Scleroderma – The Uncommon Disease

Scleroderma is the medical term describing a disease affecting many different parts of the body and in which symptoms vary enormously.

Although Scleroderma is still poorly understood, it is apparent that the body's immune system fails to adequately protect the connective tissues. (Connective tissues hold muscles, blood vessels, fat and skin together.)

In Scleroderma sufferers this tissue is replaced by a type of scar tissue called fibrosis. Because connective tissue occurs throughout the whole body, this disease affects many and various organs and can produce a wide range of symptoms. Progression of the condition is also enormously varied in sufferers.

Following is a list of the most common symptoms, but it must be stressed that some people will experience very few of them, while others may suffer rather more.

- Colour changes in the hands and feet, usually on exposure to the cold. This is called Raynaud's phenomenon.
- Prominent capillaries can occur over the face and fingers.
- Chilblains or – in extreme cases – ulceration of fingers or toes.
- Thickening of the skin which may occur in patches or may affect all of the fingers or toes or face. Rarely, it may involve an extensive part of the body.
- Dryness of the eyes, mouth and vagina.
- Reflux oesophagitis and peptic ulceration causing indigestion and heartburn.
- Little nodules of calcium deposited on the fingertips and over bony prominences.
- Stiffness in the muscles and joints may occur as the tendons and joint linings become thickened.
- The wall of the bowel may thicken, causing diarrhoea or constipation.
- Tissues in the lung may thicken and this may lead to hypertension and kidney impairment.

Once again, by no means does everyone with Scleroderma suffer all of these effects.

There is no known cure for Scleroderma. However, the disease can be managed.

Nursing Care of Patients with Scleroderma

Often when a person with scleroderma is hospitalised for surgery or treatment of another condition, they find that the nursing staff may have limited knowledge of scleroderma.

In response to this situation, the following care plan was developed for a person with scleroderma to take to hospital and give to the nursing staff on admission.

A number of people who have used this care plan have reported the positive response they received from the nursing staff who found it so much easier to provide quality care with the information provided on this sheet.

NOTE: The manifestations of the disease vary from patient to patient. The disease process is not always visible, and patients could suffer if the validity of their problems were questioned.

This is an extract from an Australian Nursing Journal, reproduced with the kind permission of the author, Sr Rachel Rossiter, RN, BHSc (Nsg), BCoun., a nurse counsellor at the Scleroderma/ Lupus Resource Centre at the Royal Newcastle Hospital, NSW. The Nursing Care Plan was initially put together by Sr Penny Stanford and later expanded and updated by Sr Rachel Rossiter. Our thanks to them and to the Scleroderma/Lupus Resource Centre, for the use of this material.

A publication of:
Scleroderma Australia. PO Box 167,
Nedlands, WA 6909
t. (02) 9990 5159
email: info@sclerodermaaustralia.com.au
www.sclerodermaaustralia.com.au

A HOSPITAL CHECKLIST

A Guide to Nursing Patients with Scleroderma

scleroderma australia
support • education • research