



breast
cancer
care

Stronger together:
support services for people living
with and beyond breast cancer

Who we are and what we do

Breast Cancer Care is the only UK-wide charity providing specialist information and support for people affected by breast cancer and the healthcare professionals who care for them. For over 40 years we've helped thousands of people feel better informed, more confident and in control, supporting them to manage their day-to-day life and the emotional upheaval of breast cancer.

As a healthcare professional you know more than anyone that a breast cancer diagnosis changes everything and that people can feel overwhelmed, scared and alone. So we want to work closely with you to help ensure your patients get the best support, information and care. We offer expert, tailored and friendly support services to enhance and complement the care you provide. We're here to listen, understand, care and help people move forward with more confidence when hospital-based treatment has finished.

For more information about our services contact us on **0345 077 1893** or email **services@breastcancercare.org.uk**

Your guide to free services for your patients: contents

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*Moving Forward® is a registered trademark.

Introduction

As a healthcare professional you know that people affected by breast cancer have many different needs and concerns. Their diagnoses, prognoses and treatments vary widely, as do their life circumstances.

Breast Cancer Care's telephone Helpline, website, online Forum and Information Points provide a wealth of information and support for everyone affected by breast cancer, as well as resources for healthcare professionals. And for groups who benefit from a more tailored approach, we've designed services to meet their needs.



Helpline and Forum Questions about breast cancer? Or if your patients want more information, to talk things through or find more support, Breast Cancer Care's Helpline experts are available by phone or email. And if they want to get in touch with other people affected by breast cancer our online Forum is available 24 hours a day.

See page 8



Information resources in print and on our website

Our award-winning range of publications and other information resources are available in print and online. We also supply Information Points free of charge for hospital clinics and cancer support centres. Topics covered by our extensive portfolio include breast cancer diagnosis and treatment, and breast health.

See pages 9 and 10



The BECCA mobile app serves up trustworthy tailored information and supportive ideas for people trying to adapt to daily life once hospital-based treatment ends. Daily 'flashcards' are delivered to their mobile phone.

See page 11



Moving Forward helps people to adjust to life after hospital-based treatment. It is provided in partnership with NHS trusts and health boards across the UK. Information and support encouraging self-management of ongoing physical and emotional issues is provided in four sessions over four weeks. Importantly, people also have the chance to share their experiences with peers in a safe and caring environment.

See page 12



Someone Like Me is a one-to-one peer support service that pairs a patient, friend or family member with a trained volunteer with similar experience. People are carefully matched for a variety of factors, including their treatments, personal circumstances, priorities and concerns.

See page 18



Living with Secondary Breast Cancer sessions are monthly meet-ups supporting people to live with secondary breast cancer, and complementing their treatment and care. Regular sessions in a safe and relaxed environment give information about all aspects of living with the disease, along with the chance to meet and talk openly with other people with the same diagnosis.

See page 22



Younger Women Together information and support events are for women aged up to 45 who have been diagnosed with primary breast cancer. This comparatively small group of patients often feel particularly isolated as their concerns about family, fertility, career and sexuality are not usually the same as those of older women.

See page 24

How our services work

Find out more about how Breast Cancer Care's services work, how they align with government policies and the evidence for their effectiveness.

Working in partnership

People can access our services through our website or Helpline and we have Information Points in more than 160 NHS hospitals. These are stocked with our patient information so that it's freely and easily available.

But your help is invaluable, signposting and explaining our services to your patients. Without this, it's harder for us to reach the right people – an invitation from a trusted healthcare professional has been proven to be more effective to encourage people to take up services than any type of marketing. Even better if it's delivered face to face.

However, the last thing we want to do is to add to your workload, so we provide you with all the tools and resources you need.

We can help you to support your patients in the ways that best meet their needs.

Underpinning national strategies and local pathways

There is a strong commitment to empowering patients in key national policy documents:

- Achieving world-class cancer outcomes: a strategy for England 2015–2020
- Cancer Delivery Plan for Wales 2016–2020
- Beating Cancer: Ambition and Action, launched by the Scottish Government in March 2016

These strategies highlight the need for high-quality information for patients living with and beyond cancer, and recognise the benefits of support services.

In England and Wales there is a commitment to providing these key elements of the Recovery Package for cancer patients (see Box). In Scotland, the strategy envisages health, social care and the third sector working together so that transition for everyone with a cancer diagnosis is not only supportive but also meets the needs of the individual.

The Recovery Package

'The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer.'

Macmillan Cancer Support.

It was developed and tested by The National Cancer Survivorship Initiative. One element of the package is an education and support event for patients to help them move forward with confidence after cancer diagnosis and treatment.

Our services can play a significant role in the implementation of supported self-management, enabling patients to make informed choices and encouraging peer-to-peer support networks that often last for months or years.



Helpline

If you as a healthcare professional have a question about breast cancer – or if your patients want more information, to talk things through or find more support – our experts are at the end of a phone line. All calls are answered by specialist breast care nurses or highly trained Helpline staff.

Whatever your patients' concerns, you can be confident that the information they'll receive is clear, accurate and up-to-date.

Call free on
0808 800 6000

We are open six days a week

Monday to Friday, 9am–4pm,
Saturdays, 9am–1pm.

Website and Forum

Our website is a wide-ranging resource of expert information about breast cancer and breast health, as well as blogs and real-life stories so people know that they are not alone with their life-changing diagnosis.

It also explains all our services, and volunteering and fundraising opportunities, as well as a wealth of information for healthcare professionals. Go to breastcancercare.org.uk

The welcoming online Forum is there for your patients, with practical and emotional support at any time of the day or night. Whether they're worried about their breasts, wondering how they'll cope with their diagnosis or treatment, or concerned about a friend, they'll find this a welcoming community of understanding people offering 24-hour access to online support.

'I really want to thank all of you... on this forum... for making this extremely difficult time in my life as easy as possible for me to deal with... You make me laugh, make me feel better on a down day. You give all the best advice from the heart but most of all, you understand.'

Visit the Forum at
forum.breastcancercare.org.uk



Information resources

You can rely on our award-winning range of publications and other information resources. Whether it's for you or your patients, topics covered by our extensive portfolio include breast cancer diagnosis and treatment, and breast health.

All resources are free, written by clinical specialists and reviewed by independent healthcare professionals and people affected by breast cancer. Both our print and online patient information is accredited by the NHS England Information Standard as high quality, user-friendly, accurate and up-to-date.

See the full range and order free at breastcancercare.org.uk/publications

Information Points

Our patient information can be displayed on Breast Cancer Care Information Points, which we place on request and free of charge in hospitals and cancer support centres.

Each stand has a selection of top titles from our range of information resources including leaflets on breast health and breast cancer. The stands come in two types: freestanding or wall-mounted.

The Information Points are stocked and maintained by volunteers recruited, trained and supported by us.

Our Information Points make it easy for people visiting breast clinics to find the right leaflets and resources. They also help breast care nursing teams to keep patients well informed and save them time ordering supplies.

'We've always used Breast Cancer Care publications to back up our discussions with patients, but we also like patients to be able to choose for themselves the booklets that may be useful to them. Our Information Point, in the entrance to the unit, is the perfect way to display valuable resources to those we care for.'

Heidi Barclay,
Clinical Nurse Specialist,
Broomfield Hospital, Essex

If you would like to discuss placing an Information Point in your location, please call our Services Support Team on **0345 077 1893**

The BECCA mobile app

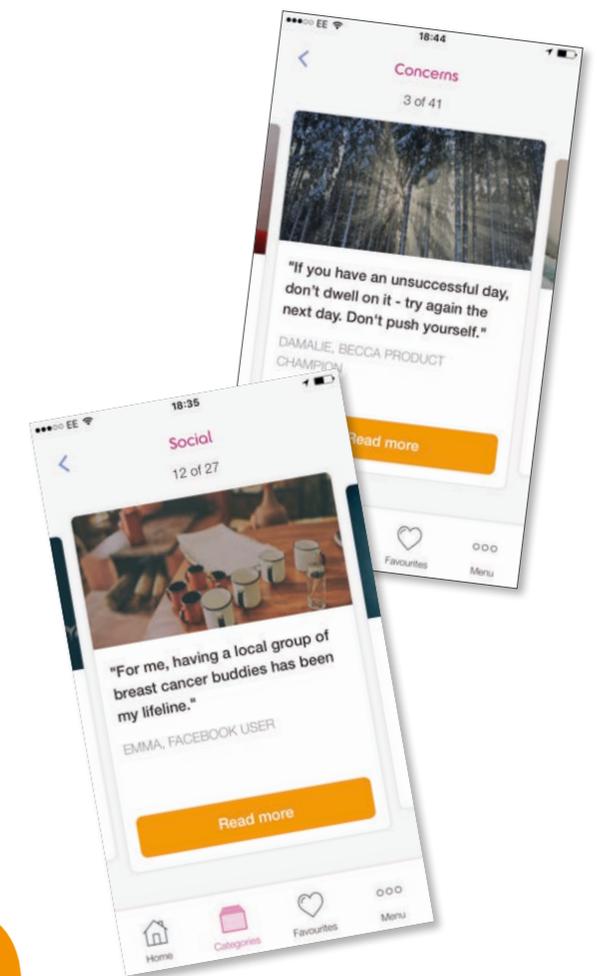
The BECCA app supports people as they come to terms with their experience, delivering day-to-day strategies and tips direct to their mobile phone. Simple flashcards cover a range of topics, from wellbeing and mindfulness to insights from other patients, reminding people that they're not alone and helping them to adjust to life beyond breast cancer.

The app can be accessed 24 hours a day, complementing the Moving Forward course and available for anyone to use if they are looking for support to move on.

Kim Hulme, 47, from Dartmoor in Devon, was diagnosed in May 2016. She has been using the BECCA app since she finished treatment.

'Living in a remote area, I felt cut off from support and was desperate for something I could access online... BECCA has been absolutely perfect for me. It has reminded me to look after myself and helped me change how I feel. For instance, I felt really wobbly about exercise and needed to know how to get back into it slowly – the app has helped me do that.'

You can find the app by searching for 'BECCA' in the **App store** and **Google Play**



Moving Forward

The Moving Forward course supports people adjusting to life after hospital-based treatment. Four weekly sessions provide the information and support people need to help manage ongoing physical and emotional issues. Sharing their experiences with others in a safe and caring environment is also important and one of the benefits highlighted by participants.

The need

Research shows that many people with breast cancer are left with a range of unmet needs following treatment. Factors that can negatively impact on their quality of life include:

- side effects of treatment, including fatigue, lymphoedema and menopausal symptoms
- physical changes such as weight gain and chronic pain
- psychological problems such as anxiety, depression and altered body image
- relationship, intimacy and fertility issues
- financial and employment problems

National cancer strategies recognise these issues, with a clear commitment to making the patient experience as important as clinical excellence and providing support for people to live well beyond a diagnosis of breast cancer, through initiatives such as the Recovery Package (see box page 6). But pressure on NHS resources and the growing numbers of people living with and beyond breast cancer has left gaps in provision so that patients often miss out on this vital support.

Moving Forward addresses some of these gaps by supporting patients to manage their condition with knowledge and confidence. And because this reduces the need for expensive routine follow-up appointments, clinical time is freed-up for other patients.

As Moving Forward courses are planned and delivered in partnership with healthcare professionals, together we can ensure that they provide information and support specifically tailored to breast cancer patients, acknowledging and meeting the needs outlined above.

What we offer and how it works

The course is aimed at patients who are near the end of their hospital-based treatment for primary breast cancer or who have finished their primary treatment within the past two years.

'I gained comfort from being in a room with people who have all been in the same boat as me. And now I feel that I've been given a chance at life.'

Carol, Cardiff

'When treatment finished I was delighted, but I also felt quite isolated. Breast Cancer Care enabled me to accept that I'm not alone in my worries for the future, and helped me find a way to share how I feel with those close to me.'

Suzanne, Birmingham

The programme

Typically, weekly three-hour sessions are run over four weeks, either in a suitable room in the hospital or at another local venue. Patients are asked to commit to the full course, and up to 20 people attend, giving them the chance to get to know each other and share experiences. Sessions are run by a facilitator commissioned by us, or by a member of Breast Cancer Care staff, assisted by trained volunteers.

Participants are:

- helped to understand the impact that breast cancer can have
- reassured that their fears and concerns are normal
- supported in coping with anxiety
- encouraged to feel confident in sharing their experiences within the group
- given the information they need about the possible longer-term effects of treatment
- supported in discussing changes in body image
- supported in discussing the impact on relationships
- helped to recognise possible symptoms of recurrence, and advised on how to report them and how to access more psychological support

Healthcare professionals give talks on a range of key subjects with allotted time for discussion and peer-to-peer support.





The NHS and Breast Cancer Care working together

We now run over 200 Moving Forward courses a year in partnership with NHS trusts and health boards across the UK. The success is built on:

- clearly defined partnerships with clinicians, breast care nurses and clinical nurse specialists
- programmes tailored specifically for breast cancer patients as a result of Breast Cancer Care and healthcare professionals working together to identify needs
- expert speakers and high-quality information, including a copy of our comprehensive Moving Forward resource for every attendee
- time allocated for informal group discussions and peer support
- accessible times and venues

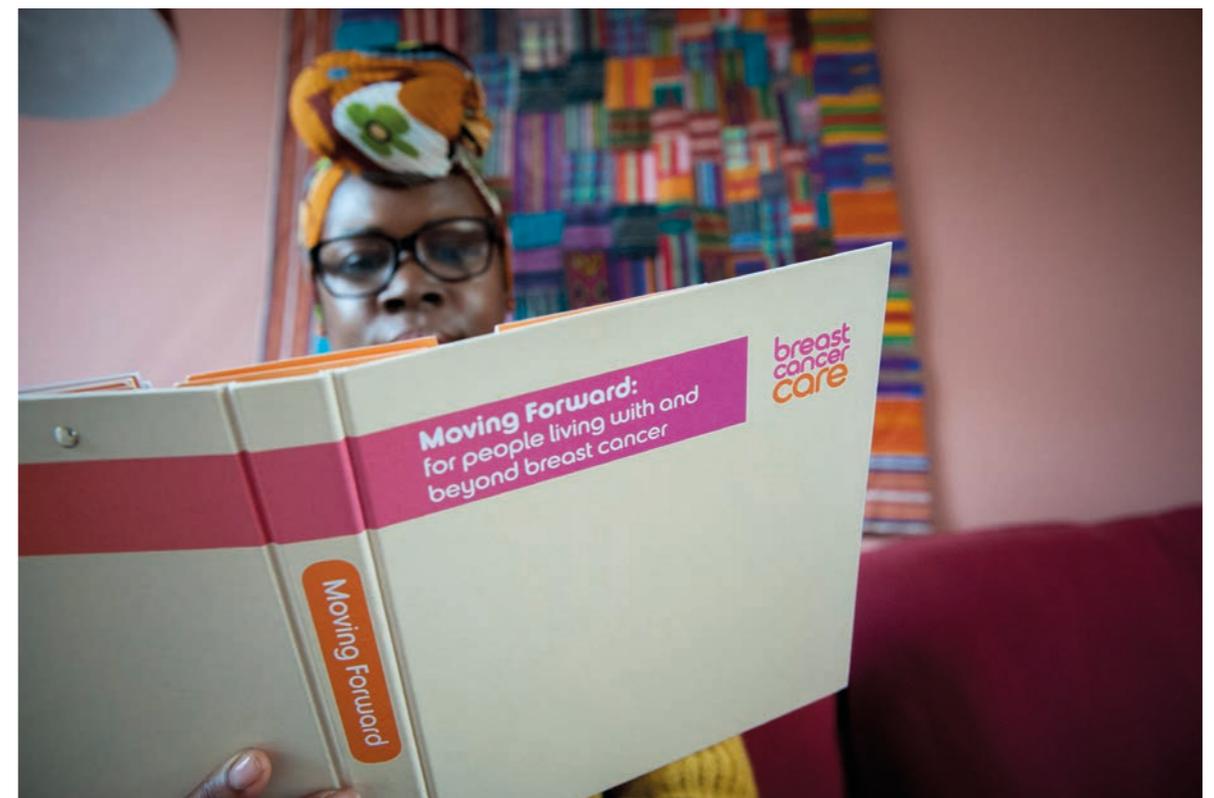
Moving Forward resource

From signs and symptoms of recurrence to dealing with fatigue and financial issues, this resource complements the Moving Forward course. It offers practical solutions, sources of further support and insights from other people in the same situation.

The role of healthcare professionals	Breast Cancer Care's role
Providing specialist knowledge in planning and delivering the sessions and assisting with sourcing expert speakers	Structuring the course, including tailoring the content
Providing the venue and IT equipment	Coordinating the course, handling the registration, administration and facilitation of the groups
Referring patients to the course by explaining the benefits and encouraging attendance	Training and supporting Moving Forward facilitators and volunteers to deliver courses
Contributing to ongoing improvements through review meetings	Conducting the evaluation and compiling reports for each course

We understand the pressures faced by healthcare professionals, so Moving Forward is designed to ensure that your involvement adds as little as possible to your workload. We provide speakers

with briefings and a toolkit of resources to help them plan and deliver their sessions. We also carry out monitoring and evaluation, providing partners with feedback and impact reports.



Moving Forward: for people living with and beyond a diagnosis of primary breast cancer

Support from healthcare professionals

The programme is firmly backed by the healthcare professionals delivering it. They see it as complementing their work in supporting patients through diagnosis, treatment and recovery, and providing an essential part of the Recovery Package.

‘We have had lots of positive feedback, particularly about the invaluable peer support that comes through shared experiences and the lasting friendships that have developed.’

Fiona Armitage and Angela Oakley,
Breast Care Nurses,
Royal Hallamshire Hospital, Sheffield

‘The Moving Forward course is invaluable in supporting patients, either during or at the end of their treatment.’

Julie Smith,
University Hospital Llandough, Cardiff

‘The course allows patients an opportunity to explore and discuss the issues affecting them in a safe and confidential environment, putting to rest any fears and anxieties related to their diagnosis and treatment.’

Finola Woodhouse, Breast Care Nurse,
Western General Hospital, Edinburgh

Meeting the specific needs of breast cancer patients

Moving Forward is the only health and wellbeing intervention specific to breast cancer patients, providing tailored post-treatment support and information. In our 2017 survey of over 800 course attendees, conducted by independent researchers Frontline, 96% of respondents said that they preferred a breast-specific format.

Clinical nurse specialists understand that the course can address sensitive issues such as sexuality, body image, menopausal symptoms and fertility, which can be difficult to discuss on generic cancer support courses.

Conversely, generic cancer support courses can be dominated by the larger numbers of people with breast cancer, which can lead to people with less common cancers feeling marginalised.

‘Sharing experiences with other people with breast cancer can help patients to normalise their situation, make sense of what has happened and develop a range of strategies to help them adjust and build their confidence.’

Dr Emma Selwood,
Clinical Psychologist, London

‘Moving Forward provides an opportunity to give patients a broader perspective about breast cancer and how we make decisions on treatment. As a clinician it is also good to see patients in a slightly less formal and time-pressured environment than the clinic.’

Matthew Barber, Consultant Breast Surgeon,
St Johns Hospital, Livingston

‘The course is very helpful for breast care nurses as well as patients, as it gives us a platform to discuss anything that patients feel needs addressing, particularly issues that are not always brought up in clinic.’

Mags Moore, Breast Care Nurse,
Glan Clwyd Hospital, Rhyl

How do patients access the service?

The most straightforward way for patients to access a Moving Forward course is through direct referral from a breast care nurse or other healthcare professional to Breast Cancer Care’s Services Support Team.

When we set up a course in partnership with you, we arrange a simple referral system where patients are contacted by us at the relevant time and invited to register on the next available course. The process works best when patients are told about the course at an early stage and when the course is seen as part of the patient pathway.

Details of all Moving Forward courses are also available on our website.

Call 0345 077 1893
Website [breastcancercare.org.uk/moving-forward](https://www.breastcancercare.org.uk/moving-forward)

Someone Like Me

Someone Like Me is a one-to-one peer support service, matching the patient with a trained volunteer whose experience of breast cancer and/or personal circumstances are similar to their own. It is also open to partners, families and friends and accessed by telephone or email.

The need

Every patient's breast cancer is different, and their particular concerns will vary too. The chance to speak to someone who has been through the same diagnosis and experienced similar concerns can deeply complement the expert support provided by the clinical team.

Increasingly, patients are asked to make decisions about their treatment, for example, reconstructive choices or when chemotherapy is predicted to offer only marginal benefit. Speaking with a trained volunteer with first-hand experience of treatments or who has faced a similar decision can help patients to make informed choices. Equally, it's for people who might just be feeling down, isolated or want to chat through more emotional issues.

'I was trying to work out how I would manage to go back to work after my diagnosis. It was the process of going back to work after a long break that caused me the most grief, rather than my treatment. The service put me in touch with Arlene, who has been brilliant... It has been really useful to talk to someone who "gets it" – she understands the fears, the concerns and the hopes, and has helped me confirm what to do next.'

Lisa Rüll, Nottingham

What we offer and how it works

Someone Like Me is for people who have, or have had, primary breast cancer and people undergoing genetic testing or who have received a genetic diagnosis, as well as for their partners, family and friends.

We aim to support people with whatever concerns them most. Our team will talk in depth with your patient to get a clear picture of their diagnosis and treatments, their personal circumstances and the issues currently affecting them, for example, having surgery, chemotherapy and/or radiotherapy. This enables us to select the volunteer best placed to provide the sort of support the patient is seeking – whether it's making an informed decision about treatments or reconstructive surgery, coping with the shock of diagnosis, managing family life or regaining some sort of normality after treatment.

Our Someone Like Me volunteers:

- listen
- offer emotional support and practical tips
- share their own experiences without providing medical advice
- support patients in making informed decisions without being directive or imposing their own views

Volunteers go through a careful selection process followed by comprehensive training, which includes role-play and covers topics such as listening skills, appropriate disclosure, how to avoid creating dependency and ending support. All are assigned an experienced mentor and they receive ongoing support, supervision and training throughout their time in the role.

The vast majority of our volunteers have had a diagnosis of breast cancer but some are partners of people who have had breast cancer. Others have an altered gene that increases their risk of breast cancer but have not had a cancer diagnosis.



How do patients access the service?

Patients can access Someone Like Me directly by phone, email or through our website. A member of the team will chat through their circumstances and concerns to enable us to identify the best possible match. We can also, with patient consent, accept direct referrals from healthcare professionals.

Call 0345 077 1893

Email someonelikeme@breastcancercare.org.uk

Email support is also offered by some volunteers if patients prefer. Profiles of these volunteers are on our website and they can be emailed directly. Breast Cancer Care staff monitor the first contact emails to ensure all patients receive an appropriate and timely response.

‘We identify a patient’s concerns through an assessment with them. Often people feel isolated and vulnerable after they’ve been diagnosed, or feel that they need to talk to someone about the treatment decisions they need to make. If we think that they’d benefit from speaking to a volunteer who’s been in a similar position to them, I’ll tell them about the service or I’ll ask for their consent to be referred. It’s easy for me to drop the team an email with their name and number. The patient then has someone to talk to outside of their family and friends, which can help them feel less alone.’

Deborah Mumford, Breast Care Nurse,
Royal Glamorgan Hospital

Case study: Jackie Milani, London

Being diagnosed with breast cancer in April 2017 was a ‘real shock’ for 59-year-old Jackie Milani. Apart from having children and having her tonsils out, she’d not been in hospital before. She was so shocked that initially she couldn’t eat.

She said, ‘My diagnosis was triple negative and while I was having my chemotherapy I started to feel that I wasn’t coping and I really needed to talk to someone who had had a similar experience.’

‘Someone Like Me arranged for a volunteer called Annie to call me. She’d been through it six years ago.’

‘I’ve spoken to her a few times, and she is very supportive, uplifting, with a lovely voice and so positive. She helped me to realise that if I needed support, it was OK. She told me that once you get into the rhythm of your treatments, it can go so quickly – which I found to be the case.’

‘I feel that I’ve learnt so much and been so lucky. I’m now doing my daily, normal things like cleaning the bathroom or going shopping. I can’t sing the praises of the NHS highly enough. And having support from someone with the same diagnosis as me has been a great comfort.’

Living with Secondary Breast Cancer

This service is for women with incurable secondary breast cancer, bringing them together to support each other, and providing information and support tailored to their particular needs.

The need

When patients receive a life-limiting diagnosis of secondary breast cancer it can affect every area of their lives. Their practical and emotional support needs will vary as time goes on and they are likely to be on treatment for the rest of their lives. Yet our research shows that all too often women with secondary breast cancer have less access to a clinical nurse specialist than people with a primary diagnosis and that their information needs aren't always met (research reports available at breastcancercare.org.uk/secondary)

'Diagnosis was like an earthquake as I was a fit, keen mountaineer. My strength and confidence were destroyed. Knowing that it is incurable means you have to face your own mortality and I took a long time to come to terms with this. I can't plan ahead with any certainty and my life revolves round my three-weekly visits to hospital, which have now been going on for 11 years.'

Chris Jowett, Dunlop, Kilmarnock

What we offer and how it works

Our Living with Secondary Breast Cancer support service has been running across the UK since 2011. Working together with the NHS, the service complements the treatment, care and support that healthcare professionals provide.

Monthly sessions held in a safe and relaxed environment cover all aspects of living with the disease. Just as important, they also offer patients the chance to meet and talk openly with other women with the same diagnosis.

Each group is led by a qualified counsellor skilled in group facilitation and in supporting people with a life-limiting illness, while the clinical aspects are overseen by Breast Cancer Care's in-house secondary breast cancer clinical nurse specialist.

And for women under 45, we hold an annual event, Younger Women with Secondaries Together. This brings people together for two full days, usually from Friday to Saturday, with free accommodation on the Friday night, giving them the time they need to build supportive friendships. See the next section.

Case study: Ione Wyatt, Dorset



Nine years after Ione had treatment for primary breast cancer a scan for backache showed that the cancer had spread to several parts of her body.

In 2014 at age 69, 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.

'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.'

How do patients access the service?

Patients can get in touch by phone, email or via our website. We try to speak to everyone before they come along to answer any questions and ensure the service will meet their needs.

We are also happy to accept referrals direct from healthcare professionals if patients provide consent for us to contact them.

Call **0345 077 1893**

Email **secondaryservices@breastcancercare.org.uk**

Website **breastcancercare.org.uk/lwsbc**

Attending a session like this for this first time can be quite nerve-racking for a patient so we know that an invitation handed out by a trusted healthcare professional accompanied by active encouragement makes it much more likely they will come along.

Younger Women Together

Younger Women Together information and support events are for women aged up to 45 who have been diagnosed with primary breast cancer in the previous three years. These younger patients can feel particularly isolated; concerns about family, fertility, career and sexuality are not always the same as those of older women.

The need

In the UK, fewer than 6,000 women aged 45 and under are diagnosed with breast cancer each year. This means they are unlikely to meet anyone of a similar age in clinic or while having treatment. Additionally, serious illness may not be something they and their friends have previously encountered. At the same time, a breast cancer diagnosis often forces women to make decisions about their future much earlier than they would otherwise do and it can have a major impact on both their families and their careers.

‘The London Younger Women Together event was fantastic. Not only did I make friends who “get me”, but I learnt that I wasn’t on my own. So many of my issues were shared. It was great to be able to talk and to get so much advice on what I can do and the support that’s out there.’

Amanda MacLean
(diagnosed in 2015 when she was 41)

‘Patients find the peer support from meeting others in a similar situation invaluable and new friendships are formed. They can talk openly about their fears and concerns in a safe environment, learning and understanding their own cancer journey – allowing them to question and find out their own way to move forward.’

Linda Hammel, Nurse Specialist in Breast Care, St John’s Hospital, Livingston

What we offer and how it works

Younger Women Together events bring together up to 40 women for two full days. They usually run from Friday to Saturday with free accommodation for participants on the Friday night.

The event features whole-group sessions with presentations from experts on topics such as:

- management of breast cancer in younger women
- physical activity
- nutrition and diet myths

There are also less formal small-group sessions with plenty of discussion on subjects such as fertility, menopausal symptoms, intimacy and sexuality, and breast surgery and reconstruction. All sessions are delivered by experts, often from within the NHS, and women have plenty of time to ask questions.

The moments between sessions, including the Friday evening, are equally important as informal opportunities for women to share experiences, talk about the impact of their diagnosis and build support networks, which often last for many years.

Women are able to:

- meet other women in a similar situation, helping to reduce their feelings of isolation
- share experiences and talk about the impact of their diagnosis
- hear from and ask questions of expert speakers on a range of topics
- learn how they can move forward with their life after breast cancer

A typical programme

Every Younger Women Together event includes presentations from healthcare professionals and discussions among participants on topics such as:

- the clinical management of breast cancer in younger women
- breast surgery and reconstruction
- menopausal symptoms
- relationships and communication
- intimacy and sexuality
- fertility after treatment
- lymphoedema
- mindfulness and laughter
- patients’ personal perspectives

Once a year we hold a tailored event, Younger Women with Secondaries Together, for women in the same age group whose cancer has spread and is no longer curable. The format is similar but the topics covered are designed for this audience including, for example, palliative care, talking to children and adjusting and adapting to a life-limiting illness.

How do patients access the service?

Eligible patients complete a registration form.

Call **0345 077 1893**
Email **youngerwomen@breastcancercare.org.uk**
Website **breastcancercare.org.uk/ywt**



Evidence of the benefits of our support services

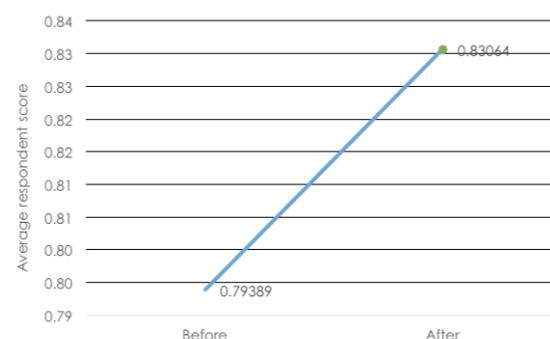
Moving Forward courses

Initial research (Kirshbaum et al, 2016) conducted by Breast Cancer Care with Calderdale and Huddersfield NHS Foundation Trust, showed that the trial model for follow-up (Moving Forward course followed by discharge to open access) provided an acceptable alternative to routine hospital-based follow-up. This supported the evidence for a stratified pathway for low-risk cancer patients incorporating self-management education.

In 2017, as part of an economic evaluation of Moving Forward, standardised patient self-reported measures were used to explore further the impact of the course. This is one of the first studies to evaluate a survivorship intervention for cancer patients using EQ-5D, an internationally recognised tool for measuring quality of life.

The average EQ-5D score for the general female population is 0.85, considered to be an indicator of 'normal' quality of life. The Moving Forward course was shown to make a significant difference to quality of life with the average score increasing from 0.79 prior to attending the course, to 0.83 one month after attending.

Changes in average quality of life score pre- and post-course



Moving Forward enables people to become active self-managers of their own health and wellbeing. This was demonstrated in our evaluation using the Patient Activation Measure (PAM), a metric that measures changes in self-confidence within the context of self-management programmes. Our evaluation showed that Moving Forward increases self-confidence. People who reported that they were struggling with health concerns after breast cancer stated that they were able to make and maintain positive lifestyle changes as a result of attending the course.

Reference

M Kirshbaum et al. Open access follow-up care for early breast cancer: A randomised controlled quality of life analysis. *European Journal of Cancer Care*, 2016

Someone Like Me service

A joint study of 44 women by Kings College London and Guy's and St Thomas' NHS Foundation Trust found that people using the Someone Like Me service had an improved quality of life compared to a control group and that they were less distressed and worried at three-month follow-up. Perceived isolation also decreased during the study period for people receiving the service but increased significantly for those who did not.

Women using Someone Like Me reported:

- feeling reassured, empowered and validated – 71% said they received useful information, practical tips and support
- experiencing empathy – 68% said they felt less alone and isolated
- achieving 'normalisation'
- finding a 'sounding board'
- feeling that they were in a safe shared space
- gaining strength
- thinking more positively – 73% said it gave them hope for the future
- changing their perspective

The researchers recommended that the service be offered as part of a holistic care package complementing the work of healthcare professionals at diagnosis, during treatment and post-treatment.

Living with Secondary Breast Cancer

In 2016, we commissioned an independent study of the impact of Living with Secondary Breast Cancer (Breast Cancer Care, 2017), which found that healthcare professionals valued the service. Many saw it as addressing patients' needs holistically in a way that clinical services could not, complementing clinical care and helping healthcare professionals to deliver an integrated care pathway.

Healthcare professionals also valued the fact that the service was delivered outside the hospital, a place so often associated with traumatic events such as diagnosis and treatment. And they noticed that people receiving the service became more involved in decision-making, communicated more clearly and developed better coping strategies. It also helped healthcare professionals to raise difficult subjects: in fact, healthcare professionals noticed that the women now often started such conversations themselves.

Reference

Living well with secondary breast cancer: how our support service helps. Impact evaluation report of the Living with Secondary Breast Cancer service. Breast Cancer Care, London 2017



The breast cancer support charity

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 are here to offer support and information, and campaign for better care.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

Central office

Breast Cancer Care
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1-3 Brixton Road
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