

Mystery illness

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The good news for Julia Gibson was that her cancer was long gone. The bad news was the unexplained swelling in her arm years after her radiation treatments. The lump was gone. The cancer was gone. But five years later, the surgery and treatments she'd had were instigators of a new problem in her life.

Julia Gibson, 62, stood with her arms raised in front of a mirror. She compared arms. Scrutinized her right, and noted, "I have no elbow." It looked swollen. And lately, she'd been having trouble fitting it into the sleeve of her blouses. Her right arm was unusually big. Bigger than her left. And growing.

She was worried because it was on the same side as the breast cancer she'd had back in 2000. She'd had the lump removed as well as some lymph nodes under her arm, which later tested positive for cancer. After that, she had eight months of chemotherapy and five weeks of radiation.

When she first noticed her arm swelling, she put up with it for awhile. Then it got bigger, from her wrist way on up to her shoulder. It felt heavy and uncomfortable and it made her back ache. Then it started to hurt too much to do the things in life she enjoys, such as knitting, sewing and painting. She remembers going to a quilt show with her sister. Her arm was so sore and swollen, she made herself a sling so she could rest it while she walked. Having her arm hang down all day would have been unbearable. Even in the sling it hurt.

Then it got infected. Her arm turned red and felt hot. The Port Colborne woman had a fever and felt sick and tired all the time. Her arms shook so much she couldn't hold a glass of water. Her doctor prescribed antibiotics, but it always came back. Some days, she was too sick to enjoy her three grandchildren. And she worried that might lose her arm.

She told her oncologist who realized the problem right away: lymphedema. Simply put, it's a chronic swelling in one part of the body, caused by a problem with the lymphatic system. Think of the lymph network as a sort of waste disposal system. The network runs alongside blood vessels. Its job is to remove impurities.

Primary lymphedema happens at birth or any time in life, for unknown reasons that relate to a malformation of the lymphatic system. Secondary lymphedema is triggered by a trauma, surgery or treatment such as radiation. But often it happens months, even years, afterwards.

There hasn't been a lot of research done, so it's not understood why some people who had surgery and radiation develop lymphedema while others never do, says Anna Kennedy, executive director of the Lymphovenous Association of Ontario. Nonetheless, it begins when the lymph nodes are either damaged or removed.

Think of lymph nodes as traffic lights that direct the flow of lymph fluid. If nodes are damaged or removed - most commonly through cancer surgery and treatments - then the traffic doesn't flow as well. It's like four lanes of traffic getting reduced down to two. All you need is one accident (something as simple as a scratch that triggers an infection) and everything starts to back up, says Kennedy. There is traffic chaos. Lymph fluid doesn't know where to go. "It just sits under the tissue and can't move," says Kennedy.

Fluid backs up and causes swelling. And if that swelling isn't treated, it can cause problems that range from an infection called cellulitis (red, blotchy skin with sudden fever and chills) to hardening of the skin, delayed wound healing, pain from heaviness and psychological distress. Trouble is, few family doctors even recognize the signs, says Kennedy.

Herself a lymphedema patient, she woke up one morning with a grossly swollen leg. It had been five years since her surgery for cervical cancer. It took about three months to get a diagnosis, after ruling out blood clots, tumours and other blockages. One night she typed the words "swollen leg post cancer" into her computer search engine and read the word "lymphedema" for the first time.

"I hear the same story on our help line," she says. "I got cancer X number of years ago. I had treatment, radiation and then I get this swelling and nobody knew what it was, until I read an article on it ..."

But even once diagnosed, the story doesn't get much better. There is no cure for lymphedema. But it can be successfully managed by a treatment called Combined Decongestive Therapy (CDT). Across Ontario, there are only about 60 people trained in CDT, says Kennedy. Typically, they include registered massage therapists, physiotherapists, occupational therapists and registered nurses.

In Niagara, there are two. Cindy Schultz from St. Catharines and John Mulligan in Welland are both registered massage therapists trained in CDT.

Simply put, CDT consists of an intensive phase to reduce the swelling as much as possible and a longterm maintenance phase to keep the swelling down. It involves several therapies that include manual lymph drainage, compression bandaging and garments, exercises and skin care.

Manual lymph drainage is like massage but not, says Schultz. It's a much lighter touch and involves moving fluid to areas of the body that have enough lymph nodes to drain it. Schultz gently twists, pulls and stretches the surface of the skin, where the network of lymph vessels lie. The idea is to manually get rid of excess fluid. After that, the limb is bandaged tightly to replace skin pressure lost from lymphedema and prevent the swelling from returning.

Every day for just over a week, Gibson's bandage was adjusted. As she lost fluid, it was made smaller, so it stayed tight.

After one massage treatment and bandaging, her skin was so wrinkled they figured she'd lost about a cup of fluid.

Mulligan says people are often skeptical at first. "That doesn't last long," he says. "There's a dramatic difference after the first treatment. "It gives their life back to them." They can once again buy clothes off the shelf. They can walk and care for themselves. They don't suffer repeated infections. And they feel more confident, he says. "It makes them feel more whole."

In addition to people with lymphedema, the treatment seems to help people with sprains, post-surgical swelling, women who are pregnant with swollen ankles, people with skin conditions such as acne or rosacea, or with head colds or ear problems, he says.

Eventually, Gibson's treatments were reduced to once a month. And instead of a tight bandage, she wears a compression sleeve. It's custom-made in Germany and costs just over \$500. She only takes it off at night. Gibson also uses special skin care cream to keep her arm soft and prevent cracking and infections. And even though the compression sleeve is hot in the summer and is a reminder of the cancer she once had, she's not complaining. "You know what? I'll take it," she says. "I feel blessed that I have a solution to my problem." "I'm living. I'm enjoying my life." That includes her three grandchildren, all her hobbies and volunteer work with her church. She wants to let other people know, so they can find treatment.

Tom Kutlesa wishes he knew. Back in 2006, he was in a car accident that left him with multiple injuries including a crushed right leg. He was a passenger in a car being driven on the QEW in St. Catharines, that flipped several times before stopping. Part of his injuries included damaged veins and lymph vessels. But it would take a year and a half for the 25-year-old to finally receive appropriate treatment for the lymphedema that had developed. Problem was, no one identified it as lymphedema.

"People said, live with it. It takes time," he says. "It was out of control for a long time. I didn't know what to do," he says.

For months, he suffered from a grossly swollen ankle and a wound near that area that grew and changed, but never really healed. One doctor even suggested he might have to consider amputation if it didn't get better. Along the way, he was treated by a nurse practitioner who put his leg in a compression cast, then a compression stocking. Soon, it was noticeably better. But eventually, the wound started to reappear and Kutlesa was left once again searching for answers. Eventually, he saw a wound specialist in Dundas, who put his leg in an even tighter stocking and suggested manual lymphatic drainage. That's when his life changed.

Nearly a year and a half after the accident, in September 2007, Kutlesa met up with Cindy Schultz, the registered massage therapist who had helped Gibson's swollen arm. "When I left her office, I felt like I had a new leg," he says. There was less swelling. And he could move his ankle. He's in the process of getting a custom-made stocking from Germany to replace the one he currently wears. He, too, wants people to know about lymphedema so they can find help quicker.

"A lot of people told me, Tom, relax. Nothing's wrong. Trust the doctors," he says. "They were putting bandages over the top. "I found a way to heal this from the inside out."

Two registered massage therapists in Niagara offer Combined Decongestive Therapy, including Manual Lymph Drainage:

- Cindy Schultz, Port Health Clinic 600 Ontario St., in the Port Plaza. 905-684-6066.
- John Mulligan, B Elliott and Associates Medical Massage Therapy Clinic at 706 East Main St.n Welland. 905-788-3214.

For more information:

- *Lymphovenous Association of Ontario, www.lymphontario.org.*
- *Lymphedema Association of Quebec, www.infolympho.ca.*
- *The National Lymphedema Network, www.lymphnet.org.*

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Early warning signs of Lymphedema

- Swelling that occurs gradually or suddenly.
- Feeling of heaviness and/or limited flexibility.
- Tightness, hardness or indenting of the skin when pressed.
- Achiness or bursting or shooting pain.
- More swelling on hot, humid days or after exertion.
- Infection (cellulitis) in the affected area.

Complications if left untreated

Infection, called cellulitis, is the greatest danger and requires antibiotic treatment. Signs of cellulitis include: red blotch or rash that may be itchy; increased swelling; increased temperature of the skin; sudden onset of high fever and chills.

- Fibrosis or hardening of the tissues.
- Delayed wound healing.
- Pain from heaviness or reduced mobility.
- Difficulty carrying out daily tasks.
- Psychological distress.

Source: Lymphedema Association of Quebec.

Figure:

It took a year and a half for 25-year-old Tom Kutlesa to finally receive a diagnosis and appropriate treatment for the lymphedema that had developed following a car accident. staff photo by Cheryl Clock

Registered massage therapist Cindy Schultz, above, works on Julia Gibson's arm recently. Gibson developed lymphedema in her arm a few years after having surgery for breast cancer. Schultz was able to reduce the size of Julia's arm through different strategies including a light massage treatment called Manual Lymph Drainage. Julia also must wear a compression garment, right. staff photos by Cheryl Clock

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