Appendix 2

Questions and answers on the management of lymphedema related to breast cancer

A guide for women and their physicians

What is lymphedema?

Lymphedema is the swelling that occurs when a protein-rich fluid called "lymph" collects in part of the body. In lymphedema related to breast cancer, this pooling of fluid usually occurs in the upper arm, where it can lead to pain, tightness and heaviness, and recurrent skin infections.

What causes lymphedema?

Normally lymph flows through the lymphatic vessels and eventually enters the blood stream. Sometimes the flow of lymph is interrupted by damage to the vessels and the oval-shaped structures called "lymph nodes" that are located along the vessels.

In breast cancer patients, damage to the lymphatic pathways can be caused by the cancer itself, infection or certain breast cancer treatments. For instance, lymphedema can occur following removal of the lymph nodes in the armpit or "axilla" (called "axillary lymph node dissection"; see guideline 4 on the removal of lymph nodes during breast cancer surgery [www.cma.ca/cmaj/vol-158/issue-3/breastcpg/0022.htm]. Lymphedema can also occur when radiation therapy to the armpit causes scarring and blocks or slows the flow of lymph.

In many cases, lymphedema develops within the first year after surgery or radiation therapy, but it can develop at any time. It can be a temporary or a long-term problem.

How is lymphedema measured?

If you or your doctor suspect that you have developed lymphedema after surgery or radiation therapy, you will need to be assessed. Your doctor may use a tape measure to compare the distance around each of your arms at different points and around your wrists and hands. A difference of 2 cm at any of these measurement points may require treatment. Your doctor will also check for tightness and feelings of heaviness in your arms. This assessment will allow your doctor to determine whether your lymphedema is mild, moderate or severe (severe lymphedema rarely occurs following breast cancer treatments). There are other methods of measuring lymphedema, such as water displacement, but they are used less often.

My doctor says I have lymphedema. What are my treatment choices?

Before you begin treatment for lymphedema, you will want to make sure that you do not have any other problems related to your original breast cancer. Your doctor will check for infection in your arm and tumours in your armpit. Your doctor will also check for blood clots in your armpit (called "axillary vein thrombosis"). Once your doctor has ruled out these

problems, you can begin treatment for lymphedema.

Usually you will be offered treatment that involves wearing a compression garment. Other treatments, such as using a pneumatic compression pump or undergoing massage and physical therapies, are sometimes offered in addition to, or instead of, a compression garment. However, you should keep in mind that, at this time, the only treatment that can be recommended on the basis of scientific evidence — information from studies involving large numbers of women — is the use of a compression garment.

Compression garments

A compression garment (sometimes called a "compression sleeve") is a tight-fitting piece of elastic clothing that covers all or part of the arm. It may also cover the wrist or part of the shoulder. Good compression garments are usually custommade. They should be replaced every 4 to 6 months or when they begin to lose their elasticity. Ideally, trained personnel should fit the garment for you.

A compression garment works by putting pressure on your swollen arm and stopping the collection of lymph in any one area. Your doctor may recommend that you wear the garment 24 hours a day or that you wear it only during waking hours. Whatever your doctor recommends, you should keep in mind that research shows that the long-term and consistent use of compression garments for lymphedema will result in improvement.

Pneumatic compression pumps

A pneumatic compression pump is a device with a sleeve that can be inflated with compressed air in order to massage the arm. The device squeezes the lymph away from the hand and arm and toward the body. There are several commercially available pumps, ranging in complexity and cost. Most pumps used by therapists, clinics and patients are complex and cost several thousand dollars.

Unfortunately, no studies have been published regarding the most effective kind of pump, the most desirable pumping time or the best pressure levels. One thing that is known, though, is that you should not use pump therapy if you have an active infection or problems with blood clots (called "deep vein thrombosis").

Massage and physical therapies

Massage and physical therapies are used to help the fluid drain from the affected area. Manual lymph drainage is a massage technique that involves the skin surface only. The therapist tries to improve drainage from the arm by clearing out the main lymphatic pathways of the body, starting in the neck and moving to the main part of the body. Complex

physical therapy, also called complex decongestive physiotherapy, is a treatment routine that involves manual lymph drainage, skin care, bandaging, exercises and the use of compression garments.

In one study, the use of a compression garment combined with manual lymph drainage was compared with the use of a compression garment alone. Women in both groups had reduced arm volume and improvement in symptoms. However, manual lymph drainage did not provide additional benefit over the compression garment alone.

Other therapies

There are other therapies for lymphedema that you may hear about: laser treatment, electrical stimulation, transcutaneous electrical nerve stimulation (TENS), cryotherapy, microwave therapy, thermal therapy, surgery, and drug therapy with diuretics or benzopyrones. There is no research that indicates whether these therapies are useful. These therapies require further study and are not recommended at this time.

What should I do if I am having pain?

You must tell your doctor if you are having pain. Most often, the best way to control the pain is to control the lymphedema. You may need to change your treatment in some way. If changing your treatment does not help the pain, your doctor may prescribe an anti-pain medication (see guideline 10 on pain management [www.cma.ca/cmaj/vol-158/issue-3/breastcpg/0071.htm]).

What can I do to help myself?

There are several things you can do to manage your lymphedema and prevent complications:

 Look after your skin. Avoid cuts, pinpricks, hangnails, insect bites, pet scratches and burns to the affected arm. If your skin is injured, be sure to clean and protect the wound immediately. Stay away from substances that you are allergic to or that you find irritate your skin. Whenever possible, avoid blood pressure monitoring in the affected

- arm and avoid medical procedures that require pricking the skin in the affected arm (vaccination, blood drawing, insertion of an intravenous needle, acupuncture, and venography or lymphangiography [x-ray assessments that involve injections]).
- Treat skin infections promptly. Usually skin infections are streptococcal that is, they are caused by bacteria called "streptococci." On rare occasions an infection may be staphylococcal caused by bacteria called "staphylococci." In either case, the infection should be treated immediately with antibiotics such as penicillin. If you have recurrent infections, you may want to take regular preventive doses of antibiotics or receive monthly injections of penicillin. Your doctor may want you to have an emergency home supply of an antibiotic, to be taken at the first sign of infection. If you are visiting a remote area, be sure to take along a supply of antibiotics.
- Use saunas, steam baths and hot tubs with care. Heat can make your lymphedema worse. Be cautious about exposing yourself to hot environments.
- Travel with care. Some patients report that their lymphedema is worse when they travel to places with a hot climate. Some also report that their lymphedema is worse during flights. If you have a compression garment, you should wear it when travelling by air.
- Exercise your arms. Activities that exercise your arms may
 help control your lymphedema. Although some doctors say
 you should avoid activities such as rowing, tennis, golf,
 skiing, squash and racquetball, there is no research to
 suggest that these sports promote or worsen lymphedema.
 In fact, in one study, 20 women with breast cancer
 competed in the strenuous sport of dragon boat racing and
 found that the activity did not promote or worsen
 lymphedema. Some experts recommend that you wear a
 compression garment during exercise.
- Maintain an ideal body weight. Being overweight can contribute to the development of lymphedema and may make the use of compression garments or pneumatic compression pumps less effective.

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