

After breast cancer treatment: what now?

breast
cancer
Care

This booklet explains what happens after hospital-based treatments for primary breast cancer finish. It includes information on follow-up care, signs and symptoms of recurrence to be aware of, and how you might feel after treatment ends.



This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

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

The logo for Breast Cancer Care, featuring the words "breast", "cancer", and "care" stacked vertically. "breast" and "cancer" are in a pink color, and "care" is in a yellow color. The font is a bold, sans-serif typeface.

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When hospital treatment ends

If you're coming to the end of or have just finished treatment for breast cancer, you may be wondering what happens next.

This booklet explains what will happen when your hospital-based treatments, such as surgery, chemotherapy or radiotherapy, finish.

What happens now?

You'll continue to be monitored once hospital treatment has ended. This is known as follow-up.

Different people are followed up in different ways, and this is explained on page 5.

After treatment finishes, you may have an appointment to:

- explain your planned follow-up and any regular tests you'll be offered
- provide you with information about managing treatment side effects
- tell you about possible signs and symptoms of recurrence to be aware of (see page 12)
- review any needs and concerns
- give you information about possible future changes to any treatment you're still having, such as hormone therapy

Am I cured?

Many people want to know if they're cured after treatment. The term 'cured' means there's no chance of the breast cancer coming back. While most people's cancer won't come back, your treatment team may not use words like 'cured' or 'all clear'. They're more likely to talk about your percentage chance of surviving five or ten years and beyond.

The risk of cancer coming back is different for each person and depends on many factors. In the UK, the number of people surviving breast cancer has risen greatly over the past decade. But it's still important to be aware of signs and symptoms to look out for (see page 12).

Having trouble coping?

The end of treatment can be a difficult and emotional time for a number of reasons.

Breast Cancer Care's Moving Forward courses and information can help you adjust to life after treatment.

You can find out more about Moving Forward and Breast Cancer Care's other support services on page 15.

Follow-up after treatment

How you're followed up after treatment finishes depends on your individual needs, such as how likely you are to have side effects from treatment and the risk of your cancer coming back. It also depends on the arrangements at the hospital where you've been treated.

You'll usually be offered regular mammograms (see page 7), depending on the type of surgery you've had.

You may or may not also have regular appointments.

Follow-up without regular appointments

You may not be offered any regular follow-up clinic appointments after treatment ends. Instead, before being discharged from the breast clinic, you'll be given information to help you manage your health after treatment.

After this you can see your GP or access the breast clinic if you have concerns or symptoms that need to be checked by a doctor or nurse.

If you're offered this sort of follow-up plan, you should be given details of who to contact, how best to do this and the types of concerns or symptoms to report.

Follow-up with regular appointments

You may be offered planned appointments with members of your healthcare team. How often this happens varies.

Many people are followed up at the hospital and have regular appointments with their surgeon or oncologist. Some people may also

be followed up by their GP or have a combination of hospital and GP appointments.

In some hospitals follow-up is provided by the breast care nurse unless there are particular concerns.

Sometimes follow-up appointments take place by phone or email, and you'll only visit the breast clinic for a mammogram if there's a concern or symptom that you or your doctor feels should be checked.

Follow-up appointments usually focus on how you're feeling. You can explain any problems, symptoms or treatment side effects you have. This is also your opportunity to ask questions. Writing your questions down beforehand can help you get the most out of the appointment.

If you attend in person you may have a physical examination that includes your breast or chest area as well as any other area of concern.

If you have any concerns you may be referred to another healthcare professional, for example a physiotherapist if you're having problems with arm movement or a pain clinic if you have persistent pain.

Follow-up after clinical trials

If you have taken part in a clinical trial during your treatment, your follow-up may vary depending on which trial you have been part of. Your research nurse will give you information on how you will be followed up.

The Recovery Package

The Recovery Package is made up of ongoing care and support at the end of treatment. It might not be offered in all areas or may be called something else.

You may hear your treatment team talk about the Recovery Package or about parts of the package separately.

If you're not offered any parts of the Recovery Package you can ask your healthcare team for more information.

The Recovery Package is made up of four main parts.

Holistic needs assessment and care planning

A holistic needs assessment (HNA) helps you think about your needs and concerns across all areas of your life and find possible solutions. It will consider your physical, social, psychological and spiritual needs.

You may be offered an HNA at various times throughout your diagnosis and treatment and at the end of treatment. After each assessment you'll be given a copy of a written care or action plan.

Treatment summary

This is a summary produced by your hospital team at the end of treatment and sent to your GP. It includes information about treatment side effects, signs and symptoms of a possible recurrence, symptoms that should be referred to your treatment team, and any action that needs to be taken by the GP. You may also receive a copy of the treatment summary.

A GP review

This is a meeting with your GP, within six months of diagnosis, to review any concerns you have and to help you understand what information and support is available in your local area. If you haven't been offered a review and would like one, contact your GP.

Health and wellbeing support event

This could include an appointment at a health and wellbeing clinic, which provides advice on healthy living and physical activity or an invitation to a group event or workshop. Our Moving Forward courses offer information and support on adjusting to life after treatment (see page 15).

Mammograms and other tests

After your treatment, you'll be invited to have regular mammograms (breast x-rays).

If you had breast-conserving surgery (also known as a wide local excision or lumpectomy), you will have a mammogram on both breasts.

If you had a mastectomy, with or without reconstruction, you will only have a mammogram on your other breast.

If you've had a double mastectomy, you won't be offered mammograms.

How often will I have mammograms?

Most hospitals follow the recommendations below from the National Institute for Health and Care Excellence (NICE).

If you're under 50, you'll have a yearly mammogram until you're invited to take part in a national breast screening programme, usually around the age of 50.

If you were already eligible for breast screening when diagnosed, you'll have a yearly mammogram for five years. After this, you'll be offered routine screening.

All women aged 50 to 70 are invited for mammograms every three years as part of a national breast screening programme. After the age of 70 you can still have regular mammograms but you'll need to arrange this yourself by contacting the screening unit covering your area. In some areas in England, women are invited before the age of 50 and after 70 as part of a trial.

Women who remain at high risk because of a family history of breast cancer or who carry an altered BRCA gene will be offered regular tests for a longer period. For more information, see our booklet **Family history, genes and breast cancer**.

Other tests and scans

You won't usually have other routine scans and tests unless you have symptoms that need checking. Several large studies have shown having regular scans when there are no symptoms is not useful in finding recurrence and doesn't improve overall survival.

Some people may be offered scans to check their bone strength. This is because some treatments for breast cancer, such as hormone therapy and chemotherapy, can affect the bones and increase the risk of developing osteoporosis (thinning of the bones).

Can breast cancer come back?

The treatment you've had will have been given to reduce the risk of breast cancer coming back.

After treatment, most breast cancers don't come back. But sometimes breast cancer can return. It's also possible to develop a new primary breast cancer.

Recurrence

Recurrence is the term used for breast cancer that has come back after treatment. There are several different types of recurrence, depending on where in the body the cancer has returned.

Local recurrence

If breast cancer comes back in the chest, breast or armpit area, or in the skin near the original site or scar, it's called local recurrence. Having local recurrence doesn't mean the cancer has spread.

Treatment for a local recurrence will depend on what treatment was given before, but may include surgery, radiotherapy or drug treatments.

Locally advanced breast cancer (also known as regional recurrence)

If breast cancer comes back and spreads to the tissues and lymph nodes around the chest, neck and under the breastbone, it's called locally advanced breast cancer.

Treatment will depend on what treatments were given before, but may include surgery, radiotherapy or drug treatments.

People who have locally advanced breast cancer are thought to have an increased risk of cancer cells spreading to other areas of the body. Treatments such as chemotherapy, hormone and targeted therapies work throughout the whole body.

Secondary (metastatic) breast cancer

Sometimes breast cancer cells can spread from the primary cancer in the breast to other parts of the body. This is called secondary or metastatic breast cancer. You may also hear this called stage 4 or advanced breast cancer.

Secondary breast cancer commonly affects the bones, lungs, liver and brain.

Secondary breast cancer can be treated, but cannot be cured. Treatment aims to control the cancer, relieve any symptoms, and maintain health, wellbeing and a good quality of life for as long as possible.

A new primary breast cancer

Having breast cancer in one breast slightly increases the risk of developing another breast cancer. A new primary breast cancer can occur either in the same breast after breast-conserving surgery, or in the other breast.

This would be treated as an entirely new breast cancer and not a recurrence.

Checking for changes

Whether you've had breast-conserving surgery or a mastectomy, with or without reconstruction, it's important to be aware of any changes to the breast, chest or surrounding area. This is important even if you're having follow-up appointments or regular mammograms.

It can be difficult to know how your breast or scar area should feel, especially as the area can change over time as it repairs and heals.

After treatments such as surgery and radiotherapy, you may experience pain and sensations such as burning and numbness in the scar area and under the arm. The area around the scar may feel lumpy, numb or sensitive. If you have pain that gets worse or is severe, contact your GP or treatment team.

How to check

There's no set way to check for any changes.

You'll need to get to know how the area looks and feels so you know what's normal for you. This will help you to feel more confident about noticing changes and reporting them early to your GP or treatment team.

It's also important to be aware of any new changes in the other breast and to report these as soon as possible.

Get used to looking at and feeling both sides of your chest regularly. You can do this in the bath or shower, when you use body lotion, or when you get dressed. There's no need to change your usual routine. Decide what you're comfortable with and what suits you best.

Who to contact if you have a concern

During follow-up

Calling your breast care nurse can be a good way to discuss any concerns in between your follow-up appointments. They may be able to make you an earlier appointment if you need to see your specialist.

If you have any new symptoms that are worrying you, you can also see your GP between appointments.

Alternatively, you can phone the hospital and ask for an earlier appointment.

After follow-up

After you have been discharged from your follow-up appointments, your GP may be your main contact to get concerns checked quickly. When speaking to your GP, make sure they know about your breast cancer, particularly if you were diagnosed some time ago.

If necessary your GP can refer you back to your treatment team. Alternatively, you may be able to contact the breast care nurse or hospital you were discharged from to report any concerns.

Signs, symptoms and changes

Talk to your GP or breast care nurse about ANY symptoms that are:

- new or unusual for you
- don't have an obvious cause
- don't go away

Changes to the breast or chest area

Whether you've had breast-conserving surgery or a mastectomy, with or without reconstruction, it's important to be aware of any changes to either side, such as:

<ul style="list-style-type: none">• swelling on your chest, in your armpit or around your collarbone	<ul style="list-style-type: none">• liquid (discharge) that comes from the nipple without squeezing it
<ul style="list-style-type: none">• a change in shape or size	<ul style="list-style-type: none">• swelling in the arm or hand
<ul style="list-style-type: none">• a change in skin texture, such as puckering or dimpling	<ul style="list-style-type: none">• redness or a rash on or around the nipple or on the skin
<ul style="list-style-type: none">• the nipple has become inverted (pulled in) or looks different, for example changed its position or shape	<ul style="list-style-type: none">• a lump or thickening that feels different (with your treated breast this could be on or away from the scar line)

to be aware of

Signs of secondary breast cancer

It's not possible to list all the symptoms of secondary breast cancer.

Tell your breast care nurse or GP if you have any symptoms that are new, don't have an obvious cause and don't go away, such as:



unexpected weight loss and a loss of appetite



discomfort or swelling under the ribs or across the upper abdomen



severe or ongoing headaches



a dry cough or feeling of breathlessness



altered vision or speech



feeling sick most of the time



loss of balance or any weakness or numbness of the limbs



feeling much more tired than usual



any lumps or swellings under your arm, breastbone or collarbone



pain in your bones, for example in the back, hips or ribs, that doesn't get better with pain relief and may be worse at night

Can I reduce my risk of recurrence?

Many people want to know if there's something they can do to reduce the risk of cancer coming back after treatment.

As with the risk of breast cancer developing, the risk of a recurrence is largely out of a person's control. But research suggests that regular exercise, maintaining a healthy weight and keeping your alcohol intake within current guidelines may help reduce your risk of recurrence.

Our booklet **Diet and breast cancer** has more information about diet, lifestyle and the risk of breast cancer coming back.

You can also find more information and tips on lifestyle after treatment in:

- BECCA – the Breast Cancer Care app
- Moving Forward courses and information
- Vita – our free magazine for anyone affected by breast cancer

To find out more, see our website breastcancercare.org.uk or call the Helpline on **0808 800 6000**.

Coping emotionally

Your feelings when treatment ends

Many people expect to feel relief once their hospital-based treatments have finished, and for some people this is the case. But for others, coming to the end of treatment can be a difficult and emotional time.

You may have focused on getting through the treatment and only have time to reflect on the impact of your diagnosis once treatment has finished.

Having much less contact with the hospital can leave you feeling isolated, while family and friends may have moved on and expect you to do the same.

You may still have side effects, either from hospital treatment or ongoing treatment such as hormone therapy, as well as fears about whether the cancer could come back.

You may feel more anxious as your follow-up appointment or mammogram approaches. Events such as the anniversary of the day you were diagnosed, had surgery or started to lose your hair may take you back to that time and cause a range of emotions.

Support after treatment

For some people, getting support after treatment has finished is as important as it was at diagnosis and during treatment.

Some people benefit from talking therapy, such as counselling. You can speak to your GP or treatment team about this.

Breast Cancer Care's Moving Forward courses and book can help you adjust to life after treatment.

There may also be local services such as support groups or health and wellbeing events. Your local cancer information centre will have details.

Our Someone Like Me service puts you in contact by phone or email with someone else who's had breast cancer and who's been trained to help.

Online, you can chat to other people going through breast cancer on our professionally moderated Forum.

Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone or read more about breast cancer, here's how you can.



Speak to our nurses or trained experts. Call our free Helpline on **0808 800 6000** (Monday to Friday 9am–4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it's like to have breast cancer.



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at forum.breastcancercare.org.uk



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at breastcancercare.org.uk



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you. Visit breastcancercare.org.uk/in-your-area

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate online

Donate using your debit or credit card breastcancercare.org.uk/donate

Donate by post

Please accept my donation of **£10/£20/my own choice of £**

I enclose a cheque/PO/CAF voucher made payable to **Breast Cancer Care**

Name _____

Address _____

_____ Postcode _____

Email address _____

Telephone _____

In addition, we'd love to keep you updated about our work and provide you with other opportunities to get involved with Breast Cancer Care. Please tell us how you would like to hear from us (by ticking these boxes you confirm you are 18 or over)

- I'd like to hear from you by email
- I'd like to hear from you by text message or SMS
- Please do not contact me by post
- Please do not contact me by telephone

We never give your information to other organisations to use for their own purposes. To change your preferences, or find out more information on how we use your data, please view our privacy policy at breastcancercare.org.uk or contact supporter services on 0345 092 0800.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG, Chester House, 1-3 Brixton Road, London SW9 6DE

Breast Cancer Care is a working name of Breast Cancer Care and Breast Cancer Now, a charity registered in England and Wales (1160558) and Scotland (SC045584).

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About this booklet

After breast cancer: what now? was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



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Breast Cancer Care and Breast Cancer Now are uniting to create one charity for everyone affected by breast cancer. Our aim is that by 2050, everyone who develops breast cancer will live and be supported to live well.

From research to care, our new charity will have people affected by breast cancer at its heart – providing support for today and hope for the future. We'll find ways to prevent the disease, improve early diagnosis, develop new treatments, campaign for better care, and support people with the physical and emotional impact of breast cancer.

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

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