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My experience

From despair to chair! My arm lymphoedema journey

Anita Wallace, Chair of the Lymphoedema Support Network (LSN), took a diagnosis of breast cancer in her stride. Much harder to deal with was the development of arm lymphoedema. Here, she shares her experience describing her journey from despair to Chair, and how the LSN can help others like her.

Every woman dreads the thought of finding a lump in her breast and I was certainly no exception. But, in 1992, when I was relatively young, I did discover a lump and had to face up to the fact that it wasn't just other women this happened to.

Following a biopsy, breast cancer was confirmed. I needed further surgery, followed by four weeks of radiotherapy and a 6-month course of chemotherapy.

Anita Wallace

Overall, I coped with my treatment very well, and learnt to develop a positive, up-beat attitude and had every confidence in both my treatment and prognosis. So much so, that both my surgeon and oncologist asked me to speak to several of their patients in the hope that I could encourage them and be of support. I continued to do this for quite some time.

A lymphoedema diagnosis

Three years later, when I developed lymphoedema following a blood pressure reading on my at-risk arm, it was a very different story. I was relieved to be referred to a lymphoedema clinic, but my delight was short lived. I was seen by a physiotherapist, who kept her notes in a pocket diary, and whose first words to me were: 'well you do have lymphoedema, but you had better get used to it, because there is very little that can be done'.

Those words had a devastating effect on me; in fact, I found this new development far more difficult to deal sigvaris

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with than my cancer. It took me six months to even begin to come to terms with my fat arm. I had always taken a pride in my appearance and not being able to wear my usual clothes upset me and I lost confidence in myself. On top of this, my arm felt heavy and sometimes ached. I couldn't believe I was given very little information, practical help, or support. I felt isolated and alone.

The one good thing the physiotherapist did for me, however, was to provide a leaflet about the Lymphoedema Support Network (LSN) and I eventually joined the charity. At last, I wasn't alone with my condition as I found others like me who were living with lymphoedema. I felt supported and it was through this organisation that I contacted a manual lymphatic drainage (MLD) therapist who turned my life around.

She suggested a two-week intensive course of bandaging and MLD, which greatly reduced the volume of my arm. She also taught me how to control the condition. I learnt about the importance of self-management, and it was through her that I learnt about daily skin care, compression, exercise and self-massage. I also better understood how beneficial it is to learn as much as possible about the condition.

Discovering my self-management routine

Subsequently, over the years, I have attended several clinics and tried several types of compression sleeves. For me personally, a flat-knit garment is best for keeping my swelling under control. I often use an applicator to put on the sleeve and a rubber glove to help smooth out any wrinkles. I moisturise my skin at night with an unperfumed moisturiser and shower in the morning with a product that doesn't dry my skin. Having had cellulitis – a skin infection – several times in the past, I now take a low-dose antibiotic every day. Although I am aware of antibiotic resistance, if I stop taking the tablets the cellulitis recurs within weeks. Therefore I will need to take this medication for life.

I'm a great believer in keeping active as it helps to move lymph fluid around the body. Even when I'm working on my computer all day, I make sure I get up at regular intervals and walk around. I have learned to accept my condition but it takes time to work out a self-care routine that works. We are all different, and what works for one individual may not work for another.

Working for the LSN

I have worked with the LSN since 1997, initially as a volunteer, then a Trustee and now as Chair. This has given me the opportunity to share experiences with others who also live with lymphoedema. I certainly know how I felt about developing the condition, and can empathise with how they feel, and understand the difficulties they may experience in trying to adjust to this chronic condition. I feel honoured to be able to make a difference to other people's lives by providing as much information about lymphoedema as possible, the words of that physiotherapist still ring in my ears.

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