



Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do. Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call our free helpline on **0808 800 6000**.



# Your follow-up after breast cancer: what's next?

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A large print version of this booklet can be downloaded from our website, [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk). It is also available on audio CD or in Braille on request. Call **0845 092 0808** for more information.

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## Introduction

When you reach the end of treatments that involve regular visits to hospital, such as chemotherapy or radiotherapy, you will still have regular follow-up appointments. These may be more frequent at first, becoming less so as time goes on. The purpose of follow-up appointments is to check how you are recovering both physically and emotionally. They are a time when any concerns or problems you may have can be checked out. This leaflet aims to give you information about what to expect at your follow-up appointments and also talks about terms that you might hear at the end of your treatment.

The leaflet also explains the difference between breast cancer recurrence and spread. We hope this helps you to understand what your specialist is looking out for at your follow-up appointments. It also describes symptoms to be generally aware of that you may want to report to your doctors or breast care nurse between follow-up appointments or after your follow-up has ended.

## Follow-up appointments

The time between appointments will vary in each hospital and will also differ for each person depending on their individual situation. You should be given a name and contact number to ring (this will usually be for the breast care nurse) if you have concerns or symptoms which may suggest you need to be seen sooner than your appointment date. You can also see your GP (local doctor).

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

Several years ago people were followed up indefinitely. While some found this reassuring, others found ongoing hospital visits stressful and evidence has shown this is not helpful in finding any recurrence (the cancer coming back in the breast) or new disease. The current recommendations are that you are followed up for at least two years (but this may sometimes be as long as five years) and then you can be discharged from regular appointments.

Your follow-up appointment will focus on how you are feeling so you can explain any problems, symptoms or treatment side effects you have noticed, for example, any pain, stiffness, menopausal symptoms or fatigue. This is also your opportunity to ask questions and many people find writing these down beforehand helps them get the best out of this consultation.

Your follow-up appointments will often be at the hospital where you had your treatment. They will usually be in person but can sometimes be by telephone.

### Consultation in person

At your appointment you may be seen by your consultant, a doctor from their team or a breast nurse specialist. In some areas you may see your GP.

You will have a physical examination that includes your chest area and the doctor/nurse will check out any other areas of concern. They may refer you to another health professional for advice, for example, a physiotherapist if you are having problems with arm movement. Blood tests are not done routinely but may be if there is a need to check your recovery from treatment or if you have any new symptoms that need investigating.

### Consultation by telephone

Occasionally you may be offered your follow-up appointments by telephone. While this doesn't happen in all areas it gives the opportunity to speak with your breast care nurse or doctor and to ask questions. You would need to visit the breast clinic if there was any concern that you both felt needed checking.



## Follow-up mammograms and breast screening

Following your treatment you will be invited to have a regular mammogram (breast x-ray). If you have had a mastectomy a mammogram will be done on your other breast. After breast conserving surgery (lumpectomy or wide local excision) you will have mammograms on both breasts.

The time between mammograms will vary depending on the hospital where you are having your follow-up, but these will generally be offered every 1-2 years for up to 10 years after your diagnosis. Women aged 50 years and over will then be invited for a mammogram by the National Breast Screening Programme every three years up until the age of 70. (This age range is due to change to 47-73 over the next few years.)

Whether you have had breast conserving surgery or a mastectomy (with or without reconstruction) it is important to remain breast aware after your treatment, even if you are still having follow-up appointments or regular mammograms. Being breast aware means knowing how your breast(s) looks and feels. If you notice any changes that aren't normal for you contact your GP, breast care nurse or specialist.

## Other tests and scans

Apart from regular mammograms, you won't normally have routine scans and tests. This is because several large studies have shown this is not useful in finding further cancer spread and doesn't improve overall survival (see section on *Cancer 'survival' and 'cure'*). Further investigations will not be done routinely unless you have symptoms which need checking out.

If you have had an early menopause due to your breast cancer treatment or your specialist team has concerns about the effect your treatment might have on your bone strength, it may be recommended that you have regular bone density scans every 1-2 years.



## Cancer 'survival' and 'cure'

The way you hear cancer survival being described may seem confusing. Terms like 'all clear' and 'cure' are often used in the press or on TV but these might not be used by your specialist.

In the UK the survival of people with breast cancer has improved greatly over the last decade and many will have no further problems after they finish their treatment.

Your specialist may speak in terms of your percentage chance of surviving five years and beyond. For breast cancer, five year survival statistics are used as a way of describing how well you may be. The greater your chance of surviving five years and beyond is a guide to how well you will probably be in the future. Each person's risk of the cancer coming back varies. This depends on many factors such as the size, type and features of the cancer and whether the lymph nodes (glands) were affected. The risk of recurrence is higher in the first few years with the risk reducing in later years.

Many people who have cancer want to know if they are 'cured'. Although many people will indeed be cured, this term means there is no chance of the cancer coming back and it is virtually impossible to give a guarantee that a person has definitely been cured. The term 'all clear' is also used sometimes and this means there is no evidence or sign of cancer following your treatment at that point in time. You may also hear the term 'remission'. This is generally associated with other types of cancer but again means there is no sign of disease at this time. So, in order to be as clear and honest as possible your specialist is more likely to speak in terms of your survival.

## Types of recurrence

At your diagnosis and after surgery many tests will have been done to find out the type of breast cancer you had. The results are used in planning your individual treatment to ensure it is as effective as possible to reduce the risk of the breast cancer coming back.

While most people have no further problems, sometimes breast cancer can return after (primary) treatment. It can come back in the chest/breast area, in the skin near the original site or in the scar. This is called local recurrence, meaning the cancer cells have remained in the local area and may not have spread to other parts of the body. This is not generally thought to be actual spread of the cancer but cancer which has not been completely removed by the initial treatment. If this happens you will need further treatment, but it is important to remember that this local recurrence is treatable.

If you notice any changes in the skin around your scar line or chest area, contact your breast care nurse or specialist.

Breast cancer can also come back when it has spread past the breast and armpit (axillary) lymph nodes. This is called regional recurrence and can occur in the tissues and lymph nodes around the chest, neck and under the breastbone. How this is treated will depend on what treatments you had previously but could include surgery, radiotherapy and drug treatments.

Again, if you notice any changes to your chest wall, armpit or the area around your collarbone, contact your breast care nurse or specialist.

People who have breast cancer in one breast can be at slightly higher risk of developing a new primary breast cancer on the other side. This would be treated as a new cancer, not recurrence, with individually planned treatment.

# Secondary breast cancer

While the aim of treatment for primary breast cancer is to prevent the cancer coming back or spreading, some people may develop secondary breast cancer. This is when breast cancer cells spread beyond the breast to a distant part of the body forming a cancer which is made from the same cells as the breast cancer. You may also hear it called metastatic, stage 4 or advanced breast cancer.

Secondary breast cancer is most likely to develop in the bones, lungs, liver and sometimes the brain. One or more areas of the body can be affected. Secondary breast cancer cannot be cured but it can be controlled, sometimes for many years, and treatments are improving all the time.

## Symptoms of secondary breast cancer

It is difficult to list all the symptoms of secondary breast cancer but any symptoms which don't improve over several weeks and have no obvious cause need to be checked out with your doctor.

It is important to remember that many symptoms of secondary breast cancer may be the same as those of other conditions. For example, aches and pains in the bones may be due to ageing, arthritis or drug treatment side effects. Breathlessness and chest pain can be symptoms of a bad cold. If you have any persistent or unexplained symptoms the best thing to do is to talk to your specialist or breast care nurse.

## Symptoms you may want to report

- Pain in the back or hips that does not improve with painkillers and which is often worse at night.
  - Unexplained weight loss and a loss of appetite.
  - A constant feeling of nausea.
  - Discomfort or swelling under the ribs or across the upper abdomen.
  - Feeling constantly tired.
  - A dry cough or a feeling of breathlessness.
  - Severe headaches – usually worse in the mornings.
- Some of these symptoms, such as tiredness and loss of appetite, can be normal effects people experience after cancer treatment. But if these types of symptoms don't improve your doctor may be able to investigate the many possible causes.





## Who to contact if you have a concern

### During follow-up

There are people available to speak to you between your follow-up appointments and many people find phoning their breast care nurse can be an easy way to discuss any concerns. They may make you an earlier appointment if you both feel you need to see the specialist sooner. If you have any new symptoms that are worrying, you can 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 follow-up appointments your GP may be your main contact to get concerns checked quickly. If they think you need to be seen back 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 before. Alternatively, you may still be able to contact the breast care nurse or hospital you were discharged from.

## Your feelings

Everyone will have different feelings when they no longer need to be seen regularly by their medical team. Some people feel relieved that they can now start getting their lives back to normal. Others may be concerned about what can happen in the future and anxious about losing contact with the hospital. Most people worry about the cancer coming back. This is perfectly normal but it usually lessens with time.

If you are finding moving on difficult, you might want to talk to someone about how you are feeling. This could be your breast care nurse or GP. They may be able to arrange one-to-one support or counselling locally or tell you about breast cancer support groups in your area. You can also talk to someone who has been through a similar experience through Breast Cancer Care's peer support service. Many people find this particularly useful in the first couple of years after treatment (as a way of talking to someone who can appreciate how you are feeling). You can find out more about this by contacting our helpline.

## Further help from Breast Cancer Care

Breast Cancer Care's information service covers every aspect of breast cancer. Our award-winning range of publications can be ordered for free or accessed at any time on our website. Our confidential helpline is there if you have any questions – perhaps you want to check something you've read, or run through information you received from your healthcare team. You can also email your questions to our Ask the Nurse service, which can be found on our website.

As well as information we offer emotional and practical support services including telephone support groups, one-to-one support, and local events where you can meet people in a similar situation and share experiences.

For more information, call our national helpline on **0808 800 6000** (for Typetalk prefix **18001**) or visit **[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)**

## Other organisations

### Cancerbackup\*

3 Bath Place  
Rivington Street  
London EC2A 3JR

Office: 020 7696 9003  
Freephone helpline: 0808 800 1234  
Email: [info@cancerbackup.org](mailto:info@cancerbackup.org)  
Website: [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

Cancerbackup is the leading national information and support charity for people affected by cancer. Services include a helpline, staffed by specialist cancer information nurses, a website, cancer information booklets and local information centres. All Cancerbackup services are free to people affected by cancer.

### Macmillan Cancer Support\*

89 Albert Embankment  
London SE1 7UQ

Telephone: 020 7840 7840  
Macmillan CancerLine: 0808 808 2020  
Textphone: 0808 808 0121  
Email: [cancerline@macmillan.org.uk](mailto:cancerline@macmillan.org.uk)  
Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Macmillan Cancer Support is helping people who are living with cancer through the provision of immediate practical and emotional support. Specialist services include Macmillan nurses and doctors, cancer centres, a range of cancer information and direct financial help. The Macmillan CancerLine provides information and emotional support. Textphone available.

\* These organisations were in the process of merging at the time of going to print.

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Breast Cancer Care is committed to equal opportunities and access for all.

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For all breast cancer or breast health concerns call our free, national helpline on **0808 800 6000** (for Typetalk prefix **18001**) or visit **[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)**

Donations from the public make it possible for us to provide publications like this one free to people affected by breast cancer. If you would like to make a donation, please send your cheque to: Breast Cancer Care, RRKZ-ARZY-YCKG, 5-13 Great Suffolk Street, London SE1 0NS. Or donate via our website at [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)