Managing Lymphedema for the Melanoma Patient

A guide to upper and lower limb lymphedema for the newly diagnosed melanoma patient

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We would like to show our appreciation and gratitude to the following individuals who provided their expertise and review for the development of this booklet:

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- Anne Kennedy, Executive Director of the Lymphedema Association of Ontario
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- Linda Blanchfield, RMT, CLT-LANA, Certified Therapist and Senior Instructor, Dr. Vodder School - International
- Nadine Maraj-Nyiri, RMT, CDT, Dalecliff Medical Centre
- Robert Harris, Director, Dr. Vodder School – International
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We would like to send a very special thank you to our patient group, without whom we could not have completed this booklet!

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The Melanoma Network of Canada (MNC) is a national, patient-led, charitable organization. The mission of the MNC is to provide melanoma patients and their caregivers with current and accurate information and services about the prevention and treatment of melanoma.

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Table of Contents
Introduction ................................................................. 2
Lymphatic system and lymphedema .......................... 2
Lymphatic system ....................................................... 2
Risk factors for lymphedema ...................................... 4
Some common risk factors ................................. 4
Risk reduction and prevention ............................... 4
Development of lymphedema ................................. 8
Stages ........................................................... 8
Early signs and symptoms of lymphedema ............. 9
Management of lymphedema ................................. 9
Complete decongestive therapy .............................. 9
Intermittent pneumatic compression therapy ............. 11
Low-level laser therapy ........................................... 12
Surgical therapy ................................................... 12
Pharmaceutical treatments ...................................... 13
Natural supplements .............................................. 13
Complementary and alternative treatments ............. 13
Exercise .......................................................... 13
Summary of management ...................................... 14
Psychological health ................................................ 14
Complications of lymphedema ............................... 15
Treatment costs ..................................................... 15
Resources .......................................................... 16
Websites ........................................................... 16
Books .............................................................. 17
Glossary ............................................................. 18
References .......................................................... 19
Notes ................................................................. 21
Introduction
This booklet provides information about secondary lymphedema and its management for the melanoma patient with newly diagnosed lymphedema. It is written based on research and current best practices. We hope this booklet helps you understand lymphedema and its management. For more in-depth learning, please refer to the Resources section, page 16.

Lymphatic system and lymphedema

Lymphatic system
The heart and blood vessels make up the circulatory system of the body. When blood travels through the body, some fluid from the blood leaves the blood vessels to carry nutrients into the tissues. This tissue fluid is made up mostly of protein and water. This fluid then drains into lymph vessels and becomes lymph fluid. The vessels carry lymph fluid from all the areas of the body to the neck. There the lymph fluid enters the circulatory system again. Muscles in the body help the lymph fluid travel through the lymphatic vessels. The lymphatic system also includes lymph nodes, which contain immune system cells. These cells help defend the body from infection by removing bacteria and viruses.

Lymphedema
Lymphedema is the build-up of lymph fluid in the body's tissues due to damage in the lymphatic system. It occurs when the lymph system cannot remove the fluid it normally does from the tissue. This build-up causes abnormal swelling, often of an arm or leg. Lymphedema can be primary or secondary.

Primary lymphedema is seen in people who are born with abnormalities in the lymphatic system. Secondary lymphedema is a complication that can occur after cancer treatments (e.g., surgery, lymph node removal, radiation therapy). Lymphedema is usually seen in the part of the body that had the specific cancer treatment. Secondary lymphedema is the most common type of lymphedema in North America. It is important not to confuse lymphedema with water retention. Lymphedema is a very different condition and requires specific treatment.

Why does lymphedema occur?
Cancer therapy can damage the lymphatic system. The lymph system cannot remove the fluid it normally does from the tissue. This damage can slow the movement of lymph fluid in part of the body, causing fluid to build up. The extra fluid can cause swelling, often in the arms, legs, chest, face, and genitals. Slow movement of the lymph fluid also decreases the immune function of the lymph nodes and the amount of oxygen and nutrients reaching your body tissues.
Risk factors for lymphedema

After cancer treatment, a lifelong risk exists of developing lymphedema. Lymphedema may develop when the cancer is treated, after weeks, months or many years, or not at all. If you experience swelling after cancer therapy, see a health care professional right away.

Some common risk factors include:

• Surgery with removal of the lymph nodes in the armpit
• Radiation causing inflammation and fibrosis, or scarring, of the skin
• Radiation to the breast, or to lymph nodes in the armpit, under the breast, or under the collarbone
• Drainage or wound complications
• Infection
• Cording: a web of thick, ropelike structures under the skin of your inner arm
• Formation of a “seroma” – a pocket of clear fluid that sometimes develops after surgery, after the drains have been removed
• Active cancer
• Any weight gain or being overweight
• A family history of lymphedema-related conditions
• Trauma in an at-risk arm or leg, such as an injection or having a blood sample taken
• Chronic skin disorders and inflammation
• High blood pressure
• Chemotherapy
• Sedentary lifestyle

Risk reduction and prevention

Because the damage to the lymphatic system is permanent, lymphedema is a chronic, or long-term condition. Fortunately, there are several things you can do to reduce the risk of worsening your lymphedema and to improve your quality of life.

If you have a definite diagnosis of lymphedema

2. *Report changes*: Report any change in size, weight, color, temperature, sensation, or skin condition of your lymphedema.
3. *Manage your body weight*: Weight gain is a major risk factor for lymphedema. Maintain a normal body weight; seek professional help to lose weight if you are overweight.
4. *Nutrition*: There are no foods that will prevent or control lymphedema but one should always strive to eat a balanced diet by following the Canada’s Food Guide. A low salt and fat diet improves overall health and circulation.
5. *Drink enough fluids*: Make sure you drink 2 to 3 litres of fluid a day.
7. *Wear compression garments*: You should be measured for a custom fit by a professional who has been certified to measure compression garments (many lymphedema therapists are certified in this). Follow the manufacturer’s recommendations. Replace the garment as recommended.
8. *Manage infection*: Episodes of cellulitis, or inflammation of the tissues, need to be treated urgently because they can worsen your lymphedema by destroying lymph vessels in the affected area. Signs and symptoms of cellulitis may include redness, heat, pain, fever, and flu-like symptoms. If you get an infection, you need antibiotics from a physician immediately. If you get recurrent cellulitis, talk to your health care provider about the preventative use of antibiotics.
9. *Care for your skin*: Keep the affected area clean and dry. Moisturize each evening to avoid skin cracking. Lotion should not be applied right before putting on any compression garment because it will cause the fibres of the compression garment to breakdown. Use a pH neutral lotion that does not cause you an allergic reaction. Always use sunscreen with SPF 30 or higher and wear protective clothing to avoid sunburn!
10. *Body waxing*: Body waxing for hair removal is not recommended for those affected with lymphedema.
11. **Avoid skin trauma:** Trauma to the affected area (including incidents such as bug bites or cuts to the skin) can worsen lymphedema. If you do not recover or your lymphedema worsens, contact your health care provider.
   
   a. If you need to have blood taken, use a non-lymphedema limb. Do not allow the technician to make multiple or traumatic searches for veins. If a traumatic venipuncture occurs, immediately wash the area, apply a cold pack, and then raise the limb until the swelling decreases.
   
   b. For scratches, punctures, or breaks in the skin of the affected area, wash with soap and water, pat dry, and then apply a topical antibacterial ointment.
   
   c. Wear protective clothing and footwear that does not constrict the affected area when doing an activity that could lead to trauma.
   
   d. Toenail care may need to be done by professionals (podiatrists). Always maintain hand and foot hygiene. Always use clean instruments and avoid cutting cuticles.
      - If you are having nails done by someone else (at a spa or beauty salon), make sure that the tools used are sterilized. Ask if they use an autoclave for sterilization purposes—dipping instruments in bacteriocide in not an acceptable substitution.
      - Avoid artificial nails because of increased fungal infection risk. Fungal infections should be treated immediately, even if no swelling has occurred (including even mild athlete’s foot).

12. **Avoid constriction:** Avoid constriction of the affected part, such as tight socks or a tight bra. No indentations should be left in the tissue by the garments that are worn.

13. **Prevent burns and frostbite:** Avoid exposure to extreme heat (e.g. via hot tub, sauna, whirlpool, and sun tanning) or cold that could cause a burn or frostbite. Remove yourself from adverse temperatures if you have increased swelling.

14. **Surgery:** If you need to have surgery on an affected area, tell your surgeon about your condition. If your lymphedema does not worsen after surgery, continue with your prior care routine. If your lymphedema worsens after surgery, seek care from a lymphedema therapist.

15. **Avoid periods of prolonged inactivity:** Prevent stasis, or stoppage of the normal flow of a blood or lymph. Move, change position, and exercise throughout the day.

16. **Varicose veins:** If you have varicose veins, check with your health care provider to determine if varicose vein treatment could help improve the lymphedema. Proper compression needs to be applied immediately post treatment.

17. **Air travel:** Air travel is associated with a risk of blood clots in veins. It is recommended that you wear your usual compression garments during air travel. It is also very important to move around, exercise the affected part, and maintain good hydration during the flight.

**If you are at risk of developing lymphedema**

People who have not shown signs of lymphedema but had lymph node removal or radiation therapy should consider the same precautions with the following changes:

1. **Compression garments:** Wearing compression garments during exercise is likely unnecessary unless you have noticed that swelling occurs during exercise.

2. **Varicose veins:** Varicose veins can be managed by wearing support stockings. If swelling worsens, contact your health care provider.

3. **Air travel:** The risk of lymphedema with air travel is unclear. It is recommended that you review the pros and cons of wearing compression garments during air travel and make an informed, personal decision. If, while wearing a garment on an airplane, the swelling increases or the garment becomes tight, remove it immediately. It is important to move around, exercise, and maintain good hydration during air travel.

4. **Blood pressure cuffs:** The risk of having blood pressure taken on the at-risk arm is unknown. If possible, use the opposite arm.

Controversy exists as to whether the following carry a risk of lymphedema:

1. **Mammograms:** There is no evidence that mammograms cause or worsen breast lymphedema.

2. **Razors:** There is no evidence that shaving with a clean razor on clean skin causes or increases lymphedema. However, a common sense and safe approach is recommended — do not shave areas of severe lymphedema or use electric or rusty razors.
Development of lymphedema

Stages
Lymphedema is divided into stages.

Stage 0
This is the latent stage of lymphedema. You may feel heaviness in the affected limb, but will not have visible symptoms.

Stage 1
This is the reversible lymphedema stage. The swelling is very soft and you can indent it by pressing on it with a finger. It will bounce back when you lift your finger. Raising the limb can help to reduce the swelling.

Stage 2
This is the spontaneously irreversible lymphedema stage. At this stage your skin will be less elastic and less able to indent with pressure and bounce back. This is due to fibrosis, or scarring. Raising the limb will not resolve the swelling.

Stage 3
This is the lymphostatic elephantiasis stage. Much more fibrosis and swelling are present. You may have swelling that does not indent, a more obvious Stemmer sign, and deeper skin folds on the wrists and ankles. You may often get infections of the skin and nails.

In Stage 2 and Stage 3, new fat tissue forms and prevents the swelling from indenting. This formation of fat tissue may explain why traditional therapies may not completely reduce the swelling in these stages.

Early signs and symptoms of lymphedema
The following are common signs and symptoms of early lymphedema:
- Clothing, jewelry, sleeves, shoes, or rings fit tighter.
- You feel heaviness, fullness, or tightness in the affected area, especially at the end of the day and in hot weather.
- You feel aching or discomfort in the affected limb.
- You cannot move your affected area as well as before.
- You notice painless swelling in all or part of the affected limb. Natural skin folds may become deeper.
- You have a positive Stemmer sign.
- You can indent the swelling and the tissue bounces back after.
- The color and temperature of the skin is normal. The skin may be shinier and drier than normal.
- Symptoms may change during your menstrual cycle.

Management of lymphedema
No cure exists for lymphedema, but appropriate treatment can manage this condition and reduce the size of your arm or leg. Lymphedema is best managed with a certified lymphedema therapist. Please consult the Resources section (page 16) for province-specific websites on where to find certified lymphedema therapists. Not all therapies you may read about in magazines or on the internet are safe and effective. Always discuss any change to a current therapy or a new therapy with a certified lymphedema therapist.

Several different therapies can help manage your lymphedema.

Complete decongestive therapy

Note: If you have any of the following conditions, you should speak to the specialist who treats your condition and should NOT start complete decongestive therapy (CDT): active infections, deep vein thrombosis, congestive heart failure, kidney conditions or lung conditions. You should CHECK with a health professional before starting complete decongestive therapy if you have hypertension, paralysis, diabetes, or bronchial asthma.

Complete decongestive therapy is widely considered by lymphedema experts to be the gold-standard treatment. It has two phases.
Phase I
Phase I involves frequent visits to a lymphedema therapist to decrease your swelling and teach you how to maintain these gains, using a self-management program. Complete decongestive therapy is performed daily (5 days/week) for 3 to 8 weeks. Phase I consists of the following:

• **Manual lymphatic drainage massage** is a gentle massage technique that uses rhythmic circular movements to increase flow of lymph fluid and increase its pumping rate. It is performed for 40 to 60 minutes on the affected limb.

• **Compression garments** are worn on the affected area during most daytime hours, except when bathing. These garments may be sleeves, stockings, bras, compression shorts, face or neck compression wear, etc. At night, looser compression bandaging is recommended. If you have more severe lymphedema, you may need additional night garments or advanced day garments.

• **Weight loss**: Complications and the volume of lymphedema are likely to increase with obesity. Weight loss or maintenance of normal weight is an important part of lymphedema management.

• **Education**: Many studies have shown that a person’s understanding of lymphedema is important to getting the best long-term results. Make sure that you learn as much as you can about risk-reduction practices, self lymphatic drainage, skin care, signs and symptoms of infection, proper fit and care of garments, and the importance of exercise and weight control.

Intermittent pneumatic compression therapy
Before starting intermittent pneumatic compression, it is important to consult a lymphedema health care expert. Intermittent pneumatic compression is not a stand-alone treatment and must be used with complete decongestive therapy and compression garments. For some people, intermittent pneumatic compression can be a useful addition to Phase I or Phase II complete decongestive therapy.

This therapy moves stationary fluid from the tissues into the lymphatic vessels using pressure produced by a pump. Several types of pumps are commercially available; they have different features and costs. Most pumps are complex and cost several thousand dollars. Acceptable pumps should have pump garments with multiple chambers that compress in a specific pattern. This pattern is determined individually for your type of lymphedema. Acceptable pump pressures range from 30 to 60 mm Hg. In general, lower pressures are considered to be safer. The length of each treatment is usually one hour. You should not use intermittent pneumatic compression if you have active infection or deep vein thrombosis.

Phase II
A self-management program helps you maintain the progress you made in Phase I. Success in Phase II depends entirely on your commitment. Phase II continues manual lymph drainage, home therapeutic exercises and the following:

• **Compression garments** are worn on the affected area during most daytime hours, except when bathing. These garments may be sleeves, stockings, bras, compression shorts, face or neck compression wear, etc. At night, looser compression bandaging is recommended. If you have more severe lymphedema, you may need additional night garments or advanced day garments.

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Low-level laser therapy

Low-level laser therapy has shown some potential for treatment, especially of the upper limb. However, insufficient research has been performed to recommend low-level laser therapy for lymphedema.

Surgical therapy

Since patients manage well with conventional therapy, surgery is rarely a consideration. Surgery has many risks and is done by very few surgeons. When surgery is performed, it should be accompanied by complete decongestive therapy. Surgery does not eliminate the need for compression garments and Phase II self-management.

Liposuction

Liposuction is not generally considered an effective treatment for lymphedema. Liposuction removes extra fat tissue and should be considered only if the affected limb cannot be indented and has not improved with complete decongestive therapy. Liposuction should never be performed with edema that can be indented. Lifelong compression garments are needed to prevent the return of lymphedema due to the scarring of lymph vessels that can occur from the procedure. The risks of liposuction include bleeding, infection, skin loss, abnormal sensation and recurring lymphedema.

Debulking surgery

Debulking surgery is more invasive than liposuction and also is not considered an effective treatment for lymphedema. It should only be considered if the affected limb has not improved with CDT. Debulking surgery removes the hard connective tissue and fat tissue in the affected limb. After the surgery, compression garments are required to prevent the return of lymphedema. The potential risks of this surgery include prolonged hospitalization, poor wound healing, nerve damage or loss, significant scarring, destruction of the remaining lymphatic vessels in that body part, loss of limb function, return of swelling, poor cosmetic results, and decreased quality of life.

Microsurgical lymphatic venous anastomosis

This surgery may often complicate and/or exacerbate lymphedema. This surgery reconnects lymph vessels to other lymph vessels or veins to improve lymphatic drainage. Microsurgical lymphatic venous anastomosis can only be performed on patients who have specific characteristics, such as some undamaged veins and lymph vessels in the affected limb. However, insufficient research has been performed to recommend this therapy as treatment for lymphedema.

Pharmaceutical treatments

It is recommended that you do not treat lymphedema only with drugs or dietary supplements. Diuretics are ineffective for lymphedema, but if you have high blood pressure or heart disease, do not stop diuretic therapy without first checking with your health care provider. Drugs such as Coumarin and Diosmin have not been found to be effective and have negative side effects.

Natural supplements

Insufficient research on natural supplements has been performed to recommend them as therapy for lymphedema. Due to potential interactions with prescription drugs and other negative side effects, you should check with your health care provider before taking any natural supplement.

Exercise

Exercise increases lymph flow and improves muscular strength, cardiovascular function, and psychological wellbeing. It is important for an exercise program to be tailored to your specific situation. While exercise helps to move lymph fluid because your muscles contract when you breathe more deeply, exercise can also increase swelling in the affected limb because it increases the heart rate. Finding the right types of exercise is a balancing act. You are encouraged to follow these exercise guidelines:

• Engage in activities involving flexibility, resistance, and low-impact aerobic benefit, such as Nordic walking, swimming, yoga and cycling.
• Raise the affected limb to at least the level of the heart throughout the day.
• Warm up and cool down as part of your exercise.

Tissue grafts

Tissue grafts have attempted to bring new lymph vessels into an affected area. However, insufficient research has been performed to recommend grafts as therapy for lymphedema.
Complications of lymphedema

Lymphedema affects the body’s circulation at a microscopic level. This affects oxygen and nutrient delivery to the tissues and can result in many complications. Limbs may feel heavy, tight or achy (e.g. if the arm is tried after working in the garden all day). If you experience any pain, see your lymphedema therapist. The use of painkillers with CDT is not recommended, especially with the use of compression therapy. If there is pain with compression, then less compression can be used. If compression is not tolerated at all, then the source of the pain must be found and dealt with before compression is used.

When lymphedema is untreated, the affected limb accumulates metabolic waste, proteins, and pressure. Lymphostatic fibrosis can develop. Lymphostatic fibrosis causes the skin to break down and can lead to an infection called cellulitis. Infection can cause even more damage to the lymphatic system, resulting in a vicious cycle of infection and worsening lymphedema. If the affected area develops an ulcer, or break in the skin, you may lose function of your limb. These complications do not often develop in lymphedema that is treated.

Treatment costs

Lymphedema can become an expensive condition to manage. You can minimize your costs by doing the following:

- Contact your private insurance company to see if they will pay for physiotherapy treatments and/or lymphedema garments.

- Contact your provincial assistive devices program. The website http://www.lymphovenous-canada.ca/treat.htm has comprehensive information about treatment centres and cost coverage within each province.

Psychological health

Lymphedema often causes psychological distress and decreases quality of life. Psychological effects include anxiety, fear, depression, loss of body image and self-esteem, and decreased sexual drive. If you are experiencing psychological distress and it has not resolved within three months, obtain a referral for specialist care.

Contact a lymphedema association for more information (See Resources, page 15). Overcoming the Emotional Challenges of Lymphedema by Elizabeth J. McMahon, Ann B. Ehrlich is a book that addresses the psychological issues of lymphedema and offers some coping methods.
Resources

The successful management of lymphedema requires a comprehensive approach. We encourage you to pursue further knowledge from a diverse range of sources. Below are some recommended websites and books.

Websites

International Lymphedema Framework (http://www.lympho.org/) is an internationally recognized charity that works to improve the management of lymphedema worldwide. It regularly publishes evidence-based position papers on many aspects of lymphedema care.

National Lymphedema Network (www.lymphnet.org) is an internationally recognized non-profit organization providing education and guidance to lymphedema patients, health care professionals, and the public by providing information on preventing and managing lymphedema.

Canadian Lymphedema Foundation (www.lymphedema.ca) is an organization established to promote and support lymphatic research in Canada.

Lymphovenous Canada (www.lymphovenous-canada.ca) links people in Canada with dysfunctional lymphatic systems with health care professionals and support groups in their communities and around the world. The website also lists the latest developments in scientific research and treatment.

Lymphedema Association of Ontario (http://www.lymphontario.ca/resources.html) is an organization that aims to improve access to quality lymphedema information, resources and services. They have helpful information about general lymphedema management, programs and services, an online store where books, CDs and DVDs can be purchased, and information about treatment product manufacturers, retailers, and service providers.

LAQ/AQL: Lymphedema Association of Quebec

BCLA: British Columbia Lymphedema Association
http://www.bclymph.org

LAM: Lymphedema Association Manitoba
http://www.lymphmanitoba.ca

LAS: Lymphedema Association of Saskatchewan
http://www.sasklymph.ca

ALA: Alberta Lymphedema Association
http://www.albertalymphedema.com

Lymphnotes (www.lymphnotes.com) is an online information resource and support group for those with lymphedema and for the family, friends, and therapists who care for them.

Dr. Vodder School International (www.vodderschool.com) provides high-quality education in the Dr. Vodder method of manual lymph drainage and combined decongestive therapy and lists certified therapists by area. You can also find a list of currently certified lymphedema therapists in Canada on this website: http://www.vodderschool.com/find-a_therapist

National Cancer Institute (http://www.nci.nih.gov/cancertopics/pdq/supportivecare/lymphedema/patient): This patient summary is adapted from the summary on lymphedema written by cancer experts for health professionals.

Lymphedema Association of Australia, Inc. (www.lymphoedema.org.au): This website contains a summary of information about lymphedema, its causes and treatment, and related matters, together with essential reference material.

Cancer BACUP (http://www.cancerbacup.org.uk) is Europe’s leading cancer information service, with over 4,500 pages of up-to-date cancer information, practical advice, and support for cancer patients, their families, and caregivers. Search the site for the terms lymphedema and manual lymph drainage.

Books

Coping With Lymphedema. Joan Swirsky, Diane Sackett Nannery. An educational read about lymphedema prevention and maintenance with great relevance for the breast cancer patient. A great addition to your health library.


Glossary

Cellulitis: Infection in subcutaneous tissue

Edema: Swelling of a body area due to the collection of fluid

Fibrosis: Scarring, or hardening of body tissues

Interstitium/interstitial spaces: The space between cells in a tissue

Lymph: Also called lymphatic fluid; tissue fluid that has entered the lymphatic system

Lymphatic system: Also called lymphatics; the system of vessels that drain lymphatic fluid from the tissues and the lymph nodes and circulate important immune cells to help with immune defenses

Lymphostatic fibrosis: Thick, rough skin that contains increased fluid

Lymph nodes: Organs in the lymphatic system that, with the help of immune cells, remove viruses and bacteria that have entered our body

Nordic walking: A sport or activity that is performed with walking poles similar to ski poles

Stasis: Stationary body fluids, such as lymphatic fluid

Stemmer sign: The skin of the top of the fingers and toes cannot be lifted, or lifted with difficulty, compared with the unininvolved limb

Tissue graft: A surgical procedure that moves tissue from one area of the body to another

Ulcer: An open sore on the body that does not heal and is caused by a break in the skin

Venipuncture: Puncturing of a vein to take a sample of blood or inject a drug

References


