MACMILLAN
CANCER SUPPORT

UNDERSTANDING BREAST CANCER IN WOMEN

> ‘I was very emotional and quite wobbly. I found it very difficult to deal with. And even though I am a strong person, I needed a lot of support.’

Rocio, diagnosed with breast cancer in 2014.

About this booklet

This booklet is about breast cancer in women. It is for women who are having tests for breast cancer and 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 a separate booklet called **Understanding secondary breast cancer** that we can send you.

Men can also get breast cancer, but this is rare. Our booklet **Understanding breast cancer in men** is about early and advanced breast cancer in men. See page 146 for ways to order this information.

How to use this booklet

The 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 on page 5 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 this booklet, there are details of other organisations that can help (see pages 151 to 155).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Quotes

Throughout this booklet, we have included quotes from people affected by cancer. Some are from our Online Community (**community.macmillan.org.uk**). The others are from people who have chosen to share their story with us. Some quotes are from Rocio, who is on the cover of this booklet. She has chosen to share her story with us. 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**, Monday to Friday, 9am 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, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Contents

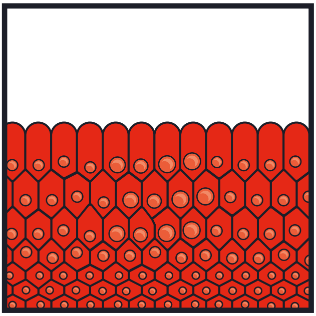
THE BREASTS AND BREAST CANCER

What is cancer?

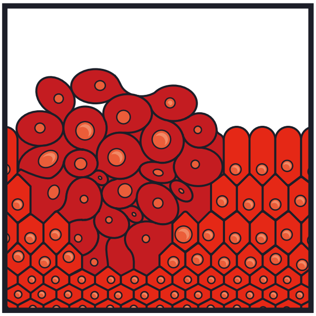
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can’t be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 12 to 13). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

The breasts

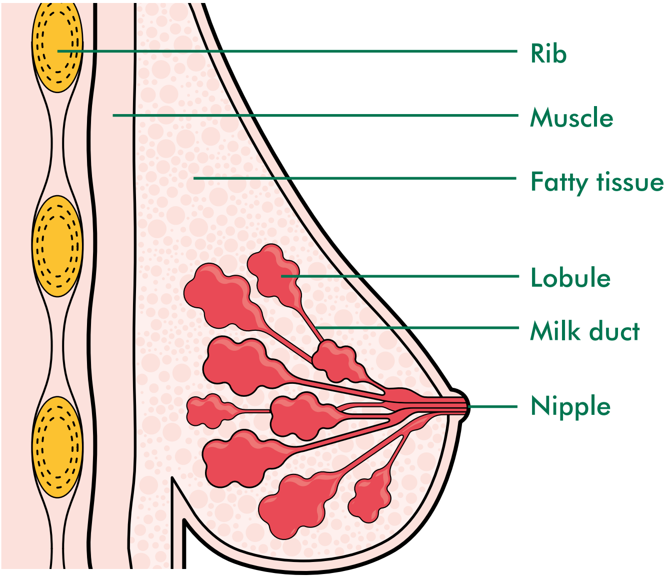
Breasts are made up of:

- fatty tissue
- supportive (connective) tissue
- glandular tissue containing lobes.

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

The tissue of the breast spreads into the lower armpit (axilla), which contains lymph nodes (glands). These are part of the lymphatic system, which protects us from infection and disease (see pages 12 to 13).

Side view of the breast



It is common for women's breasts to be a different size or shape from each other. Women who have periods may notice their breasts change at different times of the month. A woman's breasts also change through pregnancy and menopause. These changes are linked to the different levels of the hormones oestrogen and progesterone the body produces.

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

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

The lymphatic system

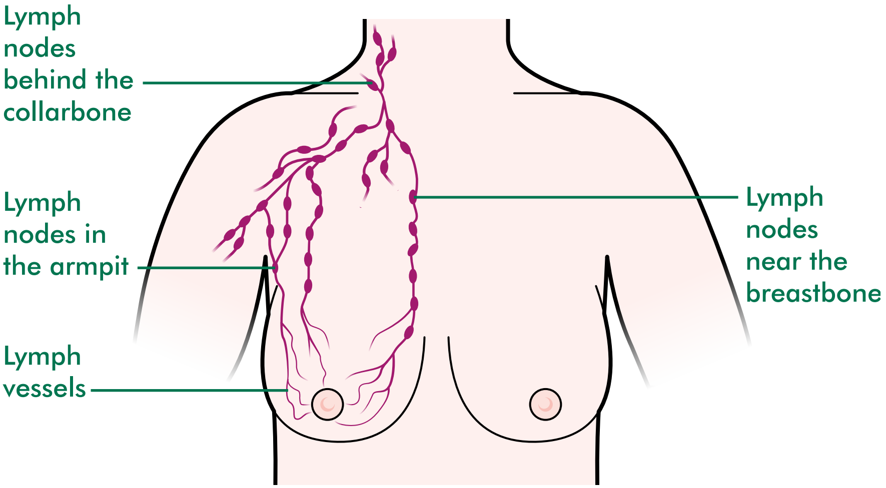
The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

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

Breast cancer and 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 tests (see pages 24 to 30) to look for cancer cells in the lymph nodes. There are also lymph nodes near the breastbone and above the collarbone.

The lymph nodes near the breasts



Risk factors and causes

Each year, about 55,000 women are diagnosed with breast cancer in the UK. It is more common in women who are aged 50 and over. But it can also affect younger women. Improvements in treatment mean more women are surviving breast cancer.

The exact cause of breast cancer is unknown. But certain things can increase your chance of developing it. These are called risk factors. Having one or more risk factors does not mean you will definitely get cancer. And if you do not have any risk factors, it does not mean you will not get breast cancer.

Breast cancer is likely to be caused by a combination of different risk factors, rather than just one.

Age

The strongest risk factor for breast cancer is increasing age. About 8 out of 10 women diagnosed (80%) are over the age of 50. Breast cancer is rare in women under 30.

Having had breast cancer before

Your risk is increased if you have had breast cancer or ductal carcinoma in situ (DCIS) before. In this case, you will have regular follow-up appointments (see page 110). Any changes in the same breast or the other breast can be checked quickly.

Breast conditions

Having certain breast conditions can also increase the risk of developing breast cancer:

- Lobular carcinoma in situ (LCIS). This is when there are abnormal cell changes in the lining of the lobules.
- Atypical ductal hyperplasia. This is when there are slightly abnormal-looking cells in the milk ducts in a small area of the breast.

Women with these non-cancerous (benign) conditions are usually monitored regularly, so any changes can be found early.

We have more information about these breast conditions on our website. Visit **macmillan.org.uk**

Dense breast tissue

Dense breast tissue is when the breast is mostly made of glandular and connective tissue with very little fatty tissue. Women whose mammograms show dense breast tissue have an increased risk of breast cancer compared with women whose mammograms show mainly fatty tissue.

Hormonal factors

The female hormones oestrogen and progesterone can affect your breast cancer risk. Factors that can increase your risk include the following:

- Taking hormone replacement therapy (HRT) for more than 5 years, especially if you are taking combined HRT (oestrogen and progesterone). When you stop HRT, your risk reduces again.
- Not having had children.
- Having had your first child after the age of 30.
- Not breastfeeding your children, or breastfeeding for less than a year in total.
- Starting your periods early (under the age of 12) or having a late menopause (after the age of 55).
- Taking the contraceptive pill. But the risk reduces if you stop taking it.

Family history and breast cancer risk

Most women who get breast cancer do not have a family history of it. Or if you have only one female relative diagnosed with breast cancer over the age of 40, your risk is unlikely to be very different from other women the same age as you.

But sometimes breast cancer can run in families. The chance of there being a family link is bigger when:

- a number of family members have been diagnosed with breast cancer or related cancers, such as ovarian cancer
- the family members are closely related
- the family members were diagnosed at a younger age
- a man in your family has been diagnosed with breast cancer.

Fewer than 1 in 10 breast cancers (10%) are thought to be caused by a change (alteration) in a gene running through the family. In hereditary breast cancer, BRCA1 and BRCA2 are the two genes most often found to have a change.

Women with triple negative breast cancer (see page 45) are sometimes offered genetic testing. This is offered even if they do not have a family history of breast cancer. Most breast cancers caused by a change in the BRCA1 gene are triple negative. Your 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 a booklet called **Cancer and genetics: how cancer sometimes runs in families** that has more information (see page 146)

Lifestyle factors

Certain lifestyle factors may slightly increase your breast cancer risk.

Being overweight

The risk of breast cancer is higher in women who are overweight, particularly after the menopause. This is because being overweight may change hormone levels in the body. Keeping to a healthy weight can help reduce the risk of breast cancer. We have information about keeping to a healthy weight (see page 117)

Alcohol

Regularly drinking alcohol increases your risk of developing breast cancer. But the risk is small for women who drink within the recommended guidelines (see page 120).

Smoking

Smoking may cause a slight increase in breast cancer risk. This seems to be linked with starting smoking at a younger age and smoking for a longer time. We have information on stopping smoking that has more information (see page 146).

Radiotherapy to the chest at a young age

Women who have had radiotherapy to the chest before the age of 30 (for example to treat Hodgkin lymphoma) have an increased risk of breast cancer.

Symptoms

It is important to see your GP if you have any of the following symptoms or notice anything that is unusual for you.

Possible signs and symptoms of breast cancer can include:

- a lump in the breast
- thickening of the skin or tissue of the breast, or dimpling of the skin of the breast
- a lump or swelling in either armpit
- a change in the shape or size of the breast, such as swelling in all or part of the breast
- a nipple turning in (inverted nipple)
- a rash (like eczema) on the nipple
- discharge or bleeding from the nipple
- pain or discomfort in the breast that does not go away, but this is rare.

> ‘I had been ignoring the fact that the shape of my breast had changed. It had always been lumpy and I just thought it was changes in my body because I was nearing the menopause.’
>
> **Beverley**

A lump in the breast is the most common symptom of breast cancer, but most breast lumps are not cancer. They are usually lumps either filled with fluid (a cyst) or made up of fibrous and glandular tissue (fibroadenoma).

But it is very important to get any of these symptoms or anything else that is unusual for you checked by your GP. The earlier breast cancer is diagnosed and treated, the more successful treatment is likely to be.

During pregnancy, a woman's breast tissue changes and sometimes a lump or another breast cancer symptom could be confused with this. If you are pregnant and have any of these symptoms, it is important to see your doctor. Your symptoms should be checked in the same way as in women who are not pregnant. Our booklet **Cancer and pregnancy** has more information that you may find helpful (see page 146).

> 'It is probably nothing, but if there is that chance there's something, early detection is the best prevention of anything bad happening. The treatment is hard, but it is better than losing your life.'
>
> **Annmarie**

> ‘I went to the hospital for an examination, but they did a biopsy too. I didn’t think that cancer could be the end result.’
>
> **Rocio**

DIAGNOSING BREAST CANCER

How breast cancer is diagnosed

You usually start by seeing your GP. They will examine you and refer you to a breast clinic to see a specialist. You should get an appointment for the breast clinic within 2 weeks.

Some women are referred through NHS breast screening programmes, because there are changes on their mammogram. Breast screening is a way of finding breast cancer at an early stage, when it is too small to be felt or seen.

At the breast clinic

At the clinic, you will see a specialist breast doctor or a nurse practitioner. You may also see a breast care nurse. They usually ask you if:

- you have had any other breast problems
- anyone in your family has had breast cancer.

The doctor or nurse will examine your breast and the lymph nodes (see pages 12 to 13) in your armpits and around your neck. After this, they will explain the tests you need.

You may have many of the tests on the same day, as well as getting the results. But you might have to wait up to 2 weeks for some results. You may also need to come back to the hospital for further tests.

Mammogram

A mammogram is a low-dose x-ray of the breast. You will need to undress down to your waist. The radiographer will position you so your breast is on the x-ray machine.

Next, your breast will be firmly pressed with a clear, plastic plate. This keeps your breast still and helps get a clear picture. You might find this uncomfortable or even painful. But this should only last for as long as the mammogram takes.

You will have two x-rays of each breast taken from different angles. This helps to makes sure as much of the breast is as x-rayed as possible. Women who have very large breasts might need extra x-rays to make sure all the breast tissue is included.

Mammograms are usually only used for women over the age of 40. In younger women, the breast tissue is more dense (has less fat). This makes it difficult to detect any changes on the mammogram. Women under the age of 35 are usually offered an ultrasound of the breast. But if you are under the age of 35 and are diagnosed with breast cancer, you may also have a mammogram.

Having a mammogram

Breast ultrasound

An ultrasound uses sound waves to build up a picture of the breast tissue. It can show if a lump is solid (made of cells) or if it is a fluid-filled cyst. It can also show whether a solid lump is regular or irregular in shape.

You will be asked to remove the clothes from the top half of your body. Then you lie down on a couch with your arm above your head. The person doing the scan puts a gel onto your breast tissue. They move a small device over the area. A picture of the breast tissue shows up on a screen. An ultrasound only takes a few minutes and is painless.

Ultrasound of the lymph nodes

You will also have an ultrasound of the lymph nodes in the armpit. If any of the nodes feel swollen or look abnormal on the ultrasound, the doctor will take a biopsy of them.

Breast biopsy

If an abnormal area is found in the breast, the doctor will need to take a sample of cells (biopsy). Most biopsies are done at the breast clinic on the same day you have your mammogram and ultrasound.

The doctor removes a small piece of tissue or a sample of cells from the lump or abnormal area. A doctor who specialises in studying cells (pathologist) looks at the sample under a microscope to check for cancer cells.

For a few days after the biopsy, your breast may feel sore and bruised. Taking painkillers and wearing a supportive bra will help with this. Any bruising will go away in a couple of weeks.

There are different ways of taking a biopsy. Your doctor or nurse will explain the type you will have.

Fine needle aspiration (FNA)

This is a quick, simple test. The doctor or a specialist nurse puts a very fine needle into the area and withdraws a sample of cells into a syringe.

Needle (core) biopsy

The doctor or a specialist nurse will do this test. They use a needle to take small pieces of tissue from the lump or abnormal area. Before taking the biopsy, they inject some local anaesthetic into the area to numb it. They may use ultrasound or a mammogram to help guide the needle to the right place.

You may feel a little pain or a sensation of pressure for a short time during the biopsy. They can take several samples at the same time.

Vacuum-assisted biopsy (VAB)

This is a way of taking needle biopsies using a vacuum-assisted method. The doctor gives you an injection of local anaesthetic into the skin to numb the area. They then make a small cut and put a needle through it into the breast. A mammogram or ultrasound picture helps them guide the needle to the right area.

The doctor places the needle, which is attached to a suction device, into the area. Using gentle suction, they remove the breast tissue into a small container. They can take several biopsies without needing to remove the needle and put it in again.

Excision biopsy

Occasionally, the doctor makes a cut in the skin and removes the lump or abnormal area. They usually do this under a general anaesthetic, but they can sometimes do it using local anaesthetic.

Usually, you have stitches that dissolve and do not need to be removed.

Wire localisation

Sometimes, an x-ray or ultrasound is used to guide a fine wire into the breast. The wire marks exactly where the surgeon should take the biopsy. This is usually done when a mammogram or ultrasound shows an abnormal area that is too small for the doctor to feel. The surgeon removes the wire when the excision biopsy is done.

Clip insertion

When a needle biopsy is done, sometimes a tiny metal marker or clip is placed where the biopsy was taken. The clip shows up in mammograms and marks the area where the biopsy was taken. This helps the surgeon find the exact area again if you need to have more breast tissue removed later on. The clip is very small and will not cause you any harm or discomfort, even if it is not removed. If a breast cancer is diagnosed, the clip is usually removed during surgery.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, family or a close friend. Your specialist nurse or one of the organisations listed on our database, can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Further tests

If the biopsy results show there are breast cancer cells, you will need more tests before you start treatment. You may have blood samples taken. This is to check your general health and how well your kidneys and liver are working. You may have an x-ray of your chest to check your lungs and heart.

You may also have other tests to find out more about the size and position of the cancer. Some women may have a bone scan and CT scan to check if the cancer has spread to other parts of the body.

The results of your tests will help you and your doctor decide on the best treatment.

MRI scan

An MRI scan uses magnetism to build up detailed pictures of your body. It may be done to find out the size of the cancer and help doctors decide which operation you should have. The MRI scan may show areas that your doctor would like to take a closer look at. Some women may have a second ultrasound and biopsy after the MRI.

An MRI scan is painless and takes about 30 minutes.

The scanner is a powerful magnet, so you will be asked to remove any metal belongings, including jewellery, before the scan. If you have any metal implants or have worked with metal or in the metal industry, tell your doctor.

Before the scan you may be given an injection of dye into a vein in your arm. This is called a contrast medium and can help the images from the scan to show up more clearly.

You will be asked to lie very still on a couch, inside a metal cylinder. The scan is noisy, so you will be given earplugs or headphones.

Bone scan

This test shows up abnormal areas of bone. You have a small amount of a radioactive substance injected into a vein. You will need to wait for 2 to 3 hours after the injection before you have the scan. The scan may take an hour. Abnormal bone absorbs more radioactivity than normal bone and shows up on the scan pictures.

The amount of radioactive substance used is small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan. After this, your body will have got rid of the radioactivity in your urine.

If you are pregnant or breastfeeding, it is important to phone the scanning department before the test for advice.

If you are travelling through an airport in the days following your scan, you could take your appointment letter with you. Some airport scanners may detect the small amounts of radiation in your body.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–20 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

Having a CT scan

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)

This is the earliest form of breast cancer. In DCIS there are cancer cells in the ducts of the breast (see page 10) but these cells are contained (in situ). They have not spread into normal breast tissue.

DCIS may show up on a mammogram and is commonly diagnosed when women have breast screening.

We have a booklet called **Understanding ductal carcinoma in situ (DCIS)** that has more information (see page 146).

Lobular carcinoma in situ (LCIS)

LCIS is not breast cancer. There are changes in the cells lining the lobes. These show a woman has a small increased risk of developing breast cancer later in life. But most women with LCIS do not get breast cancer. We have separate information about LCIS on our website. Visit **macmillan.org.uk**

Invasive breast cancer

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

No special type (NST)

This includes ductal invasive breast cancer, which is the most common type of breast cancer. About 7 to 8 out of 10 of all breast cancers (70% to 80%) are this type.

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

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.

Other types of breast cancer

Invasive lobular breast cancer

About 1 in 10 invasive breast cancers (10%) start in the lobes of the breast. This type can sometimes be difficult to diagnose on a mammogram because of the way it grows. Some women may need an MRI scan (see pages 31 to 32).

Inflammatory breast cancer

This is when cancer cells grow along 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 on our website about these types of breast cancer. Visit **macmillan.org.uk**

Staging and grading for breast cancer

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

- the stage of the cancer
- the grade of the cancer
- whether the cancer has receptors (see pages 44 to 45) for hormones or a protein called HER2.

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

- the biopsy, when the tissue was examined
- other tests that were done on the cells.

Your specialist doctor and nurse will talk to you about this. They will explain how it helps you and your doctor decide on your treatment plan.

Staging

The stage of a cancer describes its size and whether it has spread from where it started. There are different systems for describing 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 (see pages 12 to 13) and which nodes are involved. For example, N0 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. For example, M0 means the cancer has not spread (metastasised) to other parts of the body.

Sometimes the final TNM staging may not be certain until after surgery to remove the cancer (see pages 56 to 77) .

The number staging system

Breast cancer can also be divided into four number stages. This is done by grouping the TNM staging together to give an overall number stage.

We have a table over the next two pages that explains the number staging system in more detail.

Stage 1 or 2 breast cancer is often called early breast cancer. Stage 1 is divided into two stages.	
Stage 1A	• The cancer (lump) 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 (micrometastases) have spread to lymph nodes in the armpit.
Stage 2 is divided into two stages.	
Stage 2A	• The cancer cannot be found in the breast or the cancer is 2cm or smaller. It has also spread to 1 to 3 lymph nodes in the armpit or near the breast bone. **Or** • The cancer is between 2cm and 5cm and has not spread to the lymph nodes in the armpit.
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 three 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 (see page 36).	
Stage 3A	• The cancer cannot be found in the breast, or the cancer is 5cm or smaller. It has spread to 4 to 9 lymph nodes in the armpit. **Or** • The cancer is bigger than 5cm. It is in up to 3 lymph nodes in the armpit or near the breast bone.
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 has spread to 10 or more lymph nodes in the armpit. **Or** • The cancer has spread to lymph nodes below the breast bone, above or below the collar bone and to 4 or more lymph nodes in the armpit.
Stage 4 breast cancer is also called secondary or metastatic breast cancer. We have a booklet called Understanding secondary breast cancer (see page 146).	
Stage 4	• The cancer has spread to other parts of the body, such as the bones, liver or lungs.

Grading

The grade of a cancer gives an idea of how slowly or quickly it might grow. The grade is based on how the cancer cells look under a microscope compared with normal cells. The cells are examined by a doctor called a pathologist, who studies tissue samples and is an expert in cell types.

Grade 1 (low-grade cancer)

The cancer cells look similar to normal cells (they are 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 and grow slightly faster than grade 1 cells.

Grade 3 (high-grade cancer)

The cancer cells look very different from normal cells (they are poorly differentiated). They may grow more quickly than grade 1 or 2 cells.

Receptors

Breast cancer cells may have receptors (proteins) that hormones or a protein called HER2 can attach to and encourage the cells to grow. A pathologist (see page 53) tests the cancer cells that were taken during the biopsy or surgery for these receptors.

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, particularly oestrogen, can encourage breast cancer cells to grow.

Breast cancer that has receptors for the hormone oestrogen is called oestrogen receptor-positive (ER-positive) breast cancer. The term ER is used because the American spelling of oestrogen is estrogen. About 70% of breast cancers are ER-positive. Hormonal therapies (see pages 96 to 101) work well for ER-positive breast cancer.

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

Breast cancer cells may also have receptors for the hormone progesterone (PR-positive).

Receptors for HER2

Some breast cancers have too much of a protein (receptor) called HER2 (human epidermal growth factor receptor 2) on the surface of their cells. This is called HER2-positive breast cancer. The extra HER2 protein encourages the cancer cells to divide and grow.

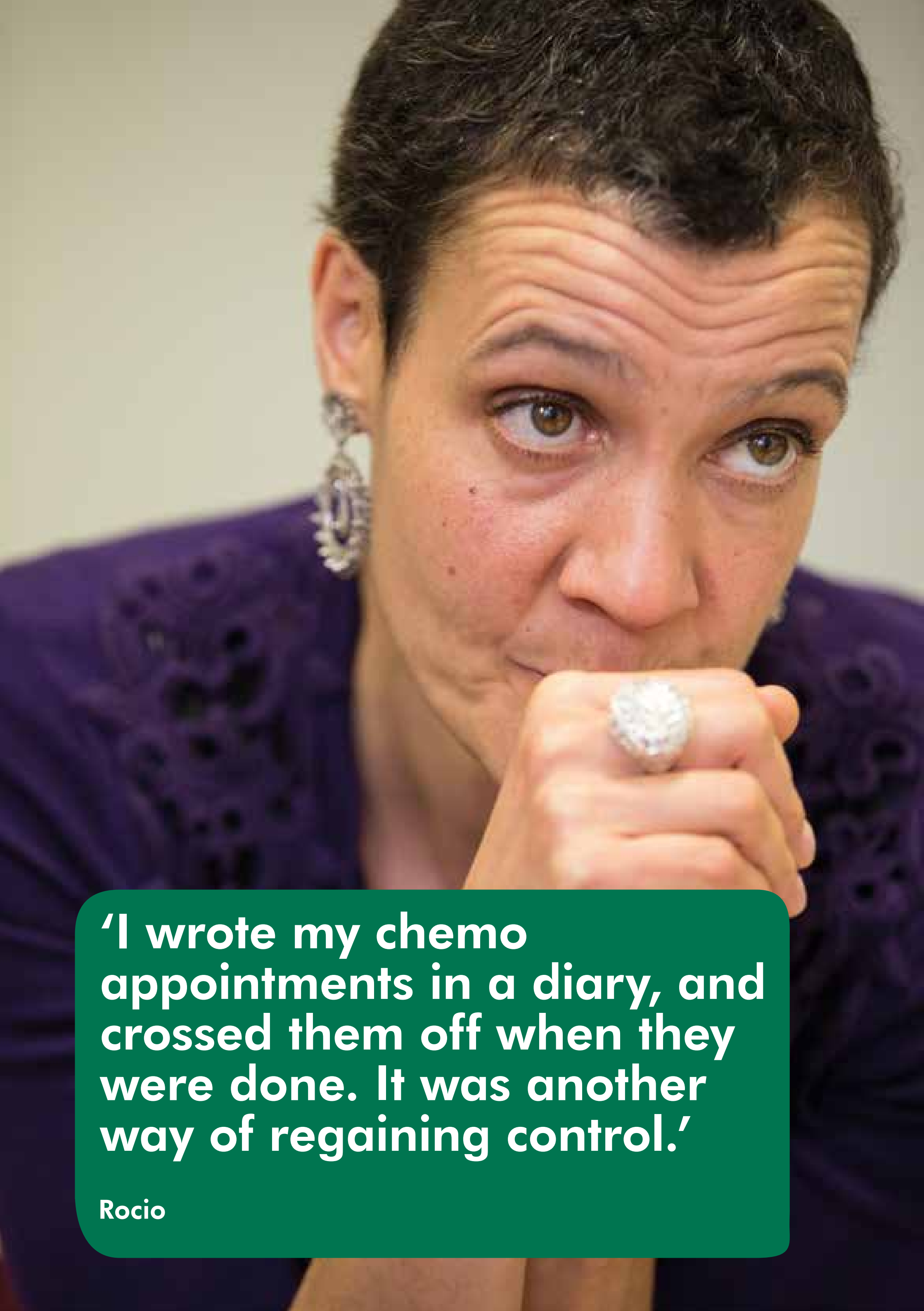
Between 15 and 20 out of every 100 women with breast cancer (15 to 20%) have HER2-positive cancers.

Specific targeted therapy drugs (see pages 102 to 105) are used to treat HER2-positive breast cancer. They lock on to the HER2 protein and stop the cells 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. It affects up to 1 in 5 women (15 to 20%) with breast cancer and is more common in younger women.

We have more information about triple negative breast cancer on our website – visit **macmillan.org.uk**



‘I wrote my chemo appointments in a diary, and crossed them off when they were done. It was another way of regaining control.’

Rocio

TREATING BREAST CANCER

Treatment overview

The first treatment for breast cancer is often surgery (see pages 56 to 76) to remove it. After surgery, you may have treatments to reduce the risk of the cancer coming back. These treatments include radiotherapy (see pages 78 to 85), hormonal therapy (see pages 96 to 101), chemotherapy (see pages 86 to 95) and targeted therapy drugs, such as trastuzumab (see pages 102 to 105). Some women have treatments before they have surgery.

Drugs called bisphosphonates (see pages 106 to 107) are sometimes given to reduce the risk of breast cancer coming back. They can also be used to protect your bones from the side effects of treatments, such as hormonal therapies.

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
- if the cancer cells have oestrogen receptors (ER positive)
- if the cancer has HER2 receptors (HER2 positive)

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

Treatments for breast cancer are improving. Better treatments mean that more women are cured or living longer. Your cancer doctor may ask you if you would like to take part in a research trial. We have a booklet called **Understanding cancer research trials (clinical trials)** which explains this in more detail.

Treatment before surgery

You may have treatments such as chemotherapy or hormonal therapy before surgery. This is to shrink the cancer and make it easier to remove, or if the cancer is growing more quickly.

Surgery

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

- breast-conserving surgery – this is where the cancer and some surrounding normal breast tissue is removed
- a mastectomy – this is when the whole breast is removed.

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

Some women also have surgery to make a new breast shape (breast reconstruction – see page 61) during the operation. Others choose to have this done at a later time.

Treatment after surgery

Your cancer doctor will usually offer you one or more of the following treatments after surgery. These treatments can reduce the risk of the cancer coming back.

Your cancer doctor and specialist 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 women and their doctors make informed decisions about treatment after surgery for breast cancer.

It can show how much treatments may reduce the risk of the cancer coming back. You might find it helpful, especially if your cancer doctor has asked you to decide about whether to have chemotherapy.

Sometimes, doctors may suggest having a tumour profiling test (see page 52) 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 (see pages 12 to 13).

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 oestrogen-receptor (ER) positive, you will be given hormonal therapy for a few years. The drug or treatment you have will depend on if you have been through the menopause or not.

Targeted therapy

If you have HER2 positive breast cancer, you will usually be given a targeted therapy drug called trastuzumab. You may also have a drug called pertuzumab (Perjeta®).

Treatments and fertility

Some treatments for breast cancer can affect your fertility (see pages 115 to 116). This may be temporary, but for some women it can be permanent. Before treatment starts, your doctors and nurses will talk to you about this. If your treatment could affect your fertility, they will explain what may be done to help preserve your fertility.

Tumour profiling tests

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

If the results show a low risk of the cancer coming back, it means you may not need chemotherapy. Your cancer doctor or specialist nurse can tell you more about this. Your cancer doctor may suggest having tumour profiling tests if you have breast cancer that:

- is ER positive cancer and HER2 negative
- has not spread to the lymph nodes
- is in an intermediate risk group (between low risk and high risk) for the cancer coming back in another part of the body.

There are different tumour profiling tests. You are likely to have Oncotype DX, EndoPredict or Prosigna if you are having treatment on the NHS. Your cancer doctor or specialist 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

A team of specialists meet to discuss the best treatment options for your situation. This multidisciplinary team (MDT) includes:

- a surgeon, who specialises in breast surgery and may do breast reconstruction surgery
- a plastic surgeon, who specialises in breast reconstruction
- a cancer doctor (oncologist), who specialises in chemotherapy, radiotherapy, hormonal therapy and targeted therapy
- a specialist nurse, who gives information and support
- a radiologist, who specialises in x-rays and scans
- a pathologist, who specialises in studying tissue samples and cells.

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

After the MDT meeting, your cancer doctor or specialist nurse will talk to you about the treatment options. You can decide together on the best treatment plan for you.

> ‘I had four people sit with me and each individual told me what they were going to do and the role they played.’
>
> **Sandra**

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Surgery

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

- the size of the cancer
- the position of the cancer
- what you prefer.

Your surgeon and specialist 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 called a wide local excision (WLE). It may also be called a 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 (mastectomy). You can usually choose to have breast reconstruction at the same time as a mastectomy or later. Breast reconstruction is making a new breast shape. Some women may decide not to have it at all.

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

You may have hormonal therapy or chemotherapy before your operation. The aim is to shrink the cancer to try to avoid a mastectomy.

Wide local excision (breast-conserving surgery)

The surgeon removes the cancer and some normal looking tissue around it (the margin). This is called a wide local excision (WLE). You might also hear it called a lumpectomy. After a WLE, most women are pleased with the appearance of their breast.

If the cancer is very small, you may need to have a fine wire put into the breast before surgery. This marks the area to be removed and means the surgeon can find it more easily. This is called wire localisation. The wire is then removed along with the area of cancer during the operation.

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.

Surgeons can use different ways to help improve the appearance of your breast if you need a larger area of tissue removed. They may reshape the breast by moving the breast tissue around and making it smaller. Sometimes, they take tissue from somewhere else in the body to help reshape the breast.

Your surgeon may suggest you have the other breast made smaller so that both breasts are the same size. This can be done at the same time as surgery or later.

Radiotherapy after breast-conserving surgery

Your surgeon will usually advise you to have radiotherapy (see pages 78 to 85) after breast-conserving surgery. Radiotherapy after a WLE reduces the risk of the cancer coming back in the breast.

Having breast-conserving surgery, followed by radiotherapy, is as effective at treating breast cancer as a mastectomy.

Clear margins

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

- there is DCIS (the earliest possible form of breast cancer) 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 will reduce 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 (called multifocal breast cancer)
- there is widespread DCIS (see page 34) in the breast.
- you have had radiotherapy to the chest before to treat another cancer, such as a previous breast cancer or Hodgkin lymphoma
- you have a family history of breast or ovarian cancer.

> ‘It was a hard decision as I really didn’t want a breast removed, but I have a young family and did not want to leave any doubt.’
>
> **Asma**

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 immediate breast reconstruction. You can choose to delay breast reconstruction until after you have finished radiotherapy or chemotherapy.

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

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. You do not have to make a definite decision at this point, but it will help the surgeon to plan your mastectomy.

Breast reconstruction is specialised surgery done by a plastic surgeon or oncoplastic surgeon. There are different types of reconstruction. A new breast shape can be made using:

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

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.

We have a booklet called **Understanding breast reconstruction** which has more information (see page 146).

Choice of treatment

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

Your surgeon and specialist 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 (see page 114) 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 may 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 one operation to get clear margins.
- You need at least 3 weeks of radiotherapy after surgery (some women will also need radiotherapy after a mastectomy).
- Radiotherapy has short-term side effects. Some women may also have long-term side effects.

Mastectomy

Advantages

- You may not need radiotherapy after a mastectomy. But some women will need it. Ask your cancer doctor about this.
- You may feel less worried after the operation because the breast tissue has been removed.

Disadvantages

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

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

Talking to other women who have already had surgery can also help. Your specialist 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 on our Online Community or at the Breast Cancer Care online forum. Visit **community.macmillan.org.uk** or **forum.breastcancercare.org.uk**

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:

- remove any lymph nodes that contain cancer cells (you may need more treatment if only some lymph nodes were removed)
- give information about the stage of the cancer, which helps when making decisions about having other treatments.

There are different types of lymph node surgery.

Sentinel lymph node biopsy (SLNB)

A sentinel lymph node biopsy (SLNB) is a way of checking the lymph nodes in the armpit. It is not suitable for everyone. You may have an SLNB if the ultrasound, or fine needle aspirate of your armpit was normal.

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

During an SNLB, surgeons remove the smallest number of lymph nodes possible (usually 1 to 3) to see if they contain cancer cells. Removing only a small number of lymph nodes reduces the risk of side effects that can happen after lymph node surgery. These include swelling of the arm known as lymphoedema and stiffness of the arm and shoulder.

The lymph nodes that are the most likely to have cancer cells in them are called the sentinel lymph nodes. These are the first ones that lymph fluid drains to from the breast.

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 lymph 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 women have radiotherapy to the rest of the lymph nodes instead of more surgery.

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

How an SLNB is done

Before the sentinel lymph nodes can be removed, the surgeon needs to check which nodes are the sentinel lymph nodes.

Before the surgery, the surgeon injects a harmless amount of radioactive liquid into your breast. During the operation, they use a handheld machine to find the lymph nodes that have picked up the radioactive liquid. The surgeon may also inject a blue dye into your breast during the operation. This stains the sentinel lymph nodes blue. The lymph nodes that pick up the radioactive liquid or become blue first are the sentinel lymph nodes.

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

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 clearance. It aims to remove any nodes within the area close to the cancer, that contain cancer cells.

An ALND is usually done when:

- there are cancer cells in the fine needle aspiration (FNA) or biopsy of the lymph nodes
- the SLNB or sampling shows there are cancer cells in the lymph nodes.

There is an increased risk of developing swelling of the arm called lymphoedema after having an ALND. We have more information about lymphoedema and taking care of your arm on pages 112 to 113.

Before your operation

Before your operation, you may be seen at a pre-assessment 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 specialist nurse will talk to you about how your breast will look after your surgery. They may show you photographs of other women who have had breast surgery. They may also put you in contact with someone who has had the same operation. Or you can contact a local support group or Breast Cancer Care (see page 151).

You will usually come into hospital on the day of your operation. You will meet the doctor who gives you the anaesthetic (anaesthetist).

The nurses may give you elastic stockings (TED stockings) to wear during and after the operation to help prevent blood clots.

After your operation

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

Most women who have breast cancer surgery can go home the same day or the following day. If you have breast reconstruction at the same time as a mastectomy, you will stay in hospital for longer (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. The nurses will tell you how to look after it before you go home.

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 and do not need to be removed. If you do not have stitches that dissolve, they are usually removed about 7 to 10 days after your operation. You can arrange this with your practice or district nurse, or it may happen at your outpatient appointment.

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 drain is usually left in for a few days. You can go home with the drain still in place. A practice nurse or a district nurse may check 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 lymph nodes removed, 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. Your specialist nurse will usually give you the painkillers to take. If you have had a mastectomy, you may need painkillers for 1 or 2 weeks. Tell your cancer doctor or specialist 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
- redness
- swelling around the wound or discharge coming from it
- feeling unwell with a fever.

Tell your nurse or 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, or very close to, the wound. 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 you are worried about swelling that does not seem to be going away. Your cancer doctor or breast care nurse may need to drain the fluid with a needle and syringe. This may cause some discomfort when it is being done.

Stiff shoulder or arm

After a mastectomy or having lymph nodes removed, your shoulder or arm may feel sore or stiff.

Your physiotherapist or nurse will show you some arm exercises to do. This will help improve the movement in your shoulder and arm, and 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 this until you can move your arm as well as you could before your operation.

Breast Cancer Care have 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 during or after the operation. It may slowly improve over a few months, but it can sometimes be permanent. Talk to your surgeon or specialist nurse if you are worried.

Cording

If you had surgery to remove lymph nodes in the armpit, you may develop cording (or axillary web syndrome) after the operation. This 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 one. 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 because of changes in the lymphatic vessels after surgery.

If you are worried, ask your specialist nurse for advice. Cording often gets better on its own, but you may need to see 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, **Managing the late effects of breast cancer treatment** (see page 146).

How your breast looks

It is common to have some swelling and bruising around the breast after your operation. This should improve after a few weeks. If it does not, tell your specialist nurse.

Wearing a crop top or sports bra might feel more comfortable until the swelling goes down. You will need to wear a supportive bra in hospital after your surgery and when at home. Some hospitals recommend wearing a bra all the time in the first few weeks. This can help to support the breast and reduce bruising. It can help to get some advice from your breast care nurse about this.

If you had an SLNB (see pages 65 to 71), you may see the blue dye in your skin for a few weeks. This is normal.

Scars

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

Scars from breast-conserving surgery are usually small, but it depends on the size of the tissue that was 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 the scar as small as possible so it is less noticeable.

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

If you have pale skin, your scar will be red immediately after your operation. If you have dark skin, your scar will be darker. The scar will also be firm and slightly raised. Over time, it will flatten and fade. Everyone's skin heals differently. If you have dark skin or fair, freckled skin, scars can take longer to fade. This means they may be more noticeable for longer.

If you are worried about your scar, talk to your specialist nurse or surgeon. We have more information about scarring after breast reconstruction in our booklet **Understanding breast reconstruction** (see page 146).

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 specialist 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.

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 or less feminine. This may also affect your sex life. Some women find that breast reconstruction can help give them back their confidence and feelings of femininity.

We have a booklet called **Body image and cancer** that has more information (see page 146).

Breast prosthesis

If you do not have breast reconstruction at the same time as mastectomy, your specialist nurse will give you a prosthesis (false breast) to wear inside your bra. The prosthesis is soft and lightweight. It is often called a comfie or softie. You can wear it straight after your operation.

When your wound has healed, usually about 6 weeks after your surgery, you can choose a permanent prosthesis made of soft plastic (silicone). It will be matched to the size and shape of your other breast and your skin colour. Many women find their confidence gradually improves as they get used to it.

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

When you get home

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

Some insurance policies give specific time limits for not driving after surgery. Contact your insurance company to let them know you have had an operation. Most people are ready to drive about 4 weeks after their operation. 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 specialist nurse. You should carry on with the exercises you were shown 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 specialist nurse to check your wound is healing properly. They will also tell you about the tissue removed during surgery (pathology) and the stage of the cancer.

If you had a WLE, your surgeon will explain whether the margins around the cancer were clear or if you need another operation. Sometimes cancer cells are found very close to, or in, the margin. Although this can be upsetting news, it can usually be treated successfully.

The surgeon and specialist nurse will also talk to you about any further treatment you need. This may be radiotherapy, chemotherapy, targeted therapy or hormonal therapy. In some situations, your doctors may discuss having a tumour profiling test (see page 52) to help decide about having chemotherapy.


A

Late effects of surgery

Some women may have problems with the effects of surgery for months or longer after their operation. Tell your specialist 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 specialist 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 because of swelling or injury 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

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

Lymphoedema

Surgery or radiotherapy to the lymph nodes in the armpit can cause swelling of the arm (lymphoedema – see pages 112 to 113). If you notice any swelling in your arm or breast, speak to your specialist nurse or cancer doctor. Treatment can be more effective if it starts earlier. We have more information on reducing the risk of lymphoedema.

We have a booklet called **Managing the late effects of breast cancer treatment** that has more information (see page 146).

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells.

Normal cells can also be damaged by radiotherapy, which may cause side effects. But careful planning and newer ways of giving radiotherapy have reduced the risk of damage to healthy tissue and nearby organs. 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. Some women may have radiotherapy as part of a research trial.

Having radiotherapy

Radiotherapy after breast-conserving surgery

If you have breast-conserving surgery, your cancer doctor will recommend you have radiotherapy to the breast afterwards.

You usually start radiotherapy 4 to 6 weeks after surgery. If you are also having chemotherapy, radiotherapy is given after chemotherapy.

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

Radiotherapy after a mastectomy

You may still need radiotherapy to the chest after a mastectomy. 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 lymph nodes from your armpit and they contained cancer cells, you may have radiotherapy to the rest of the lymph nodes. Some women also have radiotherapy to the lymph nodes above the collarbone and lymph node close to the breastbone.

Having radiotherapy

You will have radiotherapy as an outpatient. It is usually given using equipment that looks like a large x-ray machine. You might hear it called external beam radiotherapy (EBRT).

You usually have radiotherapy as a series of short, daily treatments. These are called sessions. The treatments are given from Monday to Friday, with a rest at the weekend. The person who operates the machine is called a radiographer. They will give you information and support during your treatment.

You usually have radiotherapy for 3 weeks. Women who had breast-conserving surgery may have an extra dose (booster dose) to the area where the cancer was. Sometimes the booster dose is given at the same time as radiotherapy to the rest of the breast. Or it may be given at the end of the 3 weeks. This means you will need a few more treatments. Your doctor will tell you how many treatments you will need.

If you have radiotherapy to your left breast, you may 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. It keeps you still and also moves your heart (which is behind your left breast) away from the treatment area. DIBH helps protect your heart during your treatment and reduces the risk of late effects.

Some women may have intensity-modulated radiotherapy (IMRT). This is another type of external beam radiotherapy. It shapes the radiotherapy beams and allows different doses of radiotherapy to be given to different areas. This means lower doses of radiotherapy are given to healthy tissue surrounding the tumour.

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

Radiotherapy to part of the breast

Less commonly, some women are given radiotherapy to part of the breast instead of the whole breast. There are different ways of doing this.

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

Internal radiotherapy

Some women are given radiotherapy from inside the body instead of to the whole breast. This is called brachytherapy and 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 is usually during a stay in hospital or given 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 from inside the body (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 from a special machine.

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

Intrabeam radiotherapy is not suitable for everyone and is not widely available on the NHS. The National Institute for Health and Care Excellence (NICE), which only covers England and Wales, have approved its use, but not as standard treatment. It should only be used in hospitals that already have intrabeam machines.

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 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. If you are worried about them, talk to your radiographer.

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. 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, your 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. There is usually an intercom, so you can talk to them if you need to during your treatment.

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

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. After treatment finishes, it may be 1 to 2 or weeks before side effects start getting better. After this, most side effects usually slowly go away.

Your cancer doctor, specialist 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

Your skin in the treatment area may get red, dry and itchy. Dark skin may get darker or have a blue or black tinge. Your specialist 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 start to improve 2 weeks after radiotherapy finishes.

Here are some tips:

- Do not put anything on your skin in the treatment area without checking with your specialist or radiographer.
- Have cool or warm shower rather than a bath if you can. Turn away from the spray to protect the treated area.
- Pat the area dry gently with a soft towel – do not rub.
- Wear loose clothing that is less likely to irritate your skin.

You need to avoid exposing the treated area to the sun for at least a year after treatment finishes. Use suncream with a high sun protection factor (a minimum of 30 SPF) to protect your skin if it is exposed.

Tiredness

This is a common side effect that may last for up to 2 months after treatment. Try to get plenty of rest and pace yourself. Balance this with some physical activity, such as going for short walks, which will give you more energy.

Aches and swelling

You may have a dull ache or shooting pains in the treated area that last for a few seconds or minutes. You may also notice that the area becomes swollen. These effects usually improve quickly after treatment. You might still have aches and pains in the area after radiotherapy.

Late effects of radiotherapy

Radiotherapy to the breast may cause side effects that happen months or years after radiotherapy. They are called late effects. Newer ways of giving radiotherapy are helping reduce the risk of these late effects happening. If you are worried about late effects, talk to your cancer doctor or specialist nurse.

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

Radiotherapy can damage small blood vessels in the skin. This can cause red, spidery marks (telangiectasia) to show.

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.

It is rare for radiotherapy to cause heart or lung problems, or problems with the ribs in the treated area. This usually only happens if you had treatment to your left side. Tell your cancer doctor if you notice any problems with your breathing, or have any pain in the chest area.

Our booklet **Understanding radiotherapy** has more information about radiotherapy and what to expect (see page 146).

Chemotherapy

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

When you have chemotherapy

Chemotherapy for breast cancer can be given either before or after surgery to remove the cancer. Your cancer doctor or specialist nurse will talk to you about the benefits of chemotherapy in your situation and explain the likely side effects.

Before surgery

You may be offered chemotherapy before surgery if the cancer is large or is growing more 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.

Chemotherapy is given to:

- shrink the size of the cancer – if it works well, you may only need the cancer removed instead of the whole breast
- reduce the risk of the cancer coming back.

After surgery

Your cancer doctor may recommend you have chemotherapy after surgery to reduce the risk of breast cancer coming back. This is called adjuvant chemotherapy. Your cancer doctor or specialist nurse will explain the benefits of this to you and the likely side effects.

Having chemotherapy

You are usually offered chemotherapy if the cancer:

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

How chemotherapy is given

You usually have chemotherapy in a chemotherapy day unit. Most drugs are given into a vein (intravenously), but some are given as tablets.

The nurse gives you chemotherapy drugs into a vein by injection or as a drip (infusion). It can be given through:

- a cannula – a short, thin tube put into a vein in your arm or the back of your hand
- a central line – a long, thin tube inserted into a vein in your chest
- a PICC (peripherally inserted central venous catheter) line put into a vein in the arm and threaded through to a vein in the chest
- an implantable port (portacath) that is put into a vein, with an opening (port) under the skin on your chest or arm.

Chemotherapy is often given as a few sessions of treatment. Each session takes a few hours. After the session, you have a rest period of a few weeks. The chemotherapy and the rest period is called a cycle of treatment.

The length of a cycle depends on the chemotherapy drugs you are taking. Most cycles are 1 to 3 weeks. Your cancer doctor or specialist 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 often includes drugs called:

- anthracyclines – such as epirubicin and doxorubicin (Adriamycin®)
- taxanes – such as docetaxel (Taxotere®) and paclitaxel (Taxol).

These drugs are commonly used in combination with other chemotherapy drugs, including fluorouracil (5FU) and cyclophosphamide.

Some commonly used combinations include:

- FEC – fluorouracil (5FU), epirubicin and cyclophosphamide
- FEC-T – FEC followed by docetaxel
- AC – doxorubicin (Adriamycin) and cyclophosphamide
- EC – epirubicin and cyclophosphamide
- TC – docetaxel and cyclophosphamide
- carboplatin and paclitaxel
- EC-T – epirubicin and cyclophosphamide followed by docetaxel
- EC-P – epirubicin and cyclophosphamide followed by paclitaxol
- FEC-P – fluorouracil (5FU), epirubicin and cyclophosphamide followed by paclitaxel (carboplatin may sometimes be added to this combination).

We have more information on all of these drugs on our website. Visit **macmillan.org.uk**

Your cancer doctor may offer you a choice of chemotherapy treatments. If so, you will be given more information to help you decide.

If you have HER2 breast cancer, you may have a targeted therapy called trastuzumab (Herceptin®) with your chemotherapy.

Sometimes the targeted therapy drug pertuzumab (Perjeta®) is given in combination with trastuzumab and chemotherapy. The combination may be used before surgery if there is a high risk of the cancer coming back.

Anthracycline chemotherapy drugs are not usually given at the same time as trastuzumab because they can both affect the heart. Your cancer doctor or specialist nurse can give you more information about this.

Side effects

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines and will usually go away once treatment has finished.

Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that's planned for you. The main side effects are described here as well as some ways to reduce or control them.

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 called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have 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.

Symptoms of an infection include:

  - feeling shivery
  - a sore throat
  - a cough
  - diarrhoea
  - needing to pass urine often.

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.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor or nurse if you have any bruising or bleeding that you can't explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red bloods cells in your blood. These cells carry oxygen around your body. If the number of red cells is low you may feel tired and breathless. Tell your doctor or nurse if you feel like this.

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

You may feel sick in the first few days after chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. 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 and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Feeling tired

Feeling tired (fatigue) is a common side effect. 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 operate machinery.

Hair loss

You usually lose all the hair from your head. You may also lose your eyelashes, eyebrows or 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. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is usually temporary, and your hair will usually grow back after treatment ends. But rarely, the hair loss is permanent. Hair may not grow back or it may be thinner than before. If you are worried about this, talk to your cancer doctor or nurse.

> ‘I have a lovely shaped head and scalp and am enjoying trying out scarves, hats and wigs. Some were lent to me by a dear friend who has been on the same journey.’
>
> **Jan**

Sore mouth

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

If your mouth is sore:

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

Bowel changes

Chemotherapy can cause constipation or diarrhoea. Constipation can usually be helped by drinking plenty of fluids, eating more fibre in your diet and doing some gentle exercise. You may need to take medicine to help (laxatives). Your doctor can prescribe these or you can buy them at a pharmacy.

Diarrhoea can usually be easily controlled with medicine, but tell your doctor if it is severe or continues. It is important to drink plenty of fluids if you have diarrhoea.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment affects the nerves, which 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 while having chemotherapy, and for some time afterwards. This is because the chemotherapy drugs could harm a developing baby. It is important to use effective contraception. You can discuss this with your cancer doctor or specialist nurse.

Early menopause

Younger women may find chemotherapy brings on an early menopause, which can be difficult to cope with. We have more information about early menopause (see page 116).

Fertility

If you are worried about the effect chemotherapy may have on your fertility (see pages 115 to 116), it is important to talk about this with your cancer doctor before treatment starts. There are different options that may help women to preserve their fertility. This includes freezing eggs or embryos (fertilised eggs).

Hormonal therapy

Hormones help control how cells grow and what they do in the body. The hormones oestrogen and progesterone, particularly oestrogen, can encourage some breast cancers to grow.

Hormonal therapies reduce the amount of oestrogen in the body or stop it attaching to the cancer cells. They only work for women with oestrogen-receptor (ER) positive cancers.

Your cancer doctor will advise you to take hormonal therapy to reduce the risk of the breast cancer coming back. It also helps reduce the risk of getting a new breast cancer in your other breast. Sometimes hormonal therapy drugs are given before surgery to shrink a cancer and avoid a mastectomy.

You usually take hormonal therapy drugs for a number of years. For some women, this could be 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 or not
- the risk of the cancer coming back
- how the side effects are likely to affect you.

We have more information about individual hormonal therapy drugs on our website. Visit **macmillan.org.uk**

Taking your hormonal therapy

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

Most women cope well with the side effects of hormonal therapy. They may be more of a problem in the first few months, but usually get better over time. If the side effects do not improve or are difficult to cope with, talk to your specialist nurse or cancer doctor. They can prescribe drugs to help and suggest ways of coping. If you are still having problems after this, then your cancer doctor may suggest changing to a different type of hormonal therapy.

Types of hormonal therapy

Tamoxifen

Tamoxifen is an anti-oestrogen drug that stops oestrogen attaching to breast cancer cells and making them grow. It is usually given to women who have not been through the menopause. Some women take it for a few years and then go on to take an aromatase inhibitor (see pages 98 to 99).

Tamoxifen can also be given to women who have been through the menopause and have a low risk of the cancer coming back. Or it may be prescribed for post-menopausal women who have problems with their bones. Tamoxifen does not cause bone thinning in women who have been through the menopause. If you have bad side effects with aromatase inhibitor drugs, you may be given tamoxifen instead.

Tamoxifen is taken daily as a tablet.

The side effects are similar to the effects of the menopause and may include:

- hot flushes and sweats
- weight gain
- tiredness.

Tamoxifen can slightly increase the risk of a blood clot. In post-menopausal women, it can slightly increase the risk of womb cancer. It is important to tell your cancer doctor if you have any vaginal bleeding. We have more detailed information about these side effects.

Your cancer doctor may advise you to take tamoxifen for 5 to 10 years. If you are close to menopause when you start taking it, your doctor may change you to an aromatase inhibitor after a few years of taking tamoxifen. They may do blood tests to check your hormone levels first.

There may be situations where continuing with tamoxifen may not be suitable. If any side effects of tamoxifen become a problem, you may need to take a different hormonal therapy.

Women who want to get pregnant must stop taking tamoxifen because it can harm an unborn baby. Talk to your cancer doctor or specialist nurse if you want a break from tamoxifen to try to get pregnant.

Aromatase inhibitors (AIs)

Aromatase inhibitors (AIs) are the main hormonal therapy used for women who have been through the menopause. They stop oestrogen being made in the fatty tissue. Your cancer doctor may prescribe an aromatase inhibitor such as anastrozole, letrozole or exemestane.

AIs may also be given to younger women with drugs to stop the ovaries working, or after the ovaries have been removed (see page 101).

These drugs are taken daily as a tablet. Side effects can include:

- joint and muscle pain
- hot flushes
- tiredness.

Your bone health

If taken over a long period of time, AIs can cause bone thinning (osteoporosis). Before you start an AI, you have a scan called a DEXA (dual-energy x-ray absorptiometry) scan, to check your bone health (density).

If you are at risk of osteoporosis, your cancer doctor may prescribe drugs called bisphosphonates to protect your bones. Some women may already be taking bisphosphonates to reduce the risk of breast cancer coming back.

Your doctor may advise you to take calcium and vitamin D supplements to help strengthen your bones. There are things you can do to look after your bones including eating healthily and doing regular exercise such as walking.

Ovarian suppression or ablation

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

- Ovarian suppression, which stops the ovaries making oestrogen and causes a temporary menopause.
- Ovarian ablation, which removes the ovaries and causes a permanent menopause.

These treatments lower oestrogen levels, which reduces the risk of breast cancer coming back. But they can also affect your bone health. Before treatment starts, you 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®) is a drug that stops the ovaries making oestrogen and causes a temporary menopause. You may have goserelin on its own or with tamoxifen or an AI.

Goserelin stops the pituitary gland in the brain from sending messages to the ovaries to produce oestrogen. The side effects are similar to menopausal symptoms and include:

- hot flushes and sweats
- joint pain
- low sex drive.

Your specialist nurse will give you goserelin as a monthly injection under the skin of the tummy (abdomen). After treatment, your 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 taking goserelin.

Removing the ovaries (ovarian ablation)

This may be an option for women who do not want to take goserelin injections. You will usually have tamoxifen or an AI as well as ovarian ablation.

Removing the ovaries involves a small operation. It can often be done during a short stay in hospital using keyhole surgery. The surgeon makes a small cut in the tummy area and inserts a thin tube with a tiny light and camera on the end (laparoscope). The surgeon removes the ovaries through the cut using the laparoscope, which has a small surgical instrument attached to it. Women usually recover quickly from this operation.

If you have this surgery, your periods will stop straight away and you will have your menopause. It also means you will no longer be able to have children. Becoming infertile because of cancer treatment can be hard to cope with, but there is support available.

Hormonal therapy before menopause

Your doctor may recommend one of the following:

- tamoxifen, an anti-oestrogen drug
- goserelin on its own or with tamoxifen or an AI
- surgery to remove the ovaries on its own or with tamoxifen or an AI.

Hormonal therapy after menopause

Your doctor may prescribe one of the following drugs:

- an aromatase inhibitor such as anastrozole, letrozole, exemestane
- the anti-oestrogen drug tamoxifen and an aromatase inhibitor (one type is given after the other)
- tamoxifen on its own.

Targeted therapies

Targeted therapies interfere with the way cancer cells grow.

The main targeted therapy drug used in breast cancer treatment is trastuzumab. It reduces the risk of breast cancer coming back in women with HER2 positive breast cancer. It may be given with chemotherapy, or on its own. This can be before or after surgery and radiotherapy.

You may have trastuzumab in combination with another targeted therapy drug called pertuzumab (Perjeta®) and a chemotherapy drug. The combination may be used before surgery to treat HER2 positive breast cancer that has a high risk of coming back.

Trastuzumab and pertuzumab attach to the HER2 receptors on the surface of breast cancer cells and stop them from dividing and growing.

We have more information on all the drugs mentioned here on our website. Visit **macmillan.org.uk**

Trastuzumab

You usually have trastuzumab every 3 weeks for 1 year. It is given in the chemotherapy day unit or outpatient department.

You have trastuzumab as a drip (infusion) into a vein or as an injection under the skin (subcutaneously).

As a drip

A nurse gives the first dose slowly, usually over 90 minutes. This is because some people can have a reaction. The nurses monitor you during the drip and for about 4 to 6 hours afterwards.

You need to stay in hospital during this time. If you have no problems, you have the next doses over 30 to 60 minutes. You can also go home soon after the treatment is finished.

By injection

A nurse gives you the injection into your thigh. This only takes a few minutes. You are monitored for a few hours after the first injection. This is to make sure you do not have a reaction. But after the next injections, you will be monitored for a much shorter time.

Side effects of trastuzumab

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

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

Any side effects usually get better within a few hours of the drip finishing.

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

You may have tests to check your heart before and during treatment, to make sure the drug is not causing any damage. Trastuzumab is not usually given to people who already have serious heart problems.

Pertuzumab

Pertuzumab is given every 3 weeks. It is given as a drip into a vein. 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 drip 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 checks on your heart during treatment. Your cancer doctor or specialist nurse will give you more information about the side effects and ways of coping with them.

Pertuzumab may not be widely available on the NHS. If a drug is not available on the NHS, there may be different ways you are still able to have it. Your cancer doctor can give you advice about this.

Bisphosphonates

Bone protection

Certain hormonal therapies and chemotherapy can cause an early menopause, which increases the risk of bone thinning (osteoporosis).

Your cancer doctor may prescribe bisphosphonates if you are at risk of, or you already have, bone thinning (osteoporosis). Your cancer doctor will probably also advise you to take calcium and vitamin D supplements to help strengthen your bones.

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

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

Adjuvant bisphosphonates

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

- been through the menopause
- had treatment, for example with goserelin (see page 100), to stop your ovaries from working.

The bisphosphonate drugs most commonly used in adjuvant treatment are:

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

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

We have more information about these drugs on our website. Visit **macmillan.org.uk**

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 rare side effects can include effects on the kidneys and osteonecrosis of the jaw (when bone in the jaw dies).

Your doctor will check your blood regularly to see how your kidneys are working. Looking after your teeth and gums can reduce the risk of jaw problems. It is important that you have a dental check-up before starting bisphosphonates.

> ‘I think people forget how important it is to learn something new. That enriches you I think. It’s like therapy.’
>
> **Rocio**

AFTER YOUR TREATMENT

Follow-up

After treatment, you will have regular check-ups with your doctor or contact with your breast care nurse. You will have yearly mammograms every year for 5 years. After this, depending on your age, you can have mammograms through NHS breast screening programmes.

Younger women usually continue to have yearly mammograms after the first 5 years until they reach the age for breast screening.

At first, your check-ups may be every few months. But eventually you may have them once a year. If you notice any new symptoms between appointments, it is important to contact your doctor or nurse for advice. They will give you contact numbers, so you do not have to wait until your next appointment.

Instead of routine appointments, your breast care nurse may give you information on what to look out for. They will ask you to contact them or your cancer specialist if there is anything you are worried about. Some women may have their follow-up appointments at a nurse-led clinic. They only see their cancer specialist if something needs to be checked further.

Many women find they get anxious for a while before appointments. This is natural. It can help to get support from family, friends or a specialist organisation (see pages 151 to 155). You can also contact our cancer support specialists on **0808 808 00 00**.

Be aware of changes

You will 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 have had.

Your breast care nurse can tell you what you should expect and what to look out for. It is also important to be aware of what to look out for (see pages 20 to 21) in your untreated breast.

If you notice anything unusual between appointments, contact your cancer specialist 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.

Some women may have treatment side effects that do not improve after a few months. Or they 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 or if you develop new ones.

Lymphoedema

Lymphoedema is a swelling of the arm or hand. 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.

If just one or two of the lymph nodes were removed (a sentinel lymph node biopsy – see pages 65 to 69), the risk of lymphoedema is low. If you are not sure about 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, always ask your doctor or nurse to check it. The earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully.

Reducing the risk of lymphoedema

There are things you can do to help reduce your chances of developing lymphoedema. It is important to protect your arm and hand, and to look after the skin in that area. Here are some tips:

- Keep your skin clean and moisturise every day with unperfumed cream or oil to keep it in good condition.
- Treat even small grazes and cuts straight away. Wash the area thoroughly and cover it if necessary.
- See your GP immediately if you get any signs of infection around a cut, for example if it becomes red, hot or swollen.
- Try to avoid needles in the arm on the side that has been treated. This includes blood tests, injections, drips or acupuncture. Avoid having your blood pressure taken in that arm too.
- Wear gloves and long sleeves when doing household tasks, DIY, gardening or looking after animals.
- To avoid burns, use oven gloves or pot holders and long sleeves when cooking and baking.
- Use insect repellent to prevent insect bites. If an insect stings you on or near the affected area, get medical advice.
- Use nail clippers instead of scissors to cut your nails. Never push back or cut the cuticles. Use cuticle cream instead.
- Use an electric razor if you shave under your arms. Numbness under the arm is common. It can be easy to cut yourself with a blade razor, especially if you have a bumpy scar.
- Cover up or use a high sun-protection factor (SPF) cream of at least 30.

We have a booklet called **Understanding lymphoedema** that has more information (see page 146).

Sex and fertility

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

Sexuality

Breast cancer and its treatments and side effects may affect your sex life and your feelings about yourself as a woman.

Difficulties often slowly improve after treatment, but for some women it may take longer. 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**.

Some people may find it helpful to talk to a sex therapist. We also have a booklet called **Cancer and your sex life – information for women** that may help (see page 146).

Contraception

Your cancer doctor or breast care nurse will advise you not to use contraception that contains hormones. This includes the pill or coils (intra-uterine devices) that release hormones. This is because these can slightly increase the risk of breast cancer.

Your GP can give you advice about methods of contraception. Coils that do not contain hormones, or barrier contraception methods such as condoms, a diaphragm or cap, are usually the most suitable.

Pregnancy

Having a family can be an important part of life after cancer. Some women do not have difficulties getting pregnant naturally after treatment, particularly if they are under the age of 35.

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 women 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 hormone 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.

Fertility

Some breast cancer treatments may affect your ability to have children (fertility). Your periods may stop during treatment. If you are a younger woman, they may start again after it has finished. If you are close to your natural menopause, chemotherapy can bring on 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, these can be fertilised with their sperm, and the embryos (fertilised eggs) 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.

We have a booklet called **Cancer treatment and fertility – information for women** that has more information (see page 146).

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

Early menopause or menopausal symptoms

Some treatments can cause an early or temporary menopause. Hormonal therapies 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, which could encourage breast cancer cells to grow.

If your menopausal symptoms are severe and nothing else has helped, some doctors may occasionally prescribe HRT. You will need to talk about this with your cancer doctor so you know the possible benefits and risks.

Early menopause can increase the risk of bone thinning (osteoporosis). We have a booklet called **Bone health** that includes helpful tips on keeping them healthy (see page 146).

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

We also have a video about coping with menopausal symptoms (see page 146).

Well-being and recovery

After breast cancer treatment, some women choose to make some positive lifestyle changes. You may have already followed 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 illnesses 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.

Our booklet **Healthy eating and cancer** has more helpful information (see page 146).

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 some evidence that regular physical activity may help reduce the risk of breast cancer coming back.

We have a booklet called **Physical activity and cancer** (see page 146) that has some useful tips. You can also watch videos about the benefits of physical activity at **macmillan.org.uk,** including stories from people with cancer.

> ‘During my chemotherapy, I didn’t really have that much time to see people. I’m doing more things now and meeting up with friends. I have a personal trainer to build up my fitness and I go on exploring trips with my boyfriend.’
>
> Laura

Look after your bones

Oestrogen helps keep bones healthy and strong. Aromatase inhibitors (see pages 98 to 99) and treatments that cause an early or temporary menopause lower oestrogen levels in the body. This can increase the risk of bone thinning (osteoporosis).

To keep your bones healthy:

- keep physically active
- eat a healthy diet with enough calcium and vitamin D
- do not smoke.

We have a booklet called **Bone health** that has more information (see page 146).

Look after your heart

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

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

We have a booklet called **Heart health and cancer treatment** which has more information about looking after your heart (see page 146).

Stop smoking

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

Stick to sensible drinking guidelines

It is best to limit alcohol intake and include one or two alcohol-free days each week. Current NHS guidelines suggest that both men and women should:

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

A unit of alcohol is:

- half a pint of ordinary strength beer, lager or cider
- one 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 a stressful time in your life. One way of coping with stress is to make time to relax. Some examples of ways to relax or reduce stress 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 using relaxation techniques to control breathing
- being more physically active and looking after your well-being
- talking to someone about how you feel.

We have a booklet called **Cancer and complementary therapies** that has more information about relaxation techniques (see page 146).

> ‘My advice is definitely treat yourself well. There are many ways to make yourself feel good, if you have the energy. Maybe do a course or learn something new that you hadn’t thought about doing.’
>
> **Rocio**

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.

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 specialist or specialist nurse. They can refer you to a psychologist or counsellor who specialises in the emotional problems of people with cancer.

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 women 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.

Support groups

Self-help or support groups offer a chance to talk to other women who understand what you are going through. We can give you information about support groups in the UK. Call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups**

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 and to ask questions, 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 **community.macmillan.org.uk**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects.

It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way. Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help. We have a booklet called **How are you feeling? The emotional effects of cancer** that might be helpful (see page 146).

> ‘I had to stay strong. I think your mental state is key when it comes to getting through these things. It was horrible and I wouldn’t wish it on my worst enemy, but you have to stay positive and you will get through it.’
>
> **Ravinder**

Your relationships

The experience of cancer may have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can have an effect on relationships. Any problems usually improve over time, especially if you can talk openly about them.

Your partner

Some couples become closer through a cancer experience. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who've been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse.

Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other. Our booklet **Cancer, you and your partner**, may help (see page 146).

Family and friends

Your family and friends may not always understand if you aren't feeling positive about getting on with things, and may not know how big an effect treatment is having on your life. Talking about how you feel will help them give you the support you need.

Our booklet **Talking about cancer** has more useful tips.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information about talking to someone with cancer.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 146).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have a booklet called **Talking to children and teenagers when an adult has cancer**.

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly 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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant. How much you get will depend on your situation and needs. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

More information

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 one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 155). Our booklet **Help with the cost of cancer** has lots more information – see page 146.

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can 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, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer has more information** – see page 146 .

FURTHER INFORMATION

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life 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
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you'd 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**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

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’s why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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 **macmillan.org.uk/selfhelpandsupport**

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**

The Macmillan healthcare team

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.

> ‘Everyone is so supportive on the Online Community, they know exactly what you’re going through. It can be fun too. It’s not all just chats about cancer.’
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

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

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're 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 (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Other useful organisations

There are lots of other organisations that can give you information or support.

Breast cancer support organisations

Asian Women Cancer Group

Tel 07934 591 384
Email info@asianwomencancergroup.co.uk
www.asianwomencancergroup.co.uk
Helps women of all cultures who have been affected by breast cancer. Provides the support women may need, from emotional support to financial guidance.

Breast Cancer Haven

Tel 020 7384 0000 (London)
Email info@thehaven.org.uk
www.breastcancerhaven.org.uk
Havens are day centres providing support, information and complementary therapies before, during or after cancer treatment. Has a network of centres around the UK. Details of other UK Haven centres are on the website.

Breast Cancer Now

Tel 0808 800 6000 (Mon to Fri, 9am to 4pm, and Sat, 9am to 1pm)
www.breastcancernow.org
Provides information and support for anyone affected by breast cancer. Specialist breast care nurses run the helpline. Also committed to fighting breast cancer through research and awareness.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their carers, families and friends, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339 (Mon to Fri, 9am to 1pm)
Email nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Helpline 0808 800 4040 (Mon to Fri, 9am to 5pm)
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 (Mon to Fri, 9am to 5pm)
Email info@cancersupportscotland.org
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
Email enquiries@maggies.org
www.maggies.org
Has a network of centres in various 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 (Mon to Fri, 10am to 1pm)
Email helpline@pennybrohn.org.uk
www.pennybrohn.org.uk
Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline 0808 808 1010 (Daily, 8am to 8pm)
Email info@tenovuscancercare.org.uk
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.

Cancer registries

The cancer registry

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 one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie

Scottish Cancer Registry

Tel 013 1275 7050
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300 (Mon to Fri, 10am to 4pm)
Email bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Samaritans

Helpline 116 123
Email jo@samaritans.org
www.samaritans.org

Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial or legal advice and information

Advice NI

Helpline 0800 915 4604

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

Benefit Enquiry Line Northern Ireland

Helpline 0800 232 1271 (Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone 0289 031 1092
www.nidirect.gov.uk/money-tax-and-benefits

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

You can also call the Make the Call helpline on 0800 232 1271 to check you are getting all the benefits you are eligible for.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat, find details for your local office in the phone book, or contact:

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.

Unbiased.co.uk

Helpline 0800 023 6868
Email contact@unbiased.co.uk
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
(Mon to Fri, 10am to 6pm)
Email info@lgbt.foundation
www.lgbt.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.

YOUR NOTES AND QUESTIONS

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 our Senior Medical Editor, Dr Rebecca Roylance, Consultant Medical Oncologist.

With thanks to: Morven Angus, Lead Breast Clinical Nurse Specialist; Dr Sophie Barrett, Consultant Medical Oncologist; Ms Joanna Franks, Consultant Breast and Oncoplastic Surgeon; Mr Michael Hallissey, Consultant Surgeon; Dr MB Mukesh, Consultant Oncologist; Catherine Richmond, Therapy Radiographer; Dr Elinor Sawyer, Consultant Clinical Oncologist; Ms Karyn Shenton, Breast and Oncoplastic Consultant; and Catherine Walsh, Breast Care Nurse Specialist.

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

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

European Society for Medical Oncology. Primary breast cancer: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. Annals of oncology 26 (supplement 5): v8–v30. 2015.

National Institute for Health and Care Excellence (NICE). Early and locally advanced breast cancer: diagnosis and management. July 2018.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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

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

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.

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

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

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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 affected 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 who act on our behalf.

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If you’d rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about breast cancer in women. It is for women who have been diagnosed with breast cancer. There is also information for family members and friends.

The booklet explains the signs and symptoms of breast cancer in women. It also explains the different treatments, how to manage side effects and ways to cope with some of the feelings you may have.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

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, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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