



INFORMATION ABOUT

Lymphoedema following treatment for breast cancer

This information has been developed to help you understand the signs and symptoms of lymphoedema following treatment for breast cancer, how to reduce the risk of developing lymphoedema and what you can do to help manage the condition if you develop it.

This information replaces Chapter 13: *Lymphoedema* in the National Breast Cancer Centre's *A Guide for Women with Early Breast Cancer 2003*.

WHAT IS LYMPHOEDEMA?

How common is lymphoedema?

SIGNS, SYMPTOMS AND DIAGNOSIS

What are the signs of lymphoedema?

How is lymphoedema diagnosed?

If you have lymphoedema what impact might it have?

HOW TO REDUCE THE RISK OF LYMPHOEDEMA

HOW IS LYMPHOEDEMA MANAGED?

Experimental treatments

Treatments for which there is little or no evidence of benefit

COPING WITH LYMPHOEDEMA

QUESTIONS TO ASK YOUR DOCTOR

WHAT IS LYMPHOEDEMA?

Lymphoedema is a swelling of the arm, leg, breast or other part of the body that occurs because of a build-up of fluid in the body's tissues.

Fluid from the body's tissues usually drains into lymphatic vessels, which are typically close to the blood vessels. This fluid is called lymph. Lymphatic vessels carry the lymph fluid to lymph nodes, where substances that could be harmful, such as bacteria, are filtered out and destroyed. This helps to protect the body from infection. The lymph then passes back into the blood. There are lymph nodes all around the body, including the armpit, groin, stomach, chest and neck.

During treatment for breast cancer, lymph nodes may be removed from the armpit or breast region by surgery or damaged by radiotherapy. This can stop the lymph from flowing freely and can cause fluid to build up in the arm or breast. If left untreated this build-up of fluid can be difficult to control.

Lymphoedema can develop months or even years after treatment for breast cancer. Lymphoedema usually develops gradually.

Lymphoedema is **not** the same as the swelling or pain in the breast, armpit or arm that immediately follows surgery or radiotherapy to the breast or armpit.

HOW COMMON IS LYMPHOEDEMA?

There are a variety of ways of measuring lymphoedema. We don't know exactly how many people develop lymphoedema in the arm or breast after treatment for breast cancer. Estimates vary from one in ten people to one in three people treated for breast cancer. The risk seems to be higher for people who have several lymph nodes removed and for those who have both surgery **and** radiotherapy to the armpit. However, it is important to realise that many people who have lymph nodes removed and radiotherapy to the armpit will not develop the condition.

SIGNS, SYMPTOMS AND DIAGNOSIS

WHAT ARE THE SIGNS OF LYMPHOEDEMA?

Early signs of lymphoedema to look out for can include:

- a feeling of 'heaviness', 'tightness' or 'tension' in the arm or breast
- swelling of the arm, breast or hand (you may notice indentations in the skin from tight clothing or jewellery, or rings, bracelets or watches may feel tighter than usual)
- discomfort or aching of the arm, hand, chest or breast area
- skin that feels warmer than usual.

Some of these early signs may come and go. If you notice one or more of the changes above, it does not necessarily mean you will develop lymphoedema. However, if it is lymphoedema, identifying the signs early and starting appropriate management can help.

There often can be other changes, not associated with the lymphoedema but with surgery or radiotherapy. These changes include reduced range of movement, loss of muscle strength, changes in sensation and tingling in the arm or fingers. These changes should not be mistaken for signs of lymphoedema.

It is important to tell your doctor or breast care nurse promptly about any changes that develop after the initial side effects of treatment have passed.

HOW IS LYMPHOEDEMA DIAGNOSED?

Lymphoedema is usually diagnosed if the arm or breast swells after the initial side effects of treatment for breast cancer have passed. In addition to looking at the affected area, the most common way for doctors to assess lymphoedema is to measure the circumference of the arm with a tape measure and compare it with the other arm. Others may use a technique called bio-impedance which measures fluid levels in the arm.

IF YOU HAVE LYMPHOEDEMA, WHAT IMPACT MIGHT IT HAVE?

People who have developed lymphoedema after treatment for breast cancer report a number of symptoms in addition to the early signs described above. Often, the symptoms are mild and may last for only a short period of time, with little impact on daily activities. For some people however, the symptoms can be more severe and/or long-lasting.

Some people have problems lifting their arm because of symptoms like stiffness, heaviness, pain or loss of strength. Sometimes this can affect the ability to perform household tasks, or activities such as sport and exercise. The swelling associated with lymphoedema can sometimes mean that people are dependent on others for help, or have to change the way they dress. Some people feel upset, embarrassed, frustrated, anxious or depressed about the swelling and discomfort in their arm or breast.

Lymphoedema also increases the risk of infection in the affected area. This means that care needs to be taken to avoid damaging the skin which can impact on some daily activities (see 'How to reduce the risk of lymphoedema').

The symptoms of lymphoedema can be managed with appropriate care. A qualified lymphoedema therapist may be able to help – ask your breast care nurse or doctor for a referral.

HOW TO REDUCE THE RISK OF LYMPHOEDEMA

It is not possible to tell who will develop lymphoedema after treatment to the armpit for breast cancer. Studies to reduce the risk of lymphoedema have focused on surgical or radiotherapy techniques that are less damaging to the lymphatic system. These include:

- a technique called sentinel node biopsy, where only the primary draining lymph node(s) is/are removed from the armpit initially to check whether breast cancer has spread outside the breast; this technique is associated with fewer problems of arm swelling, movement and sensation than removal of all the lymph nodes from the armpit (called an axillary clearance)
- methods to limit the amount of radiotherapy given to the breast or armpit area – these are still being tested in clinical trials.

There are some actions that individuals can take after treatment for breast cancer that **may** help to reduce the risk of developing lymphoedema. It is important to note that there is no evidence from clinical studies that these suggestions will definitely prevent lymphoedema.

This advice may also be helpful for people who have developed lymphoedema to help stop the condition from getting worse. Suggestions are outlined below.

- **Reduce the risk of infection by keeping the skin healthy and take precautions to limit cuts, burns or insect bites to the treated arm** – for example:
 - keep the skin supple using a moisturising cream
 - wear gloves when washing dishes
 - wear gloves and a long-sleeved shirt when gardening or handling pets
 - use insect repellent
 - if shaving the armpit, use an electric razor instead of a wet razor
 - if having blood samples taken, or an injection or intravenous drip, use the non-treated arm
 - clean any scratches, grazes or cuts immediately using an antiseptic solution, use an antibacterial cream and cover the area with a clean, dry plaster.

See a doctor as soon as possible if any signs of an infection appear, such as redness or inflammation.

- **Try to avoid activities that will put an additional fluid load on the lymphatic system** – for example:
 - avoid sunburn to the arm or breast
 - don't have saunas or very hot showers or baths that will overheat the arm or breast
 - try to keep to a healthy weight.
- **Try to avoid activities that will slow or halt lymph flow** – for example:
 - avoid having blood pressure measurements taken on the affected arm
 - don't wear a poorly fitting bra or tight clothing.
- **Keep active** to help the circulation of fluid in the arm and breast:
 - follow a gentle exercise routine and if you want to exercise more vigorously, work up to this slowly and always warm down slowly
 - talk to your doctor, a lymphoedema therapist or physiotherapist if you have questions about what activities are best for you.

It has been suggested that air travel may increase the risk of developing lymphoedema. While the evidence for this is not strong, it may be helpful to wear a compression garment (see next section for more information about compression garments) and to perform gentle exercises during the flight.

HOW IS LYMPHOEDEMA MANAGED?

There is no known cure for lymphoedema, but it can be managed with appropriate care. The aim of management is to reduce and control the swelling and improve the range of movement of the affected area.

There is limited evidence about the best way to manage lymphoedema. The treatments recommended will vary depending on the stage of the lymphoedema and the severity of symptoms. Some of these methods are still being tested. Talk to your GP about what treatment options may be suitable for you. A qualified lymphoedema therapist can help by developing an individualised treatment program – ask your breast care nurse or GP for a referral.

Information about different ways to manage the condition is listed below.

- **Exercise** – studies suggest that gentle exercise can help to reduce the symptoms of arm lymphoedema by helping lymph to flow through the lymphatic vessels. Some research also suggests that combining gentle exercise with deep breathing may help to reduce symptoms. Talk to your GP or lymphoedema therapist about what exercises are most appropriate for you.
- **Elevation** – experts believe that raising the arm, for example by supporting the arm on several pillows, can help reduce the symptoms of lymphoedema in the early stages of the condition. However, this has not been tested extensively in studies.
- **Compression garments** – these are tightly fitting elastic garments worn on the affected arm. Studies suggest that wearing a compression garment can help to reduce the swelling associated with lymphoedema by stopping fluid from building up and moving excess fluid out of the arm. Wearing a compression garment may be recommended at times when the arm is swollen, or during certain activities such as sport, or air travel. It may be combined with other forms of treatment such as manual lymphatic drainage (see below). Compression garments should be fitted professionally and replaced when they lose their elasticity. Lymphoedema of the breast and arm may also be treated using compression bandaging rather than a compression garment. Ask your GP, surgeon, breast care nurse or lymphoedema therapist for more information.

● **Manual lymphatic drainage (decongestive physiotherapy)** – this is a special form of massage of the affected area that aims to improve the way in which the lymphatic vessels are working and help reduce the build-up of fluid. Experts believe this is an effective method to manage the symptoms of lymphoedema. Such treatments should be given by a qualified lymphoedema therapist.

EXPERIMENTAL TREATMENTS

● **Laser therapy** – studies have investigated the use of laser therapy to help soften scar tissue and improve the function of the lymphatic vessels. However, further research is needed to determine whether this is an effective treatment for lymphoedema and to compare results with those of other management approaches.

● **Drug treatments** – antibiotics can be used to treat infections in areas affected by lymphoedema but have not been shown to prevent the development of lymphoedema. Some studies have examined the use of drugs to reduce the symptoms of lymphoedema. These include drugs that contain chemicals called benzopyrones or bioflavonoids. However, results to date are inconclusive. Some drugs may have side effects or interact with other medications. It is important to talk to your doctor before taking any over-the-counter drugs to treat lymphoedema. Diuretics are not effective for the treatment of lymphoedema.

● **Surgery** – ongoing studies are examining whether surgical techniques such as liposuction or lymph node transplantation are effective in managing the symptoms of lymphoedema in people who do not respond to physical therapy or have recurrent infections. Early results suggest that these methods may have some benefits, but further research is needed before this form of treatment can be recommended.

TREATMENTS FOR WHICH THERE IS LITTLE OR NO EVIDENCE OF BENEFIT

- **Ultrasound** – there is currently little evidence to support the use of ultrasound in the treatment of lymphoedema.
- **Diet** – no specific diet is recommended for people with lymphoedema. However, being overweight or obese may increase the risk of lymphoedema or worsen symptoms.
- **Heat** – use of microwave or heat therapies is not recommended for the treatment of lymphoedema and such treatments may actually make the condition worse.
- **Hyperbaric oxygen** – there is insufficient evidence to support the use of 100 per cent oxygen as a treatment for lymphoedema.
- **Complementary therapies** – there is currently no evidence to support the use of complementary therapies for the management of lymphoedema.

If you have lymphoedema, check your arm or breast regularly for any changes and see your doctor as soon as possible if you notice any change in size, worsening of symptoms or any signs of infection.

If your arm or breast swells quickly or becomes red and warm, see your doctor straight away. This may be a sign that you have an infection that needs to be treated with antibiotics.

Research is ongoing into methods for preventing, diagnosing and managing lymphoedema. This research will help to provide more evidence-based information in the future.

COPING WITH LYMPHOEDEMA

If you develop lymphoedema you may experience a range of feelings in addition to the physical symptoms of the condition. You may feel upset or embarrassed about how your arm or breast looks, and it may affect the way you feel about your body and your relationships with others. If you are diagnosed with lymphoedema, it is not uncommon to feel upset or sad. Most people find that these feelings ease with time, as they learn how to manage the condition.

Talking to others can help. You may find it helpful to talk to those close to you and let them know how you are feeling. Or you may prefer to talk to a member of your treatment team, such as your GP or breast care nurse. Sharing your experiences with other people who have experienced lymphoedema can also help. The Cancer Helpline on 13 11 20 can let you know about support groups in your local area.

If you have feelings of anxiety or depression that are overwhelming you, talk to your GP. Treatments are available that can help. You may find it helpful to talk to a specialist, such as a counsellor, psychologist, or sex therapist, about how you are feeling.

QUESTIONS TO ASK YOUR DOCTOR

Listed below are some questions you may like to ask your doctor or lymphoedema therapist about lymphoedema.

- Who should I contact if I develop signs of lymphoedema?
- Can you refer me to a qualified lymphoedema therapist?
- How much will it cost to see a lymphoedema therapist?
- What treatment do you recommend for my lymphoedema?
- What is the evidence that the treatment you are recommending will work?
- Where can I get a compression sleeve fitted?
- When should I wear my compression sleeve?
- How much will my compression sleeve cost?
- What type of moisturiser should I use?
- Can I have some antibiotic cream to keep at home?
- Who should I contact if I notice signs of an infection?
- Can I exercise after my breast cancer treatment?
- What types of exercises can I do?
- Are there any techniques I can use at home to help my lymphoedema?
- If I change doctors should I tell them about my breast cancer treatment?
- Can I talk to someone about how I am feeling?

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