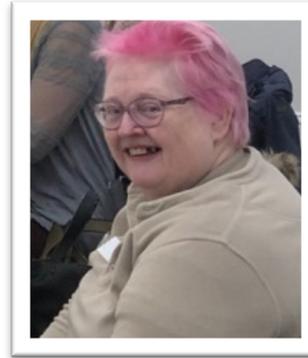


LIZ'S STORY



I was diagnosed with breast cancer. I wasn't given my breast cancer pack until the day of my operation. I studied the pack and the need to be careful of my arm so that I didn't develop lymphoedema. This was a good job because I had to inform the ward doctor about using my opposite arm for medical procedures such as injections and blood pressure. He thanked me as no one had explained this to him.

Lymphoedema appeared very slowly, eighteen months later I had mild lymphoedema. I got the breast cancer nurse to confirm my diagnosis, and my GP to refer me to a clinic. I developed cellulitis about a year later. I was unable to speak to my nurse at Springhill Hospice who ran a clinic one day a week.

INCORRECT ANTIBIOTICS

My doctors gave me an incorrect dose of antibiotics and stopped them before the cellulitis cleared. My arm grew and grew, until my nurse Donna arranged a transfer to St Anne's and at the same I joined the LSN. By reading one of their books, discovered I had grumbling cellulitis.

On my first appointment at St Anne's Hospice, I explained the grumbling cellulitis and that I had restarted antibiotics. Kath said "Double the antibiotics and get more from the doctor. Treatment can only start when you are clear of infection" I returned to the GP with the LSN cellulitis document explaining to doctors how it should be treated and requested the additional medication. My lower arm was 92% bigger and my upper was a third bigger; this was the biggest it has ever been. I had to use my coat as a sling on the days my arm felt so heavy.

AFFECTED MY MENTAL HEALTH

This affected my mental health and I was glad treatment could start. I was treated for 18 months by Kath and she was really impressed with my progress. By then my arm measured 19%, there was still a blockage but there was a queue of people waiting with greater need and 18 months of treatment had taken its toll on my mental and physical health. I needed a break!

I was returned to the care of Springhill Hospice. Donna had undergone training in MLD and MLLB, eager to practice this new skill but funds were not available. Disheartened, Donna left and I have had two more nurses since. About a year ago, Springhill Hospice closed its service and I have been left without a lymphoedema nurse.

CELLULITIS TWICE IN THE LAST 9 MONTHS

Since leaving St Anne's I have had cellulitis twice in the last nine months. I have had no service. I have not had the percentage details on my arm since Donna left. Every nurse measures differently and I had no confidence in the last nurse. When I arrived for my last appointment at Springhill Hospice, I was told my nurse had left and my heart sank but luckily the nurse I had before her was in the building and she did a quick sleeve order but sadly confirmed my fears that my last sleeves had been too slack. My arm has got bigger again. I have met the nurse who is trying take over the service and hopefully she should be ready soon.

Over the years I have had many problems with prescriptions, doctors, chemists, compression sleeve supplier and by being sent for treatment to Bolton (Kath really looked after me and taught me a lot) it was just because Bolton has no direct transport links with Rochdale. I could have been sent to Oldham but they treated Oldham patients only at that time; when they were forced to open up the service but it wasn't long before it collapsed under the pressure. I have managed this with the support

of my long suffering husband who has had to deal with my melt downs behind closed doors knowing he couldn't help. We all try to hide our feelings, on one occasion I was making my own way home via Manchester, walking in the street after treatment, a blockage in my arm cleared with a sudden pain which left me in agony and near to tears. I hid this from the world around me. Those who have lymphoedema in their arms feel sad for those who have it in their legs and guess what, the legs feel sad for the arms. We lose our independence in different ways.

LIZ'S STORY

*see appendix for full story

