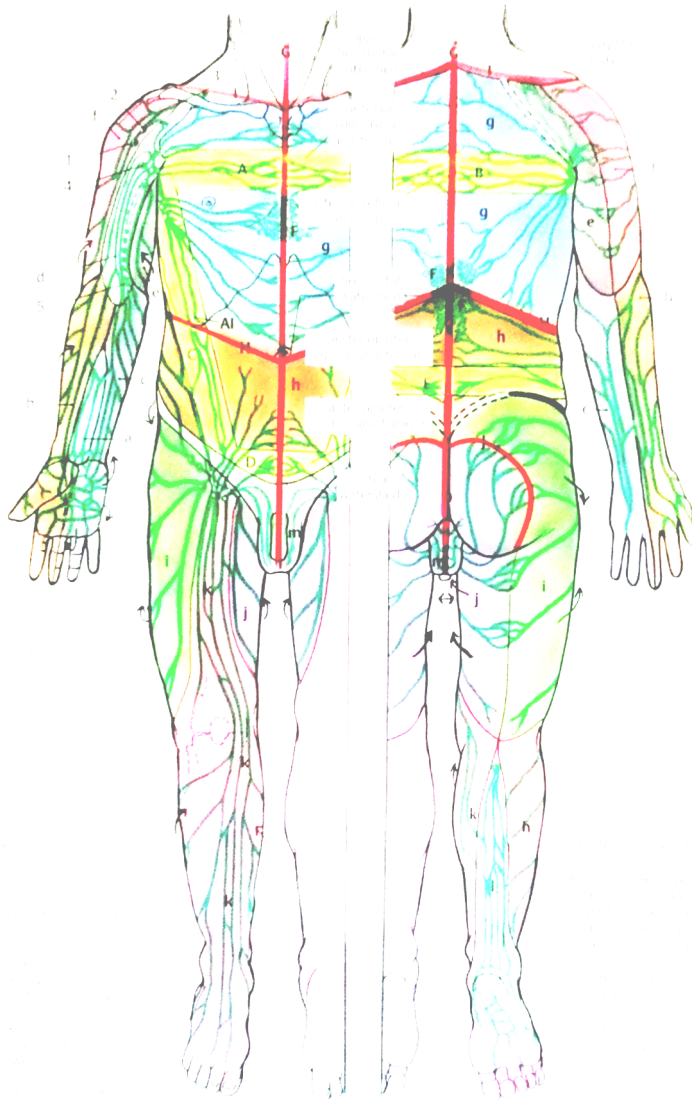


Lymphedema

What every cancer patient at risk should know.

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WHAT IS LYMPHEDEMA?

Lymphedema is defined as an abnormal accumulation of tissue proteins with edema and chronic inflammation, caused by deficiency, damage or blockage of lymphatic vessels and/or nodes.

If this sounds a bit confusing, the [Canadian Lymphedema Framework](#) (CLF) has done its best to clarify:

“Lymphedema is a lifelong condition caused by a buildup of lymph fluid. This happens when the lymphatic system is either faulty or damaged and cannot function as normal. It leads to chronic (long-lasting) swelling in the tissues where the lymph flow is blocked. Lymphedema most commonly presents in a limb (arm/hand or leg/foot), but it can also be present in the breast, trunk, genitals, or head and neck.”

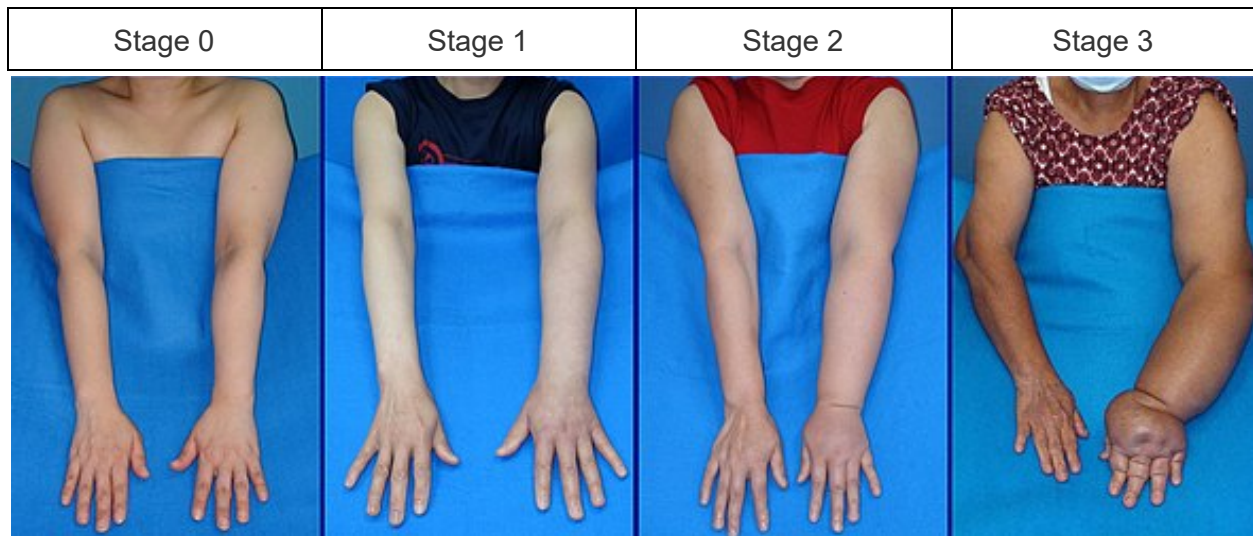
Primary lymphedema is a genetic condition that a person is born with. In regards to cancer and cancer treatments, lymphedema is considered to be secondary and can be caused by surgery that removes lymph nodes, radiation therapy to lymph nodes, cancer that spreads to the lymph nodes, an infection or inflammation that damages lymph vessels, and/or injury to the lymph nodes. The [Canadian Cancer Society](#) has more to read on the topic as does the [CLF](#).

Common symptoms include a feeling of heaviness, tightness, fullness or heat in the affected area. Clothing, shoes or rings/watches may begin to feel tighter, but not due to weight gain. There can also be associated aches, shooting pain, or pins and needles in the affected area.

What might be observable is a swelling that can be sudden, gradual or occasional. Most often the swelling is in an arm or leg, but it can also be in the chest, trunk of the body, head or neck. Skin may begin to feel tight or stretched, and sometimes its texture feels thicker.

There are four stages of lymphedema that describe its progress from early to advanced. The signs of lymphedema and treatment needed are different at each stage. When you are diagnosed with lymphedema, a Certified Lymphedema Therapist (CLT) will assess your stage. In order to assess accurately, a CLT will consider the degree of swelling, the health of the underlying tissue, and whether you have had infections such as cellulitis, inflammation, or other complications.

Knowing the stage helps the therapist develop the best treatment plan for you and determine a likely prognosis. Early intervention is key. The best outcomes are achieved when lymphedema is caught and treated early



Stage 0: Latent/Early

There are subtle changes in the tissue, skin and how an affected limb feels, but no visible sign of swelling. This stage may continue for months or years before visible swelling occurs.

Stage 1: Mild (swelling can be reversed)

The first visible signs of swelling show at this stage. The swelling is soft and may indent with thumb pressure (called pitting). When the affected arm or leg is raised, the swelling tends to reduce. The swelling often comes on by the evening but has gone by morning.

Stage 2: Moderate (swelling cannot be reversed)

Raising the affected limb no longer reduces tissue swelling at this stage. Pitting may still occur, but more pressure may be required to show an indent. In later stage 2, pitting may not be possible due to a buildup of fatty tissue or hardening of the tissue (fibrosis).

Stage 3: Advanced

The swelling is extreme, the skin has hardened (fibrotic) and pitting is no longer possible. The skin may also be dry and thicker with warty growths and leakage of lymph fluid (called lymphorrhea).

[Canadian Lymphedema Framework](#)

Common concerns of lymphedema:

As though hearing the word cancer wasn't stressful enough, learning that you may be at risk of a lifelong condition as a result of the lifesaving treatments has the potential to put your adrenals into overdrive. You wouldn't be alone if you were left feeling overwhelmed and confused with more questions than answers. The realm of the unknown has more power to scare us than any other, it seems. Understanding the reality of the risks and prevalence is one of the first steps along the lymphedema pathway, second only to how it will actually affect your quality of life.

“Lymphoedema can substantially affect the daily quality of life of patients, as, in addition to aesthetic concerns, it can cause discomfort and affect the ability to carry out daily tasks.

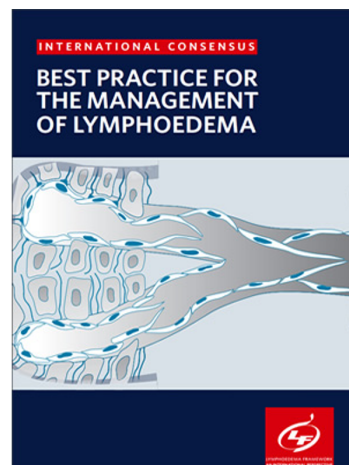
Although estimates of lymphoedema prevalence following cancer treatment vary widely depending upon the diagnostic criteria used and the duration of follow-up, lifelong lymphoedema affects approximately one in seven individuals treated for cancer.” (1)

Addressing those concerns:

Living with lymphedema isn't without its unique set of challenges, but despite our concerns, there is hope. With the proper supports in place including medical health care teams, allied health care teams, community resources, and family and friends, a person can learn to live with this condition, keep calm and carry on. Quality of life does not have to diminish, and in fact having this condition may contribute to new fun activities and friendships you might not otherwise have been exposed to.

There are international standards already established in regards to the treatment and maintenance of lymphedema. The Best Practices, along with other documents, can be found and downloaded on the [International Lymphedema Framework's \(ILF\) website](#).

The best treatment for lymphedema is CDT (Combined/Complete Decongestive Therapy). It includes an education on lymphedema to empower you with knowledge; compression therapy to reduce and contain swelling; lymphatic drainage (a special type of gentle massage) to improve lymph flow, direct fluids to other drainage pathways, and unblock or soften hard tissues; skin care education to avoid infection; and exercises to promote lymphatic function and flow.





During the intensive phase of treatment, the goal is to reduce swelling with compression bandaging, lymphatic drainage, good skin care and exercise. Treatments are typically once a day for 3-5 weeks, depending on the degree of swelling. Sometimes treatments take longer, and sometimes they resolve quicker. Modifications are often made to accommodate the individual's needs and situation. Treatments are based on individual presentation and progress.

Once stable, the goal of the maintenance phase is to keep your condition stable through use of compression garments, ongoing skin care, regular exercise and self-massage for lymphatic drainage. Ultimately, we (your therapists) consider the treatment a success when you are living life to the fullest, comfortable with managing and maintaining the condition, and are no longer reliant upon us (but are aware you have our total support and are welcome back at any time).



Having control over your health is priceless. The following can be found through the [National Lymphedema Network \(NLN\)](#) and is based on an international consensus of things a person can do in order to feel more in control and reduce one's risk:

Ways to reduce risk with lymphedema:

1. Avoid inactivity. Muscle contraction improves lymphatic function and can be done quickly and easily without any equipment. Try to move each joint in the affected limb in all directions 10 times each hour.
2. Extreme temperatures hot and cold. Prolonged exposure to heat (>15 minutes) can cause increased swelling in the limb. Avoid hot tubs and saunas, as well as heating pads or ice packs on the affected limb.
3. Constricting the limb. Tight clothing, watches, bracelets, or even a heavy purse over the shoulder or arm can restrict lymphatic flow and cause increased swelling.

4. Trauma and injury. While not always avoidable, injury to a limb with lymphedema can cause lymphatic overload. Wear gloves when gardening or using tools, do not cut cuticles, and if a cut does occur wash immediately with soap and water and monitor for any signs of infection.

HOW TO CHOOSE A THERAPIST

Whether you are diagnosed with lymphedema, suspect it, or are at risk, we recommend doing your research to find the right fit. The right therapist is waiting for you, waiting to treat you as a whole person, with a support team of their own whose collective experience and education is at the ready. To find a certified lymphedema therapist in your area, please first check with the [BC Lymphedema Association](#) (BCLA).

Certified lymphedema therapists are experts in assessing and treating lymphedema. They must first be part of a regulated health care profession including nursing, physiotherapy, occupational therapy, and massage therapy. In order to certify, therapists must train for a minimum of 135 hours with a recognized school. The [Lymphology Association of North America](#) (LANA) is the leading authority on standards of training and an [exhaustive list of qualified schools](#) can be found on their website.

With this knowledge in hand, do not hesitate to interview prospective therapists. Frequently asked questions could include:

- What is your training?
- What is your experience?
- How do you treat lymphedema or what are your protocols?
- Are you comfortable bandaging or using compression therapy?
- What can be done if I'm Stage 0?
- What if I want deep tissue massage or scar tissue management (at any stage)?

A good therapist will want to ask you questions too. Frequently asked questions could include:

- Do you have Congestive Heart Failure?
- Are your kidneys in good shape?
- Have you been assessed for blood clots through Doppler/Ultrasound?
- Are you currently being treated for cancer?
- Is there any chance you have an active infection?
- Have you been assessed and cleared for compression therapy through an ABI (Ankle/Brachial Index)

Your therapists will also want to know about any other pre-existing conditions or possible comorbidities as well as any medications (whether they be prescriptions, non-prescription, supplements, or vitamins).

As therapists, our ultimate goal is to get you to a place where you no longer require our services. However, you may request our ongoing support at your discretion. 😊 Helping you to navigate this confusing world and build the support services you need in order to live well with lymphedema is our passion.

References:

- (1) Rockson SG, Keeley V, Kilbreath S, Szuba A, Towers A. Cancer-associated secondary lymphoedema. *Nat Rev Dis Primers*. 2019 Mar 28;5(1):22. doi: 10.1038/s41572-019-0072-5. PMID: 30923312.

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British Columbia Lymphedema Association (<https://www.bclymph.org/>)

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Lymphedema Association of North America (<https://www.clt-lana.org/>)

National Lymphedema Network (<https://lymphnet.org/>)