

My patient journey with lymphoedema

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It is July 2013. I'm walking towards the centre of a town I do not yet know. It is my first visit. From the train, a few days ago, I caught a glimpse of quaint little boutiques, pretty clothes, colourful flowers and dainty things in general. But I'm not going shopping for any of that. I'm going to buy dish gloves and plasters; dish gloves for putting compression stockings on properly and plasters for the blisters on my fingers! I am on a 3-week lymphoedema rehabilitation programme in this small Swedish town. Up until now, it's been lovely: beautiful lodgings on the outskirts, great food, nice people, a swimming pool, t'ai chi and yoga classes.

But now tears are falling down my face. I no longer see the pretty day I woke up to. All I see is a life ahead of me — a life of compression garments, exercise, sweating, and staying in the shade.

Of course, I knew I had a lymphatic issue. That's the very reason I'm here.

After ten years of wondering why my ankles were so swollen and after countless erysipelas infections and a sea of confusion, I have finally managed to find the magic words: "LYMPH!" "Lymphatics!" "Lymphoedema!"

But what I hadn't quite understood, until now, was how it was going to affect my life, and how much work it would mean. I just thought that once I knew what was wrong with me, surely someone would be able to fix it for me. Make it go away. And then all would be well again.

To set the context of my problem, when I was 24 years old — I am now 42 — I developed Hodgkin's disease; a cancer of the lymph system. It was successfully treated with chemotherapy and radiation therapy. Afterwards, I was told that the

radiotherapy might, ironically, cause breast cancer later on. But I decided not to worry about it, and got on with my life, studies, work.

About five years later, I was out at dinner with friends, wearing tight-fitting boots, sitting down for several hours, chatting away and eating. The next day, I noticed a very swollen ankle.

I was reasonably happy with my life at this time. I had gained some weight over the years and maybe missed out on a few too many workout classes, but this didn't worry me particularly. At that time, I had no idea the body had a lymphatic system. I knew I had lymph nodes, of course — after the Hodgkin's disease — but not what those nodes actually did. I had no idea that it was a whole system and that one could, and should, pay attention to it.

So, I went to see a doctor, thinking maybe I had developed a blood clot from sitting down for so long. Over the next few weeks, I was very thoroughly examined. No blood clot was found.

"So why am I still so swollen?" I asked doctor after doctor. I only received shrugged shoulders and raised eyebrows. They didn't know. "It can happen," they said. "I don't know why, but the main thing here is to see there's nothing wrong with your blood circulation," they said.

Fine. I could understand that, and I was glad too. "But is there really nothing wrong when an ankle suddenly becomes so swollen, though?" I couldn't help asking. They were beginning to get tired of me, I could tell. They were done. There was nothing wrong with me.

Years passed. It got worse. And by now the other ankle was swollen as well. I thought, well, this is what it's like getting older. I am just so vain, thinking of how my legs look now compared to a couple of years ago. I just need to find myself a really long skirt and be glad to be alive at all.

It wasn't that bad after all. It was only me

who noticed. I realise now that I was lucky: my lymphatic system still worked ok.

In October 2011, I developed an erysipelas infection. And then another one and another. During that winter, I had erysipelas seven or eight times. I'd had one or two before, years ago, but never this many, this often.

But doctors, again, were left shaking their heads. I couldn't believe that they didn't seem to have any explanation as to why I kept getting these infections.

I still can't believe it. So many different doctors, with all their years of education, sending me home with yet another round of antibiotics and orders to "call back if it gets any worse". No one ever mentioned the "L" word.

Eventually, someone mentioned that maybe my immune system was somewhat suppressed in this particular area of my upper leg, and that was the reason why the erysipelas infections kept attacking me there.

In early 2012, I was diagnosed with breast cancer. I was scared, of course, but not really surprised. After all, I had been warned about that before.

Chemotherapy followed. Six cycles. After the fifth, my left foot swelled up, just at the base of the toes. A nurse told me to stroke it regularly, "because you don't want it to stay that way". No, surely not! I stroked and stroked and it went away. After the sixth and final round of chemo, it didn't go away. Now my foot was swollen, as well as my ankles. This wasn't right. I wanted to sort this out once and for all

That is when, at last, I googled. I can't believe it took me so long — after all I am a journalist — but I guess I'd had other things on my mind. I googled: "Erysipelas + circulation." And there it was. "Lymph. The lymphatic system. Lymphoedema."

After this, everything began to fall into place. When I finally knew what I was looking for, I found it. I asked my



Hodgkin's doctor — whom I still saw yearly — if there was anyone at the hospital who treated the lymphatic system, and she replied she thought there was one nurse, working in the radiation therapy department, who was 'interested in the lymphatic system'. This at a large university hospital in Gothenburg, Sweden's second largest city.

I finally got to see this nurse. How wonderful she was! She recognised me from my radiation treatments 16 years earlier and immediately saw the connection between what I had been through and how my legs looked. She told me there were several lymphoedema therapists at the hospital and promptly sent me there. They, in turn, sent me to a treatment centre specialising in lymphoedema, in the summer of 2013.

It was heaven. Three weeks of learning about the lymphatic system, of physical exercise, treatments and therapies. Three weeks surrounded by medical staff who mention the lymphatic system without hesitation, as if, indeed, it was something perfectly normal and well known. People who look at my legs and say things like: "Oh, for sure, you have a problem with the circulation of your lymph, that's why your ankles are all swollen." "Seven bouts of erysipelas, you say? And no one has mentioned

lymphoedema?" And this followed by a very comforting 'tut-tut-tut' sound, which made me want to cry with relief.

I was so happy. And then I crashed. Because when I finally learned more about this mystery lymphatic system, I also learned how lymphoedema would affect the rest of my life. When I got my new compression garments, they were so tight they scraped my fingers — hence the need to buy rubber gloves and plasters.

I learned I was supposed to exercise every day, wearing full compression. This was at the height of summer. I was sweating in all my new bandages and sweating even more from eating the post-breast cancer treatment medicine, tamoxifen.

Sweating my way through the morning gym class at the centre, wearing three layers of compression, and with fingers sore from putting it all on, I suddenly broke down in tears. I had realised: this is what it's going to be like from now on. I will have to sit in the shade because heat makes it worse, and I can't sunbathe with all of this compression anyway. I won't have any time to work, what with all this exercise I'm supposed to be doing, and since only getting dressed — while sweating — takes forever, I'll never make it to work on time. I won't be able to wear any nice clothes because

nothing fits with all this bandaging on. Also, any social life seems out of the question. I simply won't have any time left in the day.

It seemed clear to me that I would now have to move to a tiny cottage somewhere deep in the woods. There, wearing very wide clothing, I shall spend all day putting on compression garments, using 'simple lymph drainage techniques' on myself, doing qigong exercises and carefully moisturising my skin — all of this while taking regular, deep breaths.

As I walk there in the July midday sun, I do not yet know that things will get better.

My lymph therapist will find me compression garments that fit — no need for sore fingers from putting them on. I won't need three layers at all times. I will not always sweat. I will discover the joy in working out regularly, especially in the water. I will join networks and meet people who share my experiences.

I will be asked to tell my story in the *Journal of Lymphoedema* — a publication which, only a year ago, I could not even imagine existed.

And, who would have thought, I will even come to appreciate my compression garments. Because, as I have found, on a cold Swedish November's day, they do keep you quite warm.