Fact sheet 1- The lymphatic system

The lymphatic system is a network of vessels that picks up excess fluid from the tissues and returns the fluid to the bloodstream near the heart.

It is normal for fluid leak to out from blood vessels. The fluid leaks out to surround the cells picks up dead cells and other waste, and provides nutrients to cells that might otherwise miss out. Most of the fluid that leaks out from blood vessels moves back into the bloodstream. The lymph vessels pick up larger particles, like proteins, that are to big to re-enter the blood stream.

Lymph moves along due to changes in fluid pressures, body movement, breathing and a one way valve system.

As lymph moves along it is filtered through thousands of bean shaped lymph nodes. Foreign particles, like bacteria, are filtered out and white cells that give immunity are present in the lymph nodes.

Lymph moves at about 120 mls per hour (depending on movement). Usually 2-4 litres of lymph per day are moved around the body. Lymph vessels can expand enormously but usually carry only about one-tenth their maximum load. When the lymph load is too great, swelling occurs.
Fact sheet 2 - What is lymphoedema?

Lymphoedema is swelling caused by a build up of lymph fluid in the body tissues especially in the layer of fat under the skin. Normally lymph flows through lymph vessels, but if the lymphatic system is damaged or inadequate it cannot handle the usual amount of lymph, and fluid builds up in the tissues.

Lymphoedema results in swelling of the limbs and may involve the trunk or head as well. Lymphoedema causes swelling in the affected area, discomfort, loss of movement and calls for practical and psychological adjustment.

Prevention is the best approach. See the Fact Sheet ‘What triggers lymphoedema and what may make it worse?’ or the pamphlet on lymphoedema.

How will I know if I am getting lymphoedema?

Watch out for changes in sensation, feelings of tightness, heaviness or swelling on the side the lymph nodes have been removed. You may notice a change in skin colour or the feel of the skin. Rings bracelets, clothing or shoes may feel tighter. Speak to your doctor. See the Fact Sheet on ‘Where to go for help to manage lymphoedema?’

Primary lymphoedema

Lymphoedema can be either ‘primary’ or ‘secondary’.

Primary lymphoedema refers to lymphoedema that arises spontaneously because of a poorly formed lymphatic system and affects about 1 in 6000 people. Primary lymphoedema:
- can arise at birth or at puberty or at 30-40 years or later
- makes up 5-10% of all lymphoedemas.

There are some excellent Internet sites and articles on how to handle children with lymphoedema, e.g. [http://www.lymphedemapeople.com/thesite/lymphedema_childrens_pediatric.htm](http://www.lymphedemapeople.com/thesite/lymphedema_childrens_pediatric.htm)

Secondary lymphoedema

Secondary lymphoedema may occur in some people as a result of trauma, surgery and radiation to the lymph nodes, or a parasitic worm carried in mosquitoes (filariasis).

- reports vary about the number of people who develop lymphoedema. A New Zealand study reported studies showing 7-38% of women developed lymphoedema following surgery for breast cancer
- sentinel node biopsy and less radical surgery is reducing the numbers of people with lymphoedema
- lymphoedema may arise 3-6 months after surgery or may appear years later.
Stages of lymphoedema

Stage one
Acute phase - swelling lessens overnight. The skin is soft and when pushed in leaves a dent that fills again in a few seconds. Swelling is reduced by elevation and the limb is often normal or almost normal looking in the morning. The limb swells up again during the day. If this type of lymphoedema occurs in the first 12-18 months after surgery, due to overuse, it is often reversible with treatment and care.

Stage two
The skin thickens, hardens and becomes less elastic. There is less skin pitting. The limb becomes more sensitive to infection. By this time the condition is chronic, progressive and currently irreversible.

Stage three
Significant swelling and toughening of the skin is evident. Skin folds and deep crevices may occur. The limb may leak lymph fluid. Good early care can often prevent such problems.

References
Nursing Praxis in NZ, 12(2), 4-15.
Mosby: St Louis.
Fact Sheet 3 - Massage for lymphoedema

In New Zealand the current treatment for lymphoedema is based on four "cornerstones" of care

- light touch massage
- compression bandages or garments
- extra special care of the limb
- paced exercise.

A trained lymphoedema massage specialist does the massage for lymphoedema. The massage can be taught to people with lymphoedema and their family, friends or caregivers. The lymphoedema massage therapist will check your limb and ask questions about your symptoms and treatments.

Measurement

The limb is often measured. The measurements may be compared to an unaffected limb and also used to check whether the treatment is working. You and your family can be taught how to measure your limbs.

How does the massage work?

Massage uses light slow strokes. The massage is designed to clear the backlog of lymph and help the lymphatic system to work better or to open new channels in nearby healthy tissue.

The massage starts on the unaffected side and gradually clears away the lymph to make room for lymph from the affected side.

A word of caution. Lymphoedema massage may not suitable for you. Consult your doctor if

- you are having treatment for heart failure or blood clots
- you have an infected limb, such as cellulitis or an inflamed limb
- you are pregnant
- you have active cancer
- you are having radiotherapy, as the local area is not massaged.

Ordinary massage may make your lymphoedema worse as it may stir up extra fluid. Get advice from a qualified lymphoedema massage therapist.

How can I find a lymphoedema massage therapist?

See the Fact Sheet in this series "Where do I go for help to manage lymphoedema?"

References


Fact Sheet 4 - Compression garments or bandages for lymphoedema

Why are compression garments/bandages used?

For many people compression garments/bandages help to keep lymphoedema under control. Research has shown that compression garments/bandages are the most effective treatment for lymphoedema. Ideally compression garments are worn all waking hours to keep the swelling down and stop the skin from stretching. Try to see your compression garment like spectacles, hearing aids or dentures – just something you need to wear. Your lymphoedema therapist or garment stockist can advise on the best treatment.

How compression do garments/bandages work?

No one understands completely how compression works but it is thought that compression increases the pressure in the fluid under the skin to

- reduce the leaking and
- improve the flow of leaked fluid back into vessels.

Compression garments may not be appropriate if

- blood flow is poor
- the area is numb and the skin likely to crack without you knowing - check regularly
- the limb is infected e.g. cellulitis. The symptoms of cellulitis are pain, redness, and swelling. The area of redness increases until treatment is received.
- the skin is blistering or prone to ulcers
- you are having radiotherapy and the garment rubs the skin.

When wearing compression garments/bandages

- use aqueous cream or moisturiser to moisturise the limb as oil breaks down the garment fabric
- always use rubber gloves to put garment on as it increases the life of the garment and reduces snagging
- replace garment every 4 - 6 months
- make sure the garment fits well with no creases
- garments should be firm but not cause pain, swelling or extra numbness
- handwash garment in warm water with mild detergent. Gently squeeze dry in a towel (do not wring) and dry in shade
- compression garments can be left off at night if the limb reduces in size overnight and measurements confirm this.

References

Badger, C., Peacock, J.L, & Mortimer, P. (2001). Multilayer bandaging followed by compression hosiery was more effective than


Fact Sheet 5 - Exercise and lymphoedema

Exercise is thought to help the person with lymphoedema as movement

- improves the pumping of the lymph along the vessels
- increases the uptake of fluid back into the lymph vessels
- keeps the joints flexible
- strengthens muscles and prevents muscle wasting.

Advice on exercise fits into two categories - general exercise and specific lymphatic exercises.

General Exercise

Until recently it was thought that people with lymphoedema could not undertake strenuous exercise but research has shown that weight lifting and aerobic exercise did not make women with breast cancer more likely to develop lymphoedema or make lymphoedema worse for those with the condition. However exercise should be gentle in the first year to eighteen months after surgery. Some people think that if some exercise is good then more must be better. This may not be the case. Exercise should be reduced if it causes limb heaviness, aching or swelling.

Daily exercise as tolerated is helpful. The best form of exercise is exercise you enjoy doing. Try walking, swimming, cycling, or rowing. Some tips are

- start slowly and build up
- wear your compression bandage or garment unless swimming
- keep a track on whether exercise affects the limb - monitor and modify
- keep cool during exercise - try wetting the compression garment with fresh water
- during swimming no compression garment is needed as the water provides the pressure. Keep the temperature of water below 34º or lower for lap swimming
- drink plenty of water (this is not reported as making the lymphoedema worse)
- if you have skin and tissue shrinkage from surgery (e.g. mastectomy) start gently, increasing the flexibility of the shoulder and chest
- use your affected limb as normally as possible but use with care
- some sports put strain on the lymphatics – notice how your body responds. If you don’t wear a compression garment try wearing one when you exercise
- try out different things and see what works for you
- it is important to warm up and warm down (i.e. start and finish slowly)
- vary the exercises doing smaller numbers of a range of exercises and then repeat the circuit. Rotating the exercises produces less muscle soreness than doing multiple sets of the same exercises.
Specific lymphatic exercises

Lymphatic exercises are
- gentle slow movements
- designed to stimulate the lymph flow and open up the lymph nodes
- done in sequence to drain fluid systematically
- undertaken daily.

In a study by Casley-Smith & Casley-Smith, (1997) people who did lymphatic exercises daily for 3 months before starting massage treatment had less of a reduction from massage. It is thought that the exercises had reduced the limb size before the other treatment started.

Exercises are available from Lymphoedema Therapists. Michael Mason has excellent handbooks. See Fact Sheet ‘Where do I go for help to manage lymphoedema?’

References


Fact Sheet 6 Care of the Limb

The aim of good skin care is to be sure that the skin is as healthy as possible and to keep the normal supple skin texture. The limb and nearby trunk area usually become dry and the skin may become dry and flaky over time. Dry skin may crack and is more susceptible to infection.

To keep the skin healthy

- clean regularly - use aqueous cream or a very mild soap
- dry skin well, especially between the cracks
- moisturise the skin every day with aqueous cream, (available on prescription) moisturisers (available on prescription) or oil (e.g. almond). NOTE Don’t use oil if you are wearing a compression garment as it can break down the garment fabric.
- if the skin gets very dry and flaky, soft paraffin or paraffin combined with aqueous cream can be used.
- treat any fungal infections with anti fungal cream or powder
- treat even the most minor cut. Keep it clean, dry, cover with a fabric plaster
- protect the limb from injury and protect from rapid changes in temperature
- use an electric razor on the limb and surrounding areas so as not to nick the skin
- protect the skin from sunburn and insect bites
- treat burns, even minor ones quickly with cold running water

Seek medical advice quickly if infection develops. The symptoms of a serious infection are PAIN that doesn’t reduce over the day, redness which increases in size, swelling, and tenderness with or without fever.

See also the Fact Sheet 8 in this series on ‘What triggers lymphoedema and what may make it worse?’

References


Fact Sheet 7 - Getting used to life with lymphoedema

For some people thinking they may have lymphoedema or getting the diagnosis of lymphoedema can be shattering. Others may have lived with the swelling for years without getting treatment. Some people worry that the swelling means that the cancer is returning and the swollen limb may be a constant reminder of the experience of cancer. For others with primary lymphoedema just getting a diagnosis may have taken years. “Much of the difficulty adjusting to lymphoedema can be attributed to what one study called ‘abandonment by medicine’ Lack of knowledge and concern by the medical professionals, lack of pre treatment counseling and effective management ... physicians adopt a wait and see approach.” (Davis, 1998, p.48). However the awareness and understanding of lymphoedema by health professionals is growing. Once you get lymphoedema you may find that life is never the same again. You may find that lymphoedema makes you feel angry, anxious or depressed. Be assured there is help available, and there is a lot you can do for yourself.

Early detection and treatment increase the chance of recovery or of keeping the problem manageable.

The challenge for the person with lymphoedema is to take charge of the situation and if possible find a good lymphoedema therapist (see Fact Sheet – Where do I go for help to manage lymphoedema?).

Lymphoedema can often be a life changing experience and calls on you and your partner/family/support system to be adaptable.

Some issues will worry you more than others. You may find that you need to do things differently, such as the need to
- adapt clothing to accommodate the swelling or the compression garments
- get used to wearing compression garments
- pay extra costs - paying for compression garments and massage in Auckland and some other areas around the country
- change the way you do household tasks or work
- work out ways to fit in time for exercise and massage
- learn to take extra special care with your limb and treat cuts and burns promptly.

The list of precautions may seem endless. It is worth taking the time to set things up so that you can prevent injury and nip problems in the bud. See the list for the survival kit in the Fact Sheet ‘What triggers lymphoedema and what may make it worse?’

You may find it helpful
- to join the Lymphoedema Support Network, attend meetings or get the newsletters – your local Cancer Society will have contact information
- read up about what you can do for yourself.
A study into the effects of Lymphoedema (Hare, 2000) found that important issues were getting information, making lifestyle changes, coping with loss and anxiety and also counting the blessings of support from family and friends.

After the period of adjustment you can resume your life and continue to live life to the full.

References


Fact sheet 8 - What triggers lymphoedema and what may make it worse?

Lymphoedema can occur spontaneously in someone susceptible or may be triggered by an event. Lymphoedema can develop within months of surgery /radiation or arise decades later. Events that are known to trigger the beginning of lymphoedema include:

- air travel, due to the changes in air pressure
- injury to the limb e.g. sprains, fractures, wounds or skin punctures, e.g. mosquito bites, injections, blood tests in the susceptible limb
- infections in the skin on the susceptible limb
- exposure to excessive heat including sunburn
- burdening the limb by carrying heavy bags on the susceptible hand/arm or standing on susceptible leg for long periods
- constriction on the limb from blood pressure tests, tight clothes, and jewellery or sleep position.
  - be careful and get well fitting back packs
  - take care with sleeping position.

Some people wonder whether overuse of the limb and exercise in the first 18 months after surgery can trigger lymphoedema.

What can I do to reduce my chance of getting lymphoedema?

Air travel
Wear a compression garment/s during air travel. Your surgeon or lymphoedema therapist can advise you on how to get one. Move around on the aircraft and move your head, neck and limbs. Leave the garment on for at least 4 hours after the flight. No matter how tired you are, go for a walk or swim after landing, whatever you can manage.

Injury, infections, burns, constriction and changes in temperature
Protect yourself from injury. Wear gloves/shoes and long sleeves/trousers when gardening. Protect yourself from sunburn. If your arm is susceptible take extra care not to cut or burn yourself. Wear rubber gloves when washing up and protect your hands when doing things like cooking, fishing, sewing or cutting up things. Avoid blood tests, injections, IV drips and blood pressure tests on the susceptible side. Use an electric razor on the susceptible limb and area. If your leg is susceptible take care at the beach, protect your feet from cuts and grazes and treat fungal infections promptly.

Minor injuries
Treat even minor burns with cold running water. Keep an antiseptic or antibiotic in the house. Treat minor cuts. Run the cut under cold water to wash germs out. Dry the cut carefully and cover with fabric plaster. Keep the cut clean, dry and covered for a few days. Change the plaster at least daily. If the cut gets wet change the plaster. If the cut looks a bit red, gets warm or more painful then put on some antibiotic cream. See a doctor immediately if your skin is painful, hot, or red or looks infected. This can be serious.
If your leg is at risk, ask the doctor for an anti fungal cream. Treat athlete’s foot. Chafing – if the skin is dry some people have found cornflour is useful to prevent chafing.
Keep a healthy weight

The bigger you are the more lymph you produce but your lymph vessels aren’t any bigger.

What may make lymphoedema worse?

All the things listed above can make your lymphoedema worse. The academic literature and research studies do not really discuss stress or diet. For information on activities see the Fact Sheet in this series on ‘Exercise and lymphoedema’.

Some people think that lymphoedema can be made worse by certain activities, food and stress. If your lymphoedema flares up it may be worth thinking about what you did the day before. Think about stress levels, activity and what you ate. Internet web sites list foods that some people have found made their lymphoedema worse. For example fatty or salty foods, caffeine, alcohol, spices mono sodium glutamate or smoking.

You may want to try stopping certain foods for a few days and then restart the foods one by one, every 3 or 4 days to see if food affects your lymphoedema.

Get a survival kit

The book ‘Coping with lymphedema’ by Joan Swirsky and Diane Sackett Nannery lists things to keep on hand including:

- a filled prescription for antibiotics with instructions from your doctor
- antiseptic or antibiotic cream - keep two tubes on hand and carry with you when you travel
- for those with lymphoedema of the leg, an anti-fungal powder, ointment or cream, to place in your socks or stockings or shoes to prevent fungal infections
- fabric plasters, especially for hands and feet that get wet. A fabric plaster will dry out
- insect repellant
- for those with lymphoedema of the arm
  - several well insulated wrist high oven mitts
  - pairs of rubber gloves
  - a pair of cotton gloves (useful when doing the housework)
  - a pair of fisherman's fillet gloves (flexible, metal mesh, available from sports / fishing shops), useful for cooks who cut themselves.

References


Fact sheet 9 - Where do I go for help to manage lymphoedema?

Finding a lymphoedema therapist

If you have had treatment for cancer the surgeon may refer you to a lymphoedema therapist. Your breast care nurse and/or Cancer Liaison Nurse can refer you to a lymphoedema therapist. A list of lymphoedema therapists is printed with this series.

Lymphoedema support groups

The local Cancer Society can give you the contact details of the nearest lymphoedema support group. If you subscribe to the support group you may get a newsletter. Some lymphoedema support groups sell handbooks on lymphoedema management. Contacts for lymphoedema networks include:

Auckland Lymphoedema Support Network, c/- Auckland Cancer Society, 1 Boyle Crescent, Grafton, Auckland. Ph. (09) 308 0160.

Lymphoedema Association of Australia. 94 Cambridge Tce., South Australia 5061, Australia..

Or contact your local Cancer Society.

Handbooks and Books

There are some excellent handbooks on lymphoedema including:


Piller, Neil. Recognition, Treatment and Management of a Lymphoedema Leg (26 pp.)
Recognition, Treatment and Management of the Lymphoedema Arm (23 pp.)
Recognition, Treatment and Management of the Lymphoedema of the Breast
Recognition, Treatment and Management of Primary Lymphoedema.

http://som.flinders.edu.au/FUSA/Surgery/staff/Piller.htm

Some of these handbooks / books may be available from the Cancer Society or the lymphoedema support groups.

**Internet**

There are thousands of sites with information on lymphoedema. Some useful sites include:

American Society of Lymphology [http://www.lymphology.com](http://www.lymphology.com)


National Lymphoedema Network (California) [http://www.lymphnet.org/](http://www.lymphnet.org/)

LYMPHOEDEMA THERAPISTS IN NEW ZEALAND – 2009 - FeB
(Please note this list covers people who have had specialised training in lymphoedema management that we are aware of). Training abbrev. BL=Brenda Lee CS = Casley-Smith F = Foeldi Clinic MM = Michael Mason, MOC=Maree O’Connor, pp = Private practice V = Vodder trained. Disciplines RN = Registered Nurse MT = Massage Therapist NT = Natural Therapist PT = Physiotherapist RT = trained Radiation Therapist

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