

The Fingers in Systemic Sclerosis (Scleroderma)

The fingers can be affected in several different ways in people with systemic sclerosis (scleroderma). This leaflet describes three common problems, which can occur separately or together - Raynaud's phenomenon, finger ulcers, and calcinosis, all of which can be very troublesome. In addition, other finger problems can occur in systemic sclerosis. For example, thickening of the skin can lead to what are termed 'contractures' when the fingers become bent and are unable to straighten fully, interfering with the function of the hand.

RAYNAUD'S PHENOMENON


Most people with systemic sclerosis experience Raynaud's phenomenon, which means the fingers change colour in response to cold or to emotional stress. Raynaud's is caused by poor blood supply to the fingers due to narrowing of the blood vessels. Classically the fingers turn white, then blue, and then red, although many people do not experience all three colour changes. The red phase, when the fingers are rewarming, is often the most painful and can be associated with a tingling feeling. The toes may also be affected.

How do we test for Raynaud's phenomenon?

Raynaud's is a clinical diagnosis. In other words, your doctor will make the diagnosis on the basis of what you tell him/her, and what he/she finds on examination. In addition, your doctor may arrange some tests. Examples of these are a blood test to check for certain proteins called antibodies, and a test called nailfold microscopy when the edge of your fingernail is examined under the microscope. This test is not painful and allows small blood vessels called capillaries to be visualised. Another test called thermography involves putting your hands in front of a thermal imaging camera and watching how quickly they rewarm after being cooled down.

How is Raynaud's phenomenon treated?

It is important to keep warm and to stop smoking. There are a large number of different drug treatments which may be helpful, most of which act by opening the blood vessels to increase the blood supply to the fingers. There are many of these drugs, some of which may include sustained release (i.e. slow-acting) nifedipine, diltiazem, amlodipine and losartan. There are many others, too. Because of the way they work, many drugs used to treat Raynaud's can cause headaches and/or flushing, but these side effects may be minimised by starting with a low dose and gradually increasing. You should discuss drug treatment with your doctor.



Three common problems associated with Systemic Sclerosis are **Raynaud's Phenomenon**, **Finger Ulcers** & **Calcinosis**

CALCINOSIS

'Calcinosis' means collection of insoluble calcium salts within or beneath the skin, and often occurs in people with systemic sclerosis, especially with the 'limited' type of systemic sclerosis or CREST (an old fashioned term for limited systemic sclerosis, the 'C' stands for calcinosis). Calcinosis tends to occur over pressure points, for example at the finger tips.

How do we test for calcinosis?

Usually calcinosis is obvious on examination, and so no special tests are required. However, if your doctor is not sure, then an X-ray may be arranged - this will demonstrate calcinosis very clearly.

FINGER ULCERS

Finger ulcers are breaks in the finger skin. They occur commonly in people with systemic sclerosis, especially at the tips of the fingers or over pressure points, for example over the joints where the skin is especially stretched. Finger ulcers are most common in people with severe Raynaud's. They can be extremely painful and can become infected.

How are finger ulcers treated?

If you develop a finger ulcer, then you should seek medical advice. Your doctor may prescribe antibiotics if there is any question that the ulcer is infected, and may increase your Raynaud's medication. If an ulcer is very painful and difficult to heal, and especially if associated with a worsening of your Raynaud's, then it may be necessary for you to have an intravenous infusion of a medication called Iloprost. This means coming into hospital for several days, however each person is different and may involve a longer stay in hospital. Iloprost is very effective at improving the finger circulation. Surgical treatment of ulcers is occasionally required, for example to clean up the ulcer ('debridement'), but this is only rarely necessary.

General treatment of finger problems

Finger problems as described above can be very disabling. It is important to maintain good finger function (therefore finger exercises are recommended, as well as moisturising daily to keep the skin supple), and it is often beneficial to see a physiotherapist and/or an occupational therapist. Discuss this with your doctor or specialist nurse.

How is calcinosis treated?

There are currently no medications known to help calcinosis, despite many different treatments having been tried, however some people find wax treatment beneficial. Sometimes infection can develop around an area of calcinosis, requiring treatment with antibiotics. Occasionally surgery is required. However, surgery only reduces the calcinosis rather than removing it completely, and the calcinosis may 'grow back'.

Finger Exercises

Finger exercises

Practice making a fist and then stretching all your fingers out like a star.

Touch each one of your finger tips with your thumb tip. Now gently slide your thumb tip down the side of each finger.

With your hands face down on a table lift each finger up in turn.

Blocking exercises (fingers have 3 joints)

Using a block (edge of table, other finger, matchbox, etc.) work the individual finger joints by "Blocking Off" before the end crease, actively bend the end of the finger and assist with the other hand to gain full bend. Straighten out fully, assisting if necessary. Repeat with the block placed before the second crease. Repeat with the block placed before the third crease (in the palm of the hand).

Scleroderma & Raynaud's UK

We are here for you, to support you through your diagnosis and to help you understand and manage your condition.

We know how important it is to join a community that understands your condition, provides expert information and support, works for you to improve access to treatment and care whilst driving research into more effective treatments as we work to find a cure.

Ways we can support you

Our informative website has up to date, specialist information on Scleroderma and Raynaud's, personal stories from the community on managing the conditions and details on services and events that are available in your local community. You can find information, support and friendship through our online community: www.sruk.co.uk

Our helpline operates 365 days a year providing support and information to everyone affected by or interested in Scleroderma and Raynaud's: **0800 311 2756**. Our experienced helpline volunteers understand the challenges and difficulties you face and provide a confidential space to talk through worries or concerns.

To order printed copies of SRUK publications, please call: **020 3893 5998** or email: info@sruk.co.uk

Find out more about the work of the charity and how we can support you by visiting our website: www.sruk.co.uk or calling our friendly team on: **020 3893 5998**.

Interested in joining our community?

We have a variety of ways that you can join the community. Our most popular is to become a member. For a small subscription fee you will receive 4 magazines per year, free attendance at annual conference, priority booking for educational events and member only discounts for our shop products.

Find out more about all the ways you can join the community by visiting our website: www.sruk.co.uk or calling our friendly team on: **020 3893 5998**.

We are here for you,
when you need us.

0800 311 2756

Our helpline operates
365 days a year

Visit us today

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Sources used

We rely on several sources to gather evidence for our information. All our information is in line with accepted national or international clinical guidelines where possible. Where no guidelines exist, we rely on systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals, and government publications.

If you would like further information on the sources we use on a particular publication, please contact the Information and Support Services team at info@sruk.co.uk

Valuing your feedback

As someone who has received a copy of this booklet, we would very much value your opinion on whether it meets the needs of people affected by Scleroderma and Raynaud's. Please complete the survey online at sruk.co.uk/publications

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Bride House
18-20 Bride Lane
London
EC4Y 8EE
T: 020 3893 5998
E: info@sruk.co.uk

Helpline: 0800 311 2756

www.sruk.co.uk

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