What is lymphedema (the basics)

Lymphedema is a build-up of lymph fluid, usually in an arm or leg. Your lymphatic system is part of your immune system. Lymph fluid keeps our tissues free of infection. The fluid is filtered through lymph nodes (glands) on its way to the bloodstream. When return flow of the lymph fluid is impaired, excess lymph accumulates, usually in an arm or leg, causing lymphedema. The goal is to reduce swelling and to help make your arm or leg function normally.

The lymphatic system

Lymphedema in cancer patients can be caused by the cancer affecting the lymph nodes or lymph vessels, or it can be caused by treatment. Surgery to remove lymph nodes (called lymph node dissection) or treatment with radiotherapy to the lymph nodes can impair the return flow of lymph fluid, leading to lymphedema.

Who gets it?

Lymphedema usually occurs in an arm or leg. It can develop after cancer treatment with surgery or radiotherapy. Most people with lymphedema had breast cancer treatment, because breast cancer is relatively common. But other cancer survivors, such as survivors from cervix cancer, melanoma or vulva cancer can also get lymphedema if their lymph nodes have been treated or removed.

We know more about lymphedema after breast cancer treatment because it is more common. Most women with breast cancer do not get lymphedema. Estimations of the risk of lymphedema after breast cancer treatment vary widely. This is partly because different researchers used different definitions for lymphedema.

One big study led by B.C. researchers found the chance of lymphedema to be 4 - 8% after breast cancer treatment. Another larger review quoted a 15% chance of lymphedema overall when other cancers are looked at.

Lymphedema is more likely if surgical removal of lymph nodes and lymph node radiation have both been used to treat the cancer.

Lymphedema is known to be more common in overweight individuals, and can develop after repeated infections of the affected limb.

If lymphedema develops, it is likely to be permanent. So it is important to keep lymphedema well controlled at an early stage.

Can I help to prevent it?

Doctors are aware of the risk of lymphedema. During a biopsy, surgeons usually try to use sentinel node biopsy, which is a more limited surgery than standard lymph node dissection. This has significantly reduced the numbers of cancer treatment related lymphedema.

Some risk factors for lymphedema can be managed. If you are concerned about lymphedema, there are things you can do to help:

- Maintain a healthy body weight
- Avoid injury to the affected limb (arm or leg)
- Watch closely for infections and report them to your healthcare provider
- Regular, moderate exercise is also helpful. Lymphedema is not a reason for not participating in exercises. Even gentle progressive weight lifting has been shown to be safe when appropriate compression sleeves are worn.
Signs, Symptoms and Diagnosis

How do I know if I have lymphedema?

- Swelling can result from other conditions. Your doctor will want to rule out other causes.
- You may be developing lymphedema if you notice that your hand or foot is puffy or your arm or leg feels heavy.
- Your sleeve, wristwatch, rings or socks may leave deep impressions in your skin. As the lymphedema sets in, you may have pain in your arm as the backed-up fluid stretches the arm tissues and nerves. You may also experience pain in your upper back and shoulder because of the extra arm weight that these joints have to support. Report these symptoms to your doctor.
- If your surgery was in the lower body, swelling may show in your leg or foot. Report all your symptoms to your doctor.

Your doctor will look for increased swelling in your hand, arm or leg and will measure and compare with a measuring tape.

Stages

Stages of lymphedema are not like cancer stages. The stage just describes how much lymphedema there is, and helps the healthcare team decide on the best treatment options.

There are four stages of lymphedema:

- Stage 0 or Latent – Subtle changes in the tissue and a sensation of heaviness, but no measurable swelling
- Stage 1 or Mild – First visible signs of swelling. “Pitting” or tissues indent with pressure but return to normal with reduction of pressure
- Stage 2 or Moderate – Tissues harden, pitting may not be possible
- Stage 3 or Advanced – Tissues hard, pitting not possible, skin dry and may be seeping with lymph fluid

Treatment

Treatment is best when physicians, physiotherapists, nurses, massage therapists, and psychosocial counsellors work together.

Once lymphedema develops, lifelong management is important. Treatment can control but does not cure the lymphedema.

Early lymphedema can be treated with a compression garment alone.

- A compression garment consists of sleeves, stockings or gauntlets (which are like gloves). These garments require measurements by a certified fitter in a medical appliance shop or a pharmacy that specializes in such garments. A list of these shops is available at the B.C. Lymphedema Association website: http://www.bclymph.org/

- Your family doctor, oncologist or nurse practitioner can write a prescription for the garment. You can bring the prescription to the fitter.

- If the prescription specifies that it is cancer treatment related, Pharmacare (MSP) covers part of the cost of the garment after a specific deductible is reached.

- The garment will need to be replaced every 6 – 12 months.

More advanced lymphedema needs to be treated with a combination of compression therapy, compression garment, and/or pneumatic compression. These complex treatments are best coordinated and initiated by a Certified Lymphedema Therapist.

- Several massage therapy schools can certify a lymphedema therapist. In B.C. most of the therapists are certified by the Vodder School in Victoria. These therapists can have a physiotherapy, nursing or massage therapy background. A list of the certified therapists can be obtained from the Vodder School (https://vodderschool.com) or the B.C. Lymphedema Association website: http://www.bclymph.org/

- Compression therapy uses a combination of massage, manual lymphatic drainage and compression bandaging to reduce the swelling. This is sometimes called Complex Decongestive Therapy (CPD). It often involves a series of sessions costing $70 – 150 each.

- If you qualify for “premium assistance” with MSP, your costs will be covered. Unfortunately the expenses are not covered by the standard provincial pharmacare MSP.

- Lymphedema patients who cannot afford private massage therapists can possibly be referred by their physician or nurse practitioner to hospital-based physiotherapy departments.

- Another treatment option to reduce swelling is pneumatic pumps which use an inflatable sleeve. The sleeve has many sections to provide serial compressions to the affected limbs. Treatment sessions can be long (1 – 2 hours each). The pumps are expensive and tend to be equipped in the physiotherapy departments of regional hospitals only.

- The compression therapy is then followed by a maintenance phase with compression garments.
When should I not have lymphedema treatment?
If you have an infection or a blood clot in your affected limb you should not have lymphedema treatment, especially compression and massage (MLD and CDP) therapy.

Are there other therapies for lymphedema?
The following therapies may or may not work. They need further study before they can be recommended. These therapies include: laser; electrical muscle stimulation; cryotherapy; transcutaneous electrical nerve stimulation (TENS); microwave; thermal therapy.

What does not work?
Therapies that should not be used are:
- Diuretics do not work. These are pills to reduce water retention.
- Benzopyrones. These can poison the liver.
- Therapeutic ultrasound. This can cause cancer growth in mice. Don't confuse therapeutic ultrasound with the very safe diagnostic ultrasound that you may have had to diagnose a breast lump.

Follow-up after Treatment
Gentle exercise helps to control lymphedema by stimulating lymphatic drainage. These exercises include most activities of daily living, swimming, biking, and walking.

In the past, vigorous repetitive exercise against resistance was discouraged by some healthcare professionals. Examples of this type of exercise include rowing, cross-country skiing, playing tennis and lifting weights.

Newer studies of the effects of exercise on lymphedema seem to show no harm. Over one hundred B.C. women with breast cancer have become dragon boat racers. They have not been found to develop more lymphedema.

Gentle progressive weight lifting has also been shown to be safe when a compression sleeve is worn during the exercise.

Discuss your planned exercise program with your doctor, physiotherapist or healthcare team.

Try to maintain an ideal body weight. Obesity is a risk factor for developing lymphedema and makes established lymphedema harder to control.

Keep the limb at risk clean, and use moisturizer to keep the skin from drying out.

Health professionals used to discourage blood taking, blood pressure measurements and injections in the arm on the side of breast surgery. A study was published in 2016 about women who have had these procedures in the arm on the breast surgery side. The researchers studied a large number of breast cancer survivors and they showed no increase in risk of lymphedema. These were women who had not been diagnosed with lymphedema. Now we know that it is probably safe to have the occasional blood pressure measurement and injection in that arm if no swelling has been noticed.

The same study also did not find any higher risk of lymphedema in women who travel by airplane. There have been some reports of arm swelling developing after long flights. However, if you do not find any new arm swelling after an air trip, no special precautions are needed on flights. If you already have swelling before the trip, your fitted arm sleeve should be worn during the flight.

Watch very closely for infections in your arm. An arm or leg with lymphedema is more prone to infections. These can show up as a region of progressive redness, warmth and pain.

- Report any infection to your doctor
- Infections in the arm should be treated promptly with antibiotics
- If infections recur a few times in the arm, you may benefit from some antibiotics taken for a week per month, or your doctor can give you a prescription to start yourself on antibiotics at the earliest sign of infection. Consult your doctor.

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