This Information Sheet is written for people with lymphoedema.

**What lymphoedema is**

Lymphoedema is the swelling of part or parts of the body that occurs when the lymphatic system is not working properly. The lymphatic system consists of many tiny channels throughout the body called lymph vessels or lymphatics.

Like blood vessels, these join together to form larger channels. The lymphatic system carries lymph, a colourless, watery fluid that contains lymphocytes – a type of white blood cell. The lymph is filtered through a number of nodes, or glands, before going into the bloodstream. Lymph nodes range in size from as small as a pinhead to as large as a baked bean.

In some parts of your body there may be just a few, whereas in your armpit there are, generally, 30–50 nodes.

Some factors that may cause lymphoedema are:

- birth abnormality, which may not show until later in life (primary lymphoedema).
- where lymph nodes are blocked, damaged or cut (secondary lymphoedema), for example:
  - after surgery to lymph nodes
  - radiation treatment to lymph nodes.

Not everyone who has the above treatments will develop lymphoedema, and of those who do, many will only experience mild swelling.

**Tumours may cause lymphoedema**

It is important to recognise the difference between lymphoedema and other causes of swelling, such as a clot, heart failure, or a cancer that has come back. These need different treatment.
Lymphoedema management

Lymphoedema is not curable. In most cases it can be controlled with treatment. See a lymphoedema therapist for an assessment and a treatment plan.

Contact your local Cancer Society for a lymphoedema therapist in your area. Treatment may include:

• massage
• compression
• self-care education
• exercise.

Tips for self-care

Skin care of the affected limb

Good skin care can help minimise the risk of infection.

If build-up from lymphoedema sits close to the skin surface, the limb may become infected through cuts, scratches or insect bites.

See your doctor immediately:

• if any pain, redness or heat is present in the affected limb.
• you notice any red lines tracking along the limb.
• if you feel generally unwell.

Always complete the prescribed course of antibiotics. If signs and symptoms persist after a course of antibiotics, seek medical advice. The infection may not have completely cleared.

• Avoid sunburn, cover up and use 30+ sunscreen when outdoors.
• Instead of soap try a body wash, for example, QV wash soap alternative or Dove soap. They are non-lathering gentle cleansers that do not dry out the skin.
• Wear gloves when gardening or doing dishes.
• Try to avoid insect bites, cuts and scratches. Treat any that occur with antiseptic ointment or spray, for example, Savlon and, Stingose. You may be prescribed an antibiotic ointment, for example, Bactroban.
• If possible, use the unaffected arm to have your blood pressure, injections or blood taken.
• Avoid the use of hot water bottles, or ice or heat packs on your affected limb.
• Spa baths are not recommended.
• Always wear your compression garment as shown. If you do not have a compression garment contact your local Cancer Society or your therapists. You may need to wear a garment for air travel or land journeys at high altitude, for example, tramping or long car journeys.
• For arm lymphoedema, use the unaffected arm for carrying heavy parcels.
• For leg lymphoedema, avoid standing or sitting still for long periods. Do gentle exercises every 15 minutes, such as changing your leg position, bending, stretching, or circling your foot at the ankle. Try to get up and walk around every hour if possible.
• Treat all infections, such as athlete’s foot, promptly.
Tips for diet
A balanced diet low in fat and high in fibre is important. Eat plenty of fresh fruit and vegetables. Drink around 10 glasses of fluid daily, especially water. Try to maintain the ideal weight for your height and build. Putting on weight can make lymphoedema more difficult to control. Low protein intake may worsen the condition by weakening the connective tissue. Eat easily digested protein, such as chicken, fish, tofu or low fat dairy products.

Tips on exercise
Regular exercise, such as walking and swimming can be very good for you. Muscular action will help to move the fluid out of the swollen limb.

Tips on self massage
Learn how to do this. Your lymphoedema therapist will show you how.

Wearing compression garments
These should be fitted by a lymphoedema therapist or another trained person. They should be worn according to the therapist’s instructions and cared for according to the manufacturer’s instructions. On average, a garment will last the user four months. You can get garments on prescription from your specialist in the public health sector.

Your emotional well-being
Talking about your experience can be very helpful. Other people with lymphoedema can be a great source of support, advice and experience. Check with your local Cancer Society for lymphoedema support groups or education in your area.

Your workplace and lymphoedema
Check that your work situation is not making your lymphoedema worse, for example, computer set-up, heavy lifting or pushing, or repeated movements.

Lymphoedema therapists
These are usually nurses, physiotherapists or massage therapists who have undertaken specialised training in lymphoedema management.

Check that your therapist has the appropriate training.

• If there are no trained lymphoedema therapists in your area, check with your local Cancer Society. They may know of someone willing to work with you, perhaps in liaison with therapists in other centres.

• Lymphoedema therapists generally work in private practice. Costs are generally not covered by medical insurance, but you need to check your policy if you have one.

• If your lymphoedema is moderate to severe, your lymphoedema therapist will probably recommend a course of Complex Physical Therapy (CPT). This can be successful in reducing and controlling swelling, and the earlier it is started in the development of lymphoedema, the higher the likelihood of success. CPT involves bandaging and massage (daily for 2 – 3 weeks), along with exercise, skin care, dietary advice and the fitting of a compression garment.

Other treatments for lymphoedema
• Compression pumps – these are used rarely, and should only be used after recommendation and instruction by your therapist.

• Surgery – this is also used rarely because of limited benefits and risk of worsening the swelling.

• Diuretics are NOT useful in reducing the fluid in lymphoedema.

• Complementary therapies – while there is no scientific evidence that these have benefit, some therapies may be very helpful in improving well-being and assist in coping with lymphoedema.

• Seek treatment early: see a lymphoedema therapist early in the development of lymphoedema, or if there is any increase in existing lymphoedema.
Lymphoedema therapists — Contact your local Cancer Society for a list of trained lymphoedema therapists in your area.

Suggested websites for more information

The following organisations have websites with free information available online. If you do not have access to the internet, contact the Cancer Information Helpline 0800 CANCER (226 237) who can provide this information for you.

- The National Breast and Ovarian Cancer Centre (Australia):
  www.nbocc.org.au/lymphoedema/

- The Lymphoedema Association of Australia:
  www.lymphoedema.org.au

- British Lymphology Society:
  www.lymphoedema.org/bls

- Lymphoedema Support Network:
  www.lymphoedema.org/lsn/

- Flinders Medical Centre:

- Lymph Notes.Com:
  www.lymphnotes.com