



Lymphedema FAQS

WHAT IS LYMPHEDEMA?

Lymphedema is a chronic lymphatic disease that results in disfiguring swelling in one or more parts of the body. It can be hereditary (Primary Lymphedema) or it can occur after a surgical procedure, infection, radiation or other physical trauma (Secondary Lymphedema). In breast cancer, for example, it can appear in the arm on the same side as the cancer, after lymph nodes are removed from the armpit region for cancer staging. Primary Lymphedema often occurs in the lower extremities. Lymph is the protein-rich body fluid that accumulates when the lymphatic system for fluid transport is damaged.

WHY IS THE LYMPHATIC SYSTEM IMPORTANT?

Fluid transport is one very important component, but many do not realize that the lymphatic system is part of the immune system. It fulfills the function of "immune trafficking," the process whereby infection-fighting cells can be mobilized to the tissues that require assistance. When the lymphatic system is compromised by surgery, trauma, or improper development, the affected part of the body is prone to recurrent infection because of the faulty surveillance mechanism.

WHY IS IT THAT I WASN'T WARNED ABOUT THE RISK OF LYMPHEDEMA PRIOR TO MY SURGERY?

Regrettably, many doctors are still very under-educated about the lymphatic system in general and, specifically, about the problem of lymphedema. Here at Stanford we're trying to rectify ignorance about lymphedema through specific educational initiative and I believe that nationally awareness is also increasing. Patients can also help their doctors to learn. Physicians must learn from their patients about their lymphedema experiences so that they will be better prepared to deal with their future patients.

AS A BREAST CANCER SURVIVOR, WHAT IS MY RISK OF GETTING LYMPHEDEMA?

Estimates vary and, fortunately, the risk has been progressively declining. In the beginning, breast cancer surgery carried a 50% risk of lymphedema development. Today, patients who have axillary lymph node dissection have a lifetime risk of 15-25%. For individuals whose surgery is limited to sentinel node techniques, without adjuvant radiation, the risk is about 6%.

HOW DOES SURGERY AFFECT MY RISK OF LYMPHEDEMA?

The risk is chiefly aligned with lymph node removal. Individuals that have just lumpectomy, or other surgical interventions, are at such low risk that it is impossible to estimate. Sentinel node techniques, alone, are used in about 40% of current breast cancer patients. The sentinel node technique is defined as the removal of no more than four lymph nodes, where the risk is about 6%. If you have more than four lymph nodes removed, the risk rises to 15% to 25%.

DOES RADIATION INCREASE THE RISK OF LYMPHEDEMA?

Yes, radiation can traumatize the lymphatic system equivalently to surgery, even if surgery is not done. However, just as all surgery is not alike, not all radiation therapy is the same. In general, radiation therapy confers risk that is roughly equivalent to axillary lymph node dissection and increases the risk associated with surgery if both treatments are performed.

IF I HAVE HAD LYMPH NODES REMOVED UNDER ONE ARM, DO I HAVE TO WORRY ABOUT THE LYMPH NODES IN OTHER AREAS OF MY BODY?

No. The lymphatic system is present throughout the body, but lymphedema is a regional disease that affects only the part of the body that is subjected to surgery or radiation.

DO I HAVE TO WORRY ABOUT THIS FOR MY WHOLE LIFE?

The proper term to use is "vigilance." Stated positively, the primary risk for lymphedema development is in the first year following surgery and radiation therapy, when 90% of the cases occur. By the end of 3 years, 95% of the cases will have appeared. If you don't have lymphedema after 3 years of vigilance, the risk remains, but it is quite small. If you take the proper precautions and use the proper surveillance, the risk can be maintained as small as possible.

WHAT ABOUT EXERCISE AFTER CANCER SURGERY?

While, in the long run, exercise is very beneficial, it is very important to give your body adequate time for healing and to not push the exercise early on. This is not to say that patients shouldn't be very active at mobilizing the shoulder, because women are also prone to "frozen shoulder" after a mastectomy. However, do not push the physical activity until the body is ready to do it. For the first three to four weeks, it is important to remain relatively inactive and, thereafter, to try to become progressively more active.

AND WHAT ABOUT EXERCISE DURING RADIATION THERAPY?

There are similar concerns. One can expect a certain amount of inflammation related to the radiation, and it would be important to avoid over-taxing the lymphatic system. Accordingly, it is reasonable to “take it easy” during radiation therapy.

SHOULD I BE USING MY ARM (OR LEG) FOR EVERYDAY ACTIVITIES?

Yes, absolutely. Bear in mind, however, that physical activity increases blood flow, which increases the formation of lymph in the arm or leg at risk. You don't want to push the lymphatic system “over the edge.” Once you recognize your threshold for activity, you can gently extend your limits over time, perhaps, in addition, by using a Class I compression garment during activity that is perceived to be physically stressful.

AFTER SURVIVING BREAST CANCER SURGERY AND CHEMOTHERAPY, I'VE DEVELOPED LYMPHEDEMA. I'M ANGRY THAT I HAVE TO GO THROUGH THE REST OF MY LIFE WITH SWELLING, WEARING A SLEEVE AND RESTRICTING MY ACTIVITIES. IS THERE ANYTHING YOU CAN SUGGEST TO HELP WITH THAT?

The anger and the frustration are very understandable and very common. It seems like a second punishment after enduring so much to get your life back. Unfortunately, at this time, with current treatment techniques, the incidence of lymphedema breast cancer survivors remains at 15–25. There are no simple answers to this question. It is important to strive to keep life as normal as possible in the face of the fixed demands related to the presence of lymphedema. Seeking support from your fellow patients is also often a wonderful way to collectively share the experience and help to mitigate the anger. The ability to talk about the problem is an important step toward acceptance.

PRIOR TO MY CANCER DIAGNOSIS, I LED A VERY ACTIVE LIFESTYLE. NOW I AM NERVOUS THAT MY FORMER ACTIVITIES COULD CAUSE LYMPHEDEMA TO EMERGE. WHAT DO YOU ADVISE?

My earnest advice is that once you are a cancer survivor, you must enjoy the gift of life. This means not placing boundaries on what your definition of being alive. It is true that there is a small, finite risk of lymphedema appearing for the first time in somebody at risk, or becoming worse in someone who already has it. However, with the appropriate precautions, those risks are quite small. It is very important, activity by activity, to weigh the risk-to-benefit ratio. There is some finite risk of lymphedema with activities like surfing rock climbing, to choose two random examples. But you have to weigh the importance to your life of those continuing experiences. With or without “risky” activities appropriate treatment for lymphedema is essential when the lymphedema appears. It is very important to faithfully use the garment that is provided to you, particularly during the activity poses theoretical risk. It is very important to maintain surveillance for changes in the limb-at-risk. Take precautions against infection when there are breaks in the skin and seek medical attention early if any changes are observed. When you go outside, put on a sun block, because sunburn can aggravate lymphedema. When you are working in the kitchen, be careful. When you're in the garden, be careful, and wear gloves if there is the possibility of skin trauma. But what you want to lift, lift. What you want to do, do. And where you want to go, go. Just be careful.

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