

Julia Bell – Head of Publishing, Breast Cancer Care

Breast Cancer Care is the only UK-wide charity providing information and support for people affected by breast cancer. Every year around 58,000 women in the UK are diagnosed with the disease, which can affect not only the person concerned but also their family and friends.

Our roots as a charity are in the experiences of one woman, Betty Westgate, who was diagnosed with breast cancer in the 1960s. She was horrified by the lack of information and support for women in her situation. This led her to set up the Mastectomy Association in 1973, from which Breast Cancer Care directly descended.



So now our extensive portfolio of on and offline patient information is central to the services we provide and is widely used by breast care nurses and medical experts nationwide. It helps to ensure people understand more about their disease, its potential impact and their treatment options. This in turn helps patients to play as full a part as they want in their treatment and recovery, and to be less battered and bewildered by what can be a shattering experience.

This means we have a deep responsibility to ensure our patient information is accurate, up to date, accessible and supportive. We therefore use every strategy available to keep driving up standards in all these areas.

That means using the Patient Information Forum network and events to support our aims.

The networking and educational opportunities we have gained through PIF are probably best illustrated by the trail of events that has led us to present a research poster at the PIF annual conference in May 2016.

Through the PIF network, which includes the NHS England Information Standard workforce and the research-based Health Literacy Group, I learned about the Community Health and Learning Foundation (CHLF).

One of the things that motivates me most about my work is trying to make sure that as many people as possible have easy access to our patient information. This can be both by creating multimedia access points and by improving the way the base level information is written in the first place.

As the CHLF shares that passion, I was delighted to be able to commission them to do focus group user testing on behalf of Breast Cancer Care on some of our easy-to-read products.

The results were enlightening and have provided us not only with insight into improving the products tested but also with general principles to use right across our portfolio that will help make everything just that bit clearer. It is fascinating and heartening to see those principles embedding with the whole team responsible for writing and producing our patient information, from clinicians through to designers. Also, to see new products emerging.

Sometimes it can be quite gruelling dealing with cancer all day every day, but occasionally something comes along that reminds you why it really is worthwhile.

I had one such experience just this weekend (as I write) when I was at a large social event. An old friend came up to me whom I had not seen for 20 years. She told me about her breast cancer diagnosis 18 months ago. But as I was offering sympathy, she got very animated and explained she only wanted to say how helpful she had found our Primary Breast Cancer resource pack. 'It was lovely,' she said. 'It told you everything you needed to know. I put it on the shelf where I could look at it. It filled me with confidence.'

Now that's what I call job satisfaction.