An interview with Victoria Sullivan, Director, Cancer Care Program; and Heather White, Occupational Therapist, Queen Elizabeth II Health Sciences Centre, Halifax

Victoria Sullivan is the Director of the Queen Elizabeth II Health Sciences Centre's Cancer Care Program which has a once-monthly lymphedema clinic

Victoria: The lymphedema clinic opened about two and a half years ago in January 2001. It started as a pilot program and developed into a permanently funded program designed to help women with post breast cancer lymphedema. Referrals are received from across Nova Scotia and from other Atlantic provinces.

Heather: The clinic program is the result of the combined efforts of a number of committed individuals from various professions including oncologists, nurses, physiotherapists and occupational therapists as well as the patients who have inspired us all. At present, there is a 1.0 position dedicated exclusively to the lymphedema clinic. This position is filled by a physiotherapist and myself, an occupational therapist both working on a part-time basis. In addition, we also have occupational therapists who are involved in lymphedema care within the hospital based setting in Capital Health and see patients as a part of their outpatient caseload. A number of oncologists and other health care professionals at the Nova Scotia Cancer Centre have provided considerable support to the organization and ongoing development of the clinic program. We are also very fortunate that there are a number of private practice therapists certified in CLT in Halifax who can provide treatment for people with lymphedema.

Victoria: The clinic is held one afternoon a month with a group education session and an initial individual assessment done by either an occupational therapist or a physiotherapist. The therapists then do a follow-up phone call to review education and help the individual sort out what is the most appropriate treatment for them. The actual treatment may be carried out in the private clinics (CLT), by the outpatient therapists within the hospital setting (garments, Lymphopress).
A Lymphedema Trust Fund has been established that has provided financial support for an OT and PT from our centre to take a course at the Kessler-Lerner Institute on lymphedema management including training in manual lymph drainage and complex decongestive lymphedema treatment. As a result of their education, the therapists have been able to strengthen their knowledge and expertise of lymphedema and its different treatment options. This training has also resulted in the development of a pilot CLT treatment program where individuals affected by lymphedema meeting specific criteria will receive CLT treatment by one of the certified therapists at the organization.

In addition, we have had patients and families who wanted to contribute to lymphedema treatment in this area. Their contributions went into the Trust Fund which helped pay for the staff attendance at conferences, copies of the publication *Lymphedema - a Breast Cancer Legacy* which is produced by Breast Cancer Action Ottawa, and numerous other educational resources that have been very beneficial for patients as well as therapists.

As awareness of lymphedema and the clinic has grown we have seen a definite increase in the number of referrals to the program. The initial aim of the clinic was aimed at breast cancer-related lymphedema. Increasingly we are getting requests to provide treatment to other patients with lymphedema - such as those with lymphedema related to other types of cancer such as head and neck cancers or melanomas, primary lymphedema and combined forms of lymphedema. We are currently reviewing our program to determine how to best meet the needs of these client populations.

One of the major obstacles for lymphedema care in Nova Scotia is the fact that we don't have universal access to funding for compression garments for breast cancer survivors with lymphedema. Some people are able to get coverage for their garments though private insurance coverage but for many, funding remains a challenges. The "On the Front-line Fund", a trust fund established through monies raised by the Titz and Glitz group, a dedicated group of volunteers, has provided valuable financial support for breast cancer patients who require assistance. In some cases, people on social assistance may also be able to get assistance from the government.

**Victoria:** There is a research component to the program. The group is just getting started on a pilot research study funded by the Atlantic Chapter of the Canadian Breast Cancer Foundation and the Capital Health Research Foundation. It is our hope that our research will complement some of the exciting work that is being done elsewhere in the country.

**Heather:** One of the mandates of our clinic program was to further our understanding of lymphedema management through clinical research. With considerable guidance and leadership from Dr. Dan Rayson, a medical oncologist, we were able to put together a research proposal. We are very pleased that our pilot proposal has received funding grants from the Atlantic Chapter of the Canadian Breast Cancer Foundation and the Capital Health Research Foundation and are looking forward to getting our study underway in the next few months. The aim of the study is to further explore the efficacy of two different methods that have been used to provide compression therapy during Complex Lymphedema Treatment. The two methods that we will be comparing are compression bandaging versus compression garments.

*For more information on the Nova Scotia lymphedema program you can contact: Victoria Sullivan, Director, Cancer Care Program, Queen Elizabeth II Health Sciences Centre at: Vickie.Sullivan@cdha.nshealth.ca*