Treatments and side effects

breast cancer care

Treating breast cancer

personal experience professional support

Contents

Introduction	**5**
Types of breast cancer	**7**
Ductal carcinoma in situ (DCIS)	8
Invasive breast cancer	8
Grade, size and stage of the cancer	**11**
Grade	11
Tumour, Node and Metastases (TNM) cancer staging system	12
Other tests to help decisions about your treatment	**15**
Hormone receptor test	15
HER2 test	16
The multidisciplinary team	**17**
Discussing treatment options	**18**
Questions you may want to ask	18
Asking for a second opinion	19
Declining treatment	19
Online decision-making tools	20
Treatment for younger women with breast cancer	21
Treatment	**22**
Ductal carcinoma in situ (DCIS)	22
Invasive breast cancer	22
Surgery	23
Chemotherapy	29
Radiotherapy	30
Hormone (endocrine) therapy	31
Targeted therapies	32
Treating breast cancer that is ‘triple negative’	33
Clinical trials	33

Cancer-related fatigue 34

Complementary therapies 35

After treatment 36

Further support 38
Breast Cancer Care 38
Other organisations 40

Introduction

This booklet describes the range of treatments you may be offered if you have been diagnosed with primary (early) breast cancer (breast cancer that is not known to have spread beyond the breast or the lymph nodes (glands) under the arm (the axilla). Although we sometimes refer to 'women' in the text, most of the information also applies to men who have been diagnosed with breast cancer. Men may find it more helpful to read our Men with breast cancer publication.

Breast cancer is not one single disease, there are several types. It can be diagnosed at different stages of development and can grow at different rates. It's difficult to predict what course breast cancer will take in each person. Your specialist team will consider a number of different factors when working out the best treatment for you. These may include whether you are pre- or post-menopausal, your general health and specific information found out about your cancer from breast tissue removed during a biopsy or surgery.

Treatment for breast cancer can include surgery, chemotherapy, radiotherapy, hormone therapy or targeted therapy, either alone or in any combination or order.

We hope this booklet will give you a better understanding of what treatments you may be offered and why. You may find this information helpful when you're talking to your specialist team about your treatment.

We refer to 'your doctors' or 'your specialist team' throughout this booklet because it's recommended that breast cancer treatment is carried out by different specialists who work together as a multidisciplinary team (see page 17).

You will usually have access to a breast care nurse who is a member of the specialist team treating you. There should be opportunities for you to discuss your treatment options with your breast care nurse or another member of the specialist team and to ask any questions.

We recommend that you use this booklet alongside our:

- **Resource pack for primary (early) breast cancer**. The resource pack complements the information in this booklet and gives you somewhere to keep all the details about your treatment.
- **Breast cancer and you: diagnosis, treatment and the future**, which looks at some of the emotional issues that can arise in the early weeks and months after a diagnosis.

Once breast cancer is confirmed, your specialist team will discuss your treatment options with you and prepare a treatment plan. However, your treatment plan may change as more information about your breast cancer becomes available (such as the results of tests done on the breast tissue removed during an operation).

We have more detailed information on each of the different treatment options, including surgery, chemotherapy, radiotherapy, hormone therapy and targeted therapy. We recommend you read the publications on your specific treatments when you know what these will be.

Types of breast cancer

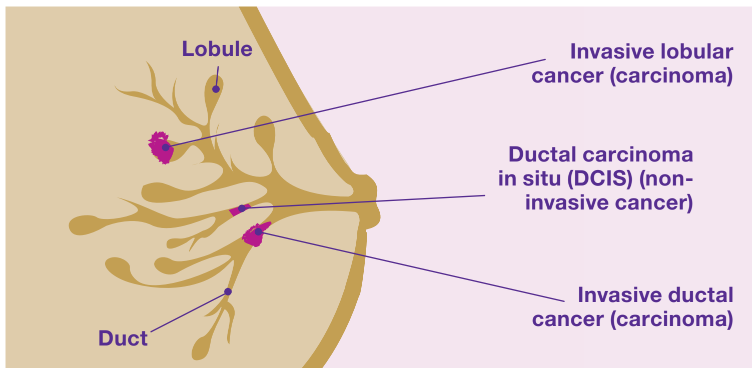
Breasts are made up of lobules (milk-producing glands) and ducts (tubes that carry milk to the nipple), which are surrounded by glandular, fibrous and fatty tissue. Breast cancer, also known as carcinoma of the breast, starts when cells in the breast begin to divide and grow in an abnormal way.

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

Breast cancer can be non-invasive (also described as 'in situ') or invasive. Non-invasive breast cancer has not yet developed the ability to spread into surrounding breast tissue or to other parts of the body. Invasive breast cancer does have the potential to spread to other areas of the body.

Having breast cancer in one breast means you have a very slightly higher risk of developing cancer in the other breast compared to someone who has never had breast cancer.

Different types of breast cancer



Ductal carcinoma in situ (DCIS)

Ductal carcinoma in situ (DCIS) is an early form of breast cancer, sometimes described as intraductal or non-invasive cancer. This means that the cancer cells are inside the milk ducts (in situ) and have not yet developed the ability to spread either outside the ducts into surrounding breast tissue or to other parts of the body. There are three different grades of DCIS (see page 11). If DCIS is left untreated, the cells may eventually develop the ability to spread and become invasive breast cancer.

DCIS does not usually have any noticeable symptoms (although it may sometimes be felt as a lump). It's most commonly diagnosed following a routine mammogram (breast x-ray) as part of a national screening programme.

For more information see our **Ductal carcinoma in situ (DCIS)** factsheet.

Invasive breast cancer

The majority of breast cancers are invasive. This means they have the potential to spread to other areas within the breast or through the lymph system or bloodstream to somewhere else in the body. If you have invasive breast cancer it doesn't mean the cancer has or will spread, just that this is a possibility.

Invasive ductal breast cancer of no special type

The most common breast cancers are invasive ductal breast cancers of no special type (NST), also referred to as not otherwise specified (NOS). This means that when the cancer cells are looked at under a microscope they have no distinct features that class them as a particular type.

For more information read our **Invasive ductal breast cancer** factsheet.

Other breast cancers are known as special type. This means when the cancer cells are looked at under a microscope they do have distinct features that class them as a particular type and make them different from each other. There are several special type breast cancers which are described opposite. Generally they are treated in the same way as invasive breast cancer of no special 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 begun to spread outside the lobules and into the breast tissue. Invasive lobular breast cancer is generally no more serious than other types of breast cancer.

For more information see our **Invasive lobular breast cancer** factsheet.

Inflammatory breast cancer

Inflammatory breast cancer is a rare type of breast cancer. It can grow more quickly than other types and there is a higher chance that the cancer cells may spread to other parts of the body.

Inflammatory breast cancer 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. The reddened appearance is caused by breast cancer cells blocking tiny channels (called lymph channels) in the breast tissue. The lymph channels are part of the lymphatic system involved in the body's defence against infections.

For more information see our **Inflammatory breast cancer** factsheet.

Paget's disease of the breast

Paget's disease of the breast is not the same as Paget's disease of the bone. It's an uncommon type of breast cancer that usually first shows as a change to the nipple. These changes are a sign that there is breast cancer behind the nipple, which may be invasive or in situ.

The most common symptom is a red, scaly rash involving the nipple, which may spread to the areola (the darker skin around the nipple). The rash can feel itchy or there may be a burning sensation. The nipple may be pulled in (inverted) and there may also be some discharge. The symptoms of Paget's disease can look like other skin conditions such as eczema or psoriasis.

For more information see our **Paget's disease of the breast** factsheet.

Malignant phyllodes tumours of the breast

These are rare and account for less than 1% of breast cancers. They usually appear as a smooth, hard lump of tissue that grows in the supportive tissue (stroma) of the breast. They can grow quickly and become quite large.

For more information see our **Phyllodes tumours: malignant and borderline malignant** factsheet.

Other special types of breast cancer

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

For more information on other types of breast cancer please see our individual factsheets and webpages.

Grade, size and stage of the cancer

In addition to the type of breast cancer you have, your specialist team will also look at the grade, size and stage of the cancer to help decide on the most appropriate treatment for you.

Grade

Cancer cells are given a grade according to how different they look to normal breast cells and how quickly they are growing. With invasive breast cancer there are three grades:

- grade 1 cancer cells look most like normal cells and are usually slow-growing
- grade 2 cancer cells look less like normal cells and grow faster
- grade 3 cancer cells look different to normal cells and are usually fast-growing.

With ductal carcinoma in situ (DCIS) there are also three grades and these are usually called

- low
- intermediate
- high.

For more information see our **Understanding your pathology report** booklet.

The extent of the spread of a cancer and its size is known as the stage of the disease. There are different ways to describe breast cancer stages, the most common of which is explained on the following pages.

Tumour, Node and Metastases (TNM) cancer staging system

This is a scoring system used to describe the size of the tumour (cancer) (T), the number of lymph nodes affected and (N) whether there is any spread of the cancer to other parts of the body (M is for metastases).

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

An example of breast cancer staging

Stage 1 – This is divided into two groups as follows:

- **stage 1A** the cancer is less than 2 centimetres (cm), the lymph nodes do not contain cancer cells (see page 26) and the cancer has not spread outside the breast.
- **stage 1B** no cancer is seen in the breast and there are a few cancer cells in the lymph nodes under the arm

  or the cancer is less than 0.2cm with a few cancer cells in the lymph nodes under the arm.

Stage 2 – this is divided into two groups as follows:

- **stage 2A** – the cancer is less than 2cm and the lymph nodes under the arm are affected

  or the cancer is more than 2cm but less than 5cm and there are no cancer cells in the lymph nodes under the arm

  or although no cancer is seen in the breast, there are 1–3 lymph nodes under the arm that contain cancer cells or in the lymph nodes near the breastbone (sternum).
- **stage 2B** – the cancer is larger than 2cm but less than 5cm and there are cancer cells in the lymph nodes under the arm or in the lymph nodes near the breastbone

  or the cancer is larger than 5cm and there are no affected lymph nodes under the arm.

Stage 3 – this is divided into three groups as follows:

- **stage 3A** – although no cancer is seen in the breast, cancer is found in 4–9 lymph nodes under the arm or in the lymph nodes near the breastbone

  or the cancer is larger than 2cm but less than 5cm and cancer is found in 4–9 lymph nodes under the arm or in the lymph nodes near the breastbone

  or the cancer is larger than 5cm, there are lymph nodes under the arm that contain cancer cells or in the lymph nodes near the breast bone

- **stage 3B** – the cancer is fixed to the skin or chest wall with no cancer cells in the lymph nodes under the arm

  or the cancer is fixed to the skin or chest wall, with up to 9 lymph nodes under the arm or the lymph nodes near the breastbone affected.

- **stage 3C** – the cancer can be any size and has spread to 10 or more lymph nodes under the arm and near the breastbone, or to nodes above the collarbone (supraclavicular fossa nodes) or below the collarbone (infraclavicular nodes).

Stage 4 – the cancer can be any size, the lymph nodes may or may not contain cancer but the cancer has spread to other organs of the body, such as distant lymph nodes, lungs, bones, liver or brain.

If your cancer is found in the lymph nodes under the arm but nowhere else in the body you do not have stage 4 breast cancer.

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 secondary, metastatic or advanced breast cancer. For more information see our **Secondary breast cancer resource pack** and factsheets.

The aim of treatment for primary breast cancer is to reduce the risk of the cancer returning in the breast or spreading to other parts of the body. If your cancer is high grade, large or if it has affected the lymph nodes under the arm, you are at a higher risk of the breast cancer spreading to other parts of your body.

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 and what they involve. These tests may include:

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

If you want to know more about the staging system your hospital uses, or the stage of your cancer, ask your doctor 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 are offered the most appropriate and effective treatment.

Hormone receptor test

All breast cancers are tested using tissue from a biopsy or after surgery to see if they have receptors within the cell that bind to the female hormone oestrogen and stimulate the cancer to grow (known as oestrogen receptor positive or ER+).

If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy (see page 31) they think is most appropriate.

When oestrogen receptors are not found (oestrogen receptor negative or ER-) tests may be done for progesterone (another female hormone) receptors. As oestrogen receptors play a more important role than progesterone receptors, the benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). 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.

See our **Understanding your pathology report** booklet for more information on oestrogen receptor testing.

HER2 test

Around 20% of breast cancers have a higher than normal level (called over expression) of a protein called HER2 on their cell surface, which stimulates them to grow. These cancers are called HER2 positive or HER2+.

HER2 testing 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 a drug from a group known as targeted therapies (see page 32). The most commonly used one is trastuzumab (Herceptin).

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

For more information on HER2 testing see our **Understanding your pathology report** booklet.

The multidisciplinary team (MDT)

The multidisciplinary team (specialist team) is a number of different specialists who work together to provide the best treatment and care. The MDT usually includes the following healthcare professionals:

- **surgeon(s)** or **oncoplastic surgeons** (a breast cancer surgeon with specific training in plastic surgery)
- **medical oncologist(s)** (cancer drug specialist)
- **clinical oncologist(s)** (radiotherapy and/or cancer drug specialist)
- **radiologist(s)** (specialises in the use of imaging, such as x-rays and ultrasound, to diagnose and treat disease)
- **breast care nurse** (provides information and support to anyone diagnosed with breast cancer)
- **chemotherapy nurse** (trained to give cancer drugs)
- **pathologist** specialist in examining tissue and cells
- **diagnostic radiographer** (trained to carry out x-rays and scans)
- **therapy radiographer** (trained to give radiotherapy treatment)
- **research nurse** (who can discuss the option of taking part in a clinical trial and what this might involve – for more on clinical trials see page 33).

You will see several members of the specialist team at different times during your treatment. Other healthcare professionals may also contribute to your care, such as counsellors, psychologists, plastic surgeons, physiotherapists and pharmacists.

Discussing treatment options

When your specialist team has all the information from the tests they will consider the best treatment for you. This is the point where you can decide how much, or how little, involvement you want.

Everyone is different. Some people want to know everything they can about their disease and expect to be fully involved in making choices about their treatment. Others may want to be well informed about what is going on but prefer to leave the treatment decisions to their doctors. Some may want to know as little as possible and let the decisions be made by their doctors. You can change your mind about how much involvement you want at any stage of your treatment.

Whatever you decide, you don't have to be rushed into treatment. A few extra days to think about what you really want, and a chance to discuss your options with your breast care nurse, partner, friends, family or GP (local doctor), will make no difference to the progress of the disease.

Questions you may want to ask

You will probably have some questions and you should feel free to ask for as much information as you need. Questions might include:

- why is this the best treatment for me?
- are there any other options?
- how long will my treatment take?
- what are the possible side effects?
- are there any long-term implications for me?
- how will the treatment impact on my everyday life?
- will the treatment affect my fertility?
- where will I need to go for treatment? Will I have to travel far?

Your specialist team will be able to explain anything you don't understand.

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 necessarily 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 again there is no evidence to suggest this will make a difference to the outcome.

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 the alternatives carefully before making a final decision and think about staying in touch with your specialist team for continuing support. You may also want to discuss your decision with your GP.

Online decision-making tools

There are a number of online decision-making tools designed to help your doctors and you make an informed decision about your treatment, from considering which type of surgery to have to what other treatment to have after surgery. Some examples are below but your specialist team may mention others to you as well.

- **BresDex**
  BresDex (Breast Cancer Decision Explorer) is an interactive decision-making tool for women recently diagnosed with breast cancer who have been given a choice between breast conserving surgery (lumpectomy or wide local excision) followed by radiotherapy, or mastectomy (removal of all the breast tissue including the nipple area). For more information visit the BresDex website www.bresdex.com

- **Adjuvant! Online**
  Adjuvant! Online 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 makes estimates about the benefits of chemotherapy, hormone therapy and targeted therapies after surgery based on information about you and your breast cancer. It can be accessed by your specialist team and the public. For more information visit the PREDICT website: www.predict.nhs.uk

- **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 11). You're given a score which puts you into a prognostic category of good, moderate or poor. Five year survival is then estimated depending on which category you're placed in.

  For more information visit Cancer Research UK's website: www.cancerresearchuk.org

- **Oncotype DX test**
  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 be of help to you.

Treatment for younger women with breast cancer

Women who have not reached the menopause when they are diagnosed with breast cancer often face additional concerns when making decisions about their treatment. Uncertainty over the impact of treatments on fertility, new relationships, family life and career opportunities may all affect treatment decisions.

Take the time to think about what you want, both now and in the future. Only you can decide on the treatment that's right for you. For more information see our **Younger women with breast cancer** booklet and **Fertility issues and breast cancer treatment** factsheet.

Treatment

Ductal carcinoma in situ (DCIS)

DCIS (see page 8) may, if left untreated, develop into invasive cancer. Low-grade DCIS is less likely to become an invasive breast cancer than high-grade DCIS. Treatment for non-invasive cancer therefore aims to remove the cancer before it develops the ability to spread.

Currently, there is no single approach suitable for everyone with DCIS and the treatment offered to you will depend on factors such as the extent of the DCIS, the grade and where it is within the breast. Treatment will usually include surgery (either breast-conserving surgery or a mastectomy with or without reconstruction) to remove the affected area.

Breast-conserving surgery may be followed by radiotherapy – see below for more information on these treatments. Once the breast tissue has been removed and examined, it may be that invasive cancer is found as well as non-invasive cancer. If this is the case it may alter your recommended treatment.

For more information please see our **Ductal carcinoma in situ (DCIS)** factsheet.

Invasive breast cancer

Treatment aims to:

- remove the cancer in the breast and any affected lymph nodes under the arm – this is called local control. Surgery and radiotherapy are treatments for local control.

- destroy any cancer cells that may have already spread from the breast into the body through the bloodstream or the lymphatic system and to reduce the risk of cancer affecting other parts of the body in the future – this is called systemic treatment. Chemotherapy, hormone therapy and targeted therapy are all types of systemic treatment.

You will be recommended combinations of these treatments depending on the individual characteristics of your cancer and your general health.

Surgery

Surgery is the first treatment for most people with breast cancer. The aim is to remove the cancer with a margin (border) of normal breast tissue to reduce the risk of the cancer coming back in the breast (known as local recurrence) and to try to stop any spread elsewhere in the body. National guidance states that following a diagnosis of breast cancer you should have your planned surgery within 31 days of you agreeing to have treatment.

The type of breast surgery recommended for you depends on the type and size of the cancer, where it is in the breast and how much surrounding tissue needs to be removed. It will also depend on the size of your breasts. 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 (called primary or neo-adjuvant treatment). This may result in less extensive surgery.

There are two main types of breast surgery. The illustrations of the different types of surgery are shown on page 25.

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 trying to ensure the cancer has been completely removed.

A far less common operation is a quadrantectomy, where approximately a quarter of the breast is removed (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, there is increasing use of oncoplastic surgical techniques, which means combining breast cancer surgery with plastic surgery. This means there is less likely to be a visible indentation and that the shape and symmetry of the breasts are maintained. For more information see our **Breast reconstruction** booklet.

Your pathology report will say how close the cancer cells are to the edges. If the cancer cells do reach the edge of the tissue you may need more surgery and this can sometimes mean having a mastectomy to ensure all the cancer has been removed.

Mastectomy

This means removal of all the breast tissue including the skin and nipple area (called a simple mastectomy). You may also have some or all of the lymph nodes removed with the breast tissue (see page 26). If you are going to have a mastectomy your breast surgeon will discuss breast reconstruction with you (see page 28).

If you're going to have a breast reconstruction at the same time as the mastectomy (immediate breast reconstruction), depending on your individual situation, your breast surgeon may discuss other types of mastectomy.

- **A skin sparing mastectomy**
  This is removal of the breast and nipple area without removing much of the overlying skin of the breast.

- **A nipple-sparing mastectomy**
  This is removal of all the breast tissue, without removing much of the overlying skin and the nipple area of the breast.

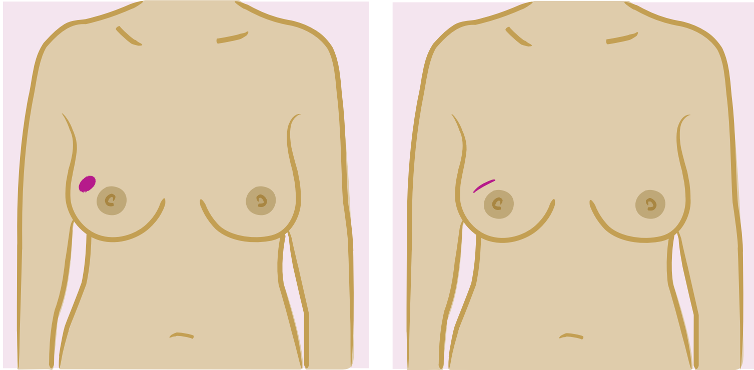
For many cases of either non-invasive or invasive cancer, breast-conserving surgery followed by radiotherapy is sufficient treatment for local control. In other cases, a mastectomy will be recommended. Your specialist team will explain why they think a particular operation is best for you. Examples of when a mastectomy may be recommended include:

- the cancer takes up a large area of the breast

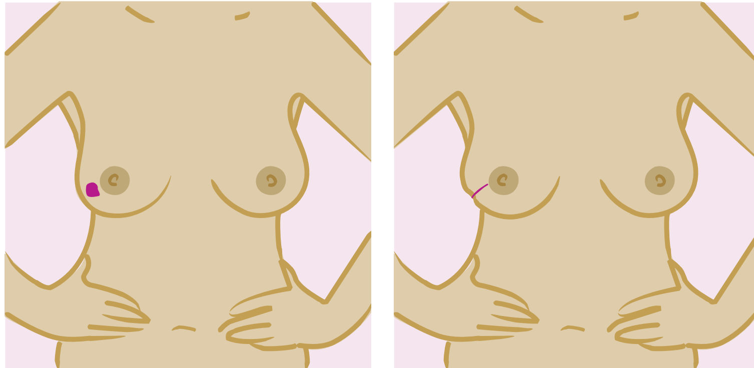
- there is more than one area of cancer in the breast.

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

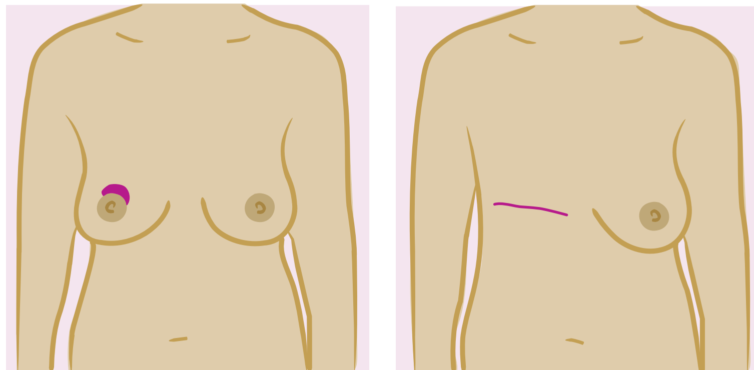
Breast-conserving surgery (wide local excision or lumpectomy)



Breast-conserving surgery (quadrantectomy or segmental excision)



Mastectomy (simple mastectomy)



NB Exact location of scar/s will vary according to size and site of the cancer and the type of surgery.

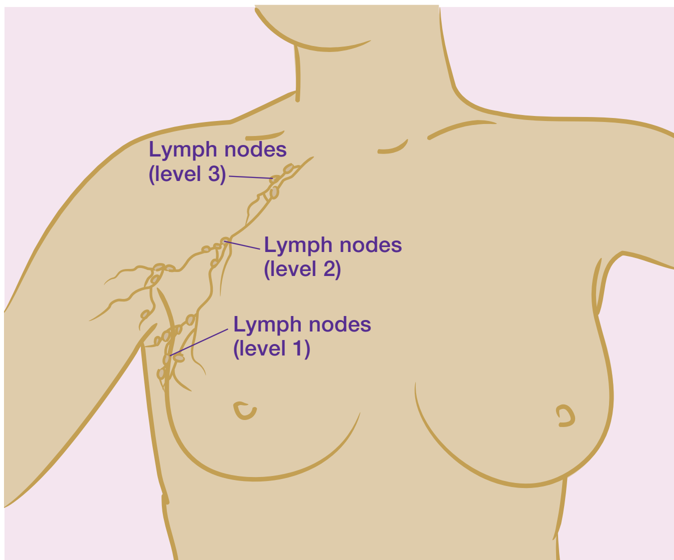
Which operation?

Some people will be offered a choice between breast-conserving surgery and a mastectomy. More than half of early stage breast cancers are treated by breast-conserving surgery, usually followed by radiotherapy. Studies have shown that long-term survival is the same for breast-conserving surgery followed by radiotherapy as for mastectomy. You may find it helpful to talk through your choices with your breast care nurse. Bresdex is an online decision-making tool that can help some people make a decision if they aren't sure which surgery is best for them (see page 20.)

See our **Your operation and recovery** booklet to read more about what to expect before your admission to hospital, during your stay, when you return home and during your recovery from surgery.

Surgery to assess and/or remove lymph nodes

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



The above 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 (glands) under the arm (the axilla) contain cancer cells. This helps them decide whether or not 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, an FNA (fine needle aspiration) will be done to see if the cancer has spread to the lymph nodes. In this case you will 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).

Even if the tests before surgery show no evidence of the lymph nodes containing cancer cells, you may still need to have a sample of the lymph nodes from level one 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.

Sentinel lymph node biopsy is usually carried out at the same time as your cancer 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.

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 (primary or neo-adjuvant treatment), 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.

Lymphoedema risk following surgery under the arm (axilla)

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

Lymphoedema is a chronic (long-term) condition which can be a distressing side effect of breast cancer and its treatments. It can develop months, or even years, after treatment. For more information, including precautions you can take, see our **Reducing the risk of lymphoedema** factsheet.

Breast reconstruction

National guidance states if you are advised to have a mastectomy, your specialist team should discuss breast reconstruction with you.

Breast reconstruction can be done at the same time as your mastectomy (immediate reconstruction) or months or years later (delayed reconstruction).

You may be offered a delayed reconstruction if there are medical reasons why an immediate reconstruction isn't possible.

There are a number of different types of breast reconstruction but they may not all be suitable for you, depending on your age and general fitness, your body shape, the type of breast cancer you have and any future treatment you may need.

You might need to be referred to another surgeon within the same hospital or a hospital elsewhere if a particular reconstruction option is not available within your specialist team. You may need more than one operation and/or surgery to the other breast for the best cosmetic result. You can discuss the details with the surgeon who is going to do the operation and ask to see photographs of the results of other operations they have done.

If you prefer to wait and see how you feel after surgery, then tell your specialist. Some women decide later that they would like to have a reconstruction. Others find that while waiting they become used to

living without a breast or adapt to wearing a prosthesis (see below) and eventually decide against having a reconstruction.

For more detailed information see our **Breast reconstruction** booklet.

Breast prostheses (artificial breast forms)

If you have a mastectomy and don't have a reconstruction you may want to wear a prosthesis to restore your breast shape. There are several different types of prostheses available, including those that fit inside a bra and those that stick directly to the skin.

The NHS entitles you to both a temporary (soft fibre-filled) prosthesis called a softie or comfy and permanent (silicone) prosthesis without having to pay for them. Your breast care nurse, ward nurse or the hospital's appliance officer can fit you with a temporary prosthesis before you go home after surgery. After about six to eight weeks, when your wound has healed, you can be fitted with a permanent prosthesis.

For more detailed information see our booklet **A confident choice: breast prostheses, clothes and bras**.

Chemotherapy

Chemotherapy is treatment using anti-cancer (also called cytotoxic) drugs which aims to destroy cancer cells. It's known as a systemic treatment because the whole body is exposed to the drugs. Chemotherapy can be given before surgery (called primary or neo-adjuvant chemotherapy), or after surgery (called adjuvant chemotherapy) and before radiotherapy. The aim of chemotherapy is to destroy any cancer cells that may have spread from the breast to other parts of your body. Primary chemotherapy may also reduce the size of the breast cancer.

Your specialist team will make a decision about whether to recommend chemotherapy depending on the type of breast cancer you have, whether or not the lymph nodes are affected and the size and grade of the cancer. Following surgery, your doctors may use one of the decision-making tools described on page 20 to decide if chemotherapy is suitable for you.

There are many different types of chemotherapy drugs and they can be used in different combinations. Chemotherapy can also be given in different ways, for example, into a vein (intravenously) in the hand or arm

or by mouth (orally) as a tablet or capsule. However, chemotherapy drugs, will usually be given intravenously for primary breast cancer.

Chemotherapy drugs can cause side effects and many people worry about this part of their treatment. Some of the most common side effects are nausea and vomiting, hair loss or thinning, sore mouth, mouth ulcers, tiredness and a temporary drop in a number of blood cells (white blood cells, red blood cells and platelets). A drop in white blood cells can mean you are temporarily at greater risk of infection. Side effects will vary according to the drugs you are given and your specialist team will prescribe other drugs to help you cope with them.

Your chemotherapy will usually start a few weeks after surgery, giving 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 why it cannot be given, for example a wound infection.

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 specific chemotherapy factsheet(s).

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.

If you have had breast-conserving surgery you will usually be given 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 underarm (axilla) instead of surgery or following sentinel lymph node biopsy.

Depending on the grade, stage and lymph node involvement of the breast cancer, radiotherapy may also be recommended to the lymph nodes on the side of your neck, around your collarbone (called supraclavicular fossa (SCF) nodes), only on the side you have had your surgery.

If you're also going to have chemotherapy as part of your treatment, radiotherapy is usually given after chemotherapy has finished. It's given as an outpatient over a few weeks.

Once you have been assessed by your specialist team as being ready to receive radiotherapy (after surgery or chemotherapy), national guidance states that treatment should begin within 31 days of you agreeing to the treatment. However, some people have to wait a bit longer. Radiotherapy may also be delayed for medical reasons, such as waiting for a surgical wound to heal.

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

Hormone (endocrine) therapy

You may be advised to have hormone therapy if tests show your breast cancer is hormone receptor positive (see 'Hormone receptor test' on page 15). Your specialist team will discuss with you which hormone therapy they think is most appropriate.

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

Women can have hormone receptor positive breast cancer whether or not they've been through the menopause. Before the menopause the ovaries produce most of the oestrogen circulating around the body. After the menopause the ovaries no longer produce oestrogen. However, small amounts are still produced in a woman's body fat and can still affect breast cancer growth.

Examples of breast cancer hormone therapies include tamoxifen, anastrozole (also known as Arimidex), letrozole (also known as Femara), exemestane (also known as Aromasin) and goserelin (also known as Zoladex). The type of hormone therapy given will depend on a number of factors such as whether you are pre- or post-menopausal and 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** factsheet.

If you are having chemotherapy, hormone therapy is usually given afterwards and is taken for several years. Some people have the same drug throughout, 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, for example, when a person is not fit enough to have an anaesthetic.

In pre-menopausal women, the ovaries can be stopped permanently (called ovarian ablation) by surgery to remove the ovaries (called a bilateral oophorectomy) or by radiotherapy to the ovaries. Your doctor or breast care nurse will explain what is involved if ovarian ablation is an option for you.

Targeted therapies

This is a group of drugs that block the growth and spread of cancer by interfering with the biology of the cancer cells. They target specific processes in the cells that cause cancer to grow. Targeted therapies may be more effective and less harmful to normal cells than other cancer treatments.

The most well-known targeted therapy is trastuzumab (Herceptin). Only people whose cancer has high levels of HER2 (HER2 positive), a protein that makes cancer cells grow, will benefit from having trastuzumab.

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 will not be of benefit to you. For more information see our **Trastuzumab (Herceptin)** factsheet.

The benefits of other targeted treatments for different types of breast cancer are being looked at in clinical trials, so it is likely more targeted therapies will become available in the future.

Treating breast cancer that is 'triple negative'

Breast cancers which are oestrogen (ER), progesterone (PR) and HER2 negative are sometimes referred to as triple negative. Currently, chemotherapy is the only drug treatment given outside of clinical trials for triple negative early breast cancer.

There is research being conducted to discover what stimulates triple negative breast cancers to grow, which means new drugs may be developed that work by interfering with this process. There are also chemotherapy trials under way looking at the best drug combinations to treat people with breast cancer that doesn't respond to hormone therapy or targeted therapy.

Clinical trials

Researchers are constantly trying to improve breast cancer treatments, so you may be asked to take part in a clinical trial. Clinical trials are research studies that aim to improve the treatment and care for patients. They may be used to test new drugs or other treatments such as types of surgery, varying doses of radiotherapy and differences between treatments – for example giving combinations of drugs every two weeks rather than every three weeks.

You will not be entered into a trial without your knowledge and without giving your informed consent. This means fully understanding the purpose of the trial, why you are considered suitable for it and what it will mean for you. You should be given detailed written information and plenty of time to discuss your options with a research nurse and/or your specialist team.

If you have been asked to take part in a clinical trial and you decide not to you will continue to have treatment and care as before. The decision is entirely up to you.

To find out what clinical trials are currently being carried out in the UK, visit Cancer Research UK's website: www.cancerresearchuk.org

Cancer-related fatigue

Fatigue is a very common side effect of breast cancer treatment and it may last for weeks, months or even years. Everyone knows what it feels like to be tired sometimes, but fatigue can feel much more severe. It can come and go or be unrelenting and doesn't improve with rest or sleep.

It's now recognised how distressing fatigue can be, possibly affecting concentration and causing feelings of anger, anxiety and frustration. If fatigue is affecting your life, talk to a member of your specialist team as they may be able to help you manage it. It is also important to exclude any medical reason for fatigue, for example iron deficiency anaemia (too few red blood cells), which can be easily treated.

You may also find it helpful to:

- keep a fatigue diary so you can identify any patterns
- adapt your routine to make life easier for yourself – for example, cook in batches, shop at quiet times, use a towelling robe to dry yourself rather than a towel
- try to have short achievable amounts of physical activity each day; even just a short walk can help
- let people know how you are feeling and what they can do to help.

Many studies looking at women treated for breast cancer suggest that at least 30 minutes of gentle exercise, such as going for a walk three times a week, significantly reduces fatigue levels, improves sleep patterns and quality, and generally improves quality of life.

Complementary therapies

Some people with breast cancer use complementary therapies alongside their conventional medical treatments. They are different from 'alternative' therapies, which are used instead of conventional treatments.

There's been very little reliable research into complementary therapies, so it can be difficult to judge how effective they are and whether they could affect your conventional treatment.

You should always tell your breast care nurse or doctor about the complementary therapy you want to use to ensure it won't affect any other treatment you're receiving.

For more information see our **Complementary therapies** booklet.

After treatment

Follow-up after treatment for breast cancer varies from hospital to hospital. You may be invited back to the hospital for follow-up appointments to check how you are recovering physically and emotionally.

The time between appointments will vary in each hospital and for each person depending on their individual situation. Some people are given a choice of being followed up by their GP or a mixture of both hospital and GP appointments. Some hospitals provide a system where people have access to a clinic appointment to be seen by a specialist only if or when they have a worry or concern. Others arrange regular telephone follow-up appointments.

You should be given a name and contact number (this will usually be for a breast care nurse) should you have any concerns or symptoms. You should also be given information about any future mammograms. You can also see your GP between appointments.

You may find it helpful to read our booklet **Your follow-up after breast cancer: what's next?** This discusses what happens at the end of treatment and looks at some of the common concerns as well as explaining the various options you may have about follow-up appointments.

Completing treatment can be a strange and often difficult time. After coping with both the physical and emotional demands of cancer and its treatment, it may seem a bit of an anti-climax, especially if you expected to feel relieved and happy it's all over. You may feel quite isolated, let down or even abandoned, particularly if you've had weeks or months of close attention from family and friends as well as the doctors and nurses caring for you.

You and the people close to you will be expecting things to get back to normal once treatment has finished. After what you've been through, it may not be easy just to go back to work, look after the family or pick up social activities again as if nothing had happened. Some things may have changed. For example, at home partners or children may be more independent and at work new systems may have been introduced while

you were away. You might need some time to see how you fit back into your old life or adapt to your changing role.

After treatment you may have time to reflect on what has happened to you. If there have been permanent changes in the way you look or feel it can take a long time to get used to them and to adjust to life after breast cancer treatment.

Many people worry about whether their cancer has really gone and about whether it will come back. It may take time for you to regain trust in your body and not to assume that every ache and pain is the cancer returning.

Some events may prove particularly stressful: follow-up appointments may bring back old fears and worries about the cancer returning; the discovery that a friend or relative has been diagnosed with cancer; the news that someone you met while having treatment is ill again or has died. Everyone deals with these anxieties in their own way and there are no easy answers.

The effects of your breast cancer may continue for many years following treatment. Situations may arise that remind you about it when you least expect it. However, time may also bring a greater understanding of what has happened to you and the best way to deal with these situations.

As time goes by, you may find that your breast cancer is no longer such a big part of your everyday life but continues to be an experience that has shaped you and your outlook. People do manage to look forward, make new plans and resume ones that had to be put on hold.

We recognise that the time at the end of treatment can be especially difficult. So we’ve developed a **Moving Forward resource pack** and range of services to support people at the end of their hospital-based treatment. You can find out more about these from our Helpline **0808 800 6000** or visit **www.breastcancercare.org.uk/movingforward**

Further support

Breast Cancer Care

From diagnosis, throughout treatment and beyond, our services are here every step of the way. Here is an overview of all the services we offer to people affected by breast cancer. To find out which may be suitable for you call our Helpline on **0808 800 6000** or contact one of our centres (details in the inside back of this booklet).

Helpline

Our free, confidential Helpline is here for anyone who has questions about breast cancer or breast health. Your call will be answered by one of our nurses or trained staff with experience of breast cancer. Whatever your concern, you can be confident we will understand the issues you might be facing, and that the information you receive is clear and up to date. We will also let you know where else you can go for further support.

Ask the Nurse

If you prefer not to talk directly, we can answer your questions by email instead. Our Ask the Nurse service is available on the website – complete a short form that includes your question and we'll get back to you with a confidential, personal response.

Website

We know how important it is to understand as much as possible about your breast cancer. Our website is here round the clock giving you instant access to information when you need it. As well as clinical information, you'll find real life experiences and a daily newsblog on stories about breast cancer in the media. It's also home to the largest online breast cancer community in the UK, so you can share your questions or concerns with other people in a similar situation.

Our map of breast cancer services is an interactive tool, designed to help you find breast cancer services in your local area wherever you live in the UK. Visit **www.breastcancercare.org.uk/map**

Discussion Forum

Through our Discussion Forum you can exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns online. Our dedicated areas for popular topics should make it easy for you to find the information you're looking for. The Discussion Forum is easy to use and professionally hosted. If you're feeling anxious or just need to hear from someone else who's been there, it offers a way to gain support and reassurance from others in a similar situation to you.

Live Chat

We host weekly Live Chat sessions on our website, offering you a private space to discuss your concerns with others – getting instant responses to messages and talking about issues that are important to you. Each session is professionally facilitated by a moderator and a specialist nurse.

One-to-One Support

Our One-to-One Support service can put you in touch with someone who knows what you're going through. Just tell us what you'd like to talk about (the shock of your diagnosis, understanding treatment options or how you feel after finishing treatment, for example), and we can find someone who's right for you. Our experienced volunteers give you the chance to talk openly away from family and friends.

Information Sessions and Courses

We run Moving Forward Information Sessions and Courses for people living with and beyond breast cancer. These cover a range of topics including adjusting and adapting after a breast cancer diagnosis, exercise and wellbeing, and managing the long term side effects of treatment.

Lingerie Evenings

For more confidence when choosing a bra after surgery, come along to a Lingerie Evening. Join other women who have had breast cancer for a practical guide to what to look for in a bra, an opportunity to be fitted and a chance to see how the lingerie looks on volunteer models who have all had breast cancer themselves.

HeadStrong

We can help you prepare for the possibility of losing your hair due to cancer treatment. We'll talk through how to look after your hair and scalp and show you how to make the most of alternatives to wigs, so you leave feeling that you've found something that works for you.

Information Resources

We produce free Information Resources for anyone affected by breast cancer, including factsheets, booklets and DVDs. They are here to answer your questions, help you make informed decisions and ensure you know what to expect. All of our information is written and reviewed regularly by healthcare professionals and people affected by breast cancer, so you can trust the information is up to date, clear and accurate. You can order our publications from our website or our Helpline. They are also available to download as PDFs (or in some cases as e-books) at **www.breastcancercare.org.uk**

Specialist support

We offer specific, tailored support for younger women through our Younger Women's Forums and for people with a diagnosis of secondary breast cancer through our Living with Secondary Breast Cancer meet-ups.

Other organisations

Cancer Research UK

Angel Building
407 St John Street
London EC1V 4AD
Telephone: **020 7242 0200** Helpline: **0808 800 4040**
Website: **www.cancerresearchuk.org**

Cancer Research UK is the country's leading cancer research organisation. The CancerHelp section of their website includes information on breast cancer and its treatment.

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ
General enquiries: **020 7840 7840** Helpline: **0808 808 0000**
Website: **www.macmillan.org.uk**
Textphone: **0808 808 0121** or **Text Relay**

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. It also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

Find out more

We offer a range of services to people affected by breast cancer. From diagnosis, through treatment and beyond, our services are here every step of the way.

To request a free leaflet containing further information about our services, please choose from the list overleaf, complete your contact details and return to us at the **FREEPOST** address or order online at **www.breastcancercare.org.uk/publications**

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5–13 Great Suffolk Street, London SE1 0NS

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I'd like more information

Please send me:

- ☐ Diagnosis and treatment: support for you (SM39)
- ☐ Support for people living with and beyond breast cancer (SM23)
- ☐ Support for younger women with breast cancer (SM24)
- ☐ Support for people living with secondary breast cancer (SM25)
- ☐ Best foot forward: being active after breast cancer (SM36)

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☐ I enclose a cheque/PO/CAF voucher made payable to Breast Cancer Care. (Please don't post cash.)

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Thank you for your kind donation.

My details

Name ______

Address ______

______

Postcode ______

Email address ______

From time to time we may wish to send you further information on our services and activities.

- ☐ Please tick if you are happy to receive emails from us
- ☐ Please tick here if you do not want to receive post from us

Breast Cancer Care will not pass your details to any other organisation or third party.

I am a (please tick):

- ☐ person who has/who has had breast cancer
- ☐ friend/relative of someone with breast cancer
- ☐ healthcare professional
- ☐ other (please state) ______

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This booklet has been produced by Breast Cancer Care's clinical specialists and reviewed by healthcare professionals and people affected by breast cancer. If you would like a list of the sources we used to research this publication, email **publications@breastcancercare.org.uk** or call **0845 092 0808**.

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Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

Visit **www.breastcancercare.org.uk** or call our free Helpline on **0808 800 6000** (Text Relay **18001**).

Interpreters are available in any language. Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.

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