

Scleroderma

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ARTHRITIS 
NEW ZEALAND

ENABLING A BETTER QUALITY OF LIFE

KAIPONAPONA AOTEAROA

Te whakapiki i te kounga ora

Did you know?

- Arthritis **affects one in six** New Zealanders over the age of 15 years.
- Scleroderma **affects both sexes**.
- Scleroderma affects **more women** than men.
- Scleroderma affects around **one in a thousand** New Zealanders.
- Can **occur at any age** but the peak is 40–60 years
- **Not hereditary**.
- Rarely occurs in more than one family member.
- There is **no cure** for scleroderma, but **many treatments are available** for specific symptoms.

By working with your doctor, specialist, pharmacist and Arthritis New Zealand, you can find ways to cope with scleroderma.

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What is scleroderma?

The name 'Scleroderma' literally means hard skin. Scleroderma is a rare chronic, often progressive autoimmune disease in which the body's immune system attacks its own tissues.

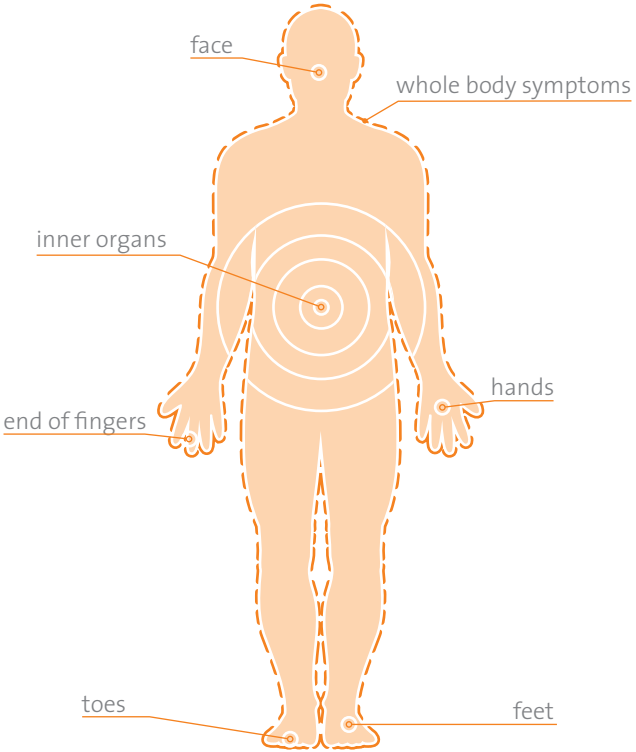
Scleroderma affects the connective tissues of the body (tissues that hold together muscles, joints, blood vessels and internal organs). The connective tissues of people with scleroderma have too much of a protein called 'collagen'. Collagen is important to give connective tissue its strength, but excess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

Types of scleroderma

There are two major types of scleroderma:

- **Localised scleroderma** (sometimes called 'morphea'), which affects only the skin and sometimes the tissues beneath it (for example, muscle).
- **Systemic sclerosis**, which also affects the other parts the body, including blood vessels, joints, the digestive system (oesophagus, stomach and bowel), and occasionally the lungs, heart and kidneys. The systemic form has two subtypes: **limited scleroderma**, including CREST syndrome, where the skin involvement is mainly limited to the hands and there is a lower chance of internal organ involvement, and **diffuse scleroderma**, in which skin involvement is generalised and organs are often involved.

Common areas affected by scleroderma



Symptoms of scleroderma

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

- 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. 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's often one of the first symptoms to appear.
- Thickening and hardening of the skin on the hands, arms and face
- Stiffness and pain in the muscles and/or joints
- Swelling of hands and feet, especially in the morning
- Thinning of the pads at the finger tips
- Small white chalky lumps (calcium deposits) under the skin
- Indigestion or heartburn
- Diarrhoea or constipation
- Shortness of breath or reduced ability to exercise
- Kidney problems and high blood pressure.



Raynaud's phenomenon. The fingers or toes turn white, then blue in the cold, and then red as blood flow returns.

Scleroderma usually starts between the ages of 25 and 55. Women outnumber men by about 4:1.



How does scleroderma progress?

Scleroderma is different for everyone. For most people scleroderma starts slowly affecting just a few parts of the body, gradually getting worse, but usually becomes stable after a few years. Some people find their symptoms improve in summer but become worse in winter.

Localised scleroderma doesn't develop into the systemic form.

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).

Who gets scleroderma?

Scleroderma usually starts between the ages of 25 and 55.

Localised scleroderma more commonly starts in childhood, whereas systemic scleroderma is more common in adults.

Overall, women outnumber men about 4:1 and the average person is diagnosed in her 40's.

What causes scleroderma?

The cause of scleroderma is not known. We don't yet know why people's immune system becomes over-active and initiates excessive production of collagen; but it is thought to be a combination of genetic and environmental factors.

Diagnosing scleroderma

There is no single test for scleroderma, an experienced doctor bases diagnosis primarily on a person's medical history and a physical examination. The characteristic thickening of the skin is often the key factor in making the diagnosis. However, tests can be helpful in establishing whether other parts of the body are involved.

Tests could include:

- blood tests
- x-rays and CT scans
- breathing tests
- a heart scan
- a skin biopsy, where a small piece of skin is removed and examined under a microscope.

Treating scleroderma

At present there is no cure for scleroderma, but many treatments are available for specific symptoms. 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.

Senecio (Bladgreis) 1922, by artist Paul Klee.
He suffered from scleroderma.



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What can I do?

- **Learn about scleroderma** – scleroderma differs from person to person but can be treated effectively, discuss with your doctor and healthcare team your treatment options.
- **Exercise** – one of the best things you can do is to follow a regular exercise regime. It will help to keep your joints flexible and improve blood flow. Your physiotherapist will design a programme to protect your skin and joints.
- **Manage Raynaud's phenomenon** – avoid where possible exposure to cold and sudden temperature changes. Keep your whole body warm and protect your hands and feet with gloves and warm socks.
- **Look after your skin** – avoid strong detergents that can irritate your skin, keep your skin clean and well-lubricated to prevent dryness and infection.
- **Avoid cigarette smoke** – smoking reduces the blood flow to the skin.
- **Manage stress** – ensure you get sufficient rest and relaxation and balance work and leisure; for support talk to your health professionals, Arthritis Educator, family and New Zealand Scleroderma support group.
- **A healthy diet** – including frequent small meals rather than the usual large meals, may help if you have trouble with swallowing or heartburn.



For more information:

Visit our website www.arthritis.org.nz
or call **0800 663463**

Other resources:

- Arthritis Research UK – www.arthritisresearchuk.org
- Australian Rheumatology Association – www.rheumatology.org.au
- Scleroderma Australia – www.sclerodermaaustralia.com.au
- www.scleroderma.org.nz

Where can I learn more?

www.arthritis.org.nz

Regional offices

Northern (Auckland) 09 523 8900

Midland/Central (Wellington) 04 570 5791

Southern (Christchurch) 03 379 6703

National office

Level 2, 166 Featherston Street

PO Box 10020, The Terrace

Wellington, 6143

Phone 04 472 1427

Fax 04 472 7066



ARTHRITIS NEW ZEALAND



Tollfree 0800 663 463

