

# The best treatment

# Your guide to breast cancer treatment in England and Wales



If you are looking for information on the treatment of secondary breast cancer (also known as advanced or metastatic breast cancer), please see Breast Cancer Now's website: [breastcancernow.org/secondary](http://breastcancernow.org/secondary)

If you are looking for information on breast cancer in men, including treatment, see [breastcancernow.org/breastcancerinmen](http://breastcancernow.org/breastcancerinmen)

# About this booklet

**This booklet sets out the standards of care that women undergoing treatment for early breast cancer can expect in England and Wales. It explains the diagnosis and treatment of early breast cancer, which is breast cancer that has not spread beyond the breast and armpit lymph nodes. It talks through the care that women diagnosed with breast cancer may experience.**

This booklet:

- sets out how early breast cancer should be diagnosed and treated
- explains why you might be offered certain tests and treatments, and what to expect if you receive them
- gives you the information you need to be able to talk to your doctors and nurses and take part in decisions about your treatment.

Throughout the booklet, you will find further information in the margins:

- quotes from professional guidelines used by doctors and nurses to plan care and treatment, which you may find helpful in discussions with your breast care team
- quotes from women sharing their own experiences of breast cancer services (these women are Breast Cancer Now supporters)
- notes on where to find further information.

This booklet contains some medical terms that are frequently used by doctors and nurses and that you are likely to come across. You will find these terms explained on pages 62–65.

If you have any questions about the topics covered in this booklet, you may wish to contact our Information Line on Freephone 0333 20 70 300 or [info@breastcancernow.org](mailto:info@breastcancernow.org)

Every effort has been made to ensure this booklet is accurate. All information was reviewed by experts and people affected by breast cancer. It aims to give a good overview of the types of treatment available for breast cancer. However, decisions about an individual's breast cancer treatment and their wider care must be tailored to that individual, taking into account their full medical history, diagnosis, needs and preferences and, where appropriate, specialist medical advice.

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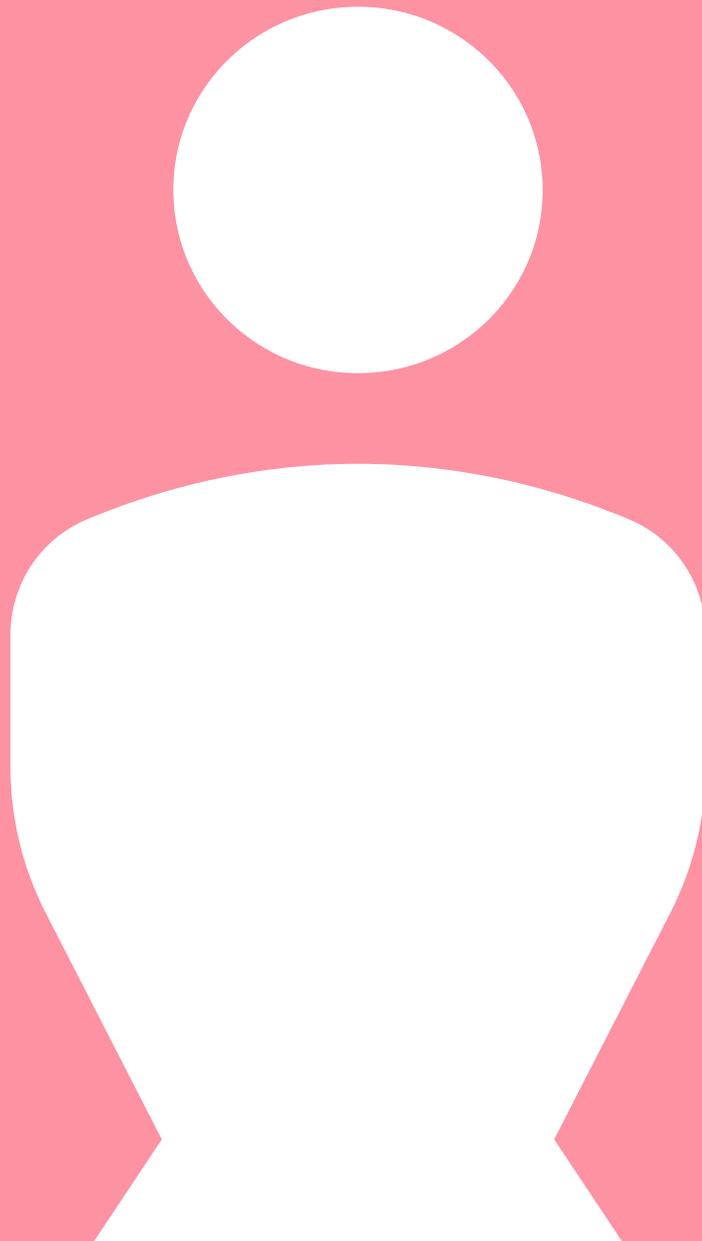
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# From referral to diagnosis

In this section we explain what to expect if you see your GP with unusual breast symptoms and in which instances they may refer you for assessment at a breast unit. We give information on the tests you may have at the clinic, what these may find and what happens next.



For more information on how to Touch Look Check your breasts for signs of breast cancer, see [breastcancernow.org/tlcbest](http://breastcancernow.org/tlcbest)

## What the guidelines say:

### Referral

[There is] a maximum two week wait from an urgent GP referral for suspected cancer to date first seen by a specialist for all suspected cancers.

*National cancer waiting times monitoring data set. NHS Connecting for Health, 2012.*

[Services should] ensure that patients are not only seen promptly but also, should they be found to have cancer, should complete diagnostic investigations and start treatment within an accepted time frame.

...Initially efforts have been directed to ensure that patients referred urgently with suspected cancer are offered an appointment with a member of the MDT [multidisciplinary team] within 10 working days.

*National standards for breast cancer services. Welsh Assembly Government, 2005.*

All patients referred to the breast clinic should receive an appointment within two weeks of the date of receipt of the referral.

*Best practice diagnostic guidelines for patients presenting with breast symptoms. Willett AM, et al, 2010.*

# The first steps

**If you notice any unusual changes to your breasts, it is important to get them checked by your GP. They can assess whether there might be anything wrong and can refer you for diagnostic tests at a hospital breast unit if needed.**

Most women going for diagnostic tests find that they do not have breast cancer. They may have a benign (non-cancerous) condition – some of these require treatment but others do not. If you have breast cancer, this can be confirmed by the diagnostic tests and you can begin appropriate treatment.

## Referral to a breast unit

If you have breast symptoms that might suggest you have breast cancer (see table overleaf), your GP should refer you to a hospital specialist. Everyone with suspected breast cancer should see a specialist promptly. In England, you should be seen by a specialist within two weeks. There is no specified maximum time patients should wait to see a specialist in Wales, though the *National standards for breast cancer services* (Welsh Assembly Government, 2005) emphasise the importance of patients being seen quickly and suggest that patients referred urgently with suspected cancer are offered an appointment within 10 working days.

## Your breast care team

It is recommended that investigations and treatment for breast cancer are carried out at a hospital with a breast unit and a specialist breast care team. This team would normally include:

- a breast surgeon and their supporting team
- a breast care nurse (or key worker/nurse consultant)
- a radiologist (a specialist in the use of x-rays and other imaging methods for diagnosis and treatment)
- an oncologist (cancer specialist)
- a pathologist (a specialist in the diagnosis of disease by the study of tissues and cells) and laboratory support staff.

The team – known as a multidisciplinary team (MDT) – will have experience diagnosing and treating breast cancer, seeing at least 100 new breast cancer patients a year.

## What women say

“It was good to know that several doctors and nurses were considering all the information and making a thorough diagnosis.”

Breast Cancer Now Supporter.

## What the guidelines say: Breast care teams

A patient who presents with symptoms suggestive of breast cancer should be referred to a team specialising in the management of breast cancer.

*Referral guidelines for suspected cancers.* National Institute for Health and Care Excellence (NICE), 2005.

It is now widely accepted that breast care should be provided by breast specialists in each discipline and that multidisciplinary teams form the basis for best practice.

*Surgical guidelines for the management of breast cancer.* Association of Breast Surgery at British Association of Surgical Oncology (BASO), 2009.

All clinicians treating breast cancer should be part of the multidisciplinary team and have designated time to attend the MDT [multidisciplinary team] meeting.

*National standards for breast cancer services.* Welsh Assembly Government, 2005.

Information on your local hospital can be found at NHS Choices [www.nhs.uk](http://www.nhs.uk) and NHS Wales [wales.nhs.uk](http://wales.nhs.uk)

## Symptoms that require a woman to be referred to a specialist clinic\*

Lump, lumpy area or change in skin texture	<ul style="list-style-type: none"> <li>• A lump that remains after your next period or that occurs after the menopause</li> <li>• A lump that appears attached to nearby skin, or that has pulled in the skin causing a dimple or change in breast shape</li> <li>• A lump that is growing</li> <li>• A lumpy area of tissue that does not go away</li> <li>• Changing breast size, with signs of fluid collection (oedema)</li> <li>• Changes (distortion) of the skin</li> <li>• In women who have had breast cancer before, a new lump or suspicious symptoms</li> </ul>
Nipple symptoms	<ul style="list-style-type: none"> <li>• Discoloured (blood stained) discharge from one nipple</li> <li>• Eczema on one nipple or another change to the nipple that does not get better with use of creams</li> <li>• Changes to nipple direction or shape, including the nipple becoming pulled in</li> </ul>
Breast pain	<ul style="list-style-type: none"> <li>• Women with minor or moderate breast pain who do not have a lump, if the pain has not improved with initial treatment (other symptoms may or may not be present)</li> </ul>
Lump in the armpit	<ul style="list-style-type: none"> <li>• Unexplained lump or swelling in the armpit that does not go away</li> </ul>

\* Adapted from: *Best practice diagnostic guidelines for patients presenting with breast symptoms.* Willett A M et al, 2010.

If your local hospital does not have a specialist breast care team, you can ask to be referred to a specialist breast unit at another hospital. In rural areas you may have to travel to a larger hospital with a specialist breast unit.

## What women say

“I was, not surprisingly, really anxious about what the lump in my breast might be. But having all the tests on the same day made the wait less drawn out.”

Breast Cancer Now Supporter

## What the guidelines say:

### Triple assessment

Wherever possible, a non-operative breast cancer diagnosis should be achieved by triple assessment (clinical and radiological assessment followed by core biopsy and/or fine needle aspiration). Whilst core biopsy is preferable due to the additional information it can provide, there may be circumstances where only a fine needle aspiration is possible.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

Diagnosis in the breast clinic is made by triple assessment (clinical assessment, mammography and/or ultrasound imaging with core biopsy and/or fine needle aspiration cytology). It is best practice to carry these assessments out at the same visit.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

# Diagnosis

**If you have been referred to hospital with a breast lump or a change in the appearance of your breasts, you will usually have three assessments (called triple assessment):**

- a physical examination of your breasts (and armpits) by a doctor or specialist nurse
- imaging of your breast by mammography and/or ultrasound
- testing a small sample of cells (a biopsy) taken from your breast or armpit using a needle.

## Triple assessment

The use of these three tests means an accurate diagnosis can be made promptly. For women with an unusual lump that can be biopsied, there is good evidence that triple assessment gives a more accurate diagnosis than just using one or two tests. However, some patients will only need a physical examination and imaging. A biopsy is only carried out if there is an abnormal area found through physical examination or imaging.

When the three tests give the same result, it is nearly always possible to give a definitive diagnosis, whether positive (cancer) or negative (not cancer – a benign condition or nothing abnormal), so appropriate treatment can be discussed as soon as possible.

All three tests should usually be carried out at the same visit to the breast unit to save you making several trips to hospital for the different tests.

## Physical examination

This is an examination of your breasts, your armpits (axillae), the area around your collarbone, and your neck, carried out by a hospital doctor or specialist nurse. Your breasts are examined to find any abnormalities, including lumps or other signs or symptoms of breast cancer. The other areas are examined to check for enlarged lymph nodes, which can be a sign of breast cancer. Lymph nodes are glands found in your armpit and other areas of your body that are part of your immune system.

## Breast imaging

This involves imaging the inside of your breasts using either a mammogram (an x-ray that uses very low doses of radiation) or an ultrasound examination (which uses sound waves). Some people may have both.

The best method of imaging for you will depend on your age and physical characteristics:

If you are 40 or over, you should be given two-view mammography, which is mammography carried out at two angles for each breast. Additional views may also be required. You may also have an ultrasound examination if your doctors think that this will provide useful extra information. Occasionally (for example for some patients with breast implants) a magnetic resonance imaging (MRI) investigation may be helpful, although this type of imaging is not routine for diagnostic assessment. An MRI is a scan using radio waves and a magnetic field to create images of the body.

If you are under 40 (or pregnant or breastfeeding), you are likely to have an ultrasound examination rather than a mammogram. This is because breast tissue in younger women and those who are pregnant or breastfeeding is often denser, making the mammogram more difficult to interpret. Any abnormalities are therefore usually picked up better by ultrasound than mammogram. However, you may need both types of imaging and it is possible for younger, pregnant or breastfeeding women to have a mammogram.

In some cases, if your hospital doctor or specialist nurse thinks you have a benign condition (such as a cyst or fibroadenoma) based on their examination of your breasts, you may be given an ultrasound examination before or instead of mammography. Ultrasound is also used to check for signs of breast cancer in the armpit lymph nodes.

## What women say

“My local hospital is small so I had to wait for the next clinic five days away to get my results.”

Breast Cancer Now Supporter

“My sister had a confirmed diagnosis within 30 minutes of her fine needle aspiration test. Her whole life turned around in those 30 minutes, but at least there was no nerve-wracking period spent waiting for news.”

Breast Cancer Now Supporter

## Biopsy

One of two techniques can be used to take a sample of cells (a biopsy) from the lump or area of abnormality in your breast and/or armpit: a core biopsy or FNA.

A pathologist will examine the sample in the laboratory to determine whether or not it contains cancer cells. A core biopsy or FNA can be used, although core biopsy is now more common. Either technique can be performed in an outpatient clinic, and you can go home afterwards (unless you have further appointments to attend). You should have a biopsy on the same day as your other tests. Both procedures use a needle and the results are usually available within a few days.

For a core biopsy, more than one sample is usually taken. A local anaesthetic is always given beforehand. Although the biopsy itself should not be painful, the local anaesthetic injection may briefly cause discomfort. Some bruising can occur at the biopsy site, but the wound is too small to need stitches and should heal quickly.

For FNA, a thin needle is used to take a sample of cells from the breast lump or abnormal area in your breast and/or armpit. FNA can be painful for some women. The test tends to be more painful if the needle has to be inserted relatively deep into your breast or when the needle has to be moved around within the breast. You may be offered a local anaesthetic before FNA to reduce any pain. However, because having a local anaesthetic can itself cause discomfort many women choose not to have this injection.

## Getting the results of your tests

You will usually have an appointment within three to five working days of your tests to receive the results. No one should have to wait longer than a week for their results.

As soon as your results are available, a member of your breast care team should give them to you (but not until you are ready to hear them). To support you, a breast care nurse should be with you and you may also want to have your partner or a friend with you if you think this will help.

When you receive your results, your doctor will explain whether or not you have breast cancer and the likely next steps for you. If any tests need to be repeated or further tests are needed, this should be explained to you clearly. Many breast care teams provide a written record for women of their results that they can refer to later.

**What the guidelines say:**  
**Getting the results of tests**

The person conducting the consultation must be a member of the multidisciplinary breast team and the breast care nurse would usually be present. It should take place in an appropriate environment with adequate privacy.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

The results of tests should be given to the patient within five working days and within three days if possible. Thus women who do not have breast cancer can be reassured and treated if necessary, while those who do may proceed rapidly to treatment.

*Improving outcomes in breast cancer. National Institute for Health and Care Excellence (NICE), 2002.*

Results of diagnostic tests should be communicated to patients within 1 week of the last diagnostic procedure.

*National standards for breast cancer services. Welsh Assembly Government, 2005.*

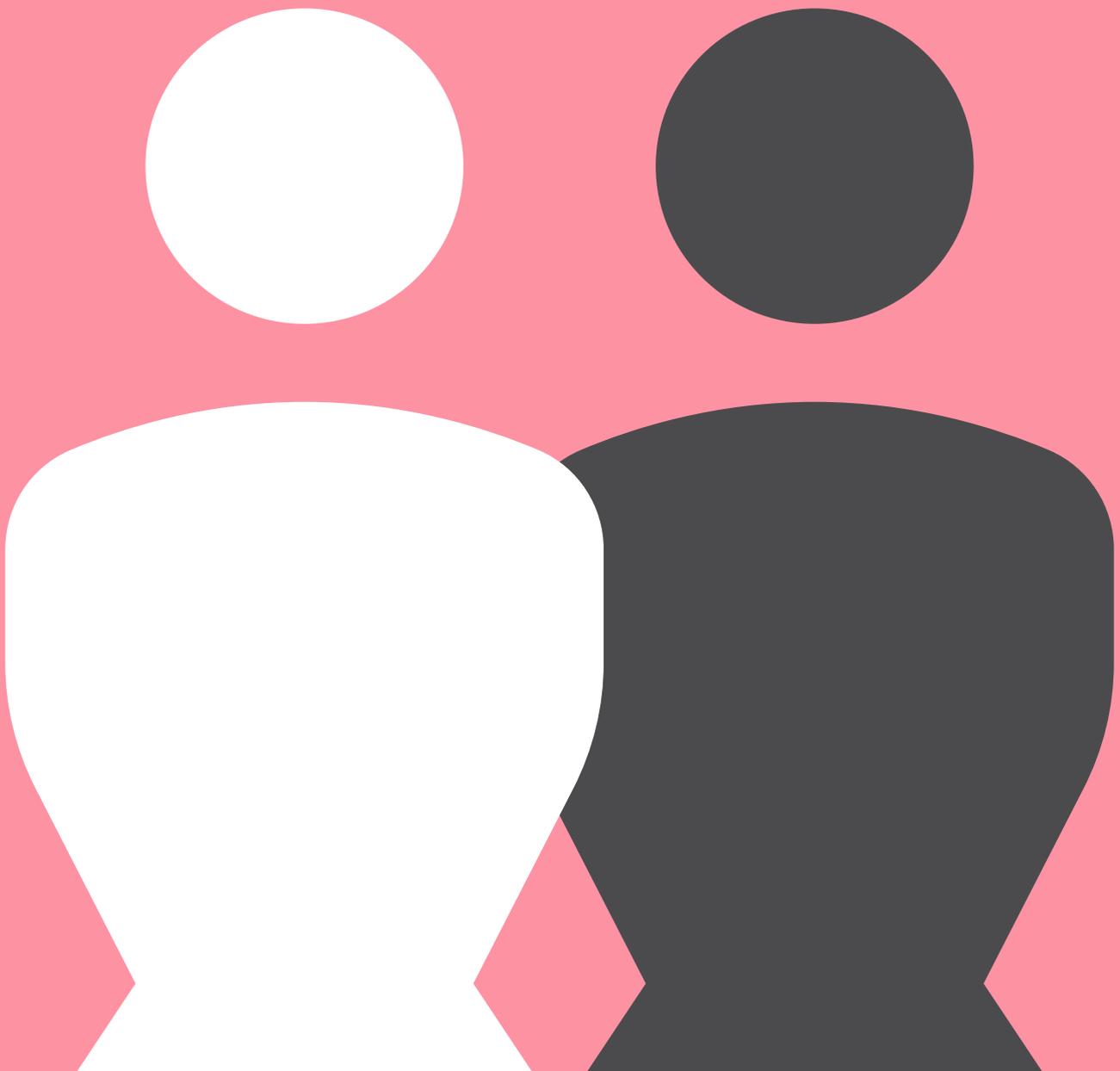
If there is anything that you don't understand about the terms used, ask your hospital doctor or breast care nurse to explain these to you.

Most women's results show that they don't have breast cancer. If your results show that you do not have breast cancer, but you have any remaining concerns or you notice any new changes to your breasts that are unusual for you, visit your GP.

If you receive a diagnosis of breast cancer, you will almost certainly need and be offered some treatment. We explain how treatment is planned in the next section of this booklet.

# Planning treatment

In this section, we explain how treatment for breast cancer is planned, including how your breast care team determines your treatment options based on the characteristics of your breast cancer, how you are involved in the decision and what support is available to you.



# Tailoring your treatment

**Different treatments work best for different types of breast cancer. So an accurate diagnosis is very important – it helps your breast care team to determine the best treatment options for you. Most women with breast cancer will have more than one treatment, and the order in which they are given can differ.**

Treatments for breast cancer include surgery, radiotherapy, chemotherapy, hormone therapy and targeted (biological) therapy.

All treatments can have beneficial effects, but can also have side effects. Tailoring treatment to individual women and their cancers gives the very best chances of successfully treating the cancer while reducing the side effects of treatment as far as possible.

Your breast unit will run tests on your breast cancer to learn as much as possible about its characteristics. These are called pathology tests and receptor tests.

A specialist doctor, known as a pathologist, performs the pathology tests by examining samples of your tumour (and possibly also a sample of your lymph nodes) under a microscope. Pathology tests are used to determine the type of breast cancer you have (page 14). They are also used to assess the size of your tumour, whether it has spread into nearby tissues in the breast and armpit, and how fast it is growing (see Staging and Grading, page 16).

Receptor tests are also performed by a pathologist in the laboratory using samples of your cancer. They look at whether the cells have specific markers (characteristics), which helps to determine which treatments will work best (page 18).

All of this information helps your breast care team to plan your treatment.

Sometimes, pathology tests and receptor tests can be performed on a sample of your tissue taken using a biopsy. However, in other instances samples of your breast cancer and/or lymph nodes may not be available until after you have had the tumour removed by surgery (if this is a part of your treatment plan). It is therefore possible that your breast care team will not be able to explain all your test results and treatment options until after you have had surgery.

**What the guidelines say:**  
**Being involved in treatment decisions**

Where there is a range of different, clinically appropriate and evidence-based treatments available, people should be able to choose the treatment that is right for them, supported by accessible information about the treatments, risks, any side effects and supportive care.

*Improving outcomes: a strategy for cancer. Department of Health, 2011.*

Patients must be given adequate time, information and support in order to make a fully informed decision concerning their treatment.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

Your own circumstances and preferences are also very important in helping to determine the best treatment options for you. Your breast care team will speak with you to gain as much information as they can about your preferences for treatment and what will help you to have the best quality of life now and in the future.

When they have your test results, your breast care team will meet to discuss the ways in which your treatment can be tailored to have the best outcome. These meetings are sometimes known as MDT (multidisciplinary team) meetings. They are designed to allow all the key people involved in your treatment to discuss together which treatments are likely to be most effective for you. Your breast care team will take into consideration any preferences you have already given. The aim is to plan the next steps, ready for discussion with you.

Your hospital doctor and breast care nurse will then discuss with you the results of your tests and their recommendations for your treatment. They will talk you through any choices there might be for you to make about your care, and can help you to make these decisions.

Many breast care teams provide a written record of your results that you can refer to later. If there is anything that you don't understand about the terms used, ask your doctor or breast care nurse to explain these to you.

For more information on how breast cancer starts and spreads, see Breast Cancer Now's website [breastcancernow.org/breastcancer](http://breastcancernow.org/breastcancer) or call 0333 20 70 300.

## Types of early breast cancer

**Breast cancer is the name given to any cancer that starts in the breast tissue. Breast cancer that is found only in the breast (and possibly armpit lymph nodes) is known as early, or primary, breast cancer. There are many types of early breast cancer.**

### Non-invasive breast cancer

Early breast cancers that are found only in the milk lobes (glands) or ducts (tubes) of the breast and not other breast tissues are known as non-invasive breast cancers. They can be thought of as an early form of breast cancer, and are sometimes called 'pre-cancerous'.

In England and Wales, over 5,000 women are diagnosed with this type of cancer each year. The most common type of non-invasive breast cancer is ductal carcinoma in situ (DCIS), also known as pre-invasive or intra-ductal carcinoma.

Non-invasive breast cancers sometimes later develop the ability to spread to surrounding tissues, becoming invasive. For this reason, women with non-invasive breast cancers are usually advised to have treatment. DCIS is usually treated by surgery, and some women may receive additional treatments, such as radiotherapy.

The effectiveness of hormone therapy for DCIS is being assessed in clinical trials.

Non-invasive breast cancer is not the same as a benign breast condition. Benign breast conditions, such as cysts and fibroadenomas, are not cancer and are rarely associated with an increased risk of developing breast cancer in the future.

For more information on different types of breast cancer, see Breast Cancer Care's website [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0800 800 6000.

## Invasive breast cancer

Early breast cancers that have spread beyond the milk lobes or ducts to the surrounding breast or armpit tissue are known as early invasive breast cancer. This is different from metastatic (advanced) breast cancer, which is invasive breast cancer that has spread to distant parts of the body.

Around 44,000 women are diagnosed with invasive breast cancer each year in England and Wales. Overall, the most common type of invasive breast cancer is invasive ductal breast cancer, sometimes called 'no special type' (NST) or 'not otherwise specified' (NOS). Invasive lobular breast cancer is another early invasive breast cancer, but is less common.

There are many rarer types of early invasive breast cancer, including inflammatory breast cancer, Paget's disease, medullary breast cancer, metaplastic breast cancer, tubular breast cancer, mucinous breast cancer and malignant phyllodes tumours.

Treatment options for invasive breast cancer can include surgery, radiotherapy, chemotherapy, hormone therapy and targeted therapy.

# Staging and grading

**Staging and grading are ways in which healthcare professionals describe the size of your breast cancer, whether and how far it has spread, and how fast it may grow (how 'aggressive' it is). Knowing your cancer's stage and/or grade helps your breast care team to plan the best treatment for you.**

Staging and grading usually happens after your breast tumour has been removed by surgery, as a pathologist will need to test the tissue in a laboratory and examine it under a microscope.

## Grading

The grade of a tumour indicates what the cells look like and gives an idea of how quickly the cancer may grow and spread. Tumours are graded between 1 and 3. A higher number indicates that the cells have greater differences to normal cells and are likely to grow and spread more quickly. Grading for DCIS is different, and is defined as low, medium or high grade.

## Staging

Staging is used to assess the size of a tumour, whether it has spread and how far it has spread. There are two main methods used for defining the stage of a cancer – the TNM system or a scale from 0 to 4. It is important for your surgeon to determine whether the cancer has spread to the armpit (axillary) lymph nodes, as this helps to plan treatment. If cancer has spread to the armpit, then additional treatments, such as chemotherapy, may help to reduce the chance of the cancer returning in the future.

All women should have an ultrasound examination of the armpit area. This uses sound waves to make an image of the inside of the armpit, to see whether there is any sign of cancer in the lymph nodes. Lymph nodes are glands found in your armpit and other areas of your body that are part of your immune system. Following the ultrasound, women will have a biopsy taken from their lymph nodes for testing, or their lymph nodes will be investigated during surgery (see page 30).

### Understanding staging terms

The tumour, nodes, metastases (TNM) system of staging describes:

- T: the size of a tumour (a code from 1 to 4, with higher numbers indicating larger tumours)
- N: the number of lymph nodes affected (X for no nodes, and a code 0–3 when nodes are affected)
- M: whether the cancer has spread to other areas of the body (0 for no spread, 1 for spread).

Another way of defining the stage of a cancer is on a scale from 0 to 4:

- Stage 0: non-invasive breast cancers, such as DCIS
- Stages 1 and 2: quite small breast cancers that have spread only to the lymph nodes, if at all
- Stage 3: breast cancers that are often larger and have spread to the lymph nodes or surrounding tissues
- Stage 4: breast cancers that have spread to other areas of the body (metastatic breast cancers).

## What the guidelines say: Receptor tests

People with newly diagnosed invasive breast cancer and, if appropriate, those with breast cancer that has come back or spread have tissue from their tumour tested to find out its 'oestrogen receptor' (ER) and 'human epidermal growth receptor 2' (HER2) status. The test results are available within 2 weeks to help plan further treatment.

*Breast Cancer Quality Standard.*  
National Institute for Health and Care Excellence (NICE), 2011.

The ER and HER2 status should be determined in every case of invasive breast cancer, with the results available for the 'postoperative results' MDT meeting.

*Surgical guidelines for the management of breast cancer.* Association of Breast Surgery at BASO, 2009.

See page 46 to learn more about hormone therapies.

# Receptor tests

Receptor tests are used to see whether breast cancers carry specific markers (characteristics). If they do, this can indicate that hormone therapy and/or targeted therapy may be effective in treating the breast cancer.

Receptor tests are extremely helpful in planning treatment, so it is important that you are offered them. If your hospital does not offer receptor tests, ask your doctor about being referred to a hospital that does. The tests are carried out by the pathologist on the biopsy samples that were taken for your diagnosis or on your breast tumour after it is removed by surgery.

Receptor tests look to see whether the cells carry specific markers, known as receptors. A receptor acts like a keyhole, allow a matching molecule to lock onto it and signal to the cell. For example, hormones can lock onto hormone receptors in breast cancer cells and signal to them to grow faster.

Receptor tests are currently used to test for the presence of:

- oestrogen receptors (sometimes known as ER)
- a receptor called HER2.

Some laboratories also test for progesterone receptors (sometimes known as PR).

HER2 testing might not be performed for women with ductal carcinoma in situ (DCIS).

## What do the results mean?

Breast cancers that have oestrogen receptors are called hormone positive (or hormone sensitive) breast cancers. They may also be referred to by the name of the receptor, ie ER positive breast cancer. Around three out of four breast cancers are hormone positive.

If you have a hormone positive breast cancer, then hormone therapies such as tamoxifen and aromatase inhibitors might be an option for your treatment (see pages 46–50). Your oncologist will discuss this with you and let you know whether they are an option in your case. This doesn't mean that they are the only treatment you will receive – your breast care team may recommend other treatments too.

If you have a hormone negative breast cancer, then hormone therapies will not work well for you. You may be offered other treatments instead.

## Receptor tests

Breast cancers that have a lot of HER2 are known as HER2 positive breast cancers. Around one in five breast cancers are HER2 positive. If you have a HER2 positive breast cancer, the targeted therapy Herceptin (trastuzumab) might be an option for you (see page 51). Your oncologist will discuss this with you and let you know whether targeted therapy is an option in your case. This doesn't mean that it is the only treatment you will receive – your breast care team may recommend other treatments too.

See page 51 to learn more about targeted therapy.

If your breast cancer cells have little or no HER2 then Herceptin will not work well for you. You will be offered other treatments instead.

The test for whether or not your breast cancer has progesterone receptors (PR) is not as useful as other receptor tests for planning your treatment and not all laboratories test for this receptor. However, knowing whether or not your breast cancer is progesterone positive can – in some cases – help your breast care team to understand how your cancer may behave.

Some breast cancers do not have oestrogen receptors, progesterone receptors or HER2 in the cells. These breast cancers are known as triple negative breast cancer. Neither hormone therapy nor Herceptin will be effective for women with this type of breast cancer. However, triple negative breast cancers may respond better than other breast cancers to chemotherapy.

## What women say

“Breast care nurses are worth their weight in gold.”

Breast Cancer Now Supporter

“Make sure you’ve someone with you at your appointment as you can forget something that’s said to you. The staff were all fantastic but if you are on your own you can be overwhelmed with all the things they tell you.”

Breast Cancer Now Supporter

“The oncology nurse was great all the way through and had lots of tips and advice based on other patients’ experience.”

Breast Cancer Now Supporter

# Having discussions about your treatment

**Your breast care team will be keen to give you as much information as you need and want about your disease and treatment. This will help you to understand your situation, feel confident about the treatment and care you are receiving and make the best choices for you.**

Professional guidelines emphasise that you should be given adequate time, information and support to make fully informed decisions about your treatment. Everyone is different and you can choose the amount of information you are given. However, it is sometimes difficult for health professionals to judge how much information is enough and how much is too much, so let them know what’s right for you.

If you feel distressed and anxious, you may find it difficult to take in all the information you are given. This may mean letting your doctor or nurse know the amount of information that is right for you at this time or when you have had enough information for the moment.

If you don’t understand something you are told, ask for an explanation, and keep asking until you are sure you understand.

It’s fine to ask questions and to ask for more support. Equally, if you would prefer not to know, you should not be bombarded by information you don’t want.

## What the guidelines say: Information and support

Following diagnosis, patients must be given adequate time, information and support in order to make a fully informed decision concerning their treatment.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

Written information in a language and format appropriate to the patient should be offered to each new cancer patient.

*National standards for breast cancer services. Welsh Assembly Government, 2005.*

All patients with breast cancer should be assigned to a named breast care nurse specialist who will support them throughout diagnosis, treatment and follow up.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

For more information on support available, contact Breast Cancer Care ([breastcancercare.org.uk](http://breastcancercare.org.uk), 0808 800 6000) or Macmillan Cancer Support ([macmillan.org.uk](http://macmillan.org.uk), 0808 808 0000).

People often find it difficult to think of questions to ask immediately after being given major new information, such as test results. You might find it useful to:

- ask for leaflets to take away and look at later, or tell your doctor or nurse that you would like a second appointment to discuss the information when you feel calmer
- take audio recording equipment into your appointment to record your consultation (some hospitals may provide this), or a pen and paper to take notes
- take a family member or friend with you, so they can help you remember the questions you want to ask and what has been said
- write your questions down as you think of them – perhaps when you are back at home – and take them with you to your next clinic visit.

You should have a named breast care nurse (or key worker) to support you throughout your diagnosis, treatment and follow up, whom you can contact at any time during working hours. Ask your breast care team whom you should contact if you need out-of-hours care or support.

If there is a choice between different treatments, you should be given information about the benefits and risks of each to help you make an informed choice about which is the best option for you, with the help of your breast care team.

It is also a good idea to visit your GP soon after you have been diagnosed with breast cancer. Your GP can help to guide you through your treatment and provide you with additional information and support.

Also, there are voluntary organisations, including the charities Breast Cancer Care and Macmillan Cancer Support, which provide information and have experienced nurses who can answer questions you may have about breast cancer. Macmillan Cancer Support can also provide advice on financial, practical and work-related issues.

## What the guidelines say:

### Access to Counselling services

All patients with breast cancer should be offered prompt access to specialist psychological support, and, where appropriate, psychiatric services.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

For more information on support available, contact Breast Cancer Care ([breastcancercare.org.uk](http://breastcancercare.org.uk), 0808 800 6000) or Macmillan Cancer Support ([macmillan.org.uk](http://macmillan.org.uk), 0808 808 0000).

# Counselling services

If you need some additional support, do not be embarrassed to ask your doctor or nurse for help – they are used to providing emotional support as well as providing treatment for the cancer itself. You can also ask your GP for help in this area.

Many hospitals now provide counselling services as they acknowledge that how you feel is an important part of your treatment. It is normal to feel low and anxious when you have been diagnosed with breast cancer, and to have good days and bad days. Some people also feel angry. Usually this disappears with time, but you may develop symptoms of depression, which may need some form of treatment. It is important to realise that many people experience this reaction at times of severe stress.

Everyone having treatment for breast cancer should be offered access to counselling or support services. You can ask your breast care nurse for more information on counselling services available to you. Your breast care team may work with the hospital's counselling service and mental health services to help you. Your breast care team or GP should be able to organise one-to-one or group therapy for you, if you would find this helpful.

# Getting treatment

In this section we look at the treatments you may be offered for early breast cancer, their benefits and side effects, and how they are given.



## What the guidelines say:

### Starting treatment

People with early invasive breast cancer, whatever their age, are offered surgery, radiotherapy and other appropriate treatments, unless other illnesses or conditions mean it is unsuitable.

*Breast Cancer Quality Standard. National Institute for Health and Care Excellence (NICE), 2011.*

There should be a maximum of one-month wait from diagnosis to [first] treatment for breast cancer.

*NHS cancer plan. Department of Health, 2000.*

Start adjuvant chemotherapy or radiotherapy as soon as clinically possible within 31 days of completion of surgery in patients with early breast cancer having these treatments.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

Patients referred as urgent suspected cancer by the GP and confirmed as urgent by a member of the MDT or their representative should, if diagnosed with breast cancer, start definitive treatment within 2 months of the receipt of the referral at the hospital.

... When diagnosed with breast cancer, patients not already included as an urgent suspected cancer referral should start definitive treatment within 1 month from diagnosis regardless of referral route.

*National standards for breast cancer services. Welsh Assembly Government, 2005.*

# Starting treatment

In England and Wales, health professionals now aim for a total waiting time from diagnosis to first treatment to be one month or less.

A number of treatments are available for early breast cancer (cancer in the breast that has not spread beyond the breast and armpit lymph nodes). These include 'local' treatments and 'systemic' treatments.

Local treatments aim to remove the cancer from the breast and armpit area. These are:

- surgery
- and/or radiotherapy.

Systemic treatments are drugs that enter the blood system and circulate throughout the body to try to prevent the breast cancer spreading or coming back. These are:

- chemotherapy
- hormone therapy
- and/or targeted (biological) therapy.

These treatments are often used one after another rather than all at the same time, and the treatments received will differ from woman to woman, depending on her breast cancer and her preferences and circumstances.

Treatments (radiotherapy and/or systemic treatments) given after surgery are sometimes called adjuvant treatments. Less commonly, these treatments are given before surgery, and are then called neoadjuvant treatments. We describe all these treatments on the following pages.

As well as standard treatment options, you may be offered the opportunity to take part in a clinical trial of a new treatment. This may be to assess the use of a current treatment given in a different way (such as a different dose) or to assess how effective a new drug is compared with a current treatment. We explain more about clinical trials on page 52.

## The best treatment

Your guide to breast cancer treatment in England and Wales

## What women say

“When you are diagnosed with cancer it feels as if you are on a rollercoaster. I asked if I could wait a couple of weeks before starting treatment so that I could find out more about breast cancer and the various treatment options. Those two weeks helped me to cope better with the shock of the diagnosis. By the time treatment started, I was better informed and felt in control of my life again.”

Breast Cancer Now Supporter

“I was anxious to start treatment as soon as possible and did have my surgery promptly and I was glad of that.”

Breast Cancer Now Supporter

“I was offered a place on a trial just after surgery had revealed the spread of my cancer to my axillary lymph nodes. It was too much too soon and I declined.”

Breast Cancer Now Supporter

Many women with breast cancer feel complementary therapies help them to cope with their illness and the side effects of conventional (medical) treatments. We provide more information about complementary therapies on page 53.

## What women say

“Having a dedicated breast surgeon with experience of working with breast cancer patients every day of their working life means they can more readily tell what type of surgery you need and provide it.”

Breast Cancer Now Supporter

“I was very scared when I went to have my surgery but the doctors and nurses couldn't have been nicer, kinder or more helpful. My surgeon was absolutely brilliant ... he was gentle, nice and showed concern.”

Breast Cancer Now Supporter

## What the guidelines say:

### Who should carry out breast surgery?

Surgical treatment of breast disease must be carried out by surgeons with a special interest and training in breast disease.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

# Surgery

**Surgery is often the first treatment for women with breast cancer. There are two main aims of surgery: to remove the cancerous tissue from your breast and to find out whether lymph nodes in your armpit (axilla) have been affected and, if so, to remove them.**

## Who should be offered surgery?

Most women with early breast cancer will be offered surgery. The main reasons why some women are not offered surgery are:

- they are not physically well enough to have a general anaesthetic and operation
- their tumour is not best treated by surgery.

These women are usually offered other treatments instead of or before surgery. Other treatments are described later in this guide.

In addition, sometimes a woman will be recommended other treatments before surgery to shrink the tumour, meaning surgery might be less extensive.

## Who should carry out surgery for breast cancer?

Your surgery should be carried out by a surgeon who specialises in breast disease. Breast surgeons should be part of the breast care team caring for you.

Each surgeon's team should treat a minimum of 30 new breast cancer cases per year. This is to ensure that they have sufficient day-to-day experience to maintain their expertise.

## What the guidelines say: Choice of surgery

A range of operations should be available. If the cancer is not too large or diffuse, surgical options include mastectomy and breast conserving surgery. In such cases, the choice should be made jointly by the surgeon and the patient, who should be fully informed of all the options and their potential risks, benefits and implications for further treatment.

*Improving outcomes in breast cancer.*  
National Institute for Health and Care Excellence (NICE), 2002.

## What women say

“Because my cancer was small I could have a lumpectomy – I had been scared about losing my whole breast.”

Breast Cancer Now Supporter

“The surgeon said I could have breast conserving surgery but after looking at lots of information I decided I would prefer a mastectomy.”

Breast Cancer Now Supporter

## What type of surgery should you have?

There are two main types of breast surgery:

- **breast conserving surgery** (also called a wide local excision or lumpectomy) – where the cancer and a small amount of surrounding tissue is removed, but surrounding healthy breast tissue is not removed. Some or all of the lymph nodes might also be removed. (Lymph nodes are glands found in your armpit and other areas of your body that are part of your immune system.)
- **a mastectomy** – where the whole breast is removed, often including some or all lymph nodes in the armpit.

The surgery you are offered will depend upon the characteristics of your breast cancer. If breast conserving surgery is possible, you will be offered this option; however, for some women, only mastectomy is recommended.

If either technique is equally suitable for you, you may be offered a choice of the surgery you have. Your breast care team should support you in making this choice by providing information and advice. Women who are offered mastectomy should also be offered breast reconstruction.

Research has shown that breast conserving surgery followed by radiotherapy is as effective as mastectomy in stopping the cancer spreading to other areas of the body and in saving lives. For people who have large breast tumours where mastectomy would be necessary, chemotherapy or hormone therapy is sometimes prescribed before surgery. These might shrink the tumour enough to allow breast conserving surgery to be performed instead. These additional treatments are called neoadjuvant therapies.

## Breast conserving surgery

Breast conserving surgery (sometimes called a wide local excision or lumpectomy) involves the removal of the breast tumour and a very small amount of breast tissue around the tumour (usually 1mm or so), called the ‘margin’. This might include removal of some or all lymph nodes (see pages 30–32).

Surgeons aim to remove a margin of healthy tissue as this helps to ensure all the cancer is removed. The tumour and surrounding tissue are sent to a pathologist who will check that the area around the tumour is cancer-free. If no cancer cells are found in this margin, it is called a ‘clear margin’ or an ‘uninvolved margin’.

## What the guidelines say: Breast conserving surgery

People with early breast cancer who have an operation to remove just the tumour and a small amount of breast tissue around it (breast conserving surgery), which may include techniques to improve appearance, have an operation that minimises the risk that the cancer will come back, as well as giving a good cosmetic appearance.

*Improving outcomes in breast cancer.*  
National Institute for Health and Care Excellence (NICE), 2002.

Patients who are found to have positive margins [cancer cells at the very edge of removed tissue] should be offered re-excision or mastectomy.

*Improving outcomes in breast cancer.*  
National Institute for Health and Care Excellence (NICE), 2002.

If the pathologist finds any remaining cancer cells at the edge of the removed tissue (or cells that might develop into cancer), this is called a 'positive margin' and you may need further surgery. This usually involves more breast tissue being removed but sometimes may mean a mastectomy is needed. This is to ensure that all the cancer has been taken out of the breast.

For women with a tumour in the centre of the breast, breast conserving surgery can sometimes be performed, provided the tumour is not too large in comparison with the size of the breast. The nipple and/or the areola (the darker area around the nipple) may need to be removed as part of the surgery. Nipple reconstruction can be carried out later. You should discuss options for reconstruction with your breast care team.

## Mastectomy

Mastectomy means the removal of the whole breast. At the same time most or all of the lymph nodes in the armpit (axillary nodes) on that side may also be removed (see pages 30–32).

Mastectomy is generally the best option for women with very large tumours, where the tumour is relatively large in comparison to the size of the breast or where the cancer is in more than one area of the breast.

Mastectomy may also be offered for other reasons, including the removal of large areas of early forms of cancer, such as ductal carcinoma in situ (DCIS).

## Reconstructive surgery

Women who have a mastectomy may also have breast reconstruction, either at the same time (immediate reconstruction) or at some time in the future (delayed reconstruction).

Reconstructive surgery is carried out to improve the appearance of the breast after cancer surgery. All women having a mastectomy should be offered the chance to discuss reconstructive surgery.

If you would like, your breast care nurse or surgeon should be able to show you example photos of how the breast may look after surgery, including after reconstruction, to help you make a decision about whether you wish to have reconstruction.

## What the guidelines say: Breast reconstruction

People with early breast cancer who are to undergo mastectomy (an operation to remove the whole breast) have the options of immediate and planned delayed breast reconstruction discussed with them.

*Breast Cancer Quality Standard. National Institute for Health and Care Excellence (NICE), 2011.*

If [breast reconstruction surgery] is not available within the breast unit, the breast team should have a recognised line of referral to a breast or plastic surgeon with particular expertise in breast reconstruction.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

## What women say

“I was offered simultaneous reconstruction at the time of my mastectomy but in fact declined. Although reconstruction was not important to me personally, I am happy that more and more women are now offered this surgery.”

Breast Cancer Now Supporter

For more information on breast reconstruction, see Breast Cancer Care's Breast reconstruction booklet available at [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

Some women prefer immediate reconstruction so that when they wake up following their mastectomy they still have the appearance of two breasts. Other women prefer to have reconstructive surgery at a future date and others decide not to have a breast reconstruction at all.

Delaying reconstruction until a later date after your cancer surgery may be the recommended option if, for practical or medical reasons, it is likely to be more successful. The pathology results from the breast tissue removed in the mastectomy operation may indicate that further treatment, such as radiotherapy, is needed – and it is sometimes better to make decisions about additional treatment before reconstructive surgery.

Many women either do not need or do not want reconstructive surgery following breast conserving surgery, but there are surgical techniques that may be suitable if you do. Your breast surgeon will explain the options available to you. If your NHS breast surgeon does not offer the type of reconstructive surgery you want, you can ask them to refer you to a surgeon that does.

Women with larger breasts who have a large tumour, where breast conserving surgery might cause a poor shape, may be offered an operation called oncoplastic resection. The operation removes the tumour, along with the surrounding tissue that would be removed in a breast reduction operation, and the breast is reshaped. A breast reduction operation is carried out on the other breast, to give balance. This operation is carried out by a surgeon trained in this specific technique. This could be a breast surgeon, possibly working with a plastic surgeon, or a specialist oncoplastic surgeon.

Women who do not have immediate reconstruction, or who choose not to have reconstruction at all, should be offered an appointment with a prosthesis fitting service. Breast prostheses, which can be inserted into the bra or stuck directly onto the skin, are used by some women after breast conserving surgery or mastectomy to even up the size and shape of their breasts under clothing. They are generally made of silicone and come in different sizes, shapes and colours, so that you can find the best match for you. Some women choose not to use prostheses.

## What the guidelines say: Breast prostheses

For patients undergoing mastectomy without immediate reconstruction, a service should be provided to supply and fit breast prostheses.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

For more information on breast prostheses, see Breast Cancer Care's website [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

## Axillary (armpit) surgery

Breast cancer can spread to the lymph nodes in the armpit (axilla). If the cancer has spread to the armpit area, surgery to remove affected lymph nodes or radiotherapy of the area can reduce the risk of the cancer coming back or spreading further.

## Checking for cancer in the armpit

Ultrasound imaging is used to check for cancer in the armpit prior to surgery. If the ultrasound shows that the cancer has spread to the armpit, breast surgery will include removal of affected lymph nodes.

If ultrasound does not detect signs of cancer in the armpit, a further examination of the armpit is carried out during breast surgery to confirm whether the armpit lymph nodes are clear of cancer. There are two main techniques used to check for cancer in the armpit lymph nodes during surgery:

- **sentinel node biopsy**, where one lymph node (possibly more) is removed from the armpit for testing
- **axillary node sampling**, where at least four lymph nodes are removed from the armpit for testing.

Most hospitals should now be using sentinel node biopsy. In the past, a technique called axillary node clearance was sometimes used to remove all lymph nodes for testing. However, because side effects can be worse after all lymph nodes have been removed from the armpit, axillary node clearance should now only be performed where cancer has been detected in the armpit in order to remove the cancer.

## Sentinel node biopsy

This procedure involves checking the first node (or nodes) that any cancer in the breast would reach if it were to spread. The recommended technique is to inject a radioactive solution (with a low dose of radioactivity) and a coloured dye into the breast before surgery. The dye and solution travel from the breast, through the lymphatic system. By using a special probe to measure the radioactivity and by observing the dye, doctors can identify the first nodes to which the dye travels, known as the sentinel nodes. This allows doctors to map the route that cancer cells would be most likely to take if they spread from the breast tumour. The technique usually identifies more than one node to which the dye first travels, although it could be just one; these identified nodes are removed and sent for microscopic examination by a pathologist.

## What the guidelines say:

### Lymph node checks

People with early invasive breast cancer are offered an ultrasound scan of the armpit (axilla) before cancer treatment starts, to look for possible spread of the cancer to the lymph nodes. If abnormal lymph nodes are found, people are offered an ultrasound-guided needle biopsy to take a tissue sample from a lymph node. If there is no evidence of abnormal lymph nodes, people are offered another test called sentinel lymph node biopsy, which is performed during surgery for the cancer.

*Breast Cancer Quality Standard. National Institute for Health and Care Excellence (NICE), 2011.*

When axillary node sampling is carried out at least four nodes should be retrieved.

*Surgical guidelines for the management of breast cancer. Association of Breast Surgery at BASO, 2009.*

## What the guidelines say:

### Armpit surgery

Offer further axillary treatment to patients with early invasive breast cancer who: have macrometastases or micrometastases shown in a sentinel lymph node [and/or] have a preoperative ultrasound-guided needle biopsy with histologically proven metastatic cancer. The preferred technique is [axillary clearance] because it gives additional staging information.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

If no cancer is found in these nodes, then it is extremely unlikely that any of the other lymph nodes are affected by cancer and it is possible to avoid further axillary surgery or radiotherapy.

Where a sentinel node contains cancer cells, the armpit area will need to be treated. An advantage of sentinel node biopsy is that the test can sometimes be completed while the surgeon is performing breast surgery, which means that the surgeon may have the option of removing the lymph nodes right away if the test is positive. Other times, further surgery or radiotherapy may be required at a later date after the initial breast surgery.

### Axillary node sampling

This procedure involves removing a small number of the lymph nodes in your lower armpit, usually four or more. The nodes taken will be sent for microscopic examination by the pathologist. If no cancer is found in these nodes, then it is extremely unlikely that any of the other axillary lymph nodes are affected by cancer and it is possible to avoid further axillary surgery or radiotherapy. If cancer is found in these nodes then additional treatment will be offered.

### Treating breast cancer in the armpit

If cancer cells are found in the lymph nodes following sentinel node biopsy or axillary node sampling, treatment of the armpit area can reduce the risk of the cancer coming back or spreading further.

One of two treatments can be used:

- removing all the remaining lymph nodes in the armpit (called an axillary node clearance)
- radiotherapy to the armpit (see page 38).

Clinical evidence suggests that these treatments are equally effective. Your doctor will discuss the advantages and disadvantages of each type of treatment with you.

## Getting treatment

For more information on the side effects of armpit radiotherapy see page 39.

The possible side effects of axillary surgery are that it can be quite painful, cause fluid to collect in the armpit (seroma), cause infections, limit arm movement (usually temporarily) and may lead to lymphoedema (swelling of the arm, which can be permanent or may come and go).

The short-term side effects of radiotherapy to the armpit can be reddening or burning of the area of skin treated (like strong sunburn) and tiredness. Lymphoedema is a possible long-term side effect. Other long-term side effects are not common.

## Length of stay and discharge

The length of time you will have to stay in hospital after surgery will vary depending on the extent of your surgery, your recovery and your personal circumstances. Some surgery is carried out as a day case; other surgery may require you to stay in hospital for a few days. Your surgeon will advise you of the best time for you to go home.

For more information on surgery and recovery, see Breast Cancer Care's leaflet *Your operation and recovery* available at [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

When you are discharged from hospital you can expect to be given information about taking care of your wound, the follow up care you will receive and any side effects you may experience.

If there is anything you don't understand, ask your breast care team.

For out-of-hours medical care contact NHS Direct or NHS 111 (see page 61 for details).

## Dealing with side effects of breast and axillary surgery

### Pain and discomfort

Any surgery is likely to cause some pain or discomfort. In general, more extensive surgery causes more discomfort. It may take the form of an occasional sharp, darting sensation. Most women find that surgery to the armpit causes more discomfort than breast surgery. This can go on for weeks, months or years, but should decrease with time. Any pain or discomfort you experience can usually be managed by painkillers. If it is a problem, you should contact your GP, hospital doctor or breast care nurse, who can recommend ways of dealing with it.

For more information on radiotherapy see page 35.

If you have had surgery to your armpit, your arm and shoulder are likely to feel sore and you will probably not be able to move your arm fully at first. You should be offered treatment by a physiotherapist, or your breast care nurse should give you an exercise programme to get your arm and shoulder movement back to normal or near normal. It is important to do the exercises even if initially your arm is moving well, especially if you are to have radiotherapy.

## What the guidelines say:

### Lymphoedema

Patients should be informed of the early signs and symptoms of lymphoedema and who to contact should they develop. Everyone who develops symptoms of lymphoedema should be assessed by a lymphoedema specialist.

*Best practice for the management of lymphoedema. Lymphoedema Framework, 2006.*

Instructions should be given on functional exercises, which should start the day after surgery, to all breast cancer patients undergoing axillary surgery. This should include relevant written information from a member of the breast or physiotherapy team.

Patients should be referred to the physiotherapy department if they report a persistent reduction in arm and shoulder mobility after breast cancer treatment.

Ensure that all patients with early breast cancer who develop lymphoedema have rapid access to a specialist lymphoedema service.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

## Infection

It takes a few weeks for wounds to heal after surgery and during this time there is a risk of the area becoming infected. It's important that any infection is treated promptly, to prevent it causing problems with the wound healing and also to prevent you becoming unwell. Your surgeon and breast care nurse will let you know how to reduce the risk of the area becoming infected and will tell you what signs to look out for. These include the wound becoming more painful, swollen or warm, redness, fluid leaking from the wound or feeling unwell with a fever. Infections can be treated with a course of antibiotics.

## Seroma

After breast or armpit surgery, fluid can collect in the area and cause swelling. This is known as seroma. Many women develop seroma after their surgery under the arm and/or in the breast or chest.

Seroma is not a serious problem but can cause discomfort or restrict arm movement. It usually gets better on its own over time, but sometimes the fluid will need to be removed using a needle and syringe (known as aspiration). This simple procedure is usually performed by a nurse and should not be painful. After aspiration, the fluid may come back again, in which case the procedure may need to be repeated a few times over coming weeks.

Let your breast care nurse or surgeon know if think you have a seroma and it is causing you difficulty.

## Lymphoedema

Surgery and radiotherapy treatment to the armpit can result in long-term swelling of your arm, hand, breast, chest, back and/or armpit on the treated side, known as lymphoedema. It is estimated that at least one in five patients who undergo surgery for breast cancer will go on to develop lymphoedema in their arm. Estimates on this vary and the exact figure is not currently known; however, it is more likely in people who have also had armpit surgery.

Lymphoedema can develop soon after treatment, or months or years later. It can be uncomfortable and can restrict your arm movement. Although most people have mild symptoms that can be easily controlled (such as slight swelling or an uncomfortable arm), some people suffer more debilitating effects. There are several things you can do to reduce the risk of lymphoedema, which your breast care team can explain to you.

## Getting treatment

For more information on managing lymphoedema, see Breast Cancer Care's publication *Living with lymphoedema after breast cancer*, available at [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

For support on managing lymphoedema, see the Lymphoedema Support Network's website at [lymphoedema.org](http://lymphoedema.org) or call 020 7351 4480.

Lymphoedema cannot be cured, but the swelling can usually be reduced and controlled if it is managed effectively. If you notice any arm or shoulder swelling, let your breast care team or GP know right away, as the earlier lymphoedema treatment is started, the better the chances of it being well controlled. They will arrange for assessment and treatment of the condition, and can refer you for specialist help.

Assessment to find out the cause and extent of the swelling (usually carried out by specially trained nurses and physiotherapists) will help to decide the most suitable treatment.

Arrangements for access to many of the lymphoedema treatments are still quite variable, despite steps being taken to improve this situation.

If you have mild lymphoedema symptoms, you should be given the information and support you need to manage your condition yourself. This may include training for you or your carer in specialist massage, compression garments, practical advice and support to help you cope.

If you have more severe swelling or symptoms, you should receive complex decongestive therapy (CDT), which aims to reduce swelling or to stop the conditioning worsening. This includes the support listed above as well as a specialist massage conducted by a lymphoedema therapist called manual lymphatic drainage (MLD) and/or specialist compression therapy.

If you have lymphoedema you should have regular reviews with a lymphoedema specialist to assess your condition and determine the support you need.

# Radiotherapy

**Radiotherapy – treatment with radiation – is usually given after surgery. It aims to destroy any cancer cells remaining after surgery. Having radiotherapy after surgery for early breast cancer has been shown to reduce the likelihood that the cancer will come back.**

Radiotherapy is usually given externally, being delivered from outside the body, through the skin, using high energy x-rays. It can also be given internally, with a radioactive source being placed inside the body for a short time; however, this is not standard treatment and is not used except in clinical trials.

If you are pregnant, any treatment programme must be carefully planned so it does not risk harming your baby. You should talk to your radiologist about the options available for you.

## **What the guidelines say:**

### **Who should have radiotherapy?**

Patients with early invasive breast cancer who have had breast conserving surgery with clear margins should have breast radiotherapy. Offer adjuvant chest wall radiotherapy to patients with early invasive breast cancer who have had a mastectomy and are at a high risk of local recurrence. Patients at a high risk of local recurrence include those with four or more positive axillary [armpit] lymph nodes or involved resection margins [positive margins].

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

### **Who should be offered radiotherapy?**

In general, radiotherapy is offered to all women, although some women with a very low risk of recurrence may choose not to receive it, based on the balance of benefits and risks, the recommendations of their breast care team and their own preferences. If you have had breast conserving surgery, you should be offered radiotherapy. If you have had a mastectomy, you might be offered radiotherapy of your chest wall (the area behind the breast). In addition, if sentinel lymph node biopsy or axillary node sampling show that your breast cancer has spread to lymph nodes in your armpit and these have not all been removed by surgery, you will be offered further surgery or radiotherapy to your armpit to treat these.

Radiotherapy is usually given after surgery and/ or chemotherapy, or sometimes between courses of chemotherapy. It usually involves a course of treatment lasting three weeks.

### **Where and how should radiotherapy be given?**

You may need time for wounds to heal or to complete chemotherapy before you are ready to have radiotherapy. Professional guidelines state that it should start within four weeks of you being ready to receive it. Speak to your breast care team if you are concerned about the length of time you are waiting for radiotherapy.

### What the guidelines say:

#### Timing of radiotherapy

Start adjuvant chemotherapy or radiotherapy as soon as clinically possible within 31 days of completion of surgery in patients with early breast cancer having these treatments.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

Radiotherapy centres should have sufficient staff and capacity to guarantee access to radiotherapy within four weeks of identification of need.

*Improving outcomes in breast cancer.* National Institute for Health and Care Excellence (NICE), 2002.

Regional Cancer Networks... are implementing a commissioning strategy... for radiotherapy to ensure recommended waiting times [of maximum four weeks' wait] are met routinely from March 2009.

*Designed to tackle cancer in Wales: A Welsh Assembly Government policy statement.* Welsh Assembly Government, 2006.

Radiotherapy is given at larger hospitals, sometimes referred to as cancer centres. A number of cancer specialists, including clinical oncologists (doctors trained to give radiotherapy and chemotherapy) and radiographers (professionals trained in operating radiotherapy equipment), will be based at the centre. You may have to travel some way for your radiotherapy if your cancer centre is not in your own town or city. You will not usually need to stay in hospital overnight while you are having radiotherapy, unless you are unwell.

#### Planning

Your breast care team will plan which areas should be treated with radiotherapy at a planning session before your treatment starts. During your radiotherapy planning appointment, you will be carefully positioned by a radiographer. One or both of your arms will be raised so they are away from the breast and outside the area that will receive radiotherapy (the treatment field). Hospitals use different methods for supporting your arms, such as a special rest for your shoulders, handgrips or elbow supports. If you feel uncomfortable, tell the radiographer as soon as your arms are positioned. You need to be able to lie comfortably during your actual treatment sessions, which take a few minutes. When you are lying comfortably in this position, images of your upper chest area will be collected using a CT-simulator or a CT-scanner. These help with treatment planning.

Once the areas for treatment have been agreed, they may be permanently marked with small tattoos to ensure that the exact areas are treated each time. These tattoos are usually up to six small black dots. The process of making these marks can be slightly uncomfortable. If you do not want permanent tattoos, you should let the radiographers know: in some instances they may be able to offer temporary ink marks instead. However, this would mean that you would have to take care not to wash off the temporary marks during the period of treatment.

#### Treatment

An important part of getting the most out of radiotherapy is having the right dose. The aim is to destroy any cancer cells left after surgery, while doing as little damage as possible to the cells in normal body tissues. During a course of radiotherapy, a small amount of radiation is given at each treatment session. Each woman's radiotherapy course is designed to best treat her breast cancer by tailoring the amount of radiation given per session, the number of sessions and the timeframe between sessions. The overall course of radiotherapy is called a 'radiotherapy dose schedule' or a 'radiotherapy fractionation regimen'.

## What the guidelines say:

### Which areas of the body should be treated?

Offer an external beam boost to the site of local excision to patients with early invasive breast cancer and a high risk of local recurrence, following breast conserving surgery with clear margins and whole breast radiotherapy...

Offer adjuvant chest wall radiotherapy... to patients with early invasive breast cancer who have had a mastectomy and are at a high risk of local recurrence. Patients at a high risk of local recurrence include those with four or more positive axillary lymph nodes or involved resection margin.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

Patients treated by mastectomy with higher risk disease may also be considered for adjuvant chest wall radiotherapy.

*Surgical guidelines for the management of breast cancer.* Association of Breast Surgery at BASO, 2009.

Radiotherapy is frequently given daily (Monday to Friday) over a period of three weeks, although other schedules are also commonly used. Each treatment takes a matter of minutes. Most women report that radiotherapy is not painful. However, some do find it painful, usually because they have to lie still for several minutes while it is taking place and this may make your arm uncomfortable, especially after surgery. The treatment can also cause a skin reaction, a bit like sunburn, which may become painful towards the end of the treatment course. You will be reviewed through your treatment to assess how you are getting on and to identify any side effects, which may need treatment (see page 39).

Radiotherapy is given using a large machine that emits radiation, called a linear accelerator or Linac, which can be moved around you. It is very important that you lie still during treatment, although the movement caused by breathing is fine. You should relax as much as possible.

The machine is positioned close to your breast or chest wall, without touching it, and the area is normally treated from two angles – each side of the breast – creating two treatment fields. This technique means that most of the radiation goes sideways through the breast and very little radiation affects other tissues, such as the lungs. If the lymph node areas in the armpit and at the base of the neck are to be treated, additional radiation will be used and will be directed at these areas.

### Which areas of the body should be treated?

#### The breast

Radiotherapy to the breast should normally be given to women who have breast conserving surgery. Research has shown that radiotherapy halves the risk of the cancer returning. Some research has also found that radiotherapy given in addition to drug treatments, such as chemotherapy or hormone therapy, improves survival compared with drug treatments without radiotherapy.

Radiotherapy is a standard treatment, but for some women the risks of radiotherapy may outweigh the benefits. Research studies are investigating whether women at low risk of recurrence need radiotherapy after breast conserving surgery.

For more information on breast conserving surgery see page 27.

For more information on mastectomy see page 28.

For more information on axillary surgery see page 30.

## **The tumour area in the breast**

After breast conserving surgery some patients will have breast boost radiotherapy of the whole breast. A breast boost gives an extra dose of radiation to the area from which the tumour was removed. Breast boosts are used if it is felt that a cancer is more likely to recur in the same area. It is often given to younger women, as studies show they are most likely to benefit. If breast boost treatment is an option for you, your breast care team will explain the risks and benefits.

## **The chest wall**

Following mastectomy, women at high risk of local recurrence should be given radiotherapy to the chest wall (the area immediately behind the breast) and associated tissues nearby (such as overlying skin and fat). Key considerations in deciding whether to give radiotherapy to the chest wall include the tumour's size and how fast it is likely to grow (or how 'aggressive' it is – see the information on staging and on grading (page 16), whether there was a cancer-free area around the tumour and whether cancer was found in the armpit lymph nodes.

## **The armpit (axilla)**

If cancer is found in one or more lymph nodes of the armpit, there are two main treatment options: further axillary surgery (lymph node clearance) to remove the remaining lymph nodes or giving radiotherapy to the armpit.

If radiotherapy is given to the armpit, the area at the base of the neck may also be treated to reduce the risk of recurrence at this site. These two treatment options have been used for many patients over many years, and they appear to be relatively safe and effective. Neither has yet been shown to be better than the other and research is ongoing.

## What the guidelines say: Side effects of radiotherapy

Patients should be given clear information about both anticipated benefits and potential hazards of radiotherapy.

*Improving outcomes in breast cancer.*  
National Institute for Health and Care Excellence (NICE), 2002.

## What women say

“After a few weeks I began to feel tired, the skin became red and a bit sore and the tissue in the breast hardened and looked like orange peel. Sometimes I also felt nauseous. Nonetheless I was able to carry on working throughout and eventually the skin returned to normal. It helped to visualise the radiation as the healing rays of the sun – melting away any rogue cancer cells.”

Breast Cancer Now Supporter

For more information on radiotherapy and skin care, see Cancer Research UK's website [cancerresearchuk.org](http://cancerresearchuk.org) or call 0808 800 4040.

For out-of-hours medical care, contact NHS Direct or NHS 111 (see page 61 for details).

For more information on lymphoedema see page 33.

## Dealing with side effects of radiotherapy

Most people have short-term side effects from radiotherapy treatment. These include:

- reddening of the area of skin treated
- possible burning (like a strong sunburn) to that area
- tiredness.

It's important that your radiologist or others in your breast care team explain the risks and benefits of radiotherapy before you begin treatment. Side effects may develop slowly as the treatment progresses but should disappear within a few weeks of the treatment finishing. Your breast care nurse can give you advice on managing side effects, such as using a lotion to relieve dry skin and avoiding wearing underwired bras, shaving your underarm or using certain deodorants and talcum powder.

Long-term side effects are generally very mild, such as slight hardening of the treated tissue, known as fibrosis. Careful planning, correct positioning at the start of each treatment session and using a good treatment regimen will reduce the chance of this damage to normal tissue.

A few women experience other long-term side effects, but these are not common. They can involve the skin (including a colour change), bone, lung, heart or nerves in the treated area. There is also a small risk that radiotherapy can cause a new cancer to develop. The types of side effects experienced will vary from person to person. The techniques now used for radiotherapy allow your doctors to minimise the side effects and reduce any risk of damage to the heart. Lymphoedema is a possible long-term side effect where the armpit has been treated by radiotherapy.

**What the guidelines say:**  
**Chemotherapy**

Chemotherapy should only be given in units or centres where close supervision by oncologists and chemotherapy nurse specialists is available, plus expert pharmacy and 24-hour laboratory and emergency clinical support. Chemotherapy should be given in a designated day case area.

*Improving outcomes in breast cancer.*  
National Institute for Health and Care Excellence (NICE), 2002.

# Chemotherapy

**Chemotherapy is treatment with one or more anti-cancer (cytotoxic) drugs. It aims to prevent the breast cancer spreading or coming back. Having chemotherapy makes it less likely that your breast cancer will come back in the future.**

Chemotherapy used in addition to surgery may reduce the chance of a woman's breast cancer coming back (recurring). However, not all women need chemotherapy. Most women having chemotherapy are treated with at least two different drugs – this is known as multi-agent chemotherapy or combination therapy. Chemotherapy is a systemic treatment, which means it circulates throughout the body. It affects healthy body cells as well as cancer cells – and this is what causes side effects. The dose of chemotherapy given is calculated very carefully to have the greatest impact on cancer cells and the least impact on normal body cells. However, most people have some side effects with chemotherapy (see page 42).

## Who should be offered chemotherapy?

Whether or not you are recommended to have chemotherapy will depend on a number of factors, including the characteristics of your breast cancer, such as its grade and stage (see page 16). Your judgement of whether the potential benefits outweigh the side effects of treatment is also important.

If chemotherapy is recommended for you, your oncologist will talk you through the particular types of chemotherapy they recommend, and any choices that you have. Along with your breast care nurse, they can help you to make any decisions you may have to make.

Women with a low risk of their cancer recurring are not normally offered chemotherapy, as there is a good chance of their cancer not recurring even without having chemotherapy. For these women, the benefits of taking chemotherapy are likely to be outweighed by the side effects or risks.

Women with breast cancer that has spread to or beyond their lymph nodes, women with HER2 positive breast cancer and women with triple negative breast cancer are often offered chemotherapy.

## When and how is chemotherapy given?

If chemotherapy is prescribed, it is usually given after surgery (adjuvant treatment). Occasionally it is given before surgery (neoadjuvant treatment), for example when the tumour is large compared with the size of the breast or is fast-growing. The aim of this is to shrink the breast tumour enough to allow breast conserving surgery to be carried out rather than a mastectomy or to make an operation feasible.

If a woman is to have both chemotherapy and radiotherapy, the chemotherapy is usually given first. Sometimes, radiotherapy may be given between two courses of chemotherapy.

## How is chemotherapy given?

The way in which your chemotherapy is given – the particular drugs and when they are administered – is called a regimen.

Chemotherapy drugs are usually given directly into your bloodstream – either by injection into a vein or through a drip into a vein over a period of minutes or hours (an infusion). Some women find the insertion of the needle uncomfortable, but chemotherapy treatment does not usually cause any other pain. You may be offered a chemotherapy regimen that involves taking drugs as tablets, but this is not common.

Chemotherapy is given as a course of treatment, usually lasting several months. The course is divided into smaller units called cycles. You will usually be given chemotherapy by a specialist chemotherapy nurse as an outpatient at a specialist centre. Your overall wellbeing will be reviewed before each cycle takes place to see how you are and whether you are well enough for treatment.

Chemotherapy also affects blood cells, so your blood count must be checked before each chemotherapy cycle.

## Which chemotherapy drugs should be used?

Your chemotherapy should be planned to suit your particular needs. Research studies have shown that combination chemotherapy (using more than one drug) is generally more effective than treatment regimens based on just one drug. This is because the different drugs act in slightly different ways, so together they have potentially greater impact on cancer cells.

For more information on different chemotherapy regimens, see Macmillan Cancer Support's website [macmillan.org.uk](http://macmillan.org.uk) or call 0808 808 0000.

## What the guidelines say: Side effects of chemotherapy

Offer information and counselling for all women about the possibility of early menopause and menopausal symptoms associated with breast cancer treatment.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

Cytotoxic chemotherapy should be carried out under the supervision of an oncologist who is a member of the breast care team. There should be adequate pharmacy support. There must also be adequate facilities and medical cover for the management of the complications which may arise. Patients, staff and GPs must be given full details of how to access this cover.

*Guidelines for the management of symptomatic breast disease.* Association of Breast Surgery at BASO, 2005.

## Getting treatment

In general, if two chemotherapy regimens are likely to have the same effect on cancer cells, but one has less severe side effects, the regimen with less severe side effects should be prescribed. Before beginning treatment, you should discuss with your oncologist any potential side effects of treatments and how they might affect your quality of life.

Standard adjuvant chemotherapy offered in specialist cancer centres may be one of a number of regimens, including:

- FEC (5-fluorouracil, epirubicin, cyclophosphamide)
- FEC-T (5-fluorouracil, epirubicin, cyclophosphamide, docetaxel)
- E-CMF (epirubicin, cyclophosphamide, methotrexate, 5-fluorouracil)
- EC (epirubicin, cyclophosphamide)
- AC-T (doxorubicin, cyclophosphamide, paclitaxel)
- CMF (cyclophosphamide, methotrexate, 5-fluorouracil)
- TAC (docetaxel, doxorubicin, cyclophosphamide)
- TC (docetaxel, cyclophosphamide).

Other regimens may also be used. If the chemotherapy regimen you are offered is not a combination of drugs including one or more of those above, ask your doctor or nurse if there is a particular reason for this and whether one of these regimens might help you.

## Dealing with side effects of chemotherapy

Most women suffer some short-term side effects with chemotherapy treatment, although these vary a great deal.

Different people's bodies can react differently to the same type and dose of drugs, so your reaction may be very different to that of another woman on the same chemotherapy treatment.

Common short-term side effects with chemotherapy include: tiredness, nausea, vomiting, a sore mouth, mouth ulcers, muscle and joint aching, diarrhoea, hair loss (anything from slight to complete), weight gain and menopausal symptoms.

## What women say

“I was so busy grinning and bearing the side effects – just assuming that this was something I’d have to tolerate – that it didn’t dawn on me at first to ask the nurse if there was something I could take to make me feel better. I wish I’d known earlier.”

Breast Cancer Now Supporter

“I was very sick with the chemotherapy and they did everything they could to make it better. Do tell your nurses if you are feeling sick, they will do everything they can to ease any symptoms.”

Breast Cancer Now Supporter

“I had brilliant friends and we always planned something for the third week after chemo when I was feeling better. That acted as a milestone and every session I counted it as 20% done, 50% done etc, so six months of chemo went really quickly.”

Breast Cancer Now Supporter

For more information on scalp cooling techniques see Macmillan Cancer Support’s website [macmillan.org.uk](http://macmillan.org.uk) or call 0808 808 0000.

You may also experience a reduction in the number of blood cells in your blood, which can result in increased bleeding from cuts and grazes, nose bleeds or you may bruise more easily. A reduction in the level of blood cells may also lead to neutropenia, which increases your risk of infection, and less commonly anaemia, which can make you tired (see page 44).

The more common side effects can vary from very mild to severe, but there are treatments available to eliminate or reduce most of them and your breast care nurse or oncologist may be able to help if you are having problems. Most side effects will stop after each treatment cycle ends. Some side effects, such as anaemia, may mean that you need to alter your chemotherapy course.

## Hair loss

Many women undergoing treatment for breast cancer will be told that their particular chemotherapy treatment will cause hair loss – which can be anything from slight to complete. However, not all chemotherapy treatments will result in hair loss. Your oncologist should advise you of the side effects of your particular regimen.

If you lose some or all of your hair, it will start growing back at the end of your treatment, or sometimes before this. Losing your hair can be a very emotional and distressing experience. Many women wear a wig during this time.

If you decide to have a wig, you are entitled to one free on the NHS, if it is supplied through a hospital service. You should ask at the hospital or clinic. The procedures for getting wig services vary between hospitals, but your breast care or chemotherapy nurse should be able to guide you through the process. You should be able to have your wig fitted before you lose your hair.

Wig suppliers to the NHS are required to give all people choice in the type of wig they get, and to treat them with dignity and empathy. When you go for a wig fitting you should have a private area to try on your wig, and there should be a competent person available to cut and restyle the wig you choose. Some women use scalp cooling techniques, such as a ‘cold cap’, to try to reduce hair loss. However, scalp cooling may not be suitable for all women, or with all types of chemotherapy, and some women report that it didn’t work for them. There are no national guidelines on the use of scalp cooling and services vary between hospitals.

For more information on hair loss and the HeadStrong service, see Breast Cancer Care's website [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

### What women say

“My hair started to grow back after the chemo but I was still wearing the wig. I went to London with my friends and they told me they thought it was time I took it off, so I pulled it off in the street and put it in my shopping bag there and then. They then took me into Harrods for a makeover. For me, that was the right way to make the change from wearing a wig.”

Breast Cancer Now Supporter

“I loved being bald. It gave me a chance to be an ill person and not to have to pretend to be ‘normal’ by wearing a wig.”

Breast Cancer Now Supporter

“I didn't like losing my hair and I didn't know whether to shave it or not. It was emotionally very hard when it was falling out.”

Breast Cancer Now Supporter

For out-of-hours medical care contact NHS Direct or NHS 111 (see page 61 for details).

You may also like to attend a HeadStrong appointment. HeadStrong is a free service provided by Breast Cancer Care at several locations throughout England and Wales, where trained volunteers can give you advice on how to look after your hair and scalp before, during and after treatment. They also teach scarf tying techniques and give you the chance to try on and buy a variety of hats, scarves and hair pieces.

### Infections

Chemotherapy can also reduce the level of infection-fighting blood cells, called neutrophils, in your blood. This is called neutropenia and it increases your chance of getting an infection.

If you are at risk of neutropenia or you develop neutropenia during your chemotherapy course, then you might be prescribed granulocyte-colony stimulating factor (G-CSF) to treat this and therefore reduce your risk of infection. Your chemotherapy dose may be reduced or chemotherapy delayed until your neutrophil levels improve.

In addition, you will be given information about the possibility of infections and will be given information on how to help reduce the chances of getting an infection. Infections can become serious if untreated, so your breast care team will let you know what to look out for and in which instances you should seek prompt medical advice. For example, if you feel feverish, ‘fluey’ or unwell, you should seek medical advice from your breast care team (or out of hours care).

### Anaemia

Anaemia – a reduction in the number of red blood cells – associated with chemotherapy is unusual, but can sometimes affect women quite severely. Anaemia caused by chemotherapy treatment is usually mild, but severe anaemia can make you feel very tired and unable to do most things. During the course of your chemotherapy you will have regular blood tests to check your blood cell levels. If anaemia is a problem, usually the chemotherapy dose is reduced or the chemotherapy is delayed until blood cell levels return towards normal. If necessary, you may be given a blood transfusion or treated with a drug called erythropoietin to boost the levels of red cells in your blood.

For more information on breast cancer and pregnancy, see Breast Cancer Care's booklet *Breast cancer during pregnancy* available at [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

## Effects on fertility

Chemotherapy can affect fertility either temporarily or permanently. This depends on the particular chemotherapy drug as well as your age. If you have not been through the menopause you might have menopausal symptoms during chemotherapy treatment, such as loss of your periods, hot flushes, sleep disturbance and vaginal dryness. For most women under the age of 40, these symptoms end when treatment has finished, with fertility returning to normal. However, many older women become permanently infertile and enter an early menopause.

If you are concerned about the fact that chemotherapy might result in loss of your fertility, discuss this with your doctor and ask about what could be done to help before starting your treatment. For women who would like to retain the option of having a child after chemotherapy, some hospitals can offer services such as the collection and freezing of embryos or eggs before the chemotherapy treatment. However, this is a relatively new technique and, unfortunately, it is often unsuccessful in leading to future pregnancy. These procedures are likely to delay the start of cancer treatment.

Some chemotherapy drugs are safe to take at some stages of pregnancy, whereas others are not. If you are pregnant when due to have chemotherapy (or any other treatment for breast cancer), it is very important to discuss this with your doctor. It is possible to have some chemotherapy treatments in the second and third trimesters; your doctor will discuss the risks and benefits of treatment with you. You should avoid becoming pregnant if you are receiving chemotherapy.

## What the guidelines say:

### Who should be offered hormone therapy

All women with hormone receptor positive tumours should be offered hormone treatment.

*Improving outcomes in breast cancer.* National Institute for Health and Care Excellence (NICE), 2002.

Postmenopausal women with ER-positive early invasive breast cancer who are not considered to be at low risk should be offered an aromatase inhibitor, either anastrozole or letrozole, as their initial adjuvant therapy. Offer tamoxifen if an aromatase inhibitor is not tolerated or contraindicated.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

## What women say

“I would like to see patients provided with the best hormone therapy suited to them as individuals. Also, it’s so very important that their quality of life is maintained.”

Breast Cancer Now Supporter

# Hormone therapy

Hormones are naturally occurring substances that control the growth and activity of cells in the body. The female hormones oestrogen and progesterone are essential for normal sexual development and the functioning of female reproductive organs and they help to maintain healthy bones and heart. However, they can also encourage the growth of some breast cancers. Around three out of four breast cancers are sensitive to hormones in this way.

Hormone therapies block the production of these female hormones or stop the hormones from signalling to the breast cancer cells. As well as stopping cancer cell growth in response to hormones, they also interfere with the usual role of hormones in the body, and so can cause symptoms of the menopause.

Hormone therapies are only effective in treating breast cancers that are hormone positive (also known as hormone sensitive). These are breast cancers with oestrogen receptors in the cancer cells. Hormone therapies for breast cancer should not be confused with hormone replacement therapy (HRT), which is used to treat the symptoms of menopause. HRT **increases** the levels of hormones in the body, whereas hormone therapies **decrease** hormone levels.

Hormone therapies are usually prescribed after surgery (adjuvant treatment). Just as chemotherapy is sometimes given before surgery to make the operation easier, the same can be true of hormone therapy. Hormone therapy can be given before surgery (neoadjuvant treatment), with the aim of shrinking the tumour to make the operation easier to perform.

## Who should be offered hormone therapy?

All patients should have a receptor test to assess whether or not their breast cancer is hormone positive (see page 18). This allows their breast care team to determine whether or not hormone therapies are an option for their treatment. All patients with hormone positive breast cancer should be offered hormone therapy, unless there is a reason this would be unsuitable. However, some women with a very low risk of their breast cancer recurring may choose not to receive it, based on the balance of benefits and risks, the recommendations of their breast care team and their own preferences.

Patients given hormone therapy before surgery are usually older patients, as hormone therapy can be useful in ensuring they are sufficiently well and strong to have surgery. Patients with hormone negative breast cancers will not be offered hormone therapy, as it will not be effective in treating their breast cancer.

**What the guidelines say:**  
**Hormone therapy**

The aromatase inhibitors anastrozole, exemestane and letrozole, within their licensed indications, are recommended as options for the adjuvant treatment of early ER-positive invasive breast cancer in postmenopausal women.

The choice of treatment should be made after discussion between the responsible clinician and the woman about the risks and benefits of each option. Factors to consider when making the choice include whether the woman has received tamoxifen before, the licensed indications and side effect profiles of the individual drugs and, in particular, the assessed risk of recurrence.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

**Types of hormone therapy**

Two types of hormone therapy that are commonly used are:

Hormone therapy	Recommended use
Tamoxifen	For the treatment of women with hormone positive breast cancer. It can be used in women both before and after the menopause
Aromatase inhibitors, eg anastrozole (Arimidex), exemestane (Aromasin) and letrozole (Femara)	As an addition or alternative to tamoxifen for post-menopausal women with hormone positive breast cancer

Women are usually offered one of the following treatment options:

- five years of treatment with anastrozole, letrozole or tamoxifen
- two or three years of tamoxifen, followed by an aromatase inhibitor for two or three years
- five years of treatment with tamoxifen, followed by letrozole for a further four years.

The exact treatment will vary from person to person. Your doctor will discuss with you which programme of hormone therapy is likely to be most suitable for you.

Tamoxifen has been commonly used in the treatment of hormone positive early breast cancer for many years. Tamoxifen works by preventing oestrogen from signalling to cancer cells and encouraging them to grow. Most women who are given tamoxifen take it for five years. The usual dose is one 20mg tablet, taken once a day.

## Getting treatment

Recent research shows there is benefit to extending tamoxifen treatment to 10 years, so this longer length of treatment may be offered to women more often in the future.

Aromatase inhibitors are a newer type of treatment recommended as an addition or alternative to tamoxifen for post-menopausal women with hormone positive breast cancer. They work by reducing the production of oestrogen in the body. Aromatase inhibitors are given as tablets once a day and the dose depends on the particular drug.

## Ovarian ablation

In addition to hormone therapy, completely blocking the production of hormones by the ovaries can help in the treatment of hormone positive breast cancer. This is known as ovarian ablation. Some chemotherapy treatments cause the ovaries to stop producing hormones. Alternatively, some women who are still having periods (pre-menopausal) can have ovarian ablation using one of three methods:

- removing the ovaries by surgery (usually keyhole surgery, which minimises scarring) – this is, of course, permanent
- giving a low dose of radiotherapy to the ovaries, which also permanently stops them from working
- treatment with drugs called LHRH (leuteinising hormone releasing hormone) analogues (eg goserelin, also known as Zoladex) – these drugs can stop the ovaries working, but only temporarily. The ovaries should start working again when you stop taking the drugs.

The methods of ovarian ablation offered to women may vary.

For pre-menopausal women who wish to keep the option of having children in the future, Zoladex treatment should be considered. For women with hormone positive breast cancer who have not had the menopause and have a low risk of recurrence, there is good evidence that blocking the ovaries' release of hormones works as well as CMF (cyclophosphamide, methotrexate, 5-fluorouracil) chemotherapy.

**What the guidelines say:**  
**Dealing with the side effects of hormone therapy**

Offer information and counselling for all women about the possibility of early menopause and menopausal symptoms associated with breast cancer treatment.

...The selective serotonin reuptake inhibitor antidepressants paroxetine and fluoxetine may be offered to women with breast cancer for relieving menopausal symptoms, particularly hot flushes, but not to those taking tamoxifen.

...Soy (isoflavone), red clover, black cohosh, vitamin E and magnetic devices are not recommended for the treatment of menopausal symptoms in women with breast cancer.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

Offer bisphosphonates to patients identified as [being at high risk of bone loss].

*Guidance for the management of breast cancer treatment-induced bone loss.* A consensus position statement from a UK expert group, 2008.

**Dealing with side effects of hormone therapy**

Some women find the menopausal side effects of hormone therapy difficult to manage. However, to get the most from your hormone therapy it is important not to miss treatments or stop treatment. If you are suffering from severe side effects and considering stopping your treatment, we recommend that you discuss this with your breast care team or GP.

**Tamoxifen**

If you have not yet had the menopause and are taking tamoxifen, you are likely to experience some menopausal symptoms, such as loss of your periods, hot flushes, sleep disturbance and vaginal dryness. The menopausal symptoms should disappear when you stop taking tamoxifen, unless your natural menopause has arrived by that time. It is very important that you do not become pregnant while taking tamoxifen, because it may harm your baby.

If you have had the menopause and are taking tamoxifen, you may also experience some menopausal symptoms. These should generally disappear when you stop taking the drug.

Other, much rarer side effects with tamoxifen include an increased risk of thrombosis (blood clots) – most of which are not serious but do need treatment – and eye problems. There is an increased risk of cancer of the lining of the womb (endometrial cancer) in post-menopausal women but this is also rare. This risk should be balanced against the benefits of tamoxifen in reducing the risk of your breast cancer coming back. The risk of endometrial cancer with tamoxifen is much lower than the risk of breast cancer recurrence without it. However, post-menopausal women who experience any bleeding from the vagina while taking tamoxifen should contact their oncologist, breast care nurse or GP as they may need to be referred for a gynaecological examination.

For out-of-hours medical care contact NHS Direct or NHS 111 (see page 61 for details).

## Aromatase inhibitors

Some women taking aromatase inhibitors may experience menopausal symptoms such as hot flushes and vaginal dryness. Pain and stiffness to do with the muscles and joints are more common in women using aromatase inhibitors than in those using tamoxifen, and the risk of osteoporosis (weak bones) is higher. Women who are taking an aromatase inhibitor should have their bone density measured at the start of treatment to assess their risk of osteoporosis. Some women may need to take vitamin D and calcium supplements. If they are at high risk of osteoporosis they may need an additional treatment with bone-strengthening drugs called bisphosphonates.

Rare side effects with aromatase inhibitors include feeling sick, hair thinning, tiredness and headaches.

## Managing menopausal symptoms

Some treatments are available for women of all ages to help reduce menopausal symptoms and you should discuss with your oncologist whether there are any options available for you. Unfortunately, the only way to completely get rid of menopausal symptoms is to use HRT (hormone replacement therapy) and women who have had breast cancer are usually advised not to take HRT. Some women may be offered other drugs to help relieve menopausal symptoms, for example a class of antidepressants called selective serotonin reuptake inhibitors (SSRIs) can help to relieve hot flushes. There are risks and benefits associated with these drugs and it is important that you discuss these fully with your doctor before deciding to take any treatment to relieve menopausal symptoms.

There are a number of things you can do that may help to reduce menopausal symptoms, such as exercising and cutting out caffeine and nicotine.

Some natural remedies may help with menopausal symptoms. However, it is important that before you begin taking any supplements you discuss these with your oncologist first, as there is no conclusive evidence that they are effective and they may interfere with your hormone therapy. Women with breast cancer are recommended not to use soy (isoflavone), red clover, black cohosh, vitamin E and magnetic devices.

## What women say

“Hot flushes were a nightmare, but I considered them bearable compared to having cancer.”

Breast Cancer Now Supporter

# Targeted (biological) therapy

Targeted therapies attack cancer cells directly (ie target them). They do not usually affect healthy tissue and so do not usually cause side effects such as sickness and hair loss. Herceptin (also known as trastuzumab) is a targeted treatment available for early breast cancer.

## What the guidelines say: Herceptin

Trastuzumab, given at 3-week intervals for 1 year or until disease recurrence (whichever is the shorter period), is recommended as a treatment option for women with early-stage HER2-positive breast cancer following surgery, chemotherapy (neoadjuvant or adjuvant) and radiotherapy (if applicable).

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

## Who should be offered Herceptin?

Herceptin targets breast cancers that have high levels of a protein called HER2. These breast cancers are known as HER2 positive breast cancers and account for around one in five breast cancers. Herceptin can be an effective treatment for HER2 positive breast cancer. However, not all patients with HER2 positive breast cancer will benefit from Herceptin treatment. In addition, patients with HER2 negative cancers (those with low levels of HER2) do not benefit from Herceptin.

For these reasons, you will need to have your cancer tested to see if it is HER2 positive before Herceptin treatment can be considered. This is achieved using receptor testing (see page 18).

There are three requirements for women to be prescribed Herceptin:

- they should have HER2 positive breast cancer
- their heart should be working normally (adequate cardiac function) – due to the risk of Herceptin causing heart damage
- they must have had surgery, chemotherapy and, if appropriate, radiotherapy.

## Dealing with side effects

As with all cancer treatments, women taking Herceptin may experience some side effects. Herceptin does not cause hair loss and feelings of sickness like chemotherapy, but it may cause flu-like symptoms in some patients, and it can lead to heart problems. Due to this risk, Herceptin may not be a suitable treatment for everyone and all patients should have their cardiac function assessed before treatment. Cardiac function should be further monitored every three months during treatment and every six months for two years after treatment has stopped.

For details of clinical trials currently recruiting patients, see the UK Clinical Trials Gateway website [ukctg.nihr.ac.uk](http://ukctg.nihr.ac.uk)

For more information on clinical trials, see Macmillan Cancer Support, Cancer Research UK (details of both on page 61) or ask your hospital.

### What women say

“I joined [a clinical trial]. I really liked the extra monitoring and it made me feel less on my own.”

Breast Cancer Now Supporter

“I was offered a place on a trial just after surgery had revealed the spread of my cancer to my axillary lymph nodes. It was too much, too soon and I declined.”

Breast Cancer Now Supporter

## Clinical trials

**Clinical trials are the most effective and reliable way of finding out which are the best treatments and of comparing new treatments with well-established treatments. In some cases they have led to new and better treatments being identified, in others they confirm that established treatments are still the best.**

In clinical trials, patients are split into different groups. Each group receives a different treatment, so that the success and side effects of these different treatments can be compared. It's important to know that if you take part in a clinical trial, you probably won't know which treatment you are receiving until the trial ends. You also cannot choose which treatment you are given. This is so that the results of the trial are not influenced by people's views of which treatment might be best. You may receive a standard treatment that is currently available on the NHS or you might receive a new treatment, for example a different dose of an existing drug, a new radiotherapy regimen or a newly developed drug.

There are many clinical trials taking place for breast cancer. Breast Cancer Now believes that you should be offered the chance to be included in relevant clinical trials should you wish. However, it is important that you are happy to take part: you should have full information before you agree. Don't be afraid to say no if you don't want to take part in a trial – this will not affect the overall care you receive from your breast care team.

Some people find participating in a trial rewarding, as they are helping to advance medical knowledge and shape future cancer diagnosis and treatment. Clinical trials offer the chance for some participants to receive new and potentially better drugs; however, there is no guarantee that these are better than the standard treatment or that you will receive the new drug.

If you participate in a trial your progress will be closely monitored, which can be reassuring but means you are likely to have more appointments to attend. If you are not responding to the treatment, or are experiencing too many side effects, you should be given the option to withdraw or change treatment.

## **What the guidelines say:** **Complementary therapy**

Complementary therapies including acupuncture, hypnosis, cognitive behaviour therapy (CBT) and relaxation techniques may all ameliorate some menopausal symptoms. Their value may reflect the personalised treatment and time spent with the patient.

*Early and locally advanced breast cancer: diagnosis and treatment. National Institute for Health and Care Excellence (NICE), 2009.*

## **What women say**

“The hospital provided reflexology. It was really good and was really nice to look forward to when you’re battling along with chemotherapy.”

Breast Cancer Now Supporter

For more information on complementary therapies see Cancer Research UK’s website [cancerresearchuk.org](http://cancerresearchuk.org) or call 0808 800 4040.

# Complementary therapies

**Many women with breast cancer feel complementary therapies help them to cope with their illness and the side effects of conventional (medical) treatments.**

Complementary therapies include therapies such as relaxation techniques, massage, acupuncture and aromatherapy used alongside conventional treatments. They are not aimed at curing disease, although some may have a positive effect on patients’ wellbeing. They are often used to ease side effects of conventional treatment.

When certain therapies are used in place of conventional treatments such as chemotherapy or radiotherapy, they are called ‘alternative therapies’. Breast Cancer Now does not advise the use of alternative therapies.

Complementary therapies can be administered by doctors, specialist cancer centres, therapy practitioners or by patients themselves, and may be available at breast units and hospitals and other centres around the country, as well as outside the NHS. Your doctor or nurse will be able to tell you about what is available at your hospital and area. If you are receiving treatment for breast cancer, it is important to check with your specialist before you use any complementary therapies, eg dietary supplements, in case they interfere with your conventional treatment.

# What happens next?

Find out what you can expect after your treatment for breast cancer.



## What women say

“Just after my treatment, follow up was really important for me because I saw someone who was approachable and supportive. It gave me a chance to ask about the things that had been worrying me and to be reassured.”

Breast Cancer Now Supporter

## What the guidelines say: Follow up

[I]t is recommended that patients should be followed up for 5 years but this period may vary with local and clinical trial protocols.

*Surgical guidelines for the management of breast cancer.* Association of Breast Surgery at BASO, 2009.

After completion of adjuvant treatment...for early breast cancer, discuss with patients where they would like follow up to be undertaken. They may choose to receive follow up care in primary, secondary, or shared care.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

People having treatment for early breast cancer are offered personalised information and support, including a written follow-up care plan and details of how to contact a named healthcare professional.

*Breast Cancer Quality Standard.* National Institute for Health and Care Excellence (NICE), 2011.

The MDT should ensure that patients are assessed for ongoing support following treatment for breast cancer.

*National standards for breast cancer services.* Welsh Assembly Government, 2005.

# Follow up

The purpose of follow up is to deal with the side effects of treatments, provide psychological support and to detect and treat any local recurrence of breast cancer.

## Planning your follow up

Follow up plans may vary across England and Wales and can also differ depending on the type of breast cancer and the treatments a woman has received. Most doctors would agree with patients being seen every three to 12 months for the first one or two years and once a year after that, with annual mammography as described below. Some patients at high risk of their breast cancer returning may be seen more often.

The length of follow up varies in different centres; it is most often five years. At the end of this time it is important that you continue to attend your mammogram appointments and that you know how to get back in touch with your breast care nurse should you need to.

After you have been treated for breast cancer, you and your breast care team should agree on a care plan. This plan should include:

- The names of healthcare professionals who are providing your follow-up care
- The dates for any ongoing drug treatment
- Plans for follow-up mammography
- Contact details in case you need to access specialist care
- Contact details of local support services, such as for lymphoedema support.

## What the guidelines say: Follow up investigations

Women treated for early breast cancer have an annual breast screen for 5 years after treatment. After 5 years women who are 50 or older have breast screening according to NHS Breast Screening Programme timings, whereas those under 50 continue with annual breast screening until they reach 50 and start screening through the NHS Breast Screening Programme.

...People with early invasive breast cancer do not undergo investigations for cancer elsewhere in the body if they have no symptoms that the cancer has spread.

*Breast Cancer Quality Standard. National Institute for Health and Care Excellence (NICE), 2011.*

## Detecting breast cancer recurrence

Sometimes, a woman's breast cancer can come back (recur).

Recurrences happen when breast cancer cells survive initial treatment and grow into new tumours.

There are three types of recurrence:

- local recurrence – when the breast cancer comes back in the same place
- regional recurrence – when breast cancer comes back in nearby tissues, eg the skin, chest muscles, breast or collar bone area
- distant recurrence – when the breast cancer comes back in other areas of the body (metastatic breast cancer).

Your breast care team planned your treatment especially to treat your breast cancer and to reduce the likelihood of it returning or spreading. However, some risk remains of the breast cancer coming back or you developing a new breast cancer, which is why women are offered follow up mammograms and examinations. These help to ensure that, if you do have a local or regional recurrence, this is picked up early.

The chance of recurrence differs from person to person, depending on the characteristics of their breast cancer and how well it responded to treatment.

As part of your follow up, you should be offered annual mammography. You will also be seen regularly by a breast care nurse or doctor for a few years (often five) for a physical examination and to discuss any problems or concerns you may have.

For women who are already using the NHS Breast Screening Programme, annual screening should continue for five years, after which you will go back to having screening every three years as normal. For younger women, annual mammography should continue until they are eligible for routine NHS breast screening.

Women who have a high risk of developing breast cancer again due to their family history (including those who carry faults in known breast cancer genes) may be offered additional screening, depending on their age and level of risk. If you have a confirmed family history of breast cancer, your family history or genetics specialist can explain any additional screening for which you are eligible.

## Follow up

If your mammogram or physical examination detects possible signs of breast cancer, this doesn't necessarily mean that the cancer has come back or that it has become more aggressive than before. However, you will need diagnostic tests to confirm whether or not your breast cancer has come back, so that you can begin a new course of treatment if required.

Follow up care aims to detect local and regional recurrence, or a new breast cancer, but you will not usually have tests to detect a distant recurrence (metastatic breast cancer). This is because performing routine tests for metastatic breast cancer in women without symptoms has not been shown to increase survival.

Your breast care team should explain symptoms to look out for in your breasts, armpits and other areas of your body. If you do notice any unusual symptoms, report them to your breast care team or GP. Don't wait for your next routine appointment to do this.

For more information on life after breast cancer, see Breast Cancer Care's resource pack *Moving Forward*, available at [breastcancercare.org.uk](http://breastcancercare.org.uk) or call 0808 800 6000.

## Further support and care

It is important that you are cared for even after your treatment has finished, and that your health and support needs continue to be met. Sometimes, side effects of treatment can remain for some time, or even permanently, after cancer treatment and you may develop new side effects, such as lymphoedema, after your treatment ends. You should be told, and be given written information, about the side effects of cancer treatment to look out for so that you can report these to your breast care nurse or GP and receive further treatment or support if needed.

You should also have a contact number for your breast care nurse, so you can talk about any concerns you may have. If you require more specialist services, for example lymphoedema services, you should be given appropriate information about these. If you think you would like psychological support after your treatment, this should be available to you. Your breast care nurse or GP will be able to arrange this.

Women with a family history of breast cancer and their families are able to access family history services. For women with sufficiently strong family histories, this may include genetic testing to determine whether inherited faults in known breast cancer genes run in the family.

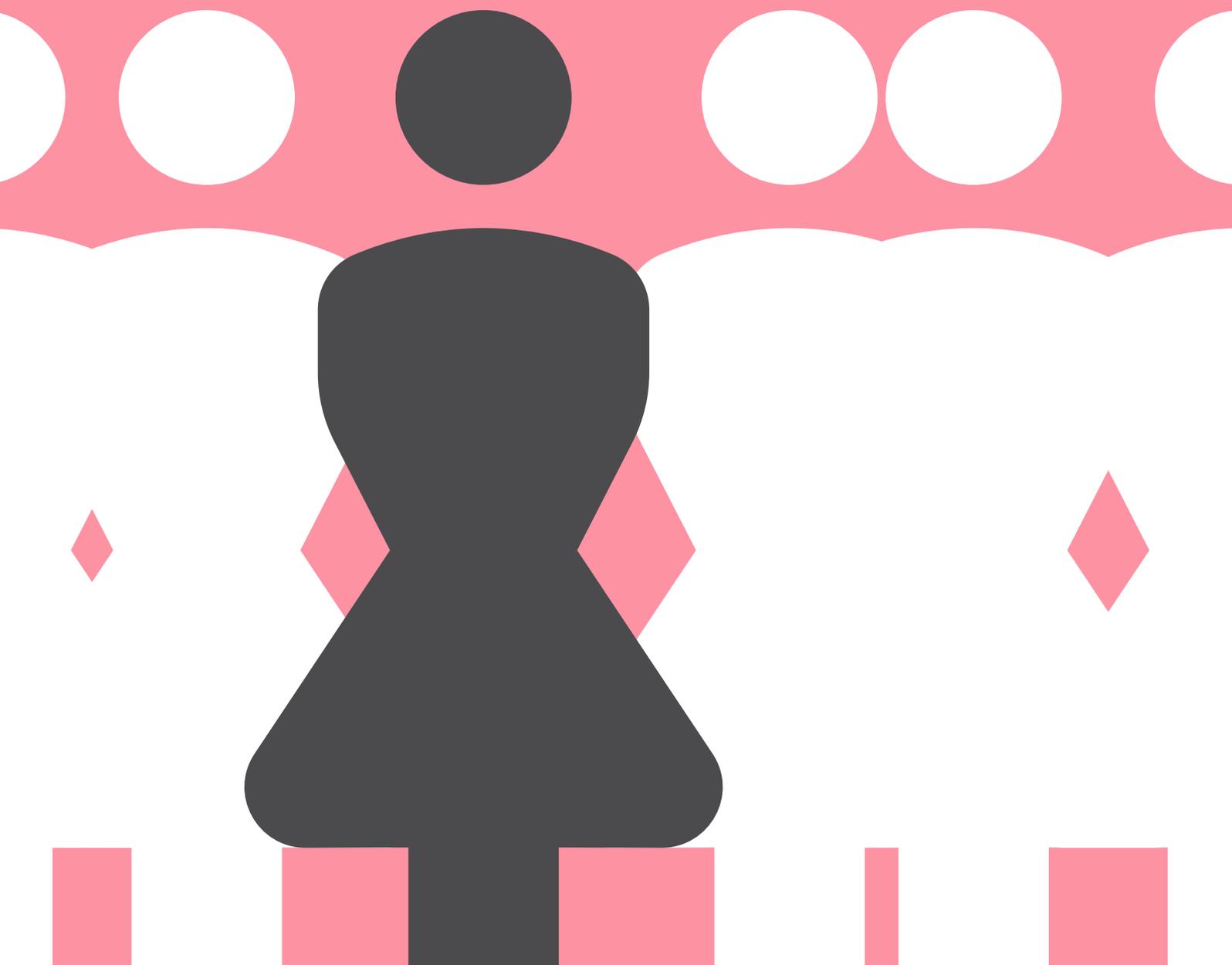
For more information on family history services, see Breast Cancer Now's website [familyhistory.breastcancernow.org](http://familyhistory.breastcancernow.org) or call 0333 20 70 300.

Women who have been diagnosed with breast cancer and who have a family history may be offered earlier and more frequent breast screening and risk-reducing surgery to help them manage their risk of developing another breast cancer. Risk-reducing surgery can be removal of the breasts (mastectomy), removal of the ovaries (oophorectomy), or both.

## The best treatment

Your guide to breast cancer treatment in England and Wales

# More support and information



# Quick guide to further support and information

More information and advice on a variety of topics is available from Breast Cancer Now and other charities and health organisations. You may also wish to ask your breast care nurse for information from your local health service.

If you have a question that is not covered by this booklet or the information sources listed below, please feel free to contact us by email at [info@breastcancer.org](mailto:info@breastcancer.org) or by calling our Freephone Information Line 0333 20 70 300 and we will be happy to help.

See the following pages for full contact details of each organisation.

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## Support

Emotional support and practical advice (including someone to talk to)	Breast Cancer Care Macmillan Cancer Support Breast Cancer Haven (Hereford, Leeds, London) Penny Brohn Cancer Care (Bristol) Tenovus (Cardiff)
HeadStrong: hair loss support and advice sessions	Breast Cancer Care
Out-of-hours medical care	NHS Direct or NHS 111
Lymphoedema support	Lymphoedema Support Network

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## Information

Breast awareness (how to <i>Touch Look Check</i> your breasts for signs of breast cancer)	Breast Cancer Now, see <a href="http://breastcancer.org/tlcbest">breastcancer.org/tlcbest</a>
Breast cancer in men	Breast Cancer Now's website, see <a href="http://breastcancer.org/breastcancerinmen">breastcancer.org/breastcancerinmen</a>
Breast prostheses	Breast Cancer Care
Breast reconstruction	Breast Cancer Care
Chemotherapy regimens	Macmillan Cancer Support

More support and information

Clinical trials	Cancer Research UK and Macmillan Cancer Support (for details of current trials see <a href="http://ukctg.nihr.ac.uk">ukctg.nihr.ac.uk</a> )
Complementary therapies	Cancer Research UK
Family history services	Breast Cancer Now, see <a href="http://familyhistory.breastcancer.org">familyhistory.breastcancer.org</a>
Financial and practical information (including benefits, returning to work, ill-health retirement and travel insurance)	Macmillan Cancer Support
Hair loss and scalp cooling	Breast Cancer Care and Macmillan Cancer Support
Life after breast cancer	Breast Cancer Care
Local NHS services	NHS Choices (England) NHS Wales (Wales)
Lymphoedema	Lymphoedema Support Network Breast Cancer Care Breast Cancer Haven
Metastatic breast cancer	Breast Cancer Now, see <a href="http://breastcancer.org/metastatic">breastcancer.org/metastatic</a>
Pregnancy and breast cancer	Breast Cancer Care
Radiotherapy and skin care	Cancer Research UK
Surgery and recovery	Breast Cancer Care
Types of breast cancer	Breast Cancer Care
Younger women with breast cancer	Breast Cancer Care

**Breast Cancer Care**

Breast Cancer Care is a national organisation offering information and support. Its services include a national helpline, leaflets and fact sheets and a network of volunteers who can offer one-to-one support.

Email:  
[info@breastcancercare.org.uk](mailto:info@breastcancercare.org.uk)

Helpline: Freephone  
0808 800 6000  
(text relay 18001)  
9am–5pm Mon to Fri or  
10am–2pm on Saturdays

Website:  
[breastcancercare.org.uk](http://breastcancercare.org.uk)

**Breast Cancer Haven**

Breast Cancer Haven provide, free of charge, a wide range of support and therapies to improve your wellbeing with, and beyond, breast cancer. They have centres in Hereford, Leeds and London.

Email:  
[info@thehaven.org.uk](mailto:info@thehaven.org.uk)

Phone: 020 7384 0099  
9.30am–5pm Mon to Fri

Website:  
[thehaven.org.uk](http://thehaven.org.uk)

**Breast Test Wales**

Breast Test Wales organises NHS breast screening in Wales.

Website:  
[screeningservices.org.uk/btw](http://screeningservices.org.uk/btw)

### **Cancer Research UK**

Independent organisation dedicated to cancer research. They work to improve our understanding of cancer and develop better ways to prevent, diagnose and treat the disease.

Freephone: 0808 800 4040  
9am–5pm Mon to Fri

Website:  
cancerresearchuk.org

### **Lymphoedema Support Network**

Lymphoedema Support Network is a UK organisation for anyone with lymphoedema. It provides advice, support and information on treatments.

Email:  
admin@lymphoedema.  
freemove.co.uk

Helpline: 020 7351 4480  
9am–5pm Mon to Fri

Website: lymphoedema.org

### **Macmillan Cancer Support**

Macmillan Cancer Support helps to provide the expert care and practical and emotional support that makes a real difference to people living with cancer.

Freephone: 0808 808 0000  
9am–8pm Mon to Fri

Website: macmillan.org.uk

### **NHS Cancer Screening Programmes**

NHS Cancer Screening Programmes organises breast screening in England.

Website:  
cancerscreening.nhs.uk/  
breastscreen

### **NHS Direct Wales (Galw Iechyd Cymru)**

NHS Direct Wales (Galw Iechyd Cymru) provides health advice and reassurance in English and Welsh, 24 hours a day, 365 days a year.

Phone: 0845 4647

Website:  
nhsdirect.wales.nhs.uk

### **NHS Choices**

NHS Choices is the online ‘front door’ to the NHS. It is England’s biggest health website and gives information you need to make choices about your health.

Phone: 111

Website: nhs.uk

### **NHS Wales**

NHS Wales is the gateway to information about health and health services in Wales.

Website: Wales.nhs.uk

### **Penny Brohn Cancer Care**

Penny Brohn Cancer Care is a Bristol-based charity that helps people to live well with the impact of cancer.

Email:  
helpline@pennybrohn.org

Helpline 0845 123 2310  
9.30am–5pm Mon to Fri

Website:  
pennybrohncancercare.org

### **Tenovus**

Tenovus is a Cardiff-based charity that brings care, treatment, support and research to the heart of the community.

Free helpline: 0808 808 1010  
(8am–8pm, 7 days per week)

Website: tenovus.co.uk

## Some medical terms explained

**Adjuvant treatment** – treatment given after other treatment eg chemotherapy given after surgery, *see also neo-adjuvant therapy*

**Advanced breast cancer** – *see metastatic breast cancer*

**Aggressive cancer** – cancer that is growing quickly

**Anaemia** – a lower than normal number of red blood cells (or reduction in haemoglobin in the blood). This reduces the amount of oxygen the blood can carry, leading to symptoms such as tiredness and a lack of energy

**Anastrozole (Arimidex)** – a type of aromatase inhibitor, *see also hormone therapy*

**Anthracyclines** – group of chemotherapy drugs, includes doxorubicin and epirubicin

**Aromatase inhibitors** – type of hormone therapy used to treat breast cancer by blocking the production of oestrogen in the body, *see also hormone therapy*

**Axilla** – a medical term for the armpit

**Axillary clearance** – removal of all the lymph nodes from the armpit

**Axillary node sampling** – removal of a few lymph nodes from the armpit to test them for the presence of cancer

**Bilateral** – both sides of the body, eg a bilateral mastectomy is the removal of both breasts

**Biopsy** – removal of tissue for examination under a microscope

**Breast care team** – a team of specialists, including doctors and nurses, responsible for the care of a patient with breast cancer

**Breast conserving surgery** – surgery that removes the tumour and a small margin of surrounding healthy tissue, but not the whole breast. Also known as lumpectomy or wide local excision

**Breast prosthesis** – an artificial breast (commonly put in a bra pocket or stuck directly to the skin)

**Breast reconstruction** – surgery to rebuild a breast after a tumour is removed

**Chemotherapy** – drug treatment that aims to destroy cancer cells, usually injected into the bloodstream, but can also be injected into muscle or given as a tablet

**Clear margin** – see *uninvolved margin*

**Combination chemotherapy** – treatment with a number of chemotherapy drugs at the same time

**Complex decongestive therapy (CDT)** – a form of treatment for lymphoedema that aims to reduce swelling or to prevent the condition worsening

**Contraindication** – a condition or circumstance that indicates that a particular medicine or treatment is not suitable for a particular person to receive

**Core biopsy** – removal of tissue using a needle to examine in the laboratory to check for cancer cells

**Cytologist** – expert in diagnosing disease by studying cells

**Cytotoxic** – substances that are toxic (poisonous) to cells, either stopping them from dividing into new cells or killing them

**DCIS (ductal carcinoma in situ)** – an early form of breast cancer (non-invasive breast cancer) that is confined to the milk ducts and has not spread to neighbouring tissues

**Early breast cancer** – cancer in the breast that has not spread beyond the breast and armpit lymph nodes

**Endocrine therapy** – see *hormone therapy*

**Estrogen** – American spelling of oestrogen (see *oestrogen*)

**Exemestane (Aromasin)** – type of aromatase inhibitor, see also *hormone therapy*

**Family history of breast cancer** – having an unusually high number of close relatives with breast cancer, often at a younger age than would normally be expected. For more information, see *familyhistory.org* [breastcancer.org](http://breastcancer.org)

**Fibrosis** – thickening or scarring of connective tissue

**Fine needle aspiration (FNA)** – biopsy using a thin needle to extract cells to see whether they are cancerous

**Fractions (of radiotherapy)** – one dose of a radiotherapy treatment programme (usually given on one day)

**Goserelin (Zoladex)** – type of hormone therapy

**Grading** – measure of how different the cancer cells are to normal cells, which gives an estimate of how aggressive a cancer is

**Gray/Gy** – a unit of measurement for radiotherapy doses

**HER2** – a protein (a receptor) found in the cells of some breast cancers. HER2 positive breast cancers may be treated with the targeted therapy Herceptin, often in addition to other treatments

**Herceptin (trastuzumab)** – a treatment for breast cancer that may be used to treat breast cancers that are HER2 positive (approximately one in five breast cancers)

**Hormones** – naturally occurring substances in the body that control the growth or activity of cells in the body

Hormone positive breast cancer – also known as hormone sensitive breast cancer, these breast cancers are stimulated to grow by hormones in the body. These breast cancers (about three out of four breast cancers) may be treated with hormone therapy, often in addition to other treatments

**Hormone replacement therapy (HRT)** – a treatment for symptoms of the menopause, which works by raising the levels of female hormones in the body

**Hormone therapy (also known as endocrine therapy)** – drug treatment used to stop the hormones oestrogen and progesterone from helping breast cancer cells to grow. Hormone therapies (tamoxifen and aromatase inhibitors) may be used to treat hormone positive breast cancers

**Imaging** – techniques, including mammography, that allow doctors to get a detailed picture of internal body structures

**Inflammatory breast cancer**

– a rare type of breast cancer that is characterised by inflammation (redness and swelling) of the breast

**Invasive breast cancer**

– cancer that has spread beyond the specific area where it first developed into neighbouring healthy tissues

**Involved margin** – an area around the tumour site left after surgery that is affected by the cancer and needs further treatment

**Local recurrence** – the reappearance of cancer cells after treatment, in the same place the tumour was originally found

Letrozole (Femara) – type of aromatase inhibitor; a hormone therapy

**Lumpectomy** – see *breast conserving surgery*

**Lymphatic system** – part of the immune system; carries antibodies and cells that fight infection around the body in lymph fluid

**Lymph node** – a gland which is part of the immune system; it filters lymph fluid, fights infection and forms white blood cells

**Lymphoedema** – long-term swelling in the tissues, which can occur in the arm or upper body after breast cancer surgery or radiotherapy. It is caused by a build-up of excess fluid in the tissue

**Mammogram** – an x-ray of the breast using very low doses of radiation that aims to detect signs of breast cancer

**Mastectomy** – surgery to remove the breast, and possibly some or all lymph nodes of the armpit

**Metastatic breast cancer** – breast cancer that has spread beyond the breast or armpit to other, distant areas of the body, forming new tumours

**MRI (magnetic resonance imaging)** – a type of scan using radio waves and a magnetic field to create images of the body

**Multi-agent chemotherapy** – see *combination chemotherapy*

**Multidisciplinary team (MDT)** – a team of health professionals with a variety of roles and specialisms, who work together to provide treatment and care

**Neoadjuvant therapy** – treatment given before surgery, eg the use of chemotherapy before surgery to shrink a large tumour so surgery can be performed

**Neutropenia** – a reduction in the level of infection-fighting blood cells, called neutrophils

**Non-invasive breast cancer** – breast cancer confined to the milk ducts or glands and has not spread to neighbouring tissues

**Oestrogen** – a female hormone that is naturally found in the body. It is essential for normal sexual development and the functioning of female reproductive organs

**Oestrogen receptors** – a protein in some breast cancer cells to which oestrogen can bind, promoting cell growth, see also *hormone positive breast cancer*

**Oncologist** – a doctor specialising in the treatment of cancer, known as either a clinical or medical oncologist depending on their area of speciality

**Oncoplastic resection** – surgery involving lumpectomy and cosmetic surgery, sometimes to both breasts, to even their appearance

**Ovarian ablation** – completely blocking the release of hormones by the ovaries, either by surgery, radiotherapy to the ovaries, or treatment with drugs

**Paget's disease** – a rare type of invasive breast cancer that is characterised by skin changes to the nipple

**Pathologist** – a doctor specialising in the diagnosis and classification of diseases by laboratory tests, such as examination of tissue and cells under a microscope

**Physiotherapist** – a specialist in providing physiotherapy, which involves massage and manipulation of the body to promote healing and wellbeing

**Positive margin** – see *involved margin*

**Post-operative** – occurring after an operation

**Primary breast cancer** – an initial cancer that started in the breast tissue or armpit (in some cases, this may spread and form new tumours, known as *metastatic breast cancer*)

**Progesterone** – a naturally occurring female hormone. It is essential for normal sexual development and the functioning of female reproductive organs

**Radiographer** – a person trained to operate equipment involving radiation, eg for x-rays, mammograms and radiotherapy

**Radiologist** – a doctor specialising in the use of x-rays and other imaging methods for diagnosis and treatment

**Radiotherapy** – the use of high energy x-rays to destroy cancer cells

**Receptor tests** – tests of breast cancer tissue conducted in the laboratory to see whether the cancer cells have specific markers (receptors). This helps to determine whether hormone therapy and/or targeted therapy will be effective treatments

**Reconstruction** – see *breast reconstruction*

**Regimen** – a programme of treatment

**Secondary breast cancer** – see *metastatic breast cancer*

**Sentinel node biopsy** – a way of checking to see whether cancer has spread to the lymph nodes in the armpit; sentinel nodes are the first nodes in the armpit to which cancer could spread

**Side effects** – unwanted symptoms caused by medical treatment

**Staging** – indication of the size and spread of a cancer

**Symptomatic breast cancer** – cancer which is identified because the patient experiences symptoms, rather than through routine screening

**Systemic treatment** – treatment that affects the whole body, such as chemotherapy and hormone therapy

**Tamoxifen** – a hormone therapy used for the treatment of hormone positive breast cancer, see *also hormone therapy*

**Targeted therapy** – treatments that directly target the cancer cells, eg Herceptin

**Taxanes** – group of chemotherapy drugs, eg Taxotere

**TNM (tumour, nodes, metastases) assessment** – a method used for *staging*

**Triple assessment** – initial testing for breast cancer, carried out in a breast clinic, which includes physical examination, imaging of the breast and biopsy

**Triple negative breast cancer** – a type of breast cancer that does not carry three particular receptors in the cancer cells, which are for hormones and a protein called HER2

**Tumour** – an abnormal growth or swelling of tissue which may or may not be cancerous

**Ultrasound imaging** – technique for taking pictures of the inside of the body using sound waves

**Uninvolved margin** – area around a removed tumour that contains no cancer cells

**Wide local excision** – see *breast conserving surgery*

# Guidelines

Several sets of guidelines have been produced for the diagnosis and treatment of breast cancer over the past few years. Many of these guidelines have been used in the preparation of this booklet. The main ones specific to England and Wales and referred to here are:

## England and wales

*Breast Cancer Quality Standard.* National Institute for Health and Care Excellence (NICE), 2011.

*Early and locally advanced breast cancer: diagnosis and treatment.* National Institute for Health and Care Excellence (NICE), 2009.

*Surgical guidelines for the management of breast cancer.* Association of Breast Surgery at BASO, 2009.

*Oncoplastic breast surgery: a guide to good practice.* Association of Breast Surgery at BASO, 2007.

*Improving outcomes in breast cancer: manual update.* National Institute for Health and Care Excellence (NICE), 2002.

## England only

*Best practice diagnostic guidelines for patients presenting with breast symptoms.* Alexis M Willett, Michael J Michell, Martin J R Lee, 2010.

*National cancer waiting times monitoring data set.* NHS Connecting for Health, 2012.

*Improving outcomes: a strategy for cancer.* Department of Health, 2011.

## Wales only

*Designed to tackle cancer in Wales: a Welsh Assembly Government policy statement.* Welsh Assembly Government, 2006.

*National standards for breast cancer services.* Welsh Assembly Government, 2005.

The information in this booklet is based on current best practice guidelines and aims to give you the best information available. All information was reviewed by appropriate experts and people affected by breast cancer. We advise readers with concerns about breast cancer to discuss them with a healthcare professional. If you would like more information about the sources of evidence on which this publication is based, please contact [info@breastcancer.org](mailto:info@breastcancer.org) or call 0333 20 70 300.

# About Breast Cancer Now

**Breast Cancer Now is the UK's largest breast cancer charity, created by the merger of Breast Cancer Campaign and Breakthrough Breast Cancer.**

Our cutting-edge research is focused entirely on breast cancer. Right now, we're funding around £23 million worth of ground-breaking research projects, supporting nearly 450 of the world's brightest researchers at more than 30 institutions across the UK and Ireland. Together, they're working to discover how to prevent breast cancer, how to detect it earlier and how to treat it effectively at every stage so we can stop the disease taking lives.

Everything we do is rooted in the realities of women affected by breast cancer. We're the catalyst that connects the laboratory bench with the hospital bedside, the GP's office, the MP's surgery and the policies that govern our health service. And it's only by working together that we'll truly make an impact on this devastating disease.

If we all act now, we believe that by 2050 everyone who develops breast cancer will live. We need to invest at least £300 million in research over the next 10 years if we're to achieve these ambitious goals. Please join us and help support vital research into breast cancer now.

## How Breast Cancer Now drives improvements in breast cancer services

Breast Cancer Now works to ensure that people affected by breast cancer have access to the most appropriate and best possible services and treatments based on their needs. Our aim is to make sure the best standards in early detection and diagnosis, treatment and support are available for all.

To this end we have developed this booklet and the Service Pledge for Breast Cancer.

Our Service Pledge goes beyond this booklet to set out the standards which Breast Cancer Now believes individual breast units should aspire to achieve. For the past 10 years, staff members in breast units across the UK have joined Breast Cancer Now's Service Pledge to work alongside patients to develop their own local pledges. These pledges outline both the standard of service patients can expect at their unit and a set of improvements that they are working towards. These improvements, identified by patients, ensure that the local pledges reflect the priorities of women with breast cancer. For more information on the Service Pledge, contact Breast Cancer Now: visit [breastcancernow.org/servicepledge](http://breastcancernow.org/servicepledge) or call 0333 20 70 300 (ask for the 'Service Pledge team' when you get in touch).

## Contact us

### Breast Cancer Now

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This document is based on up-to-date research evidence and aims to give the best information available. All information was reviewed by appropriate experts and members of the public. We advise readers with concerns about breast cancer to discuss them with a health professional.

If you would like more information about the sources of evidence on which this publication is based, please contact [info@breastcancernow.org](mailto:info@breastcancernow.org) or call 0333 20 70 300.

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