



Lymphedema:

A possible late effect of some cancer treatments

UHN

For cancer patients who may be at risk of getting lymphedema

Did you know?

Lymphedema (lim-fa-deem-a) is the swelling of a body part caused by a build up of lymph fluid. It is possible to develop it as a result of cancer treatment following surgery and radiation therapy.

You may be at risk for lymphedema if you have had:

- surgery that involved removal of lymph nodes
- radiation to an area of your body where lymph nodes were removed

It is common for lymph nodes to be removed or radiated for patients with:

- breast cancer
- gynecologic cancer
- head and neck cancer
- melanoma
- genitourinary cancer
- gastrointestinal cancer (anal)

This pamphlet will help you know if you are at risk of getting lymphedema.

If you are at risk, this pamphlet will help you:

- know what strategies may lower your risk of getting lymphedema
- know the signs to help you recognize lymphedema early and reduce the impact it has on your life
- find help if you have questions, or are concerned that you may have lymphedema

Please visit the UHN Patient Education website for more health information: www.uhnpatienteducation.ca

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Author: Aleksandra Chafranskaia PT, MHSc Sylvia Crowhurst RMT/CDT Linda Durkee RN, BScN, Med Pamela Hammond RMT, MSc Stephanie Phan OTReg(Ont)

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Lymphedema – Knowing your Risk

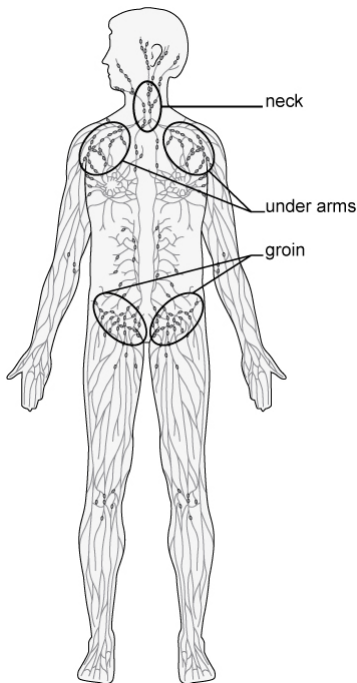
What is lymphedema?

Lymphedema is a swelling of a body part caused by a build up of fluid in the tissues due to damage to your lymphatic system. Lymphedema can affect areas of your body that are not being properly drained because lymphatic nodes are missing or damaged. Your lymphatic system can be damaged if you were treated for cancer by having:

- surgery that involved removal of lymph nodes
- radiation to an area of your body where lymph nodes were removed

The picture below shows the different areas in your body that have lymph nodes.

The Lymphatic System



Circles show where clusters (groups) of lymph nodes are in your body that are commonly removed during cancer treatment

NOTE: In this pamphlet, the area that is not properly drained due to a damaged lymphatic system is referred to as “the affected area of the body”. This is usually the area of your body that was treated for cancer.

How do I know if I am at risk of getting lymphedema?

Your risk of getting lymphedema depends on:

- The number of lymph nodes you had removed and the amount of the soft tissue removed during the surgery
- Whether you also had radiation involving your lymph nodes and the amount of radiation you have received to the area

Other health conditions may make your risk higher. Speak to your doctor for more information.

Lowering your Risk – What You Can Do

Why do I need to know if I am at risk of getting lymphedema?

Lymphedema can cause a number of concerns, including:

- a higher risk for infection on the affected part of your body
- difficulty moving the affected part of your body (like your arm, leg, neck or jaw)
- trouble finding clothing that fits properly over the affected part of your body
- problems with self-image

Please note that there is still more about lymphedema that needs to be researched and tested.

What can I do to lower my risk of getting lymphedema?

Although there are no proven strategies to prevent lymphedema, there are several things you can do that may lower your chance of getting it.

1. Take care of your skin.

The most important thing you can do is to avoid breaks or cuts in your skin that could lead to an infection (like cuts, pinpricks, animal scratches, burns, insect bites and stings), especially in the affected part of your body. See instructions on the next page for what to do if you do get a cut or scratch.

- Always keep your skin in the affected part of your body clean and dry
- Use lotions and creams often to keep your skin, cuticles and nails moisturized
- Avoid bug bites and sunburn by using insect repellent and sunscreen
- Take care of your nails on the affected body part
 - If you get a manicure or pedicure, make sure that all equipment and tools (including the washing basin) are sterilized. Ask your manicurist not to cut your cuticles.
 - When cutting your nails, be careful not to cut or injure yourself. Try filing your nails instead
 - Clip toenails straight across instead of rounding as this helps to prevent ingrown toenails
 - Do not cut your cuticles

- Take extra care when shaving or removing body hair on the affected part of your body. Check skin closely for irritation and cuts after hair removal.
- Wear clothing that protects the affected area of your body when doing any activity that may cause an injury or make your skin sensitive.
 - For example, wear gloves when baking, washing dishes, gardening; wear long sleeved shirts or long pants when gardening or using tools etc.
- If possible, offer the unaffected parts of your body for injections and/or blood collection.

What to do if you get cuts, scrapes, torn cuticles, hang nails, insect bites, or burns on the affected area of your body:

1. Care for the injury

- Wash the area with soap and warm water
- Apply antibiotic ointment or cream (like Polysporin™ or a similar drug store brand)
- Cover with a band-aid

OR

- Wash and apply a liquid bandage such as Nexcare™ Skin and Crack Care or New Skin™ liquid bandage (antibiotic ointment or cream is not needed when using a liquid band aide)

2. Look for early signs of infection. The area may be infected if it is:

- red
- swollen
- getting larger
- warm or hot to the touch
- tender or painful

IMPORTANT: If you think you may have any of these symptoms on the affected part of your body, call your doctor right away because it may be an infection. If your doctor is not available go to a walk in clinic, urgent care centre or Emergency. Be sure to tell the doctor that you have been treated for cancer and explain your concerns about lymphedema.

2. Avoid constricting (squeezing) the affected area of your body.

Keep the circulation flowing in the affected part of your body to avoid any fluid build up. Below are some examples of how you can avoid constricting areas of your body that may be affected.

If your affected area is in the head and neck

Clothing

- Avoid tight collars, ties and jewelry

At the doctor and dentist's office

- Tell your health care provider that you are at risk for lymphedema because of your cancer treatment.

If your affected area is in the upper body

Clothing

- Do not wear tight jewelry or clothing (such as blouses that have tight cuffs) on your affected body part
- For women: do not wear bras that are too tight or have straps that dig in to your shoulders if your arm is affected. To avoid this, make sure that you are properly fitted for your bra. If you have bras with underwire, save them for special occasions.

At the doctor's office

- If possible, offer your unaffected arm to have your blood pressure taken, offer the unaffected parts of your body to receive any kind of injection or needle
- Tell your health care provider that you are at risk for lymphedema because of your cancer treatment.

Everyday

- Avoid using arm or shoulder straps on the affected side when you are carrying a purse, bag, or briefcase for prolonged periods of time.

If your affected area is in the lower body

Clothing

- Avoid socks, pants, underwear, and stockings that have tight elastic bands if your legs are affected.
- Wear well-fitted, closed toe shoes instead of sandals and slippers. Wear soft protective socks. It is best not to go barefoot.
- Break in new shoes gradually to avoid blisters.

At the doctor's office

- Offer your arms or unaffected leg and buttock to receive any kind of injection or needle instead of your affected leg or buttock.
- Tell your health care provider that you are at risk for lymphedema because of your cancer treatment.

Everyday

- Do not cross your legs for a long time while sitting.

3. Avoid very hot or very cold temperatures.

Very hot and very cold temperatures can bring more fluid build-up to the affected part of your body. For example:

- Do not use hot tubs or saunas unless approved by your healthcare team.
- Do not use hot or cold packs on the affected part of your body.
- In very cold weather keep the affected area warm by wearing a scarf, hat, coat and gloves, and/or long underwear and keeping your feet warm and dry.

4. Stay active.

Regular exercise helps drain fluid from your arms and legs. Most people who are at risk of lymphedema can safely exercise if they follow these guidelines:

- Pace yourself during activity. Stop and rest as needed, drink plenty of water.
- Start slowly and increase the time and intensity of your exercise one step at a time. Don't expect that you will return to your pretreatment exercise level right away.
 - Example: Add 2 minutes to each walking session every 1 to 2 weeks. Do this until you reach 3 to 5 hours of total walking time each week, then slowly increase your pace.
- When doing resistance training make sure you do the exercises correctly and increase weight and repetitions appropriately.
- Look for any change in size, shape, texture, soreness, heaviness or firmness in the affected part of your body during and after activity. If the affected part of your body starts to hurt during exercise, stop what you are doing. Try to raise the leg or arm above your heart level for 10 minutes to drain extra lymph fluid away from that part of your body.

Remember: Always check with your doctor before starting any new kind of exercise.

5. Keep a healthy weight

Being overweight may increase your risk of getting lymphedema after cancer treatment. A healthy diet and physical activity may help keep your weight under control. Talk to your family doctor or a dietitian about a plan for healthy eating and physical activity.

6. Travel

When you are traveling by air, remember to move about the plane and move the affected arm or leg regularly during the flight. Many people at risk for lymphedema travel by air and do not develop lymphedema. Some people may notice swelling. This swelling may be temporary. If you experience this, talk with your doctor about the need to wear properly fitted compression garments to prevent it in the future.

Keep in mind that benefits of wearing compression garments to prevent lymphedema have not been fully researched.

The Warning Signs for Lymphedema

Knowing the signs and symptoms of lymphedema can help you catch it early. Early treatment is your best defense in managing lymphedema.

You may develop early warning signs in the part of your body where you had lymph nodes treated and/or removed. Lymphedema can happen on one or both sides of your body in the following general areas:

- **Head & Neck:** face and/or neck area
- **Upper Body:** finger(s), hand(s), arm(s), armpit(s), shoulder(s), breast(s), chest, or back
- **Lower Body:** toe(s), foot/feet, leg(s), genitals or lower abdomen (belly area)

Watch for the important warning signs listed below to help you notice symptoms of lymphedema early:

- Swelling or increase in size
- A feeling of tightness, stiffness or heaviness
- Aching or pain
- Difficulty using the affected area of your body for daily activities and exercise
- For people who have had lymph nodes treated and/or removed in the head and neck area, swelling inside the mouth that makes it difficult to speak or say words properly

If you experience any of these warning signs in the affected part of your body, tell your doctor right away and watch for any swelling that may follow.

Remember that lymphedema can happen at any time, even years later.

How to check for swelling

You can check for swelling by looking in the mirror and comparing the side of your body where you had lymph nodes removed or treated with the side that did not get treated. Swelling can happen for many reasons. Always tell your doctor if you notice any swelling just in case it is lymphedema. Only your doctor can find out why you have swelling and if it may be lymphedema.

If you have Lymphedema

What should I do if I think I have lymphedema?

There can be many causes for swelling, so it is important to be seen by your oncologist or family doctor. For a listing of trained therapists who can treat lymphedema, contact the Lymphedema Association of Ontario (see below for contact information).

How is lymphedema managed?

Lymphedema care can help lower the swelling, stop it from getting worse and lower the chance of problems related to lymphedema in the future. Lymphedema care may include skin care, a special form of massage, specific exercises, bandaging, and fitting for a compression sleeve or stocking. These treatments may be prescribed by one of your oncology doctors and are given and taught by a specially trained therapist.

For more information

Lymphedema Awareness class at Princess Margaret

Learn more about lymphedema and have your questions answered. For class times and locations, check the Princess Margaret Patient & Survivorship Education Calendar by:

- Picking up a copy at the Patient & Family Library (main floor)
- Visiting www.theprincessmargaret.ca/en/calendar/pages/default.aspx?et=pf



Attend a class in your language. You can book a medical interpreter for this class at no cost to you. To book, please call 416-581-8604. Five weekdays advance notice is required.

National Lymphedema Network

www.lymphnet.org

Check the National Lymphedema Network website for their position on risk reduction and air travel.

Lymphedema Association of Ontario

www.lymphontario.ca

Phone: 416-410-2250 or 1-877-723-0033

Contact the Lymphedema Association of Ontario for resources and information.

Remember, with help from your health care team, lymphedema can be managed!

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