

# Secondary. Not second rate

Manifesto for change

breast  
cancer  
care



## Our Vision

We want every person living with incurable secondary breast cancer to receive the care and support they need, when they need it.

We know that many people with secondary breast cancer receive care which is inferior to the care that is received by people with primary breast cancer. This is unacceptable, but it is not inevitable.

## The Problem

Forgotten. Isolated. Invisible.

This is how many of the estimated 36,000 people living with secondary breast cancer tell us they feel<sup>1</sup>. It is a result of inadequate support and care and we must not allow this to continue. We know that:

- a failure to recognise the signs and symptoms of secondary breast cancer is leading to delays in diagnosis and access to vital treatment
- a lack of information and support is leaving people with secondary breast cancer feeling isolated and unsupported
- there are too many instances where people with secondary breast cancer do not have access to vital specialist nursing support
- inadequate or non-existent data on the number of people with secondary breast cancer makes it impossible for NHS Trusts and Health Boards to effectively plan services to meet local need



<sup>1</sup> Maher, J. and McConnell, H. (2011) New pathways of care for cancer survivors: adding the numbers, British Journal of Cancer

## Our calls for action

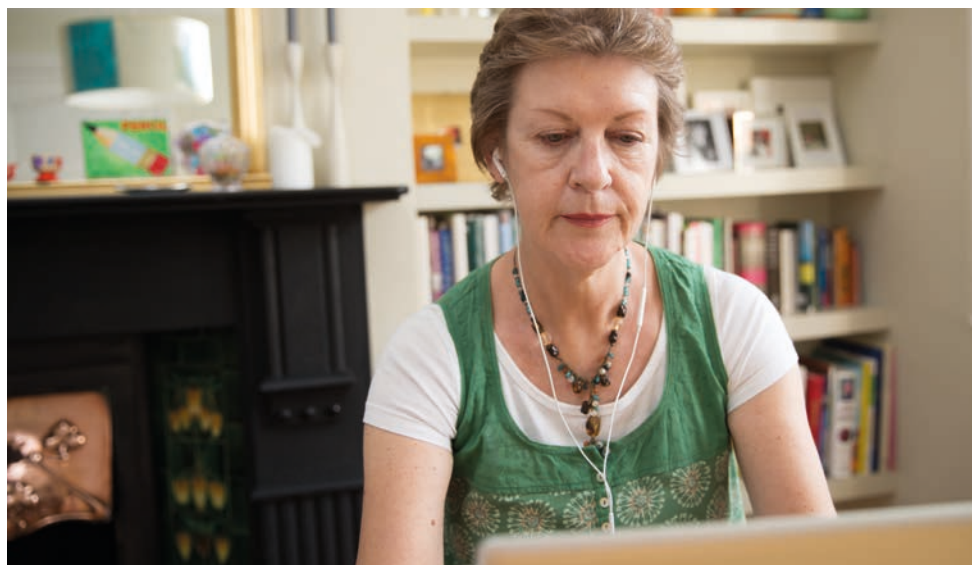
To make our vision a reality we want:

1. **EVERY** breast cancer patient and all relevant healthcare professionals to be aware of the possible signs and symptoms of secondary breast cancer
2. **EVERY** patient to be fully supported from diagnosis through treatment and as they approach end of life
3. **EVERY** person diagnosed with secondary breast cancer to have access to a specialist nurse with the right skills, knowledge and experience
4. **EVERY** Hospital Trust and Health Board to collect data on their patients with secondary breast cancer and for this data to be published nationally.

**Recognising the signs and symptoms of secondary breast cancer can lead to an earlier diagnosis. 58% of people living with secondary breast cancer that we asked did not know the signs and symptoms of secondary breast cancer.**

- **We want** all patients to be given information on the possible signs and symptoms of secondary breast cancer when they finish their hospital-based treatment for primary breast cancer. This should include a referral to a breast cancer specific health and wellbeing event, such as Breast Cancer Care's Moving Forward course, to raise awareness of these issues.
- **We want** GPs to be supported to identify possible cases of secondary breast cancer at the earliest stage possible. Common symptoms of the disease should be flagged on patients' records when there is a previous diagnosis of primary breast cancer.
- **We want** the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) to update guidance for healthcare professionals on recognising the signs and symptoms of secondary breast cancer, and on informing patients of what to look out for following treatment for primary breast cancer.

**'I never thought for one minute it was cancer... I should have probably known it could come back in your bones.'**



**People living with secondary breast cancer are not getting the information and support they need, when they need it. Of the people we asked only a third were told about relevant counselling services; only 6% accessed pain clinics. Unless patients know about available services and can access them, they cannot benefit from them.**

- **We want** people living with secondary breast cancer to be referred to a specific secondary breast cancer support service, such as Breast Cancer Care's Living with Secondary Breast Cancer service.
- **We want** people living with secondary breast cancer to be given the right information and support at the right time, from the right people.

**Support from a specialist nurse is key to a person having a positive experience of care. Despite this, three quarters of the NHS Trusts and Health Boards that we asked told us they do not have enough specialist nursing care for people with secondary breast cancer<sup>2</sup>.**

- **We want** everyone with secondary breast cancer to have support from a designated clinical nurse specialist who has the right skills, knowledge and experience, as well as allocated time and resource.

<sup>2</sup> In Scotland and Wales, the picture is less negative than it is in England, with 33% and 60% of Health Boards respectively reporting that there is not enough specialist nursing care for people with secondary breast cancer

‘When I had primary breast cancer there were two nurses and I was given a phone number for anything I needed at all. With my secondary breast cancer diagnosis this support is just not there. There’s no one person with all the specialist skills to help me through.

‘Being told I had incurable secondary breast cancer felt like going into the abyss. It is hugely isolating. What I need most is emotional and psychological support, yet I still don’t have a specialist nurse. No one I can ring for day-to-day support or questions, or to point me in the right direction for other information. I’ve had to find my own way through the dark days.’

The collection of data on the number of people diagnosed and living with secondary breast cancer has been compulsory in England since 2013. However, only a third of Hospital Trusts we asked were collecting data in full. It is hardly surprising that many hospitals find it difficult to plan services when they do not know the number of people who require care and treatment in their area.

- **We want** Public Health England to make the data that has already been submitted publicly available.
- **We want** Public Health England to support data collection by providing Hospital Trusts with clearer guidance on the data they should be collecting and how they should be collecting it.

In Scotland and Wales the collection of data on people with secondary breast cancer is not currently mandatory. However, the need to collect data has been recognised in Wales and the Scottish Cancer Registry provided an estimate in 2013 in Scotland.

- **We want** the Scottish Cancer Registry to update the estimated number of people with secondary breast cancer on an annual basis.
- **We want** the Welsh Government to introduce mandatory data collection for people with secondary breast cancer in line with their stated intentions.

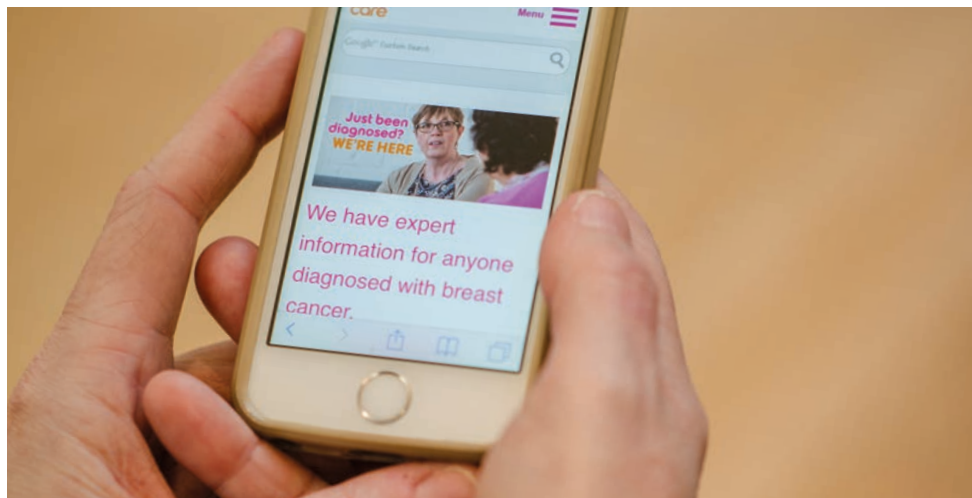
With your help, we can ensure people living with incurable secondary breast cancer get the care and support they need.

## Show your support.

- Pledge your support to our manifesto: [breastcancercare.org.uk/secondary](https://breastcancercare.org.uk/secondary)
- Share the manifesto on twitter [#BCCare](https://twitter.com/BCCare) [#NotSecondRate](https://twitter.com/BCCare)
- Join our Campaigns Network for all the latest information  
[breastcancercare.org.uk/submission/join-campaigns-network](https://breastcancercare.org.uk/submission/join-campaigns-network)

Everybody living with secondary breast cancer should receive high quality information, support, treatment and care. To support the provision of this, Breast Cancer Care has developed Standards of Care for what people living with secondary breast cancer should be able to expect<sup>3</sup>.

If you have any questions, contact [campaigns@breastcancercare.org.uk](mailto:campaigns@breastcancercare.org.uk)



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](https://breastcancercare.org.uk)

<sup>3</sup>Breast Cancer Care, Standards of care for people with secondary (metastatic) breast cancer, 2017; [https://www.breastcancercare.org.uk/sites/default/files/files/cool062\\_standards\\_of\\_care\\_a4\\_poster\\_2017\\_final.pdf](https://www.breastcancercare.org.uk/sites/default/files/files/cool062_standards_of_care_a4_poster_2017_final.pdf)