SCLERODERMA
& RAYNAUD'S UK

Raynaud's Phenomenon

TERMINOLOGY

There has been much confusion over the name and more recently the word 'Disease' has been dropped, the condition simply being called Raynaud's or Raynaud's phenomenon. Raynaud's can be subdivided into primary and secondary.

EARLY SIGNS

When 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 very worrying at first, especially if the fingers then change to a bluish colour followed by bright red. Not knowing why this happens can often make matters worse, as stress can exacerbate the problem. At this point it is worth going to your GP to find out what is wrong. More often than not if these colour changes are occurring in the hands and possibly in the feet, nose or ears, a diagnosis of Raynaud's will be given.

Why the name?

The name Raynaud's Disease was given to this condition by a French doctor, Maurice Raynaud in 1862 when he first described the phenomenon.

Who gets it?

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 disappears in the early twenties, although this is not always the case.

Secondary Raynaud's which is much less common, is associated with an underlying disease or external factors. This is more serious and early and accurate diagnosis is essential.

TREATMENT

Treatment remains the most challenging problem in Raynaud's but does not always require pharmacological intervention. In many patients with mild Raynaud's, wearing warm clothing, protecting themselves from the cold and avoiding changes in temperature will obviously help. Portable heating aids can be invaluable during the cold weather. Your G.P. can advise on treatments which may help to alleviate the condition. Drug therapy is indicated for those suffering 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. Avoid beta blockers as these can make Raynaud's worse.

SURGERY

A surgical procedure, called a cervical sympathectomy for Raynaud's phenomenon, has been shown repeatedly to produce little or no benefit and is therefore no longer popular with patients or surgeons. In severe cases this operation can now be performed by laser. Lumbar sympathectomies for the feet however, can produce good results and can be carried out by injection rather than surgery. A sympathectomy-like operation on the fingers and/or hand has been shown to relieve severe pain and to heal finger ulcers. This operation is not a cure but the attacks are often less severe.

What is scleroderma?

The word scleroderma comes from two Greek words ‘sclero’ meaning hard and ‘derma’ meaning skin. The hallmark of the disease is an over production of collagen. Collagen is the major protein of the connective tissue which binds the body together. It is found in the skin, blood vessels, joints and internal organs. In this condition the skin, usually of the hands and feet becomes stiff, tight and shiny. This is because of swelling and then thickening of the connective tissue which becomes fibrotic or scarred. Internal organs can also be affected in a similar way.

What is the connection between Raynaud’s and scleroderma?

Raynaud’s can be the first symptom of scleroderma and may occur many years before other symptoms. However, only a very small proportion of Raynaud’s sufferers will develop scleroderma.

Suggested Tests

BLOOD TESTS

If you have Raynaud’s severely or if the condition appears to be getting worse, it is worth going to your GP and asking for a blood test in order to eliminate or confirm the presence of an associated condition, such as scleroderma or systemic lupus erythematosus. If it is abnormal your GP will almost certainly wish to seek further help by referring you to a specialist centre.

The blood test aims to look for the presence of antinuclear antibodies, which mark out the connective tissue diseases. If you have mild Raynaud’s which is little more than a nuisance, the chances are that you have Primary Raynaud’s. This means that it is benign and taking drugs such as vasodilators which open up the blood vessels, allowing blood to flow through more easily, or simply keeping warm may be sufficient.

NAILFOLD CAPILLAROSCOPY

In this test the capillaries at the base of the nail may be examined with an ophthalmoscope, magnifying lens or with a capillary microscope, to look for abnormal patterns. The result is positive if significant damage to the very small blood vessels is observed. There are however, a group of patients who have abnormal nailfold capillaries and/or positive antinuclear antibodies, but who after follow up do not develop definite connective tissue disease. These patients have autoimmune Raynaud’s.

THERMOGRAPHY

This test is performed by means of a state-of-the-art infra-red camera that sees the heat generated by the human body and translates it into colour scale which can map a patient’s skin temperature. The measurements are made in a cool, temperature-controlled room, where the patient first rests for 15 minutes to acclimatise. Electronic images are then taken using a thermal imaging camera which detects the infra-red radiation which is continuously given off. The amount of radiation detected depends on the temperature of the surface viewed and the images are colour-coded to show the temperature distribution. Lower temperatures appear as blue and higher ones as red, pink or white. Thermography is non-invasive which makes it particularly suitable for use with children and for repeated measurements.

LASER DOPPLER

This technique is used mostly as a research tool at a number of specialist centres. Laser Doppler measures the blood flow in the small skin vessels by illuminating the skin with very low power laser light, and detecting the light scattered back from the skin. Some forms of laser Doppler involve attaching a probe to the skin surface, whereas others involve a light beam that scans accross the skin surface to produce an image of blood flow over an area. Further refinements allow those measurements to be made whilst the skin is gently heated, or whilst a test drug is applied to a small area of skin.

STOP SMOKING

Smoking is known to provoke an attack so if you smoke, stop smoking now! Smoking damages the lining of the blood vessel wall and affects the smooth muscle. Smooth muscle is exquisitely sensitive to cigarette smoke and to the chemicals that get into the blood stream from cigarette smoke. It can also cause an immediate spasm in the blood vessel.

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

www.sruk.co.uk

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**

Published: February 2022
Next review: February 2025

Trusted Information Creator

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

@WeAreSRUK **/WeAreSRUK**

Registered Charity England & Wales No. 1161828