

After breast cancer treatment: what now?

breast
cancer
care

This booklet explains what happens after your hospital-based treatments finish. It includes information on follow-up care, being breast and body aware, the ways breast cancer may come back, 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**



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Introduction

This booklet explains how you will continue to be monitored after your hospital-based treatments (such as surgery, chemotherapy or radiotherapy) finish. This is known as follow-up.

It also describes symptoms to be aware of and to report to your specialist team between follow-up appointments or after your follow-up has ended.

While most people have no further problems after their treatment, sometimes breast cancer can come back. This is known as recurrence. The booklet describes the different types of recurrence. It also describes the possible signs of secondary breast cancer (breast cancer that has spread to other parts of the body).

It also talks about how you might feel at the end of treatment. Breast Cancer Care's **Moving Forward** pack contains more information about the physical and emotional effects of finishing treatment.

Follow-up

How you are followed up will depend on your individual needs and the arrangements at the hospital you've been treated in. You'll probably find your contact is more frequent at first, becoming less so as time goes on.

Many people are followed up at the hospital and will have regular appointments with their surgeon and oncologist. Some people are given a choice of being followed up by their GP (local doctor) or a combination of hospital and GP appointments.

In some areas you will be followed up by the breast care nurse unless there are any particular concerns. In other areas follow-up appointments will be over the phone and you will only need to visit the breast clinic if there's any concern or symptom that you or your doctor feel should be checked out.

Your follow-up appointments will focus on how you are feeling so you can explain any problems, symptoms or treatment side effects, for example any pain, stiffness, menopausal symptoms or fatigue. This is also your opportunity to ask questions. Many people find writing their questions down beforehand helps them get the best out of the appointment. You can also take someone with you to appointments.

You will usually have a physical examination that includes your breast and/or chest area as well as any other area of concern.

You may be referred to another healthcare professional for advice, for example a physiotherapist if you're having problems with arm movement.

Open access

Some people won't be given any regular follow-up appointments, but can contact the breast clinic if they have concerns or symptoms and would like to be seen by a doctor or nurse at the hospital. This is called open access. If you are offered this sort of follow-up you should be given the details of who to contact.

Follow-up after clinical trials

If you've taken part in a clinical trial during your treatment, your follow-up may vary depending on which trial you have been part of. In this case the research nurse will be able to give you a better idea of how you will be followed up.

The Recovery Package

You may hear about the Recovery Package or similar initiatives. The Recovery Package is a package 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 also hear your specialist team talk about parts of the package separately.

The Recovery Package is made up of four main parts.

- **Holistic Needs Assessment and care planning**

You may have a Holistic Needs Assessment (HNA) at various times throughout your diagnosis, treatment and at the end of treatment. This will consider your physical, social, psychological and spiritual needs as a whole. After each assessment you will 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, and any action that needs to be taken by the GP. You will also receive a copy of the Treatment Summary.

- **Cancer Care Review**

This is a meeting with your GP within six months of diagnosis. It aims to help you understand what information and support is available to you in your local area.

- **Patient education and support event**

This could include a Health and Wellbeing Clinic, which aims to provide advice on healthy lifestyle and physical activity. Our Moving Forward course also offers information and support on adjusting to life after treatment (see page 19).

Will I have any regular tests?

After your treatment, you will have regular mammograms. If you have had breast-conserving surgery (a wide local excision or lumpectomy), you will have a mammogram on both breasts. If you have had a mastectomy, with or without reconstruction, you will only have a mammogram on your other breast.

The time between mammograms may vary depending on the hospital where you have your follow-up. Most hospitals will follow the recommendations below set out by the National Institute for Health and Care Excellence (NICE), an independent organisation responsible for providing evidence-based national guidance on effective ways to prevent, diagnose and treat ill health.

NICE recommendations for breast screening

You will have a yearly mammogram until you are invited to take part in a national breast screening programme, usually around the age of 50. As part of the screening programme, you'll been invited for a mammogram every three years until the age of 70 (in England this is changing to 73).

If you were already eligible for breast screening when diagnosed, you will have a yearly mammogram for five years. After this, you will be invited to have a mammogram every three years up until the age of 70 as part of a national breast screening programme.

After the age of 70 you can still have regular mammograms but you won't be routinely invited, so will need to arrange this yourself.

Women who remain at high risk due to a family history of breast cancer or who carry an altered BRCA gene will need to have regular tests for a longer period. For more information, see our **Breast cancer in families** booklet.

Other tests and scans

Many people feel they would like or should have regular body scans or blood tests to detect early signs of a possible recurrence (breast cancer coming back). You won't normally have routine scans and tests unless you have symptoms that need checking. Several large studies have shown these are not useful in finding recurrence and do not improve overall survival.

Some treatments for breast cancer can affect your bones, which can increase your risk of developing osteoporosis. To assess your bone strength (bone mineral density) you should have a DEXA (dual energy X-ray absorptiometry) scan if:

- you are starting hormone therapy with an aromatase inhibitor
- your breast cancer treatment has brought on the menopause
- you are starting ovarian suppression therapy.

DEXA scans may be repeated around every two years for some people. For more information see our **Osteoporosis and breast cancer treatment** booklet.

Continuing to be breast aware (looking and feeling for any 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 after your treatment, even if you're still having follow-up appointments or regular mammograms.

After treatment for breast cancer 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.

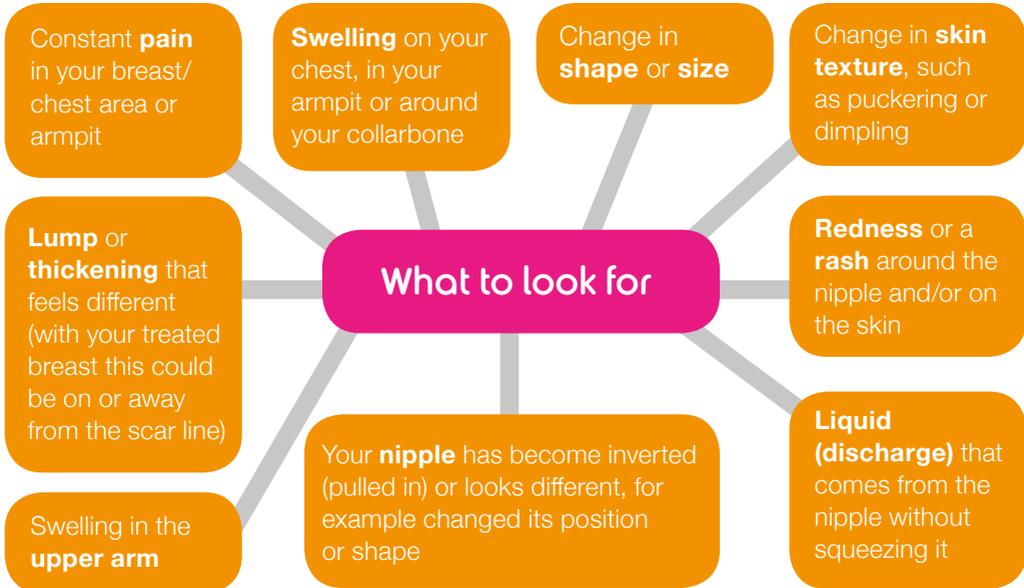
Immediately after surgery and in the weeks that follow, people can experience pain and sensations such as burning and numbness in the scar area and under the arm (axilla). The area around the scar may feel lumpy, numb or sensitive.

You will need to get to know how it looks and feels so you know what is normal for you. This will help you to feel more confident about noticing changes and reporting them early to your GP or breast care nurse. It's also important to be aware of any new changes in the other breast and to report these as soon as possible.

There's no right or wrong way to check for any changes. 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. Just decide what you're comfortable with and what suits you best.

Being breast aware – what to look and feel for

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. If you notice a change, even if it's not listed here, tell your GP or breast care nurse.



If you have had a breast reconstruction you should be aware of the above changes, as well as other changes that may be to do with the reconstruction itself. For more information see our **Breast reconstruction** booklet.

Cancer 'cure' and 'survival'

You may hear words like 'cure' and 'all clear' in the press or on the TV but these might not be used by your specialist.

Many people who have cancer want to know if they are 'cured'. The term 'cured' means there is no chance of the breast cancer coming back. While most people will be 'cured', it is virtually impossible to give a guarantee as each person is different.

The term 'all clear' is also used sometimes and this means there's no sign of cancer after your treatment at that time. You may also hear the term 'remission'. This term is generally associated with other types of cancer, but again means there's no sign of disease at this time.

Your specialist team is more likely to speak in terms of your survival over time. They may talk about your percentage chance of surviving five or ten years and beyond. For breast cancer, five and ten year survival statistics are used as a way of describing how well you may be. Each person's risk of the cancer coming back varies. This depends on many factors, such as the size, type and grade of the cancer and whether the lymph nodes (glands) were affected. The risk of the cancer coming back (recurrence) is higher in the first few years and reduces as time goes on. But recurrence can happen even many years after treatment, which is why you still need to be aware of any changes.

In the UK, the number of people surviving breast cancer has risen greatly over the past decade and most people diagnosed with primary breast cancer will not have a recurrence.

A new primary breast cancer and breast cancer recurrence

While most people have no further problems, sometimes breast cancer can come back. It's also possible to develop a new primary breast cancer. This is when a new breast cancer develops, rather than the original cancer coming back.

New primary

Having breast cancer in one breast means you have a slightly higher risk of developing another breast cancer than someone who has never had 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.

Local recurrence

If breast cancer comes back in the chest or breast area, or in the skin near the original site or scar, this is called local recurrence. This doesn't mean the cancer has spread. Treatment for a local recurrence will depend on what treatment you had before, but could include surgery, radiotherapy and 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, this is called locally advanced breast cancer. Treatment will depend on what treatments you previously had, but could include surgery, radiotherapy and 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 are given because they work throughout the whole body.

Secondary (metastatic) breast cancer

When breast cancer spreads to other parts of the body, this is called secondary breast cancer. This happens when cancer cells are carried away from the breast through the lymphatic system or the bloodstream. These cancer cells can then form secondary cancers in other parts of the body. You may also hear this called stage 4 or advanced breast cancer.

Secondary breast cancer can develop anywhere in the body, but it's most likely to develop in the bones, lungs, liver and brain. Only one area of the body may be affected or there may be a number of different areas. Secondary breast cancer can be controlled, sometimes for many years, and treatments are improving all the time, but it cannot be cured.

Being body aware – the signs and symptoms of secondary breast cancer

Although there are some signs and symptoms of secondary breast cancer shown on this chart, it's not possible to list them all. So if your symptoms are new, don't have an obvious cause and don't go away, tell your breast care nurse or GP about them.



Remember, some of these symptoms, such as tiredness and loss of appetite, can be normal effects many people experience after cancer treatment. But if these types of symptoms don't improve, your doctor may decide to investigate the many possible causes.

Who to contact if you have a concern

During follow-up

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

If you have any new symptoms that are worrying you, you can also see your GP between appointments for advice. 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. If they think you need to be seen at the breast clinic they can refer you. When speaking to your GP, make sure they know about your breast cancer, particularly if you were diagnosed some time ago.

Alternatively, you may still be able to contact the breast care nurse or hospital you were discharged from.

Health and wellbeing

Many people wonder if there is something they can do to keep well and reduce the risk of cancer coming back. There is a lot of information, particularly in the press, that is often confusing and conflicting about lifestyle and cancer.

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

Our Moving Forward course explores this in detail. We also have information on our website and you can call our Helpline to talk through any particular concerns you have. For more information see our website breastcancercare.org.uk or call the Helpline on **0808 800 6000**.

Your feelings

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

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

You may feel isolated or abandoned as you now have much less contact with the hospital. It's possible family and friends have moved on and expect you to 'put it all behind you'.

You may still be experiencing effects of hospital treatment or side effects from ongoing treatment such as hormone therapy, as well as trying to manage fears about whether the cancer could come back and worrying about every ache and pain.

You may feel more anxious as your follow-up appointment approaches. Other 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 different emotions.

For some people, getting support after their 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 specialist team about this.

Breast Cancer Care's Moving Forward courses and information are here for anyone who has had a diagnosis of primary breast cancer, helping you approach life after treatment with more confidence.

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 discussion Forum.



4 ways to get support

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



Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).



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.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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We might occasionally want to send you more information about our services and activities

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We won't pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG,
5-13 Great Suffolk Street, London SE1 0NS



About this booklet

After breast cancer treatment: 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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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**

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