

EURACARE

PATIENT INFORMATION FORM

RAYNAUD'S, SCLERODERMA & ASSOCIATED DISORDERS

What is Raynaud's?

Raynaud's is a common condition where the blood supply to the extremities is interrupted or reduced. This usually affects the fingers and toes, but occasionally the nose or ears.

Attacks are usually provoked by cold or a sudden change in temperature. During an attack the affected part first becomes white, then turns blue as the tissues use up the oxygen and finally bright red as the arteries relax and fresh blood rushes in.

Raynaud's can vary in form, from very mild to severe and requiring treatment. Anyone of any age can suffer from Raynaud's, but younger women are affected more commonly. It seems to be a change in temperature, rather than just cold exposure that precipitates an attack, so although worse in winter, it can occur in summer. Stress or anxiety can also provoke a Raynaud's attack. Some cases of Raynaud's are associated with some other diseases (called secondary Raynaud's).

What is scleroderma?

Although over 95% of patients with scleroderma have Raynaud's, the chances of someone with Raynaud's developing scleroderma is small - it is less than 2% women and 6% in men.

The word scleroderma means hardening of the skin, although the condition is not limited to the skin. It is a disease of the connective tissue, which is the tissue that holds our bodies together. Therefore, not only the skin can be affected, but also internal organs. Most sufferers have the mild form where there is limited skin involvement, usually of the hands and feet, becoming stiff and shiny. The gullet may also be affected making eating and swallowing difficult.

Some patients also form tiny deposits of calcium under the skin (calcinosis) which can cause ulcers. In the more severe form, called diffuse scleroderma, wide areas of skin and internal organs such as the lungs, bowel heart and kidneys are affected. Localised scleroderma can be divided into two types:

- Morphea scleroderma
- Linear scleroderma

How are these conditions diagnosed?

The history of the disease is most important. Blood tests may help, as can examining the small blood vessels at the base of the nail, which is called nail fold capillaroscopy.

Is it hereditary?

There is no evidence at present that either Raynaud's or scleroderma are directly inherited. There is however a genetic predisposition, so that the chances of being affected are greater if a relative has the problem.

How are they treated?

Your GP or specialist may prescribe a vasodilator, which is a drug that relaxes the blood vessels. Occasionally, your specialist may feel an operation called a sympathectomy may be of benefit. This involves either cutting or destroying the nerves that cause the arteries to constrict. This operation is more successful for Raynaud's of the feet; however, it is not recommended for most cases as it does not usually produce longer term benefits.

People who develop Raynaud's as teenagers often have a form that is benign and will disappear with age. Unfortunately, this is not true in all cases, and sometimes Raynaud's does persist.

There is no cure for scleroderma at present but there are many effective treatments available to alleviate specific symptoms. As each case is different you should discuss these issues with your doctor.

How can I help myself?

There are several things you can do which may help. The most important is to stop smoking, take regular exercise and keep warm.

Smoking

If you are a smoker you must make a sincere and determined effort to give up completely. Tobacco is harmful as it causes the blood vessels to constrict, decreasing the blood flow to the fingertips. Your GP should be able to discuss strategies for you to give up smoking or arrange for you to see a smoking cessation counsellor. Nicotine replacement may also help, and you should discuss this with your doctor or pharmacist.

Eating for warmth

Eating and drinking can help you keep warm. Try to eat lots of small meals to maintain your energy, high protein foods, milk, meat, fish, and fresh vegetables are best. Hot meals and plenty of hot drinks are essential.

Exercise Gentle exercise will help your circulation. Try to avoid sitting for long periods. Get up and walk around the room, moving arms and legs to maintain the circulation. Do not however let your fingers or toes get cold. In cold weather take exercise indoors.

Clothing

Tight clothing should be avoided as this may restrict blood flow. Hands and feet should always be adequately covered. A scarf should be used to keep the face warm in cold weather and a hat and several layers of clothing should be used

to keep the head and trunk warm. Feet are especially prone to cooling; therefore, a good thick pair of socks is essential. Wet shoes and clothes should be changed as soon as possible.

Associated conditions

Vibration White Finger (VWF)

Those who work with vibrating tools tend to develop Raynaud's especially if the vibration is coarse and of low frequency. This can become permanent even after the work has stopped. VWF is an industrial disease, which may be eligible for compensation.

Chilblains

These usually appear on the extremities; fingers, toes, and ears. The skin may first become itchy, then red, swollen and very tender to touch. Chilblains occur because of defective circulation on exposure to cold. Clothing that rubs should be avoided.

Rheumatoid Arthritis

Arthritis affects the lining of the joints. This lining produces a fluid that lubricates the joint and when affected by rheumatoid arthritis it becomes inflamed and swollen. More fluid is produced causing a red, painful swollen joint. About 10% of rheumatoid arthritis sufferers have Secondary Raynaud's.

Systemic Lupus Erythematosus

This is characterised by a rash sometimes seen on both cheeks and the bridge of the nose, and chronic inflammation of the blood vessels and connective tissues of the body. There is associated tiredness, joint pain, mouth ulcers, hair loss and Raynaud's.

Erythromyalgia

This is a chronic disorder characterised by persistent warmth, pain and redness, mainly affecting the feet and lower legs. Most sufferers also experience Raynaud's symptoms.

Chemical or drug induced Some chemicals at work (vinyl chloride) or drugs such as Beta Blockers, migraine tablets or the oral contraceptive may aggravate Raynaud's, therefore, if you are prescribed any medicines and you experience Raynaud's type symptoms, check with your GP who may be able to alter your medication.

Finally:

Some of your questions should have been answered by this leaflet but remember that this is only a starting point for discussion about your treatment with the doctors looking after you. Make sure you are satisfied that you have received enough information about the procedure.

Giving my consent. The staff caring for you will ask your permission to perform the procedure. You will be asked to sign a consent form that says you have agreed to the procedure and that you understand the benefits, risks and alternatives.