

Approaching your doctor

Tips on discussing lymphedema with your health care providers

By Anna Towers

Q I have had gynecological cancer treatment and now have lymphedema of both legs. My surgeon referred me for stockings to the knee, which I couldn't wear. I found out later that it was the wrong prescription. Also, I learned that she should have referred me for bandaging beforehand because my swelling was very "pitting." She looks like she is trying her best but why don't oncologists know more about lymphedema treatment and how to prescribe or refer?

A Although the situation is improving, oncologists and physicians in general receive no formal training in lymphedema management. There are few, if any, medical schools that offer oncology residents even a half-day of systematic clinic experience in lymphedema assessment and care.

There are very few specialized academic lymphedema clinics in which to base this teaching. However, within the next few years we should see considerable improvement in this area. In the meantime, sometimes it is patients that have to educate their oncologists!

Q What should I say to my oncologist? I don't want to seem ungrateful or make waves...

A Late referral for lymphedema is a common problem. Many oncologists still think that mild swelling is "OK" and nothing

to be concerned about. So, the first message should be: patients need to know about prevention and should be referred to a knowledgeable lymphedema therapist at the first signs of swelling.

This would ensure that the therapy is done according to established international standards of care (www.lympho.org), including: compression bandaging to reduce significant pitting edema; the prescription of flat-knit, thigh-high stockings where required (in the case of surgery and/or radiotherapy leading to lymphedema of the lower extremities); lifestyle and exercise advice, as well as other therapy modalities that might be indicated such as MLD and/or training in self-lymphatic massage.

Q I did eventually link up with a certified lymphedema therapist who taught me bandaging and other things that I could do. I now have stockings that work better. But I did have to invest a few thousand dollars to get to this point! And I have to continue to spend money! What could I do to try to improve things for other people facing this problem, as well as for myself?

A I encourage patients to speak with their oncologists and family physicians about their successes, failures and any reimbursement or financial issues that they face. If your cancer centre does not have a lymphedema service, ask your oncologists why not. Cancer-related lymphedema is a



Active within the CLF since its founding in 2009, **Dr. Anna Towers** is a palliative care physician and Associate Professor in the Department of Oncology, McGill University. She trained in lymphedema management in Australia under Drs. John and Judith Casley-Smith and since 1995 has run an academic lymphedema program at the McGill University Health Centre. She also teaches in the Vodder School.



complication that needs to be looked after properly, according to best practice guidelines, under Medicare as much as possible, just as all other aspects of cancer care. We are, after all, in a highly developed country! We should be able to take pride in all aspects of oncology care, including rehabilitation issues. Sometimes patients need to complain and advocate. In my experience, institutions and Ministries of Health listen to patients a lot more than they listen to lymphedema experts.

You can also speak with oncology nurses and physiotherapists. If your cancer centre has no Medicare-funded lymphedema service as well as a rehabilitation program, write a letter of complaint to the director of the cancer centre and to your provincial or territorial Minister of Health. You might need to include photos of your lymphedema, compression devices and expense receipts if appropriate. In this way you will be doing a lot to promote development of lymphedema services in your community and beyond!

Q I feel uncomfortable writing letters like that. Where can I get help with that kind of advocating? I really don't want to upset my oncologists.

A There is information on the website of the Canadian Lymphedema Framework that you may find useful. However, the best resource would be your provincial Lymphedema Association. Do join them and speak with the volunteers there. They are there to help advocate as well as to provide you with support. **LF**