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.

The Scleroderma Foundation of Victoria provides practical help, education and support for sufferers and their families.

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.

- For more information, contact the Scleroderma Foundation of Victoria (address on front cover).

SCLERODERMA VICTORIA

A Hospital Checklist

A Guide to Nursing Patients with Scleroderma

Author???

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Care Plan for Person With Scleroderma

Problem	Tick	Management
Diminished elasticity in blood vessel walls causes increased susceptibility to cold and painful spasms in extremities. (Raynaud's Phenomenon)		Provide extra blankets. Avoid draughts. Maintain warmth, particularly pre and post-op when patient unable to communicate.
Oesophageal reflux. Oesophagitis		Elevate head of bed. Provide extra pillows. Sit upright when eating and after meals. Administer anti-acids after meals.
Reduced oesophageal peristalsis.		Discuss food preferences and swallowing difficulties. Ensure adequate and appropriate dietary intake.
Bowel involvement. Diarrhoea and/or constipation. Faecal incontinence.		*Assess for dietary requirements and medication regime.* *Refer to dietitian.*
Dry mouth, dry eyes. (Sjogren's Syndrome/ sicca syndrome)		Ensure drinking water readily accessible. Mouth toilet when patient unable to drink. Assist with instillation of eye drops or ointment if patient unable to self-administer, particularly pre and post-op and prior to sleeping.

Problem	Tick	Management
Fragile skin on hands, prone to ulceration and slow healing.		Provide protection during surgery or procedures. Assist with ADL's as necessary. Refer to occupational therapist.
Hardened skin.		Extra care required with venipuncture and blood pressure measurement.
Painful feet.		Avoid injury, e.g. during transfer and ambulation.
Painful joints		Assist with repositioning. Provide extra pillows. Massage and application of heat. Anti-inflammatory medications as ordered. Physiotherapy assessment.
Reduced capacity to cope		Create calm, supportive environment. Encourage stress reduction techniques. Refer for social work assessment.
Shortness of breath on exertion.		Allow patient to set the pace during physical activity.

For Scleroderma sufferers:

Please tick the boxes which apply to you, add anything extra in the "Notes" box provided overleaf, and hand to the nursing staff on admission to a ward.