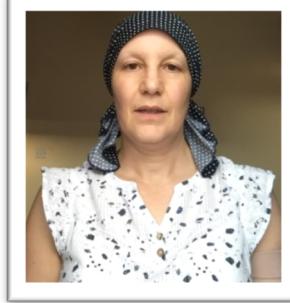


# NINA'S STORY



After I had chemo finished all my limbs and face swelled, I had an appointment at the Nightingale. They arranged for me to see the Lymphoedema team as they thought I had lymphoedema in my arm. They had a cancellation so I was seen straight away. I was diagnosed with lymphoedema then. I attend the Nightingale annually for a check-up.

## What treatment do you receive?

My lymphoedema is mild and well controlled so I don't have any. My arms are measured to check my lymphoedema hasn't worsened and my prescribed sleeves are still the right size for me. I'm also asked if I've had any problems.

I self-manage my lymphoedema. I do the skincare routine every night. I also regularly do the simple lymphatic drainage procedure. I don't manage it every night but probably an average of 5 nights a week. I wear my sleeve every day.

I take care not to cut my hand or arm. If I occasionally do, I wash it and put on antiseptic cream. I don't lift heavy weights if I can help it with my affected arm, or have injections or my blood pressure taken on that side. I do yoga and was careful to build up weight bearing using this arm.

I used to use kinesio tape but when the risk of corona virus increased and hand washing became more thorough and frequent I stopped using it. I didn't want a wet plaster on my hand all day.

## What makes your service a good one?

I have found the Nightingale to be fantastic. The staff are friendly and approachable. I feel confident in their abilities when I see them. They give you advice and tips as well as diagnosing and measuring.

The staff's dedication is shown in the way Karen advised me to make an appointment when she saw me outside of a clinical setting.

When I had my DIEP operation my arm swelled so that my sleeve no longer fitted. I asked the physio if she could make an appointment with the Lymphoedema Team while I was in hospital. Karen came to see me on the ward, measured me for a new sleeve and provided me with one. Wearing the sleeve worked really quickly and I was soon back in my usual sleeve. This was excellent service and prevented any potential further issues.

## If you would make improvements to your care, what would you recommend?

I would definitely improve the way sleeves are ordered. The Nightingale has provided my GP with full details of the sleeves I need. Two each of a sleeve with a hand piece, two each of a sleeve without a hand piece and two gloves. My prescription is sent to Daylong by the GP who sends me my sleeves through the post. On several occasions the GP has put the wrong sleeve on the prescription. I then have to get another prescription. This is unnecessary work

for all involved, an unnecessary expense as the wrong sleeves can't be returned and causes a time delay in receiving my new sleeves.

It would be helpful for kinesio tape to be available on prescription or at a discount.

When I was diagnosed, my lymphoedema notes were only held by the Lymphoedema Team. If I saw another person at the Nightingale they didn't have my lymphoedema notes. It would have been helpful if everyone had my full records. Apologies if this has since changed.

## NINA'S STORY

Nina had breast cancer and after lymph node removal developed lymphoedema. Nina was seen for lymphoedema as she was still under the care of the Nightingale for her breast cancer. Nina attends the Nightingale service once a year. Her lymphoedema is well managed; she wears a sleeve. Nina feels that she has had excellent care from the nightingale. Problems she has had in her care have been from her GP when she has handed her prescription into her GP and she has then been given incorrect garments. Kinesio tape has been advised by her service but this is not prescribed. When she has seen different staff at the Nightingale they don't have her patient notes as they are kept only by the lymphoedema team and aren't on an electric system accessed by all at the service.