

MACMILLAN
CANCER SUPPORT

UNDERSTANDING SECONDARY BREAST CANCER





Since my diagnosis, I have learnt how to adjust and come to terms with my new self. I am still Carol – a mother, wife, sister, friend and colleague.

Carol, diagnosed with secondary breast cancer

About this booklet

This booklet is about secondary breast cancer. This is breast cancer that has spread to another part of the body. It is for anyone who has been diagnosed with secondary breast cancer.

The booklet explains the signs and symptoms of secondary breast cancer. It also explains the different treatments, how to manage symptoms and ways to cope with some of the feelings you may have.

Although it cannot be cured, secondary breast cancer can be controlled. Women are living for longer because of new and improved treatments. Treatments help to relieve symptoms and control the cancer, sometimes for many years.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

At the end of this booklet, there are details of other organisations that can help (see pages 119 to 124). There is also space to write down questions and notes for your doctor or nurse (see page 125).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Quotes

Throughout this booklet, we have included quotes from people affected by cancer. These are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

For more information

We have a separate booklet about early or primary breast cancer called **Understanding breast cancer in women**. Men with breast cancer may find it helpful to read our booklet **Understanding breast cancer in men**. It includes information about treating early and advanced breast cancer. See page 114 to order a copy.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at [**macmillan.org.uk/cancerregistry**](https://www.macmillan.org.uk/cancerregistry)

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What is secondary breast cancer?

Secondary breast cancer is when cancer cells spread from the breast to other parts of the body. Cancer that starts in the breast is called primary breast cancer.

In many women, primary breast cancer never comes back after treatment. But sometimes, the cancer cells spread to other parts of the body through the blood or the lymphatic system. The lymphatic system protects us from infection and disease. It is made up of fine tubes that connect to groups of lymph nodes (glands) throughout the body.

Breast cancer cells that have spread may begin to grow and form another tumour. This is called a secondary breast cancer or metastatic breast cancer. Sometimes, women recently diagnosed with primary breast cancer also have a secondary cancer. This can be found through tests (see pages 19 to 26).

The secondary cancer is made up of breast cancer cells. Doctors treat it with the same drugs used to treat breast cancer. For example, a secondary breast cancer in the lung is treated as breast cancer, not as a lung cancer.

The most common places for breast cancer to spread to are the:

- bones
- lungs
- liver
- skin
- brain.

This does not mean that secondary breast cancer will spread to all of these places.

Breast cancer can spread to other parts of the body, such as the bone marrow, ovaries or lining of the abdomen (peritoneum). This is less common. If you need more information about this, you can call our cancer support specialists on **0808 808 00 00**.

Local and regional recurrence

Sometimes, breast cancer comes back in the treated breast or the scar, but has not spread anywhere else in the body. This is called a local recurrence. If breast cancer is in the lymph nodes in the armpit, close to the breast bone, or in the lower neck, this is called a regional recurrence.

When cancer cells block the lymph nodes in the armpit, fluid can build up in the arm and cause swelling. This is known as lymphoedema (see page 74).

Although these recurrences are not in other parts of the body (secondary cancer), your doctor usually recommends you have tests. These are to check that the cancer has not spread further.

If the cancer has not spread anywhere else in the body, you will have:

- surgery, if possible
- radiotherapy to the area
- chemotherapy.

The treatment you have will depend on the previous treatments you had for primary breast cancer.

Signs and symptoms

Symptoms

The symptoms of secondary breast cancer depend on where in the body the cancer has spread.

You may also have some general symptoms. These can include:

- feeling more tired than usual
- losing your appetite
- feeling generally unwell for no obvious reason.

These symptoms can be caused by other conditions. But speak to your GP, cancer doctor or specialist nurse if you have any of them. Always tell them if you develop new symptoms, especially if they last more than 1 or 2 weeks.

The bones

The most common symptom of secondary breast cancer in the bone is an ongoing ache in an area of bone. It may be painful when you move around, or you may find it difficult to sleep because of the pain.

Aches and pains are common. They can be caused by different things, such as hormonal therapy or menopause (see pages 38 to 43). But it is important to tell your cancer doctor if your symptoms continue.

If the cancer has spread to the bones, it can often be controlled for many years with different treatments.

Women with secondary breast cancer in the bones may develop other bone problems. These are not common when you have just been diagnosed, but it is important to know about them.

Too much calcium in the blood

If the bone is damaged by the cancer, it can release calcium into the blood. Calcium is stored in the bones. A high level of calcium in the blood (hypercalcaemia) can cause symptoms such as:

- feeling tired, sick or thirsty
- passing more pee (urine)
- constipation
- feeling confused.

Doctors can see an increase in calcium levels on a blood test before symptoms develop. They can treat this with drugs called bisphosphonates (see pages 68 to 69).

A break in the bone

If the bone is gradually damaged by the cancer, it may become weaker. Sometimes, a very weak bone can break (fracture). Treatment usually starts before a bone is weak enough to break.

Pressure on the spinal cord

If the cancer has spread to the bones or the spine, it may cause pressure on the spinal cord. This is called spinal cord compression (see pages 64 and 78). Symptoms can include:

- unexplained pain in the back, around the chest and neck, or down the arm and legs
- numbness or pins and needles in toes, fingers or buttocks
- unsteadiness or difficulty walking
- problems controlling your bladder or bowel.

It is very important to let your cancer doctor or specialist nurse know immediately if you have any of these symptoms. Doctors can usually treat spinal cord compression successfully when it is diagnosed quickly.

The lungs

The first symptoms of a secondary cancer in the lungs may be a cough that does not get better, or feeling breathless.

If there are cancer cells in the tissues that cover the lungs (pleura), it can lead to irritation. This causes fluid to build up and press on the lungs, making you breathless. This is called a pleural effusion. Your doctor can drain the fluid away to make your breathing easier.

Doctors use different treatments to treat and manage breathlessness (see page 78).

The liver

If there is a secondary cancer in the liver, you may have discomfort or pain in the area of the liver. The liver is under the lower ribs on the right side of the tummy (abdomen).

Other symptoms can include:

- feeling sick
- losing your appetite
- feeling very tired and generally unwell.

Sometimes, secondary breast cancer in the liver causes a build-up of bile in the blood. This is called jaundice. Symptoms include yellowing of the skin and whites of the eyes, and itchy skin.

You may be given chemotherapy to improve these symptoms. See pages 45 to 55 for more information about chemotherapy.

The skin

Secondary breast cancers can sometimes develop on or just below the skin. This is called skin secondaries or metastases. This may happen in some women who already have secondary breast cancer.

It is not the same as local recurrence (see page 9). With a local recurrence the cancer comes back in the treated breast or scar, but there are no secondary cancers anywhere else in the body.

Secondary cancer that affect the skin may look like either:

- a firm painless lump on the skin or many lumps of different sizes
- an area of skin that is red and swollen (inflamed).

Other possible symptoms include pain, bleeding, and sometimes infection.

Skin secondaries can appear near the area of the primary cancer, such as the skin of the chest or around the scar. Less commonly, they may develop in other areas of skin, such as on the scalp, neck, back and upper limbs.

Different treatments can be used to treat skin secondaries, including electrochemotherapy (see pages 48 to 49).

The brain

A secondary cancer in the brain may cause symptoms such as headaches and feeling or being sick. These symptoms are caused by increased pressure in the brain. They may be worse first thing in the morning.

Other symptoms will depend on the part of the brain that is affected. They can include:

- weakness or numbness in an arm or leg
- dizziness
- loss of balance
- changes in mood or personality
- seizures (fits).

It is normal to feel very worried about a cancer that affects the brain. But treatments can usually control the symptoms quickly.

Doctors give radiotherapy to the head to improve the symptoms (see pages 63 to 65). They also give drugs called steroids (see pages 70 to 71).

The meninges

Sometimes, breast cancer cells spread to tissue that covers the brain and spinal cord (meninges). Doctors call this meningeal metastases or carcinomatous meningitis. It causes symptoms similar to a secondary cancer in the brain.

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DIAGNOSING SECONDARY BREAST CANCER

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How secondary breast cancer is diagnosed

You may see your GP with a new symptom. Your GP may arrange tests or refer you directly to your cancer doctor.

Or, you may have contacted your cancer doctor or specialist nurse yourself. Your follow-up appointment may have included advice on signs or symptoms to contact them about.

Most women have some symptoms of a secondary breast cancer. But some do not have obvious symptoms. Your doctor may notice something at your routine follow-up appointment that needs checking. Tests then show there is a secondary cancer.

Sometimes, women recently diagnosed with primary breast cancer also have a secondary cancer.

Tests and scans

Your cancer doctor will examine you and ask questions about your symptoms and general health. You usually also see a specialist nurse who will give you information and support.

Your cancer doctor and specialist nurse will explain which tests you need. This will depend on your symptoms. You will usually have some of the following tests.

Blood tests

Blood tests cannot diagnose secondary breast cancer. But they may show that you need further tests. They can be used to do the following:

- Check how well the liver and kidneys are working.
- Check the level of calcium in the blood.
- Measure the number of blood cells to show how well the bone marrow is working. The bone marrow is where blood cells are made.
- Measure tumour markers. Some cancers produce proteins (tumour markers), so the levels of them in your blood may be raised. The results are not always reliable. Your doctor can tell you whether this test is helpful in your situation.

X-rays

Bones

If you have a painful area in your bones, you may have an x-ray to check for signs of cancer. The x-ray may also show weakened areas of bone that are at a higher risk of fracture. It may not show small areas of secondary cancer. You will usually have a bone scan (see the next page) to confirm the diagnosis.

Lungs

A chest x-ray can help to see if there is secondary breast cancer in the lungs. It can also show any build-up of fluid between the membranes on the outside of the lungs (the pleura). You will also usually have a CT scan (see page 22).

Bone scan

Before a bone scan, a tiny amount of a mildly radioactive substance is injected into a vein, usually in the arm. This moves around the body in the bloodstream. Abnormal areas of bone absorb more radioactivity than normal bone, so will show up on a scanner.

The scan is done 2 to 3 hours after the injection. It produces a picture of the bone. Bone scans cannot always show whether an abnormal area is caused by cancer or other conditions, such as arthritis. Sometimes you may need more detailed scans, such as CT or MRI scans. You may need an x-ray if you have not already had one.

Liver ultrasound

A liver ultrasound uses soundwaves to build up a picture of the liver. It is painless and only takes a few minutes. The person doing the ultrasound spreads a gel onto your tummy (abdomen). They pass a small device like a microphone, which produces sound waves, over the area. A computer changes the sound waves into a picture. You may have a CT scan of the liver rather than an ultrasound.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You may be given a drink or injection of a dye, which allows some areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You will probably be able to go home as soon as the scan is over.



Having a CT scan

PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings, including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Biopsy

You may need a biopsy. This is when a doctor removes a small piece of tissue or sample of cells. A doctor who is an expert in cell types (pathologist) looks at it under a microscope. They do this to look for cancer cells and find out more about the type of cancer.

They can see if the cells have come from a cancer that started in the breast (primary cancer). A secondary breast cancer is always made up of the same cells as the primary breast cancer. The most common type is invasive ductal breast cancer.

If you have had breast cancer before, your doctor may be able to diagnose a secondary cancer from your scan results. But they may still recommend a biopsy.

A biopsy gives doctors information about whether the secondary cancer has receptors (proteins) for hormones or for HER2 (see pages 28 to 29). Hormone and HER2 receptors can encourage the cancer to grow. In some women, this may not be the same as when the primary breast cancer was diagnosed. It may mean a different treatment will need to be used.

If you have not been diagnosed with primary breast cancer before, you will need to have a biopsy. This is to confirm the diagnosis and to find out which receptors the cancer has.

Where you have the biopsy taken from depends on your symptoms and scan results. For example, you may have a biopsy taken from your lungs or liver.

Having a biopsy may depend on whether your doctor thinks the area is easy to reach.

Having a biopsy

Your doctor will talk to you about what having a biopsy involves and if there are any possible risks. You usually have the biopsy under a local anaesthetic as an outpatient. The doctor uses an ultrasound or a CT scan to help them guide the needle to the right place (see page 22).

After the biopsy, the area may feel a bit uncomfortable for a couple of days. You can take regular painkillers to help with this until the pain goes away.

'I found the appointment when they said they were suspicious the hardest. I was prepared for the worst. It is okay to have up and down moments. It makes you human.'

Nj

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, family or a close friend. Your specialist nurse or one of the organisations listed on pages 119 to 124 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.



Staging and receptors

The stage of a cancer describes its size and if it has spread from where it started. This information helps you and your doctor make decisions about your treatment.

Doctors often stage breast cancer using a system that divides it into four number stages. Secondary breast cancer is always stage 4. This is when the cancer has spread to other parts of the body such as the bones, liver or lungs.

Receptors

Breast cancer cells may have receptors (proteins). Hormones, or a protein called HER2, can attach to the receptors and encourage the cells to grow. A doctor called a pathologist tests cancer cells taken during a biopsy or surgery for receptors.

Hormone receptors

Breast cancers with receptors for the hormone oestrogen are called oestrogen receptor (ER) positive breast cancer. About 7 in 10 (70%) breast cancers are ER positive. Hormonal therapies are often used to treat ER positive breast cancer (see pages 38 to 43).

Breast cancers that do not have hormone receptors are called oestrogen receptor negative (ER negative).

Breast cancer cells may also have receptors for the hormone progesterone (PR). This is called PR positive breast cancer.

Receptors for HER2

Some breast cancer cells have too many receptors called human epidermal growth factor receptor 2 (HER2) on their surface. This type of breast cancer is called HER2 positive breast cancer. The extra HER2 protein encourages the cancer cells to divide and grow.

Between 15 and 20 in 100 (15 to 20%) breast cancers are HER2 positive. All women diagnosed with breast cancer have tests on the cancer to see if the cancer is HER2 positive or not.

Specific targeted therapy drugs are used to treat HER2 positive breast cancer (see pages 56 to 61). They do this by locking onto the HER2 protein to stop the cells dividing and growing.

Triple negative breast cancer

Some cancers do not have receptors for HER2 or the hormones oestrogen and progesterone. This is called triple negative breast cancer. It affects up to 1 in 5 women (20%) with breast cancer. It is more common in younger women.



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Treatment overview

The aim of treatment for secondary breast cancer is to:

- control the cancer
- help you live well for longer
- improve symptoms.

You may have different or combined treatments one after the other to keep the cancer under control. You might find you can get on with your day-to-day life between treatments.

Your cancer doctor and specialist nurse will talk to you about your treatment options, so you can talk about what you prefer. They can also help you make decisions about treatment. They can offer more support if you need it, and refer you for more specialised help to cope with your emotions.

New treatments and different ways of giving existing treatments are being developed. Your cancer doctor may talk to you about taking part in a research trial.

The treatment you have will depend on different things, such as:

- where the secondary cancer is in your body
- whether the cancer is oestrogen-receptor (ER) positive or HER2 positive (see pages 28 to 29)
- previous breast cancer treatments you have had and how long ago you had them
- your symptoms and general health.

The main treatments to control secondary breast cancer are:

- hormonal therapy drugs
- chemotherapy
- targeted therapy drugs.

You may have a combination of treatments. Other treatments can be used to control symptoms.

If the cancer is ER positive, your doctor will talk to you about having hormonal therapy. There are different drugs and treatments that can be used. If the cancer is not HER2 positive (see page 29), you may be given a hormonal therapy drug called an aromatase inhibitor, along with newer targeted therapy drugs.

Chemotherapy is often used to treat secondary breast cancer. You may have chemotherapy with a single drug or sometimes a combination of drugs. It may be given along with a targeted therapy drug.

If you have HER2 positive breast cancer, you will usually be given targeted therapy drugs. There are different drugs that can be used.

Your cancer doctor may give you radiotherapy to relieve pain from a secondary cancer in the bone. You can also have drugs to help strengthen bones.

Radiotherapy can also be used to shrink secondary cancer in the brain or lymph nodes.

Sometimes surgery is used to remove a small tumour in the brain or liver, or to help strengthen a weak bone.

Your doctor can refer you to a cancer doctor or specialist nurse who is an expert in symptom control at any time during or after treatment. This helps make sure that any difficult symptoms you have are controlled. You can see them in hospital, or nurses can visit you in your own home. You may be able to see a specialist nurse at home and in hospital.

If, at any point, you decide not to have further treatment, they will support you and help to control your symptoms. Experts in this area are sometimes called palliative care specialists.

Planning your treatment

In most hospitals, a team of specialists meets to decide on the best treatment for you. This multidisciplinary team (MDT) may include a:

- cancer doctor (oncologist), who specialises in giving cancer treatments
- specialist nurse, who gives information and support
- specialist surgeon (if needed)
- doctor or nurse who specialises in controlling symptoms (palliative care specialist)
- radiologist, who analyses x-rays and scans
- pathologist, who advises on the type and extent of the cancer.

It may also include other healthcare professionals, such as:

- a physiotherapist
- a dietitian
- an occupational therapist
- a psychologist
- a social worker
- a counsellor.

Your cancer doctor and specialist nurse will discuss treatment options with you. Remember to ask questions about anything you do not understand or feel worried about. You can discuss the benefits and disadvantages of different treatments with your cancer doctor or specialist nurse. You can also talk to our cancer support specialists on **0800 808 00 00**.

The benefits and disadvantages of treatment

Many people worry about having cancer treatments because of the possible side effects. But these can usually be controlled with medicines. Treatment can be given for different reasons, and the benefits will depend on your individual situation.

Usually treatments for secondary breast cancer can help control the cancer, relieve the symptoms and help you live well for longer.

There may be a time when the treatment has little effect on the cancer, but you still get side effects. Making treatment decisions in this situation is always difficult. You may want to talk about it with your cancer doctor, specialist nurse and people close to you. If you decide not to have treatment, you will be given medicines to control any symptoms. This is sometimes called supportive or palliative care.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you. You may also find it helpful to have a list of questions ready so that you can make sure your concerns are covered during the discussion.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions. You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Hormonal therapies

Hormones help control how cells grow and what they do in the body. The hormones oestrogen and progesterone can encourage breast cancer cells to grow, particularly oestrogen.

Hormonal therapies lower the level of oestrogen in the body, or block oestrogen from attaching to the cancer cells. They only work for women who have oestrogen receptor (ER) positive cancers (see page 28).

Hormonal therapies are often the first treatment for women with ER positive secondary breast cancer when the cancer is mainly in the bones. Some women have chemotherapy first and then hormonal therapy.

The hormonal therapy treatment you have depends on:

- whether you have been through the menopause
- other hormonal therapies you have had before.

Some women have hormonal therapy alongside targeted therapy (see pages 56 to 61). Targeted therapy drugs interfere with signals that tell the cancer cells to grow.

Ribociclib (Kisqali®) and palbociclib (Ibrance®) are newer targeted therapies used to treat secondary breast cancer. They are given with hormonal therapy drugs called aromatase inhibitors, to women whose breast cancer is oestrogen receptor positive and HER2 negative.

An aromatase inhibitor drug called exemestane may also be given with another targeted therapy drug called everolimus. But this will not be given as a first treatment.

It takes a few weeks or months before your doctors can tell how well your hormonal therapy treatment is working for you. Your cancer doctor will usually arrange for you to have a scan to check this. If one hormonal therapy does not work, or stops working, your cancer doctor can usually prescribe another type.

Different types of hormonal therapy

There are different types of hormonal therapies. Most of them are taken as tablets or as an injection under the skin. They are usually easy to take.

The side effects are usually quite mild and will depend on the drug you are taking. Some side effects are similar to menopausal symptoms. If you have not been through the menopause, some hormonal therapies can cause a temporary menopause.

If you have problems with the side effects of hormonal therapy, talk to your specialist nurse or cancer doctor. They can usually help treat or manage any problems. Most women are already taking hormonal therapy and may be used to managing their side effects.

Aromatase inhibitors (AIs)

Aromatase inhibitors (AIs) are the main hormonal therapy used in women who have been through the menopause. They stop oestrogen being made in the fatty tissue of the body.

You may have them along with a targeted therapy drug. In women who have not been through the menopause, they can be given with treatments to stop the ovaries working (ovarian suppression).

There are different types of aromatase inhibitor. These include:

- anastrozole
- letrozole
- exemestane.

If you were already taking an aromatase inhibitor when the cancer came back, your cancer doctor will prescribe a different one. You take them daily as a tablet.

Side effects include:

- tiredness
- joint and muscle pain
- hot flushes.

Aromatase inhibitors can also cause bone thinning (osteoporosis). Your cancer doctor may prescribe vitamin D and calcium or bone strengthening drugs to help protect your bones.

Anti-oestrogens

Tamoxifen

Tamoxifen stops oestrogen from attaching to breast cancer cells and encouraging them to grow.

You take tamoxifen daily as a tablet. The side effects may include:

- hot flushes and sweats
- weight gain
- tiredness.

When you take tamoxifen for secondary breast cancer that has spread to the bone, the pain may be worse for the first few days. This will gradually improve.

Fulvestrant

Your doctor may prescribe fulvestrant if other hormonal therapies are no longer working. If you have not been through the menopause, you have it with a drug called goserelin. This stops the ovaries from working.

You have fulvestrant as an injection into a muscle in your buttock. The first three injections are given 2 weeks apart. After this, you have the injection once a month. The side effects are similar to the side effects of tamoxifen.

Ovarian suppression

If you have not been through the menopause, you usually have either:

- drugs to stop your ovaries making oestrogen
- surgery to remove your ovaries.

You have these treatments along with an aromatase inhibitor drug, or sometimes with tamoxifen.

Drugs that stop the ovaries making oestrogen

If you have not been through the menopause, you may be given a drug called goserelin. It stops the pituitary gland in the brain sending messages to the ovaries to produce oestrogen. This stops the ovaries making oestrogen. You have a temporary menopause while you are taking the drug.

The side effects are similar to menopausal symptoms and include:

- hot flushes and sweats
- joint pain
- low sex drive.

Your specialist nurse will give you goserelin as an injection every month under the skin of the tummy (abdomen).

Ovarian ablation

Ovarian ablation reduces the amount of oestrogen in the body. This is done by removing the ovaries.

You can have a small operation to remove the ovaries. This can often be done during a short stay in hospital using keyhole surgery. The surgeon makes a small cut in the tummy area and inserts a thin tube with a small light and camera on the end. This is called a laparoscope. They use this to remove the ovaries through the cut. Women usually recover quickly from this type of operation.

If you have ovarian ablation, your periods will stop straight away and you will have the menopause.



Having chemotherapy

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs are carried in the blood and can reach cancer cells anywhere in the body.

Chemotherapy is commonly used to treat secondary breast cancer. It may be given after you have had treatment with hormonal therapy (see pages 38 to 43). Or may be given as a first treatment. This is usually if the cancer:

- does not have receptors for oestrogen (ER) negative (see pages 28 to 29)
- is HER2 positive and ER negative
- is triple negative
- has spread to the liver or lungs
- is growing quickly (high grade).

If you have HER2 positive breast cancer, you will usually have a targeted therapy drug with chemotherapy.

Sometimes, a type of chemotherapy called electrochemotherapy is used when secondary breast cancer has spread to the skin.

You may find our **Understanding chemotherapy** booklet useful (see page 114).

Chemotherapy drugs for secondary breast cancer

Your cancer doctor or specialist nurse will explain which drug, or drugs, are likely to be most helpful in your situation. The chemotherapy drugs commonly used to treat secondary breast cancer are:

- capecitabine (Xeloda®)
- carboplatin
- cyclophosphamide
- docetaxel (Taxotere®)
- doxorubicin (Adriamycin®)
- epirubicin (Pharmorubicin®)
- gemcitabine (Gemzar®)
- paclitaxel (Taxol®)
- eribulin (Halaven®)
- vinorelbine (Navelbine®).

You may have a single drug or a combination of drugs together. Women with HER2 positive breast cancer may have chemotherapy with a targeted therapy drug. Your cancer doctor and specialist nurse will talk to you about the drugs that are best for your situation. They will explain the benefits and the likely side effects and involve you in making decisions.

The drugs you have will depend on any previous chemotherapy you have had. If you have not previously had an anthracycline drug, such as doxorubicin or epirubicin, you may have either one of these. Your cancer doctor may also suggest trying an anthracycline drug if it has been a long time since you last had it. If you have already had an anthracycline drug, you may have docetaxel.

If you need more chemotherapy, drugs such as vinorelbine or capecitabine can also be used. A drug called eribulin may be given to women who have already had 2 courses of chemotherapy.

How chemotherapy is given

You have your treatment in the chemotherapy day unit. Your specialist nurse will give you chemotherapy into a vein as an injection or as a drip (infusion). You have it through:

- a cannula – a short thin tube the nurse puts into a vein in your arm or hand
- a central line – a long thin tube inserted into a vein in your chest
- a PICC (peripherally inserted central venous catheter) line – this is put into a vein in the arm and threaded through to a vein in the chest
- an implantable port (portacath) – this is put into a vein and has an opening (port) under the skin on your chest.

Women with breast cancer that has spread to the skin may be given chemotherapy directly into the skin tumours. This is called electrochemotherapy.

You may be given some chemotherapy drugs as tablets you can take at home.

You usually have chemotherapy as a session of treatment, followed by a rest period of a few days or weeks before the next session. This allows your body to recover from the side effects. The chemotherapy session and rest period make up a cycle of treatment. Your cancer doctor or specialist nurse will explain how many cycles of treatment you need.

Electrochemotherapy

Electrochemotherapy may be used to treat secondary breast skin tumours. The cancer doctor gives a low dose of a chemotherapy drug either into the vein or into the tumour. They then give a small electrical pulse directly to the cancer cells. This allows the chemotherapy to get into the cancer cells to help destroy them. Because it is given directly to the cancer cells, there is no damage to healthy tissue nearby.

You will usually only need a single treatment of electrochemotherapy, but it can be given again if needed. You can usually have it as a day patient under a general anaesthetic. If treatment is given to a small area, it may be given using a local anaesthetic.

Side effects of electrochemotherapy

Your cancer doctor or specialist nurse will talk to you about any possible side effects and what you can do to manage them. Most side effects affect the area that is being treated.

The side effects of electrochemotherapy are different to side effects of chemotherapy. This is because a very low dose is used. You may get some mild sickness or feel breathless. Always let your cancer doctor or specialist nurse know about any side effects or new symptoms you have. We have listed some common side effects below.

Skin changes

After treatment, the specialist nurses will cover the treated area. They will explain how to look after it before you go home. The area usually develops a scab over it, but this usually improves over a few weeks. The skin in the treated area may become lighter or darker and this may be permanent. Contact your doctor or specialist nurse straight away if the area becomes red, hot or swollen, or if there is any discharge.

Pain or cramps

If you have a local anaesthetic and are awake during treatment, you might have some muscle cramps when the electrical pulses are given. This improves soon after the treatment is finished.

You may have pain in the treated area for a few weeks, but it is usually mild. Your doctor can prescribe painkillers for you to take until the pain goes away.

Side effects of chemotherapy

Chemotherapy drugs can cause different side effects. The side effects depend on the drug or drugs you have. You will not have them all, and many of them can be well controlled with medicines.

Your doctor or nurse will explain the most likely side effects and how to manage them. Side effects usually go away once treatment has finished.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time.

G-CSF (granulocyte-colony stimulating factor) is a type of drug called a growth factor. It encourages the body to make more white blood cells.

Your doctor may give you G-CSF:

- if the number of white blood cells is very low
- to stop the number of white blood cells getting low.

You have it as a small injection under the skin.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

Anaemia (reduced number of red blood cells)

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. You will usually feel more energetic and less breathless.

Feeling sick or being sick

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can try. We have more information about controlling nausea and vomiting.

Tiredness (fatigue)

You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing. Balance rest with some physical activity – even going for short walks will help increase your energy levels. We have helpful tips on coping with tiredness.

Hair loss

Your hair will get thinner or you may lose all the hair from your head. You may also lose your eyelashes, eyebrows or other body hair. Hair loss usually starts after your first or second treatment.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary and your hair will usually grow back after treatment ends.



Sore mouth

You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Diarrhoea

Your doctor can prescribe drugs to control this. Make sure you drink at least 2 litres (3½ pints) of fluids every day if you have diarrhoea. Follow the advice you were given and let your doctor know if the diarrhoea is severe or does not improve.

Constipation

This treatment can cause constipation. It may help to:

- drink at least 2 litres (3½ pints) of fluids each day
- eat high-fibre foods, such as fruit, vegetables and wholemeal bread
- do regular gentle exercise, like going for short walks.

If you have constipation, contact the hospital for advice. Your doctor can give you drugs called laxatives to help.

Soreness and redness of palms of hands or soles of feet

This is called palmar-plantar or hand-foot syndrome. It gets better when treatment finishes. Your doctor or specialist nurse can give you advice and prescribe creams to improve the symptoms. If it is severe, your doctor may need to reduce the dose of chemotherapy. It can help to keep your hands and feet cool and to avoid tight-fitting socks, shoes and gloves.

Numb or tingling hands or feet (peripheral neuropathy)

These symptoms are caused by the effect of certain drugs on the nerves. It is called peripheral neuropathy. You may also find it hard to fasten buttons or do other fiddly tasks.

Always tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes, but in some people they may never go away. Talk to your doctor if you are worried about this.

Contraception

Your doctor will advise you to use effective contraception. This is because the drugs may harm a developing baby. You can talk to your doctor or specialist nurse about this.

Sex

If you have sex within the first couple of days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluid.

Targeted therapies

Targeted therapy drugs interfere with the way cancer cells signal or interact with each other. This stops them growing and dividing. There are different targeted therapy drugs and they all work in different ways. Targeted therapies are sometimes called biological therapies.

You usually have targeted therapy drugs with chemotherapy, or sometimes with hormonal therapy drugs. The type of targeted therapy drug you have depends on whether the cancer is:

- HER2 negative and oestrogen receptor (ER) positive (see pages 28 to 29)
- HER2 positive
- triple negative.

Your cancer doctor will explain which targeted therapy drug or drugs are suitable for your situation.

HER2 negative cancer

If the cancer is HER2 negative and ER positive, your cancer doctor may advise having certain targeted therapy drugs with hormonal therapy.

Palbociclib and ribociclib

Palbociclib (Ibrance®) and ribociclib (Kisqali®) are given with aromatase inhibitors. They are given to women with secondary breast cancer who:

- have been through the menopause
- have ER positive and HER2 negative breast cancer.

These drugs are called kinase inhibitors. A kinase is a protein that helps cells in the body grow and divide. These drugs block (inhibit) the kinase proteins. This helps slow down how quickly the cancer is growing or spreading.

They are both taken as tablets, usually for 3 weeks at a time. You then have a week off before starting them again.

These drugs can reduce the number of blood cells in your blood. This increases the risk of side effects such as infection, bleeding or anaemia. Other side effects include tiredness, hair thinning and diarrhoea.

Everolimus

Everolimus is a targeted therapy drug that may be given with the hormonal drug exemestane. You need to have already had treatment with certain hormonal therapy drugs before you can have it (see pages 38 to 43).

Everolimus works by blocking a protein called mTOR, which makes some cancer cells grow. It can help slow down how quickly the cancer is growing. Everolimus also stops the cancer cells making new blood vessels. This may help shrink the cancer.

You take everolimus as a tablet once a day. Common side effects of everolimus are:

- a rash
- sore mouth
- tiredness
- diarrhoea.

HER2 positive cancer

If the cancer is HER2 positive, you may have the targeted therapy drugs:

- trastuzumab
- pertuzumab (Perjeta®)
- trastuzumab emtansine (Kadclya®).

Trastuzumab

Trastuzumab is the main targeted therapy drug used to treat secondary breast cancer that is HER2 positive. It attaches to the HER2 protein (receptor) on the breast cancer cells and stops them from dividing and growing.

You can have trastuzumab every 3 weeks as a drip (infusion), or as a small injection under the skin. It can be given:

- with pertuzumab and chemotherapy drugs, such as docetaxel (Taxotere[®])
- with chemotherapy drugs, such as paclitaxel (Taxol[®]), docetaxel, vinorelbine (Navelbine[®]) or capecitabine (Xeloda[®]).

Side effects of trastuzumab are often mild. You may have:

- flu-like symptoms
- diarrhoea
- headaches.

Some women may have an allergic reaction, but this is less common. Trastuzumab may also cause changes to the way the heart works. You will have tests to check your heart before and during treatment. If it causes any problems, your cancer doctor may prescribe drugs to treat these. Or, they may advise you to stop taking trastuzumab for a while.

If the cancer spreads to the brain or spinal cord (central nervous system), you usually continue taking trastuzumab. Your cancer doctor may also give you other drug treatments or radiotherapy to control the cancer in the central nervous system (CNS).

Pertuzumab

Pertuzumab is another targeted therapy drug that attaches to the HER2 protein (receptor). But, it attaches to a different part from trastuzumab.

Pertuzumab is usually given with trastuzumab and the chemotherapy drug docetaxel. If you have not had a targeted therapy drug or chemotherapy before, this may be given as a first treatment. You have it as a drip every 3 weeks. Side effects include:

- increased risk of infection
- skin changes
- joint and muscle pain
- diarrhoea.

Pertuzumab may also affect the heart. You will have tests to check your heart during and after treatment.

Trastuzumab emtansine

Trastuzumab emtansine (Kadcyla®) is trastuzumab with the chemotherapy drug emtansine attached to it. Trastuzumab targets and delivers the chemotherapy to the cancer cells. You have it as drip every 3 weeks. It may be given after you have previously had treatment with trastuzumab, docetaxel or paclitaxel, either separately or together.

Side effects of trastuzumab include:

- low white blood cells, which increase the risk of infection
- low platelet cells, which increase the risk of bleeding
- low red blood cells, which can make you tired (anaemia)
- sore mouth
- diarrhoea.

Triple negative breast cancer

Triple negative breast cancer is breast cancer that does not have receptors for HER2 or for hormones. Different targeted therapy drugs may be used in clinical trials to treat triple negative breast cancer.

Olaparib (Lynparza[®]) is a targeted therapy drug called a PARP inhibitor. PARPs are proteins that help damaged cells repair themselves.

Olaparib blocks (inhibits) how PARP proteins work in cancer cells that have a change (mutation) in the BRCA1 or BRCA2 gene. This is more common in triple negative breast cancer. You take olaparib as a tablet. Side effects of olaparib include:

- feeling sick
- diarrhoea
- tiredness.

Having radiotherapy



Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is used to relieve pain and other symptoms when breast cancer has spread to the bones, skin or brain.

Radiotherapy is usually given as a series of short, daily treatments, Monday to Friday. You have it in the hospital radiotherapy department. Each treatment will only take a few minutes. You may only need 1 session, or a few sessions, of treatment. Radiotherapy is not painful, but during treatment you have to lie in a position that may be uncomfortable. Your cancer doctor may suggest that you take a painkiller half an hour before having radiotherapy to help with this.

Radiotherapy does not make you radioactive. It is perfectly safe to be with other people, including children, after treatment. If you have any questions about radiotherapy, you can ask your cancer doctor or the staff in the radiotherapy department.

Side effects of radiotherapy

You may have some mild side effects of radiotherapy.

The main side effect is tiredness (fatigue). This sometimes lasts for a few weeks after treatment finishes. Other side effects depend on the area of your body being treated and how much radiotherapy you have.

Always tell your specialist nurse or radiographer about any side effects. There are usually ways in which they can be treated or managed. Side effects stop or improve gradually when treatment finishes. See our booklet **Coping with fatigue** (see page 114).

Radiotherapy to the bones

Radiotherapy can:

- shrink a secondary cancer in the bone
- strengthen the bone
- reduce pain.

It may take 3 to 4 weeks before treatment works, so you will need to carry on taking painkillers during this time. Some people find the pain feels worse for a few days before it starts to improve. Your cancer doctor may prescribe steroid tablets to help with this (see pages 70 to 71).

Feeling very tired is a common side effect. This should slowly improve a few weeks after treatment finishes. Try to pace yourself and get as much rest as you need. It helps to balance this with some gentle exercise, such as short walks, if possible.

If the area treated is close to your tummy, for example the ribs or spine, you may feel sick. Your cancer doctor can prescribe anti-sickness drugs to control any sickness.

Radiotherapy to the pelvis can sometimes cause diarrhoea. Your cancer doctor can prescribe anti-diarrhoea drugs to control this.

You can find out more in our **Understanding secondary cancer in the bone** booklet (see page 114).

Spinal cord compression

Doctors can also give a short course of radiotherapy to the spine. This is used when a tumour is close to, or pressing on, the spinal cord. This is called spinal cord compression (see page 78).

It can cause different symptoms such as pain in the back or around the chest, and difficulty walking. Spinal cord compression is not common, but needs to be treated quickly to prevent permanent damage to the nerves.

Radiotherapy to the brain

Radiotherapy can help shrink and improve the symptoms of a secondary cancer in the brain. You may have up to 2 weeks of treatment.

Radiotherapy to the brain can cause some hair loss, but this is usually temporary. Your hair should start to grow back a few months after the treatment has finished, but it can sometimes remain patchy. This is caused by different doses of radiotherapy being used on different parts of the brain. The skin on your scalp may also become dry and feel irritated. Your specialist nurse or radiographer (person who gives you the radiotherapy) will give you advice on looking after the skin.

You may feel very sleepy or drowsy for a few weeks. Tiredness can continue for weeks or months after treatment. Get plenty of rest but try to take regular short walks to give you more energy.

Radiotherapy to the brain may make you feel sick or be sick. Your cancer doctor can prescribe anti-sickness tablets or steroids to control this.

Sometimes a type of radiotherapy called stereotactic radiotherapy is used to treat small brain tumours. But it is only available in some specialist hospitals and is not suitable for everyone. It uses high doses of radiation which are targeted directly at the tumour. This causes less damage to surrounding tissue.

We have a booklet called **Understanding radiotherapy** that we can send you (see page 114).

Surgery

Surgery is not usually used to treat secondary breast cancer. This is because the cancer is usually in more than one area. But it is sometimes used in certain situations.

Surgery to strengthen a weakened bone

If a secondary breast cancer has weakened a bone, usually in the hip or leg, you may need an operation to strengthen it.

You have the operation under a general anaesthetic. The surgeon puts a metal pin into the centre of the bone and may fix a metal plate to it. The pin and plate stay in permanently. It holds the bone in place and prevents it from breaking.

If one of your hip joints has been affected by the cancer, you may have surgery to replace the joint. Surgery is also sometimes used to treat secondary breast cancer that has spread to the spine.

You have to stay in hospital for a week or longer after the operation so you can recover fully. But most women can get up and start walking 2 days after surgery. You usually have radiotherapy to the bone afterwards.

We have a booklet called **Understanding secondary cancer in the bone** that you may find helpful (see page 114).

Liver surgery

Sometimes, it may be possible to remove a small cancer in a single area of the liver. This is major surgery that is done by a specialist liver surgeon.

Another treatment called radiofrequency ablation may be used instead of surgery, but this is not a standard treatment. The cancer doctor places needles in the liver tumours. Heat from a laser or microwave is then passed through the needle directly into the tumour to destroy cancer cells.

We have more information in our **Understanding secondary cancer in the liver** booklet (see page 114).

Brain surgery

Some people may be able to have surgery to the brain. This is usually if there is only a single tumour in the brain. The tumour must also be in an area where it is possible to operate.

You will be referred to a specialist brain surgeon (neurosurgeon) to assess whether surgery is possible. The surgeon and specialist nurse will tell you what to expect before and after your operation. You will usually be in hospital for at least a week.

Your cancer doctor will prescribe steroids to reduce the swelling around the tumour and improve your symptoms. You take them before your operation and for a few weeks afterwards, depending on your symptoms. You usually have radiotherapy to the brain after you have recovered from the operation (see page 65).

Bone-strengthening drugs

If you have secondary breast cancer that has spread to the bones, you may be given bone-strengthening drugs.

Bisphosphonates and a targeted therapy called denosumab are drugs that strengthen the bones. They also relieve bone pain and reduce the risk of a broken bone (fracture). Your cancer doctor may prescribe these to reduce the risk of developing further problems.

Bisphosphonates can also be used to treat high levels of calcium in the blood (hypercalcaemia) – see page 77. You usually have bisphosphonates as a drip (infusion) or as tablets. The main bisphosphonates used include:

- zoledronic acid (Zometa®) – this is given as a drip every 3 to 4 weeks
- pamidronate (Aredia®) – this is given as a drip every 3 to 4 weeks
- ibandronate (Bondronat®) – this is given as a tablet once a day, or as a drip every 3 to 4 weeks.

A type of monoclonal antibody called denosumab (Xgeva®, Prolia®) can also help strengthen your bones. You have it as an injection under the skin every 4 weeks.

Side effects

Your cancer doctor or specialist nurse will explain the possible side effects. These will depend on the type of drug you have. Always tell them about any side effects you have or if you develop any new symptoms.

Side effects of bisphosphonates

The side effects of bisphosphonates are usually mild. They can include:

- feeling sick
- headaches
- flu-like symptoms, such as chills and muscle aches
- diarrhoea
- constipation
- heartburn.

If you have bisphosphonates by drip, you may find the pain in your bones get worse for a short time. Your cancer doctor can prescribe painkillers until this wears off.

Find out more about each drug on our website (see page 114).

Side effects of denosumab

The side effects of denosumab are usually mild. They can include:

- diarrhoea
- skin rashes
- pain in the muscles and joints.

Jaw problems

Very rarely, bone-strengthening drugs can damage the bone in the jaw (osteonecrosis). Tell your cancer doctor straight away if you have any problems with your teeth or jaw.

Your cancer doctor will ask you to have a dental check-up before starting treatment with bone-strengthening drugs. Having dental treatment or dental problems can increase the risk of osteonecrosis of the jaw. Always tell your dentist you are taking bone-strengthening drugs.

Steroids

You may have steroids as part of your treatment. Steroids are used help control symptoms and help you to feel better.

Steroids may be given:

- with certain chemotherapy drugs to prevent an allergic reaction or to reduce sickness
- to reduce swelling and control pain when there is a secondary cancer in the liver
- to reduce pressure and relieve headaches and sickness when there is a secondary cancer in the brain
- to improve appetite and energy levels, although this is usually for a short time.

Side effects of steroids

Steroids are usually only given for short periods of time. This means that the side effects are less likely to be a problem. Possible side effects include:

- indigestion or heartburn – taking your steroids with food as prescribed should help
- having more energy or feeling restless – let your cancer doctor or specialist nurse know if this is a problem
- difficulty sleeping – try taking your steroids earlier in the day
- increased appetite and weight gain – talk to your specialist nurse or a dietician if you are concerned about this
- a higher blood sugar level – you may have blood or urine tests to check for this.

Sometimes steroids are given in high doses. The dosage is gradually reduced after treatment with radiotherapy or chemotherapy. Having higher doses of steroids for a longer period of time may cause more side effects. These can include:

- mood swings
- weight gain
- swollen feet or legs, because of fluid retention
- an increased risk of infection
- bruising easily
- an increased risk of diabetes, or if you already have diabetes your sugar levels may be harder to control.

Talk to your cancer doctor or specialist nurse if you are concerned about side effects you are having.

We have more information about steroids on our website (see page 114).

Managing symptoms

The symptoms of secondary breast cancer are usually helped with cancer treatment. Sometimes this works quickly and you may notice an improvement within a few days. But sometimes it may take a few weeks before you feel better.

But there are also lots of other ways to control and manage symptoms. Always let your doctor or specialist nurse know if you have new symptoms or if your symptoms get worse.

Many hospitals have doctors and nurses who are experts in treating pain and other symptoms. They are sometimes called supportive or palliative care specialists.

There are different symptoms, and many of them depend on where the cancer has spread to. You will not get all the symptoms mentioned here. Some women get very few symptoms.

'I think it just takes some time to adjust to what and how you do things and listen to your body. We are just always so busy and used to what we could do before.'

Nj

Tiredness

Feeling very tired (fatigue) is a common symptom. Treatments may help improve tiredness. You are likely to be tired during treatment and for a while afterwards. But this should slowly improve. Make sure you get enough rest. But it can help to try to balance this with some physical activity.

Sometimes tiredness is caused by a low number of red blood cells. This is called anaemia. Your doctor can do a blood test to check this. They may prescribe drugs to treat anaemia. You may need to have a blood transfusion.

We have a booklet called **Coping with fatigue** that might be helpful (see page 114).

Feeling sick

Your doctor can prescribe different anti-sickness drugs. You usually take them by mouth. But they can also be given as a skin patch, suppositories, or injections under the skin. Remember to:

- take your anti-sickness drugs as prescribed – this is usually about 20 to 30 minutes before meals
- let your doctor or specialist nurse know if the drug you are taking is not working, so they can prescribe a different one.

Constipation

This can be caused by some chemotherapy drugs, anti-sickness drugs and, often, by painkillers. Your doctor can prescribe a medicine called a laxative to stimulate the bowel.

Things you can do to help are:

- eat more fibre
- drink plenty of fluids
- be more physically active if you can – for example, go for short, regular walks.

Lymphoedema (swelling of the arm)

You may develop lymphoedema as a result of treatments or because the cancer is blocking lymph nodes in the armpit. There are effective ways of reducing the swelling and managing lymphoedema. These include:

- wearing a special sleeve
- massage
- bandaging your arm.

If you notice any swelling in your arm or hand, always let your doctor or specialist nurse know as soon as possible.

We have a booklet called **Understanding lymphoedema** that has more information (see page 114).



Pain

There are many different painkillers. The painkiller you have will depend on the type of pain you have. You may need a combination of drugs.

You usually have painkillers by mouth. But they can also be given as a skin patch, suppository (put into the back passage) or an injection into the skin.

It is important to:

- take your painkillers regularly, to give you constant pain control
- let your doctor or specialist nurse know if the painkillers are not controlling your pain.

Radiotherapy is very effective at treating bone pain if the cancer has spread to the bones. Bone-strengthening drugs can help to reduce bone pain.

Steroids are used to reduce swelling and control pain. We have more information about controlling pain.

Treating bone pain

If breast cancer has spread to the bones and is causing pain, there are different ways it can be controlled. You may be given:

- drugs called non-steroidal anti-inflammatory drugs (NSAIDs)
- bone-strengthening drugs called bisphosphonates or denosumab
- a single session or short course of radiotherapy.

Radiotherapy is very effective at treating bone pain but can take a few weeks to work. Take your painkillers regularly until the radiotherapy works. Find out more in our **Managing cancer pain** booklet (see page 114).

Treating bone problems

In some women, secondary breast cancer in the bone may cause problems that need treatment. There are ways in which they can be managed.

Strengthening a weakened bone

If there is a risk of a bone breaking, your doctor may advise having surgery to strengthen or repair the bone. This is done under a general anaesthetic. You may have radiotherapy before or after surgery. This can help repair the bone or try to get rid of any cancer cells.

Too much calcium in the blood (hypercalcaemia)

Secondary cancer in the bone can cause calcium to go from the damaged bone into the blood. If you have high levels of calcium in the blood, you may:

- feel very tired and thirsty
- pass lots of urine (pee)
- feel sick
- be irritable and confused.

Tell your doctor or specialist nurse if you have these symptoms.

Your specialist nurse or doctor will give you a drip (infusion) of fluids to flush the extra calcium from your body. They also give you bisphosphonates as a drip to lower the calcium levels. Your symptoms should go away within 2 days.

Spinal cord compression

Spinal cord compression is not common, but it is very important that it is diagnosed quickly. It can happen when the cancer grows in, or near to, the spine and presses on the spinal cord and nerves.

Symptoms of spinal cord compression can include:

- unexplained pain in the back, around the chest, neck, or down the arm or legs
- numbness or pins and needles in toes, fingers or buttocks
- unsteadiness or difficulty walking
- problems controlling your bladder or bowel.

It is important to let your cancer doctor or specialist nurse know immediately if you have any of these symptoms. The earlier treatment starts, the more likely it is to be effective. Steroids, radiotherapy and surgery may all be used, depending on your situation. Your doctor or specialist nurse will give you more information. You can also find out more on our website (see page 114).

Breathlessness

There are different things that can cause breathlessness. Tell your doctor or specialist nurse if this happens.

Sitting down when you are doing everyday things such as washing, dressing or making food can help you to manage breathlessness. There are also controlled breathing or relaxation techniques that can help.

We have a booklet called **Managing breathlessness** that we can send you (see page 114).

Pleural effusion

If cancer cells spread to the lining of the lungs (pleura), it can cause fluid to build up. This is called a pleural effusion. It can make you breathless. Your doctor can treat this by passing a narrow tube into your chest to drain off the fluid. This usually improves your breathing straight away. If it comes back, the fluid can usually be drained again. It may be possible to have a special catheter put in that allows you to drain the fluid into a bottle while you are at home. You can find more information about pleural effusion on our website (see page 114).

Pleurodesis

To stop fluid build-up, your doctor may recommend a treatment that seals the two layers of the pleura together. This is called a pleurodesis. You will need to have a short stay in hospital.

You usually have it done during a CT scan. You have a tube put into your chest to drain the fluid. The doctor injects sterile talcum powder through the same tube. This helps seal the layers of the pleura together.

A pleurodesis can also be done using a procedure called video-assisted thoracoscopic surgery (VATS). You need to stay in hospital for a few days to have this. A specialist lung doctor makes 1 or 2 small cuts and puts a flexible tube into your chest. This is called a thoracoscope. The tube has a light and camera at the end, so the doctors can see into your chest. They drain any fluid and then spray sterile talcum powder through the tube.

After a pleurodesis, you usually have a chest drain in place until any remaining fluid has been removed. You can usually go home when it has been removed.

Build-up of fluid in the tummy (ascites)

Ascites is a build-up of fluid between the two layers of the peritoneum. This is a membrane that lines the tummy (abdomen). It can be caused by cancer that has spread to the liver or to the peritoneum. Ascites causes the tummy to swell, which can make you feel full, breathless or sick.

To treat ascites, doctors usually make a small cut in the tummy and insert a tube to drain the fluid. This will quickly improve your symptoms. You can have it done again if the fluid builds up again. It may be possible to have a catheter put in that allows you to drain the fluid while you are at home.

Treating symptoms of a secondary brain tumour

A secondary brain tumour can cause different symptoms, such as headaches or weakness in an area of the body. These can be frightening, but the symptoms can often be controlled with:

- drugs called steroids, that reduce swelling in the brain caused by a tumour
- a course of radiotherapy to the head or sometimes a specialised type of radiotherapy called stereotactic radiotherapy.

Radiotherapy can often improve symptoms quickly. You can also have drugs to treat headaches or to control fits (seizures) if needed.

We have more information about secondary brain tumours on our website (see page 114).

Complementary therapies

Some women find using certain complementary therapies alongside their medical treatments helps them to feel better. This may include:

- relaxation therapies
- visualisation
- yoga.

Some complementary therapies may help reduce treatment side effects or symptoms. They may also make you feel less anxious. Always let your cancer specialist know if you are having any complementary therapies, as some may interact with chemotherapy or other treatments. This includes complementary therapies that involve taking supplements or other medicines.

We have a booklet called **Cancer and complementary therapies** that you may find helpful (see page 114).



AFTER TREATMENT

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Clinic visits

You will see your cancer doctor or specialist nurse regularly during and after treatment. This helps make sure any problems can be managed during ongoing treatment. How often this is will depend on your treatment plan. For example, after a course of chemotherapy, your clinic visits will be less often.

You have regular scans or x-rays to check how the cancer is responding to treatment. If you notice new symptoms between appointments, contact your cancer doctor or specialist nurse.

Appointments are a good opportunity for you to talk to your cancer doctor or specialist nurse about any concerns you have.

It is natural to get anxious before appointments. It may help to get support from family, friends or one of the support organisations we have listed on page 119 to 124.

'I have regular checks and will have treatment for the rest of my life. It is a strange thought that this is not something they can cure. I am still accustoming to that.'

Bianca

Living with secondary breast cancer

Coping with secondary breast cancer is both physically and emotionally demanding. But many women are now living longer and better lives with treatment. There may be long periods when the cancer is under control and you can get on with living your day-to-day life. It is important to take care of yourself and get support.

'I try not to wallow, but the enormity of the situation does get to you sometimes, and you have to ride it out. Allow yourself 'off' days, but try to keep busy.'

Annette

Get enough rest

When you are coping with symptoms or recovering from treatments, you use up more energy. This means that getting enough rest is important. Try to:

- get a good night's sleep
- ask family and friends to help with things around the house and the shopping
- pace yourself and save energy for the things you want to do.

Keep physically active

If you can, take regular, short walks. This will:

- give you more energy
- reduce stress
- help you sleep better.

Walking helps look after your bones. This is important if you have had an early menopause or are taking aromatase inhibitors, as they increase the risk of bone thinning. You can try to slowly increase the amount you do. But be careful not to overdo it. You can find out more information in our **Bone health** booklet (see page 114).

Being more active can also help look after your heart. We have a booklet called **Physical activity and cancer treatment** that has more information about keeping active (see page 114).

You can ask your cancer doctor, GP or specialist nurse for advice about the type and amount of physical activity that is right for you.

Eat healthily

This can improve your general health and you will feel better and have more energy. Eating well can also help you manage any weight gain you may have had during treatment.

Try to eat:

- plenty of fruit and vegetables a day
- more chicken and fish (especially oily fish)
- less red and processed meat
- more high-fibre foods.

Even if you have lost your appetite, try to keep eating well with regular snacks. There are different supplement drinks to help make sure you get enough calories and nutrients. Some of these are available on prescription.

Your cancer doctor or specialist nurse can refer you to a dietitian if you need more advice.

We have booklets called **Healthy eating and cancer** and **Eating problems and cancer**, which has useful tips on eating difficulties (see page 114).

Sex life

Your sex life may be affected by cancer and its treatment. This can happen because of the physical and emotional effects of cancer and its treatment. You may feel too tired or anxious to have sex. Even if you do not feel like having sex, there are intimate and affectionate ways of showing how much you care for someone.

As you recover from treatment, your sex drive may slowly improve. If symptoms or side effects of treatment are causing problems during sex, controlling these may help to improve things.

If you have a partner, you may both need time after treatment to adjust. But having secondary breast cancer does not mean that sex cannot be a part of your life.

Talking openly about any difficulties or concerns about your sex life may help sort out any misunderstandings. For example, it may reassure your partner that sex will not harm you or make the cancer worse. Or that they cannot catch the cancer by having sex.

Ask your cancer doctor or specialist nurse for advice if you are having problems with your sex life. Some people may find it helpful to talk to a sex therapist. You can contact a therapist through the College of Sexual and Relationship Therapists (see page 122).

You may find our **Cancer and your sex life - information for women** booklet useful (see page 114).

Contraception

Your cancer doctor or specialist nurse may advise you not to use contraception that contains hormones. This includes the pill or coil (intra-uterine device), which both release a progestogen hormone. Non-hormonal coils or barrier contraception, such as condoms or the cap, are the most suitable. Your cancer doctor, specialist nurse or GP can give you advice.



Early menopause and menopausal symptoms

Chemotherapy can affect the ovaries and cause an early menopause. Hormonal treatments can also cause a temporary menopause or menopausal symptoms.

Doctors do not usually advise taking hormone replacement therapy (HRT). This is because it contains oestrogen, which may encourage breast cancer cells to grow. Some cancer doctors may prescribe HRT if your symptoms are severe and other drugs have not helped. It is important to talk this through with your cancer doctor or specialist nurse so you understand the possible risks and benefits.

We have more information on breast cancer and menopause on our website (see page 114).

Hot flushes and sweats

Low doses of antidepressants, such as paroxetine and fluoxetine, can reduce hot flushes. You should not take these if you are taking tamoxifen. This is because antidepressants can affect how tamoxifen works. An antidepressant called venlafaxine can be given instead.

Vaginal dryness

Non-hormonal creams and water-based lubricants can help reduce discomfort from vaginal dryness during sex.

There are also pessaries and creams that contain a small amount of oestrogen, which may be prescribed in low doses. Many breast specialists think only a very small amount of oestrogen from the creams and pessaries are absorbed by the body. This makes them safe to use in small doses. Talk about this with your cancer doctor first.

Infertility

Becoming infertile can be very hard for some women to cope with, whether they already have children or not.

Some women may find it helpful to talk through their feelings with a trained counsellor. If you need more specialised help, your cancer doctor can arrange this for you.

Other effects

Menopausal symptoms can also include:

- a low sex drive
- mood swings
- difficulties with concentration or memory.

There are different ways to manage menopausal symptoms.

Emotional support

You are likely to have different feelings to cope with, as well as managing any symptoms, and your treatment. You may also be worried about practical issues, such as work or finances.

It is important to get the support you need during treatment. You can get support from:

- your healthcare team
- your partner, if you have one
- family
- friends
- support groups.

Try to be open about how you are feeling. Tell your cancer doctor or specialist nurse about any concerns you have, or if you think you may be depressed or are very anxious. They can support you or advise you on getting more help.

'You will eventually accept who you have become. Always ask for help when you need it, whether it is physical or emotional.'

Annette

Some women find it helpful to talk to someone experienced in helping people with cancer with their emotional problems. This may be a counsellor or psychologist. Your cancer doctor or specialist nurse can usually arrange this.

Support groups

Self-help or support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges as you. You can call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** for information about cancer support groups across the UK.

Online support

Many people now get support through the internet. There are online support groups, social networking sites, forums, chatrooms and blogs for people affected by cancer. You can use these to ask questions and share your experience.

Our Online Community at **macmillan.org.uk/community** is a social networking site where you can talk to people in our forums, blog your journey, make friends and join support groups.

Breast cancer is less common in younger women. If you are diagnosed with secondary breast cancer at a young age, then coping with uncertainty about your future can be very hard. Talking with other younger women in a similar situation may help you to feel less isolated.

Breast Cancer Care have different services specifically for women under the age of 45. This includes events and a private Facebook page where you talk to other women going through the same thing.



YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects.

It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need. Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail (see page 114). It also has suggestions for coping with them.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our online community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping. If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking to someone who has cancer** has more suggestions if you have a friend or relative with cancer (see page 114). If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful (see page 114). It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)



Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

You may worry about how to talk to your children about having secondary breast cancer and the future. We have information about talking to children and teenagers when the cancer is advanced. You might find our booklet **Talking to children and teenagers when an adult has cancer** useful (see page 114).

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.



WORK AND FINANCIAL SUPPORT

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Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 114). Our Online Community forum **Travel insurance** may also be helpful. Visit [macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 123).

Our booklet **Help with the cost of cancer** has lots more information (see page 114).



Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 114). There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 114).



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About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Breast cancer organisations

Asian Women Cancer Group

Tel 07934 591384

Email info@asianwomenscancergroup.co.uk

www.asianwomenscancergroup.co.uk

Helps women of all cultures who have been affected by breast cancer. Provides the support women may need, from emotional support to financial guidance.

Breast Cancer Care

Helpline 0808 800 6000

(Mon to Fri, 9am to 5pm, Sat, 10am to 1pm)

Textphone 0808 800 6001

Email info@breastcancercare.org.uk

www.breastcancercare.org.uk

Provides information, practical help and emotional support for anyone affected by breast cancer. Specialist breast care nurses run the helpline. Also offers a peer support service where anyone affected by breast cancer can be put in touch with a trained supporter who has had personal experience of breast cancer.

Breast Cancer Care Scotland and Northern Ireland

Tel 0345 077 1893

Email movingforward@breastcancercare.org.uk

Breast Cancer Care Wales

Tel 0845 077 1893

Email movingforward@breastcancercare.org.uk

Breast Cancer Haven

Tel 020 7384 0000 (London)

Email info@thehaven.org.uk

www.breastcancerhaven.org.uk

Havens are day centres providing support, information and complementary therapies before, during or after cancer treatment. They have a network of centres around the UK. Details of other UK Haven centres are on the website.

Breast Cancer Now

Tel 0333 20 70 300

(Mon to Thu, 9am to 5pm, and Fri, 9am to 4pm)

Email supporterengagement@breastcancer.org

www.breastcancer.org

Committed to fighting breast cancer through research and awareness.

Breast Cancer Now – Scotland

Tel 0131 226 0763

Email scotland@breastcancer.org

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151

Email info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus

Northern Ireland

Helpline 0800 783 3339

(Mon to Fri, 9am to 1pm)

Email nurseline@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

Email info@cancer

supportscotland.org

**www.cancersupport
scotland.org**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Irish Cancer Society**Tel** 1800 200 700

(Mon to Fri, 9am to 5pm)

Email cancernurseline@

irishcancer.ie

www.cancer.ie

Has a freephone cancer helpline staffed by nurses trained in cancer care.

You can also chat to a nurse online and use the site's message board.

Maggie's Centres**Tel** 0300 123 1801**Email** enquiries@

maggiescentres.org

www.maggiescentres.org

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK**Helpline** 0303 3000 118

(Mon to Fri, 9.30am to 5pm)

Email helpline@penny

brohn.org.uk

www.pennybrohn.org.uk

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline 0808 808 1010

(Daily, 8am to 8pm)

Email info@tenovuscancer.org.uk

www.tenovuscancer.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodto talk.org.uk**

College of Sexual and Relationship Therapists

Tel 020 8543 2707

Email info@cosrt.org.uk

www.cosrt.org.uk

Has a directory of therapists to help members of the public find professional support in their local area.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030

(Mon to Fri, 10am to 10pm, and Sat, 10am to 6pm)

Email helpline@lgbt.foundation

www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling.

The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Tel 0800 220 674

(Mon to Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

Textphone 028 9031 1092

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Details for your local office can be found in the phone book or on one of the following websites:

England and Wales

Helpline 03444 111 444

www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060

www.cas.org.uk

Wales

Helpline 03444 77 2020

www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1181

www.citizensadvice.co.uk

Department for Work and Pensions (DWP)

Disability Living Allowance

Helpline 0345 712 3456

Textphone 0345 722 4433

Personal Independence

Payment Helpline 0345 850 3322

Textphone 0345 601 6677

Carer's Allowance Unit 0345 608 4321

Textphone 0345 604 5312

www.gov.uk/browse/benefits

Manages state benefits in England, Scotland and Wales.

You can apply for benefits and find information online or through its helplines.

**Personal Finance Society –
'Find an Adviser' service**

Tel 020 8530 0852

**www.thepfs.org/yourmoney/
find-an-adviser**

Use the website to find qualified financial advisers in your area.

Support for carers

Carers UK

**Helpline (England, Scotland,
Wales)** 0808 808 7777

(Mon and Tue 10am to 4pm)

Helpline (Northern Ireland)

028 9043 9843

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK.

Can put people in contact with support groups for carers in their area.

**Advanced cancer and
end-of-life care**

**Marie Curie Cancer Care
Helpline** 0800 090 2309

(Mon to Fri, 8am to 6pm
and Sat, 11am to 5pm)

Email supporter.services@
mariecurie.org.uk

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editors; Dr Rebecca Roylance, Consultant Medical Oncologist, Professor Mike Dixon, Professor of Surgery & Consultant Surgeon; and Dr Russell Burcombe, Consultant Clinical Oncologist.

With thanks to: Morven Angus, Lead Breast Clinical Nurse Specialist; Dr Sophie Barrett, Consultant Medical Oncologist; Dr RB Mukesh, Consultant Clinical Oncologist; Catherine Richmond, Therapy Radiographer; Claire Ryan, Macmillan Nurse Clinician Metastatic Breast Cancer; Richard Simcock, Consultant Clinical Oncologist; and Dr Virginia Wolstenholme, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories. We welcome feedback on our information. If you have any, contact [**cancerinformationteam@macmillan.org.uk**](mailto:cancerinformationteam@macmillan.org.uk)

Sources

We have listed an example of a source used in the booklet below. If you'd like further information about the sources we use, please contact us at [**cancerinformationteam@macmillan.org.uk**](mailto:cancerinformationteam@macmillan.org.uk)

National Institute for Health and Clinical Excellence (NICE). www.nice.org.uk Pathways Advanced Breast Cancer. Updated 2017 (accessed November 2017)

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money

Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Date / / _____

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

This booklet is about secondary breast cancer. It is for anyone who has been diagnosed with secondary breast cancer. There is also information for family members and friends.

The booklet explains the signs and symptoms of secondary breast cancer and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

**MACMILLAN
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RIGHT THERE WITH YOU**

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