The best treatment
Your guide to breast cancer treatment in Scotland
About this booklet

This booklet sets out the standards of care that women undergoing treatment for early breast cancer can expect in Scotland. It explains the 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 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 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
• 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 70–73.

If you have any questions about the topics covered in this booklet, you may wish to contact our Information Line on freephone 08080 100 200 or 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 take into account their full medical history, diagnosis, needs and preferences and, where appropriate, specialist medical advice.
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From referral to diagnosis

In this section we explain what care to expect if you visit your GP with unusual breast symptoms. We look at what to expect when you see your GP and in which instances they may book you an appointment at a breast unit. We give information on the tests you may have at the clinic, what these may find, waiting times and what happens next.
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, your GP should refer you to a hospital specialist (see table on page 6). Everyone with suspected breast cancer should see a specialist promptly. No national target has been set specifically for the time from GP referral to a woman’s appointment at a breast clinic in Scotland; however, Breast Cancer Now believes that, ideally, women should be seen within two weeks of their GP’s decision to refer them.

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)
- 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.
### Symptoms that require a patient to be referred to a specialist clinic*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>breast lump</strong></td>
<td>- any new lump (either on its own or in an area that was already lumpy)</td>
</tr>
<tr>
<td></td>
<td>- new lumpiness in one breast or armpit not linked to your period</td>
</tr>
<tr>
<td></td>
<td>- abscess (collection of pus) or mastitis (inflammation of a mammary gland) not related to breastfeeding that doesn’t improve with antibiotics</td>
</tr>
<tr>
<td></td>
<td>- an abscess if you are over 40</td>
</tr>
<tr>
<td></td>
<td>- a cyst that keeps refilling or coming back</td>
</tr>
<tr>
<td></td>
<td>- a lump in a lymph node in your armpit</td>
</tr>
<tr>
<td><strong>breast or armpit pain</strong></td>
<td>- ongoing pain in one breast or armpit, if you have gone through the menopause</td>
</tr>
<tr>
<td></td>
<td>- pain associated with a lump</td>
</tr>
<tr>
<td></td>
<td>- continuing pain that interferes with your lifestyle or sleep and that hasn’t got better with simple measures such as wearing a well-supporting bra and common supplements, eg, evening primrose oil</td>
</tr>
<tr>
<td><strong>nipple symptoms</strong></td>
<td>- ongoing blood-stained discharge if you are under 50</td>
</tr>
<tr>
<td></td>
<td>- discharge from both nipples sufficient to stain clothing</td>
</tr>
<tr>
<td></td>
<td>- any nipple discharge if you are over 50</td>
</tr>
<tr>
<td></td>
<td>- new inverted nipple (it is now pointing inwards but previously did not)</td>
</tr>
<tr>
<td></td>
<td>- nipple eczema, if not present elsewhere or relieved by steroid treatment</td>
</tr>
<tr>
<td><strong>changes to breast skin</strong></td>
<td>- an area of your skin that has become tight or attached to the tissue below (known as ‘tethering’)</td>
</tr>
<tr>
<td></td>
<td>- ulceration (an open sore)</td>
</tr>
<tr>
<td></td>
<td>- an abscess or inflammation that is not relieved by antibiotic treatment</td>
</tr>
<tr>
<td></td>
<td>- an abscess or inflammation if you are over 40 (you should be referred for a mammogram in this instance)</td>
</tr>
</tbody>
</table>

* Adapted from: Scottish referral guidelines for suspected cancer. Scottish Cancer Group/Scottish Executive Health Department, 2007.
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

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.

Patients with breast cancer are managed within a structured multidisciplinary network of care locally, and in the region.


Patients attending for diagnostic purposes should be seen by a clinician with special training in breast diseases (consultant surgeon, breast physician or staff grade surgeon with special training in breast diseases) or a senior trainee in breast surgery.


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 Scotland, most patients are seen in breast units that treat a large number of patients, but in more remote areas there will be units that see fewer patients. However, evidence suggests that if these units are properly supported and linked to a wider network, they can perform to the same standard as the larger units. This is important because it means some women can avoid having to travel long distances to the larger centres.
Diagnosis

If you have been referred to hospital with a breast lump or a change in the appearance of your breasts, tests for breast cancer will usually include three processes – called triple assessment – based on:

- 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 and/or armpit using a needle.

Triple assessment

The use of these three tests can increase the speed and accuracy of diagnosis. 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, a biopsy might not be used for women who have a sign or symptom of breast cancer other than a lump.

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.

Breast imaging

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


Imaging of symptomatic disease, which requires specialist referral, should only be performed as part of triple assessment (clinical examination, imaging and needle biopsy [fine needle or core biopsy]).


Ultrasound of the axilla [armpit] should be carried out in all patients when malignancy [cancer] is expected. If lymph nodes showing abnormal morphology [looking unusual] on ultrasound are found, needle sampling should be carried out under ultrasound guidance.


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

- If you are 35 or over, you should be given two-view mammography – 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. For some patients (for example those with breast implants) a magnetic resonance imaging (MRI) investigation may be helpful. An MRI is a scan using radio waves and a magnetic field to create images of the body.

- If you are under 35 (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 pregnant or breastfeeding women to have a mammogram.

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 sometimes used to check for signs of breast cancer in the armpit lymph nodes.

**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 fine needle aspiration (FNA). A pathologist will examine the sample in the laboratory to determine whether or not it contains cancer cells.

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, although for FNA the needle is thinner. With FNA, doctors can get the results immediately – however, they will not be able to make a diagnosis until they have the results of all your tests. With core biopsy, results can take a few days, but give fuller and more precise information than FNA.
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 be painful for a short while. 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 will be offered a local anaesthetic before an FNA. This reduces the pain experienced during and after the procedure. However, having local anaesthetic injected into the breast can itself be painful and some women choose not to have this injection.

**Getting the results of your tests**

Most women should receive their results within 14 days (ten working days) of having diagnostic tests. 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.

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.
Diagnosis

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 breast that are unusual to 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 support 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 (pages 25–54).

All treatments can have beneficial effects, but can also have side-effects. Tailoring treatment to individual women and their cancer 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 15). 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 17).

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, which helps to determine which treatments will work best (page 19).

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.
Planning treatment

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.
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 confined to a very specific area of the breast and that have not spread to surrounding tissues in the breast or armpit 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 Scotland, over 500 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.

Invasive breast cancer

Early breast cancers that have spread beyond a very specific area of the breast to the surrounding breast and/or armpit tissue are known as early invasive breast cancer. They are different from secondary breast cancer, which is invasive breast cancer that has spread to distant parts of the body.

About 4,500 women are diagnosed with invasive breast cancer each year in Scotland. 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.

For more information on different types of breast cancer, see Breast Cancer Care’s website breastcancercare.org.uk or call 0800 800 6000.
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. For example, if cancer has spread to the armpit, then 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. Following this, women will have a biopsy taken from their lymph nodes for testing, or their lymph nodes will be investigated during surgery (see page 31).
Understanding staging terms
The tumour, nodes, metastases (TNM) system of staging describes:

- T: the size of a tumour (a code from 1 to 4)
- N: the number of lymph nodes affected (X for no nodes, and a code 0–3 when nodes are affected)
- M: whether and how far the cancer has spread (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
- Stage 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 (secondary breast cancers).
Receptor tests

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

You can find more detail about hormone therapy and targeted therapy on pages 49–54. As receptor tests are so helpful in planning treatment, it is important that you are offered one. If your hospital does not offer one, ask your doctor about being referred to a hospital that will. The test is 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 key hole, allowing 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)
- progesterone receptors (sometimes known as PR)
- and/or a receptor called HER2.

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.

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 will be offered other treatments instead.

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 might be an option for you. 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.

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.

HER2 testing is not usually performed for women with ductal carcinoma in situ (DCIS).

Whether or not your breast cancer has progesterone receptors does not directly relate to your treatment options. However, knowing whether or not your breast cancer is progesterone positive can help your breast care team to understand how it 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. Hormone therapy and Herceptin will not be effective for women with this type of breast cancer. However, triple negative breast cancers may respond better than other breast cancers to chemotherapy.

See page 54 to learn more about targeted therapy.
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 a fully informed decision 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 women say

“I don’t know what I would have done without my breast care nurse. She was really there for me and helped me through the difficult time when I was getting used to having breast cancer.”
Breast Cancer Now Supporter

“To begin with, I wasn’t given enough information – only enough to get me to the next appointment. Too much would have been overload though.”
Breast Cancer Now Supporter

“I felt there was a lack of communication in my care and would have appreciated being told there had been a case conference about me. I felt angry and disappointed that a decision had been made and no one even told me.”
Breast Cancer Now Supporter
Planning treatment

What the guidelines say:
Information and support

Patients must be given adequate time, information and support in order to make a fully informed decision concerning their treatment... The patient must know how to contact the breast care nurse.


Patients are fully informed of the different options for treatment and involved in decision-making to the extent they wish.


All women with a potential or known diagnosis of breast cancer should have access to a breast care nurse specialist for information and support at every stage of diagnosis and treatment...

Women with breast cancer should be offered audiotapes or follow up summary letters of important consultations.


For more information on support available, contact Breast Cancer Care (breastcancercare.org.uk, 0808 800 6000) or Macmillan Cancer Support (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 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.

Also, there are voluntary organisations, including the charities Breast Cancer Care and Macmillan Cancer Support, which provide information and experienced nurses who can answer any questions you may have.

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.
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.

Many of the Scottish Cancer Centres now have a Maggie’s Centre run by the charity Maggie’s to provide information, advice and support to patients.

What the guidelines say:

Counselling services

Group psychological interventions [group therapy] should be available to women with breast cancer who feel it would suit their needs.


For details of your nearest Maggie’s Centre, see page 65.
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

All treatments for patients with early breast cancer should be started as soon as is practical. Young women with oestrogen receptor negative tumours may benefit particularly from early initiation of chemotherapy following surgery.


What women say

“When you are diagnosed with cancer it feels as if you are on a roller coaster. 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. The surgeon agreed, saying he thought it was a good idea and that it would make no difference to the outcome. 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. I was such a wreck, if I had had to wait any longer I do not know what I would have done.”

Breast Cancer Now Supporter

Starting treatment

In Scotland, health professionals now aim for a total waiting time from urgent GP referral to first treatment to be 62 days (two months) or less. There is also an aim for the waiting time between the decision being made to provide a specific treatment and that treatment actually beginning to be fewer than 31 days (one month).

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 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.
What the guidelines say: Adjuvant treatment

Written local breast cancer treatment guidelines should identify which patients should be considered for adjuvant treatments (radiotherapy, endocrine therapy, chemotherapy and targeted therapies).


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 neo-adjuvant 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 55.

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 56.
The best treatment
Your guide to breast cancer treatment in Scotland

Surgery

Surgery is often the first treatment for most people with breast cancer. There are two main aims of surgery: to remove the cancerous tissue in your breast and to find out if 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 better treated by other treatments, such as drug therapy (at least in the first instance).

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

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 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.

- **a mastectomy** – where the whole breast is removed, often including some or all lymph nodes in the armpit.

What the guidelines say:

**Who should carry out breast surgery**

The management of patients with breast cancer should be assessed by a multidisciplinary team. Each consultant’s team should treat a minimum of 30 and a maximum of 150 new breast cancer cases per year. Surgical treatment of breast disease must be carried out by surgeons with a special interest and training in breast disease.


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:  

**Choice of surgery**

All women with early stage invasive breast cancer who are candidates for breast conserving surgery should be offered the choice of breast conserving surgery (excision of tumour with clear margins) or modified radical mastectomy.

The choice of surgery must be tailored to the individual patient, who should be fully informed of the options and who should be aware that breast irradiation [radiotherapy] is required following conservation and that further surgery may be required if the margins are positive.  


Units should have local guidelines regarding acceptable margin width and individual cases should be discussed at the treatment MDT [multi-disciplinary team] meeting. If, after MDT meeting discussion, the margin of excision is deemed to be inadequate then further surgery to obtain clear margins should be recommended.  


The surgery you are offered will depend upon the characteristics of your breast cancer, and 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 neo-adjuvant therapies.

**Breast conserving surgery**

Breast conserving surgery (sometimes called wide local excision or a lumpectomy) involves the removal of the breast tumour and a small amount of breast tissue around the tumour, called the margin. This might include some or all lymph nodes. Surgeons aim to remove a margin of at least 1 mm of healthy tissue. This small margin 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’.

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 indicate a mastectomy is needed, where the whole breast is removed. This is to ensure that all the cancer has been removed.
Surgery

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

“I could have had a wide local excision but I chose to have a mastectomy. The decision felt right for me and my surgeon supported me.”
Breast Cancer Now Supporter

For women with a tumour in the centre of the breast, breast conserving surgery can sometimes be performed, providing 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.

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 to remove 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.

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.

What the guidelines say:

Breast reconstruction

All patients having treatment by mastectomy... should have the opportunity to discuss their breast reconstruction options and have immediate breast reconstruction if appropriate.

What women say

“I was offered simultaneous reconstruction at the time of my mastectomy but in fact declined. This appeared to be somewhat against the expectations of my surgeon, who expressed great surprise! But 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

Delaying reconstruction until a later date after your cancer surgery may be the best 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, can now have 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 made generally of silicone and come in different sizes, shapes and colours, so that you can find the best match for you.
The best treatment
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Surgery

Axillary (armpit) surgery
Breast cancer can spread to the lymph nodes in the armpit (axilla). Lymph nodes are glands found in your armpit and other areas of your body that are part of your immune system. 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
There are two main techniques used to check for cancer in the armpit lymph nodes:

- **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 often also 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 staging**
A preoperative diagnosis of nodal disease enables definitive treatment of the axilla at the time of initial breast surgery. Patients with invasive breast cancer should undergo pre-treatment ultrasound assessment of the axilla. If morphologically suspicious nodes are identified these should be sampled, using FNA or core biopsy.


Surgical staging of the axilla is performed in all newly diagnosed patients with operable invasive breast cancer.

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.

**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.

There are two choices of treatment:

- removing all the remaining lymph nodes in the armpit (called an axillary node clearance)
- radiotherapy to the armpit (see page 40).

The evidence suggests that these treatments are equally effective. Your doctor will discuss the advantages and disadvantages of each type of treatment with you.
For more information on the side-effects of armpit surgery see page 34

For more information on the side-effects of armpit radiotherapy see page 41

**What the guidelines say:**

**Length of stay**

Patients should have the opportunity for ‘23 hour’ surgery (a maximum of one overnight stay following surgery) wherever appropriate.


For more information on surgery and recovery, see Breast Cancer Care’s leaflet *Your operation and recovery* available at breastcancercare.org.uk or call 0808 800 6000.

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**Surgery**

The 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 a 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.

When you are discharged from hospital you will 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.
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.

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.

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 and/or hand, breast, chest, back and 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.
Lymphoedema cannot be cured, but the swelling can 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. The Lymphoedema Scotland website (lymphoedema-scotland.org) will identify the nearest specialist centre to you.

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.

Who should be offered radiotherapy?

In general, radiotherapy is offered to women who have anything more than a very low risk of recurrence in the area of the breast and the nearby lymph nodes. 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 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 have radiotherapy to your armpit to treat these.

Radiotherapy is usually given after surgery and/or chemotherapy, or sometimes between two cycles of chemotherapy. It usually involves a course of treatment lasting about three to five weeks.

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 and this is currently an NHS target in Scotland. However, not all specialists currently find this practical and there are sometimes delays.

Speak to your breast care team if you are concerned about the length of time you are waiting for radiotherapy.
What women say

“Because of the distance from the hospital I had to live in the patient accommodation during the time I was having radiotherapy treatment. Staff were very caring during the planning and therapy treatments at all times. As I was able to go home at weekends, they made all the arrangements for my transport to and from the hospital for me.”

Breast Cancer Now Supporter

Where and how should radiotherapy be given?

Radiotherapy in Scotland is given at five cancer centres – in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness. A number of cancer specialists, including clinical oncologists (doctors trained to give radiotherapy) will be based at the centre and travel extensively to provide support and care to patients across the country. You may have to travel some distance for your radiotherapy if you do not live in one of these five cities. 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 so your treatment can be worked out. This may involve using a simulator machine, which is identical to a radiotherapy machine but does not give the treatment. One or both of your arms will need to be positioned 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.

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 half a dozen 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’.
Radiotherapy is frequently given daily (Monday to Friday) over a period of three to five 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 41).

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.

What the guidelines say:

**Radiotherapy to the breast**

Radiotherapy should be given following mastectomy or breast conserving surgery to reduce local recurrence where the benefit to the individual is likely to outweigh risks of side-effects.


Radiotherapy is normally given to the breast after wide local excision [lumpectomy].


**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.
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 information on staging and grading page 20), whether there was a cancer-free area around the tumour, and whether cancer was found in the armpit lymph nodes.

The armpit (axilla)

Radiotherapy to the armpit is usually only recommended when 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 three regimens have been used for many patients over many years, and they appear to be relatively safe and effective. None has yet been shown to be better than the others and research is ongoing.
Radiotherapy

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 nauseated. 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 or call 0808 800 4040.

For out-of-hours medical care, contact NHS 24 on 111 (local rate).

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.
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 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 on normal body cells. However, most people have some side-effects with chemotherapy (see page 45).

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. 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.
The best treatment
Your guide to breast cancer treatment in Scotland

Chemotherapy

When and how is chemotherapy given?

If chemotherapy is prescribed, it is usually given after surgery as an adjuvant treatment. Occasionally it is given before surgery as a neoadjuvant treatment, for example when the tumour is large compared with the size of the breast or 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 cycles 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 directly 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 weeks or 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.
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.

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 (doxorubicin, cyclophosphamide)
- CMF (cyclophosphamide, methotrexate, 5-fluorouracil)
- TAC (docetaxel, doxorubicin, cyclophosphamide) – sometimes given without doxorubicin.

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.

**Taxanes**

Taxanes are a type (or group) of chemotherapy drug that are often used in the treatment of breast cancer. They are derived from chemicals found in plants and stop cells from dividing to make new cells. The most commonly used is docetaxel (Taxotere), which is a recommended treatment and is given as part of the TAC (docetaxel, doxorubicin, cyclophosphamide) and FEC-T (5-fluorouracil, epirubicin, cyclophosphamide, docetaxel) regimens.

Taxanes can have side-effects, including an increased risk of infections, anaemia (a reduction in the number of red blood cells), nausea, diarrhoea and fluid retention. Different people may experience different side-effects to a greater or lesser extent (see dealing with side-effects of chemotherapy on page 45). Before beginning treatment, you should discuss with your oncologist any potential side-effects of treatments and how they might affect your quality of life.
Chemotherapy

What the guidelines say:

**Anthracyclines**

Anthracyclines should be prescribed in preference to non-anthracycline regimens in the adjuvant setting, as they offer additional benefits. Epirubicin may be preferred as it causes less cardiac adverse effects.


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**Anthracyclines**

Most chemotherapy regimens include drugs called anthracyclines. They interfere with enzymes involved in the copying of DNA, which is needed for cells to divide to make new cells. The names of the individual anthracycline drugs end in ‘rubcin’: doxorubicin and epirubicin are the two most widely used for patients with breast cancer.

There is evidence that anthracyclines work better than some other chemotherapy drugs; but they have side-effects including complete hair loss and, very rarely, damage to the heart (see Dealing with side-effects of chemotherapy below). Before beginning treatment, you should discuss with your oncologist any potential side-effects of treatments and how they might affect your quality of life.

**Anti-metabolites**

Several chemotherapy drugs used to treat breast cancer are anti-metabolites, for example 5-fluorouracil and methotrexate. Anti-metabolites stop cells from dividing into new cells.

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**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 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

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**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 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.

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.

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.

You may also like to attend a HeadStrong appointment. HeadStrong is a free service provided by Breast Cancer Care at several locations throughout Scotland, 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.

For more information on scalp cooling techniques see Macmillan Cancer Support’s website macmillan.org.uk or call 0808 808 0000.

For more information on hair loss and the HeadStrong service, see Breast Cancer Care’s website breastcancercare.org.uk or call 0808 800 6000.
What the guidelines say: side-effects of chemotherapy

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.


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 to treat this and therefore reduce your risk of infection.

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 and what to look out for, so you know when to seek medical advice. For example, if you feel feverish, ‘fluey’ or unwell, you should seek medical advice.

Anaemia

Anaemia – a reduction in the number of red blood cells – associated with chemotherapy is unusual, but can be 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 levels return towards normal. If necessary, you may be given a blood transfusion.

Effects on fertility

Chemotherapy can affect fertility either temporarily or permanently, and different chemotherapy drugs have different effects on fertility. 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. Sometimes these symptoms end when treatment has finished, so you start having periods again and your fertility will return to normal. However, some women become permanently infertile.

If you are concerned about the fact that chemotherapy might result in permanent 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 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.
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, the functioning of female reproductive organs and help to maintain healthy bones and heart. However, they can also promote 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, when they are called 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 given before surgery (rather than after) is called neoadjuvant treatment and aims to shrink 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 19). 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, even those at low risk of recurrence, should be offered hormone therapy. 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:

Who should be offered hormone therapy

Women with oestrogen receptor positive tumours who receive chemotherapy should be considered for additional endocrine therapy, especially if they are under 35 years.

**Getting treatment**

### Types of hormone therapy

Two types of hormone therapy that are commonly used are:

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

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**What the guidelines say:**

**Hormone Therapy**

In postmenopausal women with breast cancer, tamoxifen remains the treatment of choice as initial therapy in the adjuvant setting. If there are relative contraindications to its use or intolerance, an aromatase inhibitor can be used in its place.

Postmenopausal women should be considered for a switch to an aromatase inhibitor after either two to three years or after five years of tamoxifen therapy.

Hormone therapy

Tamoxifen has been commonly used in the treatment of hormone positive early breast cancer for some time. 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. There is no evidence that higher doses are more effective.

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 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 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 chemotherapy.

**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
Dealing with side-effects of hormone therapy

**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 menstrual bleeding while taking tamoxifen should contact their oncologist, breast care nurse or GP to let them know.

**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 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.

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.

For out-of-hours medical care contact NHS 24 on 111 (local rate).
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 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.
Targeted (biological) therapy

Targeted therapies attack cancer cells directly (i.e., 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.

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 (page 22).

The Scottish Medicines Consortium approved Herceptin to treat early breast cancer in June 2006. 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.
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 treatment 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 experiencing too many side-effects, you should be given the option to withdraw or change treatment.
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 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
What happens next?

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

After you have been treated for breast cancer, you and your breast care team should agree on a care plan. 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. Follow up care is provided by specialist breast care services.

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 (secondary 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 regular mammography. You will also be seen regularly by a breast care nurse or doctor for a few years (often around three to five) for a physical examination and to discuss any problems or concerns you may have.
Follow up

For women who are already using the Scottish 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 you are eligible for the Scottish Breast Screening Programme (usually at age 50).

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 you have breast cancer again, so that you can begin a new course of treatment.

Follow up care aims to detect local and regional recurrence, but you will not usually have tests to detect a distant recurrence (secondary breast cancer). This is because performing routine tests for secondary 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.

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 a strong family history, this may include genetics testing to determine whether inherited faults in known breast cancer genes run in the family. Women with a strong family history may also choose to have risk-reducing surgery.

**Frequency of follow up**

Follow up plans may vary across Scotland. Most doctors would agree with patients being seen every six to 12 months for the first one or two years and once a year after that, with regular mammography as described above. 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 three to 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.
More support and information

Find out about the information and support to help you during and after your breast cancer treatment.
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 on info@breastcancernow.org or by calling our freephone Information Line 08080 100 200 and we will be happy to help.

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

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## Quick guide to further support and information

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Breast Cancer Care (Scotland)
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: sco@breastcancercare.org.uk
Freephone helpline: 0808 800 6000
(Monday to Friday 9am–5pm, Saturday 10am–2pm)
Website: breastcancercare.org.uk

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.

Cancer Information Nurses: 0808 800 4040
(Monday to Friday 9am–5pm)
Website: cancerresearchuk.org

Lymphoedema Scotland
Aims to provide patients, carers and healthcare professionals with information about how to access lymphoedema care in their area and provides links to other sources of information.

Website: lymphoedema-scotland.org
Email: information@scottish-lymphoedema.org

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

Email: adminlsn@lymphoedema.freeserve.co.uk
Helpline: 020 7351 4480
(Monday to Friday 9am–5pm)
Website: lymphoedema.org/lsn

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

Email: Cancerline@macmillan.org.uk
Freephone: 0808 808 0000
(Monday to Friday 9am–8pm)
Website: macmillan.org.uk

Maggie’s Centres
Maggie’s Centres are based close to major cancer hospital treatment centres. All services are free and they offer information, relaxation, stress management and psychological support in a bright and welcoming environment. There are currently five Maggie’s Centres open in Scotland, with a further three planned or being built.

Website: maggiescentres.org
Quick guide to further support and information

Maggie’s Edinburgh
The Stables
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU
Tel: 0131 537 3131
Email: edinburgh@maggiescentres.org

Maggie’s Glasgow
The Gatehouse
Western Infirmary
10 Dumbarton Road
Glasgow
G11 6PA
Tel: 0141 330 3311
Email: glasgow@maggiescentres.org

Maggie’s Dundee
Ninewells Hospital
Tom McDonald Avenue
Dundee
DD2 1NH
Tel: 01382 632 999
Email: dundee@maggiescentres.org

Maggie’s Highlands
Raigmore Hospital
Old Perth Road
Inverness
IV2 3UJ
Tel: 01463 706306
Email: highlands@maggiescentres.org

Maggie’s Fife
Victoria Hospital
Hayfield Road
Kirkcaldy
KY2 5AH
Tel: 01592 647997
Email: fife@maggiescentres.org

NHS 24
NHS 24 works in partnership with local NHS Boards to provide patients with health advice and help when GP practices are closed.
Website: nhs24.com
Freephone: 111
Some medical terms explained

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

**Advanced breast cancer** – see secondary 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

**Anthraclyclines** – 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
Some medical terms explained

- **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 a very specific area of the breast 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
- **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 breastcancernow.org/family
- **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)
- **Goselerin (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 molecule (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
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 – see secondary breast cancer

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 a very specific area of the breast that has not spread to neighbouring tissues

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

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

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

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
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 secondary breast cancer)

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

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, some of which include waiting time standards for diagnosis and treatment. Many of these guidelines have been used in the preparation of this booklet. The main ones specific to Scotland and referred to here are:

- *Scottish referral guidelines for suspected cancer.* Scottish Cancer Group/Scottish Executive Health Department, 2007

The SIGN guidelines published in 2005, in particular, give comprehensive and evidence-based guidance on a wide range of aspects of the management and care of people with breast cancer in Scotland. These are due to be updated in 2013. Other guidelines referred to reinforce these and give more detail on specific aspects.

In addition to those guidelines specific to Scotland, the NHS in England and Wales and other UK-wide organisations such as the Association of Breast Surgery at BASO and the Royal College of Radiologists also publish a number of guidelines on breast cancer and related conditions. Where appropriate, information from the following guidelines has been included in this document:

- *Surgical guidelines for the management of breast cancer.* Association of Breast Surgery at BASO, 2009
- *Guidance on screening and symptomatic breast imaging (second edition).* Royal College of Radiologists, 2003

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@breastcancernow.org or call 08080 100 200.
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 groundbreaking 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 you can campaign for 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. Staff in breast units that join Breast Cancer Now’s Service Pledge work alongside patients to develop their own local pledges, outlining 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 in Scotland, contact Breast Cancer Now: visit breastcancernow.org/scotland or call on 0131 226 0761.