# Scleroderma

ARTHRITIS INFORMATION SHEET

This sheet has been written for people affected by scleroderma. It provides general information to help you understand how scleroderma affects you and what you can do to manage it. It also tells you where to find further information and advice.

## What is scleroderma?

The word 'scleroderma' means 'hard skin'. Scleroderma affects the connective tissues of the body (tissues that hold together joints, muscles, blood vessels and internal organs). The connective tissues of people with scleroderma have too much of a protein called collagen. Collagen is important to give connective tissue its strength, but excess collagen causes hardening and tightening of the affected area. Many different areas of the body can be affected.

There are two major types of scleroderma:

- Localised scleroderma (sometimes called 'morphea'). This form of scleroderma affects only the skin and sometimes the tissues beneath it (for example, muscle). This can lead to stiffness and difficulties moving the joints in the affected areas.
- Systemic sclerosis. This form affects the connective tissue throughout the body, including blood vessels, joints, the digestive system (oesophagus, stomach and bowel), and occasionally the lungs, heart, kidneys and muscles.

Scleroderma is an autoimmune condition. The normal role of your body's immune system is to fight off infections and diseases to keep you healthy. In an autoimmune disease like scleroderma, your immune system starts attacking your own healthy tissues. This stimulates the production of excess collagen.

## What are the symptoms?

Symptoms vary greatly from person to person and also depend on what part of the body is involved. Symptoms may include any of the following:

- Thickening and hardening of the skin, particularly on the fingers, arms and face.
- Raynaud's phenomenon: The fingers or toes turn white, then blue in the cold, and then red as blood flow returns. This is caused by narrowing of the blood vessels, in response to cold weather. It is possible to have Raynaud's without having scleroderma, but most people with scleroderma will have symptoms of Raynaud's at some time and it is often one of the first symptoms to appear.
- Small white chalky lumps (calcium deposits) under the skin.
- Stiffness and pain in the muscles and/or joints.
- Indigestion or heartburn.
- Diarrhoea or constipation.
- Shortness of breath or reduced ability to exercise.

## What causes it?

The exact cause of scleroderma is unknown. Genetics, the immune system and environmental factors may play roles in causing this condition. This has yet to be proven in research.

## How is it diagnosed?

There is no specific test for scleroderma. Your doctor will diagnose scleroderma from your symptoms, a physical examination and various tests, such as blood tests or a skin biopsy (a small piece of skin is removed and examined under a microscope). It may take several visits before your doctor can tell if you have scleroderma as the symptoms can overlap with other diseases and types of arthritis.

## What will happen to me?

Many people with scleroderma have few or minimal symptoms and are able to lead a normal, or nearly normal, life with simple treatment or lifestyle changes. However the course of scleroderma is variable and no two cases are the same. People with more severe forms of scleroderma can have serious problems with organs such as the kidneys, lungs and heart. If these organs are affected, you may need to see a specialist (for example, a kidney specialist if your kidneys are affected).

## Is there a cure for scleroderma?

Currently there is no cure for scleroderma. While there are ways you can control your symptoms, you should be wary of any products or treatments that claim to cure scleroderma.

## What treatments are there for scleroderma?

Many of the symptoms of scleroderma can be improved with medicines and/or lifestyle changes. Your doctor will tailor your treatment to your symptoms and how severe your condition is. There is no way of predicting exactly which treatment will work best for you. Your doctor may need to trial several different treatments and medicines before finding the one that is right for you. Your doctor may also need to perform regular screening tests on your lungs and heart to check for problems from scleroderma. People with scleroderma can also have problems with their teeth, and may need to see a dentist regularly.

## What can I do?

**1. Learn about scleroderma and play an active role in your treatment.** Not all information you read or hear about is trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying. Reliable sources of further information are also listed in the section below. Self management courses aim to help you develop skills to be actively involved in your healthcare. Contact your local Arthritis Office for details of these courses.

**2. Talk to your doctor about medicines.** Some medicines may help with problems with joints and muscles, blood vessels, kidneys, lungs or the digestive system. Always talk to your doctor or pharmacist before you start taking any medicines as even natural and over-the-counter medicines can have side effects. See the Medicines and arthritis information sheet.

**3. Manage Raynaud's phenomenon.** Minimise exposure to cold and sudden temperature changes. Make sure your whole body is kept warm and protect your hands and feet with gloves and warm socks. Avoid cigarette smoke.

**4. Look after your skin.** Keep skin clean, well-lubricated and warm to help prevent dryness and infections.

**5. Live a healthy life.** Regular physical activity will help keep your skin and joints flexible and boost circulation. See the *Physical activity* information sheet. A healthy diet, including frequent small meals rather than the usual large meals, may help reduce problems with the digestive system. Stop smoking and reduce stress to help your overall health and wellbeing.

**6. Acknowledge your feelings and seek support.** As there is no cure for scleroderma and it can affect many parts of your life, it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the *Arthritis and emotions* information sheet.

**CONTACT YOUR LOCAL ARTHRITIS OFFICE FOR MORE INFORMATION SHEETS ON ARTHRITIS.**

Scleroderma differs from person to person but can be treated effectively. Learn about scleroderma and your treatment options.

## FOR MORE INFORMATION

**Websites:**

Australian Rheumatology Association - information about medicines and seeing a rheumatologist
www.rheumatology.org.au

Scleroderma Australia has a number of brochures available to download at
www.sclerodermaaustralia.com.au

American College of Rheumatology
www.rheumatology.org

Arthritis Foundation (US) www.arthritis.org

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