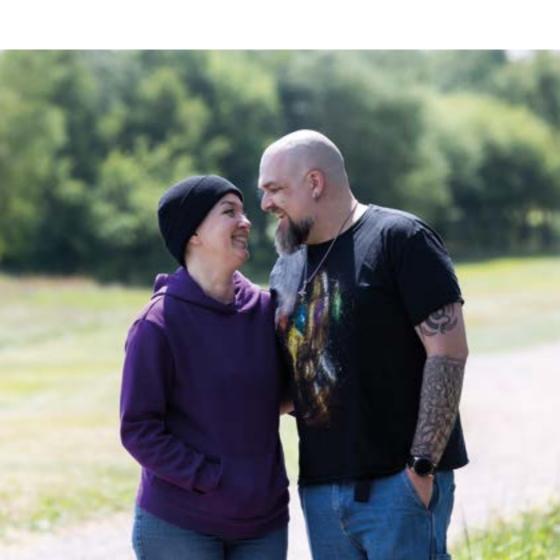
# Understanding breast cancer





I can honestly say that without the help of Macmillan I don't know how I would have got this far. Knowing that help and advice is but a phone call away is a great comfort a mental health safety net.

Sal, diagnosed with breast cancer

# **About this booklet**

This booklet is about breast cancer. It is for women who have been diagnosed with breast cancer.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

This information is about breast cancer that has not spread to other parts of the body. Breast cancer that has spread to other parts of the body is called secondary breast cancer. We have information about this in our booklet Understanding secondary breast cancer.

Men can also get breast cancer, but this is rare. We have information for men who have been diagnosed with breast cancer at macmillan.org.uk/breast-cancer-in-men

If you are trans or non-binary, you may find the information in this booklet useful. We also have more information for trans and non-binary people on our website. Visit macmillan.org.uk/transgender

### How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready. At the end of the booklet, there are details of other organisations that can help.

### Quotes

In this booklet, we have included quotes from people who have had breast cancer, which you may find helpful. These people have chosen to share their story with us. This includes Sal, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/shareyourstory

### For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call 0808 808 00 00.

# **Contents**

The breasts and breast cancer	5
Planning your treatment	19
Treating breast cancer	31
After your treatment	109
Work and financial support	127
Further information	133



# The breasts and breast cancer

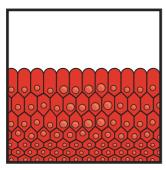
What is cancer?	6
The breasts	8
The lymphatic system	1
Types of breast cancer	12
Your data and the cancer registry	 17

# What is cancer?

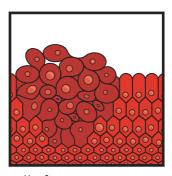
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old. damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

### Cells forming a tumour



Normal cells



Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

# The breasts

Breasts are made up of:

- · fatty tissue
- supportive (connective) tissue
- glandular tissue containing lobules.

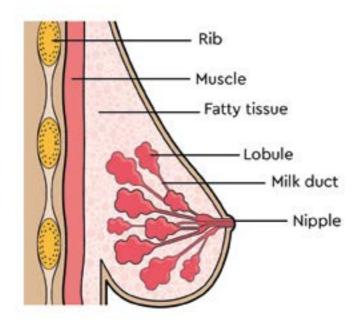
The lobules are also called milk glands. They are where breast milk is made. They connect to the nipple by a network of fine tubes called ducts.

The tissue of the breast extends into the lower armpit (axilla). This area contains lymph nodes (glands). Lymph nodes are part of <u>the lymphatic system</u>, which protects us from infection and disease.

It is common for your breasts to be a different size or shape from each other. If you have periods, you may notice your breasts change at different times of the month. Breasts also change during pregnancy and the menopause. These changes are linked to the different levels of the hormones oestrogen and progesterone. These hormones are made in the body.

Before your period, your breasts may feel tender and lumpy. During pregnancy, breasts go through a lot of changes. After the menopause, when the body makes less oestrogen, breasts may change in size and feel softer or less full.

### Side view of breast



It is important to be aware of how your breasts feel and look at different times. You should know what is normal for you.

Always contact your doctor if you notice anything unusual for you, or if there is something you are not sure about.

# The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

I was watching the television one night and I started scratching my breast, and just underneath my breast I could feel something like a lump. It was a really hard lump. I thought maybe it was a cyst. \*\*

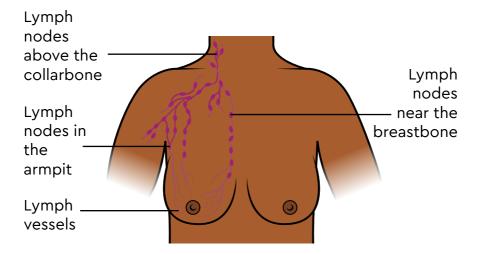
Ravinder, diagnosed with breast cancer

## Breast cancer and the lymph nodes

Sometimes cancer can spread through the lymphatic system.

If breast cancer cells spread outside the breast, they are most likely to go to lymph nodes in the armpit. You will usually have <u>tests to look</u> for cancer cells in the lymph nodes. There are also lymph nodes near the breastbone and above the collarbone.

### Lymph nodes near the breast



# Types of breast cancer

There are different types of breast cancer. Knowing the type of cancer you have helps your doctor to plan the best treatment for you.

### **Ductal carcinoma in situ (DCIS)**

In DCIS, there are abnormal cells in the ducts of the breast. But these cells are contained (in situ). They have not spread into normal breast tissue.

DCIS may show on a mammogram and is most commonly diagnosed during breast screening.

We have separate information about DCIS in our booklet Understanding ductal carcinoma in situ (DCIS).

### Lobular carcinoma in situ (LCIS)

LCIS is when there are changes in the cells lining the lobules. It is not breast cancer, but it slightly increases the risk of developing breast cancer later in life. Most people with LCIS do not get breast cancer.

We have separate information about LCIS on our website. Visit macmillan.org.uk/lobular-carcinoma-in-situ

"At first I felt like a fraud. I didn't feel ill, but at the same time I'd just been told I had breast cancer. It was a very surreal feeling. The more I went to hospital appointments, the more it sank in that this was real and was happening. ,,

### Invasive breast cancer

Invasive breast cancer means the cancer cells have spread outside the lining of the ducts or lobules and into the surrounding breast tissue. There are different types of invasive breast cancer.

### No special type (NST)

This is when the cancer cells are examined under the microscope and have no specific features. This is called breast cancer of no special type (NST) or not otherwise specified (NOS).

It is also called invasive ductal carcinoma. It is the most common type of breast cancer. About 7 to 8 in 10 of all breast cancers (70 to 80%) are this type.

#### Invasive lobular breast cancer

About 1 to 2 in 10 invasive breast cancers (10 to 20%) start in the lobules of the breast. The lobules are where breast milk is made.

The main symptom of invasive lobular breast cancer is usually a thickening or swelling of breast tissue. You may not have a lump. Other symptoms include a:

- change or dimpling of the skin of the breast
- nipple turning in (inverted nipple).

This type of breast cancer can be difficult to diagnose on a mammogram because of the way it grows. You may need an MRI scan.

The treatment for invasive lobular breast cancer is the same as for the main type of breast cancer (invasive NST). You will usually have either breast-conserving surgery or a mastectomy. This will depend on the size of the cancer and where it is. Some people may need further treatment after surgery such as:

- radiotherapy
- chemotherapy
- hormonal therapy
- targeted therapy.

Lobular Breast Cancer UK is a charity that offers support to people living with lobular breast cancer.

### **Special types**

Some breast cancer cells have features that identify them as a specific type of breast cancer. These are called special type breast cancers. They are named depending on how the cells look under a microscope. The types include tubular, medullary, mucinous and cribriform.

Rarer types include malignant phyllodes and angiosarcoma.

### Inflammatory breast cancer

This is when cancer cells spread into and block the tiny channels (lymph vessels) in the skin of the breast. The breast then becomes inflamed and swollen. Inflammatory breast cancer is rare.

### Paget's disease of the breast

This is a condition that causes a red, scaly rash (like eczema) on the skin of the nipple. Women with Paget's disease may have DCIS or invasive breast cancer.

We have more information about rarer types of breast cancer on our website. Visit macmillan.org.uk/cancer-types



# Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected by a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the <u>cancer registry in your country</u> to opt out.

You can find more information at <a href="mailto:macmillan.org.uk/cancerregistry">macmillan.org.uk/cancerregistry</a>



# Planning your treatment

Finding out you have breast cancer	20
Staging and grading for breast cancer	22
Receptors	27

# Finding out you have breast cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with primary breast cancer. We have separate information about secondary breast cancer in our booklet Understanding secondary breast cancer. This is breast cancer that has spread to another part of the body.

We have more information about possible causes, risk factors and symptoms of breast cancer at macmillan.org.uk/breastcancer

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the cancer, or you may prefer to wait until you see your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on 0808 808 00 00. They will be able to talk to you about what has happened. They can help with any worries you may have.



I was diagnosed with breast cancer in February 2022. It was a shock as I'd initially gone into hospital thinking a cyst had returned and needed to be drained.

# Staging and grading for breast cancer

Your cancer doctor needs certain information about the cancer to advise on the best treatment for you. This includes:

- the stage of the cancer
- the grade of the cancer
- whether the cancer has receptors for hormones or a protein called HER2.

This information comes from the results of the tests you have had, including:

- the biopsy
- other tests done on the cancer cells.

Your cancer doctor and nurse will explain the results of the tests and what they mean. Together you and your doctor decide on your treatment plan.

We have more information about having tests for breast cancer on our website. Visit macmillan.org.uk/tests-and-scans



# **Staging**

The stage of a cancer describes its size and whether it has spread from where it started. There are different ways to describe the stage of a cancer. The most commonly used ones are the TNM staging system and the number staging system.

### The TNM staging system

The TNM staging system gives the complete stage of the cancer:

- T describes the size of the tumour.
- N describes whether the cancer has spread to the lymph nodes and which nodes are affected. For example, NO means no lymph nodes are affected. N1 means there are cancer cells in 1 to 3 of the lymph nodes.
- M describes whether the cancer has spread to another part of the body (metastasised). For example, M0 means the cancer has not spread to other parts of the body.

Sometimes the final TNM staging may not be certain until after surgery to remove the cancer.

### The number staging system

Breast cancer can also be divided into 4 number stages under the TNM system. We have put these into a table to make them easier to understand.

<b>Stage 1 or 2</b> breast cancer is usually called early breast cancer.  Stage 1 is divided into 2 stages.		
Stage 1A	The cancer is 2cm or smaller. It has not spread outside the breast.	
Stage 1B	The cancer is not found in the breast tissue or is 2cm or smaller. Tiny numbers of cancer cells have spread to lymph nodes in the armpit. These cells are called micrometastases.	
Stage 2 is divided into 2 stages.		
Stage 2A	The cancer cannot be found in the breast tissue. Or it is 2cm or smaller. It has also spread to 1 to 3 lymph nodes in the armpit or near the breastbone.  Or  The cancer is between 2 and 5cm. And it has not spread to the lymph nodes in the armpit or near the breastbone.	
Stage 2B	The cancer is between 2 and 5cm. It has spread to 1 to 3 lymph nodes in the armpit.  Or  The cancer is bigger than 5cm but has not spread to the lymph nodes.	

**Stage 3** is divided into 3 stages. Stage 3 breast cancer is sometimes called locally advanced breast cancer. The cancer has spread to the lymph nodes, the skin of the breast or the chest muscle. The skin may be red, swollen or have broken down, causing an ulcer. Some breast cancers that have spread to the skin may be inflammatory breast cancer.

Stage 3A	The cancer cannot be found in the breast. Or it is 5cm or smaller. It has spread to 4 to 9 lymph nodes in the armpit.  Or  The cancer is bigger than 5cm. It has spread to up to 3 lymph nodes in the armpit or near the breastbone.	
Stage 3B	The cancer has spread into tissue nearby, such as the skin of the breast and the chest muscle underneath. It may have spread to 1 to 9 lymph nodes in the armpit.	
Stage 3C	The cancer may be any size. Or it cannot be found in the breast. It has spread into tissue nearby, such as the skin of the breast and the chest muscle underneath. It has spread to 10 or more lymph nodes in the armpit. The cancer has spread to lymph nodes below the breastbone and above or below the collarbone. It has spread to 4 or more lymph nodes in the armpit.	
Stage 4 breast cancer is also called secondary or metastatic breast cancer.		
Stage 4	The cancer has spread to other parts of the body, such as the bones, liver or lungs.	

This booklet is about stage 1 to 3 breast cancer. If you have stage 4 breast cancer, you may find our information about secondary breast cancer helpful. Visit macmillan.org.uk/breast-cancer-secondary

# **Grading**

The grade of a cancer describes how cancer cells look compared with normal cells. This gives an idea of how slowly or guickly the cancer may grow. A doctor called a pathologist examines the cells under a microscope. They are an expert in cell types.

#### Grade 1 (low-grade cancer)

The cancer cells look similar to normal cells. They may be described as well differentiated. They usually grow slowly. These cancer cells are less likely to spread.

#### Grade 2 (moderate- or intermediate-grade cancer)

The cancer cells look more abnormal. They grow slightly faster than grade 1 cells.

### **Grade 3 (high-grade cancer)**

The cancer cells look very different from normal cells. They may be described as poorly differentiated. They may grow more quickly than grade 1 or 2 cells. They are more likely to spread without treatment.

# Receptors

Hormones and a protein called HER2 can encourage breast cancer cells to grow. Breast cancer cells may have receptors that the hormones or HER2 can attach to. A pathologist can check for these receptors by testing the cancer cells that were taken during the biopsy or surgery.

The results help you and your doctor decide on the most effective treatment for you.

### **Hormone receptors**

Hormones help control how cells grow and what they do in the body. Hormones can encourage some breast cancer cells to grow. Oestrogen is the main hormone that can encourage this.

Breast cancer that has receptors for oestrogen is called oestrogen receptor positive or ER positive breast cancer. The term ER is used because the American spelling of oestrogen is estrogen. About 7 in 10 breast cancers in women (70%) are ER positive. <u>Hormonal therapy</u> works well for ER positive breast cancer.

Breast cancer cells may also have receptors for the hormone progesterone (PR positive breast cancer). Your doctor will explain whether testing for progesterone receptors is useful in your situation.

Breast cancer cells that are ER and PR positive are sometimes called hormone sensitive.

Breast cancer that does not have hormone receptors is called oestrogen receptor negative (ER negative).

# **HER2** positive breast cancer

Some breast cancer cells have too much of a protein called HER2 on the surface. This is called HER2 positive breast cancer. The extra HER2 protein encourages the cancer cells to divide and grow.

About 1 in 5 breast cancers (15 to 20%) are HER2 positive.

Specific targeted therapy drugs are used to treat HER2 positive breast cancer. They lock on to the HER2 protein. This helps stop the cells from dividing and growing.

# Triple negative breast cancer

Cancer that does not have receptors for either HER2 or the hormones oestrogen and progesterone is called triple negative breast cancer. About 1 in 5 breast cancers (15 to 20%) are triple negative. It is more common in younger people. But people in any age group can get it.

If you have triple negative breast cancer, you may be offered genetic testing. This is offered even if you do not have a family history of breast cancer. Most breast cancers caused by a change in the BRCA1 gene are triple negative. Your cancer doctor or breast care nurse can explain more about this to you.

If you are worried about breast cancer in your family, talk to your GP or breast specialist. They can refer you to a family history clinic or a genetics clinic.

We have more information about triple negative breast cancer on our website. Visit macmillan.org.uk/triple-negative-breast-cancer





# **Treating breast cancer**

Treatment overview	32	
Surgery	40	
Radiotherapy	64	
Chemotherapy	76	
Hormonal therapy	88	
Targeted therapy	97	
Bisphosphonates	104	

# Treatment overview

Your doctors look at different factors to help decide which treatments are likely to work best for you. These include:

- the stage and grade of the cancer
- whether the cancer cells have oestrogen receptors (are ER positive)
- whether the cancer cells have HER2 receptors. (are HER2 positive).

Your cancer doctor and breast care nurse will explain the treatments that they think are best for you. They can help you make decisions about your treatment.

The first treatment for breast cancer is usually surgery to remove it. After surgery, you may have treatments to reduce the risk of the cancer coming back. These treatments include:

- radiotherapy
- hormonal therapy
- chemotherapy
- targeted and immunotherapy drugs, such as trastuzumab.

You may sometimes have these treatments before you have surgery.

You may have drugs called bisphosphonates to reduce the risk of breast cancer coming back. These can also be used to protect your bones from the side effects of some types of hormonal therapy and chemotherapy.

Treatments for breast cancer are improving. Better treatments mean that more people are cured or living longer. Your cancer doctor may ask you if you would like to take part in a clinical trial. We have more information about these on our website. Visit <a href="mailto:macmillan.org.uk/clinical-trials">macmillan.org.uk/clinical-trials</a>

## **Treatments and fertility**

Some cancer drugs can affect whether you can get pregnant (your fertility). If you are worried about this, it is important to talk with your cancer doctor before you start treatment. The effect on fertility may be temporary, but for some people it can be permanent.

Before treatment starts, your doctors and nurses will talk to you about this. If treatment could affect your fertility, they will explain what can be done to help preserve your fertility.

### **Breast cancer and pregnancy**

If you have been diagnosed with cancer and you are pregnant or breastfeeding, we have more information. Visit macmillan.org.uk/pregnancy

## Treatment before surgery

You may have chemotherapy, hormonal therapy or targeted therapy before surgery. This is to shrink the cancer and make it easier to remove. You may also have chemotherapy and targeted therapy before surgery if the cancer is growing more quickly. Treatment before surgery is called neo-adjuvant treatment.

### Surgery

Your surgeon will talk to you about having 1 of these operations:

- breast-conserving surgery this involves removing the cancer and some surrounding normal breast tissue
- a mastectomy this involves removing all the breast tissue and sometimes the nipple on the affected side.

You will usually need some or all the lymph nodes in your armpit removed. This is done in both these operations.

You may want to have a new breast shape made during the operation. This is called breast reconstruction. You can also choose to have it done at a later time. We have more information about this in our booklet Understanding breast reconstruction.

## Treatment after surgery

Your cancer doctor will usually offer you 1 or more of the following treatments after surgery. These treatments can reduce the risk of the cancer coming back. Your cancer doctor and breast care nurse will talk to you about the most effective treatments available to you.

They may use an online tool such as PREDICT. PREDICT is designed to help people make informed decisions with their doctors about treatment after surgery for breast cancer. It can show how much different treatments reduce the risk of the cancer coming back. You might find it helpful, especially if your cancer doctor has asked you to decide whether to have chemotherapy.

Sometimes doctors suggest having a tumour-profiling test on the cancer cells. This gives more information about the risk of the cancer coming back.

#### Radiotherapy

After breast-conserving surgery, your cancer doctor will usually advise you to have radiotherapy to the rest of the breast. You may also need radiotherapy to the lymph nodes near the breast. After a mastectomy, you may need radiotherapy to the chest and possibly the lymph nodes.

#### Chemotherapy

Your cancer doctor may advise you to have chemotherapy if:

- the cancer is large
- the cancer has spread to the lymph nodes
- the cancer is a higher grade
- you have triple negative breast cancer
- you have HER2 positive breast cancer.

#### Hormonal therapy

If the cancer is <u>ER positive</u>, you will have <u>hormonal therapy</u> for a few vears.

#### Targeted therapy

If you have HER2 positive breast cancer, you will usually have a targeted therapy drug called <u>trastuzumab</u>. You may also have a drug called pertuzumab.

#### **Immunotherapy**

This uses the immune system to find and attack cancer cells. Currently, it is only available to people with triple negative breast cancer.

## **Tumour-profiling tests**

These tests look at samples of the tumour to find how active certain genes are in the cancer cells. They do not look at inherited genes. The results help give information about the chances of the cancer coming back. This can help you and your doctors make a more informed decision about having chemotherapy after surgery.

If the results show a low risk of the cancer coming back, you may not need chemotherapy. Your cancer doctor or breast care nurse can tell you more about this.

Your cancer doctor may suggest having tumour-profiling tests if your breast cancer:

- is ER positive and HER2 negative
- has not spread to the lymph nodes
- is in an intermediate-risk group this means there is between a low and high risk of it coming back in another part of the body.

There are different tumour-profiling tests. If you are having treatment on the NHS, you are likely to have a tumour-profiling test such as Oncotype DX®, EndoPredict® or Prosigna® Your doctor or nurse can tell you more about this.

Some tumour-profiling tests are available privately or are covered by private health insurance companies.

## How treatment is planned (MDT)

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT). The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT for breast cancer will usually include a:

- surgeon who specialises in breast surgery they may also do breast reconstruction
- plastic surgeon who specialises in breast reconstruction
- cancer doctor, who specialises in chemotherapy, radiotherapy, hormonal therapy and targeted therapy – they are sometimes called an oncologist
- specialist nurse, who gives information and support
- radiologist, who specialises in x-rays and scans
- pathologist, who specialises in studying tissue samples and cells.

It may also include other healthcare professionals, such as a research nurse, a physiotherapist, a psychologist, a social worker and a counsellor.

After the MDT meeting, your cancer doctor or breast care nurse will talk to you about the treatment options. It can help to write down your questions before you see them. You can decide together on the best treatment plan for you.

## Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected.

But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.



## **Second opinion**

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website.

Visit macmillan.org.uk/secondopinion



## Surgery

Surgery is the main treatment for breast cancer. The operation you have depends on:

- the size of the cancer
- whether there is cancer in the lymph nodes
- the position of the cancer
- what you prefer.

Your surgeon and breast care nurse will talk to you about your options. You may be asked to decide which operation you have.

Your surgeon may recommend breast-conserving surgery. This aims to remove the cancer safely, but keep as much of the breast tissue and breast shape as possible. This operation is also called a wide local excision (WLE) or lumpectomy. If you have breast-conserving surgery, you will have radiotherapy afterwards. This is to reduce the risk of cancer coming back in the same area.

Sometimes your surgeon may recommend having the whole breast removed. This is called a mastectomy. You can usually choose to have breast reconstruction at the same time as a mastectomy. Or you can have it later. Breast reconstruction is making a new breast shape.

Having breast reconstruction is your choice. You may decide not to have it at all. Some people decide to wear a false breast instead. This is called a prosthesis. We have more information about breast prostheses.

Surgery for breast cancer usually includes removing some or all the lymph nodes in your armpit. This is to check them for cancer cells.

Before the operation, you may have <u>chemotherapy</u>, <u>targeted therapy</u> or hormonal therapy. These aim to shrink the cancer so that you avoid a mastectomy and keep the breast shape. This is called neo-adjuvant treatment.

If you have a breast cancer gene, you may have neo-adjuvant treatment. Even if the treatment removes all the cancer, doctors will still recommend a mastectomy. This is because there is a higher risk of the breast cancer coming back.

We have more information on our website. Visit macmillan.org.uk/ breast-cancer-family-history

## **Breast-conserving surgery** (wide local excision)

Your surgeon may suggest having a wide local excision (WLE). This keeps as much of the breast tissue and breast shape as possible. It is sometimes called a lumpectomy.

During a WLE operation, the surgeon removes the cancer and some normal-looking tissue around it. This is called the margin.

Before the operation, a doctor inserts a fine wire or marker through the skin into the area where the cancer is. This is called wire localisation. The wire or marker is secured to your chest with tape or a dressing.

The doctor uses an ultrasound or x-ray to help place the marker so that it marks the area to be removed. When the surgeon does the operation, they can also use x-ray or ultrasound to help them find the right area more easily. During the operation, the surgeon removes the wire, the cancer and some surrounding tissue.

You may have a magnetic seed injected into the area instead of having wire localisation. The surgeon uses a handheld machine that can detect the seed and the area to be removed. Your cancer doctor or breast care nurse can explain more about magnetic seeds.

If a large amount of tissue is removed, the breast will be smaller than before. If this happens, the surgeon can reduce the size of your other breast. This can help make your breasts look a similar size.

#### Removing a larger area of breast tissue

Depending on the size of the cancer, you may need to have a larger area of breast tissue removed.

In this situation, surgeons can use different ways to help improve the appearance of your breast after the operation. They may reshape the breast by moving the breast tissue around and making the breast smaller. Sometimes they take tissue from somewhere else in the body to help reshape the breast. This is called breast reconstruction.

Your surgeon may suggest you have the other breast made smaller so that both breasts look a similar size. This can be done at the same time as your operation or in a separate operation later.

We have more information about breast reconstruction if you are having breast-conserving surgery and surgery to reshape the breast.

#### Radiotherapy after breast-conserving surgery

Your surgeon will usually advise you to have radiotherapy after a WLE. This reduces the risk of the cancer coming back in the breast. Having breast-conserving surgery and radiotherapy is usually as effective as having a mastectomy.

#### **Clear margins**

After breast-conserving surgery, a pathologist looks at the tissue that has been removed under a microscope. They check the area around the cancer. This is called the margin. You will need another operation to remove more tissue if:

- there is <u>DCIS</u> or some types of <u>LCIS</u> close to the edge of the area
- there are any cancer cells close to the edge of the area.

If the margins are clear, this reduces the risk of cancer coming back in the breast.

If your surgeon does not think another breast-conserving operation is likely to be successful, they may recommend a mastectomy. In this situation, you will usually be offered breast reconstruction.

## Removing the breast (mastectomy)

Breast surgeons will try to do an operation that means you can keep your breast (breast-conserving surgery). But sometimes they may recommend a mastectomy. This may be when:

- the lump is large compared to the rest of your breast
- there is cancer in different parts of the breast this is called multicentric breast cancer
- there is widespread DCIS in the breast
- the cancer is on the skin or in underlying muscle
- you have had radiotherapy to the chest to treat another cancer, such as a previous breast cancer or Hodgkin lymphoma
- you have a family history of breast or ovarian cancer and have tested positive for a genetic mutation.

#### **Breast reconstruction**

If you are having a mastectomy, your surgeon will usually ask if you want a new breast shape made at the same time. This is called an immediate breast reconstruction. You can choose to delay breast reconstruction until after you have finished radiotherapy or chemotherapy. You may choose not to have reconstruction at all. You may decide to wear a false breast instead. This is called a prosthesis. We have more information about breast prostheses.

Breast reconstruction may not be suitable for everyone. This is usually if you have medical conditions that might increase the risk of complications during surgery and after.

You may decide not to have breast reconstruction at the same time as your mastectomy. If you think you might want breast reconstruction in the future, talk to your surgeon about this before you have a mastectomy. If you are having radiotherapy, some surgeons will recommend you delay breast construction until after you have had the radiotherapy.

Breast reconstruction is specialised surgery. It is usually done by a plastic surgeon or oncoplastic breast surgeon. They are experts in breast cancer surgery and reconstruction. There are different ways of doing breast reconstruction. A new breast shape can be made using:

- a silicone implant
- your own tissue taken from another part of your body, such as the back or tummy
- a combination of an implant and your own tissue.

You may be able to talk to a surgeon who specialises in breast cancer and plastic surgery before your operation. They can talk you through your options for reconstruction.

#### Choice of treatment

A WLE and a mastectomy work equally well for treating early breast cancer. This means your surgeon and breast care nurse may ask you to decide which type of surgery you feel is right for you.

Your surgeon and nurse can explain what is involved and any possible side effects of each treatment. They will help you decide on the treatment that is best for you.

Having breast surgery can affect your body image, sex life and relationships. It is important to take your time and have all the information you need to make the right decision.

It is helpful to think about the possible advantages and disadvantages of each type of surgery before making a decision.



## **Breast-conserving surgery** and radiotherapy

#### **Advantages**

- It aims to keep most of your breast tissue and a good breast shape.
- You usually recover faster than with a mastectomy, and have a lower risk of complications.
- It may be less likely to affect your sex life and relationships.

#### **Disadvantages**

- You may need more than 1 operation to get clear margins.
- You may need radiotherapy after surgery. Some people will also need radiotherapy after a mastectomy.
- Radiotherapy has short-term side effects. Some people may have long-term side effects.

### **Mastectomy**

#### **Advantages**

- You may not need radiotherapy after a mastectomy. But some people will need it. Ask your cancer doctor about this.
- Even though a WLE and a mastectomy work equally well, you may feel less worried after a mastectomy. This is because the breast tissue has been removed.

#### **Disadvantages**

- You lose your breast permanently.
- It usually takes longer to recover after a mastectomy, and there is a slightly higher risk of complications.
- It changes your appearance. This may affect your confidence, sex life and relationships.
- If you want breast reconstruction, you will need a longer operation and possibly more surgery. Breast reconstruction is usually more than 1 operation. But reconstruction may help to reduce some of the other disadvantages.

Your surgeon and breast care nurse can answer any questions you may have and tell you what to expect. They may be able to show you photographs of women who have had surgery.

You may find it helpful to talk to others who have had the surgery. Your nurse may know whether there is a local cancer support group, where you can talk to someone who has had a similar operation.

You may also be able to find women in a similar situation through our Online Community at <a href="mailto:macmillan.org.uk/community">macmillan.org.uk/community</a> or the Breast Cancer Now online forum at <a href="mailto:forum.breastcancernow.org">forum.breastcancernow.org</a>

## Surgery to the lymph nodes

Your surgeon may remove some or all the lymph nodes in your armpit to check them for cancer cells. This can also:

- remove any lymph nodes that contain cancer cells
- give information about the stage of the cancer.

There are different types of lymph node surgery. You may need more treatment if only some lymph nodes were removed

#### Sentinel lymph node biopsy (SLNB)

A sentinel lymph node biopsy (SLNB) is a way of checking the lymph nodes in the armpit. The lymph nodes most likely to have cancer cells are called the sentinel lymph nodes. These are the first ones that lymph fluid drains to from the breast area.

Your surgeon or nurse will explain if an SLNB is an option for you.

You will have an SLNB if the ultrasound or fine needle aspiration of your armpit was normal.

During an SLNB, surgeons remove the smallest number of lymph nodes possible (usually 1 to 3). This reduces the risk of side effects that can happen after lymph node surgery. These include swelling (lymphoedema) of the arm. You may also have stiffness of the arm and shoulder.

If there are no cancer cells in the sentinel nodes, you will not need any further treatment to the lymph nodes.

If cancer cells are found in the sentinel nodes, your cancer doctor will talk to you about whether you need further treatment. You may be offered another operation to remove the remaining lymph nodes. Some people have radiotherapy to the remaining lymph nodes instead of more surgery.

In some hospitals, the sentinel nodes can be checked for cancer cells during the operation to remove the cancer. This means that if more lymph nodes need to be removed, it can be done during the same operation.

#### **Having an SLNB**

Before removing the sentinel nodes, the surgeon needs to <u>check which</u> <u>nodes</u> they are.

Before or during the SLNB, you have an injection of radioactive liquid into your breast tissue. The amount injected is harmless. During the SLNB, the surgeon uses a handheld machine to find the nodes that have picked up the radioactive liquid. The surgeon may also inject a blue dye into your breast tissue during the SLNB. The dye stains the nodes blue. The sentinel nodes are the nodes that pick up the radioactive liquid or become blue first.

The surgeon can then remove the sentinel nodes. These are tested to see if there are any cancer cells in them.

#### Other ways to find sentinel nodes

Some people have their sentinel nodes detected using a magnetic tracer. The magnetic tracer is a liquid containing tiny iron particles. It is injected into the breast tissue, where it is absorbed by the lymph vessels and sentinel nodes. A doctor or nurse can then use a magnetic probe to detect the sentinel nodes. Your doctor or nurse can explain more about magnetic tracers.

#### Removing all the lymph nodes

Sometimes the surgeon will recommend removing all the lymph nodes in the armpit. This is called an axillary lymph node dissection (ALND) or axillary lymph node clearance (ANC). It aims to remove any nodes that contain cancer cells in the area close to the cancer.

You usually have an ALND if:

- a fine needle aspiration or biopsy of the lymph nodes finds cancer cells
- an SLNB or sample of the lymph nodes shows cancer cells in the lymph nodes.

We have more information about these tests at macmillan.org.uk/ testsandscans

An ALND increases the risk of swelling of the arm. This is called <u>lymphoedema</u>. We have more information about lymphoedema and taking care of your arm. Visit macmillan.org.uk/lymphoedema

## **Before your operation**

Before your operation, you may go to a pre-operative assessment clinic. At the clinic, you may have tests to check your general health.

#### These can include:

- blood tests
- a chest x-ray
- a recording of your heart (ECG).

Your surgeon or breast care nurse will talk to you about how your breast will look after your surgery. They may show you photographs of other people have had surgery for breast cancer. They may also put you in contact with someone who has had the same operation. Or you can contact a local support group or <u>Breast Cancer Now</u>.

You will usually go into hospital on the day of your operation. You will meet the doctor who gives you the anaesthetic. They are called an anaesthetist. The nurses may give you elastic stockings to wear during and after the operation. These are called TED stockings. They help prevent blood clots.

## After your operation

Your recovery after surgery will depend on the type of operation you have.

You can usually go home the same day as breast cancer surgery or the following day.

If you have breast reconstruction at the same time as a mastectomy, you will stay in hospital for 1 to 5 days. This will depend on the type of reconstruction you have.

Your healthcare team will encourage you to start moving around as soon as possible after your operation. This can help reduce the risk of problems that can happen after surgery.

#### Your wound

You will usually have a dressing covering your wound. This may not be removed for the first few days after your operation. Before you go home, the nurses will tell you how to look after it.

After the operation, it is common to have some swelling and bruising around the wound. This should improve after a few weeks. If it does not, tell your breast care nurse. If you had an SLNB, you may see the blue dye in your skin for a few weeks or months. This is normal.

How long it takes for the wound to heal depends on the operation you had. Your wound may be closed with glue or stitches that dissolve. These do not need to be removed. If you do not have stitches that dissolve, they are usually removed 7 to 10 days after your operation. You can arrange this with your practice or district nurses at your GP surgery. Or it may happen at your <u>outpatient appointment</u>.

#### **Drains**

You may have a long, thin plastic drainage tube coming from your wound. This is attached to a drainage bag or bottle. Fluid from the wound drains into the bag or bottle.

The tube is usually left in for a few days. You can go home with it still in place. A practice nurse or a district nurse may check and remove it when you are at home. Or you might have it checked and removed at the hospital.

#### **Pain**

You will probably have some pain or discomfort around the wound. If you had <u>lymph nodes removed</u>, you may also have some pain or discomfort in your armpit.

It can help to take painkillers regularly until the pain starts to improve. This usually takes a few days. The nurses on the hospital ward will usually give you the painkiller to take. If you had a mastectomy, you may need painkillers for 1 or 2 weeks. Tell your cancer doctor or breast care nurse if the painkillers are not helping. They may be able to prescribe different ones for you to try.



## Possible problems after surgery

#### **Wound infection**

Signs of infection can include:

- warmth around the wound
- redness around the wound
- swelling around the wound or discharge coming from it
- · feeling unwell with a fever.

Tell your breast care nurse, cancer doctor or GP if you get any of these symptoms, even after you go home.

#### Fluid collecting around the wound (seroma)

A seroma is a soft bulge or swelling around the wound or very close to it. It is caused by a build-up of fluid. It usually goes away within a few weeks. Talk to your surgeon or breast care nurse if the swelling does not go away. They may drain the fluid with a needle and syringe. This may cause a little discomfort when it is being done. And it may need to be repeated if the fluid builds up again.

#### Stiff shoulder or arm

If you had a mastectomy or lymph nodes removed, your shoulder or arm may feel sore or stiff.

A physiotherapist or nurse will show you some arm exercises to do. These will help improve the movement in your shoulder and arm. They will also reduce the risk of long-term problems. You should start the exercises the day after your operation and slowly build up what you do. It is important to keep doing them until you can move your arm as well as you could before your operation.

Some people find it helps to take painkillers 1 hour before doing the exercises.

Breast Cancer Now has a leaflet about these exercises.

#### Numbness and tingling in the upper arm

You may have numbness or a tingling feeling in your upper arm. This is more likely if you had all the lymph nodes in your armpit removed.

Numbness and tingling in the upper arm is caused by swelling and damage to the nerves in your breast and armpit. This can happen during or after the operation. It may slowly improve over a few months, but numbness can sometimes be permanent. Talk to your surgeon or nurse if you are worried.

#### Cording

If you had surgery to remove lymph nodes in the armpit, you may develop cording. This is also called axillary web syndrome. It feels like a tight cord going from your armpit down the inside of your arm. You may be able to see the cord as well as feel it. Sometimes there is more than 1 cord. It can feel tight and painful and can affect the movement in your arm and shoulder.

Cording may happen days or weeks after surgery, or sometimes months later. It is less likely to happen if you only had 1 or 2 lymph nodes removed. It is not clear exactly what causes cording. It may be caused by changes in the lymphatic vessels after surgery.

If you are worried, ask your breast care nurse for advice. Cording usually gets better on its own. But you may need to visit a physiotherapist. They can help you with exercises to stretch the cord and improve your movement.

We have more information about cording in our booklet <u>Managing the</u> late effects of breast cancer treatment.

You can order our booklets and leaflets for free. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.



## Coping with a changed appearance

The first time you look at your breast or chest after surgery you may want to have someone with you. Or you might prefer to be alone. Your breast care nurse will talk to you about this and help support you.

At first, the area may look swollen and bruised. But this will settle in a few weeks. In time, the scar will flatten and fade.

If you normally wear a bra, wearing a supportive crop top might feel more comfortable until the swelling goes down. You will also need to wear a supportive top or bra in hospital after surgery and when at home. This can help to protect the breast and reduce bruising. If you are not comfortable wearing either of these, ask for some advice from your breast care nurse. They can tell you about the best way to support the breast.

Changes to your appearance can cause concerns about your body image. This is the picture in your mind of how your body looks and works. These concerns can make you feel less confident. This may also affect your sex life.

You may find that breast reconstruction can help give you back your confidence.

#### **Scars**

Before your operation, your surgeon or nurse will explain where the scars will be.

Scars from breast-conserving surgery are usually small. But this depends on the amount of tissue removed. The scars may be in the area where the cancer was, or a short distance away. This depends on where the surgeon makes the cut. Your surgeon will try to make any scars as small as possible so they are less noticeable.

If you have a <u>mastectomy</u>, the scar will be across the skin of the chest. It may go up into the armpit. If you have <u>surgery to the lymph nodes</u>, the scar will be in the armpit. It should not be noticeable from the front.

The scar will be firm and slightly raised. Over time, it will flatten and fade. If you have pale skin, your scar will be red straight after your operation. If you have black or brown skin, it will be darker.

Everyone's skin heals differently. Scars can take longer to fade if you have black or brown skin or fair, freckled skin. This means they may be more noticeable for longer.

If you are worried about scars, talk to your nurse or surgeon.

## **Breast prosthesis**

Some women choose to wear a breast prosthesis. This is a false breast. Your breast care nurse can give you one if you do not have breast reconstruction during a mastectomy. The prosthesis is soft, and you can wear it inside a bra. It is usually called a cumfie or softie. You can wear it straight after your operation.

When your wound has healed, you can choose a long-term prosthesis made of soft plastic called silicone. This usually happens about 6 weeks after your operation. The prosthesis will be matched to the size and shape of your other breast and your skin colour. You may find your confidence gradually improves as you get used to it.

You can get different types of prosthesis from the NHS. Breast Cancer Now can also give you a list of suppliers.

## When you get home

Your recovery will depend on the type of operation you have. You may need to avoid lifting or carrying anything heavy for a few weeks.

If you drive, contact your car insurance company to let them know you have had an operation. Most people are ready to drive about 4 weeks after their operation. But some insurance policies give specific time limits for not driving after surgery. Do not drive unless you feel in full control of the car.

When you are home, it is important to follow the advice you were given by your breast care nurse. You should keep doing the exercises you were given in hospital and try do some light exercise, such as walking. This can help to build up your energy so you can gradually get back to your normal activities.

## **Outpatient appointment and results**

You will have a clinic appointment to see your surgeon and breast care nurse. They will check that the wound is healing properly. They will also tell you about the tissue that was removed during surgery (pathology) and the stage of the cancer.

If you had a <u>WLE</u>, your surgeon will tell you whether the margins around the cancer are clear. If the margins are not clear, you may need another operation. Sometimes cancer cells are found very close to the margin or in it. Although this can be upsetting news, it can usually be treated successfully with a second operation.

The surgeon and nurse will also talk to you about any further treatment you may need. This may be:

- radiotherapy
- chemotherapy
- targeted therapy
- hormonal therapy.

In some situations, your doctors may discuss having a tumour-profiling test. This can help you decide about having chemotherapy.

## Late effects of surgery

Some people may have problems with the effects of surgery for months or longer after their operation. Tell your breast care nurse if you develop any of these or if you are worried about them.

#### Cording

Sometimes cording may take longer to improve. Talk to your breast care nurse if this happens. It is important to have physiotherapy to improve it. This will help stop your arm and shoulder movement being affected.

#### Pain and changes in sensation

You might continue to have numbness, tingling or pain in your upper arm. This is caused by swelling or damage to the nerves during surgery. Your cancer doctor can prescribe low doses of a drug that treats nerve pain.

#### Changes to your arm or shoulder movement

If you have problems with arm or shoulder strength after surgery, ask your cancer doctor to refer you to a physiotherapist. If moving your shoulder or arm is painful, your cancer doctor can prescribe you painkillers. Problems with your arm and shoulder usually improve after surgery. Doing exercises helps reduce the risk of long-term problems.

#### Lymphoedema

Surgery or radiotherapy to the lymph nodes in the armpit can cause swelling of the arm and breast area. This is called lymphoedema. If you notice any swelling in your arm, breast or chest, tell your breast care nurse or cancer doctor. Treatment can be more effective if it starts earlier.

We have more information in our booklets Understanding lymphoedema and Managing the late effects of breast cancer treatment.



# Radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given, while doing as little harm as possible to normal cells.

Some normal cells in the area being treated can also be damaged by radiotherapy. This can cause side effects. As the normal cells recover, the side effects usually get better.

Radiotherapy is always carefully planned by a team of experts. They will plan your treatment so it does as little harm as possible to normal cells.

Cancer cells cannot repair themselves after radiotherapy, but normal cells usually can.

Radiotherapy reduces the risk of breast cancer coming back in the area it is given to. You usually start radiotherapy 4 to 6 weeks after surgery. Sometimes it may start later. For example, you may start radiotherapy later if your wound needs more time to heal properly. If you are also having chemotherapy, you have radiotherapy after chemotherapy.

Radiotherapy is a standard treatment for breast cancer. But it may be offered as part of a clinical trial. We have more information about clinical trials at macmillan.org.uk/clinical-trials

# Radiotherapy after breast-conserving surgery

If you have <u>breast-conserving surgery</u>, your cancer doctor will usually recommend you have radiotherapy to the breast afterwards.

Some people have a very low risk of cancer coming back in the breast after surgery. If you are in this situation, your cancer doctor may talk to you about not having radiotherapy. Before you decide, you should talk about it carefully with your cancer doctor and nurse. You need to fully understand the advantages and possible risks of not having radiotherapy.

## Radiotherapy after a mastectomy

You may still need radiotherapy to the chest after a <u>mastectomy</u>. This will depend on the risk of the cancer coming back in that area. You are more likely to have radiotherapy if:

- the cancer was large
- the cancer had spread to the lymph nodes in the armpit
- there were cancer cells close to the edge of the removed breast tissue.

## Radiotherapy to the lymph nodes

If the surgeon removed some <u>lymph nodes</u> from your armpit and these contained cancer cells, you may have radiotherapy to the rest of the lymph nodes.

You may also have radiotherapy to the lymph nodes above the collarbone and behind the breastbone.

## Having radiotherapy

You have radiotherapy as an outpatient. It is usually given using equipment that looks like a large x-ray machine. This is called external beam radiotherapy (EBRT) or external radiotherapy. The person who operates the machine is called a therapy radiographer. They will give you information and support during your treatment.

You usually have radiotherapy as a series of short daily treatments. Each treatment is called a fraction or a session. You usually have 5 sessions over 1 week. Sometimes you have 15 sessions over 3 weeks. Your cancer doctor will tell you how many sessions you will need.

If you had breast-conserving surgery, you may have extra radiotherapy to the area where the cancer was. This is called a radiotherapy boost. Sometimes the boost is given at the same time as radiotherapy to the rest of the breast. Or it may be given at the end of the treatments. This means you may need a few more treatments after finishing your main course of radiotherapy.

If you have radiotherapy to your left side, you will usually be asked to take a deep breath and hold it briefly. This is called deep inspiration breath hold (DIBH). You do this at each of your planning and treatment sessions.

DIBH helps protect your heart during radiotherapy treatment to your left side. Your heart is on the left side of your chest. DIBH moves the heart away from the area being treated. It also keeps you still and reduces the risk of late effects. Respire has more information about DIBH. You may have intensity-modulated radiotherapy (IMRT). This is another type of external radiotherapy. It shapes the radiotherapy beams and allows the radiographer to give different doses of radiotherapy to different areas. This means you have lower doses of radiotherapy to healthy tissue surrounding the tumour.

External radiotherapy does not make you radioactive. After treatment, it is safe for you to be with other people, including children.

## Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. Tell the radiographer if you are worried about them or already have a tattoo in the area to be treated.

#### Treatment sessions

Your radiographer will explain what happens during treatment. At the beginning of each session, they make sure you are in the correct position. Usually, you lie with your arms above your head. If your muscles and shoulder feel stiff or painful, a physiotherapist can show you exercises that may help.

When you are in the correct position, the radiographer leaves the room and the treatment starts. The treatment itself is not painful, and it only takes a few minutes.

The radiographers can see and hear you from outside the room. You can usually talk to them through an intercom, if you need to.

During treatment, the radiotherapy machine may stop and move into a new position. This is so you can have radiotherapy from different directions to the same breast.

If your muscles and shoulder feel stiff or painful, a physiotherapist can show you exercises that may help.

## Radiotherapy to part of the breast

Less commonly, you may be offered radiotherapy to part of the breast instead of the whole breast.

Your cancer doctor or nurse will explain if this is an option for you. They will tell you what the possible side effects are, and any risks involved. They can explain how these treatments compare with external radiotherapy. It is important to have information about all your treatment options.

Radiotherapy to part of the breast can be given in different ways.

#### Partial breast radiotherapy

Radiotherapy can be given to a smaller area of the breast using external radiotherapy. This is similar to whole-breast radiotherapy. But it only treats where the lump was removed and a small area of normal tissue around it

#### Internal radiotherapy

You may have radiotherapy from inside the body (internally) instead of to the whole breast. This is called brachytherapy. It is given over a shorter time.

Hollow tubes are put into the area where the cancer was removed from. Radioactive material is placed into the tubes. The radioactive material may be left in place for a few days. This means you have to stay in hospital. Or you may have it over a few sessions as an outpatient. The radioactive material is removed each time before you go home.

#### Intraoperative radiotherapy

This type of radiotherapy is also given internally, but during breast-conserving surgery.

After removing the cancer, your cancer doctor gives a single dose of radiotherapy to the same area. They give the radiotherapy using a special machine.

After intraoperative radiotherapy, you will not usually need any external radiotherapy to the rest of the breast. But sometimes you may need a short course.

Intraoperative radiotherapy is not suitable for everyone. It is not widely available on the NHS.

The National Institute for Health and Care Excellence (NICE) has approved its use, but not as a standard treatment. NICE only covers England and Wales. It should only be used in hospitals that already have these types of machines.

# Side effects of radiotherapy

Radiotherapy can cause side effects in the area of your body that is being treated. You may also have some general side effects, such as feeling tired. Sometimes side effects get worse for a time during and after you have finished radiotherapy before they get better.

If you are having the radiotherapy over 1 week, sometimes the side effects may not start for 2 to 3 weeks after treatment.

Your cancer doctor, breast care nurse or radiographer will tell you what to expect. They will give you advice on what you can do to manage side effects. If you have any new side effects or if side effects get worse, tell them straight away.

#### Skin irritation

If you have white or pale skin, the treated area may get red, dry and itchy. If you have black or brown skin, the treated area may get darker, dry and itchy. Your nurse or radiographer will give you advice on looking after your skin. If it becomes sore and flaky, your doctor can prescribe creams or dressings to help this.

Skin reactions usually get worse after treatment for a few weeks. But they slowly start to improve 2 weeks after radiotherapy ends. Here are some tips for skin reactions:

- Do not put anything on your skin in the treated area without checking with your cancer doctor, nurse or radiographer.
- Have cool or warm showers or baths. Turn away from shower spray to protect the treated area.
- Avoid shaving, waxing or using epilators on your underarm on the affected side.
- Gently pat the area dry with a soft towel do not rub.
- Wear loose clothing. This is less likely to irritate your skin.
- Avoiding swimming if your skin is irritated.

You need to avoid exposing the treated area to the sun during radiotherapy and after treatment finishes. Use suncream with a sun protection factor (SPF) of at least 30.

#### **Tiredness**

This is a common side effect that may last for a few weeks or months after treatment. Studies show that exercise can help to manage tiredness caused by treatment. Try to get enough rest and pace yourself. But it is important to balance this with some physical activity, such as going for short walks. This can give you more energy. We have more information in our booklet Coping with fatigue (tiredness).

#### Aches and swelling

You may have a dull ache in the treated area. Or you may have shooting pains that last for a few seconds or minutes. You may also notice that the area becomes swollen.

These effects may improve after treatment. But you may still have some aches and pains in the area after treatment ends. The area can sometimes stay a little swollen after treatment.

"After the lumpectomy,
I had radiotherapy
and it was exhausting.
The radiotherapy team
were amazing and even
put up with my terrible
jokes such as, 'I'll be
having fission chips for
tea after today's round'. "

# Late effects of radiotherapy

Radiotherapy to the breast may cause side effects that happen months or years after radiotherapy. These are called late effects. Newer ways of having radiotherapy are helping reduce the risk of late effects. If you are worried about late effects, talk to your cancer doctor, breast care nurse or radiographer.

The most common late effect is a change in how the breast or chest area looks and feels.

Radiotherapy can damage small blood vessels in the skin. This can cause red, spidery marks to show. These are called telangiectasia. They may be more common if you had boost doses of radiotherapy.

After radiotherapy, your breast may feel firmer and shrink slightly in size. If your breast is noticeably smaller, you can have surgery to reduce the size of your other breast. If you had breast reconstruction using an implant before radiotherapy, you may need to have the implant replaced.

You may find the treated area sore or uncomfortable for some time. This usually improves over years. It is not uncommon to get pain in the muscle or ribs at the edge of the breast if you overdo things. Very rarely, radiotherapy may cause lung problems or problems with the ribs.

If you have radiotherapy to the left breast, very rarely it can cause heart problems. Tell your cancer doctor, nurse or radiographer if you notice any problems with your breathing, or have any pain in the chest area.

We have more information in our booklet Managing the late effects of breast cancer treatment.



# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. Chemotherapy drugs disrupt the way cancer cells grow and divide, but they also affect normal cells.

# When chemotherapy is given

You can have chemotherapy for breast cancer before or after surgery. Your cancer doctor or nurse will talk to you about the benefits of chemotherapy in your situation. They will also explain the likely side effects.

## **Before surgery**

You may be offered chemotherapy before surgery if the cancer is large or growing quickly. This is called neo-adjuvant treatment. It may also be recommended if you have:

- inflammatory breast cancer
- HER2 positive breast cancer
- triple negative breast cancer
- breast cancer that has spread to the lymph nodes.

Neo-adjuvant chemotherapy aims to:

- shrink the size of the cancer
- reduce the risk of the cancer coming back
- avoid having to remove the whole breast (a mastectomy).

### **After surgery**

Your cancer doctor may recommend you have chemotherapy after surgery. This is called adjuvant chemotherapy. It aims to reduce the risk of breast cancer coming back.

Your cancer doctor or breast cancer nurse will explain the benefits and likely side effects to you.

You are usually offered adjuvant chemotherapy if the cancer:

- has spread to the lymph nodes
- is large
- is high-grade
- is <u>HER2 positive</u>
- is triple negative.

You may also be offered it if you had a tumour-profiling test and the score was high.

# How chemotherapy is given

You usually have chemotherapy in a chemotherapy day unit. You usually have it into a vein (intravenously). But some people are given chemotherapy tablets.

If you have chemotherapy intravenously, you have it by injection or as a drip (infusion). You may have:

- a cannula a short, thin tube the nurse puts into a vein in your arm or hand
- a PICC line a fine tube that is put into a vein in your arm and goes up into a vein in your chest
- an implantable port (portacath) a disc that is put under the skin on your chest or arm and goes into a vein in your chest.

You usually have chemotherapy as a few sessions of treatment. Each session takes a few hours. After the session, you have a rest period. The session and rest period together are called a cycle.

The length of a cycle depends on the chemotherapy drugs you are having. Most cycles are 1 to 3 weeks. Your cancer doctor or nurse will tell you how many cycles you need.

#### The drugs used

Different chemotherapy drugs affect cancer cells in different ways. This is why a combination of drugs is often used. For early breast cancer, the combination usually includes drugs called:

- anthracyclines such as epirubicin and doxorubicin
- taxanes such as docetaxel, paclitaxel and nab-paclitaxel.

These drugs are commonly used in combination with other chemotherapy drugs, including cyclophosphamide and carboplatin.

If you are having both an anthracycline and a taxane, they will usually be given one after another. Your cancer doctor or nurse will explain the order you have them.

Some commonly used combinations are:

- AC doxorubicin (Adriamycin®) and cyclophosphamide
- EC epirubicin and cyclophosphamide
- TC docetaxel (Taxotere®) and cyclophosphamide
- carboplatin with paclitaxel or docetaxel
- EC-T epirubicin and cyclophosphamide, followed by docetaxel
- EC-P epirubicin and cyclophosphamide, followed by paclitaxel.

Your cancer doctor may offer you a choice of chemotherapy drugs. They will give you information to help you decide.

If you have HER2 positive breast cancer, you will have targeted therapy drugs called trastuzumab or pertuzumab. Or you may have both.

After surgery, you may continue having the drugs you had before surgery. Or you may change to trastuzumab emtansine.

These may be given if there is a higher risk of the cancer coming back, to reduce the risk. We have more information about targeted therapy for breast cancer.

## Side effects

Chemotherapy causes some side effects. But these are usually well controlled with medicines. Most side effects usually go away after treatment has finished. Not all drugs cause the same side effects.

Your cancer doctor, breast cancer nurse or pharmacist will explain what to expect from the treatment.

#### Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

#### Symptoms of an infection include:

- · feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

#### It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

You may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin.

## Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

### Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

## Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

### Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

We have more information in our booklet <u>Coping with fatigue</u> (tiredness).



#### **Hair loss**

You usually lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you if this is an option for you.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. Your scalp may be sensitive. It is important to cover your head to protect your skin when you are out in the sun.

Hair loss is usually temporary. Your hair will usually grow back after treatment finishes. Rarely, hair may not grow back. Or it may grow back thinner than before. If you are worried about this, talk to your cancer doctor or nurse. We have more information in our booklet <u>Coping</u> with hair loss.

#### Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

### **Bowel changes**

Chemotherapy may cause constipation or diarrhoea. Anti-sickness drugs can also cause constipation. Drinking plenty of fluids, eating more fibre and doing gentle exercise can help with constipation. You may need to take medicine called laxatives to help. Your GP can prescribe these. Or you can buy them at a pharmacy.

Diarrhoea can usually be controlled with medicine. Tell your doctor if it is severe or does not go away. It is important to drink plenty of fluids if you have diarrhoea.

# Numb or tingling hands or feet (peripheral neuropathy)

Some chemotherapy drugs may affect the nerves. This can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes. But for some people they may never go away. Talk to your doctor if you are worried about this.

### Contraception

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment.

The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell vou more about this.

### Early menopause

Chemotherapy can cause an early menopause, which can be difficult to cope with. This risk is higher if you are already close to menopausal age. We have more information about early menopause at <a href="mailto:macmillan.org.uk/menopausal-symptoms-and-cancer-treatment">macmillan.org.uk/menopausal-symptoms-and-cancer-treatment</a>

### **Fertility**

Some chemotherapy drugs can affect your ability to have children (your fertility). If you are worried about how chemotherapy may affect your fertility, talk to your cancer doctor before treatment starts. There are different options that may help to preserve your fertility. These include:

- freezing eggs
- freezing embryos (fertilised eggs)
- storing sperm.

We have more information in our booklet <u>Cancer and fertility</u> and at <u>macmillan.org.uk/fertility</u>

#### Sex

If you have sex in the first few days after this treatment, you should use barrier protection such as a condom or dental dam. This will protect your partner if any of the drug is in your semen or vaginal fluid.

### **Heart changes**

Some chemotherapy drugs can affect the heart. This is not common. If you are having a drug that can affect your heart, you may have some tests before you have treatment. Your cancer doctor or nurse can explain more about this. They may refer you to a cancer doctor who specialises in the effects on the heart.

# **Hormonal therapy**

Hormones help control how cells grow and what they do in the body. The hormone oestrogen can encourage some breast cancers to grow. This may also happen with the hormone progesterone.

Hormonal therapy reduces the amount of oestrogen in the body or stops oestrogen attaching to cancer cells. It only works for breast cancer that is oestrogen receptor positive (ER positive). Hormonal therapy is also called endocrine therapy.

Your cancer doctor will advise you to have hormonal therapy to reduce the risk of breast cancer coming back. It also helps reduce the risk of getting a new breast cancer in your other breast.

You may be offered hormonal therapy before surgery. This aims to shrink the cancer. It may help you avoid a mastectomy.

You usually have hormonal therapy drugs for a number of years. This may be for up to 10 years. You usually start taking them after surgery or chemotherapy.

The type of hormonal therapy you have depends on:

- whether you have been through the menopause
- the risk of the cancer coming back
- how the side effects may affect you.

We have more information about different hormonal therapy drugs and their side effects on our website. Visit macmillan.org.uk/treatmentsand-drugs

# Taking hormonal therapy

Hormonal therapy reduces the risk of breast cancer coming back. It is important to take it for as long as you have been prescribed it. Try to make taking it part of your daily routine so it becomes a habit.

Most people cope well with the <u>side effects of hormonal therapy</u>. Side effects may be more of a problem in the first few months, but they usually get better over time.

If the side effects do not improve or are difficult to cope with, talk to your breast cancer nurse or cancer doctor. They can give you drugs to help and can suggest ways of coping.

Sometimes they may suggest changing the time you take the tablet. If you still have problems, they may suggest changing to a different type of hormonal therapy.



# Types of hormonal therapy

#### **Tamoxifen**

Tamoxifen is an anti-oestrogen drug. It stops oestrogen attaching to breast cancer cells and making them grow.

You take tamoxifen once a day as a tablet.

You may have it if you have:

- not been through the menopause you may take tamoxifen for a few years and then change to an aromatase inhibitor
- been through the menopause and have a low risk of the cancer coming back
- been through the menopause and are having problems with your bones - this is because tamoxifen does not cause bone thinning
- bad side effects with aromatase inhibitor drugs you may be given tamoxifen instead.

If you are close to menopause when you start tamoxifen, you may change to an aromatase inhibitor after a few years. Your doctors may do blood tests to check your hormone levels first.

If you want to get pregnant, talk to your cancer doctor or nurse about the timing of this. You will need to have a break in your treatment, and you must stop taking tamoxifen for several months before trying to start a pregnancy (conceive). This is because tamoxifen can harm an unborn baby. Your doctor or nurse can give you more information about getting pregnant after breast cancer.

"I'm currently coping withthe side effects of radiotherapy and tamoxifen as best as I can. My left arm and hand are weak. My GP is confident it's caused by the radiotherapy but should get better in time. II

#### Aromatase inhibitors (Als)

Aromatase inhibitors (Als) are the main hormonal therapy drugs used if you have been through the menopause. They stop oestrogen being made in the fatty tissue, muscles and in the glands above the kidneys (adrenal glands). Your cancer doctor may prescribe an AI such as anastrozole, letrozole or exemestane. You take Als daily as a tablet.

Als may sometimes be given if you have not been through the menopause. But they can only be given with drugs to stop the ovaries working, or if the ovaries have been removed.

#### Your bone health

If you take Als over a long time, they can cause bone thinning. This is called osteoporosis. You may have a scan to check your bone health (density). This is called a DEXA scan. Having your ovaries removed and ovarian suppression can also cause osteoporosis.

You may already be having a drug called a bisphosphonate. These are given to help reduce the risk of cancer spreading to the bones. But they are also used to help protect from osteoporosis.

If you are at risk of osteoporosis and are not already having bisphosphonates, your cancer doctor may prescribe them to help protect your bones.

Your doctor will usually check your calcium and vitamin D levels. If these are low, the doctor will advise you to take supplements to help strengthen your bones. There are things you can do to look after your bones, including eating healthily and doing regular weight-bearing exercise such as walking.

# Ovarian suppression or removing

# the ovaries (ablation)

If you have not been through the menopause, your cancer doctor may advise having 1 of these treatments with another hormonal therapy:

- ovarian suppression this stops the ovaries making oestrogen and causes a temporary menopause
- removing the ovaries (ablation) this causes a permanent menopause.

These treatments lower oestrogen levels. This reduces the risk of breast cancer coming back. But they can also affect your bone health. You usually have a DEXA scan to check your bone health (density). Your doctor will advise you on how to look after your bones.

# Drugs to stop the ovaries making oestrogen (ovarian suppression)

Goserelin (Zoladex®) and leuprorelin (Prostap®) are drugs that stop the ovaries making oestrogen. This is called ovarian suppression. It causes a temporary menopause. This means you will not get a period while you are taking them.

These types of drugs stop the pituitary gland in the brain from sending messages to the ovaries to produce oestrogen. This causes side effects similar to menopausal symptoms. These include:

- hot flushes and sweats
- joint pain
- low sex drive
- mood changes
- osteoporosis.

You have goserelin as a monthly injection under the skin of the tummy (abdomen). You usually have leuprorelin as an injection every 3 months.

You usually have 1 of these drugs along with tamoxifen or an Al.

When you finish treatment, the ovaries usually start to produce oestrogen again. This means your periods will come back. But this may not happen if you were close to your natural menopause when you started treatment.

### Removing the ovaries (ovarian ablation)

Removing the ovaries is called ovarian ablation. It may be an option if you do not want to have the injections. You will usually have tamoxifen or an AI as well.

Ovarian ablation involves a small operation. It is done using keyhole surgery. The surgeon makes a small cut in the tummy area. They then insert a thin tube through the cut. The tube is called a laparoscope. It has a tiny light and camera on the end and a small surgical instrument attached. The surgeon uses the laparoscope to remove the ovaries through the cut. You usually recover quickly from this operation, but you may need a short stay in hospital.

If you have ovarian ablation, your periods will stop straight away and you will start the menopause. Your periods will not come back. This means you will no longer be able to get pregnant. This can be hard to cope with. But there is lots of support available.

You may find our booklet <u>Cancer and fertility</u> useful. Or visit macmillan. org.uk/fertility

## Hormonal therapy before the menopause

If you have not been through the menopause, your cancer doctor may recommend 1 of the following:

- tamoxifen
- goserelin or leuprorelin with tamoxifen or an Al
- surgery to remove the ovaries on its own or with tamoxifen or an Al.

### Hormonal therapy after the menopause

If you have been through the menopause, your doctor may prescribe 1 of the following:

- an AI such as anastrozole, letrozole or exemestane
- tamoxifen and an AI (one type is given after the other)
- tamoxifen on its own.

# Side effects of hormonal therapy

Different hormonal therapy drugs have different side effects. Some of the main side effects include:

- hot flushes and sweats
- · weight gain
- joint and muscle pain
- tiredness
- sexual effects, including vaginal dryness.

Some types of hormonal therapy can slightly increase the risk of developing a blood clot. Tamoxifen may also slightly increase the risk of womb changes and womb cancer. Tell your cancer doctor if you have any vaginal discharge or bleeding.

We have more information about the side effects of different hormonal therapy drugs. Visit macmillan.org.uk/treatments-and-drugs

I had to stay strong. I think your mental state is key when it comes to getting through these things. It was horrible, but you will get through it.

Ravinder, diagnosed with breast cancer

# **Targeted therapy**

Targeted therapy drugs interfere with the way cancer cells grow. The targeted therapy drugs used to treat breast cancer are trastuzumab (often called Herceptin®) and pertuzumab (Perjeta®). They help to reduce the risk of HER2 positive breast cancer coming back.

You may have trastuzumab on its own or with pertuzumab. They may be given together as an injection called Phesgo®.

Trastuzumab and pertuzumab may also be given with chemotherapy. You may have them before or after surgery and radiotherapy.

There are newer types of targeted therapy drug to treat HER positive breast cancer. You may have these if you have already had trastuzumab and pertuzumab.

We have more information about individual targeted therapy drugs and their side effects on our website. Visit macmillan.org.uk/treatmentsand-druas

## Trastuzumab

You usually have trastuzumab every 3 weeks for 1 year. Sometimes you may have it over 6 months. Your cancer doctor will tell you how long you need to have it for. You have it in the chemotherapy day unit or outpatient department.

You usually have trastuzumab as an injection under the skin (subcutaneously). But you may have it as a drip into a vein (an infusion).

# Side effects of trastuzumab

The side effects of trastuzumab are usually mild. You may have some side effects while you are having the infusion or injection. or up to 4 hours after. This is more likely to happen with the first dose. These side effects include flu-like symptoms, such as:

- a headache
- a high temperature (fever) and chills
- feeling sick.

Any side effects usually get better a few hours after you finish the treatment.

Another possible side effect is an allergic reaction, but this is rare. The nurses will check for signs of a reaction. If it happens, they can treat it quickly with drugs.

You may get other side effects after treatment. These include:

- diarrhoea
- headaches
- feeling sick.



#### Effects on the heart

Trastuzumab may cause changes in the way the heart works. This can cause problems in some people. Usually, the effect is mild and returns to normal after treatment ends. You may be given heart medicines to help with this side effect.

You usually have tests to check your heart before and during treatment. This is usually a scan of the heart called an echocardiogram. It helps to make sure the drug is not causing any damage.

Trastuzumab is not usually given to people who have serious heart problems. If there are any changes with your heart, you may be referred to a heart specialist doctor called a cardiologist. They may give you drugs to support your heart.

## **Pertuzumab**

You have pertuzumab every 3 weeks with trastuzumab. You have it as an infusion. The first dose is usually given slowly over about 60 minutes. This is because some people can have a reaction. The nurses monitor you during the infusion and for about 60 minutes afterwards. If you have no problems, you can have the next doses over 30 to 60 minutes.

#### Side effects of pertuzumab

The side effects of pertuzumab include:

- a headache
- diarrhoea, which can be severe
- feeling sick
- itchy skin or a rash.

Pertuzumab can also affect the heart. But you will have regular heart checks during treatment. Your cancer doctor or a nurse will give you more information about the side effects and ways of coping with them.

# **Phesgo**

Phesgo® is a combination of trastuzumab and pertuzumab. You have it as an injection under the skin (subcutaneously). The nurse gives you the injection every 3 weeks, into the thigh.

# Other types of targeted therapy drug

#### Trastuzumab emtansine

Trastuzumab emtansine is trastuzumab with the chemotherapy drug emtansine attached to it. You have it as an infusion every 3 weeks.

You may be offered trastuzumab emtansine if cancer cells are still in the breast or lymph nodes after surgery.

It is offered to people who have had chemotherapy and HER2 treatment before surgery (neo-adjuvant treatment).

#### **Neratinib**

You take neratinib as tablets. It may be used to treat breast cancer that is both HER2 positive and ER positive. It may be offered if you have had surgery and treatment with trastuzumab less than 1 year ago. Your cancer doctor or breast care nurse can explain more about whether this drug is suitable for you.

### **Abemaciclib**

You take abemaciclib as tablets. It may be used to treat early breast cancer that has a higher risk of coming back.

### **Olaparib**

You take olaparib as tablets. It may be used to treat early breast cancer that is HER2 negative and has a higher risk of coming back. It is given to people who have a gene change called BRCA1 or BRCA2. Your cancer doctor or nurse will explain if this drug is suitable for you.

We have more information about these drugs on our website. Visit macmillan.org.uk/triple-negative-breast-cancer

# Triple negative breast cancer

If you have triple negative breast cancer, you may be offered other types of targeted therapy drug.

# **Bisphosphonates**

Bisphosphonates are drugs that help to protect the bones against some effects of breast cancer treatment. They can also help reduce the risk of breast cancer coming back after treatment.

Bisphosphonates may be used in early breast cancer to:

- help protect from bone thinning (osteoporosis), a side effect of some treatments
- reduce the risk of breast cancer coming back these are called adjuvant bisphosphonates.

# **Bone protection**

Some hormonal therapy drugs can affect the bones. This is because they cause lower oestrogen levels. Some hormonal therapy and chemotherapy drugs can cause an early menopause. This increases the risk of osteoporosis.

Your cancer doctor may prescribe bisphosphonates if you are at risk of osteoporosis or already have it. They will usually also advise you to take calcium and vitamin D supplements to help strengthen your bones.

There are lifestyle changes you can make that will help look after your bones. These include:

- eating healthily
- doing regular weight-bearing exercise, such as walking
- not smoking.

We have more information in our booklet Bone health.

# Adjuvant bisphosphonates

If you have early breast cancer, bisphosphonates can help lower the risk of the cancer coming back. This is called adjuvant treatment. You have bisphosphonates for 3 to 5 years. You usually have this treatment if you have a higher risk of the cancer coming back, and you have:

- been through the menopause
- had treatment to stop your ovaries working for example, goserelin.

The bisphosphonate drugs most commonly used in adjuvant treatment are:

- zoledronic acid, which is given by a drip into a vein (an infusion) every 6 months
- clodronate, which is taken as a tablet
- ibandronic acid, which is taken as a tablet.

Your cancer doctor can tell you if adjuvant bisphosphonates may be helpful for you. It is important to consider the possible benefits against the side effects of the drugs.

We have more information about individual drugs and their side effects at macmillan.org.uk/treatments-and-drugs

# Side effects

Side effects will depend on the type of bisphosphonate you have. Some common side effects are:

- mild sickness
- indigestion
- flu-like symptoms.

Bisphosphonates do not usually cause serious side effects. But rarely they can cause problems with the jawbone. This is called osteonecrosis. It can cause the bone in the area to weaken and die.

Taking good care of your teeth and gums can reduce the risk of jaw problems. It is important to have a dental check-up before starting bisphosphonates. Tell your dentist and your cancer doctor or nurse if you have any problems with your mouth.

Rarely, bisphosphonates can affect the kidneys. Your doctor will check your blood regularly to see how your kidneys are working.

We have more information about bisphosphonates on our website. Visit macmillan.org.uk/ bisphosphonates-breast-cancer







# After your treatment

Follow-up for women with breast cancer	110
Effects after treatment	112
Well-being and recovery	118
Getting help and support	122
Talking to children	125

# Follow-up for women with breast cancer

After treatment, you will have regular check-ups with your cancer doctor or regular contact with your breast care nurse.

You will have mammograms every year for 5 years on the other breast. If you have had breast-conserving surgery, you will have mammograms on both breasts. If you have had a double mastectomy, you will not be offered mammograms.

After 5 years, if you are 50 or over, you usually have mammograms through the NHS breast screening programmes. Younger women usually continue to have yearly mammograms after the first 5 years, until they reach 50.

Instead of regular appointments, your nurse may give you information about what to look out for. They will give you contact numbers and ask you to contact them or your cancer doctor if there is anything you are worried about. You may have your follow-up appointments at a nurse-led clinic. This means you will only go to your cancer doctor if something needs to be checked further.

It is natural to feel anxious before appointments. It can help to get support from family, friends or a specialist organisation. You can also contact our cancer support specialists on 0808 808 00 00.

# Be aware of changes

You may have yearly mammograms, but it is still a good idea to know what is now normal for you. Your treated breast will look and feel different. This will depend on the treatment you had.

Your breast care nurse or cancer doctor can tell you what you to expect and what to check for. It is also important to be aware of what to look out for in your untreated breast.

Breast Cancer Now has information on how to check your breasts. We have more information at macmillan.org.uk/breastcancer

If you notice anything unusual, contact your cancer doctor or breast care nurse straight away.



# **Effects after treatment**

After treatment, you will probably want to get back to doing the things you did before diagnosis. But you may still be coping with some side effects of treatment and your feelings about having had cancer. It is important to try not to expect too much of yourself. It can often take several months to recover from the effects of treatment.

You may have treatment side effects that do not improve after a few months. You may have treatment side effects that start months or years after treatment. Always tell your cancer doctor or breast care nurse if:

- you have side effects that are not improving
- you develop new side effects.

We have more information in our booklet Managing the late effects of breast cancer treatment.

### Lymphoedema

Lymphoedema is a swelling of the arm or hand on the side you had treatment. It sometimes happens after surgery or radiotherapy to the lymph nodes in the armpit. It usually develops slowly, months or years after treatment.

Lymphoedema is more likely to happen if all or many of your lymph nodes were removed. Having radiotherapy to the armpit as well as surgery increases the risk.

You may have had only 1 or 2 lymph nodes removed. This is called a <u>sentinel lymph node biopsy</u>. The risk of lymphoedema is low after this. If you are not sure what type of lymph node surgery you had, your breast care nurse can tell you.

If you notice any swelling in your arm, hand or chest, ask your doctor or nurse to check it. The earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully.

We have more information in our booklet <u>Understanding lymphoedema</u>.

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.



# Sex and fertility

Cancer and its treatments can sometimes affect your sex life or your ability to get pregnant (your fertility).

#### Sexuality

Breast cancer and its treatments and side effects may affect your sex life and your feelings about yourself. You may have:

- loss of sex drive (low libido)
- vaginal dryness this may be caused by menopausal symptoms.

Difficulties often slowly improve after treatment, but it may take longer. Some people may continue to have difficulties.

You may feel insecure and worry about your current or future relationships. If you have a partner, it can help to talk openly with them about your feelings. You may both need some time to adjust.

Let your doctor or nurse know if any difficulties with your sex life do not improve. They may be able to reassure you or offer further help and support. If you feel uncomfortable talking to your doctor or nurse, you can call us on 0808 808 00 00. We have more information in our booklet Cancer and your sex life.

Some people may find it helpful to talk to a sex therapist. You can contact a therapist through the College of Sexual and Relationship Therapists.

#### **Fertility**

Some breast cancer treatments may affect your fertility.

Your periods may stop during treatment. If you are younger, they may start again after treatment has ended. But it may take several months for them to start again. If you are close to your natural menopause, chemotherapy can cause an early menopause.

It is important to talk to your cancer doctor about your fertility before treatment starts. Sometimes it may be possible to remove eggs from your ovaries before treatment. If you have a partner, it may be possible to fertilise the eggs with their sperm. The fertilised eggs (embryos) can be frozen and stored to use later. If you do not have a partner, you may be able to have your eggs frozen and stored.

Becoming infertile can be very hard to cope with, whether or not you already have children. You may find it helpful to talk about your feelings with a trained counsellor. If you need more specialist help, ask your cancer doctor or breast care nurse to arrange this for you.

We have more information in our booklet  $\underline{\text{Cancer and fertility}}$  and at  $\underline{\text{macmillan.org.uk/fertility}}$ 

#### Contraception

Your doctor will advise you not to get pregnant while having chemotherapy and for some time afterwards. The drugs can affect your eggs. This may harm a developing baby. It is important to use effective contraception. You can talk about this with your doctor or nurse.

Your cancer doctor or nurse will advise you not to use contraception that contains hormones. This includes the pill or implants that release hormones. Your GP can give you advice about methods of contraception. These may include:

- coils (intra-uterine devices) that do not contain hormones
- barrier methods such as condoms
- diaphragms or caps.

#### Mirena® coil

The Mirena® coil works by releasing a small amount of a hormonal medicine into the womb. The medicine is called levonorgestrel. It is an artificial type of progesterone. Doctors are unsure how much of it reaches other parts of the body after it has been released into the womb.

Studies have tried to find out if the Mirena coil could cause cancers that depend on hormones to grow. The results have been mixed. But there is currently no strong evidence to show that the Mirena coil encourages these types of cancer to grow. Because it contains progesterone, it is not usually recommended for people who have had cancers that depend on hormones to grow. This includes breast cancer.

If you are concerned, you can talk to your GP or specialist about what contraception is best for you.

#### **Pregnancy**

Having a family can be an important part of life after cancer. Your doctor may advise you to wait for 2 years before trying to get pregnant. This is because breast cancer is most likely to come back during this time. But it also gives you time to recover from treatment. Studies show that getting pregnant after breast cancer does not increase the risk of it coming back.

If you are taking hormonal therapy and are thinking of getting pregnant, it is important to talk to your cancer doctor first. If you are taking tamoxifen, you must not get pregnant. This is because it may harm a developing baby. Talk to your cancer doctor before you stop taking any medicines. We have more information about getting pregnant in our booklet Managing the late effects of breast cancer treatment.

# Early menopause or menopausal symptoms

Some treatments can cause an early or temporary menopause. Hormonal therapy can cause side effects that are the same as menopausal symptoms.

Doctors do not recommend hormone replacement therapy (HRT). This is because it contains oestrogen. This could encourage breast cancer cells to grow.

Early menopause can increase the risk of bone thinning (osteoporosis). We have more information about looking after your bones, including tips on keeping them healthy, in our booklet Bone health.

A number of organisations, including the Daisy Network, provide support to women going through the menopause.

# Well-being and recovery

After breast cancer treatment, you may choose to make some positive lifestyle changes. You may have already had a healthy lifestyle before breast cancer. But you may be more focused on making the most of your health.

## Eat well and keep to a healthy weight

After treatment, you may find you have gained some weight. This can happen with chemotherapy and hormonal therapy. When you are feeling better, it is a good idea to get to a healthy weight. You can check with your GP if your weight is within the normal range for your height.

Keeping to a healthy weight reduces the risk of some other cancers, heart problems and other conditions such as diabetes. There is some evidence that keeping to a healthy weight after menopause may help reduce the risk of breast cancer coming back. Try to:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less saturated fat and sugar
- be more physically active.

# Be physically active

Being physically active helps keep your weight healthy and can reduce stress and tiredness. It helps keep your bones strong and your heart healthy. There is evidence that regular physical activity may help reduce the risk of breast cancer coming back.

We have more information about physical activity and cancer treatment in our booklet <u>Cancer and physical activity</u>.

You can also watch videos about the benefits of physical activity, including stories from people with cancer. Visit <a href="mailto:macmillan.org.uk/">macmillan.org.uk/</a> <a href="mailto:physical-activity-cancer">physical-activity-cancer</a>



### Look after your bones

Oestrogen helps keep bones healthy and strong. Aromatase inhibitors, and treatments that cause an early or temporary menopause, reduce oestrogen in the body. This can cause bone thinning (osteoporosis). Goserelin (Zoladex<sup>®</sup>) may cause osteoporosis when you take it over a longer period of time. We have more information in our booklet Bone health.

To keep your bones healthy:

- keep physically active
- eat a healthy diet with enough calcium and vitamin D
- avoid smoking.

### Look after your heart

Some treatments for breast cancer may increase the risk of heart problems later on. To look after your heart:

- keep physically active
- · eat a healthy diet
- do not smoke
- stick to sensible-drinking guidelines.

You can get more information from the British Heart Foundation and in our booklet Heart health and cancer.

# Stop smoking

If you smoke, stopping is one of the healthiest decisions you can make. Smoking increases your risk of osteoporosis and is a major risk factor for smoking-related cancers and heart disease.

# Stick to sensible-drinking guidelines

Current NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in 1 week
- spread the alcohol units you drink in 1 week over 3 or more days
- try to have several alcohol-free days every week.

#### A unit of alcohol is:

- half a pint (285ml) of ordinary-strength beer, lager or cider
- 1 small glass (125ml) of wine
- a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at drinkaware.co.uk

### Try to reduce stress in your life

Being diagnosed with breast cancer can be stressful. One way of coping with stress is to make time to relax. This could include:

- going for a walk
- having a meal with family or friends
- listening to music or watching a film
- trying activities such as yoga, or relaxation techniques to control breathing
- being more physically active and looking after your well-being
- talking to someone about how you feel.

# **Getting help** and support

Different people can help you during and after treatment.

### Practical help

If you need help at home during or after treatment, a nurse or hospital social worker may be able to arrange this. If you have children, the social worker may arrange some help with childcare.

A social worker or benefits adviser can tell you about benefits you may be able to claim and help with other costs. We have more information in our booklet Help with the cost of cancer.

## **Emotional help**

It is common to have different, and sometimes difficult, feelings after cancer treatment. But as you recover and get back to your everyday life, these usually get easier to deal with. Talking to family and friends often helps. If you think you may be depressed, or feel helpless or anxious a lot of the time, talk to your cancer doctor or nurse. They can refer you to a psychologist or counsellor who specialises in helping people with their emotions.

We have more information in our booklet Your feelings after cancer treatment.

Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call them on 0808 808 00 00.

### **Complementary therapies**

Some people find that using complementary therapies helps them relax or cope with treatment side effects. Some hospitals or support groups may offer therapies such as relaxation or aromatherapy.

We have more information in our booklet Cancer and complementary therapies and at macmillan.org.uk/complementary-therapies

### Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. We can give you information about support groups in the UK.

# **Online support**

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer.

You can use these to share your experience, ask questions, and get and give advice based on your breast cancer experience.

Our Online Community is a social networking site where you can talk to people, write blogs, make friends and join support groups. Visit macmillan.org.uk/community



# Talking to children

Deciding what to tell children can be difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong. Sometimes their fears can be worse than the reality.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information and gradually tell them more to build up a picture.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.





# Work and financial support

Help with money and benefits	128
Work	131

# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

### **Macmillan Grants**

Macmillan Grants are small, one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills. you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on 0808 808 00 00 or visit macmillan.org.uk/grants

#### Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on 0808 808 00 00.

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community



# Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

We have more information about work and cancer on our website. Visit macmillan.org.uk/work





# **Further information**

About our information	134
Other ways we can help you	136
Other useful organisations	140

# **About our information**

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

#### Order what you need

You may want to order more booklets or leaflets like this one. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

#### Online information

All our information is also available online at macmillan.org.uk/ information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

#### Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets

- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on 0808 808 00 00.

#### The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

#### Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

#### **Macmillan Support Line**

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on 0808 808 00 00. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/ talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

#### **Macmillan Information and Support Centres**

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at <u>macmillan.org.uk/informationcentres</u> or call us on 0808 808 00 00.

#### Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

#### Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

#### Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <a href="macmillan.org.uk/financialsupport">macmillan.org.uk/financialsupport</a> to find out more about how we can help you with your finances.

#### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

#### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home.

Call us on 0808 808 00 00 to find out more about Macmillan Grants.

#### Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

#### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on 0808 808 00 00 to speak to a work support adviser.

#### Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

#### **Support groups**

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting <a href="mailto:macmillan.org.uk/selfhelpandsupport">macmillan.org.uk/selfhelpandsupport</a>

#### **Online Community**

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

#### Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

#### **Breast cancer support organisations**

#### **Breast Cancer Haven**

#### Tel 0757 263 7588

#### www.breastcancerhaven.org.uk

Delivers one-to-one support sessions, healthy eating, exercise and stress reduction classes, and a range of self-help videos and resources. These can be accessed online.

#### **Breast Cancer Now**

#### Helpline **0808 800 6000**

#### www.breastcancernow.org

Provides information and practical and emotional support to people affected by breast cancer. Specialist breast care nurses run the helpline. Also offers a peer support service where anyone affected by breast cancer can be put in touch with a trained supporter who has had personal experience of breast cancer.

#### **Daisy Network**

#### www.daisynetwork.org

Provides support to women, along with their families and partners, who have been diagnosed with premature ovarian insufficiency.

#### **Keeping Abreast**

#### Tel 0160 381 9113

#### www.keepingabreast.org.uk

Offers support for people having breast reconstruction. Provides a network of dedicated support groups and online support across the UK.

#### **Lobular Breast Cancer UK**

#### www.lobularbreastcancer.org.uk

Offers support to people living with lobular breast cancer.

#### General health support organisations

#### **Asian Women Cancer Group**

#### www.asianwomencancergroup.co.uk

Helps Asian women who have been affected by cancer. Provides emotional support and financial guidance.

#### **Black Women Rising**

#### www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

#### **British Heart Foundation**

#### Helpline 0300 330 3311

#### www.bhf.ora.uk

Provides support and information for people diagnosed with a heart or circulatory condition, and their family and friends. Also raises money to research cures and treatments.

#### **Cancer Black Care**

#### Tel 0208 961 4151

#### www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

#### **Cancer Focus Northern Ireland**

#### Helpline **0800 783 3339**

#### www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

#### **Cancer Research UK**

#### Helpline 0808 800 4040

#### www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

#### **Cancer Support Scotland**

#### Tel 0800 652 4531

#### www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### Maggie's

#### Tel 0300 123 1801

#### www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

#### **Penny Brohn UK**

#### Helpline **0303 3000 118**

#### www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

#### **Respire**

#### www.respire.org.uk

Aims to improve the patient experience by helping patients to prepare for radiotherapy

#### **Tenovus**

#### Helpline 0808 808 1010

#### www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

#### **Emotional and mental health support**

#### **Samaritans**

Helpline 116 123

Email jo@samaritans.org

#### www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

#### British Association for Counselling and Psychotherapy (BACP)

#### Tel 0145 588 3300

#### www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

#### College of Sexual and Relationship Therapists (COSRT)

#### www.cosrt.org.uk

Online information about sexual wellbeing, including having therapy and finding a therapist. Website provides a list of professional therapists.

#### Financial support or legal advice and information

#### **Advice NI**

Helpline 0800 915 4604

www.adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

#### **Benefit Enquiry Line Northern Ireland**

Helpline 0800 232 1271

Textphone **028 9031 1092** 

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

#### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

#### **England**

Helpline **0800 144 8848** www.citizensadvice.org.uk

#### Scotland

Helpline 0800 028 1456

www.cas.org.uk

#### Wales

#### Helpline 0800 702 2020

www.citizensadvice.org.uk/wales

#### **GOV.UK**

#### www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

#### **Money Advice Scotland**

#### www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

#### **NI Direct**

#### www.nidirect.gov.uk

The official government website for Northern Ireland citizens.

#### **Social Security Scotland**

#### www.socialsecurity.gov.scot/benefits

Manages the payment of government benefits to people in Scotland, including carers and Disabled people.

#### Unbiased.co.uk

#### Helpline 0800 023 6868

#### www.unbiased.co.uk

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

#### **LGBT-specific support**

#### **LGBT Foundation**

#### Tel 0345 330 3030

#### www.labt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

#### **OUTpatients (formerly called Live Through This)**

#### www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

#### **Cancer registries**

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

#### **England - National Disease Registration Service (NDRS)**

www.digital.nhs.uk/ndrs/patients

#### Scotland - Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-anddiseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/ overview

#### Wales - Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278** 

www.phw.nhs.wales/wcisu

#### Northern Ireland - Northern Ireland Cancer Registry (NICR)

Tel 0289 097 6028

www.gub.ac.uk/research-centres/nicr/AboutUs/Registry

#### Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

#### **Thanks**

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Rebecca Roylance, Consultant Medical Oncologist.

With thanks to: Dr Russell Burcombe, Consultant Clinical Oncologist; Josie Cameron, Breast Advanced Practice Radiographer; Heather Driver, Breast Cancer Clinical Nurse Specialist; Miss Joanna Franks, Breast Consultant and Oncoplastic Surgeon; Claire Herlihy, Breast Cancer Clinical Nurse Specialist; Donna McKeown, Advanced Nurse Practitioner; Sally Shanley, Breast Cancer Clinical Nurse Specialist; Dr Jenny Sherriff, Consultant Clinical Oncologist; Dr Richard Simcock, Consultant Clinical Oncologist and Consultant Medical Adviser, Macmillan.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact cancerinformationteam@macmillan.org.uk

#### **Sources**

Below is a sample of the sources used in our breast cancer information. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

ESMO. Early breast cancer clinical practice guidelines for diagnosis, treatment and follow-up. 2019, Vol 30, pp1192-1220. Available from: www.esmo.org/quidelines/quidelines-by-topic/breast-cancer/ early-breast-cancer [accessed 2023].

National Institute for Health and Care Excellence (NICE). Early and locally advanced breast cancer: diagnosis and management. 2018. Updated 2023. Available from: www.nice.org.uk/quidance/ng101 [accessed 2023].

### Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

#### 5 ways you can help someone with cancer

#### Share your cancer experience 1.

Support people living with cancer by telling your story, online, in the media or face to face.

#### 2. Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

#### 3. Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

#### Raise money 4.

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

#### 5. Give money

Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details	Do not let the taxman	
Mr/Mrs/Miss/Other	keep your money	
Name	Do you pay tax? If so, your gift will be worth 25% more to us - at no extra cost to you. All you	
Surname		
Address	have to do is tick the box below and the tax office will give 25p for every pound you give.	
Postcode		
Phone	I am a UK tax payer and	
Email	I would like Macmillan Cancer	
Please accept my gift of £ (Please delete as appropriate)	Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations until I notify you otherwise.	
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support		
OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro	I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.	
Card number		
Valid from Expiry date	Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affecte by cancer. If you would prefer us not to use your details in this way please tick this box. In order to carry out our work we may need to pass your details to agents or partners whact on our behalf.	
Issue no Security number		
Signature	If you would rather donate online go to macmillan.org.uk/donate	
Date / /		







# This booklet is about breast cancer. It is for anyone who has been diagnosed with breast cancer. There is also information for carers, family members and friends.

The booklet talks about the types and stages of breast cancer. It explains how it may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit <u>macmillan.org.uk</u>

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

Need information in different languages or formats?
We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.



Patient Information Forum