Helping patients to live better with secondary breast cancer

Impact evaluation demonstrates the benefits of our Living with Secondary Breast Cancer service
The [Living with Secondary Breast Cancer] sessions are mutual – we all help each other. I can listen to the other people and validate what they are saying and feeling. I can say which painkillers I am finding useful. If I am feeling positive that day, I can help to put some positivity into the atmosphere.

I have gained very much from supporting others. It reminds me that I can still make a contribution to the lives of others, even though I am very ill myself. It reminds me that help is mutual, not just one-sided, and that everyone can give something, no matter at what stage of illness they are. I find this is very life-affirming and comforting.

From the Living with Secondary Breast Cancer impact evaluation
What is the Living with Secondary Breast Cancer service?

When patients receive a life-limiting diagnosis of secondary breast cancer it can affect every area of their lives, and they often need considerable help to adjust and come to terms with it.

“I was devastated when I was diagnosed with secondary breast cancer. Totally devastated. They said they couldn’t cure it so I had to learn to live with it. It’s always there in the background.”

Mandy, diagnosed with secondary breast cancer at age 47

Our Living with Secondary Breast Cancer support service, running since 2011 in collaboration with NHS trusts/health boards across the UK, complements your treatment and care by helping support women to adapt and live with secondary breast cancer.

In a safe and relaxed environment, regular support sessions give information about all aspects of living with the disease. Importantly, they also offer the chance to meet and talk openly with other people with the same diagnosis.

Each support session is led by a qualified therapist with group facilitation skills and relevant counselling experience. Clinical aspects are overseen by Breast Cancer Care’s in-house secondary breast cancer clinical nurse specialist.
Key facts

- regular monthly sessions
- facilitated by an experienced therapist counsellor
- flexible: people can join when they like and attend as few or as many sessions as they like
- run in collaboration with NHS trusts/health boards
- expert guest speakers such as oncologists, clinical nurse specialists and benefits advisers
- questions and discussions encouraged
- reliable signposting to other sources of local support
- self-referrals welcome
- refreshments provided, including lunch when relevant

Patients and healthcare professionals both benefit

Because of an independent study of the impact of the Living with Secondary Breast Cancer service (see box on page 6), we know that healthcare professionals value the service in lots of ways.

Many of them tell us they view it as a local support service that addresses patients’ holistic support needs that can’t be met medically yet runs alongside the medical model of care. This helps them to deliver an integrated care pathway.

An additional benefit highlighted is that it is outside the hospital, so avoids associations with possibly traumatic treatments and diagnoses.

Healthcare professionals say they notice their patients who attend the service becoming more involved in decision-making and communicating more clearly. They also notice better coping strategies.

Then there’s the fact that it can make life easier when it comes to raising difficult subjects. As a result of attending Living with Secondary Breast Cancer sessions, healthcare professionals say women often start such conversations themselves.
I had not met anyone else who had lived for so long [as I have since diagnosis]. I was needing to meet others. I was finding it harder to cope and carry on as normal.

From the Living with Secondary Breast Cancer impact evaluation

For patients, one of the biggest reasons for going along is because they want to meet other women in the same situation, to share experiences and, for example, ‘be inspired by other women’s progress in their cancer journey’.

Some other reasons are to get help managing the emotional impact of their diagnosis, find out more about local support and about the disease, and because they often don’t feel they fit in with primary breast cancer support services.

They highlight a long list of benefits, including:

- support from other women, reducing isolation and offering reassurance
- improved emotional wellbeing
- improved self-confidence
- information and support needs met
- increased knowledge and understanding of secondary breast cancer and treatment options (for example, palliative care and the role of hospices)
- improved knowledge of support services for them and their families
- improved ability to talk to family and friends about their secondary breast cancer
Independent impact evaluation

Commissioned by Breast Cancer Care in 2016, results are based on:

- telephone interviews with 20 women attending a group
- 93 survey responses from women attending a group
- survey responses from 13 therapist group facilitators and six Breast Cancer Care staff
- telephone interviews with seven NHS stakeholders, including five secondary breast cancer nurse specialists involved in setting up the service in their localities, and two oncologists

The flexible, drop-in nature of the service means there’s no pressure to attend. So women can be part of a group even if they can’t always get to the sessions, perhaps because they are unwell, fatigued, experiencing side effects or have hospital appointments that clash.

Living with Secondary Breast Cancer local groups are flexible so new people join regularly, bringing fresh relationships and new perspectives to group discussions.
Death in a group

Understandably, both patients and healthcare professionals can be concerned about the potential impact of deaths in a group.

When it happens, there are naturally deep emotional reactions, including fear and sadness. Women cannot help but think about how long they have left.

But women we spoke to also saw it is an inevitable part of the sessions – ‘part and parcel of the diagnosis’ – and found that talking within the group helped them come to terms with both the death itself and their own position.

As well as sadness, they are often also glad to have met the person who has died.

There is no doubt that this aspect of the group has a depressing effect on those left behind, raising thoughts of one’s own death and when it will happen.

But having known these women leaves one hoping to be equally brave. And, while it’s a sad part of attending the group, that is outweighed by all the benefits it brings.

“From the Living with Secondary Breast Cancer impact evaluation

The support provided by a therapist skilled in dealing with loss and bereavement is particularly key at these times. She ensures people have the chance to remember and acknowledge the person who has died as well as providing a safe space for women to express and explore the emotions that arise.
Best things about Living with Secondary Breast Cancer groups*

- welcoming, relaxed and happy atmosphere
- expert advice, and information from other women
- wide range of issues covered, including difficult topics such as fear of death and coping with emotions
- open discussion where you can raise subjects you can’t discuss at home
- good balance of expert speakers and informal sharing time
- the therapist who facilitates the sessions
- friendship, camaraderie and companionship
- talking to others in the same situation, who understand the physical and emotional consequences

*according to respondents in our evaluation survey

Our partnership with you: how it works

Some patients find out about Living with Secondary Breast Cancer from our website or Helpline and self-refer. But your involvement as healthcare professionals is vital to spread the benefits of this supportive service to people who really need it.

Without you, it is difficult for us to identify and reach the right people, and your help is invaluable in explaining to patients what the service is and the likely benefits.

On the other hand, the last thing we want to do is burden you with a big workload. So, we supply you with all the information and tools to make it easy for you to encourage the right patients to try Living with Secondary Breast Cancer.

We know that if an invitation to attend comes from a trusted healthcare professional it’s much more effective than local promotion direct from Breast Cancer Care – and even more effective if accompanied by some face-to-face encouragement.
It has changed my life completely. [I] have become more relaxed and confident about dealing with secondary breast cancer.

From the Living with Secondary Breast Cancer impact evaluation

We provide all the letters, flyers and other information, and will send more whenever you need them. Your named Breast Cancer Care Service Development Coordinator will keep in regular contact.

Twice a year we’ll give you details of attendance figures, feedback from women, the topics that have been covered and anything else you want to know.

You are also welcome to come along to a session to meet the therapist and see a group in action.

More about referrals

Patients often self-refer to Living with Secondary Breast Cancer after hearing about it from their healthcare team. But with the patient’s consent, you can pass their details to us, and we’ll be happy to contact them.

Patients and healthcare professionals agree that patients should be told about the service within three months of a secondary diagnosis. However, it’s often important to mention it on more than one occasion as some patients may not be ready or able to come along at this point.

If possible, we like people to call us before they attend for the first time so that we can welcome them, take their details (and dietary preferences), answer questions and give them all the right information. But if you feel such a call would be a barrier for one of your patients, it’s fine for them just to come along.

There isn’t a limit on numbers so anyone is welcome to join at any time throughout the year.
Expert speakers

We’ll involve you when we’re planning the programme of speaker sessions. That way we can cover topics local women are asking you about and include themes to help cover any gaps in local services.

We’ll also ask for your help in finding excellent speakers, who can be members of the care team. For example, we’ll need to identify a clinical nurse specialist or oncologist willing to present a session on medical management of secondary breast cancer. We’ll also need to find local lymphoedema, palliative care and pain management specialists willing to take on guest speaker slots. Your help with local contacts is invaluable.

Find out more and get involved

We’d love to hear from you, whether Living with Secondary Breast Cancer already runs locally and you’d like to find out more; you want to know how your patients can access these sessions; or you’re interested in helping to establish a new service in your area.

Email: secondaryservices@breastcancercare.org.uk
Phone: 0345 077 1893

We can give you all the details and support you need, including more about the independent impact evaluation.
How the Living with Secondary Breast Cancer service helps Ione

Ione Wyatt was diagnosed with primary breast cancer 12 years ago at the age of 60. Then three years ago a scan for a backache revealed the cancer had spread to several parts of her body.

She was told she probably had around three years to live but today is still well enough to attend a Living with Secondary Breast Cancer group in Dorset.

Ione says: ‘I thought it would be very depressing but in fact it was quite different. There was a lot of laughter, [with everyone having] a chance to discuss their symptoms and what the latest techniques might be, all guided by a wonderful facilitator in our group.

‘It’s joyful – it makes us forget about the negative things and feel much more positive about what we CAN do with our lives.

‘It gives people like me a real good reason for living a lot longer.’
When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone’s experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit [breastcancercare.org.uk](http://breastcancercare.org.uk)

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