

Advanced breast cancer



The facts and your choices

Patient information booklet for postmenopausal women who have been newly diagnosed with advanced breast cancer or have already received adjuvant treatment for early-stage disease



This patient information booklet is applicable to you if you are a postmenopausal woman with newly diagnosed advanced breast cancer or if you have already received drug treatment following surgery and/or radiotherapy for early-stage disease. It is intended to provide you with some information to help you learn about your disease and to help you choose – in consultation with your doctor – a treatment for your breast cancer. It will also discuss the impact that your disease may have on your life and your family.

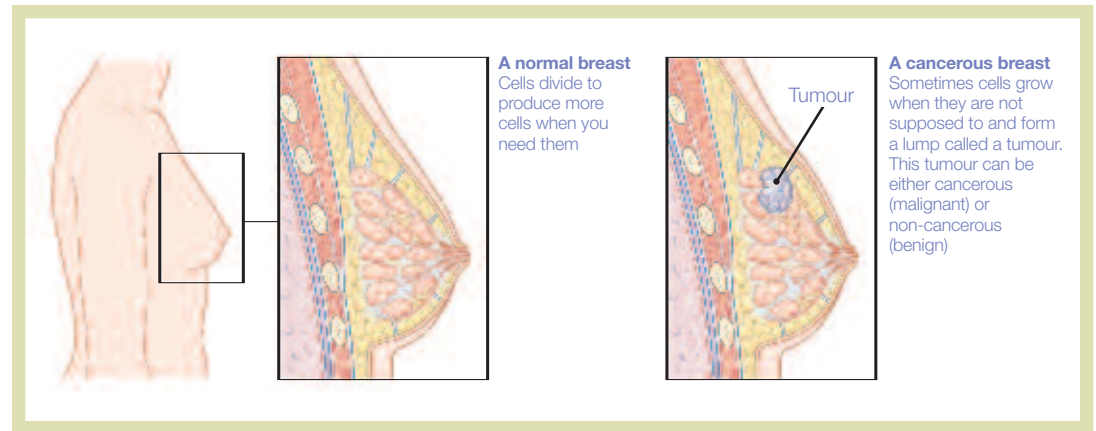
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Breast cancer: the facts

Your body is made up of individual units called cells, which constantly grow, divide, and repair themselves. However, sometimes cells divide when they are not supposed to. If these cells grow out of control they can form a lump called a tumour, which can be either cancerous (malignant) or non-cancerous (benign). A cancerous tumour is very small when it starts, but may increase in size over time.

A normal breast and a cancerous breast



Metastatic cancer:

Cancer that has spread from one part of your body to other parts.

Menopause:

The time of life when your body changes from having monthly periods to them stopping permanently.

Postmenopausal:

The time of your life when you experience no more periods.

In some cases, breast cancer cells may not stay in the breast, but spread to other parts of the body. This is known as advanced, metastatic, recurrent, or secondary breast cancer. This spread can damage normal tissues, such as bone, lungs or liver, leading to problems at these sites.

The risk of breast cancer increases with age. This is because the wear and tear of living increases the chance that a genetic abnormality, or 'mistake', will develop that your body doesn't find and fix. Approximately 75% of breast cancers are found in women over the age of 50 who are past their menopause (postmenopausal).

Breast cancer: the figures

- Each year, more than 1 million new cases of breast cancer are diagnosed worldwide.¹
- According to the World Health Organisation (WHO), breast cancer is the most common cancer amongst women worldwide.¹
- Breast cancer accounts for one in ten new cancers and nearly 25% of all female cancers.²
- One in eight women will develop breast cancer during their lifetime.^{3,4}

It is important to remember that many women continue to live productive lives for several years after being diagnosed with advanced breast cancer – it is estimated that more than 25% of women with advanced breast cancer survive for 5 years or more.⁵ However, every woman is unique and their disease and situation is also unique.

Whatever your situation, whether you are newly diagnosed or have already received treatment for your early-stage disease, this leaflet focuses on helping you to understand your disease, your diagnosis, your treatment choices and the impact your disease may have on your friends and family.

What stage is my breast cancer?

Before treating your breast cancer, your doctor must determine the stage of your disease. This is done by measuring the size of the tumour and assessing whether your cancer has spread to other parts of your body.

Stages of breast cancer	
Stage 0	Your cancer has not spread (<i>in situ</i>), for example, ductal carcinoma <i>in situ</i>
Stage I	Your tumour is localised, is less than 2 cm wide and has not obviously spread
Stage II	Your tumour is small (2–5 cm), has spread to armpit (axillary) lymph nodes, or both
Stage III	Your tumour size is larger than 5 cm and has probably spread to axillary and other lymph nodes; may have spread to your chest or overlying skin
Stage IV	Your tumour is of any size, usually affecting lymph nodes; has spread to parts of your body other than the breast, such as bones, lungs or liver (“secondary tumours”)

Advanced breast cancer refers to tumours larger than 5 cm (Stage III) or a tumour of any size that has spread to other parts of your body (metastases; Stage IV). Since it can be difficult to detect metastases directly, your doctor will check your lymph nodes to look for cancer cells. Almost all lymphatic vessels in the breast connect to lymph nodes under the arm (axillary lymph nodes). Some lymphatic vessels also connect to lymph nodes inside the chest (internal mammary nodes) and either above or below the collarbone (supraclavicular or infraclavicular nodes).

If cancer cells have entered your lymphatic system and are found in your lymph nodes, there is a higher chance that the tumour has begun to spread around your body. This is why it is important to find out if breast cancer has spread to your lymph nodes when you are choosing a treatment. When breast cancer cells reach the axillary (underarm) lymph nodes, they may continue to grow, often causing the lymph nodes in that area to swell. The more lymph nodes that are involved with the breast cancer, the more likely it is that the cancer will eventually be found in other organs as well. However, not all women with lymph node involvement develop metastases, and some women in whom the cancer has not spread to the lymph nodes later develop metastases.

Metastases: Spread of cancer from one part of your body to another. If the cancer has spread to only one part of your body it is called metastasis. If it has spread to more than one part it is called metastases.

Lymph nodes: Small organs located throughout your body that store special cells that filter out and trap bacteria and viruses, and safely eliminate them from your body. Clusters of lymph nodes can be found in your armpits, groin, neck, chest and abdomen.

Sentinel lymph node: The first lymph node that your cancer is likely to spread to.

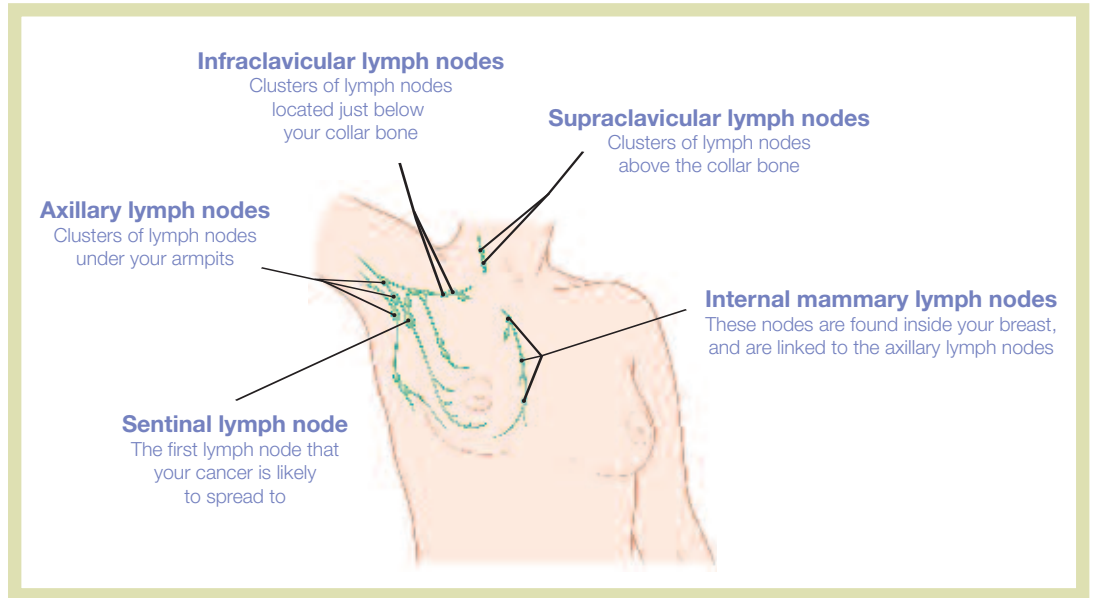
Axillary lymph nodes: Clusters of lymph nodes under your armpits.

Infraclavicular lymph nodes: Lymph nodes located just below your collarbone.

Supraclavicular lymph nodes: These lymph nodes are located right above your collarbone, at the base of your neck.

Internal mammary lymph nodes: These nodes are found inside your breast, and are linked to the axillary lymph nodes.

The location of your lymph nodes



Where can my breast cancer spread to?

If breast cancer cells spread to other parts of the body and cause secondary tumours, it is called 'metastatic' or 'advanced' breast cancer. Breast cancer cells usually spread via the lymphatic system, which is a network of channels all over the body and is similar to but separate from the veins and arteries of the bloodstream. Breast cancer cells may also spread via the bloodstream or by replacing healthy cells (e.g. the skin) that are in the same area as the original breast tumour. Although breast cancer can spread to almost anywhere in your body, some areas seem to be more vulnerable than others.

Sites that are particularly vulnerable to secondary tumours

- The affected breast or, if you have received breast surgery, the area where the breast used to be
- The opposite breast (known as the 'contralateral' breast)
- The chest wall
- Lymph nodes
- Bones
- Lungs or around the lungs
- Liver
- Brain

It is generally considered that you will live longer if your breast cancer stays within your breast, spreads to your chest wall or lymph nodes (soft tissue metastases) or to the bone (bony metastases), than if it has spread to the lung or liver (visceral metastases) or central nervous system (e.g. brain). It is, however, hard for your doctor to predict how long you will live for, as this can depend on a number of factors in addition to where your cancer has spread to: for example your tumour type, what treatments you have had before and how well your cancer responds to treatment.

Secondary tumours:

Single cells or groups of cells sometimes break away from the original tumour and move ('metastasise') to another part of the body. When they settle down and begin to grow they form secondary tumours.

Lymphatic system:

A network of channels that transport a watery clear fluid called lymph. The lymphatic system interacts with the bloodstream to drain fluid from cells and tissues.

Bloodstream:

The system of veins and arteries which carries blood around the body. Arteries carry blood away from the heart and around the body, veins carry blood back towards the heart.

Soft tissue metastases:

Secondary tumours in your chest wall or lymph nodes.

Bony metastases:

Secondary tumours that grow in your bones.

Visceral metastases:

Secondary tumours that grow in your lungs or liver.

Central nervous system metastases:

Secondary tumours in your brain or spinal cord.

Radiotherapy:

The use of 'radiation', usually X-rays, to destroy cancer or other abnormal cells in the body.

Chemotherapy:

A treatment that uses chemicals (drugs) to kill cancer cells or stop them from growing.

Monoclonal antibody (MAB) therapy:

A type of biological therapy. Antibodies are proteins that are made naturally by your body in response to infection or damaged cells. To create a new MAB, scientists have to find an antibody that attacks cancer cells, but does not harm normal cells. They separate out the antibody in the laboratory and then make millions of copies of it – all the same. These are MABS.

Hormonal therapy:

Treatment of cancer by removing, blocking, or adding hormones. Hormonal therapy slows the growth and spread of cancer cells. This is known as cytostatic therapy.

How will my doctor treat my breast cancer?

The type of treatment you receive for advanced breast cancer will depend on the type of breast cancer that you have and the areas it has spread to, how much treatment and what kind of treatment you have had in the past, and your own personal circumstances.

Many patients with advanced breast cancer live comfortably for many years. Thus, the aim of treatment is to extend your life for as long as possible and to give you the best possible quality of life. Treatment options available to you include radiotherapy, chemotherapy, monoclonal antibody therapy and hormonal therapy. Generally, surgery is not suitable for women with advanced disease due to the number of different regions of the body that are affected.

What is my tumour type?

In addition to the stage of breast cancer and where it has spread to, the type of tumour you have also differs between women. Your tumour type is based on what is making it grow and is one of the main factors determining how long you will live and what type of treatment you will receive.

Tumours that grow in response to hormones

Hormones are chemicals produced naturally in the body that circulate in the blood. Some cancer cells need the natural female sex hormone oestrogen to stay alive. Blocking the production or action of this hormone using 'hormonal therapies' can prevent or help slow growth of tumours by starving them of the oestrogen they need to grow. As a result, the cancer cells shrink or die.

Hormones: the facts

- In postmenopausal women, hormones stimulate approximately 67% of breast cancers to grow.⁶
- These types of tumours are called 'hormone receptor-positive' – also known as 'oestrogen receptor-positive', 'progesterone receptor-positive', 'hormone-sensitive' or 'oestrogen-sensitive' tumours.
- Hormone receptor-positive tumours are stimulated to grow by the natural female hormone oestrogen.
- The main source of oestrogen and the levels in your body differ depending on whether or not you have been through menopause:
 - before menopause (premenopausal), the ovaries produce most of your oestrogen
 - after menopause (postmenopausal), fat, muscle, liver, adrenal glands and the breast itself produce most of your oestrogen. Only a small amount of oestrogen is produced by your ovaries.
- The main sources of oestrogen in premenopausal and postmenopausal women therefore differ and thus the choices for treatment are somewhat different.

Hormone:

A chemical produced naturally in your body that circulates in your blood.

Oestrogen:

A natural female sex hormone.

Receptor:

A protein that is found either on the surface of cells or inside them. Receptors bind to substances such as hormones or growth factors.

Oestrogen receptor:

For oestrogen to work, it must bind to a receptor. If oestrogen binds to a receptor in tumour cells, growth is encouraged and your cancer will increase in size.

Progesterone receptor:

The receptor that binds to the female hormone progesterone.

Hormone receptor-positive:

A tumour that has a large number of oestrogen and/or progesterone receptors that is stimulated to grow by the female hormone oestrogen. Also known as oestrogen receptor-positive or progesterone receptor-positive.

Ovaries:

Oval structures in which your eggs are developed. The ovaries are located in the pelvis, one at each side of your womb.

Adrenal glands:

Small, triangular glands located on top of both kidneys that produce a number of different hormones.

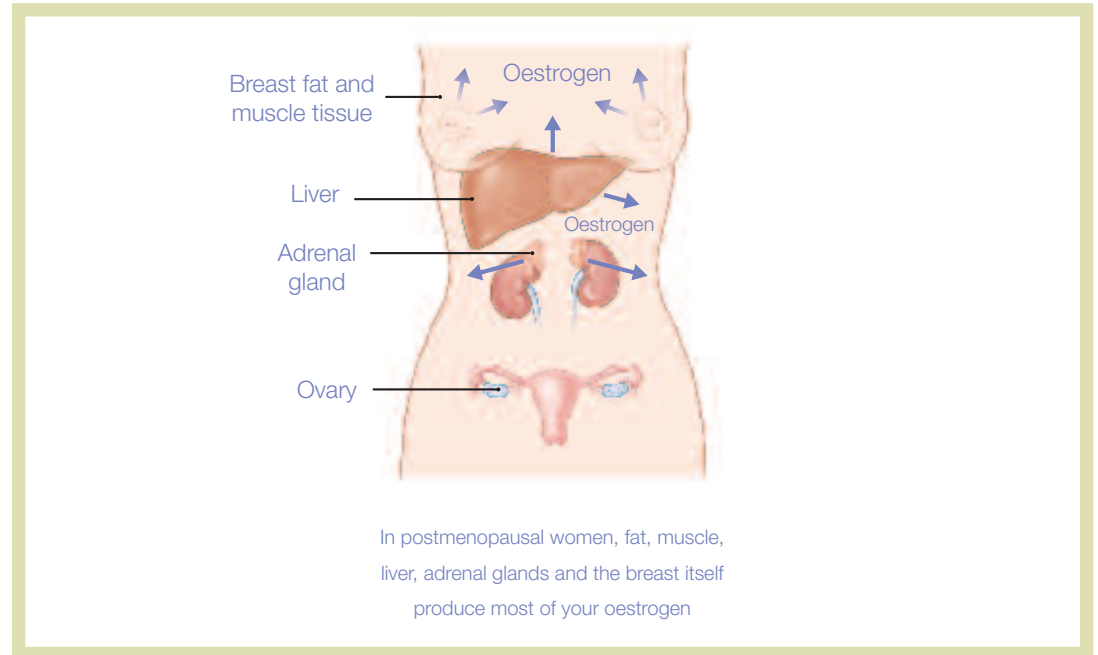
Hormone receptor test:

A test to determine whether you are hormone receptor-positive and are likely to respond to hormone therapy.

Biopsy:

The removal of a sample of tissue from your body for examination.

Sources of oestrogen in postmenopausal women



A 'hormone receptor test' will be performed on a sample of your tumour that has been removed (biopsy) to determine whether your cancer is hormone receptor-positive. The 'hormone receptor test' measures the presence of oestrogen and progesterone receptors on the tumour. Your doctor may present you with your oestrogen and progesterone receptor levels as a percentage. If you have a high percentage of either of these receptors, your tumour will be called a 'hormone receptor-positive breast cancer'. In this instance it is likely that hormonal therapy may be able to reduce the size of your tumour. The fewer receptors you have, the less likely it is that hormonal therapy will work for you.

HER2:

A receptor that helps control normal cell growth, division and survival.

HER2-positive disease:

When your breast cancer cells contain too many HER2 receptors.

Prognosis:

A prediction of the likely outcome of a disease based on your general health and the usual action of the disease.

Gene:

A piece of genetic material (DNA) which contains the instructions for producing a particular protein such as a receptor. Each gene is found at a precise location on a chromosome.

Tumours that grow in response to the HER2 protein

It is estimated that overall, 1 in 5 women will have a breast cancer that is classed as HER2 positive and only 1 in 10 women with hormone receptor-positive disease have tumours of this type. HER2 stands for Human Epidermal growth factor Receptor 2. HER2 is a receptor that is found on the surface of all cells and controls how cells grow, divide and repair themselves.⁷ However, if the HER2 gene is altered, extra receptors may be produced. This is called overexpression. Too many receptors causes increased or uncontrolled cell growth and this may be important in turning healthy breast cells into cancer cells. Too much HER2 may also result in an aggressive breast cancer (a tumour that grows and spreads quickly). Interfering with the growth stimulation produced by HER2 is another way by which tumour growth can be controlled and is separate from the process driven by oestrogen.

HER2: the facts

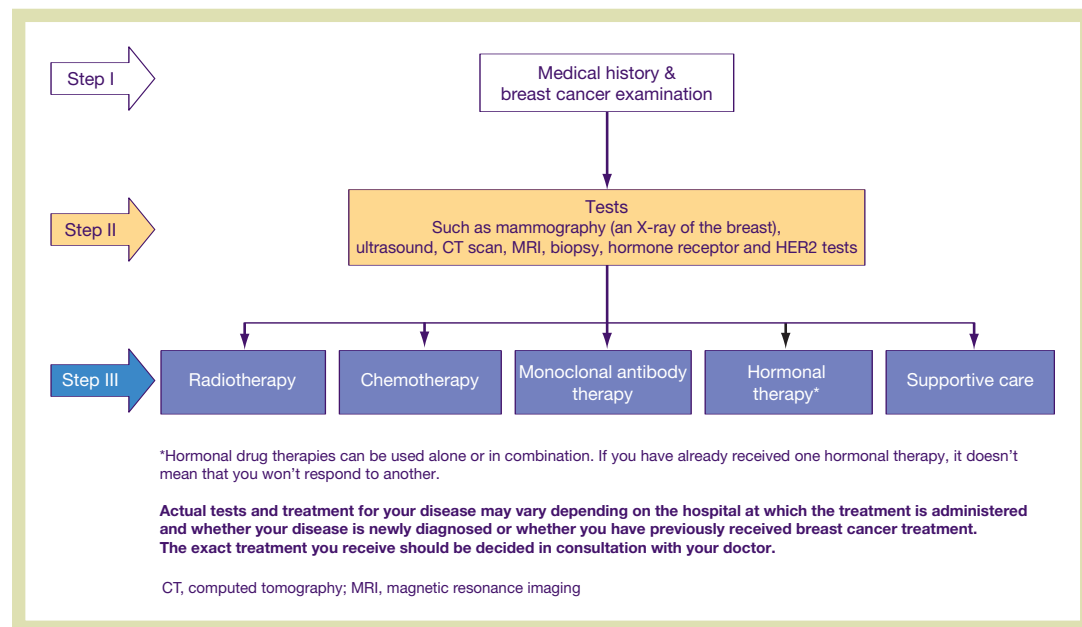
- Approximately 1 in 5 women will have a breast cancer that is classed as HER2-positive.
- Tumours that are HER2-positive tend to grow more quickly than other types of breast cancer.
- In general, prognosis and survival times are less good for women with HER2-positive cancer.

Your doctor will be able to test to see if your tumour is HER2-positive. If you have already received a hormone or HER2 test at an earlier stage of your disease, it is unlikely that you will be tested again.

What are my treatment choices?

Treatment choices available to you include radiotherapy, chemotherapy, monoclonal antibody therapy and hormonal therapy. All of these treatments aim to shrink the size of your tumour and/or relieve unwanted symptoms you are experiencing.

Possible treatment and diagnosis of your breast cancer



What are my treatment choices with non-hormonal therapies?

Radiotherapy

Radiotherapy is mostly used in the treatment of women with early-stage breast cancer but is also sometimes used in those with more advanced disease, if the tumour has spread to certain locations. Radiotherapy uses carefully measured doses of X-rays to treat where the breast tumour is situated as well as the surrounding area. The doses given are more intense than a mammogram or other common types of X-ray, and they are precisely calculated to destroy cancer cells.

Radiotherapy: the facts

- Radiotherapy uses X-rays precisely targeted to the area of your tumour
- Radiotherapy does not make you become radioactive
- Radiotherapy does not make your hair fall out

You are likely to receive treatment 5 days a week for up to 7 weeks, although your doctor will discuss this with you. Occasionally, radiation may be given twice a day over 1 week. The actual radiation treatment is painless, although there are some side effects. These side effects are usually temporary, lasting only a few weeks. However, it is possible that you may feel tired for several months after treatment ends.

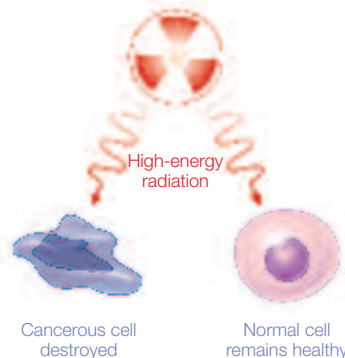
Radiotherapy: side effects⁸

- Reddening of the skin (erythema or burn)
- Sensitive skin or swelling around the area which is being treated, including swelling at the base of the throat
- Feeling sick
- Feeling tired

Since the daily appointments for radiotherapy treatment are quite short (usually around half an hour) you are likely to be able to keep to your normal routine during your treatment.

Radiotherapy as a treatment option

Radiotherapy is designed to cause as little harm as possible to normal cells



Radiotherapy is usually given every weekday for several weeks

Side effects of radiotherapy may include

- Sensitive skin
- Swelling
- Tiredness
- Redness of skin (erythema) or burn
- Feeling sick

Side effects stop after treatment ends

Erythema:

A redness of the skin.

Chemotherapy

Chemotherapy is a widely used and effective treatment for many cancers, including breast cancer, which uses drugs that damage growing cells to destroy cancer cells.⁹ You may be given just one drug at a time or several together. It can be used to shrink tumours that are both hormone receptor-positive (where oestrogen is responsible for making the tumour grow) and -negative (where other factors are making the tumour grow). In women with advanced breast cancer, it is often used in rapidly progressing disease to stabilise it before another therapy is given. It is also used when a tumour no longer responds to hormonal treatments.

Chemotherapy: the facts

- Chemotherapy works by destroying all rapidly growing and dividing cells. It kills cancer cells, including those that have spread to other parts of the body. However, it can also kill other healthy, rapidly growing cells like those found in the mouth (buccal mucosa), gut, or bone marrow.
- Chemotherapy for breast cancer usually involves different types of drug that can be used in combinations of two or more e.g.:⁹
 - 5-fluorouracil (5-FU)
 - cyclophosphamide
 - methotrexate
 - anthracyclines (e.g. doxorubicin, epirubicin)
 - taxanes (e.g. docetaxel, paclitaxel)

When chemotherapy is given, you will usually need to attend the day hospital or ambulatory care clinic as an outpatient. You will be checked by a doctor or nurse to ensure you have no signs of infection, and a blood sample will be taken. If your blood test is satisfactory, and there are no other reasons to delay or stop chemotherapy, then the treatment will be given (usually through a 'drip') before you go home. Some types of chemotherapy need to be given over a longer period of time and you may go home with a small pump (about the same size as a small music personal stereo) to give the chemotherapy over a period of days.

You may receive 2 or 3 cycles of chemotherapy to slow the progression of your disease, and then hormonal therapy may be added to your treatment (see the section on Hormone Therapies). Your doctor will discuss this with you.

Chemotherapy affects all rapidly dividing cells and therefore its side effects can occur in various parts of the body where cells are rapidly dividing (e.g. in your hair and digestive system). The side effects that you may experience depend on the type of chemotherapy you receive.

Chemotherapy: side effects⁸

- Hair loss all over your body
- Feeling sick
- Being sick
- Tiredness
- Sore mouth
- Numbness
- Tingling of the hands or feet
- Diarrhoea
- Joint or muscle pain
- Increased risk of infection

Almost all side-effects are short-term, and will begin to disappear once your therapy is finished. Additional treatments to reduce these side effects may be given before chemotherapy, such as anti-emetics (to stop you feeling sick or being sick). However, the most common side effect from chemotherapy is tiredness or fatigue, and this may continue for several months. Side effects from chemotherapy are an important consideration and you need to discuss these thoroughly with your doctor before treatment begins.

Monoclonal antibody therapy

If your cancer is HER2-positive (see 'What is my Tumour Type?') then monoclonal antibodies such as trastuzumab (also known as Herceptin®) may help. Trastuzumab is a new class of drug, which works by blocking the HER2 receptor and helping to stop your breast cancer cells from dividing and growing. Monoclonal antibody therapy also works by recruiting the body's own immune system to help destroy the cancer cells.

Monoclonal antibody therapy: the facts

- Monoclonal antibody therapy is a biological or 'immune' therapy.
- Monoclonal antibody therapy with trastuzumab will only work if you have HER2-positive cancer.
- Only 1 in 5 breast cancers are HER2-positive.

Trastuzumab is given as a drip into your arm (an 'infusion'), in the outpatient department of your local hospital. This treatment continues indefinitely, usually at weekly intervals, in order to keep the breast cancer under control. After the first few treatments it may be possible to receive the trastuzumab infusion in your own home provided these facilities have been set up and are available locally.

Anti-emetic:

A drug used to control nausea and vomiting.

Fatigue:

Tiredness that may not disappear even after rest.

Immune system:

A system in your body made up of special cells, proteins, tissues, and organs that defend you against germs such as viruses and bacteria.

Infusion:

A fluid (e.g. a drug, saline, or blood) given via a drip directly into a vein in your arm.

Occasionally, you may have an allergic reaction, particularly to the first treatment. The hospital staff will therefore check your breathing, pulse and blood pressure regularly during the infusion. If all goes well the first drip will last 1–2 hours, and subsequent doses will last about 30 minutes. Sometimes, however, in response to a mild allergic reaction, the drip may have to be slowed down over several hours. To avoid a mild reaction, paracetamol and an antihistamine may be given before the infusion.

Trastuzumab therapy: side effects¹⁰

- Flu-like symptoms
- Fever
- Chills
- Tumour pain
- Headaches
- Allergic reactions
- Diarrhoea
- Heart problems

Most side effects occur as the therapy is being given or within the next day or two, and you should be able to continue with your normal routine between treatments. However, you may also be at risk of heart problems if you are given trastuzumab for a long time, or in combination with certain chemotherapy regimens. Therefore, you may have tests done before starting treatment to assess your heart function. Women who experience heart problems can stop taking trastuzumab and start taking medications to treat heart problems. This often brings heart function back to normal after a few weeks.

What are my treatment choices with hormonal therapies?

If your cancer is oestrogen receptor-positive then hormonal therapy may help. Hormonal therapy works by blocking the production or action of oestrogen to stop or slow growth of your cancer.¹¹

Ways to stop oestrogen action in postmenopausal women

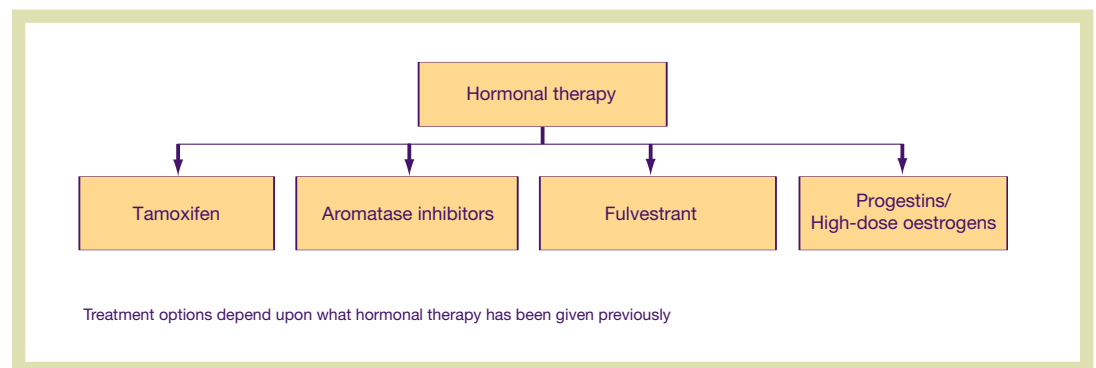
In postmenopausal women oestrogen action can be stopped by:

- Blocking its action at the oestrogen receptor inside breast cancer cells (e.g. with tamoxifen or fulvestrant).
- Blocking its production by the fat, muscle, adrenal glands and liver cells (e.g. with aromatase inhibitors).

The exact treatment should be decided in consultation with your doctor.

Your hormonal treatment choices when you have advanced breast cancer are similar to those for early stages of the disease and include tamoxifen (also known as Nolvadex[®]) and aromatase inhibitors such as anastrozole (Arimidex[®]), letrozole (Femara[®]) or exemestane (Aromasin[®]). Another hormonal drug therapy is fulvestrant (Faslodex[®]). Other hormonal treatments are also sometimes used but usually only when your tumour no longer responds to any of these therapies. You will usually only be given one hormonal therapy at a time, although your doctor will discuss this with you.

Treatment choices with hormonal drug therapy



Whether or not you receive hormonal therapy will be dependent on the tumour type, the size and spread of the cancer, as well as your own personal preference. Since tamoxifen, aromatase inhibitors and fulvestrant work in different ways to help stop the growth of your tumour; you should discuss with your doctor which one is right for you.

Hormonal drug therapy: the facts

- Hormone therapy is recommended if your tumour is growing in response to hormones.
- Hormone therapy stops the growth of breast cancer cells by blocking the production or action of oestrogen.
- When your tumour stops responding to one kind of hormonal therapy, you may be switched to another type.
- Hormonal therapy aims to reduce the impact of oestrogen on your tumour and so many of its associated side effects are similar to those experienced during menopause.

Tamoxifen

Tamoxifen is commonly used to treat hormone receptor-positive breast cancer. It is given as a once-daily tablet and can be taken for a number of years as long as it is working. Tamoxifen works by blocking the action of oestrogen at its receptor in the tumour cell, which starves the tumour and prevents it from growing.

Side effects of tamoxifen therapy are often associated with its oestrogen-blocking action, and include many of the side effects associated with menopause such as hot flushes and thinning of your hair and nails.⁸ However, tamoxifen can also cause a small stimulatory effect at certain oestrogen receptors (known as partial agonist effect) and this can potentially result in more serious side effects, although these are uncommon.

Tamoxifen: side effects¹²⁻¹⁴

Common

- Hot flushes
- Feeling sick
- Thinning of hair and nails

Rare

- Endometrial cancer
- Blood clots ('thrombosis')
- Stroke

If you are taking tamoxifen to treat your breast cancer, you may be slightly more likely to have a clot (deep vein thrombosis) and should stop tamoxifen for 4 weeks prior to any surgery.⁸ However, you should remember that the benefits of tamoxifen treatment usually outweigh the risks, and that many women do not experience any side effects during their treatment.

Deep vein thrombosis:

Blood clot usually in the veins of the leg.

Endometrial cancer:

A rare cancer of the lining of the womb. Taking tamoxifen may increase the risk of endometrial cancer by about four times the normal rate.

Stroke:

A serious condition in which the supply of blood and oxygen is temporarily cut off to part of the brain.

Aromatase inhibitors

A new class of drugs called the aromatase inhibitors are now known to be more effective than tamoxifen with fewer side effects.^{13,15-17} There are three commonly used aromatase inhibitors: anastrozole, letrozole and exemestane. Aromatase inhibitors are taken as a tablet daily and work by blocking oestrogen production in fat, liver and muscle tissues (where the majority of oestrogen is made in postmenopausal women) but they do not block oestrogen production by the ovaries (where the majority of oestrogen is made in premenopausal women). This is the main reason why aromatase inhibitors are only suitable for women who have been through menopause and whose ovaries are no longer working (see 'What is my Tumour Type?'). The side effects of preventing oestrogen production are similar to menopause, and should not significantly affect your daily life.

Aromatase inhibitors: side effects^{13, 15-18}

- Hot flushes
- Vaginal dryness
- Feeling sick
- Feeling tired
- Constipation or diarrhoea
- Hair thinning
- Headaches
- Joint or muscle pain

These side effects may last throughout the duration of your hormonal therapy, but usually disappear when you stop taking the treatment. In addition, aromatase inhibitor use may increase the risk of osteoporosis in some women; if this is a concern your doctor may monitor your bone thickness and, if necessary, prescribe a type of bone-protecting drug called a bisphosphonate.¹⁵⁻¹⁷

Osteoporosis:

A condition that can occur after menopause where the bones become 'thin' so that you are more likely to break or fracture them.

Bisphosphonate:

A drug that can reduce the risk of bone thinning and osteoporosis.

Fulvestrant

Fulvestrant is given to postmenopausal women with advanced breast cancer who have usually already tried tamoxifen. It is administered as a monthly injection into the muscle of your buttock. Fulvestrant works in a similar way to tamoxifen in that it blocks the action of oestrogen at its receptor and starves tumour cells of the oestrogen that they need to grow. However, it does not have the partial stimulatory effect of tamoxifen and it also causes the oestrogen receptors to be broken down more quickly by the body so that there are less available to bind oestrogen. The side effects of fulvestrant are sometimes fewer and are usually less serious than those associated with tamoxifen or aromatase inhibitors.

Fulvestrant: side effects^{12, 18}

- Redness, swelling or soreness at the injection site
- Stomach upset
- Headache
- Feeling tired
- Feeling sick
- Hot flushes

You may not experience any of these side effects, but even if you do, they do not usually last very long and should not disrupt your daily life.

Other hormonal therapies

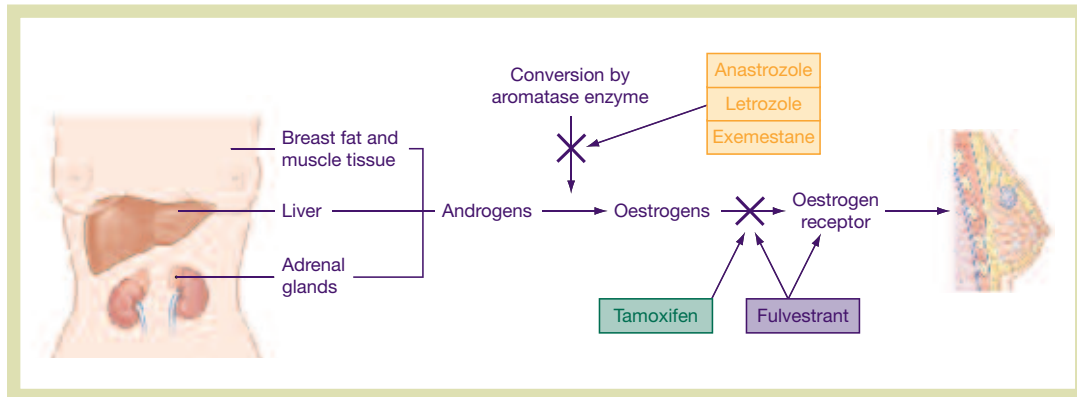
There are other hormonal therapies available, such as progestins and high-dose oestrogens. However, these are much less common treatments and are usually only used if your tumour does not respond to other types of hormonal therapy.

I have already had one hormonal therapy, will I respond to another?

If you are already receiving some kind of hormonal therapy and it is working for you then you should continue with it for as long as possible. Tumours don't always respond to the first choice of hormonal therapy or the treatment may stop working after a period of time. However, your tumour may respond to a different type of hormonal therapy, and there are several hormonal therapy options that you can try. Taking a series of hormonal therapies is normal. Some oncologists intersperse different hormonal treatments with courses of chemotherapy.

For women who have been through menopause the first choice of hormonal therapy is usually an aromatase inhibitor (anastrozole, letrozole or exemestane). If aromatase inhibitor treatment isn't working for you then you may be offered either fulvestrant or tamoxifen. All of these hormonal treatments work in different ways, either to stop oestrogen being made, or to prevent it from working, so many women take different hormonal therapies at different stages of their breast cancer.

How different hormonal therapies work



Supportive care

Pain relief

Not everyone with advanced cancer experiences pain. However, if you do get pain, it is important to let your doctor know as it can usually be well controlled. Modern painkillers, such as codeine and paracetamol, should give you relief from your symptoms without making you feel drowsy. However, morphine is often prescribed at later stages of breast cancer and this does make you feel drowsy. Alternatively, you can ask your doctor to refer you to a specialist pain clinic where you can be given non-drug treatments such as acupuncture or hypnotherapy, or learn relaxation techniques.

Home care

If you need to be looked after at home, there is help available. Your doctor will be able to advise you on the types of support available in your area.

Home care resources

- Your **general practitioner (GP)** or **primary care physician** has overall responsibility for your care when you are being looked after at home.
- **Nurses** can also visit to change dressings and give medicines.
- **Occupational therapists** are concerned with maintaining your comfort and independence at home. They may be able to arrange for aids such as toilet frames and handrails to be fitted if needed.
- **Physiotherapists** can help to keep you moving about, and are also able to help relieve pain with massage and exercise programmes.
- **Home helps** offer a variety of services including cleaning, washing, cooking and shopping.

Counselling

If you are anxious or feeling depressed about your illness, a psychologist or counsellor may be able to help. They will look at ways of helping you to cope with everything that is going on. They can also help with relationship problems, listen, and advise you on how to talk to your family at this difficult time. Ask your doctor for information on counselling services in your area.

Summary of treatments

The treatment that is appropriate for you will depend on a number of factors, for example, what type of tumour you have, how far the disease has spread (metastasised) and what treatments you have had before. You may have either chemotherapy or hormonal treatment, or you may need a combination of treatments. You should discuss all the treatment options with your doctor and make a decision that best suits your needs.

Whichever treatment you choose, you will require regular checkups by your doctor

There are important things that you, as the patient, need to consider concerning your treatment. These factors vary from patient to patient, and it may help in making a decision about treatment if you think about some of the following:

- How will the treatment impact on my family?
- How will the treatment impact on my daily life?
- Which potential side effects of the treatments available are likely to trouble me the most?
- How long will the treatment last?

You have choices

Points of discussion with my doctor

- What stage is my breast cancer?
- What are my options for treatment?
- Will I need radiotherapy? To what area of the body and for how long?
- Do I need chemotherapy? What type or combination of chemotherapy would be best for me?
- Do I have HER2-positive disease?
- Is hormonal therapy right for me? Is it in tablet form or is it an injection? How long will I need it for?
- Do I need chemotherapy as well as hormonal therapy?
- What are the potential side effects of my treatment?
- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- How can I reduce the side effects before, during and after my treatments?
- How quickly will my treatment begin?
- What are my options if I don't respond to the treatment you are recommending?
- Where can I seek emotional support for me and/or my family if needed?

Other questions for my doctor

Coping with your advanced breast cancer

Whether you have been newly diagnosed with advanced breast cancer or if it has come back after previous treatment, it is an upsetting and worrying time for you and your loved ones. Feeling a whole range of emotions is completely natural and normal. You might find it beneficial to talk to someone, a family member, friend, nurse, doctor or a religious or spiritual leader. If you are uncomfortable speaking to someone you know, you could try a support group (details are available in the Additional Resources section of this booklet) or a professional counsellor. Your doctor should be able to offer you advice on this.

Following your diagnosis, you may want to turn to your friends and family for love, companionship and support. However, you may find that some people are shocked by the news, and they may react in unexpected ways. Some may try to deny the seriousness of the situation or avoid mentioning the subject altogether, while others may become overprotective or clingy. Remember that your family and friends are also dealing with strong emotions, so it is important to talk to them and let them know exactly what you need from them.

Talking to your family

- Talk to your partner about your feelings. Discuss your treatment options and plans with them, so that they do not feel excluded.
- Trying to protect each other by denying the truth can put extra strains on your relationship, so it is important to be honest and open about how you feel.
- When words fail you or seem inadequate, just being together or having a hug may be enough.
- How and what you tell your children and grandchildren will depend on their age and how much they can understand.
- It is probably best to talk honestly with your family; just explain simply about your illness and that you may sometimes feel too tired to join in with their activities, or that you may have to spend some time in hospital.

Friends and colleagues may feel unsure how to talk to you, and it will often be left to you to make the first approach. You can tell them as much or as little as you want to about your diagnosis and outlook. Don't be afraid to tell people what you want or need from them, whether it is help at home, cheerful outings to distract you, or regular visits – they will probably welcome the chance to be of use.

There may also be times when you want to be alone – do not feel that you have to see people if you don't want to. Let someone else answer the door or the telephone, or ask the nurses to limit your visitors if you are in hospital.

Apart from your medical needs and treatment decisions there are other practical issues you may wish to take care of, to help yourself and those around you deal with the disease and its effects.

Other considerations

- At some point you may not be able to do household tasks such as shopping or cleaning. Talk to your doctor about getting practical assistance in your home such as a wheelchair, a home help, or professional carers.
- Chat with your partner and family about what will happen when you are no longer there. Making plans for their future without you and talking honestly about how you all feel may help everyone to come to terms with what is happening.
- Consider making or updating your will. This will allow you to ensure that your loved ones, and people or issues that you care about are looked after.
- Make a list of where you keep important documents such as the title deeds of your house, and details of your bank account and pension.
- Take advice on your financial situation. If you have life insurance, income protection or medical insurance, you will need to contact the insurance companies to make a claim.

Additional resources

Websites

The following websites will provide you with additional information on the treatment of your breast cancer as well as provide online support groups:

Association Of Cancer Online Resources
www.acor.org

Breakthrough Breast Cancer
www.breakthrough.org.uk

Breastcancer.org
www.breastcancer.org

Breast Cancer Care
www.breastcancercare.org.uk/

Breast Cancer Source
www.breastcancersource.com

Cancer Backup
www.cancerbackup.org.uk

Cancer Counselling Trust
www.cctrust.org.uk

Guide To Internet Resources For Cancer
www.cancerindex.org

Lavender Trust At Breast Cancer Care
www.lavendertrust.org.uk

National Cancer Institute
www.nci.nih.gov/cancertopics/types/breast

National Breast Cancer Awareness Month
www.nbcam.org

Susan Komen Breast Cancer Foundation
www.komen.org

Y-Me National Breast Cancer Organization
www.y-me.org

Patient forums

The following patient forums may enable you, together with other breast cancer patients and survivors, to learn through talks and discussions about the latest developments in breast cancer research and treatment.

Australia

Breast Cancer Network
www.bcna.org.au

Canada

Willow Breast Cancer Support &
Resource Services
www.willow.org

Quebec Breast Health Network
www.rqss.qc.ca/rqss

France

Europa Donna
www.europadonna.fr

Germany

Mamazone
www.mamazone.de/mamazone.html

Italy

Europa Donna
www.europadonna-italia.it

Japan

Akebonokai
www.akebono-net.org/contents/e_index.html

Netherlands

Borstkanker Vereniging
www.borstkanker.nl

Sweden

The Swedish Breast Cancer Association
www.bro.org.se

United Kingdom

Breast Cancer Care
www.breastcancercare.org.uk/

United States

Patient Advocate/Research Team (PART)
http://spores.nci.nih.gov/part/index_part.html

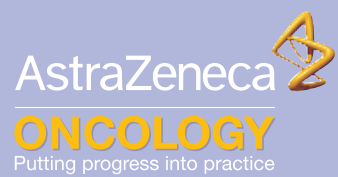
Breast Cancer Coalition
www.natlbcc.org

European

Europa Donna
www.cancerworld.org/cancerworld/home.aspx?id_sito=5&id_stato=1

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