

LYMPHOEDEMA

FACT SHEET

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This fact sheet was produced by Breast Cancer Network Australia

What is lymphoedema?

Lymph is a fluid that forms in the body and drains into the blood through a network of vessels and lymph nodes. Lymph nodes filter the fluid, trapping bacteria, cancer cells and any other particles that could be harmful to the body.

When the lymph nodes are removed, the body compensates by 're-routing' the lymph through other lymph vessels in the area. However, this system is less efficient. If these vessels are overloaded, lymph fluid may pool in the tissues, causing the swelling known as **lymphoedema**.

Not all women diagnosed with breast cancer will develop lymphoedema. Current evidence suggests around one in five women will develop the condition.

Why is lymphoedema associated with breast cancer?

If cancer cells have begun to spread from the breast they may be found in the lymph nodes under the armpit. Any lymph nodes that contain cancer cells must be removed. There are two ways of removing lymph nodes:

- axillary dissection (axillary clearance)
- sentinel node biopsy.

Axillary dissection or clearance involves the removal of all or several of the lymph nodes from the armpit. The nodes are examined by a pathologist to determine if any of them contain cancer cells. Your doctor will then use this information to help determine the best treatment for you. Unfortunately, this procedure can place a woman at increased risk of developing lymphoedema.

Sentinel node biopsy allows the surgeon to identify the first lymph node, or nodes, to which cancer cells are likely to spread from the breast. These sentinel nodes are removed during surgery and tested by a pathologist to determine if cancer cells are present. If they are found to be free of cancer, other nodes are unlikely to be affected and therefore do not need to be removed.



If cancer is found in the sentinel nodes, you may have further surgery to remove some or all of the remaining nodes. In a small number of cases, the sentinel node is unable to be identified and an axillary dissection will be recommended.

Sentinel node biopsy is available in most Australian hospitals, although the procedure may not be appropriate for everyone.

The risk of developing lymphoedema is lower with sentinel node biopsy as the number of lymph nodes removed is generally less than with an axillary dissection.

Radiotherapy to the armpit can also interfere with the natural flow of lymph, making this another risk factor in the development of lymphoedema.

Swelling and 'odd sensations' soon after surgery are not lymphoedema.

After surgery, it is normal for there to be some numbness of the armpit, upper arm and the breast or chest wall, and there is often some swelling. As the nerves begin to repair, it is also normal to experience a number of odd and uncomfortable sensations, often described as tingling or the feeling that the skin has been sunburnt or grazed.





These sensations can occur in the breast or chest wall, armpit, upper arm and upper back. The swelling and odd sensations usually settle down during the weeks or months after surgery.

Discuss your symptoms with your surgeon or breast care nurse at each visit, especially if the swelling or discomfort persists or increases.

How do you know if you have lymphoedema?

Lymphoedema can occur at any time after surgery – even many years later.

It is important to know the signs and symptoms. If lymphoedema should start to develop, the sooner you can seek advice and start treatment, the better it can be managed.

Early symptoms of lymphoedema are:

- swelling of the arm, breast or hand (you may notice that your rings, sleeves or wristbands feel tight)
- feelings of discomfort, heaviness, tightness or fullness in the arm or breast
- aching, pain or tension in the arm, shoulder, hand, chest or breast area.

What should you do if you think you have lymphoedema?

If you think you may have lymphoedema you should seek prompt advice from your medical team. You can also ask your doctor for a referral to a lymphoedema therapist.

What can trigger lymphoedema?

The most commonly recognised triggers are:

- **infections in your arm** – infections can start from cuts, scratches, injections, insect bites, burns or sunburn; anything that causes the skin to break
- **being overweight**
- **overheating your arm** – avoid sun, hot baths and showers, spas, saunas and excessive exercising in hot weather
- **injuries to your arm**
- **carrying or holding heavy parcels** – work up slowly to carrying heavy items and check for swelling
- **travelling** – sitting still during long flights, car or bus trips, and pressure variations in planes may reduce lymph flow (see more information about this on page 3)

- **restricting circulation to your upper body or arm** – blood pressure cuffs, tourniquets, bras with narrow straps, clothes that are tight around your chest or arm, and tight jewellery or watches may reduce lymph flow.

How can I reduce my risk of developing lymphoedema?

It is impossible to predict whether or not you will develop lymphoedema. However, there are ways to reduce your risk.

- Taking good care of your skin
 - Keep your skin moist and supple using a moisturising cream such as sorbolene.
 - Protect your skin from the sun with clothing and sunscreen.
 - If shaving your armpit, use an electric razor instead of a wet razor.
 - Use insect repellent and, if bitten, use a product to reduce the itchiness of the bite.
 - Protect your hands with gloves while washing dishes or gardening.
 - Treat any cuts or breaks to the skin with antiseptic.
 - If a cut, bite or break to the skin becomes red or inflamed, or your arm swells quickly or becomes red and warm, see your doctor as soon as possible as you may have an infection that requires antibiotics.
- Keeping active
 - Gentle muscle movement increases lymph flow and reduces the risk of fluid accumulating. A gentle regular exercise routine is recommended. Studies have shown that moderate exercise does not exacerbate lymphoedema if you already have it and does not make you more susceptible to developing it. There is also some evidence to suggest that exercise may even help prevent lymphoedema.
- Avoiding using the arm on the side of your surgery for blood pressure measurements, injections, blood samples or intravenous drips
 - While there is not yet enough evidence to determine whether these procedures can trigger lymphoedema, these precautions are recommended.



Lymphoedema risk during travel

Some people have reported swelling of the arm (lymphoedema) after air travel and long car, bus or train trips.

There is no conclusive evidence that the trip itself causes lymphoedema, but there are a number of theories about why travel may lead to the development of lymphoedema in the arm on the side of breast surgery. These theories include the following.

- Lymphoedema may be triggered by the combination of low cabin pressure and physical inactivity when flying.
- Any long trip (plane, car, bus or train) can involve long periods of physical inactivity, which may reduce lymphatic flow and cause swelling of the arm.
- Lymphoedema associated with travel may not be caused by the travel as such; rather it may be triggered by being extra active in preparation for travel or by changes in normal routine, such as:
 - concentrated cleaning of the house (vacuuming, ironing etc.) before the trip, placing extra strain on the lymphatic system of the arm
 - carrying heavy luggage
 - juggling luggage with heavy shoulder bags
 - giving up normal exercise routines while on holidays.

Until further evidence is available, you may like to consider some simple precautions that could minimise potential problems.

Reducing your risk of lymphoedema during travel

- Consider investing in luggage on wheels
- Try to wear your shoulder bag on the opposite shoulder to the side of your surgery.
- Exercise your arm during the trip. Consider taking a soft squeeze ball and use it regularly.
- Get up and go for a walk every couple of hours (good for the back as well as general lymphatic flow).
- If travelling by plane:
 - wear loose-fitting clothes
 - ask for a window seat so you can use the ledge to support and elevate the affected arm.
 - drink plenty of water and try to avoid alcohol.

- If travelling by car, bus or train, exercise your arm as much as possible within the confines of your seat.
- If driving, try to shift the arm around and keep the lymphatic flow moving by gently squeezing the steering wheel.
- It is generally recommended that people who have had lymph nodes removed as part of their breast cancer surgery wear a compression sleeve on long plane flights or other long trips (see below for information about compression sleeves). You can discuss this with a lymphoedema therapist or your doctor.
- Consider packing:
 - things to protect your skin from the sun, such as sunscreen and long sleeved clothing
 - moisturiser
 - insect repellent and something to stop the itch if you do get bitten
 - a small first-aid kit, including antiseptic cream.
- Seek medical advice about whether it's advisable to carry antibiotics or a prescription for them. If you are travelling overseas, it's also advisable to take an explanatory letter from your doctor.

How is lymphoedema managed?

There is no known cure for lymphoedema, but there are ways to manage it. These include good skin care, gentle exercise, lymphatic drainage massage and the use of compression garments on the affected arm.

These treatments are designed to reduce and control swelling, improve the range of movement of the affected area and prevent infections.

There are some emerging treatments such as laser therapy, which aims to soften scar tissue and improve the function of the lymphatic vessels, and pneumatic pumps, which go around the arm and inflate and deflate at intervals.

Further research is still needed on the effectiveness of these treatments, but you may like to talk to your doctor or lymphoedema therapist if you are interested in learning more about them.

Your doctor or lymphoedema therapist can talk to you about the best treatment for you. Treatments may vary depending on the severity of your symptoms and how long you have had lymphoedema.



Compression garments

If you need to wear a lymphoedema garment, it is important that it is well fitted.

Your arm should be measured by a person qualified to do this, such as a lymphoedema therapist or a supplier of compression garments. Visit the National Lymphoedema Practitioners Register (NLPR) at lymphoedema.org.au, where you can search for a lymphoedema practitioner in your area.

When wearing your compression sleeve:

- ensure the fabric is evenly spread along the arm so that the pressure is correctly distributed
- do not roll or fold down the garment top. If there is excess fabric at the top, ease the garment down over the length of the arm to ensure the fabric is evenly distributed
- make sure there are no creases or wrinkles, as these act like elastic bands and reduce lymphatic flow

- garments should feel firm and very supportive, but should not be painful to wear or cause fingers to turn blue.

If you have concerns about how a garment fits, talk to your lymphoedema practitioner.

Note: If your arm aches after a period of inactivity, there may be a build-up of fluid. Moving around and exercising the arm may help.

Compression garment subsidies

Subsidies for lymphoedema compression garments provide people diagnosed with lymphoedema with financial assistance towards the costs of their garments.

The schemes are run by state and territory governments, and cover some or all of the cost of compression garments.

Compression garment subsidies by state/territory

This table provides information about compression garment subsidy schemes, and where to find more information.

	Lymphoedema compression garment subsidy program	Basic eligibility requirements	Garment subsidy	Garment limit	Key additional conditions
ACT	ACT Equipment Scheme (ACTES) Contact: ACT Health Tel: (02) 6205 2605	<ul style="list-style-type: none"> • ACT permanent resident • Diagnosed with lymphoedema • Hold a current Centrelink Pension or Health Care Card, or meet low income criteria as outlined within the policy 	100% of garment cost is subsidised	Limit of 2 garments per 6 month period	N/A
NSW	Aids and Equipment Program (AEP) Contact: EnableNSW Tel: 1800 362 253	<ul style="list-style-type: none"> • NSW permanent resident • Diagnosed with lymphoedema • All people aged 16 years and above holding a Centrelink pension card • Those who do not have a Centrelink pension card may still be eligible, depending on the applicant's income. • Ineligible to receive equipment from other government funded schemes. 	Subsidy dependent on applicant's income	Limit of 2 sets of garments per limb, per 6 month period	Applicants will be charged an annual contribution fee of \$100 to access Enable NSW services



	Lymphoedema compression garment subsidy program	Basic eligibility requirements	Garment subsidy	Garment limit	Key additional conditions
NT	<p>Lymphoedema Compression Garment Subsidy</p> <p>Contact: The Royal Darwin Hospital Occupational Therapy Department Tel: (08) 8922 8888</p>	<ul style="list-style-type: none"> • NT permanent resident • Diagnosed with lymphoedema 	100% of garment cost is subsidised	Limit of 2 garments per limb, per 6 month period	N/A
QLD	<p>Compression garments for adults with lymphoedema</p> <p>Contact: Allied Health Professions' Office of Queensland Tel: (07) 3328 9298</p>	<ul style="list-style-type: none"> • Qld permanent resident aged 16 and above • Diagnosed with lymphoedema • Hold a current Centrelink, Pensioner or Health Care Card • Hold a Medicare Card 	Health services provide garments for eligible patients	Limit of 2 garments per limb per 6 month period	Completion of a prescription/order form by an eligible occupational therapist, physiotherapist, podiatrist, nurse or doctor. Refer to the form for practitioner eligibility criteria.
SA	<p>Lymphoedema Compression Garments Subsidy Scheme</p> <p>Contact: SA Health Tel: (08) 8226 6000</p>	<ul style="list-style-type: none"> • South Australian resident • Diagnosed with lymphoedema by a medical practitioner • Are Medicare eligible • Are not admitted as an inpatient at a hospital • Are not eligible for garments through other sources/ programs, i.e. National Disability Insurance Scheme, DVA Gold Card, work cover, private health insurance. 	100% of garment cost is subsidised	Limit of 2 sets of garments per 6 month period	The scheme is being rolled out in stages. From 14 July 2020, the following applicants can access the scheme: patients of approved private prescribers across the state, and patients of the Central Adelaide Local Network, Northern Adelaide Local Network, Limestone Coast and Flinders and Upper North Local Health Network.
Tas	<p>Lymphoedema Garment Scheme (Tasmanian Government Concessions)</p> <p>Contact: Royal Hobart Hospital Lymphoedema Service Tel: (03) 6222 8634</p>	<ul style="list-style-type: none"> • Tasmanian permanent resident • Diagnosed with lymphoedema • Hold a current Centrelink Pension or Health Care Card 	100% of garment cost is subsidised	Limit of 2 sets of garments per limb per 12 month period	Applicant must pay a \$50 co-payment per prescription to access the scheme
Vic	<p>Lymphoedema Compression Garment Program (LCGP)</p> <p>Contact: State-wide equipment program (SWEP) Tel: 1300 747 937</p>	<ul style="list-style-type: none"> • Victorian permanent residents • Diagnosed with lymphoedema • Are currently receiving a Centrelink pension or assessed as being a low or medium income earner 	40–60% of garment cost is subsidised	Limit of 6 garments per 12 month period	N/A



	Lymphoedema compression garment subsidy program	Basic eligibility requirements	Garment subsidy	Garment limit	Key additional conditions
WA	Community Aids and Equipment Program (CAEP). Contact: Disability Services Commission Tel: (08) 9426 9200	<ul style="list-style-type: none"> • WA permanent resident • Have a permanent disability • Hold a current Centrelink Pension or Health Care Card, or Commonwealth Seniors Health Care Card 	Please contact the WA Disability Services Commission for this information	Please contact the WA Disability Services Commission for this information	Please contact the WA Disability Services Commission for this information

Things to remember

- Not everyone with breast cancer will develop lymphoedema.
- Early diagnosis and treatment of lymphoedema
 - makes it easier to manage
 - reduces the amount of swelling
 - improves arm function.
- Take precautions to reduce your risk of developing or triggering lymphoedema.
- Observe your arm for any changes.
- Seek prompt medical advice if you are concerned.
- If you have had breast cancer surgery and are subsequently admitted to hospital for any reason, let the nursing staff know of your surgery so they can be sure to use the other arm for any procedures.
- There is no known cure for lymphoedema but there are ways to manage it including good skin care, gentle exercise, lymphatic drainage massage and the use of compression garments on the affected arm.

Here to help

Breast Cancer Network Australia (BCNA) works to support, inform, represent and connect Australians affected by breast cancer.

We have a wide range of free information available including booklets, fact sheets, videos and podcasts. This information can be viewed or ordered at bcna.org.au or by calling our Helpline on 1800 500 258.

Feeling overwhelmed or have further questions?

My Journey online tool

Our new My Journey online tool is available to provide quality, evidence-based information and support tailored to your individual needs and circumstances at all stages of your breast cancer

journey. My Journey can be found at bcna.org.au/myjourney

Online Network

BCNA's online network exists to connect you with others going through a similar situation at any time during the night and day. The online network can be found at onlinenetwork.bcna.org.au

BCNA Helpline

Our Helpline cancer nurses are available to help you with any questions you may have. Call 1800 500 258.

Further information and resources

Cancer Australia

canceraustralia.gov.au
1800 624 973

Cancer Australia offers comprehensive information on lymphoedema, including signs and symptoms and how it can be managed.

Two resources are available:

- *Lymphoedema: What you need to know* (booklet)
- *Guide for women with early breast cancer* (book)

National Lymphoedema Practitioners Register (NLPR)

lymphoedema.org.au

The NLPR is a public register of lymphoedema practitioners in Australia and New Zealand, including physiotherapists, massage therapists, occupational therapists and nurses. You can use the register to search for a lymphoedema practitioner in your local area.

Lymphoedema Associations

lymphoedema.org.au
1300 852 850



Each state/territory has a lymphoedema association. These are self-help organisations offering support, information and education to anyone affected by, or concerned about, lymphoedema. The national website includes a list of therapists who have been trained by the Lymphoedema Association of Australia.

Your surgeon, oncologist or breast care nurse

Your medical team will be able to discuss ways to care for your skin and arm and who to contact if you are concerned about symptoms. They will also be able to refer you to a lymphoedema therapist or lymphoedema clinic.

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