

Living with Lymphedema and its Complications

Ann Hasznosy has lived with lymphedema all her life. Although she has suffered occasional setbacks, she has found that working closely with her healthcare team – with open communication – has helped her maintain well-being. Ann is a 58-year-old retired business owner; she lives with her husband, Art, in Port Colborne, Ontario.

I was born with congenital Milroy disease, which is known today as primary stage 1 lymphedema. My case is different from most others because the disease affects my whole body. While most people with this affliction usually carry the lymphedema in either the upper or the lower extremities, the left side of my face is affected as well as my right arm and left leg. Another difference seems to be that all the traditional palliative therapies used in the treatment of this disease are, in my case, counterproductive.

“If something was a challenge, I felt it could be conquered.”

– Ann Hasznosy

Growing up

Despite these challenges, I was very fortunate when growing up. My parents always encouraged me to try whatever I wanted. If something was a challenge, I felt it could be conquered. It wasn't always easy, though, and in some instances modifications had to be made in the way I approached things. However, I was able to play many sports – including basketball, volleyball and baseball – and loved every minute of them. At one point a referee unfamiliar with my condition took the coach aside before a game and told him I would not be allowed to play as I obviously had grievous injuries! It took a lot of explaining and demonstrating that I could indeed handle the rigors of the sport before I was allowed to participate.

One great concern has always been infection. During my teens and twenties, as much as my lymphatic system was already stressed, bumps, bruises, cuts and sores took time to heal but were never really a concern. However, the ravages of time are catching up.

Treatment challenges

Around 2.5 years ago I noticed a spot on my lower left leg that I had hit repeatedly going up and down ladders and that was being bumped by grocery shopping carts. It became very angry-looking and measured



Ann Hasznosy: It is important to keep an open mind.

1.5×1.2×0.5 cm. My family physician sent me to a local wound care facility. With various treatments – including silver alginate, an absorbent silicone foam dressing and a protease-modulating matrix dressing – the wound showed a slight improvement. But after being treated for 3 months, with bandage changes 2 or 3 times a week, the wound had actually increased in size to 2.5×1.6×0.6 cm, with deterioration and increased drainage. The edges of the wound had hypergranulated and would bleed freely. Cultures were taken and it was determined that the wound had become infected. A round of antibiotics was prescribed.

I was referred to Dr. R. Gary Sibbald's wound clinic in Mississauga, Ontario. Dr. Sibbald examined the wound and felt that basal cell carcinoma was involved, which was verified by a biopsy. I am currently being treated with an imiquimod topical cream for superficial basal cell carcinoma. We have encountered a few setbacks along the way. Not knowing exactly how the lymphedemic leg would be affected by this treatment, we have had to adjust treatment frequencies, sometimes

CAWC Institute of Wound Prevention and Management

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Level 2: Skills Learning

Interactive learning and practice of wound care skills, including: local wound care; debridement, infection control and dressing selection; lower leg assessment and compression therapy; foot care and foot wear; pressure, friction and shear management.

Level 3: Attitude Learning

Steps and methods for practicing within a team to develop and sustain prevention strategies, with a focus on pressure ulcer and diabetic foot ulcer awareness and prevention.

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For more information, please contact: Diana Seminara, Event Coordinator, Canadian Association of Wound Care · 416-485-2292 x225 · diana@cawc.net

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— Ann Hasznosy

even stopping treatment for a period of time. I have had a few adverse reactions where the wound would appear to be healing, only for the skin to crack open and lymphatic fluid pour out. Hopefully now we are on the right track and improvement will continue. With my condition, any treatment is always a learning experience for everyone involved.

At my first appointment with Dr. Sibbald, there was much discussion around wearing compression socks, not only to aid the healing of my wound, but also to help with the lymphedema itself. I explained that I had tried many different compression therapies, all of which worked for a very short period before starting to aggravate my condition. Therefore, I was unwilling to go down that avenue of treatment. Many discussions later, we came to a mutual understanding that I would apply a “small” amount of compression to my leg by wearing Tubigrip “G” and would monitor the outcome. So far, the results have been positive.

The importance of communication

If I can offer any advice to others who are faced with a similar situation, it is to provide as much background information on your health issues as possible. After all, you are the one living with this condition and you can best explain your situation. The more knowledge is shared, the better for all concerned! If you don't let your healthcare professional know what has worked for you in the past or what therapies you are willing to try, then your interactions can become very frustrating. It is also important to keep an open mind.

For healthcare providers, remember that the patient is your best source of information. Although tests and reports will give you the needed facts and results, your patient's words, recollections, expressions and demeanor are also important. Not all therapies work for all patients. So, if a patient indicates that a certain treatment hasn't worked in the past, then consider exploring new avenues or options.

Finally, for both patients and healthcare professionals: Always listen carefully, communicate clearly and be willing to negotiate, if necessary. ☺

Upcoming events

Mark your calendar for these important international wound care events!

The American Professional Wound Care Association Conference 2013

April 4–7, 2013

Caribe Royale All-Suites

Orlando, Florida

Website: www.apwca.org/apwca2013

26th Annual Wound Healing Society Symposium on Advanced Wound Care

May 1–5, 2013

Colorado Convention Centre

Denver, Colorado

Website: www.woundheal.org/annual-meeting

Canadian Association for Enterostomal Therapy Conference 32nd Annual Conference

May 9–12, 2013

Toronto Marriott Eaton Centre

Toronto, Ontario

Website: www.caet.ca

Wound, Ostomy and Continence Nurses Society 45th Annual Conference

June 22–26, 2013

Seattle, Washington

Website: www.wocn.org/?page=annual_conference

MARK YOUR CALENDAR!

The 19th Annual Canadian Association of Wound Care Conference

From Innovation to Action: The Future of Wound Care is Now

November 7–10, 2013

Sheraton Wall Centre, Vancouver, British Columbia



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