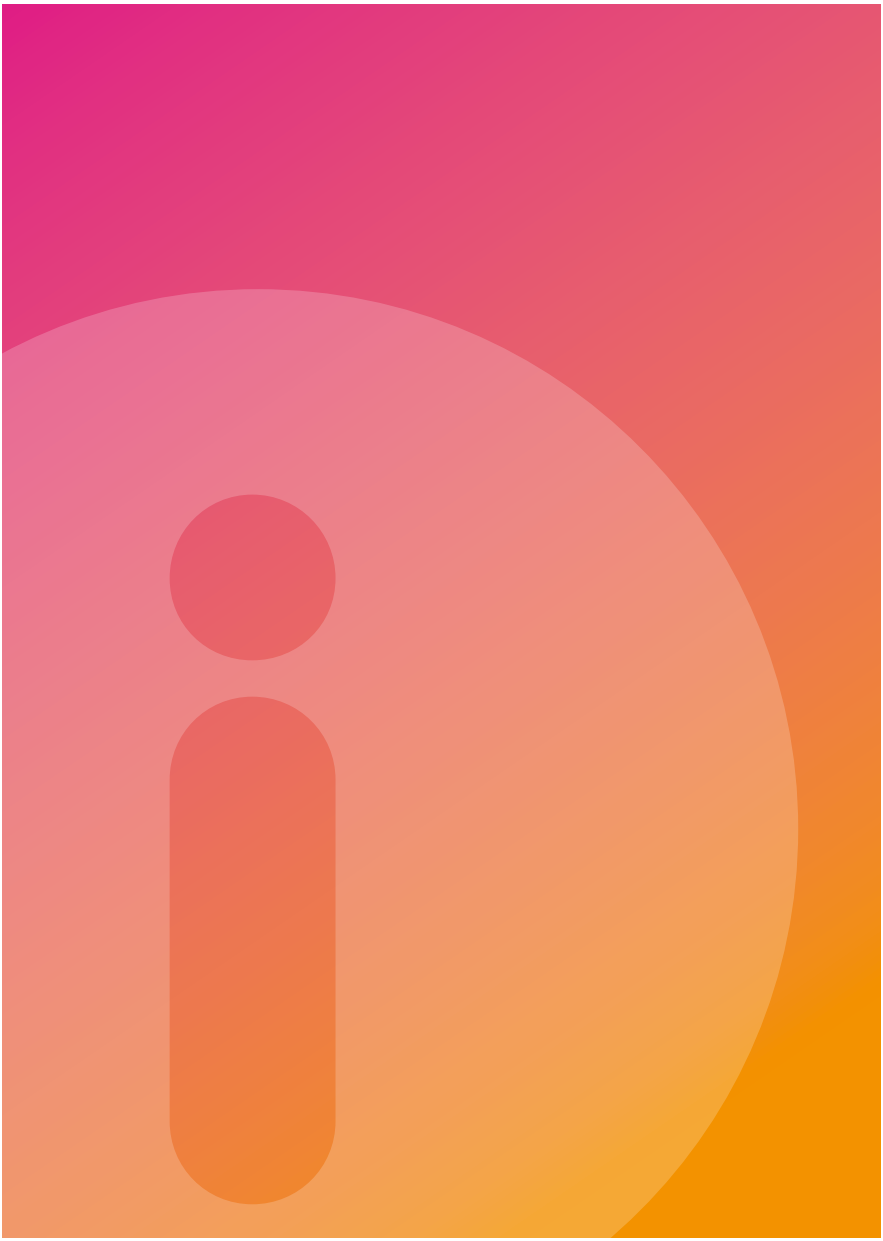
Primary breast cancer

breast cancer care



Contents

This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

breast cancer care

Introduction

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

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

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

The glossary on page 75 gives definitions of some common words relating to primary breast cancer.

As you look through this pack, you may want to know more about some topics. In each section, we've included the names of other booklets you may want to read. A list of our publications and how to order them are on page 91.

All our information is free, and you can use the pockets in this pack to store it all in one place and refer to it whenever you need to.

Personal details

Use this section to write the contact details of the members of your treatment team. For more information about what the different members of the team do, see page 31.

My contact details

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

Hospital name

Hospital number

My main contacts

Breast care nurse(s)

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

Name

Telephone

Email

Surgeon

Name

Secretary's telephone

Secretary's email

Other doctors in this team

Medical oncologist

Name

Secretary's telephone

Secretary's email

Other doctors in this team

Clinical oncologist

Name

Secretary's telephone

Secretary's email

Other doctors in this team

Outpatients' clinic

Name

Telephone

Email

Emergency/out of hours contact

Name

Telephone

Email

GP

Name

Telephone

Email

Others

Name

Telephone

Email

Name

Telephone

Email

Name

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About breast cancer

What is breast cancer?

Types of primary breast cancer

What is breast cancer?

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

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

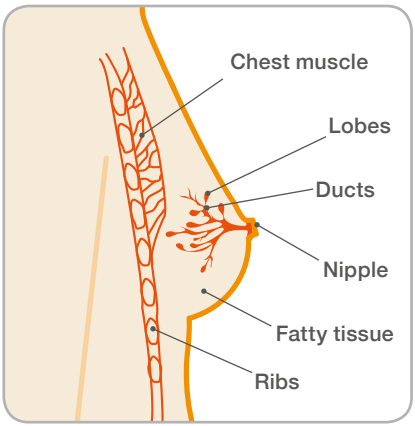
Primary breast cancer is breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm.

The breasts and lymph nodes

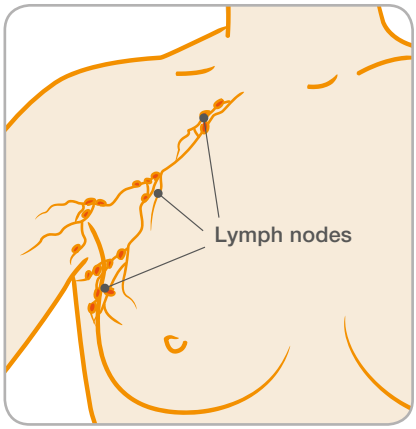
Breasts are made up of lobules (milk-producing glands) and ducts (tubes that carry milk to the nipple). These are surrounded by glandular, fibrous and fatty tissue.

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

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



The breast



The lymph nodes

Types of primary breast cancer

There are different types of breast cancer. It's important to have an accurate diagnosis so your specialist team can plan the most appropriate treatment for you.

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

Non-invasive breast cancer

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

Ductal carcinoma in situ (DCIS)

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

Invasive breast cancer

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

Invasive ductal breast cancer (of no special type)

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

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

Invasive lobular breast cancer

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

Inflammatory breast cancer

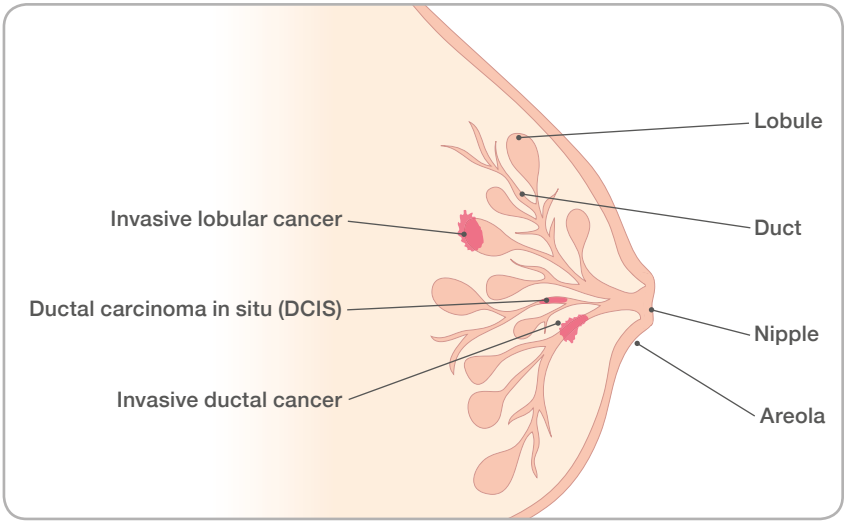
Inflammatory breast cancer is a rare type of breast cancer. It gets its name because the skin of the breast has a red, inflamed appearance, similar to that seen with some infections of the breast. The skin may also feel warm and tender to touch and may appear pitted, like the skin of an orange.

Paget's disease of the breast

Paget's disease of the breast is an uncommon type of breast cancer that usually first shows as a change to the nipple. The most common symptom is a red, scaly rash involving the nipple, which may spread to the darker skin around the nipple (areola).

Other types of breast cancer

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



Types of breast cancer

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

- Ductal carcinoma in situ (DCIS)
- Invasive ductal breast cancer
- Invasive lobular breast cancer
- Inflammatory breast cancer
- Paget's disease of the breast
- Phyllodes tumours: borderline malignant and malignant
- Tubular breast cancer
- Cribriform breast cancer
- Mucinous breast cancer
- Medullary breast cancer
- Papillary breast cancer
- Metaplastic breast cancer

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Your diagnosis

Being diagnosed with breast cancer

Deciding the best treatment for you

Grade, size and stage of the cancer

Other tests to help decisions about your treatment

Being diagnosed with breast cancer

Being told you have breast cancer can cause a range of emotions, from fear, shock and disbelief to anger, guilt and sadness.

Many people describe not being able to remember anything after they have been told their diagnosis. Having someone with you at your appointments, who can listen carefully or take notes, can be very helpful.

It can also help to write down your questions and bring them with you when you next see your specialist team, so you don't forget what you want to ask.

How are you feeling?

It's no surprise that being told you have breast cancer causes all sorts of different feelings.

Many people ask themselves 'Why me?' or 'What have I done to deserve this?' You may be worried about your treatment, or feel sad or angry that your life has suddenly changed. Many people start worrying about dying and feel anxious about their future.

Some days you may feel hopeful, other days you may feel very low. There's no right or wrong way to feel. If you feel persistently low or anxious, you may want to talk to your breast care nurse or GP (local doctor) to help you with this.

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

How much do you want to know?

You may want to learn everything you can about breast cancer and what it means, or you may want information a little bit at a time as you go through treatment. There's a huge amount of information available, especially on the internet. However, some of it can be misleading or outdated, so make sure you're getting information from websites that are trustworthy.

The information on Breast Cancer Care's website **breastcancercare.org.uk** is written and reviewed by clinical experts and based on the latest research. You can also find more information on all aspects of breast cancer in our booklets and online information.

Ask your specialist team to suggest other sources of information.

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

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

Telling other people

It may be difficult at first to tell people about your diagnosis if you're still trying to take in the information yourself. You may begin by telling those closest to you. Sometimes you may have to handle other people's feelings and even end up reassuring them.

Some people will find it difficult to know what to say and how to say it, or may ask you lots of questions. Sometimes they might say insensitive or hurtful things unintentionally. Some people may tell you about similar experiences they had or heard about, which may or may not help.

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Deciding the best treatment for you

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

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

The following factors affect which treatments are recommended for you.

- The size of the breast cancer.
- Where the cancer is in the breast.
- Whether more than one area of the breast is affected.
- The type of breast cancer.
- The grade of the cancer (see page 24)
- Whether the cancer has spread to lymph nodes (also called lymph glands) under the arm (axilla).
- The size of the area of cancer within the lymph nodes, and how many lymph nodes are involved.
- If any cancer cells are present in the lymph vessels or blood vessels that connect the breast to the rest of the body (known as lympho-vascular invasion).
- Whether your breast cancer is oestrogen receptor positive (see page 26).
- Whether your breast cancer is HER2 positive (see page 27).

As well as tests done on the breast tissue, sometimes tests on your body are needed too, such as x-rays, scans and blood tests (see page 25). These can help your specialist team find out more information and plan the best treatment for you.

Questions about my diagnosis

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

Grade, size and stage of the cancer

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

Some people find the difference between grade and stage confusing. If you're not sure which one your specialist is talking about, ask them to explain it to you.

Grade

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

With invasive breast cancer there are three grades:

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

With ductal carcinoma in situ (DCIS) there are also three grades. These are usually called low, intermediate and high. A low grade DCIS is less likely to become an invasive cancer than a high grade DCIS.

Stage

The size of the cancer and how much it has spread is known as the stage of the disease. There are different ways to describe breast cancer stages. The most common way is known as the TNM cancer staging system.

This is a scoring system used to describe the size of the cancer (T stands for tumour); the number of lymph nodes affected (N stands for nodes); and whether there's any spread of the cancer to other parts of the body (M stands for metastases).

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

The aim of treatment for primary breast cancer is to remove the cancer and reduce the risk of it returning in the breast or spreading to other

parts of the body. Generally, if the cancer is high grade, large or if it has affected the lymph nodes under the arm, there's a higher risk of the breast cancer spreading to other parts of the body.

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

Sometimes your specialist team will recommend other tests if they need more information about the stage of the cancer. This can help them decide the best treatment for you.

Your doctor or breast care nurse will explain what these tests are for, what they involve and when you can expect the results. These tests may include:

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

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

Other tests to help decisions about your treatment

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

Hormone receptor test

The hormone oestrogen can play a part in stimulating some breast cancers to grow.

If your breast cancer has receptors within the cell that bind to the hormone oestrogen, it's known as oestrogen receptor positive or ER+ breast cancer. Sometimes it's referred to as hormone sensitive breast cancer. When oestrogen binds to these receptors, it can stimulate the cancer to grow. All breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery.

A number of hormone therapies work in different ways to block the effect of oestrogen on cancer cells. If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy they think is most appropriate.

When oestrogen receptors are not found (oestrogen receptor negative or ER-) tests may be done for progesterone (another hormone) receptors. The benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case, your specialist will discuss with you whether hormone therapy is appropriate.

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

HER2 test

Around one in five breast cancers has a higher than normal level of a protein called HER2 on the cell surface, which stimulates them to grow. These cancers are called HER2 positive or HER2+.

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

If your breast cancer is HER2 positive you will usually be advised to have chemotherapy and a drug from a group known as targeted (or biological) therapies. The most widely used one is trastuzumab (Herceptin).

If your cancer is HER2 negative, then targeted therapies will not be of any benefit to you so will not be recommended.

Triple negative breast cancer

When breast cancer tests negative for oestrogen, progesterone and HER2 receptors, it's known as triple negative breast cancer. This means hormone therapy and targeted therapy drugs will not be recommended. But triple negative breast cancers can be treated with surgery, radiotherapy and chemotherapy. Research is being done to find out which chemotherapy drugs work best for triple negative breast cancer. Around 15% of people with invasive breast cancer have triple negative breast cancer.

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Having treatment

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

My specialist team

People with breast cancer are cared for by a team of healthcare professionals, each with their own expertise. This is known as the multi-disciplinary team (MDT). These are some of the people who will be involved in your care:

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

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

You may also have treatment or care from:

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

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

- counselling
- complementary therapies (see page 68)
- local support groups
- a dietitian.

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

Don't be afraid to ask

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

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

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

Many hospitals will send you copies of any letters written from one healthcare professional to another, for example from your specialist to your GP, which can be a helpful record of your diagnosis and treatment plan. You can ask for these if they are not sent to you.

Asking for a second opinion

Some people consider asking for a second opinion. This can be done through your GP, or sometimes your specialist may refer you to someone else within the same hospital or elsewhere. A second opinion may not be different from the one you have already had. The time taken to get a second opinion may delay your treatment for a few weeks, but there's no evidence that this will make a difference to the outcome of treatment.

Declining treatment

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

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

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

Clinical trials

Some people are offered the opportunity to take part in research studies that evaluate new treatments. These are known as clinical trials.

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

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

Treatments for breast cancer

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

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

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

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

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

You may need to go to different hospitals for different treatments. For example, radiotherapy services are not available at all hospitals, so you may need to have this in a different hospital to where you had your surgery. For some people this may involve some travelling. See page 70 for more information about travelling to hospital for treatment.

Knowing your options

Knowing about the options for treatment can help you decide what to do if you're offered a choice of treatments. Or you may choose to leave it to your specialist team to decide the best approach to your treatment and what information you need. There's no right or wrong way to go about it.

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

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Treatment guidelines

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

Decision-making

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

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

Adjuvant! Online adjuvantonline.com

Adjuvant! Online is an online decision-making tool. It estimates the benefit you might expect to receive from treatments such as chemotherapy and hormone therapy after surgery. It can only be accessed by your specialist team, but they can print out a copy of the results and discuss them with you.

PREDICT predict.nhs.uk

PREDICT is an online decision-making tool. It makes estimates about the benefits of chemotherapy, hormone therapy and targeted therapies after surgery based on information about you and your breast cancer.

Nottingham Prognostic Index (NPI)

The Nottingham Prognostic Index (NPI) is a scoring system that is used with the TNM cancer staging system and the grade of the cancer (see page 24). You're given a score which puts you into a prognosis (the likely outlook) category of good, moderate or poor. Five-year survival is then estimated depending on which category you're placed in.

Oncotype DX test oncotypedx.com

You may hear about tests that can help identify people who are most likely to benefit from chemotherapy. These are called gene expression profiling tests, gene expression analysis tests, or gene assays. They are only suitable for some women. The most widely used test is Oncotype DX.

The Oncotype DX test can help your specialist team decide if you would benefit from having chemotherapy and how likely it is that the cancer will return in the future. The test is carried out on breast tissue removed during surgery. It's not suitable for all types of breast cancer and your specialist team can tell you if it could help you.

Other tests

Other tests you may hear about include Prosigna, MammaPrint and EndoPredict. More research is needed before these tests are widely used.

My treatment record

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

Surgery

Surgery date(s)

Chemotherapy

Start date

Chemotherapy regimen/drugs

Radiotherapy

Start date

Number of treatments

Hormone therapy

Start date

Hormone therapy drug

Targeted therapy

Start dates

Targeted therapy drug

Other treatments

Name

Date

Name

Date

Surgery

Surgery is the first treatment for most people with breast cancer. It aims to remove the cancer with a margin (border) of normal breast tissue. This is done to reduce the risk of the cancer coming back in the breast – known as local recurrence – and to try to stop it spreading elsewhere in the body.

National guidance states that you should have your planned surgery within 31 days of you agreeing to have treatment.

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

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

There are two main types of breast surgery:

- **breast-conserving surgery**: the cancer is removed along with a margin (border) of normal breast tissue
- **mastectomy**: all the breast tissue is removed.

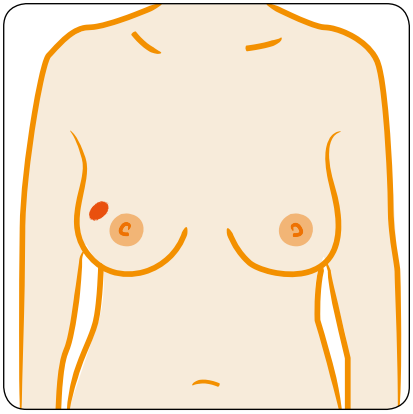
The type of surgery recommended for you depends on the type and size of the cancer, where it is in the breast, whether more than one area of the breast is affected, and how much surrounding tissue needs to be removed. It will also depend on the size of your breast.

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

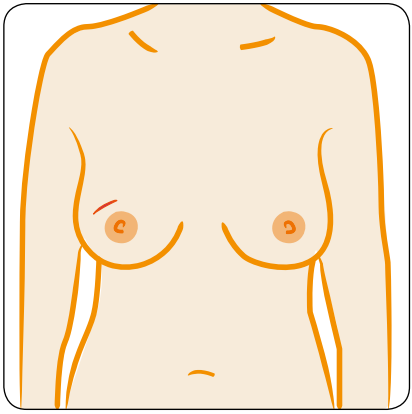
You may also have some or all of the lymph nodes removed with the breast tissue (see page 43).

Breast-conserving surgery

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



Position of cancer in breast



Example of position of scar after wide local excision

A far less common operation is a quadrantectomy, where around a quarter of the breast is removed. This is sometimes called a segmental excision. After a quadrantectomy the treated breast will usually be smaller due to the amount of tissue removed and it may also be misshapen. However, oncoplastic surgical techniques, which combine breast cancer surgery with plastic surgery, are increasingly used. This means it's less likely you'll notice a dent or a great difference between the breasts. For more information see our **Breast reconstruction** booklet.

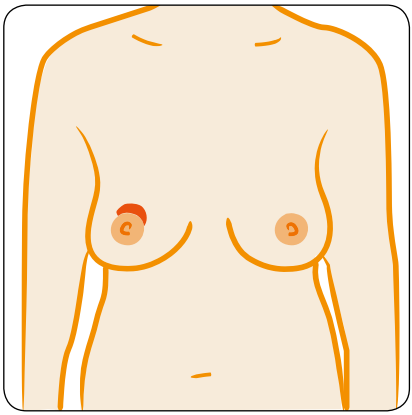
It's important that the cancer is removed with an area of healthy breast tissue around it to make sure no cancer cells have been left behind. The breast tissue removed during surgery will be tested to check the margin around the cancer. If there are cancer cells at the edges of the margin, you may need further surgery to remove more tissue. Some people may need a mastectomy to ensure all the cancer has been removed.

Mastectomy

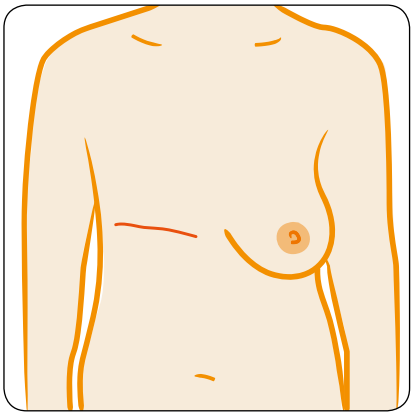
A simple mastectomy is the removal of all the breast tissue including the skin and nipple area.

Examples of when a mastectomy may be recommended include:

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



Position of cancer in breast



Example of position of scar after a mastectomy

If your surgeon recommends a mastectomy they should explain why. It may be your personal preference to have a mastectomy.

If you're going to have a mastectomy, your breast surgeon will discuss breast reconstruction with you (see page 47).

If you're going to have a breast reconstruction at the same time as the mastectomy, your breast surgeon may discuss other types of mastectomy. A skin sparing mastectomy is removal of the breast and nipple area without removing much of the overlying skin of the breast. A nipple-sparing mastectomy is removal of all the breast tissue, without removing much of the overlying skin and the nipple area of the breast.

Which operation?

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

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

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

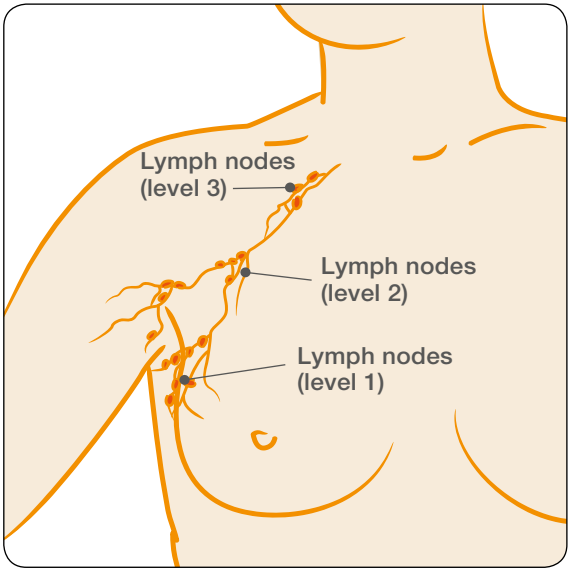
Some women who are having a mastectomy wonder whether they should have their unaffected breast removed as well. Research shows this is not usually necessary or recommended, unless someone has a higher risk of developing primary breast cancer in the other side. This might be the case if they have inherited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

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Surgery to the lymph nodes

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



This is a basic illustration of the different levels of lymph nodes. Where the lymph nodes are situated and how many lymph nodes you have will vary according to each person.

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

Usually an ultrasound scan of the underarm is done before surgery to assess the lymph nodes.

If this appears abnormal, you'll have a fine needle aspiration (FNA) or a core biopsy to see if the cancer has spread to the lymph nodes. An FNA uses a fine needle and syringe to take a sample of cells to be looked at under a microscope. A core biopsy uses a hollow needle to take a

sample of tissue for analysis under a microscope. If the FNA or core biopsy show cancer has spread to the lymph nodes, you'll usually be recommended to have all or most of your lymph nodes removed at the same time as your breast surgery (known as an axillary clearance).

Sentinel lymph node biopsy

If the tests before surgery show no evidence of the lymph nodes containing cancer cells, you usually still need to have a sample of the lymph nodes removed to confirm this. This is known as axillary sampling.

Sentinel lymph node biopsy is widely used for axillary sampling. It identifies whether or not the first, or sentinel, lymph node (or nodes) is clear of cancer cells. The sentinel node is usually in level one (see picture on page 43).

Sentinel lymph node biopsy is usually carried out at the same time as your cancer surgery but may be done before your surgery. A small amount of radioactive material (radioisotope) and a dye is injected into the area around the cancer to identify the sentinel lymph node(s). Once removed, the sentinel node(s) is examined under a microscope to see if it contains any cancer cells.

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

If the sentinel node(s) does not contain cancer cells, this usually means the other nodes are clear too, so no more will need to be removed.

If the results show there are cancer cells in the sentinel node(s) you may be recommended to have further surgery to remove some or all of the remaining lymph nodes or radiotherapy to the underarm.

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

Assessing lymph nodes during surgery

Some hospitals can assess the lymph nodes during your breast surgery. The removed nodes will be looked at by a pathologist, who will then tell the surgeon the result during the operation.

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

Questions about surgery

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

Breast reconstruction

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

You can have reconstruction either at the same time as the breast cancer surgery (immediate reconstruction) or months or years later (delayed reconstruction). Breast reconstruction often involves several operations to give you the best result possible.

The new breast shape can be created using an implant and/or your own tissue from another part of the body, usually the back or lower abdomen. Reconstructed breasts don't usually have a nipple but one can be created with surgery. Otherwise prosthetic stick-on nipples can be used.

There are usually different options available for breast reconstruction and your breast surgeon will explain which one is likely to suit you.

Most women having a whole or partial mastectomy can have immediate or delayed breast reconstruction. Some people are advised not to have a breast reconstruction because of other existing medical conditions that might increase the risk of problems and complications following surgery. If it's likely you'll need radiotherapy this often influences the choice and timing of breast reconstruction.

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

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Questions about breast reconstruction

- Who will do the reconstruction?
- Will the operation be done at this hospital?
- What types of breast reconstruction are best for me and why?
- Can I see photographs of breast reconstruction operations my surgeon has done?
- Can I talk to someone who has had breast reconstruction?
- Can I have a second opinion?
- Will having radiotherapy affect my reconstructed breast or my options for breast reconstruction later?
- How long is the waiting time for immediate or delayed breast reconstruction?
- How long might I take to recover?

Chemotherapy

Chemotherapy is treatment using anti-cancer (also called cytotoxic) drugs to try to destroy cancer cells. It's known as a systemic treatment, which means the whole body is exposed to the drugs.

Your specialist team will decide whether to recommend chemotherapy depending on the type of breast cancer you have, whether the lymph nodes contain cancer cells, the size and grade of the cancer, and whether it is HER2 positive. Following surgery, your doctors may use one of the decision-making tools described on page 35 to decide if chemotherapy is suitable for you.

When is it given?

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

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

National guidance states that treatment should begin within 31 days of you agreeing to it, unless there is a medical reason for a delay, for example because you have a wound infection.

Sometimes chemotherapy is given before surgery. This is called primary or neo-adjuvant chemotherapy. Chemotherapy before surgery may reduce the size of the breast cancer. This means some women can avoid having a mastectomy.

How is it given?

There are many different types of chemotherapy drugs and they can be used in different combinations.

Chemotherapy drugs are usually given into a vein (intravenously) for primary breast cancer.

Side effects

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

Some of the most common side effects of chemotherapy are:

- nausea (feeling sick) and vomiting
- hair loss or thinning
- sore mouth
- mouth ulcers
- fatigue (extreme tiredness).

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

- an increased risk of infection (because there are too few white blood cells)
- anaemia (having too few red blood cells)
- bruising and bleeding more easily.

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

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

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Questions about chemotherapy

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

Radiotherapy

Radiotherapy uses carefully measured and controlled high energy x-rays to destroy any cancer cells left behind in the breast area after surgery. It's given to reduce the risk of the cancer returning in the breast.

Which areas are treated?

If you've had breast-conserving surgery, you will usually have radiotherapy to the remaining breast tissue on that side.

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

Radiotherapy is sometimes given to the lymph nodes under the arm instead of surgery or after sentinel lymph node biopsy (see page 44).

Radiotherapy may also be recommended to the lymph nodes on the lower part of your neck, around your collarbone (called supraclavicular fossa or SCF nodes), on the side you have had your surgery. This depends on the grade and size of your cancer, and whether the lymph nodes under the arm contained cancer cells.

When is it given?

Radiotherapy for primary breast cancer is given after surgery.

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

National guidance recommends you shouldn't have to wait more than 31 days in England and Scotland or 28 days in Wales between surgery or finishing chemotherapy and the start of radiotherapy. However, some people have to wait a bit longer because of medical reasons or waiting for an appointment.

Ongoing research is looking at different or newer ways of giving radiotherapy. This includes intraoperative radiotherapy, where radiotherapy is given in one dose during surgery, and giving the radiotherapy over a shorter timeframe.

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Questions about radiotherapy

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

Hormone (endocrine) therapy

As the hormone oestrogen can play a part in stimulating some breast cancers to grow, there are a number of hormone therapies that work in different ways to block the effect of oestrogen on cancer cells.

You may be advised to have hormone therapy if tests show your breast cancer is hormone receptor positive (see page 26). Your specialist team will discuss with you which hormone therapy they think is most appropriate.

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

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

Types of hormone therapy

Examples of breast cancer hormone therapies include:

- tamoxifen
- anastrozole (well-known brand name is Arimidex)
- letrozole (well-known brand name is Femara)
- exemestane (well-known brand name is Aromasin)
- goserelin (well-known brand name is Zoladex).

The type of hormone therapy given will depend on a number of factors such as whether you have been through the menopause, or if you have an increased risk of, or have, osteoporosis (thinning of the bones). Some hormone therapies increase the risk of developing osteoporosis in the future. For more information see our **Osteoporosis and breast cancer treatment** booklet.

When is it given?

Hormone therapy is usually started after surgery and chemotherapy (if you're having it) to reduce the risk of the breast cancer coming back or spreading elsewhere in the body.

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

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

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Questions about hormone therapy

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

Targeted (biological) therapies

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

The most widely used targeted therapy is trastuzumab (Herceptin). Only people whose cancer has high levels of HER2 (called HER2 positive) will benefit from having trastuzumab. HER2 is a protein that makes cancer cells grow. For more information see our **Trastuzumab (Herceptin)** booklet.

Pertuzumab (Perjeta) is another targeted therapy for women with HER2 positive breast cancer. This may be given before surgery in combination with trastuzumab and chemotherapy.

There are various tests to measure HER2 levels, which are done on breast tissue removed during a biopsy or surgery. If your cancer is found to be HER2 negative, then trastuzumab and pertuzumab will not be of benefit to you.

Other targeted treatments for different types of breast cancer are being looked at in clinical trials, so it's likely that more targeted therapies will become available for primary breast cancer in the future.

Questions about targeted therapy

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

Bisphosphonates

Bisphosphonates are drugs used to slow down or prevent bone damage. They're often prescribed for people who are at risk of, or have, osteoporosis.

Osteoporosis is a condition that affects the bones. Some treatments for breast cancer can increase your risk of getting it.

You may hear bisphosphonates called bone-hardening or bone-strengthening treatment.

Recent research has demonstrated they may also play a role in reducing the risk of breast cancer spreading to the bones and elsewhere in the body in post-menopausal women. Talk to your doctors about whether bisphosphonate treatment would be suitable for you.

Questions about bisphosphonates

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

Effects of treatment

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

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

Side effects such as hot flushes or fatigue (extreme tiredness) might seem minor to other people. But they can be a constant reminder of your breast cancer and difficult to cope with over time.

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

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

Breast cancer and hair loss

Living with lymphoedema

Menopausal symptoms and breast cancer

Osteoporosis and breast cancer treatment

Reducing the risk of lymphodema

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

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

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Wellbeing and practical issues

Health and wellbeing during and after treatment

Practical issues

Finishing treatment

Breast cancer words explained

Health and wellbeing during and after treatment

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

Many people choose to look at their lifestyle to see if there are any changes they want to make.

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

Diet

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

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

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

You can find tips on healthy eating during and after treatment in our **Diet and breast cancer** booklet and on our website **breastcancercare.org.uk**

If you would like further advice you can talk to your GP, dietitian or specialist team.

Physical activity

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

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

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

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

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

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

Complementary therapies

Some people like to use complementary therapies – such as acupuncture, aromatherapy or massage – both during and after breast cancer treatment. Some hospitals offer complementary therapies so it's worth asking what is available in your area. Tell your specialist or breast care nurse about any complementary therapies you're intending to use. Some therapies, such as selected herbal remedies, have the potential to interfere with conventional treatments.

Find out more information about individual therapies, and whether they're safe to use during breast cancer treatment, in our **Complementary therapies** booklet.

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Practical issues

Work

Many people worry that having cancer may affect their current or future employment. The Equality Act 2010 protects anyone who has been diagnosed with cancer against any discrimination relating to employment – including the recruitment process. The Disability Discrimination Act 1995 protects people who live in Northern Ireland.

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

Macmillan Cancer Support has more information about how cancer and cancer treatments may have an impact on your employment. Visit www.macmillan.org.uk or call 0808 808 00 00.

Financial issues

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

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

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

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

Transport to and from hospital

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

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

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

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

You can find out more about this on the NHS Choices website nhs.uk or by asking at your hospital.

Finishing treatment

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

Moving Forward

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

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

Follow-up

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

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

For more information about follow-up, see our **Moving Forward pack** or our booklet **After breast cancer treatment: what's next?**

Call us on **0808 800 6000** or visit **breastcancercare.org.uk** for more information.

Looking forward to life after treatment

The end of your hospital treatment can be a worrying time. We're here to help you approach life after treatment with more confidence.

Moving Forward resource pack

Moving Forward is for anyone who is coming to the end of or has finished their hospital-based treatment for primary breast cancer. It includes information such as signs and symptoms of recurrence, coping with ongoing side effects of treatment, and dealing with emotional, financial and practical issues.

Vita magazine

Vita is our free quarterly magazine for anyone affected by breast cancer. It contains real life stories, features, tips on healthy living, and questions and answers about various aspects of breast cancer.

To request the publication(s) above, please complete the form and send it to our freepost address:

Breast Cancer Care
RRKZ-ARZY-YCKG
5–13 Great Suffolk Street
London SE1 0NS

☐ Please send me a free copy of the Moving Forward resource pack

☐ Please send me future issues of Vita magazine

Your details

Name:

Address:

Postcode:

Breast cancer words explained

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

A

Abdomen Belly.

Ablation Removal of or stopping a part of the body from working by surgery or other means such as hormone therapy or radiotherapy.

Abraxane A type of chemotherapy drug used to treat breast cancer.

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

Adjuvant Treatment given in addition to other treatment, for example chemotherapy or radiotherapy given as well as surgery.

Adriamycin see **Doxorubicin**

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

Adverse effect An undesired or harmful effect resulting from treatment.

Alopecia Loss of hair from the head or body.

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

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

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

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

Areola Coloured area of skin around the nipple.

Arimidex see **Anastrozole**

Aromasin see **Exemestane**

Axilla Under the arm, the armpit.

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

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

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

B

Benign Not cancer.

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

Biological therapies Also known as **Targeted therapies**.

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

Bisphosphonates A group of drugs used to treat the effects of secondary breast cancer in the bone. Also given to people with primary breast cancer to prevent or treat osteoporosis or to reduce the risk of breast cancer coming back.

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

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

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

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

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

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

BRCA1 (Breast Cancer1) An altered or faulty gene passed on at birth from either parent. People who inherit an altered BRCA1 gene have a much higher risk of developing breast cancer and some other cancers compared with the general population.

BRCA2 (Breast Cancer2) An altered or faulty gene passed on at birth from either parent. People who inherit an altered BRCA2 gene have a much higher risk of developing breast cancer and some other cancers compared with the general population.

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

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

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

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

C

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

Carboplatin A chemotherapy drug sometimes used to treat breast cancer.

Carcinoma The medical term for cancer.

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

Cells Tiny structures found in all living organisms.

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

Cellulitis An infection of the skin and tissue beneath the skin. People who have lymphoedema have an increased risk of cellulitis in the arm or chest area.

Chemotherapy Treatment aimed at destroying cancer cells using anti-cancer drugs, which are also called cytotoxic drugs.

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

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

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

Cisplatin A chemotherapy drug sometimes used to treat breast cancer.

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

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

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

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

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

Core biopsy Biopsy using a hollow needle to take a sample(s) of tissue for analysis under a microscope.

CT (computerised tomography) scan Also known as a CAT scan. A type of scan that uses x-rays to take detailed pictures across the body.

Cyclophosphomide A chemotherapy drug used to treat breast cancer.

D

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

DEXA (dual energy x-ray absorptiometry) scan A scan that measures bone density, used to assess the risk of developing, diagnosing or monitoring osteoporosis.

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

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

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

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

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

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

E

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

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

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

Endocrine therapy see **Hormone therapy**

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

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

Eribulin Also called Halaven. A chemotherapy drug used to treat breast cancer.

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

Excision Surgical removal.

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

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

F

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

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

Femara see **Letrozole**

Fibrocystic A benign (not cancer) breast condition when multiple cysts or lumpy areas develop in one or both breasts.

Filgrastim A type of GCSF, also known as Neupogen

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

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

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

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

G

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

Gemcitabine A chemotherapy drug sometimes used to treat breast cancer, also known as Gemzar.

Gemzar see **Gemcitabine**

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

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

Goserelin A hormone therapy drug, also known as Zoladex

H

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

Herceptin see **Trastuzumab**

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

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

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

Hormones Chemical messengers produced in various organs of the body that regulate growth and reproduction.

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

HRT (hormone replacement therapy) Female sex hormones, either oestrogen alone or a combination of oestrogen and progesterone, can help reduce menopausal symptoms.

Hypercalcaemia Higher than normal levels of calcium in the blood.

Hyperplasia An increase in the number and growth of cells.

Hypocalcaemia Lower than normal levels of calcium in the blood.

I

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

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

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

Inflammation The reaction of body tissues to injury, infection or irritation.

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

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

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

Intraductal see **DCIS**

Intramuscular (IM) An injection into the muscle.

Intravenous (IV) An injection into the vein.

Invasive cancer Has the potential to spread to other parts of the body.

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

K

Ki67 A protein found in cells. The higher the levels, the faster the cells are dividing and growing.

L

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

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

Locally advanced breast cancer Also known as regional recurrence. Breast cancer that has come back and spread to the tissues and lymph nodes around the chest, neck and under the breastbone.

Local recurrence See **Recurrence**

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

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

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

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

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

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

M

Malignant In cancer, uncontrolled growth. Invasive cells that have the potential to spread elsewhere in the body.

Mammogram A breast x-ray.

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

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

Methotrexate A chemotherapy drug used to treat breast cancer.

Mets Short for metastases.

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

MRI (magnetic resonance imaging) scan Uses magnetic fields and radio waves to produce a series of images of the inside of the breast.

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

Multi-focal When there is more than one area of breast cancer but all in the same quarter (area) of the breast.

N

Neo-adjuvant Cancer treatment, such as chemotherapy or hormone therapy, given before surgery. Sometimes called primary, for example primary hormone therapy.

Neupogen A type of GCSF

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

O

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

Oestrogen receptors Proteins within cancer cells that bind to the female hormone oestrogen and stimulate the cancer to grow (may be abbreviated to ER, from the US spelling estrogen).

Oncologist A doctor who specialises in cancer (oncology). An oncologist may be a medical oncologist (cancer drugs specialist) or clinical oncologist (radiotherapy and/or cancer drugs specialist).

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

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

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

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

Ovarian suppression Stopping the ovaries working using surgery or drugs.

P

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

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

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

Perjeta See **Pertuzumab**.

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

PET (positron emission tomography) scan A scan that produces a three-dimensional image giving details on both the structure and function of organs or tissue being looked at. It is sometimes combined with a CT scan.

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

Portacath Also called an implanted port. A thin, soft, hollow tube made of plastic that is put into a vein. The tube is attached to a rubber disc (port). Drugs are given into the port which is usually placed under the skin on the chest.

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

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

Prognosis The likely outlook of a disease, whether it is likely to be cured and the person's life expectancy.

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

R

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

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

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

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

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

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

Risk factor In medicine, something that increases a person's chance of developing an illness such as cancer.

S

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

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

Sentinel node biopsy (SNB) Identifies whether or not the first lymph node (or nodes) is clear of cancer cells.

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

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

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

Side effect Unwanted effect of treatments.

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

Stable disease The cancer has stayed the same size or has grown only a little.

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

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

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

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

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

T

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

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

Taxol see **Paclitaxel**

Taxotere see **Docetaxel**

T-DM1 Also called Kadcyla. A targeted therapy used to treat HER2 positive breast cancer.

TENS machine A small portable device which uses adhesive skin pads to deliver small electrical impulses to help relieve pain.

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

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

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

Trastuzumab Also called Herceptin. A targeted therapy used to treat HER2 positive breast cancer, and one of a group of drugs called monoclonal antibodies.

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

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

U

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

V

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

W

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

X

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

Z

Zoladex see **Goserelin**

Notes

Breast Cancer Care publications

Below are the names of some of our publications. To order any, tick the boxes next to the titles you want and send this form to the address on the other side of this page.

Alternatively, our full range of publications is free to order or download from our website **breastcancercare.org.uk/publications**, or call our Helpline on **0808 800 6000**

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4 ways to get support

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Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm and Saturday 9am–1pm).

Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at **forum.breastcancercare.org.uk**

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About this booklet

Primary breast cancer resource pack was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.

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