

AFTER BREAST CANCER TREATMENT: WHAT NOW?

BREAST
CANCER
NOW The research &
support charity

We're here

About this booklet

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.

When hospital treatment ends – what happens now?

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

People are followed up in different ways. You can read more about this on page 4.

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 or spread of the cancer to be aware of (see pages 12 and 13)
- Review any needs and concerns
- Give you information about possible future changes to any treatment you're still having

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 5 or 10 years and beyond. Or say there is “no evidence of disease” at the time.

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 10 years. But it's still important to be aware of signs and symptoms to look out for and report so they can be checked out (see pages 12 and 13).

Having trouble coping?

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

Our Moving Forward courses and Moving Forward booklet can help you adjust to life after treatment.

You can find out more about Moving Forward and our other support services on page 17.

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 the 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 pages 7 and 8), depending on the type of surgery you've had.

You may or may not also have regular appointments.

Follow-up without regular clinic appointments (sometimes called open access or patient-initiated follow-up)

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

After this you can contact your treatment team or see your GP 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
- The types of concerns or symptoms to report

If you're not offered this information, ask your treatment team about this.

Follow-up with regular clinic appointments

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

You may be followed up at the hospital and have regular appointments with your surgeon, oncologist (doctor who specialises in cancer) or nurse practitioner.

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

What happens at follow-up appointments?

Follow-up appointments usually focus on how you're feeling. You can explain any problems, symptoms or treatment side effects you're having.

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.

Follow-up after clinical trials

If you've taken part in a clinical trial during your treatment, your follow-up will depend on which trial you've been part of.

Your research nurse will give you information on how you'll be followed up.

The Recovery Package

The Recovery Package is a package of ongoing care and support at the end of treatment. It's made up of 4 main parts to help you feel more in control and improve your quality of life.

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

The Recovery Package might not be offered in all areas, or it may be called something else.

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

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 support and 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 should 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.

The treatment summary includes information about:

- Side effects, including those that occur during treatment and after treatment (known as late side effects)
- Signs and symptoms of a possible recurrence or spread of the cancer
- Symptoms that should be referred to your treatment team
- Any action the GP needs to take

You may also receive a copy of the treatment summary.

A Cancer Care Review

This is a meeting with your GP or practice nurse within 12 months of having treatment. The purpose is 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.

A 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 you information and support on adjusting to life after treatment (see page 17).

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'll have a mammogram on both breasts.

If you had a mastectomy (with or without reconstruction), you'll have a mammogram on your other breast.

If you had a double (bilateral) mastectomy, you will not be offered mammograms.

You might be offered other forms of follow-up depending on your individual situation.

How often will I have mammograms?

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

If you're under 50

You'll have a follow-up mammogram every year for at least 5 years. However, you may have these for longer depending on your age. At around the age of 50, you'll be invited to take part in a national breast screening programme.

If you're aged 50 to 70

If you were already eligible for breast screening when diagnosed, you'll have a yearly mammogram for 5 years.

If you're still having follow-up annual mammograms, you do not need to go for a routine screening appointment. If your screening invite includes a specific appointment date and time, you can contact your local breast screening service to let them know you do not need your appointment slot.

After your follow-up mammograms have ended, you'll be offered routine screening as part of a national breast screening programme.

If you are over 70

You'll have yearly mammograms for 5 years.

After this you can request a mammogram every 3 years as part of a national screening programme. You'll need to arrange this yourself by contacting the screening unit in your area.

Family history and altered genes

If you remain at high risk because of a family history of breast cancer, or you have an altered BRCA gene, you'll be offered regular tests for a longer period.

You may find it helpful to read our booklet **Family history of breast cancer: managing your risk**. It has more information about screening recommendations for women who have an altered breast cancer gene or a significant family history of breast cancer.

Other tests and scans

You won't usually have other routine scans and tests, unless you report any 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 remove the cancer and reduce the risk of breast cancer coming back or spreading to another part of the body.

After treatment, most breast cancers don't come back. But sometimes breast cancer can return.

People who have had breast cancer also have a slightly higher risk of developing a new primary breast cancer. This is different to a recurrence.

Recurrence

Recurrence is the term used when the same breast cancer has come back.

There are 3 different types of recurrence depending on where in the body the cancer has returned.

Tests, including a biopsy, will help to confirm the type of recurrence.

Local recurrence

If breast cancer comes back in the chest, breast or in the skin near the original site or scars, it's called local recurrence.

If you've had a lumpectomy or breast-conserving surgery, the cancer could come back in the remaining breast tissue.

If you've had a mastectomy, the cancer could come back in the chest wall or in the skin.

Having local recurrence doesn't mean the cancer has spread to other parts of the body.

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 (sometimes called regional recurrence or locally recurrent breast cancer)

If breast cancer has spread to the lymph nodes around the chest, neck, and under the arm or breast bone, but has not spread to other areas of the body, it's called locally advanced breast cancer.

Locally advanced breast cancer may also affect the chest wall or skin of the breast.

It may be referred to as stage 3 breast cancer.

Sometimes breast cancer is locally advanced when it's first diagnosed.

People who have locally advanced breast cancer are thought to have an increased risk of cancer cells spreading to other areas of the body, compared to those with stage 1 or 2 breast cancers.

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
- Brain

Other parts of the body, such as lymph nodes in the chest, armpit or neck area, the skin or abdomen (belly), may also be affected.

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 1 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.

AFTER BREAST CANCER TREATMENT

Most breast cancers don't come back after treatment, but sometimes it can return, so it's important to know what signs and symptoms to look out for.

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

It's important to be aware of any changes to your breast or chest area.

If you've had a lumpectomy or breast-conserving surgery, the cancer could come back in the remaining breast tissue.

If you've had a mastectomy, the cancer could come back in the chest wall or in the skin.

Look for changes to the other breast too.

- Swelling on your chest, in your armpit or around your collarbone
- A change in shape or size
- A change in skin texture, such as puckering or dimpling
- The nipple has become inverted (pulled in) or looks different, for example changed position or shape
- Liquid (discharge) that comes from the nipple without squeezing it
- Swelling in the arm or hand
- Redness or a rash on the skin, in or around the nipple or in the area of the scar line of your treated breast
- A lump or thickening that feels different (with your treated breast this could be on or away from the scar line)

Symptoms elsewhere in the body

Sometimes breast cancer cells can spread from the breast to other parts of the body. This is known as secondary (metastatic) breast cancer. Possible signs of secondary breast cancer include:



Feeling sick most of the time



Feeling bloated



Severe or ongoing headaches



Feeling much more tired than usual



Not being able to go to the toilet (constipation)



Feeling full quickly when eating or changes to appetite



Discomfort or swelling under the ribs or across the upper abdomen



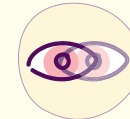
Any lumps or swellings under your arm, breastbone or collarbone



Loss of balance or any weakness or numbness of the limbs



A dry cough or feeling out of breath



Altered vision or speech



Unexpected weight loss and a loss of appetite



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

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, 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 heals.

After treatments like surgery and radiotherapy, you may have 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 treatment team or GP.

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 now normal for you. This will help you to feel more confident about noticing changes and reporting them early to your treatment team or GP.

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, so it becomes habit. 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

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

- Are new or unusual for you
- Don't have an obvious cause
- Don't go away within a couple of weeks

If you have follow-up appointments

If you still attend follow-up appointments, 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 treatment team.

If you have open access follow-up

If you have open access follow-up, you will be given details of who to contact if you have any concerns.

After your follow-up has ended

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 previous breast cancer diagnosis, 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.

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 limiting your alcohol intake 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'll also find this information on our website.

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 less frequent contact with the hospital can leave you feeling like you're lacking support. Meanwhile 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. You may also have 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.

Our Moving Forward courses and booklet 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 forum.

Find out more by calling **0808 800 6000** or visit **breastcancernow.org**

We're Breast Cancer Now, the research and support charity. However you're experiencing breast cancer, we're here.

Life-changing support

Whoever you are, and whatever your experience of breast cancer, our free services are here. Whether you're worried about breast cancer, dealing with a diagnosis, working out life with or beyond treatment – or someone you love is.

World-class research

We support over 290 of the brightest minds in breast cancer research. They're discovering how to prevent breast cancer, live well with the disease, and save lives. Every day, they get closer to the next breakthrough.

Change-making campaigns

We fight for the best possible treatment, services and care for everyone affected by breast cancer, alongside thousands of dedicated campaigners.

Could you help?

We don't get any government or NHS funding for our support services or health information. So, we rely on donations and gifts in wills to make our vital work happen. If you'd like to support us, go to breastcancernow.org/give

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

NOTES

[illegible]

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

NOTES

This image shows a blank sheet of white paper with horizontal purple lines. The lines are evenly spaced and run across the width of the page, providing a guide for writing or drawing. There are no margins, text, or other markings on the paper.

ABOUT THIS BOOKLET

After breast cancer treatment: what now? was written by Breast Cancer Now'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:
Email health-info@breastcancernow.org



You can order or download more copies from
breastcancernow.org/publications



We welcome your feedback on this publication:
health-info@breastcancernow.org



For a large print, Braille or audio CD version:
Email health-info@breastcancernow.org

Medical disclaimer

We make every effort to ensure that our health information is accurate and up to date, but it doesn't replace the information and support from professionals in your healthcare team. So far as is permitted by law, Breast Cancer Now doesn't accept liability in relation to the use of any information contained in this publication, or third-party information included or referred to in it.

We're here

Information you can trust, support you can count on

Whatever breast cancer brings, we're here for you.

Whether you're looking for information about breast cancer or want to speak to someone who understands, you can rely on us.

Call **0808 800 6000** to talk things through with our helpline nurses.

Visit **breastcancernow.org** for reliable breast cancer information.

Breast Cancer Now

6th Floor
The White Chapel Building
10 Whitechapel High Street
London E1 8QS



Patient Information Forum

Breast Cancer Now is a company limited by guarantee registered in England (9347608) and a charity registered in England and Wales (1160558), Scotland (SC045584) and Isle of Man (1200). Registered Office: 6th Floor, The White Chapel Building, 10 Whitechapel High Street, London E1 8QS.