

**Primary  
breast cancer**  
Information pack

**breast  
cancer  
care**



**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](https://breastcancercare.org.uk)**



## Help reading this pack

There is a lot of information in this pack, so we've included summary sections to help you.

Look out for the 'Sofia says' icon:

**Sofia says** 

In these sections Sofia will sum up some of the longer text in a few sentences.

There are also some pictures.

If you find it hard to take in a lot of words, you can start by reading what Sofia says.

You can also use this to remind yourself of what is in the rest of the pack.



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## About this pack

This pack is for you if you've been told you have primary (early) breast cancer. It includes information about breast cancer, its diagnosis and treatments.

Finding out that you have cancer can make you feel all sorts of emotions, such as fear, anger and helplessness. This pack describes the emotional effects of a breast cancer diagnosis and how to get support. It also covers what happens after treatment.

Not everything in this pack will apply to you because everyone is different. We've included questions you may want to ask, and at the back of the pack there's space for you to note down the answers and anything else you want to remember, such as names, telephone numbers, test results and appointment dates.

The glossary on page 78 gives definitions of some common words relating to primary breast cancer.

## Other publications

You may want to read about certain topics in more detail. Breast Cancer Care has free publications and online content on many of these subjects. Where relevant, we've included the names of other publications. Look out for this symbol:



You can order or download these from [breastcancercare.org.uk](https://breastcancercare.org.uk) or order using the form on page 103. You can also call our Helpline on **0808 800 6000** for a copy.

You can use the pockets in this pack to store everything in one place and refer to it whenever you need to.

# Your treatment details

Use this section to write the contact details of the members of your treatment team. For more information about what the different members of the team do, see page 35.

## Hospital contact details

You can write your hospital name and phone number here. This will keep your personal details private but may help to get the pack back to you if you lose it.

Hospital name

---

Hospital number

---

## My main contacts

### Breast care nurse(s)

One of your main contacts throughout treatment and afterwards will be the breast care nurse. The breast care nurse is trained to provide information and support to anyone diagnosed with breast cancer.

Name

---

Telephone

---

Email

---

### Surgeon

Name

---

Secretary's telephone

---

Secretary's email

---

Other doctors in this team

---

## Oncologist(s) (doctor who specialises in cancer)

Name

---

Secretary's telephone

---

Secretary's email

---

Other doctors in this team

---

Name

---

Secretary's telephone

---

Secretary's email

---

Other doctors in this team

---

## Outpatient clinic

Name

---

Telephone

---

Email

---

## Emergency/out of hours contact (while having treatment)

Name

---

Telephone

---

Email

---

**GP**

Name \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

**Others**

Name \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Name \_\_\_\_\_

Telephone \_\_\_\_\_

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Name \_\_\_\_\_

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**10** Call our Helpline on 0808 800 6000

# About breast cancer

- What is breast cancer?
- Types of primary breast cancer



# What is breast cancer?

Breast cancer starts when cells in the breast begin to divide and grow in an abnormal way. Breast cancer is not one single disease and there are several types.

It can be diagnosed at different stages and can grow at different rates. This means that people can have different treatments, depending on what will work best for them.

Primary breast cancer is breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm.

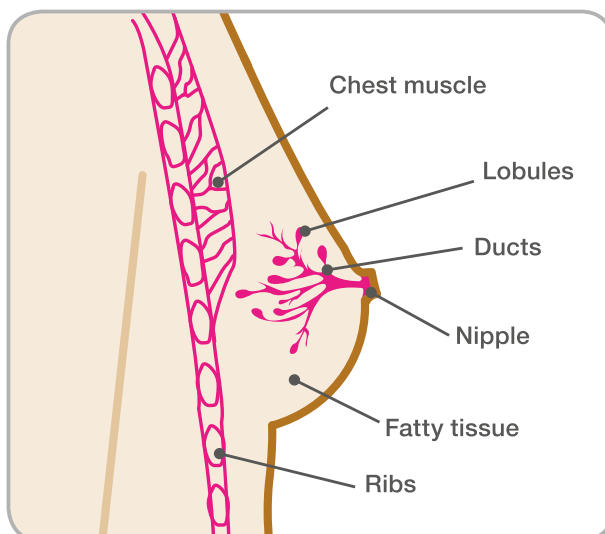
## The breasts and lymph nodes

Breasts are made up of lobules (milk-producing glands) and ducts (tubes that carry milk to the nipple). These are surrounded by glandular, fibrous and fatty tissue. This tissue gives breasts their size and shape.

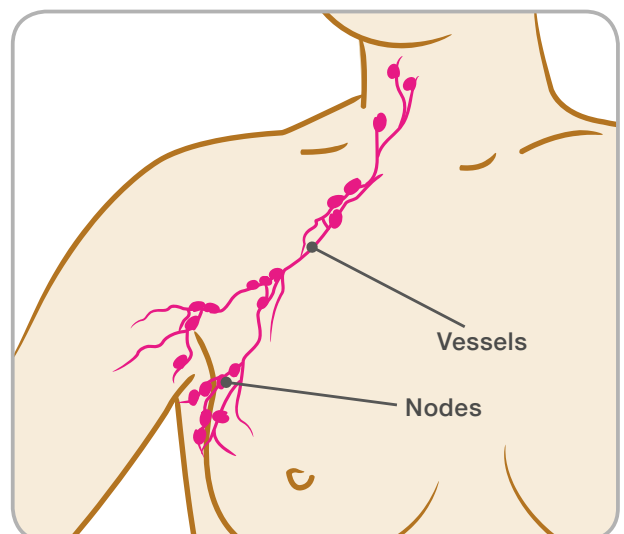
The darker area of skin around the nipple is called the areola. On the areola there are some little raised bumps called Montgomery glands. They produce fluid to moisturise the nipple.

Breasts contain a network of thin tubes called lymph vessels. These are connected to the lymph nodes (glands) under the arm.

The breast



The lymph nodes



# Types of primary breast cancer

There are different types of breast cancer.

Breast cancer can be non-invasive (also called 'in situ') or invasive.

## Non-invasive breast cancer

Non-invasive breast cancer has not yet developed the ability to spread, either within the breast or to another part of the body.

### Ductal carcinoma in situ (DCIS)

Ductal carcinoma in situ (DCIS) is an early type of breast cancer. It's sometimes called intraductal, non-invasive or pre-invasive cancer. The cancer cells are inside the milk ducts (known as 'in situ') and have not yet developed the ability to spread, either through the ducts into surrounding breast tissue or to other parts of the body. If DCIS is not treated, the cells may develop the ability to spread and become invasive breast cancer.

## Invasive breast cancer

Most breast cancers are invasive. Invasive breast cancer has the potential to spread to other parts of the body. This doesn't mean the cancer has or will spread to another part of the body, just that this is a possibility. Treatments aim to reduce the risk of this happening.

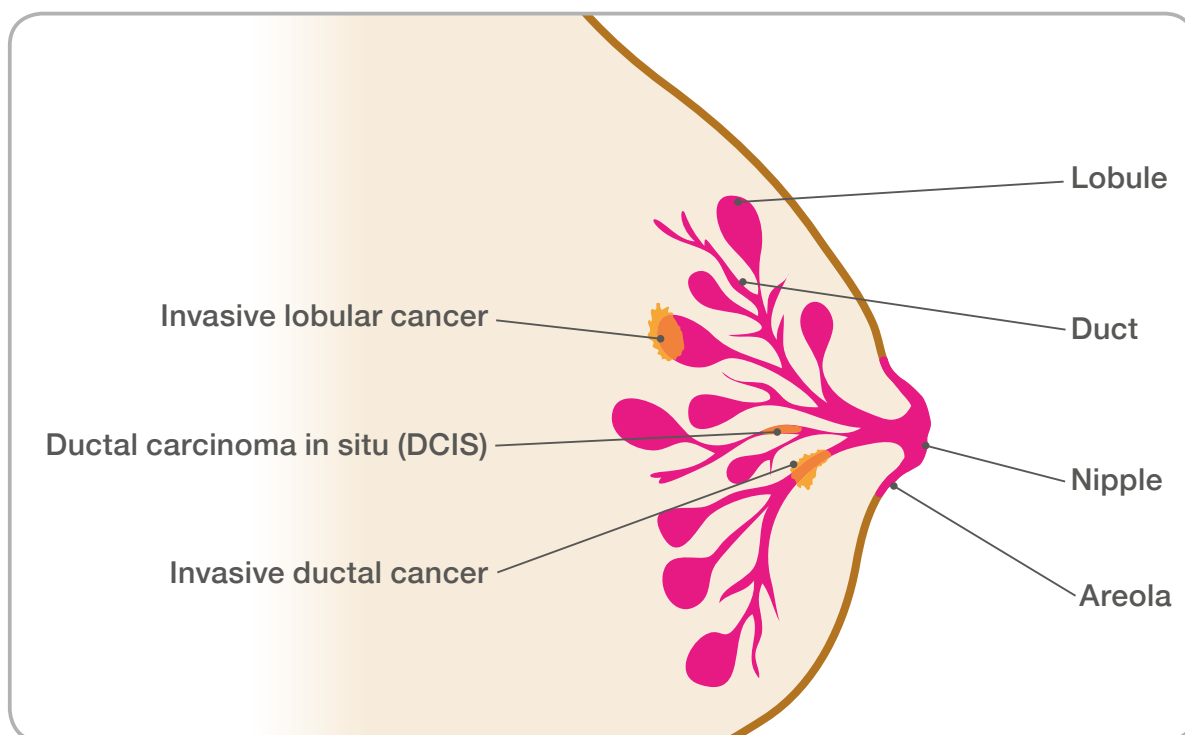
### Invasive ductal breast cancer (of no special type)

Most breast cancers are invasive ductal breast cancers. Breast cancer cells started in the milk ducts and have spread to the surrounding breast tissue.

It's also called breast cancer of no special type (NST) or not otherwise specified (NOS). This is because when the cancer cells are looked at under a microscope they have no distinct features that class them as a particular type.

### Invasive lobular breast cancer

This is the second most common type of breast cancer. Invasive lobular breast cancer occurs when cancer cells in the lobules (milk-producing glands) have spread into the surrounding breast tissue.



### Inflammatory breast cancer

Inflammatory breast cancer is a rare, faster-growing type of breast cancer. It is called inflammatory because the skin of the breast looks red and inflamed. This is caused by breast cancer cells blocking the tiny lymph channels in the breast and the skin.

### Paget's disease of the breast

Paget's disease of the breast is an uncommon type of breast cancer that causes change to the skin of the nipple, similar to eczema.

### Other types of breast cancer

There are several other rare types of breast cancer. These include tubular, cribriform, mucinous (also known as colloid), medullary, papillary, micropapillary, malignant phyllodes and metaplastic breast cancers.



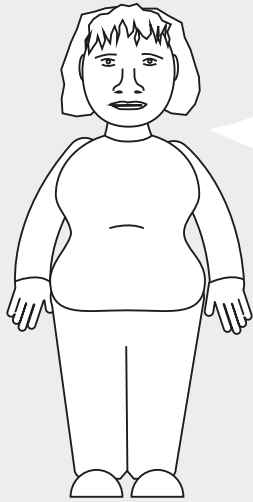
We have booklets and online information on the following types of breast cancer:

- ductal carcinoma in situ (DCIS)
- invasive ductal breast cancer
- invasive lobular breast cancer
- inflammatory breast cancer
- Paget's disease of the breast
- phyllodes tumours: borderline malignant and malignant
- tubular breast cancer
- cribriform breast cancer
- mucinous breast cancer
- medullary breast cancer
- papillary breast cancer
- metaplastic breast cancer

Visit [breastcancercare.org.uk/publications](https://breastcancercare.org.uk/publications) for more information.

## Sofia says >

## About breast cancer



Primary breast cancer is breast cancer that has not spread outside the breast or the glands under your arm.

There is more than one sort of breast cancer.

There are lots of ways breast cancer can be treated.

Breast cancer can grow at different speeds. Some breast cancers grow quite quickly, others more slowly.

Breast cancer can be found at different stages of growing. For example, when it is only inside the breast. Or when it has spread from your breast to the lymph nodes under your arm.

The glands under your arm are called lymph nodes.



# Your diagnosis

- Being diagnosed with breast cancer
- Deciding the best treatment for you
- Grade, size and stage of the cancer
- Other tests to help with decisions about your treatment



# Being diagnosed with breast cancer

Being told you have breast cancer can cause a range of emotions, from fear, shock and disbelief to anger, guilt and sadness. You may be worried about your treatment, or feel sad or angry that your life has suddenly changed. Many people start worrying about dying and feel anxious about their future.

Many people wonder ‘Why me?’ or ‘What have I done to deserve this?’ Some question if their lifestyle has caused their cancer. We know that some lifestyle factors may increase someone’s risk of developing breast cancer, but the main risk factors are being a woman, getting older and having a significant family history. We cannot control these things so try not to feel that your breast cancer diagnosis is because of something you have done.

Some days you may feel hopeful, other days you may feel very low. There’s no right or wrong way to feel. If you keep feeling low or anxious, you can talk to your breast care nurse or GP who can help you with this.

It might help to know that most people with primary breast cancer are treated successfully and more people survive breast cancer now than ever before.

Our booklet **Breast cancer and you: coping with diagnosis, treatment and the future** is for anyone coping with a diagnosis of breast cancer and its treatment. It describes some of the emotional issues people can face. It also includes information about telling other people about your breast cancer.

If you would like to read more about family history and breast cancer, see our **Family history, genes and breast cancer** booklet.

## How much do you want to know?

You may want to learn everything you can about breast cancer and what it means, or you may want information a little bit at a time as you go through treatment. There’s a huge amount of information available, especially online. However, some of it can be misleading, outdated, or may not apply to your situation. If you do look online for information, make sure you use websites that are trustworthy.

The information on Breast Cancer Care's website [breastcancercare.org.uk](https://www.breastcancercare.org.uk) is written and reviewed by clinical experts and based on the latest research. You can find more information on all aspects of breast cancer in our booklets and on our website.

Ask your treatment team to suggest other sources of information.

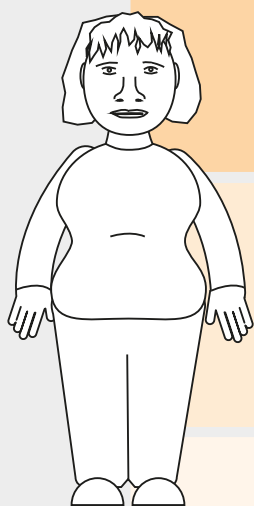
It may take a while for your treatment team to gather all the details of your diagnosis while different tests and investigations are carried out. You may get bits of information as you go along and sometimes this information can change. Waiting for tests and test results can be a particularly anxious time, so it's important to have the right support.

Don't feel afraid to ask questions to your specialist, your breast care nurse, or anyone else in your treatment team. You can also call us free and confidentially on **0808 800 6000**.

## Sofia says >

## Being diagnosed with breast cancer

You can decide how much you want to be involved in making choices about your treatment.



Some people want to be very involved in making choices about their treatment and want to know everything about their breast cancer.

Some people want to leave the choices about treatment to the treatment team and want to know everything about their breast cancer.

Some people want to leave the choices to the treatment team and to know very little about their breast cancer.

You can change your mind about this at any time while you are being treated.



You can call Breast Cancer Care free for support and information on **0808 800 6000**.

The person who answers your call to Breast Cancer Care will be a nurse or someone else who knows a lot about breast cancer.

They won't tell anyone else what you talked about.

## Telling other people

It may be difficult at first to tell people about your diagnosis if you're still trying to take in the information yourself. You may begin by telling people closest to you, and gradually tell others later, perhaps with the help of those who know already.

Some people will find it difficult to know what to say and how to say it, or may ask you lots of questions. They might say insensitive things. Some people may tell you about similar experiences they had or heard about, which may or may not help. You might find some people are avoiding you. These reactions can be hurtful, but are usually because the person doesn't know how to respond.

We have more information on telling people about your diagnosis on our website [breastcancercare.org.uk](https://breastcancercare.org.uk)

Knowing what to tell your children can also be difficult, and you will need to consider their age, character and what they already know about cancer.

Our booklet **Talking with your children about breast cancer** might be helpful.

## Deciding the best treatment for you

Your treatment team will consider many different factors when deciding the best treatment for you. These include the specific features of your cancer, as well as your age and your general health.

Several different tests will be done on breast tissue removed from a biopsy or during surgery. These tests are important because they help decide what sort of treatment will work best for you.

The following factors affect which treatments are recommended for you:

- the size of the breast cancer
- where the cancer is in the breast
- whether more than one area of the breast is affected
- the type of breast cancer
- the grade of the cancer (see page 27)
- whether the cancer has spread to lymph nodes (also called lymph glands) under the arm (axilla)

- the size of the area of cancer within the lymph nodes, and how many lymph nodes are involved
- if any cancer cells are present in the lymph vessels or blood vessels that connect the breast to the rest of the body (known as lympho-vascular invasion)
- whether your breast cancer is oestrogen receptor positive (see 'Hormone receptor test' on page 29)
- whether your breast cancer is HER2 positive (see page 31)

As well as tests done on the breast tissue, sometimes tests on your body are needed too, such as x-rays, scans and blood tests (see page 28). These can help your treatment team find out more information and plan the best treatment for you.

## Questions about my diagnosis

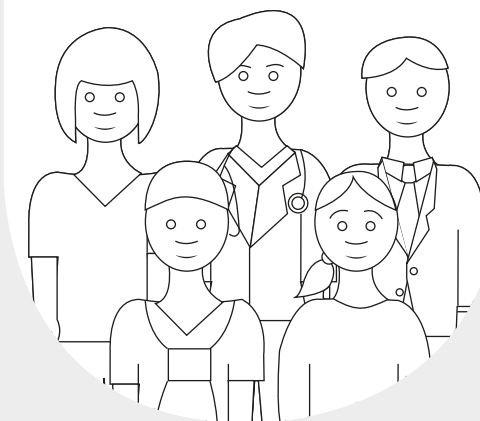
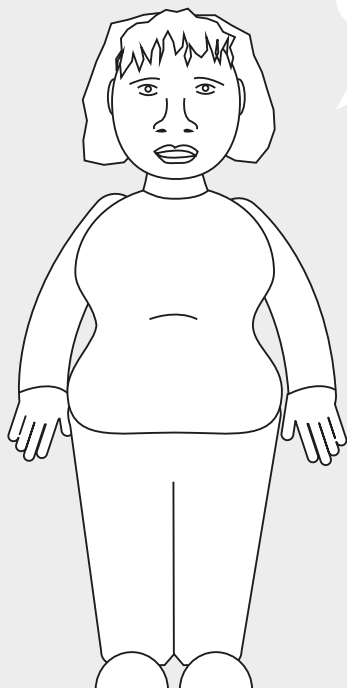
- What type of breast cancer do I have?
- What grade is my breast cancer?
- What is the size?
- Has the cancer spread to the lymph nodes?
- Is the breast cancer oestrogen receptor positive (ER+) or negative?
- Is the breast cancer HER2 positive or negative?
- Will I have any more tests? Which ones and why?
- When will I get the results?
- When does treatment start?



## Deciding the best treatment for you

To decide which treatment will be best for you, your treatment team will do some tests and checks on the cancer. These will find out:

- what sort of breast cancer you have
- how fast it is growing
- what size it is
- what might be helping it to grow



# Grade, size and stage of the cancer

To help decide the most appropriate treatment for you, your treatment team will look at the grade, size and stage of your cancer.

The terms grade and stage can be confusing. If you're not sure which one your specialist is talking about, ask them (or your breast care nurse) to explain it to you.

## Grade

Cancer cells are given a grade according to how different they are to normal breast cells and how quickly they're growing.

### Invasive breast cancer

There are three grades of invasive breast cancer:

- grade 1 – looks most like normal breast cells and is usually slow-growing
- grade 2 – looks less like normal breast cells and is growing faster
- grade 3 – looks different to normal breast cells and is usually fast-growing

### Ductal carcinoma in situ (DCIS)

There are also three grades of DCIS. These are usually called low, intermediate and high. Low grade DCIS is less likely to become an invasive cancer than high grade DCIS.

## Size

The size of your breast cancer will be measured at its widest point, usually in millimetres (mm). One inch equals about 25mm.

While in general smaller cancers may have a better outcome, size doesn't always give the whole picture and is just one part of the overall results. A small cancer can be fast growing while a larger cancer may be slow growing, or it could be the other way around.

## Stage

The stage of a cancer describes the size of the cancer and how far it has spread.

There are different ways to describe breast cancer stages. The most common way is known as the TNM cancer staging system. This is a scoring system used to describe:

- the size of the cancer (T stands for tumour)
- the number of lymph nodes affected (N stands for nodes)
- whether there's any spread of the cancer to other parts of the body (M stands for metastases, a name for this spread)

The individual scores are then grouped together to get an overall stage.

The aim of treatment for primary breast cancer is to remove the cancer and reduce the risk of it returning in the breast or spreading to other parts of the body. Generally, if the cancer is high grade, large or if it has affected the lymph nodes under the arm, there's a higher risk of the breast cancer spreading to other parts of the body.

Breast cancer can spread when cancer cells are carried away from the breast through the lymphatic system or the bloodstream. These cancer cells can then form secondary cancers (also called metastases) in other parts of the body. You may hear this called stage 4, distant recurrence or secondary, metastatic or advanced breast cancer.

Sometimes your treatment team will recommend other tests if they need more information about the stage of the cancer. This can help them decide the best treatment for you. Your doctor or breast care nurse will explain what these tests are for, what they involve and when you can expect the results. These may include:

- a bone scan
- a chest x-ray
- an abdominal and liver ultrasound scan
- a CT (computerised tomography) scan
- an MRI (magnetic resonance imaging) scan
- a PET (positron emission tomography) scan

If you want to know more about the staging system your team uses, or the stage of your cancer, ask your specialist or breast care nurse.

# Other tests to help with decisions about your treatment

Further tests will be done to find out more about your particular cancer so you're offered the most appropriate and effective treatment.

## Hormone receptor test

Some breast cancers are stimulated by the hormone oestrogen. This means that oestrogen in the body helps the cancer to grow. This type of breast cancer is called oestrogen receptor positive (ER+).

Hormone therapies block or stop the effect of oestrogen on breast cancer cells. Different hormone therapy drugs do this in different ways.

Hormone therapy will only be prescribed if your breast cancer is ER+.

Invasive breast cancers are tested to see if they are ER+ using tissue from a biopsy or after surgery. If your cancer is ER+, your specialist will discuss with you which hormone therapy they think is most appropriate.

If your breast cancer is not stimulated by oestrogen it is known as oestrogen receptor negative (ER-), and hormone therapy won't be of benefit.

Tests will also be done to see if your breast cancer is progesterone receptor positive (PR+). Progesterone is another hormone. The benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case, your specialist will discuss with you whether hormone therapy is appropriate.

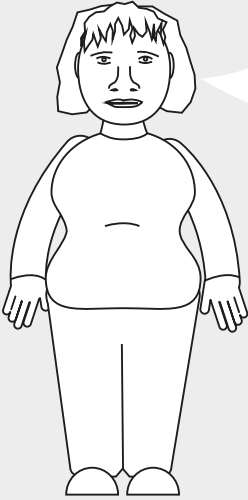
## DCIS

If you have DCIS, you may also have tests to see if your breast cancer is ER+ or PR+. However these tests aren't always necessary for people with DCIS. Your specialist can tell you if they will be done or not.

See our individual hormone drug booklets for more information.



## Hormone receptor test



A hormone is a substance made naturally in the body.

Hormone therapies aim to stop a hormone called oestrogen from helping your breast cancer to grow.

Not all breast cancers are helped to grow by hormones.

Hormone therapy will help you if you have the sort of cancer that is helped to grow by oestrogen.

To find out, tests are done on a small part of the breast cancer.

If the tests show that your cancer is helped to grow by oestrogen, it is oestrogen receptor positive. This means hormone therapy will be helpful in treating your breast cancer.

If your breast cancer is not the sort that is helped to grow by oestrogen, it is oestrogen receptor negative. This means hormone therapy won't be used in treating your breast cancer.

## HER2 test

Around one in five breast cancers has a higher than normal level of HER2 on the cell surface. HER2 is a protein that stimulates (helps) the cancer to grow. These cancers are called HER2 positive (HER2+).

Testing for HER2 is done using tissue removed during a biopsy or surgery. It's normally only done on invasive breast cancer, so is not usually mentioned if you have ductal carcinoma in situ (DCIS).

If your breast cancer is HER2 positive you will usually be advised to have chemotherapy and a drug or drugs from a group known as targeted (or biological) therapies. These include trastuzumab and pertuzumab.

If your cancer is found to be HER2 negative, then targeted therapies given for HER2 positive breast cancer will not be of any benefit.

## Triple negative breast cancer

When breast cancer tests negative for oestrogen, progesterone and HER2 receptors, it's known as triple negative breast cancer. This means hormone therapy and targeted therapy drugs will not be of any benefit. But triple negative breast cancers can be treated with surgery, radiotherapy, chemotherapy (either before or after surgery) and sometimes bisphosphonates (see page 66). Research is helping to find out which chemotherapy drugs work best for triple negative breast cancer. Around 15% of people with invasive breast cancer have triple negative breast cancer.



For more information on grade, size and stage, oestrogen receptor tests and HER2 testing, see our booklet **Understanding your pathology results**.

## Sofia says > Other tests



To decide which treatment will be best for you, your treatment team will do tests and checks on the cancer.

Someone from the treatment team will explain which tests they would like you to have and why.

When the tests have been done, your treatment team will look at what the tests show.

Together they will decide which treatments they believe will be best for you.

They will tell you what these treatments are.

If there is anything you don't understand, ask your breast care nurse to explain it to you.

You can also call Breast Cancer Care free on **0808 800 6000**.

# Having treatment

- Your treatment team
- Treatments for breast cancer
- Your treatment record
- Surgery
- Surgery to the lymph nodes
- Breast reconstruction
- Chemotherapy
- Radiotherapy
- Hormone (endocrine) therapy
- Targeted (biological) therapies
- Bisphosphonates
- Effects of treatment

The information in this section is taken from Breast Cancer Care's booklet **Treating primary breast cancer**



# Your treatment team

People with breast cancer are cared for by a team of healthcare professionals, each with their own expertise. This is known as the multidisciplinary team (MDT). They will meet regularly to discuss your care at the multidisciplinary team meeting (MDM). The team will include:

- breast care nurse
- chemotherapy nurse (trained to give chemotherapy drugs)
- clinical oncologist (a doctor who specialises in treating cancer with radiotherapy alone or radiotherapy and cancer drugs)
- medical oncologist (a doctor who specialises in cancer drugs)
- pathologist (a doctor who examines the tissue and cells removed during a biopsy or surgery)
- radiologist (a doctor who specialises in the use of x-rays, ultrasound and scans to diagnose and treat disease)
- research nurse (who can discuss the option of taking part in clinical trials)
- surgeon
- therapeutic radiographer (trained to give radiotherapy)

It's recommended that all NHS breast cancer patients have a named breast care nurse if they want one. Most private hospitals also have breast cancer nurses. Your nurse will try to answer any questions you have and will offer support during and after your hospital treatment. This role is sometimes called a 'key worker'.

You may also have treatment or care from:

- a fertility specialist
- a geneticist (doctor who specialises in genetics)
- an oncoplastic surgeon (a breast cancer surgeon with specific training in plastic surgery)
- a pharmacist
- a physiotherapist
- a plastic surgeon
- a prosthesis (artificial breast form) fitter, sometimes called an appliance officer
- a psychologist
- a wig fitter or hair loss adviser

A range of support services may also be available. This varies from area to area. You may be interested in finding out more about:

- counselling
- complementary therapies (see page 72)
- local support groups
- a dietitian

Your breast care nurse can tell you what's available to you.

## Don't be afraid to ask

There's a lot of information available for people diagnosed with breast cancer. But the people who know your situation best are those in your treatment team. Your breast care nurse is there to provide information and support throughout your diagnosis, treatment and beyond.

Talk to your breast care nurse or treatment team if you have any questions or concerns you want to discuss. They can also direct you to other useful, trustworthy sources of information and support.

Don't be afraid to ask for anything to be repeated or explained if you don't understand. It can be helpful to write down the questions you ask them and the answers they give, to refer back to. You may find it useful to take a family member or friend to any appointments so they can listen to what is said and perhaps make notes for you. You could also ask if you can record the consultation, for example on your mobile phone, if you think that would be useful.

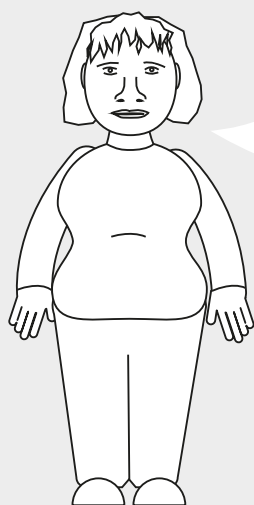
Many hospitals will send you copies of any letters written from one healthcare professional to another, for example from your specialist to your GP, which can be a helpful record of your diagnosis and treatment plan. You can ask for these to be sent to you.

## Asking for a second opinion

Some people consider asking for a second opinion about their diagnosis and treatment. This can be done through your treatment team. A second opinion may not be different from the one you have already had. The time taken to get a second opinion may delay your treatment slightly. A short delay shouldn't affect the outcome of treatment.

## Sofia says >

## Asking for a second opinion



You can ask to see a different cancer expert to check if they agree about the best treatments for you.

If you want to do this, talk to your GP or hospital doctor.

It can take a few weeks to get a second opinion, but this short delay will not affect how well your treatment works.

## Declining treatment

Very occasionally people decide not to have some or all of the recommended treatments. There may be a variety of reasons for this. Some people have very strong personal or religious beliefs that lead them to decline medical treatment. Others may be influenced by a family member or friend's experience. People's experiences of cancer and its treatments will vary hugely and will also be affected by where the cancer is in their body and how long ago they were treated.

People may be afraid of the treatments or doubtful that a particular treatment will be of benefit. Some may feel that certain treatments will affect their quality of life, or are unwilling to accept the potential disruption to their own lives or those of their families.

Choosing not to have treatment is a very personal and sometimes difficult decision to make. Those around you are also likely to have opinions about your decision. Even if you think you don't want to accept one or more of the treatments being offered, consider this carefully, and gather as much information as possible, before making a final decision. Also think about staying in touch with your treatment team for continuing support. You may also want to discuss your decision with your GP.

## Clinical trials

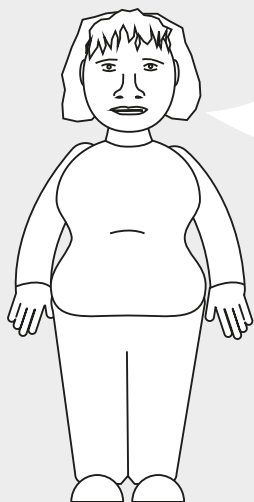
Some people are given the option to take part in research studies that look at new treatments, or new ways of giving existing treatments. These are known as clinical trials.

If you're asked to take part you'll be given lots of information about the clinical trial, including its possible benefits and drawbacks. You'll also be given enough time to decide whether you want to take part.

The decision to take part is entirely up to you. If you decide not to, you'll still be offered the best treatment available.

## Sofia says >

## Deciding not to have treatment



Sometimes people choose not to have a treatment that has been suggested for them because of what they believe in.

Sometimes people are afraid that the treatments won't work or will be too difficult to cope with.

If you feel like this, you can talk about it with your breast care nurse, treatment team or your GP. They will be able to tell you what is likely to happen with your breast cancer if you do not have treatment.

You can also call Breast Cancer Care to talk it through. We will give you as much information and support as you need to make your decision.

If you decide not to have the treatment suggested, your treatment team can still support you.



## Treatments for breast cancer

Treatment aims to remove the cancer and reduce the risk of it coming back or spreading to other parts of the body.

You may have one or more of the following treatments, not necessarily in the order below:

- surgery
- chemotherapy
- radiotherapy
- hormone (endocrine) therapy
- targeted (biological) therapy
- bisphosphonates

Your treatment team will explain the reasons for your particular treatment, but don't be afraid to ask if you have any questions.

Don't worry if the treatment you're offered is different from other people you know or meet. Everyone has their treatment tailored to their individual situation. You will also be given advice about managing side effects of treatment.

You may need to go to different hospitals for different treatments. For example, radiotherapy services are not available at all hospitals, so you may need to travel to a different hospital to where you had your surgery. See page 74 for more information about travelling to hospital for treatment.

## Knowing your treatment options

Knowing about the options for treatment can help you decide what to do if you're offered a choice of treatments. Or you may choose to leave it to your treatment team to decide the best approach to your treatment and what information you need.

You can spend a few days thinking about any treatment options you've been offered before you decide what you want to do. Delaying your treatment very slightly while you consider the options is very unlikely to make a difference to the outcome, and you may feel more in control of what's happening if you've had a chance to think things through.

## Fertility

Some treatments, such as chemotherapy, might affect your ability to have children. If this is important to you, speak to your specialist before you start treatment. For more information, see our **Fertility and breast cancer treatment** booklet.

## Treatment guidelines

When your treatment team is deciding the best treatment for you, they'll follow local and national guidelines developed by breast cancer experts and others involved in caring for people with breast cancer. These guidelines are produced so that everyone is offered the best treatment, wherever they live. If you would like more information about the guidelines you can ask your treatment team.

## Decision-making

You may have different treatment options, and your doctor may ask you to make a decision about your treatment. Some people find this straightforward, while for others it can be very difficult or worrying. If you're asked to make a decision about your treatment, it's important to understand why you're being asked to decide and to have the opportunity to ask questions about your options.

Your treatment team and you may use some of the following to help make a decision.

## Nottingham Prognostic Index (NPI)

The Nottingham Prognostic Index (NPI) is a scoring system that is used with the TNM cancer staging system and the grade of the cancer (see page 28). You are given a score which puts you into a prognosis category of good, moderate or poor. Prognosis means the likely outlook.

## PREDICT ([predict.nhs.uk](https://predict.nhs.uk))

PREDICT is an online decision-making tool. It estimates the benefits for you of chemotherapy, hormone therapy and targeted therapies after surgery based on information about you and your breast cancer. It's not suitable for everybody, but your doctor or breast care nurse can tell you if it might be useful for you.

## Genomic assays (also called gene expression profiling or gene assays)

These tests look at groups of genes found in the breast cancer. They help identify who is most likely to benefit from chemotherapy and how likely the cancer is to return (recurrence).

The tests are carried out on breast tissue removed during surgery, usually in a laboratory away from your hospital, and don't involve having any more tissue removed. The results are provided separately from your pathology report and your treatment team will consider them alongside your other pathology results to help them decide what treatments to recommend.

Genomic assays are not suitable for everyone and will usually only be considered if your breast cancer is invasive, oestrogen receptor positive (ER+) and HER2 negative and with no more than three positive lymph nodes.

If any of these tests could be of benefit to you, your treatment team should discuss this with you.

Examples of genomic assay tests include the following.

### EndoPredict

This test predicts how likely the cancer is to spread within ten years. The result, called the EPclin score, is reported as high risk or low risk.

### Oncotype DX

This test predicts how likely the cancer is to return and the likely benefit of having chemotherapy. The result, called the recurrence score, is reported as a number between 0 and 100. The higher the score, the greater the risk of recurrence of an invasive breast cancer, and the more likely it is chemotherapy will be recommended.

### The Prosigna Breast Cancer Prognostic Gene Signature Assay

This test predicts how likely the cancer is to spread within ten years. The result is reported as low, intermediate or high risk.

# Your treatment record

Use these pages to record the treatments you have and when you have them.

## Surgery

Surgery date(s) \_\_\_\_\_

## Chemotherapy

Start date \_\_\_\_\_

Chemotherapy regimen/drugs \_\_\_\_\_

## Radiotherapy

Start date \_\_\_\_\_

Number of treatments \_\_\_\_\_

## Hormone therapy

Start date \_\_\_\_\_

Hormone therapy drug \_\_\_\_\_

## Targeted therapy

Start dates \_\_\_\_\_

Targeted therapy drug \_\_\_\_\_

## Other treatments

Name \_\_\_\_\_

Date \_\_\_\_\_

Name \_\_\_\_\_

Date \_\_\_\_\_

## Surgery

Surgery is the first treatment for most people with breast cancer. It aims to remove the cancer with a margin (border) of normal breast tissue.

This is done to reduce the risk of the cancer coming back in the breast – known as local recurrence – and to try to stop it spreading elsewhere in the body.

If surgery will be your first treatment, national guidance states that you should have this within 31 days of you and your specialist agreeing to it.

The surgeon will aim to ensure the most effective surgery for the cancer as well as the best cosmetic result.

Sometimes people with invasive breast cancer may be offered chemotherapy, targeted (biological) therapy or hormone therapy before they have surgery. This may mean surgery is less extensive.

There are two main types of breast surgery:

- breast-conserving surgery: the cancer is removed along with a margin (border) of normal breast tissue
- mastectomy: removal of all the breast tissue including the nipple area

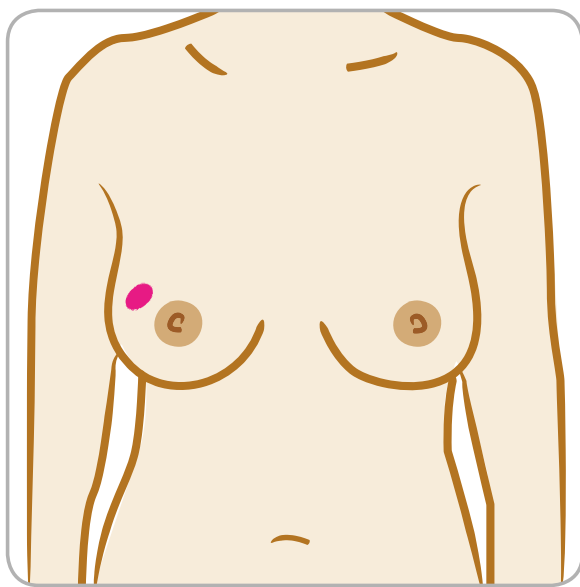
The type of surgery recommended for you depends on the type and size of the cancer, where it is in the breast and whether more than one area of the breast is affected. It will also depend on the size of your breast.

Your treatment team will explain why they think a particular operation is best for you.

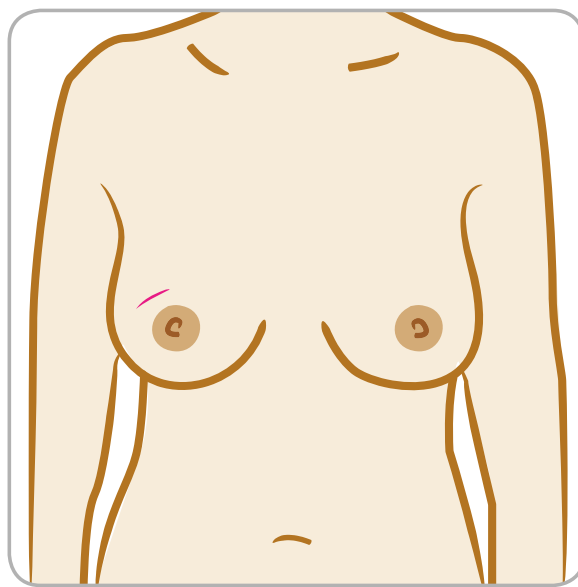
You may also have some or all of the lymph nodes removed with the breast tissue (see page 49).

## Breast-conserving surgery

Usually referred to as wide local excision or lumpectomy, this is where the cancer is removed with a margin (border) of normal, healthy breast tissue. The aim is to keep as much of your breast as possible while ensuring the cancer has been completely removed.



Position of cancer in breast



Example of position of scar after wide local excision

A far less common operation is a quadrantectomy, where around a quarter of the breast is removed. This is sometimes called a segmental excision. After a quadrantectomy the treated breast will usually be smaller due to the amount of tissue removed and it may also be misshapen.

It's more common for people to have oncoplastic surgery. This combines breast cancer surgery with plastic surgery techniques, and means it's less likely you'll notice a dent or a great difference between the breasts. For more information see our **Breast reconstruction** booklet.

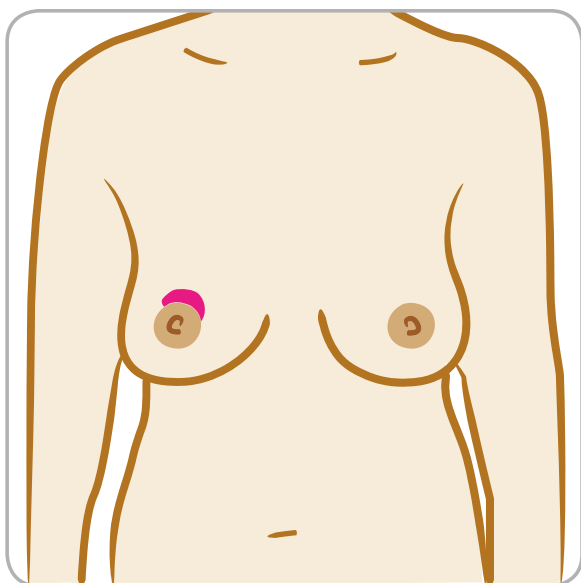
It's important that the cancer is removed with an area of healthy breast tissue around it to reduce the risk of any cancer cells being left behind. The breast tissue removed during surgery will be tested to check the margin around the cancer. If there are cancer cells at the edges of the margin, you may need further surgery to remove more tissue. Some people may need a mastectomy to ensure all the cancer has been removed.

## Mastectomy

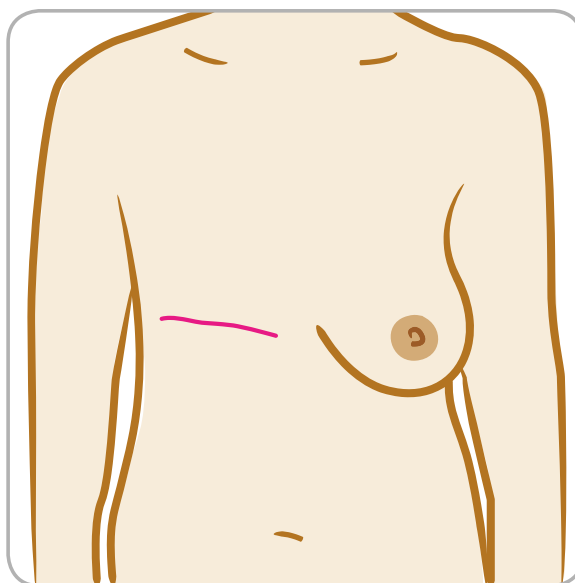
A simple mastectomy is the removal of all the breast tissue including the skin and nipple area.

Examples of when a mastectomy may be recommended include:

- when the cancer takes up a large area of the breast
- when there's more than one area of cancer in the breast



**Position of cancer in breast**



**Example of position of scar after a mastectomy**

If your surgeon recommends a mastectomy they should explain why. It may be your personal preference to have a mastectomy, even if breast-conserving surgery is an option.

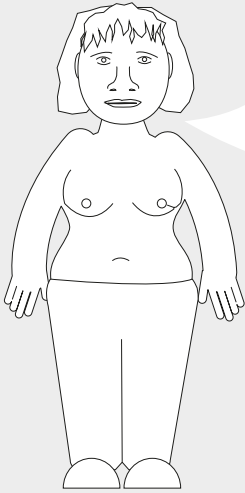
If you're going to have a mastectomy, you will usually be given the option of having breast reconstruction (see page 52).

If you choose to have breast reconstruction, you may be able to have it at the same time as the mastectomy. If this is the case your breast surgeon might discuss other types of mastectomy. A skin-sparing mastectomy is removal of the breast and nipple area without removing much of the overlying skin of the breast. A nipple-sparing mastectomy is removal of all the breast tissue, without removing much of the overlying skin and the nipple area of the breast.

## Sofia says Surgery

There are two main types of breast cancer surgery.

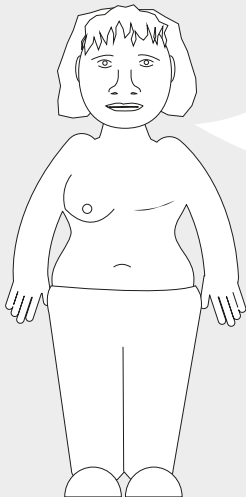
1. Breast-conserving surgery (you might also hear this called a 'lumpectomy' or 'wide local excision').
2. Mastectomy.



Breast-conserving surgery is when surgeons take out the cancer and an area of healthy breast from all around it.

The healthy part is called a margin or a border.

Breast-conserving surgery tries to keep as much of your breast as possible while taking out all the cancer.



A mastectomy is when all of your breast is taken away including the nipple area.

The treatment team usually suggests a mastectomy when:

- the cancer takes up a large part of the breast
- there is more than one area of cancer in the breast

Some people ask for a mastectomy even when it has not been suggested by the treatment team.

If you are having a mastectomy, your surgeon will talk with you about choosing whether or not to have breast reconstruction surgery.

## Which operation?

Some people will be offered a choice between breast-conserving surgery and a mastectomy.

Long-term survival is the same for breast-conserving surgery followed by radiotherapy as for mastectomy. Studies show that women who have a wide local excision and radiotherapy may be slightly more likely to have a local recurrence (when breast cancer returns in the same breast), which can be treated again. However, most people don't have a recurrence.

You may find it helpful to talk through your options with your breast care nurse.

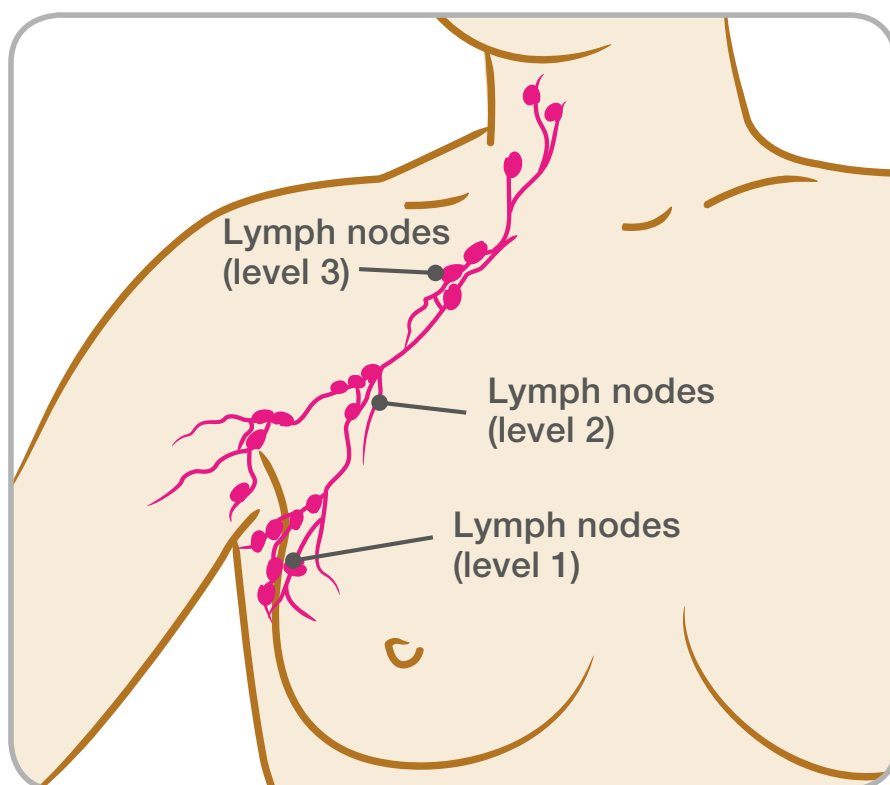
Some women who are having a mastectomy wonder whether they should have their unaffected breast removed as well. Research shows this is not usually necessary or recommended, unless someone has a higher risk of developing primary breast cancer in the other side. This might be the case if they have inherited an altered gene or have a strong family history of breast cancer. Many women overestimate their risk of developing a new primary cancer in the other breast or mistakenly believe breast cancer can spread from one breast to the other, so it's important to discuss your individual situation with your surgeon.



Our booklet **Your operation and recovery** has information about what to expect before your admission to hospital, during your stay, when you return home and during your recovery from surgery.

## Surgery to the lymph nodes

Breasts contain a network of lymph vessels that drain into the lymph nodes (glands) under the arm (axilla). Lymph nodes are arranged in three levels (1, 2 and 3 – as illustrated below). The exact location and number of nodes in each level will vary from person to person.



If you have invasive breast cancer, your treatment team will want to check if any of the lymph nodes under the arm contain cancer cells. This helps them decide whether you will benefit from any additional treatment after surgery.

Usually an ultrasound scan of the underarm is done before surgery to assess the lymph nodes. If this appears abnormal, you'll have a fine needle aspiration (FNA) or a core biopsy to see if the cancer has spread to the lymph nodes. An FNA uses a fine needle and syringe to take a sample of cells to be looked at under a microscope. A core biopsy uses a hollow needle to take a sample of tissue for analysis under a microscope.

If the FNA or core biopsy shows cancer has spread to the lymph nodes, you'll usually be recommended to have surgery to have all your lymph nodes removed. This will be done at the same time as your breast surgery (known as an axillary clearance).

## Sentinel lymph node biopsy

Sentinel lymph node biopsy is widely used if tests before surgery show no evidence of the lymph nodes containing cancer cells. It identifies whether the sentinel lymph node (the first lymph node that the cancer cells are most likely to spread to) is clear of cancer cells. There may be more than one sentinel lymph node.

A small amount of radioactive material (radioisotope) and a dye is injected into the area around the cancer to identify the sentinel lymph node. Once removed, the sentinel node is examined under a microscope to see if it contains any cancer cells.

As the dye leaves your body, you may notice a bluish-green discolouration of your urine and other body fluids for one or two days after the procedure. The skin around the biopsy site may also be stained a blue-green colour. Occasionally it can take longer for this discolouration to disappear. Some people may have a reaction to the dye but this is rare and is easily treated if necessary.

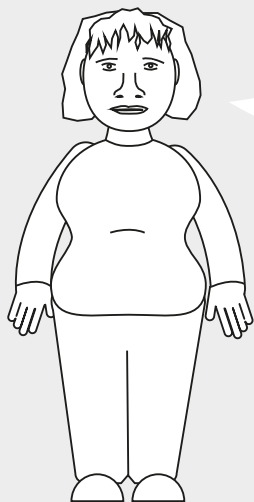
If the sentinel node does not contain cancer cells, this usually means the other nodes are clear too, so no more will need to be removed. Sentinel lymph node biopsy is usually carried out at the same time as your cancer surgery but may be done before.

If the results show there are cancer cells in the sentinel node, depending on how much is found you may be recommended to have:

- further surgery to remove some or all of the remaining lymph nodes
- radiotherapy to the underarm
- no further treatment to the underarm as long as you are having radiotherapy to the breast and chemotherapy or hormone therapy treatment

If you are having chemotherapy before your surgery, your specialist may want you to have a sentinel lymph node biopsy before starting chemotherapy. This can help with planning any further treatment to the underarm after chemotherapy.

If you have DCIS you will only need a sentinel lymph node biopsy if you are having a mastectomy, or if there is a high chance you have some invasive breast cancer.

**Sofia says** **Surgery to the lymph nodes**

Lymph node surgery is an operation to take away glands from under your arms. The glands are called lymph nodes.

The lymph nodes are part of the lymph system. The lymph system is made up of small tubes and nodes. It runs all over your body, including around your breast, into your armpits and up your neck.

Because breast cancer sometimes spreads to the lymph nodes, there are two reasons for doing lymph node surgery.

- To take lymph nodes away if tests have already shown they have cancer in them.
- So that lymph nodes can be looked at closely to see if they have cancer in them.

## Assessing lymph nodes during surgery

Some hospitals are set up to assess the sentinel lymph nodes during your breast surgery. If so, the removed nodes will be looked at by a pathologist, who will then tell the surgeon the result during the operation.

If the sentinel node(s) contains cancer cells, the surgeon may then remove more lymph nodes. Having lymph nodes assessed during surgery avoids a second operation. The most common test used is called One Step Nucleic Acid Amplification (OSNA).

### Questions about surgery

- What surgery will I need and why?
- How many lymph nodes need to be removed
- Where will the scars be?
- What will my breast area look like after surgery?
- What side effects can I expect?
- How long will I take to recover?
- Can I see some breast prostheses (artificial breast forms)?

## Breast reconstruction

Breast reconstruction is the creation of a new breast shape, or mound, using surgery. It may be done after removal of a whole breast (mastectomy) or part of the breast (breast-conserving surgery).

You can have reconstruction at the same time as breast cancer surgery, known as immediate reconstruction; or months or years later, known as delayed reconstruction. Breast reconstruction sometimes involves several operations to give you the best outcome possible.

The new breast shape can be created using an implant and/or your own tissue from another part of the body, usually the back or lower abdomen (belly). Reconstructed breasts don't usually have a nipple but one can be created with surgery and tattooing. Other techniques such as 3D tattooing can create the look of a nipple. Prosthetic stick-on nipples are also available.

There are usually different options available for breast reconstruction and your breast surgeon and breast care nurse will explain which one is likely to suit you best. It's helpful if you can take some time to consider

these options without feeling under pressure to make a decision. You may need a couple of discussions with your treatment team before you feel confident deciding what to do.

Most women who have had a mastectomy, and some who have had breast-conserving surgery, can have either immediate or delayed breast reconstruction. Some people are advised not to have a breast reconstruction because of other existing medical conditions that might increase the risk of problems and complications following surgery. If it's likely you'll need radiotherapy this may affect the options and timing of breast reconstruction.

Not everyone who's had breast surgery has reconstruction. Women may decide not to have a breast reconstruction for a number of different reasons. Any decision you make about having a reconstruction should be based on whether it's right for you.

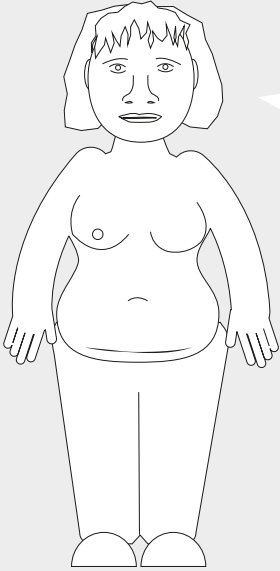
Having a breast reconstruction will not increase the chances of the breast cancer coming back.

## Questions about breast reconstruction

- Can I have breast reconstruction?
- What type of breast reconstruction is best for me and why?
- What are the benefits, limitations and risks of this type of surgery?
- When would I be able to have my surgery done?
- How long would I have to stay in hospital?
- What is the recovery time for this operation?
- Can I see photographs of breast reconstruction operations my surgeon has done?
- Can I talk to someone who has had this type of breast reconstruction?
- Who will do the reconstruction?
- Will the operation be done at this hospital?
- Can I have a second opinion?
- Will having radiotherapy affect my reconstructed breast or my options for breast reconstruction later?



## Breast reconstruction



Breast reconstruction is an operation, or more than one operation, to make a new breast shape when you have had breast cancer surgery.

There are lots of different ways surgeons can do a breast reconstruction. There are also different times when it can be done.

If you have a mastectomy, your treatment team should talk with you about:

- whether you want a breast reconstruction
- what sort of breast reconstruction would work best for you
- when you might have breast reconstruction



Our **Breast reconstruction** booklet is for women considering breast reconstruction after surgery. It explains the different types of reconstruction, and the reasons why women may or may not want to have one. You may also like to read our booklet **Breast prostheses, bras and clothes after surgery**.

## Chemotherapy

Chemotherapy is a treatment using anti-cancer drugs to destroy cancer cells. Different types of chemotherapy drugs are used to treat breast cancer. They can be given in different ways and in different combinations.

Your treatment team will decide whether to recommend chemotherapy depending on:

- the size of your breast cancer
- whether the lymph nodes are affected
- the grade of your cancer (how different your cancer cells are from normal breast cells and how quickly the cancer cells are growing)
- the oestrogen receptor (ER) and HER2 status

Our booklet **Understanding your pathology results** explains these in more detail.

Following surgery, your doctors may use one of the decision-making tools described on page 41 to decide if chemotherapy is suitable for you.

### When is it given?

Chemotherapy is usually given after surgery and before radiotherapy if you're having it. This is known as adjuvant chemotherapy. The aim is to reduce the risk of the cancer coming back, by destroying any cancer cells that may have spread from the breast to other parts of your body.

If you're having chemotherapy after surgery, it will usually start a few weeks after surgery to give your body time to recover.

Sometimes chemotherapy is given before surgery, to slow the growth of cancer. It might also be given to shrink a larger breast cancer before surgery. This may mean breast-conserving surgery is an option, rather than a mastectomy. This is called primary or neo-adjuvant chemotherapy.

There has also been research into giving chemotherapy both before and after surgery, and this may be considered for some people.

## How is it given?

Most chemotherapy drugs are given into a vein (intravenously) for primary breast cancer. However, some can be taken by mouth as tablets or capsules (orally).

## Side effects

Chemotherapy drugs can cause side effects and many people worry about this part of their treatment. These will vary from person to person.

Some of the most common side effects of chemotherapy are:

- nausea (feeling sick) and vomiting (being sick)
- hair loss or thinning
- sore mouth
- taste changes
- fatigue (extreme tiredness)

Chemotherapy can temporarily affect the number of healthy blood cells in the body. This can have a number of effects including:

- an increased risk of infection (not enough white blood cells)
- anaemia (not enough red blood cells)
- bruising and bleeding more easily (not enough platelets)

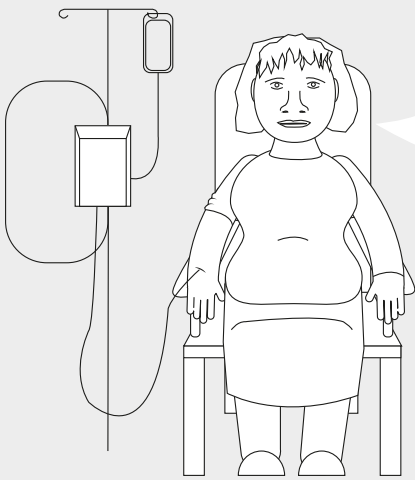
Side effects will vary according to the drugs you're given. Your treatment team will prescribe other drugs to help you cope with them.

Having chemotherapy may affect your fertility. If this is important to you, discuss this with your team before you start treatment. You can read more in our **Fertility and breast cancer treatment** booklet.

## Sofia says Chemotherapy

Chemotherapy uses drugs to kill cancer cells.

There are different sorts of drugs that can be used in different combinations.



The drugs used for treating breast cancer are usually given into a vein in the hand or arm. Giving drugs this way is called 'intravenously'.

Chemotherapy is most often given after you have had breast cancer surgery. The aim is to destroy any breast cancer cells that might have spread from your breast to other parts of your body.

It can also be given before surgery to make the cancer smaller so that it is easier to take out.

The drugs used in chemotherapy can cause a lot of different side effects. Some of the most common side effects are:

- a higher risk of infection, bruising and bleeding
- feeling and being sick
- your hair getting thinner or falling out
- having a sore mouth
- being tired
- lowering or stopping your chance of having a baby

Always tell your breast care nurse or treatment team how your treatment is affecting you. They can often suggest things to help make side effects easier to cope with.



You can read more detailed information in our **Chemotherapy for breast cancer** booklet. Once you know which chemotherapy you are going to have, you can also read our information on specific chemotherapy drugs.

## Questions about chemotherapy

- Would I benefit from having chemotherapy?
- What drugs will I be having and when?
- What are their side effects?
- What are the possible long-term effects?
- Will chemotherapy affect my fertility?
- How long will the chemotherapy take and how often will each dose be given?

## Radiotherapy

Radiotherapy uses carefully measured and controlled high energy x-rays to destroy any cancer cells left behind in the breast and surrounding area after surgery. You may hear this called adjuvant (additional) therapy.

### Which areas are treated?

If you've had breast-conserving surgery, you may have:

- radiotherapy to the remaining breast tissue on that side (whole breast radiation)
- radiotherapy to the area where the breast cancer was (partial breast radiation)
- no radiotherapy

Sometimes your specialist may recommend an extra boost of radiotherapy to the area where the invasive breast cancer was removed, even after whole-breast radiation.

Radiotherapy to the chest wall may be recommended after a mastectomy. This is more likely if cancer cells are found in the lymph nodes under the arm or if a large area of cancer is found.

Radiotherapy is sometimes given to the lymph nodes under the arm instead of surgery, or after a sentinel lymph node biopsy (see page 50). Research has shown that radiotherapy is just as effective in treating the lymph nodes under the arm as removing them surgically. Radiotherapy seems to be associated with fewer side effects than surgery. For example there is a reduced risk of lymphoedema (see page 86). However, radiotherapy isn't suitable for everyone. Speak to your doctor about whether surgery or radiotherapy under the arm is the most suitable treatment for you.

Radiotherapy may be recommended to the lymph nodes on the lower part of your neck, around your collarbone (called supraclavicular fossa or SCF nodes), on the side you have had your surgery. The radiotherapy may also include the nodes in between the breasts on either side of the breast bone (sternum). This is called the internal mammary chain. Whether you have radiotherapy to these other areas depends on the grade and size of your cancer, and whether the lymph nodes under the arm contained cancer cells.

## When is it given?

Radiotherapy for primary breast cancer is given after surgery.

If you're having chemotherapy after surgery, radiotherapy is usually given after chemotherapy has finished. You'll be given radiotherapy over a few weeks as an outpatient, which means you don't have to stay in hospital overnight.

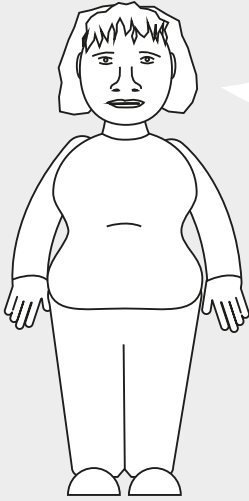
Radiotherapy will usually start a few weeks after surgery or chemotherapy. However, some people have to wait a bit longer because of medical reasons or waiting for an appointment.

Research is looking at different or newer ways of giving radiotherapy. This includes intraoperative radiotherapy (where radiotherapy is given in one dose during surgery), and giving the radiotherapy over a shorter time.



For more detailed information see our **Radiotherapy for primary breast cancer** booklet.

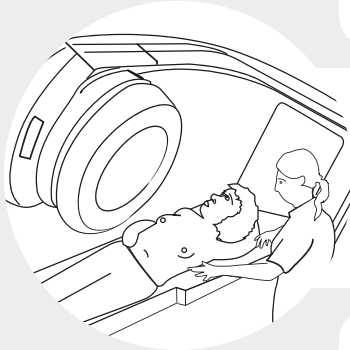
## Sofia says Radiotherapy



Radiotherapy uses x-rays to kill cancer cells.

The x-rays are carefully measured and targeted so that they kill cancer cells but cause as little harm as possible to other parts of the body.

If you are having surgery then chemotherapy, radiotherapy is usually given after your chemotherapy has finished.



Radiotherapy is given to the breast to kill any cancer cells that might be left behind after surgery.

Some other places where radiotherapy can be used to treat breast cancer are:

- under the arm to destroy any cancer cells in the lymph nodes
- the chest after a mastectomy
- the side of your neck and around your collarbone on the side where you had surgery

## Questions about radiotherapy

- Will I need radiotherapy and why?
- What are the benefits and risks?
- Which areas will be treated?
- Where will I go to have treatment?
- How long will the radiotherapy take and how often will each treatment be given?
- What are the side effects?
- Are there any long-term side effects?

## Hormone (endocrine) therapy

The hormone oestrogen can help some breast cancers to grow. There are a number of hormone therapies that work in different ways to block or stop the effect of oestrogen on cancer cells.

You are likely to be recommended to take hormone therapy if tests show your breast cancer is hormone receptor positive (see page 29). Your treatment team will discuss with you which hormone therapy they think is most appropriate.

Women can have hormone receptor positive breast cancer whether or not they've been through the menopause.

If your cancer is found to be hormone receptor negative, then hormone therapy will not be of any benefit to you.

## Types of hormone therapy

Examples of breast cancer hormone therapies include:

- tamoxifen
- anastrozole
- letrozole
- exemestane
- goserelin

The type of hormone therapy given will depend on a number of factors, such as whether you have been through the menopause.

Your treatment team will also consider if you have an increased risk of, or have, osteoporosis (thinning of the bones). Some hormone therapies increase the risk of developing osteoporosis in the future. For more information see our **Osteoporosis and breast cancer treatment** booklet.

## When is it given?

Hormone therapy is usually started after surgery (and chemotherapy, if you're having it) to reduce the risk of the breast cancer coming back or spreading elsewhere in the body. You may have it at the same time as radiotherapy or your doctor may suggest waiting to finish your radiotherapy before starting hormone therapy.

Hormone therapy is taken for several years. Some people have the same drug throughout, while others may be advised to take one type for the first few years and then switch to another type.

Sometimes hormone therapy is given before surgery (called primary or neo-adjuvant hormone treatment). This may be done to reduce the size of the cancer before surgery. If someone isn't able to have surgery for some reason they may be started on hormone therapy.

You will not usually be offered hormone therapy if you have DCIS, unless you do not have radiotherapy following breast-conserving surgery.



We have individual booklets on all the different hormone therapies used in primary breast cancer.

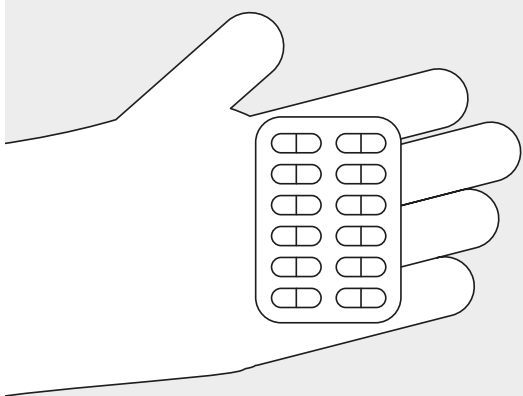
Call us on **0808 800 6000** or visit **[breastcancercare.org.uk](https://breastcancercare.org.uk)** for more information.

## Questions about hormone therapy

- Is my breast cancer oestrogen receptor positive (ER+)?
- Will I benefit from hormone therapy and why?
- What type of drug would be best for me and are there any alternatives?
- When should I start hormone therapy and how long will I take it for?
- What are the side effects?
- Will I be able to have children after taking hormone therapy?

## Sofia says >

## Hormone therapy



Hormone therapy is the name for a range of different treatments that work in a similar way.

All hormone therapies aim to stop a hormone called oestrogen from helping your breast cancer to grow.

Not all breast cancers are helped to grow by hormones.

## Targeted (biological) therapies

Targeted therapies are a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

The type of targeted therapy you are given will depend on the features of your breast cancer.

The most widely used targeted therapies are for people with HER2 positive breast cancer. HER2 is a protein that helps cancer cells grow.

There are various tests to measure HER2 levels, which are done on breast tissue removed during a biopsy or surgery. Only people whose cancer has high levels of HER2 (HER2 positive) will benefit from this type of treatment.

Examples of targeted therapies for HER2 positive breast cancer include trastuzumab and pertuzumab.

If your cancer is found to be HER2 negative, then targeted therapies given for HER2 positive breast cancer will not be of any benefit.

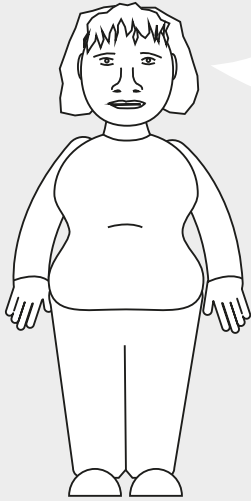
For more information see our **Trastuzumab** and **Pertuzumab** booklets.

### Questions about targeted therapy

- Is my breast cancer HER2 positive?
- Will I benefit from targeted therapy?
- How will it be given and how long will I have it?
- What are the side effects?

## Sofia says

## Targeted (biological) therapies



Targeted therapy is when drugs are used to try to block the growth and spread of breast cancer.

The drugs interfere with the way breast cancer cells grow.

Not all breast cancers can be treated with targeted therapy.

The most widely used targeted therapy is a drug called trastuzumab. It is also sometimes called Herceptin.

Trastuzumab targets a protein called HER2 because HER2 makes cancer cells grow.

# Bisphosphonates

Bisphosphonates are a group of drugs that can reduce the risk of breast cancer spreading in postmenopausal women. They can be used regardless of whether the menopause happened naturally or because of breast cancer treatment.

Bisphosphonates can also slow down or prevent bone damage. They're often given to people who have, or are at risk of, osteoporosis (when bones lose their strength and become more likely to break). Osteoporosis usually occurs as part of ageing, but some treatments for breast cancer can increase your risk of getting it.

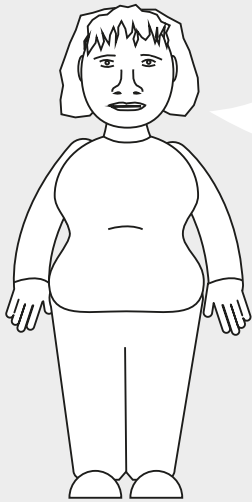
Bisphosphonates can be given as a tablet or into a vein (intravenously). It's not yet known what the best length of time to take bisphosphonates for primary breast cancer is, but they are currently prescribed for around two to five years.

The benefits of using them before the menopause are less clear, so they are not prescribed in younger, premenopausal women.

Your treatment team can tell you if bisphosphonates would be suitable for you.

## Questions about bisphosphonates

- Will I benefit from bisphosphonates?
- What are the side effects?
- How are they given?
- How long do I take them for?

**Sofia says** **Bisphosphonates**

Bisphosphonates are drugs that have more than one use in treating primary breast cancer.

1. To keep your bones strong when you are having another treatment that might have the side effect of weakening them.
2. If you are a woman who has been through the change (also called the menopause), bisphosphonates may make it less likely that your primary breast cancer will spread to other parts of your body when your treatment has finished.

If you are offered bisphosphonates to make it less likely that your breast cancer will spread, you'll probably be asked to have them for up to five years.

## Effects of treatment

Some breast cancer treatments can cause temporary side effects that stop soon after treatment finishes. However, your treatment may also cause longer-term side effects.

The side effects people experience and how long they last will vary from person to person. Some people find the physical and emotional side effects of breast cancer treatment overwhelming.

Side effects such as hot flushes or fatigue (extreme tiredness) can be a constant reminder of your breast cancer, and difficult to cope with over time.

Talk to your GP, specialist or breast care nurse about any side effects you are having and ways to manage them.



For information about, and tips on coping with, some common side effects of breast cancer treatments, see our booklets:

**Breast cancer and hair loss**

**Living with lymphoedema**

**Menopausal symptoms and breast cancer**

**Osteoporosis and breast cancer treatment**

**Reducing the risk of lymphoedema**

Our booklets on individual treatments – such as chemotherapy, radiotherapy and hormone therapy drugs – also cover side effects and how to cope with them.

Our **Moving Forward** book contains information on coping with ongoing side effects once treatment has finished.

Visit [breastcancercare.org.uk/publications](https://breastcancercare.org.uk/publications) to order or download any of the publications listed. You can also call our Helpline on **0808 800 6000** for more information.

# Wellbeing and practical issues

- Health and wellbeing during and after treatment
- Practical issues
- Finishing treatment
- Breast cancer words explained



# Health and wellbeing during and after treatment

Wellbeing means different things to different people. But it can be described as feeling content, being physically, spiritually and emotionally well, or having a sense of control over your life.

After treatment, many people choose to look at their lifestyle to see if there are any changes they want to make.

There are many conflicting ideas and theories about lifestyle and how it contributes to our health and wellbeing. This can be confusing when you are trying to understand all sorts of other information about breast cancer and its treatment.

## Diet

Knowing what to eat during and after treatment for breast cancer can be difficult. But eating healthily can make a difference to your energy levels and general wellbeing.

All foods can be included in a healthy diet as long as you get the balance right. Experts recommend eating at least five portions of fruit and vegetables a day and having a variety of different foods. In most cases, a balanced diet should mean that nutritional and vitamin supplements are not needed. If you choose to take supplements, discuss this with your breast care nurse or specialist.

Breast cancer treatments such as chemotherapy can have a range of side effects, some of which can affect how you eat and drink. You may experience a change in appetite, nausea, taste changes, a sore mouth and diarrhoea or constipation.



You can find tips on healthy eating during and after treatment in our **Diet and breast cancer** booklet and on our website [breastcancercare.org.uk](https://breastcancercare.org.uk)

If you would like further advice you can talk to your GP or treatment team. You could also ask them to refer you to a dietitian.

## Physical activity

Staying physically active during treatment for breast cancer can be difficult, especially if you have side effects and feel unwell. But even a small amount of activity can have benefits.

Physical activity can help reduce some of the side effects of treatment such as fatigue, pain and insomnia. There's also evidence that being active and maintaining a healthy weight after treatment can reduce the risk of breast cancer coming back.

If you have surgery as part of your treatment, our **Exercises after breast cancer surgery** leaflet (included in this pack) contains shoulder and arm exercises that can help you regain the movement and function you had before your operation.

If you have had any type of breast reconstruction, check with your surgeon or physiotherapist which exercises they recommend.

You can build up exercise gradually and incorporate it into your daily life. This doesn't have to mean going to the gym. Even walking can boost your energy and reduce some of the side effects of your treatment.

Before starting any type of activity, it can help to get guidance from your treatment team, to make sure the exercise you plan to do is safe, especially if it's a new activity for you.

## Complementary therapies

Some people like to use complementary therapies – such as acupuncture, Reiki or massage – during and after breast cancer treatment. Some hospitals offer complementary therapies so it's worth asking what is available in your area.

Tell your specialist or breast care nurse about any complementary therapies you're intending to use. Some, such as certain herbal remedies, may interfere with conventional treatments (treatments that have been approved for use in medical practice, such as chemotherapy or radiotherapy).



Find out more about different therapies in our **Complementary therapies, relaxation and wellbeing** booklet.

# Practical issues

## Work

Many people worry that having cancer may affect their current or future employment. The Equality Act 2010 protects anyone who has been diagnosed with cancer against any discrimination relating to employment – including the recruitment process. The Disability Discrimination Act (DDA) protects people who live in Northern Ireland.

Some people are able to continue at work during treatment, either full-time or part-time, whereas others need to take the entire time off. Some people stop working altogether after a diagnosis of breast cancer.

Macmillan Cancer Support has more information about how cancer and cancer treatments may have an impact on your employment. Visit [macmillan.org.uk](https://macmillan.org.uk) or call 0808 808 0000.

## Financial issues

Having breast cancer can affect your financial situation. Concerns about money can be particularly stressful at a time when you may feel less able to cope.

People in England being treated for cancer are entitled to all their prescriptions free of charge. To show you're eligible for free prescriptions, you need to apply for an exemption certificate from your GP or hospital. In Scotland, Wales and Northern Ireland, prescription charges have been completely abolished.

You may be entitled to certain benefits. Some hospitals provide a welfare and benefits service.

Macmillan Cancer Support has an online financial support tool [finance.macmillan.org.uk](https://finance.macmillan.org.uk) that can help you with some financial decisions you may face if you've been diagnosed with cancer. You can also call them on 0808 808 0000 for more help.

## Transport to and from hospital

When going to hospital for non-emergency tests or treatment, you'll normally be expected to make your own way there and back. You may feel able to take yourself or prefer someone to come with you. If you're driving, find out from the hospital about their parking facilities and charging.

Many people worry about getting public transport when they're having treatment. If you feel well enough to travel on public transport, ask your treatment team if it's safe to do so.

Some people are eligible for non-emergency patient transport services (PTS). These services provide free transport to and from hospital for people who have a medical need for it. You can ask at your hospital about this.

You may be able to claim a refund, under the Healthcare Travel Costs Scheme (HTCS), of the cost of travelling to hospital or other NHS premises for NHS-funded treatment or tests.

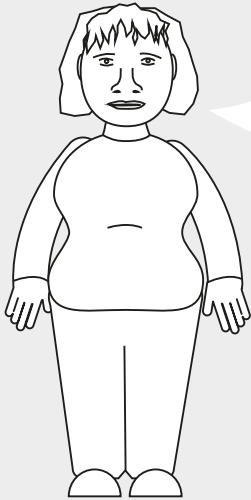
You can find out more about this on the NHS website [nhs.uk](https://www.nhs.uk) or by asking at your hospital.

## Finishing treatment

Everyone's experience of moving on after breast cancer is different. How you feel, both physically and emotionally, may be very different to someone else who has had a similar diagnosis and treatment. Most people are surprised at how emotional they feel when they finish treatment and for many, the need for support and information doesn't end when treatment finishes.

## Follow-up

At the end of your hospital-based treatment, you may continue to be monitored to check how you are recovering. This is known as follow-up. How you are followed up will depend on your individual needs and on the arrangements at the hospital you have been treated at. You'll probably find contact is more frequent at first, becoming less so as time goes on.

**Sofia says** **Finishing treatment**

When you have finished your hospital treatment, all sorts of feelings can come up. Not everyone is the same but many people find this is a difficult time. Some common feelings are:

- shock about what has happened
- worries about the cancer coming back
- worries about how to get back to a normal life
- worries about how to cope with permanent changes to your body
- worries about how to cope with changes to your relationships

These feelings, changes and concerns can take a long time to settle.

If you would like to talk about your breast cancer and how you are feeling, you can talk to your breast care nurse.

Breast Cancer Care is also here to give you support and information.

Whichever way you are followed up you will be given a name and contact number to ring (usually the breast care nurse) if you have any questions or concerns between appointments, and you can always talk to your GP about any concerns you have.

## Moving Forward

Breast Cancer Care's Moving Forward courses provide information, support and professional guidance on how to cope with and adjust to life after breast cancer treatment. The courses are run in partnership with NHS hospitals, and usually take place over half a day for three or four weeks. Topics covered include healthy eating, exercise, managing menopausal symptoms, lymphoedema, cancer fatigue, emotional wellbeing and intimacy and relationships.

You can also order Breast Cancer Care's **Moving Forward** book which looks at the subjects covered by the course.



For more information about follow-up, see our **Moving Forward** book or our booklet **After breast cancer treatment: what now?**

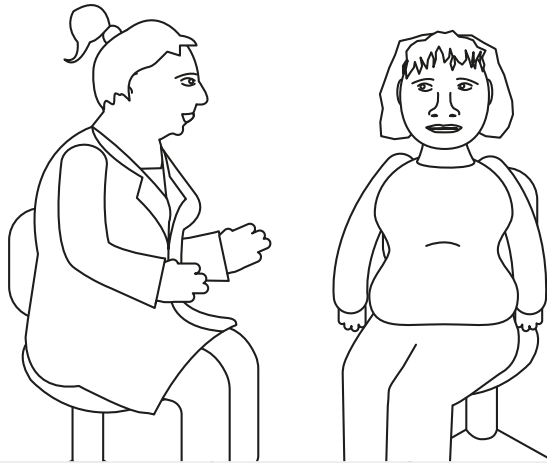
## BECCA app

Our mobile app offers information, support and inspiration to help you adjust to life after breast cancer treatment. The information is presented on easy-to-use flashcards and includes topics such as day-to-day strategies for moving forward, wellbeing and mindfulness, and links to other sources of information. All the content is reviewed by our clinical team for reliability and accuracy.

Download the app from the App Store (Apple devices) or Google Play (Android devices), or find out more at [breastcancercare.org.uk/becca](https://breastcancercare.org.uk/becca)

## Sofia says >

## Follow-up



After your hospital treatment is finished, the hospital might have a system to check how you are getting on.

This checking system is called follow-up.

Different hospitals have different follow-up. It might include:

- hospital appointments
- seeing your GP
- phone calls with your treatment team
- getting a clinic appointment if something is worrying you

# Breast cancer words explained

These definitions of medical words may help you feel better informed. If you can't find what you're looking for here, you can call our Helpline on **0808 800 6000** to talk to someone who can help.

## A

**Abdomen** Belly.

**AC chemotherapy** A combination of the chemotherapy drugs Adriamycin (also known as doxorubicin) and cyclophosphamide.

**Adjuvant** Treatment given after initial treatment, for example chemotherapy or radiotherapy given after surgery.

**Adriamycin** see Doxorubicin

**Advanced breast cancer** Breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. Also known as secondary, stage 4 or metastatic breast cancer.

**Adverse effect** An undesired or harmful effect resulting from treatment.

**Alopecia** Loss of hair from the head or body.

**Alternative therapy** Term used to describe therapies used by some people in place of standard medical treatment.

**Anaemia** Too few red blood cells in the body. It may cause symptoms including tiredness, shortness of breath and weakness.

**Anastrozole** A hormone therapy and one of a group of drugs called aromatase inhibitors. It may be known by different brand names, the most well-known being Arimidex.

**Anthracyclines** A group of chemotherapy drugs commonly used to treat breast cancer. Examples include doxorubicin (also known as Adriamycin) and epirubicin.

**Anti-emetics** Drugs used to reduce nausea (feeling sick) or vomiting.

**Areola** Coloured area of skin around the nipple.

**Arimidex** see Anastrozole

**Aromasin** see Exemestane

**Aromatase inhibitors** Breast cancer treatment that works by reducing the amount of oestrogen in the body. A type of hormone (endocrine) therapy.

**Axilla** Under the arm, the armpit.

**Axillary clearance** An operation to remove all the lymph nodes (also called lymph glands) from under the arm (axilla).

**Axillary nodes** The lymph nodes (also called lymph glands) under the arm (axilla).

**Axillary sampling** An operation to remove some of the lymph nodes (also called lymph glands) from under the arm (axilla).

## B

**Benign** Not cancer.

**Bilateral** Affecting or about both the right and left sides of body. For example, a bilateral mastectomy is removal of both breasts.

**Biological therapies** see Targeted therapies

**Biopsy** Removal of tissue to be looked at under a microscope.

**Biosimilars** Drugs that are very similar, but not identical, copies of biological therapies.

**Bisphosphonates** A group of drugs for:

- reducing the risk of breast cancer coming back in postmenopausal women
- treating secondary breast cancer in the bone
- preventing or treating osteoporosis

**Blood cells** Tiny structures produced in bone marrow. Includes red blood cells, white blood cells and platelets.

**Blood count** The numbers of red and white blood cells and platelets in a sample of blood.

**Bone marrow** Spongy material found in the hollow part of the bone where red and white blood cells and platelets are produced.

**Bone metastases** Also known as secondary breast cancer in the bone. Cancer cells that have spread from the breast to the bones.

**Bone scan** A test to help identify any abnormal changes, such as tumours, infection or fractures, in the bones.

**Brain metastases** Also known as secondary breast cancer in the brain. Cancer cells that have spread from the breast to the brain.

**BRCA1 and BRCA2** People who inherit an altered BRCA1 or BRCA2 gene from either parent have a much higher risk of developing breast cancer and some other cancers compared with the general population.

**Breast calcification** Areas of calcium deposit in one or both of the breasts.

**Breast care nurse** Provides information and support to people diagnosed with breast cancer.

**Breast-conserving surgery** Also known as wide local excision or lumpectomy. The removal of the cancer with a margin (border) of normal breast tissue around it.

**Breasts** Made up of lobules (milk-producing glands) and ducts (tubes that carry milk to the nipple). These are surrounded by glandular, fibrous and fatty tissue. This tissue gives breasts their size and shape.

## C

**Cannula** A small plastic tube through which drugs are given into a vein, usually in the arm or hand.

**Carboplatin** A chemotherapy drug sometimes used to treat breast cancer.

**Carcinoma** Another word for cancer.

**Cardiotoxicity** Damage to the heart muscle causing the heart to become weaker and less efficient. May be caused by some chemotherapy and targeted therapy drugs.

**Cell proliferation** An increase in the number of cells as a result of them multiplying and growing.

**Cells** Tiny structures found in all living organisms.

**Cellulitis** An infection of the skin and tissue beneath the skin. People who have lymphoedema (see page 86) have an increased risk of cellulitis in the arm or chest area.

**Chemotherapy** Treatment that destroys cancer cells using anti-cancer drugs.

**Chest wall** Skin, muscles and bones that make up the area of the body between the neck and the abdomen.

**Chronic** An illness, disease or condition that is long lasting and generally slow to progress.

**CISH (chromogenic in situ hybridization)** A way of measuring HER2 levels in cancer cells.

**Cisplatin** A chemotherapy drug sometimes used to treat breast cancer.

**Clinical trials** Research that aims to improve treatment or care for patients.

**CMF** A combination of three chemotherapy drugs – cyclophosphamide, methotrexate and 5-fluorouracil (5FU).

**Cognitive impairment** Difficulty concentrating or being more forgetful as a result of a cancer diagnosis or treatment. Sometimes called ‘chemo brain’ or ‘chemo fog’.

**Complementary therapies** A varied group of therapies sometimes used alongside conventional medical treatments.

**Contralateral** The other or opposite side, for example the contralateral breast.

**Cording (also known as axillary web syndrome)** Tight ‘cords’ of tissue stretching down the inside of the arm, which can occur after surgery to remove lymph nodes under the arm. Causes pain and restricts arm movement. Sometimes cords can be felt in the chest area too.

**Core biopsy** Biopsy using a hollow needle to take one or more samples of tissue for analysis under a microscope.

**CT (computerised tomography) scan** A type of scan that uses x-rays to take detailed pictures across the body.

**Cyclophosphomide** A chemotherapy drug used to treat breast cancer.

## D

**DCIS (ductal carcinoma in situ)** An early type of breast cancer where the cells have not yet developed the ability to spread outside of the ducts into surrounding breast tissue or to other parts of the body. Sometimes called pre-invasive, intraductal or non-invasive cancer.

**DEXA (dual energy x-ray absorptiometry) scan** A scan that measures bone mineral density. Used to diagnose or monitor osteoporosis, or assess the risk of developing it.

**Diagnostic radiographer** A person trained to carry out x-rays and scans.

**DIEP (deep inferior epigastric perforator) flap** A type of breast reconstruction that uses the skin and fat between the belly button and the groin.

**Differentiation** How different cancer cells are when compared to normal cells. Well-differentiated cancer cells look almost normal (a similar size and shape to normal cells); moderately differentiated cancer cells look less like normal cells (often larger and more varied shapes); poorly differentiated cancer cells look most changed and are usually fast growing.

**Docetaxel** A chemotherapy drug also known as Taxotere. One of a group of chemotherapy drugs called taxanes.

**Doxorubicin** A chemotherapy drug also known as Adriamycin. One of a group of chemotherapy drugs known as anthracyclines.

**Drug resistance** The cancer cells' ability to resist the effects of a drug.

## E

**ECHO (echocardiogram)** A type of ultrasound of the heart, to check how well it is working.

**EGFR (epidermal growth factor receptor)** Proteins on the surface of cells. When there are higher than normal levels (known as over expression) on cancer cells, they stimulate growth.

**Embolism** When blood flow is blocked, usually by a blood clot or air bubble.

**Encapsulated** Surrounded and encased. For example, an encapsulated breast implant has been encased by a build-up of dense, tough tissue, also called fibrous tissue.

**Endocrine therapy** see Hormone therapy

**Endometrial cancer** Cancer of the lining of the womb (uterus).

**Epirubicin** A chemotherapy drug used to treat breast cancer. One of a group of chemotherapy drugs known as anthracyclines.

**ER status** ER positive (ER+) means the breast cancer has oestrogen receptors. ER negative (ER-) means the breast cancer doesn't have oestrogen receptors (see Oestrogen receptors).

**Excision** Surgical removal.

**Exemestane** A hormone therapy drug, also known as Aromasin. One of a group of drugs called aromatase inhibitors.

**Expander implant** A type of breast implant used in breast reconstruction. The implant is gradually inflated with saline (salt water) through a small port.

## F

**FEC** A combination of the chemotherapy drugs 5-fluorouracil (5FU), epirubicin and cyclophosphamide.

**FEC-T** A combination of the chemotherapy drugs 5-fluorouracil (5FU), epirubicin, cyclophosphamide and Taxotere (docetaxel).

**Femara** see Letrozole

**Filgrastim** A type of GCSF, also known as Neupogen

**Fine needle aspiration (FNA)** Using a fine needle and syringe to take a sample of cells for analysis under a microscope.

**FISH (fluorescence in situ hybridization)** A test for measuring HER2 levels in cancer cells. FISH negative (FISH-) means normal levels are present, FISH positive (FISH+) means excessive amounts are present, classed as HER2+.

**Fluorouracil** Also known as 5FU. A chemotherapy drug used to treat breast cancer.

**Fraction** Each radiotherapy treatment is known as a fraction. Treatment involves several fractions given over a few days or weeks.

## G

**GCSF (granulocyte-colony stimulating factor)** A drug that boosts the levels of white blood cells in the body when they are low, for example during chemotherapy treatment.

**Gene** Stores the biological information we inherit from our parents, affecting the way we look and how our bodies work and grow.

**Grade** The system used to classify cancer cells according to how different they are to normal breast cells and how quickly they are growing.

**Goserelin** A hormone therapy drug, also known as Zoladex.

## H

**HER2 (human epidermal growth factor receptor 2)** A protein involved in the growth of cells. Around 15–20% of breast cancers have higher than normal levels of HER2 (known as HER2 positive) which stimulates the cancer to grow.

**Hereditary** Characteristics, conditions or illnesses that can be passed from a parent to their child through genes.

**Hickman line** Also known as a skin-tunnelled catheter. A fine silicone tube through which chemotherapy drugs are given. It's put into a large vein through a small cut in the chest wall, and can stay in place for several months.

**Hormone receptor** Involved in the growth of cells. In some breast cancers they bind to hormones within the cells (known as hormone receptor positive) and stimulate the cancer to grow.

**Hormones** Substances made naturally in the body. Hormones act as 'messengers' that tell organs or tissues to carry out various functions.

**Hormone therapy (also called endocrine therapy)** Drugs that work in different ways to block the effect of oestrogen on cancer cells. Only used if the breast cancer is hormone receptor positive.

**HRT (hormone replacement therapy)** A treatment containing female sex hormones – either oestrogen alone or a combination of oestrogen and progesterone – to help reduce menopausal symptoms.

## I

**IHC (immunohistochemistry)** A test for measuring HER2 levels in cancer cells. A score of 0 or 1+ means the breast cancer is HER2 negative. A score of 2+ is borderline and a score of 3+ means the breast cancer is HER2 positive.

**Immune response** An automatic defence function of the body that recognises and protects it from infection and foreign bodies, for example.

**Immunosuppression** Reduced ability of the body to protect against infection and disease. Can be caused by chemotherapy.

**In situ (breast cancer)** Breast cancer that has not developed the ability to spread outside the ducts, either within the breast or elsewhere in the body.

**Infertility** Being unable to get pregnant. May be temporary or permanent and can be caused by chemotherapy, for example.

**Inflammation** Swelling, redness or warmth caused by the reaction of body tissues to injury, infection or irritation.

**Inflammatory breast cancer** A rare type of breast cancer where the skin of the breast looks red, and may feel warm and tender ('inflamed').

**Infusion** A method of delivering fluids or drugs, usually into a vein.

**Intraductal** see DCIS

**Intramuscular (IM)** An injection into the muscle.

**Intravenous (IV)** An injection into the vein.

**Invasive cancer** Cancer that has the potential to spread to other parts of the body.

**Ipsilateral** On the same side, as opposed to contralateral.

## L

**LD (latissimus dorsi) flap** A type of breast reconstruction that uses the latissimus dorsi (a large muscle in the back just below the shoulder blade), along with skin and fat.

**Letrozole** A hormone therapy, also known as Femara. One of a group of drugs called aromatase inhibitors.

**Local recurrence** see Recurrence

**Local treatment** Specific to an area of the body, for example surgery or radiotherapy.

**Locally advanced breast cancer** Also known as regional recurrence. See Recurrence

**Lumpectomy** An operation to remove an area of breast tissue with or without a margin of healthy tissue. In breast cancer may also be called wide local excision or breast-conserving surgery.

**Lymph nodes** Also known as lymph glands. Small oval-shaped structures found in clusters throughout the lymphatic system, for example under the arm (axilla).

**Lymphatic system** The drainage and filtering system of the body, made up of lymph nodes (lymph glands), vessels and fluid. Helps to get rid of waste products and fight infection.

**Lympho-vascular invasion** When breast cancer cells invade (spread into) the lymph and blood vessels within the breast, and can be seen in these vessels under the microscope.

**Lymphoedema** Swelling of the arm, hand or breast/chest area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of surgery and/or radiotherapy to the lymph nodes under the arm and surrounding area.

## M

**Malignant cancer** Abnormal cells that divide and grow in an uncontrolled way.

**Mammogram** A breast x-ray.

**Mastectomy** Removal of all the breast tissue including the nipple area.

**Metastases** Another name for Secondary breast cancer.

**Methotrexate** A chemotherapy drug used to treat breast cancer.

**Mets** Short for metastases.

**Microcalcifications** Small deposits of calcium in the breast. They show up as white dots on a mammogram, and are sometimes a sign of DCIS (ductal carcinoma in situ).

**MRI (magnetic resonance imaging) scan** A type of scan that uses magnetism and radio waves to produce a series of images of the inside of the body. An MRI doesn't expose the body to x-ray radiation.

**MUGA (multiple-gated acquisition)** A scan using a small amount of radioactive material, to check how well the heart is working.

**Multi-centric** When there is more than one area of breast cancer in different quarters of the breast.

**Multi-focal** When there is more than one area of breast cancer but only in one quarter of the breast.

## N

**Neo-adjuvant** Treatment given before surgery. Examples are chemotherapy and hormone therapy. Sometimes called primary, for example primary hormone therapy.

**Neupogen** A type of GCSF.

**Neutropenia** When the number of white blood cells falls below a certain level. May happen as a side effect of chemotherapy. If there is also a high temperature (above 38°C), it's known as febrile neutropenia.

## O

**Occult breast cancer** Breast cancer that can't be felt or seen on imaging (for example, mammogram or ultrasound). It's usually diagnosed when someone is being investigated for symptoms elsewhere in the body, for example enlarged lymph nodes. Sometimes a biopsy in another part of the body shows cells that look like secondary breast cancer cells, indicating there is a primary cancer in the breast, even though it can't be seen.

**Oestrogen receptors** Proteins that attach to the hormone oestrogen and stimulate (help) the cancer to grow. May be abbreviated to ER, from the US spelling estrogen.

**Oncologist** A doctor who specialises in cancer (oncology). A medical oncologist specialises in cancer drugs. A clinical oncologist specialises in radiotherapy alone or radiotherapy and cancer drugs.

**Oncoplastic surgeon** A breast cancer surgeon with training in plastic surgery.

**OSNA (one step nucleic acid amplification)** A test used during surgery to see if breast cancer cells are in the lymph nodes under the arm.

**Osteopenia** Decreased bone mineral density (a measurement of bone strength) but not low enough to be diagnosed as osteoporosis.

**Osteoporosis** Literally means 'porous bones'. Decreased bone mineral density (a measurement of bone strength), meaning thinner, weaker bones that are more likely to break. It's usually diagnosed with a bone density scan (often called a DEXA scan).

**Ovarian suppression** Sometimes called ovarian ablation. Stopping the ovaries producing oestrogen using surgery, drugs or radiotherapy.

## P

**Paclitaxel** Also known as Taxol. A chemotherapy drug and one of a group of drugs called taxanes.

**Pathology** The branch of medicine that looks at how disease affects the body's cells and tissues. Each time you have tissue removed a report is written by a pathologist (a doctor who examines the tissue).

**Peripherally inserted central catheter (PICC)** A tube put into a vein in the arm through which chemotherapy drugs are given. It stays in place throughout the course of treatment.

**Perjeta** see Pertuzumab

**Pertuzumab** Also called Perjeta. A targeted therapy used to treat HER2 positive breast cancer.

**PET (positron emission tomography) scan** A scan that produces a 3D image to show the structure and function of organs or tissue being looked at. Sometimes combined with a CT scan.

**Plastic surgeon** A specialist surgeon trained in plastic surgery techniques such as breast reconstruction.

**Portacath** Also called an implanted port. A portacath consists of a port (rubber disc) connected to a thin tube. The port is put under the skin, usually in the chest. The other end of the tube goes into a large vein just above the heart. Drugs are then given into the port.

**Primary breast cancer** Breast cancer that has not spread beyond the breast or the lymph nodes (lymph glands) under the arm (axilla).

**Progesterone receptors** Proteins within cancer cells that attach to the hormone progesterone (may be abbreviated to PR).

**Prognosis** An estimate of the likely outlook of a disease, such as the likelihood of it coming back (recurrence) and the person's life expectancy.

**Prosthesis** An artificial breast form used to restore shape when all or part of the breast has been removed.

## R

**Radiologist** A doctor who specialises in the use of imaging (for example x-rays, ultrasound, CT, PET, MRI) to diagnose and treat disease.

**Radiotherapy** The use of high energy x-rays to destroy cancer cells.

**Reconstruction** Surgery that rebuilds the breast shape after all or part of the breast has been removed.

**Recurrence** When a disease or condition returns. There are different types of breast cancer recurrence.

- **Local recurrence** Breast cancer that has come back in the chest/breast area or in the skin near the original site or scar.
- **Locally advanced breast cancer (also known as regional recurrence)** Breast cancer that has come back and has spread to the tissues and lymph nodes (lymph glands) around the chest, neck and under the breastbone.
- **Distant recurrence** Also called metastatic, advanced, stage 4 or secondary breast cancer. When cancer cells from the breast have spread to other parts of the body such as the bones, lungs, liver or brain.

**Remission** When the signs and symptoms of a disease partly or completely disappear. This may be temporary or permanent.

**Risk factor** Something that increases a person's chance of developing an illness such as cancer.

## S

**Saline implant** A type of breast implant that contains a sterile liquid solution (saline). Used in breast reconstruction.

**Secondary breast cancer** When cancer cells from the breast have spread to other parts of the body such as the bones, lungs, liver or brain. Also called metastases, advanced breast cancer, secondaries or stage 4 breast cancer.

**Selective internal radiation therapy (SIRT)** A type of targeted internal radiotherapy that uses radioactive beads to deliver radiation to the cancer.

**Sentinel lymph node biopsy (SLNB)** Identifies whether the sentinel lymph node (the first lymph node that the cancer cells are most likely to spread to) is clear of cancer cells. Sometimes called sentinel node biopsy (SNB).

**Seroma** A collection of fluid that forms under a wound after an operation. It is a common and sometimes uncomfortable but harmless effect of breast surgery.

**SGAP (super gluteal artery perforator) flap** and **IGAP (inferior gluteal artery perforator) flap** Types of breast reconstruction that use fat and skin taken from the upper or lower buttock.

**Side effect** Unwanted effect of treatment.

**Silicone implant** A type of breast implant filled with silicone gel. Used in breast reconstruction.

**Stage** The size of the cancer and how far it has spread.

**Stereotactic core biopsy** Taking a sample of tissue using a needle biopsy device connected to a mammogram machine and linked to a computer. Helps locate the exact position of the area to be biopsied.

**Steroids** May be given as part of cancer treatment, for example to help with side effects of chemotherapy such as nausea and vomiting, or to control some symptoms caused by cancer.

**Subcutaneous injection** An injection into the fatty tissue under the skin.

**Surgical margin** How close the cancer cells are to the edges of the whole area of tissue removed during surgery.

**Systemic treatment** Drugs that treat the whole body, for example chemotherapy, hormone therapy and targeted therapy.

## T

**Tamoxifen** A hormone therapy drug used to treat oestrogen receptor positive breast cancer.

**Targeted therapies** Also known as biological therapies. A group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

**Taxol** see Paclitaxel

**Taxotere** see Docetaxel

**Thrombosis** Occurs when blood forms a clot. If the clot occurs in a major vein, the condition is known as a 'deep vein thrombosis' or DVT.

**TP53 gene** A gene that provides instructions for making a protein called tumour protein p53. Some people inherit an altered TP53 gene, which can result in a rare inherited cancer syndrome called Li-Fraumeni syndrome. This can increase the risk of getting breast cancer.

**TRAM (transverse rectus abdominis muscle) flap** A type of breast reconstruction that uses the large muscle that runs from the lower ribs to the pelvic bone in the groin along with skin and fat.

**Trastuzumab** A targeted therapy used to treat HER2 positive breast cancer, and one of a group of drugs called monoclonal antibodies. A well-known brand name is Herceptin.

**TUG (transverse upper gracilis) flap** or **TMG (transverse myocutaneous gracilis) flap** Types of breast reconstruction that use muscle from the inner or outer upper thigh along with skin and fat.

**Tumour** An overgrowth of cells forming a lump. May be benign (not cancer) or cancer.

## U

**Ultrasound scan** Uses high frequency sound waves to produce an image.

## V

**Vacuum assisted biopsy** Used to remove breast tissue for examination under a microscope, often when a previous biopsy was difficult to perform or more tissue is needed to make a diagnosis. Sometimes it can be used as an alternative to surgery to remove a whole area of breast tissue (called a vacuum assisted excision biopsy).

## W

**Wide local excision (WLE)** Surgery to remove breast cancer with a margin (border) of healthy tissue. Sometimes called breast-conserving surgery or lumpectomy.

## X

**X-ray** Used to produce images of dense tissues in the body such as bone or lungs.

## Z

**Zoladex** see Goserelin

## Notes about my diagnosis

[illegible]

## Notes about surgery

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 about breast reconstruction

[illegible]

## Notes about chemotherapy

This image shows a full page of blank, lined paper. It features approximately 20 evenly spaced horizontal grey lines across its entire width, providing a template for writing or drawing. The background is a solid off-white color.

## Notes about radiotherapy

This image shows a full page of blank, lined paper. It features approximately 20 horizontal blue or grey lines spaced evenly apart, typical of notebook paper. The lines extend across the entire width of the page, leaving small margins at the top and bottom. There are no vertical lines, text, or other markings on the page.

## Notes about hormone therapy

[illegible]

## Notes about targeted therapy

This image shows a full page of blank, lined paper. It features approximately 20 evenly spaced horizontal grey lines across its entire width, providing a template for writing or drawing. The margins are consistent on all sides.

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

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## Notes

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# Find out more

## Breast Cancer Care publications

To order any of Breast Cancer Care's publications, tear out this page, tick the boxes below next to the titles you want and send it to the address overleaf. Alternatively, all our publications are free to order or download from our website [breastcancercare.org.uk/publications](https://breastcancercare.org.uk/publications) or call our Helpline on 0808 800 6000.

### Managing the effects of treatment

- ☐ Breast cancer and hair loss BCC54
- ☐ Breast cancer in younger women BCC66
- ☐ Breast prostheses, bras and clothes after surgery BCC123
- ☐ Fertility and breast cancer treatment BCC28
- ☐ Living with lymphoedema after breast cancer BCC5
- ☐ Menopausal symptoms and breast cancer BCC18
- ☐ Osteoporosis and breast cancer treatment BCC75
- ☐ Reducing the risk of lymphoedema BCC15

### Signs and symptoms of the cancer coming back (recurrence)

- ☐ After breast cancer treatment: what now? BCC169
- ☐ Family history, genes and breast cancer BCC32

### You and your relationships

- ☐ Talking with your children about breast cancer BCC50
- ☐ When your partner has breast cancer BCC120

### Your wellbeing

- ☐ Complementary therapies, relaxation and wellbeing BCC55
- ☐ Diet and breast cancer BCC98

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Our free lifestyle magazine for people affected by breast cancer is full of real-life stories, health and wellbeing features, hot topics and recipes.

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## 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](https://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](https://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](https://breastcancercare.org.uk/in-your-area)**

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

If you found this pack 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.

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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)

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

Code: LP

# About this pack

**Primary breast cancer information pack** 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](mailto:publications@breastcancercare.org.uk)**



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challenges and decisions you face every day, and we  
know that everyone's experience is different.

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