

Understanding and Managing Raynaud's phenomenon webinar

Questions from our community

Access to services

Q. How do I get a referral to see a rheumatologist, what should I do and how can I get tested for scleroderma?

A. A referral to see a rheumatologist needs to be made by your GP. Your rheumatologist will also conduct a thorough exam, usually including all your joints, from your shoulders to your toes, as well as your heart and lungs. After the physical exam, you may be asked for blood and urine samples, as well as imaging like X-rays, MRIs, or ultrasounds. It also your opportunity to ask questions you may about your diagnosis, treatment, or ongoing care.

Q. I am waiting for a hospital appointment, what should I do?

A. You should contact your GP and or hospital.

Age factor

Q. Is hot weather a factor in the deterioration of the fingers for people with secondary Raynaud's or is it related to age?

A. This means that Raynaud's is caused by another condition, usually an autoimmune disease like scleroderma or lupus. Secondary Raynaud's needs more investigation and more careful monitoring for complications like ulceration or sores.

If you notice a change in your symptoms or have any other health concerns, it is important to tell your doctor, who may carry out some tests to rule out other conditions. The issue with your fingers is caused by poor blood circulation.

Q. What role does age have in getting a diagnosis of Raynaud's? What is the most common type of Raynaud's in the adult male population? Can secondary Raynaud's as opposed to primary Raynaud's develop in later adult life?

A. Raynaud's is more common in women than men and may start before the age of 30, although it can occur at any age. Raynaud's disease tends to first appear in a person's late teens or early 20s; it affects women much more frequently than men. Primary Raynaud's is the most common form of the disease in both men and women. Secondary Raynaud's disease occurs from an underlying cause, like disease, injury, or certain medications. It is usually diagnosed in people between ages 35 and 40.

Associated Conditions linked to Raynaud's.

Q. What is the connection with Mixed connective tissue disease (MCTD) and Raynaud's phenomenon?

A. Mixed connective tissue disease has signs and symptoms of a combination of disorders — primarily lupus, scleroderma, and polymyositis. For this reason, mixed connective tissue disease is sometimes referred to as an overlap disease.

In mixed connective tissue disease, the symptoms of the separate diseases usually do not appear all at once. Instead, they tend to occur in sequence over several years, which can make diagnosis more complicated.

Early signs and symptoms often involve the hands. Fingers might swell like sausages, and the fingertips become white and numb. In later stages, some organs — such as the lungs, heart, and kidneys — may be affected. There is no cure for mixed connective tissue disease.

Q. Is there a link between rheumatism and primary Raynaud's?

A. Secondary Raynaud's means that Raynaud's is caused by another condition, usually an autoimmune disease affecting the blood vessels like scleroderma, lupus, several different types of rheumatoid arthritis (RA) or Sjogren's syndrome. Secondary Raynaud's needs more investigation and more careful monitoring for complications like ulceration or sores. If you notice a change in your symptoms or have any other health concerns, it is important to tell your doctor, who may carry out some tests to rule out other conditions.

Q. Does Systemic sclerosis (SSc) cause Raynaud's?

A. No, one of the early problems people with systemic sclerosis get is sensitivity to cold. This is called Raynaud's phenomenon and it affects most people with the condition at some point. Raynaud's phenomenon occurs when the blood vessels overreact to cold, causing the fingers and toes to turn white, blue and then go red when warmed up. This causes numbness and tingling, and sometimes even pain. Swelling and puffiness of the hands and feet is also a common early feature. The fingers may look and feel swollen, making the skin lose its normal lines and look shiny.

Q. Is there a link between Raynaud's and heartburn? Is there anything which can be done to self-manage and improve this condition?

A. The first step is to see your GP as soon as possible to talk about your symptoms and ask to be referred for further testing. Your GP may refer to a specialist rheumatologist to get a diagnosis. Further information on [getting a diagnosis](#) can be found on the SRUK website.

The three main symptoms of scleroderma are swollen fingers, Raynaud's phenomenon and reflux or heartburn. Early diagnosis is important to help prevent the disease from progressing further. Further information on the link between Raynaud's and Scleroderma can be found on the [SRUK website](#).

Q I have primary Raynaud's and erythromelalgia. What is the most effective way to manage both conditions?

A. Erythromelalgia is a rare disorder that causes episodes of 'burning' pain. It is like Raynaud's in that it can affect the extremities but with Erythromelalgia, (EM) the sensation can also affect the arms, legs, and face. Further information on how to manage both conditions can be found on the [SRUK website](#).

Q Is there a link with Raynaud's and other autoimmune disorders?

A. Secondary Raynaud's means that Raynaud's is caused by another condition, usually an autoimmune disease like scleroderma or lupus. Secondary Raynaud's needs more investigation and more careful monitoring for complications like ulceration or sores.

If you notice a change in your symptoms or have any other health concerns, it is important to tell your doctor, who may carry out some tests to rule out other conditions.

Complimentary treatments/therapies

Q. Is there any scientific evidence to support acupuncture as an effective treatment for Raynaud's?

A. Overall, very little research has been published on the effects of acupuncture in patients with Raynaud's phenomenon. There is an SRUK News article, [Alternative Therapies: Do they help Raynaud's?](#) it should be noted that even if a clinical trial 'disproves' the benefits of an alternative therapy, it does not necessarily mean that it is ineffective. Many people find comfort in traditional therapies and find that they feel that symptoms are alleviated. After all, if the mind is happy, often the body can feel the benefit.

Medicine Management

Q. How long do you need to take Losartan before it takes effect?

A. There is information on the SRUK website about [Losartan](#). It is very important that your doctor check your progress at regular visits to make sure that this medicine is working properly. Blood and urine tests may be needed to check for unwanted effects. If you experience any symptoms which you think may be due to the medicine, speak with your doctor or pharmacist for further advice.

Diet and Nutrition

Q. Does a plant-based diet help with Raynaud's?

A. Having a well-balanced diet can be the key to helping you live better each day with your condition. We always recommend speaking with your GP if you have any concerns about foods, you might be eating or if you are developing digestive issues. We should all be aiming towards a healthy diet, but people living with Raynaud's should take some special care to look after themselves. Further information on managing Raynaud's can be found on the [SRUK website](#).

Q. Are caffeinated drinks best avoided in Raynaud's phenomenon? Is alcohol [within recommended limits] of any benefit?

A. The key to managing Raynaud's symptoms is to try to prevent an attack – always try to maintain a balanced, healthy diet and avoid caffeine and alcohol.

Emotional support

Q. I have lost a family member to System sclerosis (SSc) and I have symptoms of Raynaud's, including severe reflux. Where could I find out about what emotional support services are available including grievance counselling?

A. If you are concerned with your symptoms, the first step is to see your GP as soon as possible to talk about your symptoms and ask to be referred for further testing. Your GP may refer to a specialist rheumatologist to get a diagnosis. Further information on [getting a diagnosis](#) can be found on the SRUK website. Most people experience grief when they lose someone important to them. If these

feelings are affecting your life, there are things you can try that may help. Support is also available if you are finding it hard to cope with stress, anxiety, or depression. Further information about emotional support services can be found on the NHS website '[Grief after bereavement or loss](#)'

Calcinosis

Q. Could a little white spot on the side of the nose be a calcium deposit in Systemic Sclerosis (SSc)?

A. A troublesome scleroderma symptom that develops for some people is calcinosis. Calcinosis is a collection of insoluble calcium salts within or beneath the skin. It often occurs in people with systemic sclerosis, especially with the limited type. Calcinosis tends to occur over pressure points – at the fingertips, for example. The first step is to see your GP as soon as possible to talk about your symptoms and ask to be referred for further testing. Your GP may refer to a specialist rheumatologist to get a diagnosis. Further information on skin changes can be found on the [SRUK website](#).

Q. How do you treat calcinosis?

A. There are currently no medications known to help calcinosis, but some people do find that paraffin [wax baths](#) help. The warmth from the wax and its softening action can help expel deposits, but it needs to be done regularly.

Hands, Feet & Digital Ulcers

Q. Does a pit in the fingertips indicate ulceration or calcination is likely? What are the signs to look to identify ulcers?

Q. What creams can help with the pain caused by digital ulcer?

A. You can find out more about [digital ulcers here](#), including how they develop and tips on managing them.

Q. Is numbness without colour changes in fingers associated with secondary Raynaud's?

A. Numbness can happen for several different reasons. When it happens in Raynaud's it is often because the blood supply has temporarily been affected and often this is associated with colour changes. Not everyone has the typical 'triphasic' change, where the parts affected go white then blue / purple and then red, but most people do get some colour change.

Q. Is Nitro-Lingual Spray used in the treatment of Raynaud's for the hands?

A. GTN can be used in the treatment of Raynaud's, but this is in the form of a patch rather than a spray. A patch can be prescribed which is applied to the affected area overnight and then taken off during the daytime. You could talk to your GP, Rheumatology Consultant or Rheumatology Nurse for more details.

Q. An oxygen level device put on my fingers does not work. I have secondary Raynaud's and Systemic sclerosis (SSc). Is this to be expected?

A. This can sometimes happen, yes. Sometimes it can be because there are skin changes (thickening of the skin) which does not allow the device to work

correctly and sometimes it can be because the blood flow to the fingertips has been interrupted and the device cannot work as it should.

Q. I suffer from extreme attacks of Raynaud's where in addition to my hands whiten and my feet freezing, I also feel lightheaded and faint – is there a quick way of coping with this should it recur?

A. The main triggers of a Raynaud's attack are exposure to the cold and emotional stress. It occurs more commonly in women, and often presents before the age of 30. SRUK have produced information on managing Raynaud's. The key to managing Raynaud's symptoms is to try to prevent an attack – planning is vital. Here are some ways you can manage Raynaud's phenomenon symptoms and live as normal a life as possible. See [Managing Raynaud's](#) for further information.

Q. Is skin on fingers starting to split, a precursor to ulcers?

A digital ulcer or finger ulcer is a break in the skin. Digital and finger ulcers in people with scleroderma most commonly occur at the tip of the finger, sometimes extending underneath the fingernail, or over the finger joints. They can be extremely painful and can become infected, mainly due to the poor circulation and poor healing capacity. This makes daily activities very problematic.

Finger ulcers normally appear after prolonged or frequent Raynaud's spasms have damaged areas of tissue, or after a cut or knock to the finger.

They can also develop over areas of calcinosis (calcium deposits).

You should always seek medical advice if you develop a finger ulcer. You may be prescribed antibiotics if the ulcer is infected, and it may be necessary for you to have an intravenous infusion of a medication called Iloprost. This involves attending hospital for several days to receive the medication. Iloprost is very effective at improving finger circulation.

Surgical treatment is occasionally required but this is very rarely necessary.

Q I suffer from swelling and pain with my fingers and have developed blue patches around the second knuckle, this is worse following periods of being cold. Is this what is meant as an attack?

A. Raynaud's attacks can be very uncomfortable, and sometimes quite painful. It can also make everyday tasks, like buttoning a jacket or unzipping a purse, very difficult. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the hands, feet, ears, nose, lips, tongue, and nipples. Raynaud's is a common condition thought to affect up to ten million people in the UK.

Q. I suffer from ulcerated toes, what treatments are available?

A. SRUK has published some advice on this [topic here](#)
Treatments include:

- Antioxidant treatments – Vitamin C and E help your body repair blood vessels and support your skin.
- Oral vasodilators – vasodilators help to increase the blood flow to extremities where ulcers commonly form, e.g., the toes. They should be prescribed by your GP, and can include drugs such as: Losartan, Diltiazem, or Nifedipine.

- Intravenous vasodilators – These are used in more severe cases and done in a health care setting, as a drip is required.
- Antibiotics – These will be required if the ulcer becomes infected.
- Bosentan – This drug is only used in the most extreme cases and will require a person to fit multiple criteria.

Further to these medical treatments, ensuring that the wound is well dressed, and that you have the appropriate pain management system can help improve your quality of life whilst dealing with digital ulcers

Chilblains

Q. What are the most effective treatments for chilblains of the toes? Can they heal with proper care of my Raynaud's?

A. [SRUK](#) has published some information on chilblains here, which explains how they form and the best solutions for treating them.

Chilblains form due to reduced blood circulation, typically to the extremities such as fingers and toes. They usually go away in 1-2 weeks. To treat them, cover with a loose dry dressing (e.g., Melolin) and avoid constricting clothing. For example, to keep your feet warm it is better to wear one good quality layer than to wear many socks and tights etc. If the skin is unbroken, 1% hydrocortisone cream can be soothing, and will help reduce the urge to itch the chilblain – which you should not do!

Vasodilators which are recommended for improving the circulation in Raynaud's phenomenon by opening the blood vessels, can also be useful in the treatment and prevention of chilblains. Other compounds, for example those derived from Vitamin K, may also help but you should discuss these with your doctor. Calamine lotion and witch hazel are both soothing and cooling, whilst antiseptic should be applied to broken chilblains until medical attention is sought. A steroid cream rubbed onto the chilblains may reduce itch and soreness. Creams and ointments containing camphor or local anaesthetic can also be used for relief of pain in unbroken chilblains. Balmosa cream, available on prescription or from your local pharmacy, and some other topical creams can be effective.

Q. Are chilblains an indicator of Scleroderma?

A. Someone who has scleroderma can develop chilblains, however they are not specifically a symptom of scleroderma. Roughly 1/10 people develop chilblains throughout their life, something that is more common in those with Raynaud's due to the disrupted blood flow. If you are looking to diagnose scleroderma, you will have to discuss this with your GP and ask for the relevant blood tests from them.

Children and Teenagers

Q. Can a child develop Raynaud's? How can they get diagnosed?

A. [SRUK](#) have published some information on this [topic here](#). Children can get Raynaud's, although it is less common in younger age groups. It is usually no more than an inconvenience in their life, with the symptoms improving slightly with age, but it is worth asking the GP to run some tests to rule out underlying conditions as Raynaud's does not usually present until someone is a little older.

To get a diagnosis, you will need to book an appointment with your GP and explain to them that you think your child has Raynaud's. Keeping a diary of symptoms prior to the appointment would be wise, to assess whether there are any specific triggers, and the severity of the Raynaud's attacks.

Q. My teenage son developed very sore itchy toes over lockdown. Could this be Raynaud's? Is it worth getting further tests?

A. Without knowing more detail it is very hard to suggest one way or another whether your child has Raynaud's. Experiencing 'pins and needles' in the hands and toes can be a symptom of Raynaud's and could cause the toes to itch. Are your sons' sore toes brought on by environmental changes, e.g., changes in temperature? If the itching is localised to the toes, and does not impact the hands, nose, or ears, then I would suggest it might not be Raynaud's.

'Covid toes' produce similar symptoms, localised to the toes, and often can be the only symptom that someone has covid. The length of time someone can experience COVID toes varies from 10 days to several months, and there is insufficient data to suggest an average.

If the problem persists, book an appointment with the GP who will be better placed to advise you and diagnose the cause of the itching.

Managing seasonal variations

Q. Can the whole body continuously feel cold (cold intolerance) throughout the year from having Primary Raynaud's?

A. If the experience of feeling cold and being intolerant to the cold is spread across the entire body, this could be symptomatic of something other than Raynaud's, which usually impacts only the extremities (hands, feet, nose, nipples, ears). The whole body feeling cold could indicate a number of other conditions.

Q. Does the cold weather make digital sores develop suddenly even though using the usual medication for Raynaud's?

A. Yes. Digital sores (or ulcers) can develop despite the use of medication and are brought on due to reduced blood flow to the site of the ulcer, often caused by Raynaud's attacks which result from cold weather.

Q. What should you do if your Raynaud's gets worse?

Raynaud's can be partly managed through making sure to keep your hands and feet as warm as possible when exposed to cold temperature, wrapping up and eating well to maintain a good core temperature. If your usual methods of managing your Raynaud's is no longer working, a visit to the GP to discuss options such as medication is recommended.

Q. Is suffering from shivers and a Raynaud's attack linked?

A. A person shivers to increase their body temperature, as the muscle contractions produce heat. Therefore, if you are shivering you are likely to be cold, which will trigger a Raynaud's attack. To that extent the two are linked, the two symptoms result from the same factor – being cold.

Research and clinical trials

Q. I have found shock (as in changes to environment) and vibrations can also bring on symptoms. Any advice on that? Also Has any research been performed into the claims by Wim Hoff that cold therapy can help reduce Raynaud's symptoms?

A. Changes can trigger attacks, even if you are going from warm to slightly cooler. Part of that is when the temp outside is warm, blood vessels are very large, and when we enter a 'cool' but not cold environment, blood vessels overcompensate and clamp down. Dr Pauling had not heard of Wim Hoff.

Supplements

Q. Have you any advice about nondrug treatments e.g., vitamins or food supplements?

A: The one that has been evaluated the most has been Gingko Biloba advocated as a drug that may help with memory issues as it helps with blood flow to the brain. Antioxidant therapies are of interest to scleroderma clinicians. They have attempted clinical trials on this subject, but these trials have not given a clear answer yet. Reducing oxidative stress helps to manage blood vessel problems.

Q. Is it worth taking a Vitamin D supplement during the winter?

A. Yes, taking vitamin D has been recommended by the NHS between October and early March (10 micrograms a day) to maintain bone and muscle health. Vitamin D can be found in oily fish, red meat, liver, egg yolks and fortified foods. There is limited evidence to suggest that vitamin D will improve the symptoms of Raynaud's – however as it is a perfectly healthy supplement to take, it will not have a negative effect on your condition. Make sure that when taking any supplement, you only take the recommended amount.

Symptom Management

Q. What are the symptoms alongside primary Raynaud's that would indicate Systemic sclerosis (SSc)?

A. Firstly, if someone's Raynaud's is a symptom of an underlying autoimmune condition, that Raynaud's would be considered secondary. Secondly, scleroderma can be split into two types – localised and systemic. Localised scleroderma impacts just the skin, and systemic sclerosis can impact the blood circulation and internal organs in addition to the skin. They symptoms for both differ.

Localised scleroderma:

- Ulceration of the fingers or toes (around 40% of people with SSc experience this).
- Patches of thick, hard skin which can be itchy.
- Tight skin that makes it hard to move your joints.

Systemic sclerosis, the above list, and:

- Heartburn

- Hard lumps under your skin
- Problem's swallowing (dysphagia)
- Weight loss
- Fatigue
- Joint pain

Tests

Q. I have had Raynaud's for about 25 years but now due to increased issues I am starting on Nifedipine. I have also had blood tests as I was concerned about sclerosis, how can this be detected through blood?

A. Blood tests look for the antientromere antibody which is characteristic of scleroderma. There are several vascular biomarkers which present in different concentrations in the blood when a person has scleroderma, and the blood tests will also look for those.

Q. How can you be investigated/tested for Raynaud's? My GP just says it is common but what if it is secondary?

A. To establish whether Raynaud's is primary or secondary, the capillaries in your nailbed of your fingertip need to be examined using a non-invasive process called nailfold capillaroscopy. When an individual has secondary Raynaud's there will be fewer capillaries, and those there is will be abnormal in size and shape – often referred to as 'giant capillaries' or 'bushy capillaries.'

Other tests which look at the concentrations of various proteins and biomarkers (such as the antientromere antibody) in your blood can be done, which requires a blood test. In all cases you will require the tests to be done either by your GP, or in some cases through a referral to a rheumatology clinic.

Treatments

Q. Once you take an Iloprost infusion, how long until you see an impact and how long to anticipate that it will last for most patients. How is this varied from using an inhaling or nebulizer version?

A. SRUK has published information on [Iloprost here](#).

Iloprost can be inhaled through the use of a nebuliser, which turns the liquid medicine into a mist that can be breathed in. Commonly you will need 6-9 doses a day, which can be done from home once you are trained in using the device.

Iloprost can also be given as a drip into your arm, known as an infusion. The entire treatment will be done in a hospital setting and will often require a longer stay than using a nebuliser.

In both cases it works by relaxing your artery wall muscles which widen your arteries, increasing blood flow and reducing blood pressure. It usually starts to work immediately, although can sometimes take up to 6 weeks. Hands and feet should warm up relatively quickly, and within a few days you may notice improvement of ulcers. The positive effects can carry on for weeks following an infusion.

Q. How does Botox work in the treatment of Raynaud's? Is it an effective treatment?

A. There has been some research in this area which suggested that Botox could offer temporary relief from Raynaud's symptoms, however this work is not

extensive and has currently not been taken to clinical trial, meaning we cannot be certain that it would work for everyone, if at all. In 2018, BMJ reported findings that 3 female patients with secondary Raynaud's were injected with Botox in their feet, and experienced improvement in their symptoms which lasted for 7 weeks to 5 months. There have been similar pieces of work pertaining to the use of Botox to treat Raynaud's in the fingers. It is believed that the Botox causes the blood vessels in the injected area to dilate, which increases blood flow to the extremities therefore reducing the symptom of Raynaud's.

Weight management

Q. Is being underweight and having high cholesterol linked to Raynaud's?

A. Dr Pauling believes that being underweight may have links to experiencing Raynaud's, as the body tries to maintain a core normal temperature by exposing the extremities, resulting in reduced blood flow to the fingers and toes, as experienced in a Raynaud's attack. Currently no link has been found between Raynaud's and high cholesterol.

Q. Is there a correlation between Estrogen and body weight and Raynaud's?

A. There is potentially a correlation between estrogen and Raynaud's – Raynaud's is much more common in females which has led to the theory that it is linked to hormones such as Estrogen. There is limited evidence to suggest that the menstrual cycle is linked to the severity of Raynaud's attacks experienced at different points within the cycle. Dr Pauling is also of the opinion that a low body weight can encourage Raynaud's as the body maintains core body temperature by exposing the extremities. Whether there is a link between all three factors is unclear.