



Care After Breast Cancer

It shouldn't end with treatment

About Breast Cancer Care

Breast cancer changes everything. Breast Cancer Care understands the emotions, challenges and decisions people face every day. We know that everyone's experience is different. That's why we're here to offer support and information and campaign for better care.

We're the only specialist UK-wide charity providing support to people with breast cancer. Our free services include support over the phone with a nurse or someone who's been there, welcoming online forums, reliable information and local group support. We help people to live life with breast cancer and beyond. From the moment someone notices something isn't right, through their treatment and beyond, Breast Cancer Care will be there.

The importance of post-treatment support after breast cancer

This document sets out the need for improved post-treatment support for people completing their hospital-based treatment for breast cancer. It includes what patients are telling us about their needs at this stage, as well as the current provision of such support in England. It also explores what next steps are needed to ensure this vital support is available for patients, including how Breast Cancer Care's Moving Forward®¹ course is contributing to this aim.

At Breast Cancer Care we know that adapting to life after a diagnosis of and treatment for breast cancer can be extremely difficult. The difficulty of this transition has also been reflected in the focus of the UK cancer strategies.

In England, the ambition that every person with cancer has access to the elements of the Recovery Package by 2020, including access to a Health and Wellbeing event to support them to live well beyond cancer, was set out in the current cancer strategy **Achieving World-Class Cancer Outcomes: A Strategy for Cancer 2015-2020**¹.

The Scottish cancer strategy **Beating Cancer: Ambition and Action**² has a focus on supporting people to live with and beyond cancer, including via the Transforming Care after Treatment (TCAT) programme.

The **Cancer Delivery Plan for Wales 2016-2020**³ recognises the need to 'better meet the needs of people who have finished their treatment' and supports the rollout of access to elements of the Recovery Package across Wales.

What patients are telling us

A recent survey, of almost 3,000 women with a diagnosis of primary breast cancer in England⁴, conducted by Quality Health on behalf of Breast Cancer Care found alarming gaps in the information and support provided following treatment:

- Two fifths (41%) of women with breast cancer did not receive the professional support they needed to cope with the long-term effects of the disease.

¹ Moving Forward is a registered trademark for written information, training and educational services, and counselling and support services provided by Breast Cancer Care for people affected by breast cancer

- At the end of hospital treatment almost half (45%) of women with breast cancer are not told, by a healthcare professional, the cancer could come back. And over half (55%) are not given any information about the signs and symptoms of the cancer returning.
- A third (34%) of women with breast cancer have constant pain as a result of treatment. The pain has prevented a quarter (24%) from continuing with their normal daily lives.

This shows a clear need for post-treatment support and information. Despite this, over half (54%) were not told about a health and wellbeing event (generic or breast cancer specific) at the end of their hospital-based treatment for breast cancer.

The importance of tailored support

96% of breast cancer patients said that a breast cancer specific health and wellbeing course would best meet their needs at the end of treatment.

Whilst the UK cancer strategies focus on health and wellbeing events, it is not specified whether or not these should be applicable to all cancers ('generic' events) or tailored to the specific needs of each cancer type ('tumour specific' events).

Breast cancer patients represent the largest cancer patient group in the UK, with approximately 691,000⁵ people living after a breast cancer diagnosis. Breast Cancer Care believes that there is a clear need for tailored, breast cancer specific post-treatment support, to enable people to manage the specific symptoms and side effects of a breast cancer diagnosis and treatment and to live well beyond breast cancer. This need is demonstrated in the following ways:

- Breast cancer patients tell us they prefer support that is specific to breast cancer. 96% of breast cancer patients⁶ said that a breast cancer specific course would best meet their needs rather than a course for all types of cancer.
- People living with and beyond breast cancer experience a unique combination of treatment side effects that differ considerably from those of the other most common cancers in the UK.⁷ For example, many women experience menopausal symptoms and lymphoedema. Menopausal symptoms are reported by the majority of women who receive treatment for breast cancer and have been found to negatively correlate with the quality of life of patients and their partners.⁸ Lymphoedema remains a significant quality of life issue after treatment for breast cancer and consequences including anxiety, frustration, sadness, anger, fear and increased self-consciousness impact a woman's physical, psychological and emotional wellbeing.⁹
- We know that people value the opportunity to talk to others who have also experienced a breast cancer diagnosis. Facilitation of peer support and the opportunity to share experiences are extremely valuable to patients.
- With the move towards ever more tailored treatments for breast cancer, it is vital that this progress is also matched in the support people receive after treatment ends, to ensure the best outcomes and quality of life for patients.

Current provision of post-treatment support for breast cancer patients across England

We know that not all patients have access to such support. Whilst we know that implementation of this to date has been patchy, there has been no national picture available on provision of these services. This makes it difficult to identify areas where patients may not be getting this vital support.

To help us build a picture of post-treatment support provision for breast cancer patients across England, Breast Cancer Care sent Freedom of Information (FOI) requests to NHS Hospital Trusts to identify current provision.

We received responses from 96% of these organisations and found that over half (51%) of Hospital Trusts don't provide a breast cancer specific health and wellbeing event.

Provision by Cancer Alliance

Cancer Alliance	Percentage of NHS Trusts that told us they don't provide a breast cancer specific health and wellbeing event
Cheshire and Merseyside	75%
Coast, Humber and Vale	33%
East of England	60%
East Midlands	80%
Greater Manchester	30%
Kent and Medway	100%
Lancashire and South Cumbria	50%
North Central and North East London	67%
North East and Cumbria	38%
North West and South West London	57%
Peninsula	50%
Somerset, Wiltshire, Avon and Gloucestershire	22%
South East London	33%
South Yorkshire, Bassetlaw, North Derbyshire and Hardwick	0%
Surrey and Sussex	33%
Thames Valley	50%
Wessex	50%
West Midlands	86%
West Yorkshire	80%

What this means for patients

These findings show there is inadequate provision of post-treatment support for breast cancer patients across England.

A significant proportion (16%) of Hospital Trusts do not currently provide any health and wellbeing event at all for those finishing their hospital-based treatment for breast cancer, meaning patients in these areas are missing out on vital post-treatment support.

As described above, if support is available, many people are not informed about it.

In addition, only 49% of Hospital Trusts provide tailored, breast cancer specific health and wellbeing events. Instead, the support provided is intended to meet the needs of people with all cancer diagnoses. However, as described above, we believe that this generic support does not best meet the specific needs of breast cancer patients.

Breast Cancer Care's Moving Forward® course


Moving Forward is a tailored, self-management course specific to breast cancer patients. It provides crucial elements of post-treatment care, information and support, and also covers self-management of ongoing side effects.

Whether someone is experiencing side effects of treatment, wondering how to adopt a healthier lifestyle or experiencing the uncertainty and anxiety that can follow treatment for breast cancer, Breast Cancer Care's Moving Forward course is there to support them. Moving Forward provides information and support from experts on how to manage the concerns and side effects of breast cancer and its treatment, and acts as a forum for people affected by breast cancer to share their experiences and support each other.

Breast Cancer Care is currently working in partnership with 70 NHS Trusts and Health Boards across the UK to deliver Moving Forward to breast cancer patients.

The impact of Breast Cancer Care's Moving Forward course

A recent independent evaluation¹⁰ of our Moving Forward course found that it significantly improves the quality of life of participants, reducing concerns and improving emotional wellbeing. As well as benefits for the individual, the results show that Moving Forward also delivers social and economic value for the NHS and wider society.



'The course has helped me adapt to my new reality. I was taught coping mechanisms, received expert advice and shared my experience with other people who had been through similar things.'

Lurline Thomas, Moving Forward participant

Impact on the individual

The evaluation used metrics widely used by the NHS, including the EQ-5D quality of life measure.

The average EQ-5D score for female members of the general population is 0.85. This number is considered an indicator of 'normal' quality of life.

The evaluation found that those attending the Moving Forward course were moved from below average quality of life (average EQ-5D score of 0.79) to a near normal quality of life (average EQ-5D score of 0.83).

The evaluation also found that after attending a Moving Forward course there was a significant increase in patient activation as measured by the Patient Activation Measure (PAM).

PAM separates individuals into one of four activation levels. Each level provides insight into health-related characteristics, including attitudes, motivators and behaviours, which determine the ability to self-manage one's health and healthcare. The evaluation also found that after attending a Moving Forward course there was a 10% increase in people at level 4 (see figure 1).



Figure 1: Patient activation levels

The Moving Forward course therefore enables people to become 'self-managers' of their own health and wellbeing.

Impact on the NHS and wider society

As well as benefits to the individual, the results of our evaluation show clear opportunities for the NHS and wider society.

There are clear potential benefits to the NHS. People at higher levels of activation experience better health, have better health outcomes and fewer episodes of emergency care.

The evaluation also estimated, using Social Return on Investment (SROI) methodology, that for every £1 invested by Breast Cancer Care to deliver Moving Forward, the value to wider society is £4.50.

For further information on the evaluation methodology and findings, please see the [full report](#).

Conclusion

Breast Cancer Care's Moving Forward course is a tailored, breast cancer specific post-treatment support event, which has been shown to improve people's quality of life following treatment. The course provides an ideal solution to the gap in post-treatment support identified by the **Care After Breast Cancer** campaign.

Breast Cancer Care is calling for:

- Every breast cancer patient to have access to a health and wellbeing event after hospital treatment ends
- This event to be breast cancer specific, so that it is tailored to meet patients' needs and has maximum impact on their ability to live well after breast cancer
- The Government to ensure this happens by supporting Cancer Alliances to deliver breast cancer specific health and wellbeing events

Further information

For further information about the **Care After Breast Cancer** campaign, please contact campaigns@breastcancercare.org.uk or call Gunes Kalkan, Head of Evidence, Policy and Campaigns on 0207 960 3447.

References

¹ [Achieving World Class Outcomes: A Cancer Strategy for England 2015-2020](#), Independent Cancer Taskforce, 2015

² [Beating Cancer: Ambition and Action](#), The Scottish Government, March 2016

³ [Cancer Delivery Plan for Wales 2016-2020](#), Wales Cancer Network, November 2016

⁴ Figures from a Breast Cancer Care survey by Quality Health. Fieldwork was undertaken between 5 March and 18 June 2018. The sample is of 2,862 women in England with primary breast cancer, with no additional diagnoses who have finished hospital treatment.

⁵ [The Rich Picture with Cancer](#), Macmillan Cancer Support, 2014

⁶ [Moving Forward: Supporting people to live well with and beyond breast cancer](#), Breast Cancer Care, 2017

⁷ [Moving Forward: Supporting people to live well with and beyond breast cancer](#), Breast Cancer Care, 2017

⁸ Menopausal symptoms in women treated for breast cancer: the prevalence and severity of symptoms and their perceived effects on quality of life, P. Gupta, D. Sturdee, S. Palin, K. Majumder, R. Fear, T. Marshall, I. Paterson., *Climacteric*, 9:1, 2006

⁹ Lymphoedema following breast cancer treatment and impact on quality of life: A review, NR. Taghian et al, *Critical Reviews in Oncology / Haematology*, 92:3, 2014

¹⁰ [Moving Forward: Supporting people to live well with and beyond breast cancer](#), Breast Cancer Care, 2017