



Frequently Asked Questions Regarding Lymphedema

Find the answers at StepUp-SpeakOut.Org

How can I reduce my risk of developing lymphedema?

How is lymphedema diagnosed?

Where can I find appropriate lymphedema treatment?

How is lymphedema treated?

What is Manual Lymph Drainage (massage)?

Is it possible to develop lymphedema in my chest or breast?

Why do some people with lymphedema wrap their arm with bandages?

What should I know about compression garments for my arms, hands, breast or chest?

What is cording (axillary web syndrome) and how is it treated?

How does deep breathing help?

Does exercise help?

What should my personal trainer, yoga, and/or Pilates instructors know about breast cancer related lymphedema?

How should I care for my skin and nails?

What about manicures?

What other treatment options are available?

What is Kinesio taping, and how does it work?

How can I manage blood pressure, injections, IV's or blood tests?

What should I know about diet and nutrition?

How can I protect myself from lymphedema emergencies?

Am I at risk for radiation-induced brachial plexopathy?

What if I need surgery on my arm or chest?

What precautions should I take when travelling by air?

What about wearing compression garments while flying?

How should I handle mammograms?

What will my health insurance/Medicare cover, and how do I appeal for help?

Can I qualify for disability?

So, how am I going to cope with all this?

These questions and more are all answered at <http://www.stepup-speakout.org>. Please visit and educate yourself on lymphedema.

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STEPUP-SPEAKOUT.ORG

Together we can make the difference in lymphedema

Some general information for you on lymphedema: What it is and how to take appropriate risk reductions.

Please visit our website below for comprehensive information on lymphedema, risk reduction, treatments, garments and everything you need to educate and protect yourself.



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OUR MISSION: As women with post-breast cancer lymphedema, we have struggled to uncover the information we should have been given about this condition to find effective treatment and to keep lymphedema in control. To make sure that women in similar situations will not need to struggle for the needed information, we have established “StepUp-SpeakOut.Org” to provide web-based, evidence-based information on lymphedema and how to reduce the risk of and manage lymphedema to live a full life. Please visit StepUp-SpeakOut.Org for more information. Here are some simple facts to help you understand lymphedema.

WHAT IS LYMPHEDEMA?

LYMPHEDEMA (LIMF-eh-DEE-ma) following breast cancer treatment is an abnormal accumulation of lymph fluid in the affected arm, hand, fingers, wrist, elbow, shoulder, neck, breast, chest area, or any combination of these areas. The word “affected” means the same body side on which you received breast surgery or radiation. The excess fluid build-up leads to persistent swelling and other distressing symptoms, including pain, heaviness, firmness, tightness, and numbness.

Lymphedema usually develops slowly over time but it can also develop soon after surgery or radiation or even years after breast cancer treatment. Not everyone who has been treated for breast cancer will develop lymphedema, but many will. During surgery for breast cancer, the doctor usually removes part or the whole breast and at least one of the lymph nodes and some connected lymph vessels from the underarm or chest area to see if the cancer has spread. This changes the flow of lymph fluid in your affected body side and leads to the excess fluid build-up. Radiation can also affect the flow of lymph fluid in your affected body side in a similar way.

Please call your doctor if you notice the following symptoms as they may indicate an early onset of lymphedema:

- ✦ Your affected arm, hand, or breast feels full or heavy.
- ✦ Skin in your affected arm or body side feels tight or firm.
- ✦ Swelling in the affected body side (including breast, hand, fingers, elbow, shoulder, neck, breast, or chest area).
- ✦ Less movement or flexibility in your affected hand, fingers, wrist or arm.

Reducing Your Risk of Lymphedema

A recently published study showed that accurate patient education is a critical dimension of lymphedema risk-reduction. Knowledge of lymphedema and its risk reductions is essential to all breast cancer patients, and makes a difference in their long-term quality of life. In this study only fifty-seven percent of the participants reported that they received lymphedema information.

“Cancer-Related Lymphedema: Information, Symptoms, and Risk-Reduction Behaviors,” Authors: Fu, Mei R.; Axelrod, Deborah; Haber, Judith, Source: Journal of Nursing Scholarship, Volume 40, Number 4, December 2008 , pp. 341-348(8)

If you’ve been treated for breast cancer, you are at risk for lymphedema of the hand, arm, back, and chest or breast on the affected side. If your surgery was bilateral, then both sides are at risk. The risk remains for the rest of your life. The good news is that you can reduce that risk by understanding a few important principles and the safe practices that follow from them.

Promote and Protect.

Two words summarize all the risk reduction practices and make them easy to remember: “Promote” and “Protect.” That means you will promote the lymph flow in your affected arm/chest or other affected area, and protect the area from injury or infection. This can be done in a few simple ways:

Drink plenty of fluids -- staying well hydrated helps dilute lymph fluid and keep it moving freely;

Elevate the at risk arm or hand as much as possible during the day and on pillows at night; support the arm well so that it doesn’t tire;

Several times a day (or whenever you think of it) pause and do some deep breathing -- this helps stimulate the largest lymph vessels in your body and promotes lymph flow; Repeat the breathing exercise 10 to 20 times;

Several times a day (or whenever you think of it) pause and raise your hands over your head as high as is comfortable for you, and “pump” your fists open and closed 10 to 20 times. This can be done with or without a “stress ball.”

Prevent infection

Keep the skin clean (Please see the article written by Dr. Mei Fu and published in the Wounds International Preventing skin breakdown in lymphoedema Practice development Wounds International, Vol 1; Issue 4 regarding skin care.)

Keep your arm pits and the area under your breasts dry to avoid fungal infection

Keep your skin intact

Moisturize your skin daily to prevent microscopic cracks

Keep nails clean and avoid cutting cuticles

Use sunscreen or protective clothing to prevent sunburn

Use an insect repellent on any exposed skin

Avoid razor nicks and burns--see Shaving Under Our Arms on the Stepup-SpeakOut website.

Wear gloves when handling household cleaners and other chemicals

Wear rubber gloves when washing dishes

Wear sturdy work gloves when gardening or using tools

Wear a thimble when sewing to avoid needle and pin pricks to your fingers.

Use extra caution to prevent burns

Avoid skin punctures from IV’s, injections, blood tests.

Discuss with your doctor the use of prophylactic oral antibiotics with any medical procedures that involve the affected parts of your body.

Created by patients for patients, StepUp-SpeakOut.Org is a comprehensive source of accurate and pragmatic information to help you understand and cope with lymphedema after breast cancer treatment.