MORE THAN 'A BIT OF SWELLING': LIVING WITH LYMPHOEDEMA

Leoni Curtis

Many patients are told by their doctors that lymphoedema is 'just a bit of swelling'. The onset of lymphoedema after cancer treatment can be a devastating experience for many patients and is often viewed as the 'final straw'. The psychological impact can be immense as patients struggle with feelings of isolation, altered body image and a constant reminder of their cancer. Access to appropriate treatment and support is essential for the successful management of this chronic condition. Here a member of the Lymphoedema Support Network tells her story, echoing the feelings of many other people who develop lymphoedema after treatment for breast cancer.

In March 2003, I banged my left arm while walking through a car park. It was painful for a few moments but I soon forgot about it. But about a week after my encounter with the offending wing mirror, I noticed that my fingers, hand and arm had all become swollen.

Back in 1992, I had a mastectomy. I was told about the risk of developing lymphoedema and had dreaded it happening to me. I was very careful and had taken good care of my arm and made sure that I had no injections on the left side or my blood pressure taken on my left arm. I don't know why but the thought of developing lymphoedema terrified me.

As soon as I noticed the swelling I phoned my local hospital and managed to get a quick appointment. The specialist confirmed I had lymphoedema. I could not believe it was happening to me. My arm felt so painful. It was pumping and the only way I can describe it was like having my blood pressure taken all day, with the cuff getting tighter and tighter. I became terribly depressed very quickly and at times felt like ending my life.

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A month later I started treatment for my lymphoedema at Cancer Kin Centre at The Royal Free Hospital in London. I had manual lymphatic drainage (MLD), a very gentle massage, and was also given an elastic sleeve and advised of what I could do to ease the condition — and what I should avoid doing. Initially, I had MLD three times a week for several weeks and multi-layer lymphoedema bandaging every other day for two weeks. After two or three treatments, the pain became easier.

My poor arm became the centre of my life, I just wanted to massage it, exercise it and to stop it hurting. I am left-handed, and had to teach myself to use my right hand more. Writing was particularly difficult. I know I am stuck with this condition and for the first time in my life, I feel sorry for myself. I actually think it was easier to cope with the mastectomy. Now I worry that I will get an infection, get stung or bitten, cut or burnt. Once I picked up a broken jar and cut my finger. I bathed it right away and put on antiseptic and a plaster but the next day my arm was much bigger and the day after I was in terrible pain. I developed a rash and a temperature. I had antibiotics in the house in case of cellulitis, and started them immediately and luckily I recovered in a few days.

Right now my hand is looking good. I am very strict with my routine. Every morning I give it a gentle massage, every night the same again, and I also moisturise my arm. I follow my routine, wear my sleeve and use gloves for housework, cooking and every other chore. I also wear a 'bum' bag around my waist when I go shopping, so I don't have to carry a handbag and risk bumping my arm around too much. I have started going back to yoga once a week, although I am unable to do the positions that put pressure on my arm.

I am no longer depressed and I have gradually come to terms with the condition, but my arm does dominate my day – every day. I am grateful for the treatment I have received so far and for the support of the LSN, who I phoned so often at the beginning. Their kind words of encouragement helped me to carry on. Oh, but I still walk through car parks with my hands above my head to avoid another run-in with a wing mirror! JL

Leoni Curtis is a member of the Lymphoedema Support Network