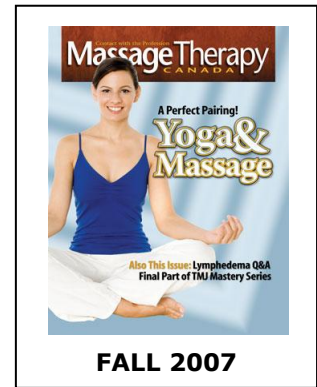


Lymphedema

10 Questions & Their Answers

Written by [John Mulligan, RMT/CLT](#)



As registered massage therapists, we spend more time with our clients than most primary health practitioners. As a result, we may be the first to recognize symptoms associated with more serious conditions.

Potentially, one of those conditions may be lymphedema. In my experience, clients suffering from lymphedema have urgent questions about their condition. Often, it is difficult for them to find answers to these questions. This article is intended to provide talking points when discussing lymphedema with your clients, so that you can have answers on hand for the basic questions and so you can refer them to other sources for more detailed information.

1. What is lymphedema?

Lymphedema is a failure of the lymph system to adequately drain the excess fluid from the skin tissues, resulting in swelling. It is a chronic, permanent condition for which there is no cure, although its effects can be minimized through treatment and management. The swelling most commonly occurs in an arm or a leg, although it can occur elsewhere in the body as well. It should not be confused with transient swelling, which occurs after surgery or trauma and normally clears up on its own.

2. Who gets lymphedema?

Anyone who has suffered damage to the lymphatic system is at risk for developing lymphedema. There are two kinds of lymphedema, primary and secondary. Primary Lymphedema has genetic origins, resulting in a malformed lymphatic system. Symptoms may appear at, or shortly after birth, later around the onset of puberty, or in adult life.

Secondary Lymphedema is the result of changes to the lymphatic system caused by anything other than genetic origin. Worldwide, the most common cause of secondary lymphedema is filariasis, a parasitic infestation that results in blocked lymphatics.

In developed countries, the leading cause of secondary lymphedema is cancer staging and treatment. Lymph nodes are removed to determine the extent of the cancer. With the lymph nodes gone, the normal lymphatic pathway is interrupted, and chronic swelling and lymphedema can be the result.

3. Why did I get lymphedema?

This is one of the most troubling aspects of lymphedema ... why me? Why does one patient with lymph node dissection develop lymphedema of the affected arm, while another does not? The answer often lies in the fact that there are variations in the lymphatic system from person to person. There can be variations in the number and calibre of lymph vessels and nodes, the number of active and latent connections between different parts of the lymph system (anastomoses) and the ability to develop or optimize collateral pathways for the lymph fluid to travel. These variations can be understood as genetic predispositions to lymphedema. Research into the causes of lymphedema is still under way, but it seems that radiation therapy in conjunction with surgery and/or chemotherapy can increase the risk of acquiring lymphedema. Also, time itself plays a part. An injured and insulted lymph system may carry on for years before its functional reserve capacity becomes exhausted. The previously healthy person then develops lymphedema.

4. Why wasn't I warned about the risk of lymphedema when I was preparing for surgery?

This is a question that every lymphedema therapist hears over and over again from clients with lymphedema. I feel that the answer lies in the primary focus area of the oncologist, which is to save the patient from cancer. Other considerations are often secondary.

Until recently, very little information on the treatment of lymphedema was available. Where lymphedema is concerned, the medical profession is in a transitional stage of incorporating and assimilating new information. As information about lymphedema and its treatment becomes more available and widespread, we can expect it to take its place in more medical schools' training programs. Sometimes patients are actually given information about lymphedema by their doctors, but they are unable to recall it later due to the shock of receiving a cancer diagnosis. This is a perfectly understandable reaction.

5. Is there anything I could have done to avoid getting lymphedema?

This question is somewhat controversial. Is lymphedema preventable? Thoughtful management of risk may or may not actually affect the onset of lymphedema. If you have had lymph nodes removed, and/or radiation therapy, you are at risk for the development of lymphedema. If you have no symptoms of lymphedema, should you alter your lifestyle to avoid a condition you may or may not develop? My advice is to use good sense; avoid traumatizing the affected limb. Avoid needle sticks, blood pressure cuffs, extreme temperatures or weighted repetitive motion activities on the affected side. Avoid straining your arm with heavy lifting. I recommend a course of manual lymph drainage therapy. Treatment is relaxing, painless and can help the lymphatic system recover through the reinforcement of connections (anastomoses) in the lymphatic system.

6. Does lymphedema have to be disfiguring?

If you have done any research into lymphedema at all, it is likely that you have seen photographs of people with elephantiasis, or Stage III lymphedema. This is the disfiguring stage of the disease. Not all lymphedemas progress to this stage. The progression of lymphedema is measured in stages. There is the latency stage, often called Stage 0, or the state of being at risk for lymphedema but having no symptoms.

Stage I can be said to have two parts, the pre-clinical and the clinical. Pre-clinical lymphedema has no visible signs, but subjective symptoms of limb heaviness and achiness are present. In clinical Stage I the onset of visible signs of lymphedema begin. There is occasional swelling, which seems to go away and then return.

In Stage II lymphedema, there is constant swelling, which does not subside overnight or with elevation. The accumulation of proteins gives the swollen limb a doughy consistency, and, if pressed with a finger or other object, will retain an impression, called "pitting."

Stage III lymphedema is also known as lymphostatic elephantiasis. This is a truly disfiguring condition. Technically, the swelling has progressed to such a degree that pitting is said to be impossible due to hardening of the tissues. This, however, is rare. Most advanced lymphedemas will present with some degree of pitting, however difficult to obtain. This staging system for lymphedema gives the impression that the progression is inexorable. It is not. The majority of cases of lymphedema never progress to the elephantiasis stage. Most of the time, the progression of lymphedema stops at Stage II, which is characterized by a swollen limb with pitting (pitting edema).

With treatment, lymphedema does not have to be a disfiguring condition. In today's Western world, lymphedema should be detected and treated while still in Stage I. The only cases where lymphedema might progress to Stage III are in places where education and treatment are completely unavailable, and even then not every case will progress to Stage III.

7. How is lymphedema treated?

Complex Decongestive Therapy (CDT) is the conservative treatment of choice for lymphedema. CDT consists of manual lymph drainage, compression therapy, appropriate exercise, breathing exercises and meticulous skin hygiene. Compression therapy consists of multi-layer specialty short-stretch bandaging and in the later stages of treatment and management, compression garments. This treatment and management strategy is largely dependent on a fully involved and motivated patient, since it involves a high degree of patient participation. Other treatment strategies do exist, but they are questionable and not supported by research. The use of sequential compression devices, consisting of a sleeve and a compression air pump was often recommended in the past, but is no longer considered a safe and effective treatment.

8. Is there surgery to treat lymphedema?

There are surgical procedures that have been used to address lymphedema. However, these procedures are currently considered to be of historical interest only. Surgery may cause further problems and is often ineffective.

9. Why can't I just ignore my lymphedema?

There are risks associated with ignoring lymphedema, including the risk that the lymphedema will worsen. Lymphedema begins as a mild or occasional problem. At this stage it is easy to ignore. However, it must be understood that lymphedema is a progressive disease. Left untreated, it will progress from mild and occasional to permanent and severe. Untreated lymphedema also frequently results in episodes of bacterial infection. Occurrences of staph (staphylococcus aureus) or strep (streptococci) infections are the most common. These episodes can be frequent or infrequent, mild or severe.

I have known lymphedema patients who required hospitalization every six weeks to receive intravenous antibiotic therapy. These infections not only weaken your health, but they can further damage the lymphatic system. They can also be life threatening and are the most important reason for not ignoring your lymphedema. The risk of infection is greatly reduced by skilled treatment and management of lymphedema.

There are other risks as well. Discomfort associated with lymphedema will probably increase over time. Range of motion in the affected limb will be reduced. The cosmetic appearance of the limb will degrade. Clothes will not fit properly over the affected limb. Usage of the limb will be reduced over time. Your body image suffers as the limb loses its normal contours.

10. Who can treat my lymphedema effectively?

Therapists who receive specialized training in treatment of lymphedema are referred to as lymphedema therapists. If they are certified by the Lymphology Association of North America (LANA), they have earned the title Certified Lymphedema Therapist (CLT). The training to become a lymphedema therapist is open to a variety of health professionals including doctors, nurses, physiotherapists, occupational therapists and registered massage therapists, among others. The LANA certification is available to lymphedema therapists who have a year of practice following their training. Their training must consist of at least 135 hours of lectures and hands-on work.

Is Your Therapist Truly Qualified?

To determine whether your therapist is truly qualified to treat your lymphedema, you may want to ask these questions:

1. How many hours was your lymphedema training course?

The correct answer is a total of 135 hours or more. There are many shorter courses available, but they do not meet LANA standards or fully prepare the therapist to treat complicated cases of lymphedema.

2. What method of treatment do you use?

The correct answer is Complex Decongestive Therapy, consisting of manual lymph drainage, compression bandaging, exercise, self-care, skin hygiene and compression garments. Some also call this same method Complex Physical Therapy (CPT) or Complete Decongestive Therapy (CDT).

While some therapists may be more conscientious than others, or more experienced, these two simple questions will reassure you that they are competent, and they should have a good understanding of their own limitations. If you have any doubts about a therapist, seek a second opinion.

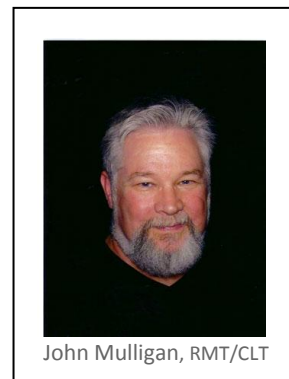
It is not realistic to imagine that these ten questions are the only questions that will be asked about lymphedema and its treatment. The information here is intended as a good beginning and a starting point for a dialogue.

To learn more about lymphedema Visit these websites

- National Lymphedema Network (<http://www.lymphnet.org>)
 - Lymphology Association of North America (<http://www.clt-lana.org>)
 - Lymphovenous Association of Ontario (<http://www.lymphontario.ca>)
 - Lymphedema Association of Quebec (<http://www.infolympho.ca>)
 - Dr. Vodder School of North America (<http://www.vodderschool.com>)
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ABOUT JOHN MULLIGAN

John Mulligan has been a massage therapist since 1997, and has successfully completed training programs in both the U.S. and Ontario. He has been a lymphedema therapist since 1998 and has taught, written and presented at conferences on the subject of lymphedema and its treatment. He has extensive experience working in a physiotherapy setting treating a post-trauma, chronic pain and lymphedema clientele. His broad training background and varied experience have given him valuable insights into the effective application of massage therapy for a wide variety of conditions. He lives with his wife in Fort Erie, Ontario, overlooking the Niagara River. Contact John at: John@LymphedemaTherapist.com



References

The text on which most of the information is based is the Textbook of Lymphology for Physicians and Lymphedema Therapists, by Földi, Földi and Kubik, published by Urban & Fischer, a division of Elsevier.