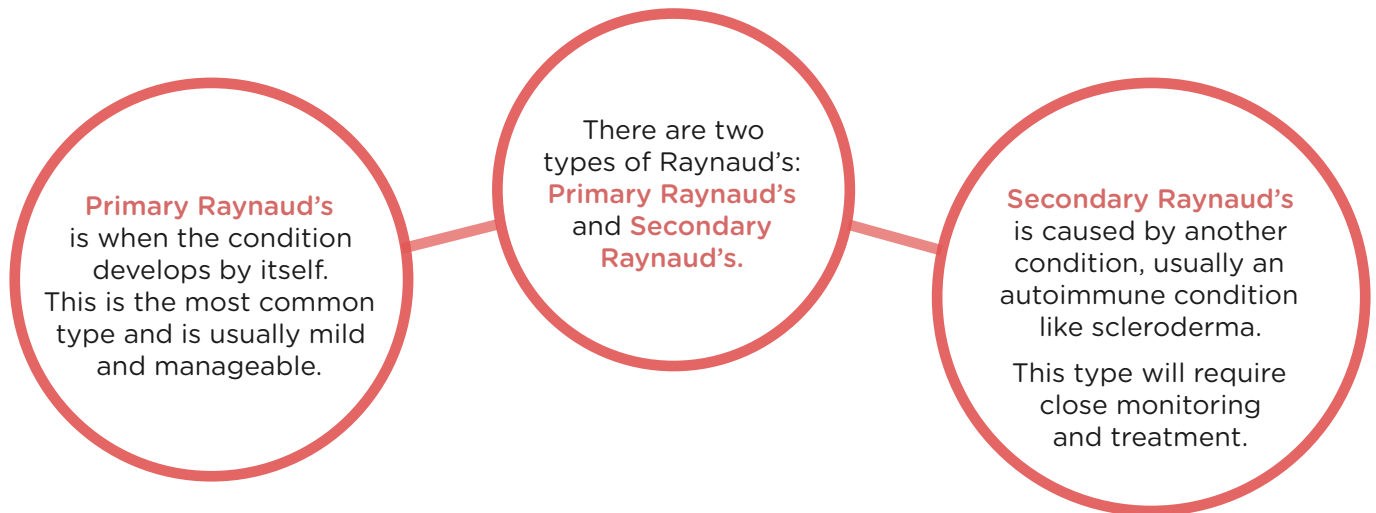


White Fingers during
a Raynaud's Attack

The Difference Between Primary and Secondary Raynaud's

Anyone of any age can develop primary Raynaud's, which occurs spontaneously without any underlying condition being present. It can be hereditary in which case it is usually fairly mild. Raynaud's is quite rare in young children but is common in teenagers and although troublesome for a few years, usually subsides in the early twenties and in some cases completely disappears.

Secondary Raynaud's is much less common, and is associated with an underlying condition or external factors. Secondary Raynaud's is usually more severe and if caused by an underlying condition will require close monitoring, in these cases early and accurate diagnosis is essential.



How Raynaud's is diagnosed

We know that many people living with Raynaud's are unaware of how an official diagnosis can be made, so we have worked with the Raynaud's team at Chapel Allerton in Leeds to develop videos explaining the different tests used to diagnose Raynaud's. **You can view all of the videos online at: sruk.co.uk/tests.** Your GP may not arrange for all of these tests to be done straight away, they may start with a simple blood test before moving onto the others.

The tests are:

Blood Tests - Blood tests can be used to check for conditions that could be causing your symptoms. These tests may include:

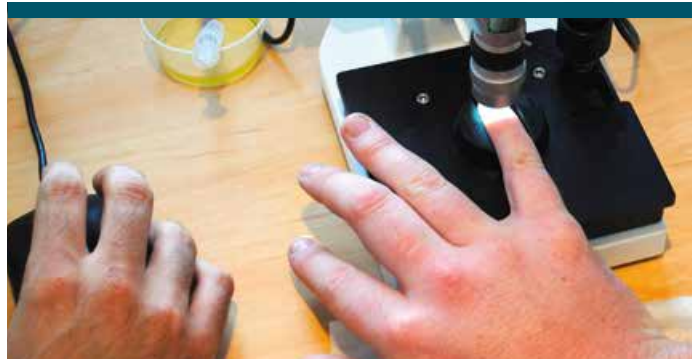
- **A full blood count** - to check for infection or a specific blood condition
- **An antinuclear antibodies (ANA) test** - to check for an overactive immune system, which is common in people with autoimmune conditions such as rheumatoid arthritis and lupus
- **Erythrocyte sedimentation rate** - this test determines the rate at which red blood cells settle to the bottom of a tube. A faster than normal rate may signal an underlying inflammatory or autoimmune disease such as arthritis or lupus

Most blood tests only take a few minutes to complete and are carried out at your GP surgery or local hospital by a doctor, nurse or phlebotomist (a specialist in taking blood samples).

For more information on preparing for a blood test and what to expect, please visit sruk.co.uk/raynauds/raynauds-getting-diagnosed/

Capillaroscopy - this is a non-invasive test where the clinician will use a microscope to look at the formation and structure of the capillaries (blood vessels) at the nailfold (the cuticle of the nail). The shapes of the blood vessels are a diagnostic marker for Raynaud's and connective tissue disease.

If you have a manicure ahead of the test, it is important to ensure the cuticle is not pushed back or cut. It is also helpful to have nail polish free nails for this test.



Cold Water Test - This is a functional test to see how the blood vessels in your hand react to cold water. You will be asked to place your hands under a thermography camera before the test begins. The water will be around 15 degrees and you will be asked to place your hands fully in the water for 1 minute.

After 1 minute, you will be asked to remove your hands and using the thermal imaging camera the clinician will see how quickly your hands take to warm up. This test helps to diagnose the severity of Raynaud's. As part of this test the clinician may also use Laser Doppler Imaging (LDI). This is a piece of equipment that uses infrared laser beams to create an image of the blood flow in the hands

Managing Your Condition

Understanding what causes your attacks is key. An attack or flare, is when you experience one or more of the symptoms of Raynaud's. These will often be triggered by exposure to the cold, any slight changes in temperature or touching cold objects. Emotions, such as anxiety or stress may also play a part. For people who smoke this can cause their Raynaud's to be more severe so it is worthwhile trying to stop smoking.

Here are a few lifestyle changes that you could do to help with symptoms.

- Avoid cold weather
- Wrap up and keep warm
- Relax and pace yourself
- Stop smoking
- Gentle exercise

Although there is no cure for Raynaud's, it can be treated and does not always require medical treatment. In many people with mild Raynaud's, wearing warm clothing, protecting themselves from the cold and avoiding changes in temperature will help.

The Cold

Living in the UK, it's hard to dodge the changing seasons and often cold, damp weather, but the weather isn't the only cold trigger. Simple actions like going shopping to a supermarket or opening the fridge or freezer door to get out food can trigger your Raynaud's. Air conditioning at home or at work can also set it off, along with sudden changes in temperature like going from hot to cold (indoors to outdoors) or getting out of a bath.

If you can understand your triggers you can take steps towards prevention, even if this means wearing gloves in the Summer.

Going Out And Wrapping Up

If you have to go out into the cold, wear several thin layers of clothing rather than one thick layer, as the air trapped between the layers will help to insulate your body. Tight clothing should be avoided as this may restrict your blood flow. Wear some form of headgear, as a considerable amount of heat is lost from the head. The torso (chest, back and stomach) should also be kept warm to protect the major organs of the body.

Thermal clothing is excellent, especially underwear which has long sleeves and long legs. Natural fibres such as wool, cotton or silk will keep you warmer than most synthetic ones. A pair of thin cotton or silk gloves under thicker mittens or gloves can give added warmth.

Portable heating aids can be invaluable during the cold weather. A selection of heating aids and gadgets are available, these include disposable, rechargeable and microwaveable heat packs, self-insulating products such as silver fibre socks and gloves.

Gloves and socks made with pure silver minimise heat loss by actively reflecting 95% of the body's energy back to the skin. This makes them a lot warmer compared to conventional socks and gloves.

You may find some useful items to help keep you warm and well at www.srukshop.co.uk. All products have been recommended by people with the conditions and all proceeds from the shop go back to the charity.

And Relax.....

Try to steer clear of stressful situations as stress and anxiety can trigger an attack. Take rests when you can to avoid getting too fatigued and pace yourself especially when you know you have a busy time or important event coming up. You can also use techniques like controlled breathing and mindfulness to help you overcome stressful occasions.

Stretch And Movement

Gentle exercise such as walking or moving your arms and legs, even when sitting, will help to stimulate the circulation. Should the cold cause you to lose feeling in your fingers and toes, reheat them slowly. Occasionally, exercise can trigger Raynaud's attacks. Look out for signs of this happening and change your fitness plan if needs be.

Diet

Always try to maintain a balanced, healthy diet and avoid caffeine and alcohol. Some food supplements have helped people affected by Raynauds, including evening primrose oil, ginkgo biloba and fish oils. Certain foods are also believed to help, like ginger, garlic and spicy food.

Stopping Smoking

It is incredibly important to stop smoking – other than the obvious health reasons, one cigarette can reduce the body's temperature by up to one degree for up to 20 minutes.



During Pregnancy

It is also important to understand that other parts of your body may be affected that haven't previously when you are pregnant.

Primary Raynaud's has little impact on pregnancy. Most people find that their Raynaud's symptoms are less severe during pregnancy, probably due to the hormonal changes that occur. However, Raynaud's symptoms may worsen three or four months after delivery, and will usually then return to the previous severity.

Practical aspects to avoid attacks should be taken during delivery, such as warming infusion fluids.

The effect of any Raynaud's medication you are taking should be considered, as some commonly used drugs are not safe during pregnancy.

Raynaud's of the nipples is commonly misdiagnosed as thrush or mastitis, so if you have Raynaud's and are having pain, throbbing, purple nipples during feeding please refer to our website for more information.



Medical Treatments

Your GP can advise on treatments to help alleviate symptoms if you are struggling day to day. It's important to seek help early to help reduce the number of attacks and frequency, which in the longer term gives a much better prognosis.

Drug therapy is indicated for those experiencing intense pain, functional impairment or digital ulcers. The treatments available provide symptomatic relief rather than cure and patient response is variable, so it is worth trying more than one drug within a particular class. Try to avoid beta-blockers as these can make Raynaud's worse.

Nifedipine

One drug, Nifedipine, a calcium channel blocker, is licensed for Raynaud's. This drug encourages the blood vessels to widen and whilst Nifedipine doesn't cure Raynaud's, it can help to relieve symptoms.

Depending on the pattern of your symptoms and how well you respond to treatment, you may be asked to take this medication every day. Alternatively, you may only need to take it as prevention; for example, during a sudden snap of cold weather.

Unfortunately, side effects of Nifedipine are common and may include headaches and dizziness, heart palpitations, odema (swelling of certain parts of the body such as hands and feet due to build-up of fluid) and constipation.

Never drink grapefruit juice when taking Nifedipine as this can make side effects worsen.

The side effects should improve as your body adjusts to the medication, but tell your GP if they continue or are causing worry. There are alternative calcium channel blockers that may suit you better.

Alternative Medications and Treatments

Other medications have been used to treat Raynaud's, which are not licensed for the treatment of it, however GP's may look at circumstances where the benefits outweigh side effects. The following treatments have all been used for Raynaud's:

- Iloprost is available for extreme cases.
- Angiotensin converting enzyme (ACE) inhibitors
- Fluoxetine, which has been used in the treatment for depression
- Botox is an experimental Raynaud's treatment, which may reduce blood vessel spasm and block pain nerves. Increasing amounts of research is emerging for it, but it is only used in selected cases and usually only in specialist centres.
- Sildenafil and Bosentan can be prescribed to open up the blood vessels in secondary Raynaud's, when ulcers may be present.
- Some people with Raynaud's have found acupuncture alleviates symptoms.

People with secondary Raynaud's are at risk of ulcers. These can become infected and take some time to heal, so it's important to avoid them if possible. We have a publication on Digital Ulcers to help you understand what causes them.

The Link Between Raynaud's And Scleroderma Explained

Raynaud's can be the first symptom of scleroderma and may occur many years before other symptoms. However, only a very small proportion of people with Raynaud's will develop scleroderma, only 1 in every 100 people with Raynaud's.

Scleroderma is a rare condition involving blood vessels, the immune system and the body's connective tissue. More formally, it is a rheumatic, autoimmune connective tissue disease, characterised by over production of collagen. The word comes from two Greek words, 'sclero' meaning hard and 'derma', skin. The number of those affected by scleroderma are currently estimated at about 12,000 in the UK.

Collagen is a protein that 'binds' the body together - present in the skin blood vessels, joints and internal organs. Scleroderma is a condition where the fibroblast cells produce too much collagen, resulting in swelling, thickening, fibrosis (hardening) and scarring both externally in the skin and progressively, internally with major organ involvement, including the kidneys, heart and lungs. Scleroderma is a life limiting condition and in some forms of the condition can be life threatening, however there are a range of treatment options available to limit the impact of the condition and many people live a full and rewarding life.

For 90% of people with Scleroderma, Raynaud's was there first symptom. This is why it's important to note any further changes to your condition, and look out for the three following symptoms.

The early warning signs are often there



Who We Are, What We Do And How to Get Involved

We are Scleroderma & Raynaud's UK (SRUK), the only UK Charity dedicated to improving the lives of people with Scleroderma and Raynaud's.

We are here to improve awareness and understanding of these conditions, to support those affected, and ultimately to find a cure.

We currently support twenty-two thousand people in the UK. Our aim is to reach out to every single person who is affected by Scleroderma and Raynaud's, providing them with the information and support they need.

By creating connections between people with the conditions and professionals, we have built a motivated community that shares knowledge and support, works in partnership on research projects, and speaks up about Scleroderma and Raynaud's. We have a stronger voice together.

What We Do

We aim to improve the lives of people with Scleroderma and Raynaud's, this is central to everything we do. We want everyone with the conditions to live as full and unlimited a life as possible, until we find a cure.

Being there for our community when they need us is paramount – we do this through our helpline, local support contacts, support groups and our online forum. We also run regular educational events and have a yearly conference to bring people together.

We are driven to make real progress towards more effective treatments and a cure. We invest in innovative research projects at the forefront of the field.

We also make our voices heard with decision-makers and politicians, pushing Scleroderma and Raynaud's to the top of the health and social care agenda.

We're here to help, so if you need to talk to someone about your condition, please contact us on **020 3893 5998**.

We have a stronger voice together

To get involved, become a member. Sign up to receive our newsletter or download a factsheet with more information about the conditions visit www.sruk.co.uk

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