

# Understanding secondary breast cancer



This booklet is about secondary breast cancer. It talks about the signs and symptoms of secondary breast cancer. It explains how it is diagnosed and how it may be treated.

The booklet has information about feelings, practical issues and money. There is also information for carers, family members and friends of people with secondary breast cancer.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call <u>0808 808 00 00</u> or visit <u>macmillan.org.uk</u> 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 <u>18001 0808 808 00 00</u>, or use the NGT Lite app.

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



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# About this booklet

This booklet is about secondary breast cancer. This is breast cancer that has spread to another part of the body.

The booklet is for women who have been diagnosed with secondary breast cancer. We have separate information for men with secondary breast cancer <u>on our website</u>.

If you are transgender (trans) or non-binary, you may find this booklet or the information on our website helpful. We also have specific information for trans and non-binary people about cancer on our website. Visit <u>macmillan.org.uk/trans-and-non-binary</u>

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. People 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 this booklet 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

This 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 <u>contents list</u> to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready. On pages <u>136 to 147</u>, there are details of other organisations that can help. There is also space to write down <u>questions and notes</u> for your doctor or nurse.

### Quotes

In this booklet, we have included quotes from people who have had secondary breast cancer, which you may find helpful. These are from people who have chosen to share their story with us. This includes Lesley, who is on the cover of this booklet. To share your experience, visit <u>macmillan.org.uk/shareyourstory</u>

## For more information

We have a separate booklet about early or primary breast cancer called <u>Understanding primary breast cancer</u>. You may find this information helpful. We have <u>web pages for men with breast cancer</u>. We also have <u>information about cancer for people who are trans</u> <u>or non-binary</u>.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on <u>0808 808 00 00</u>, 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.

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# About secondary breast cancer

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# What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal.

These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

### Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid, which is part of <u>the lymphatic system</u>.

When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

# The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

### The lymphatic system



# 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. We have more information in our booklet <u>Understanding primary breast cancer</u>.

For many people, primary breast cancer never comes back after treatment. But sometimes cancer cells spread to other parts of the body through the blood or <u>the lymphatic system</u>.

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 people recently diagnosed with primary breast cancer also have a secondary cancer. This can be found through <u>tests and</u> <u>scans</u>.

Sometimes secondary breast cancer can be the first diagnosis of breast cancer.

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

- bones
- lungs
- liver
- brain
- skin.

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
- tissue that covers the brain and spinal cord (meninges)
- ovaries
- lining of the abdomen (peritoneum).

This is less common. If you need more information about this, you can call our cancer support specialists on <u>0808 808 00 00</u>.

### Local and regional recurrences

Sometimes breast cancer comes back in the treated breast or the scar. This is called a local recurrence. Sometimes breast cancer comes back in the lymph nodes in the armpit, close to the breastbone or in the lower neck. This is called a regional recurrence.

A local or regional recurrence can occur on its own or at the same time as secondary breast cancer.

Your cancer doctor usually recommends you have <u>tests or scans</u>. This is to check to see if the cancer has spread further.

If the cancer has not spread anywhere else in the body, treatment will depend on a number of factors, including what treatment you had before. We have more information in our booklet <u>Understanding</u> <u>primary breast cancer</u>.



# Signs and symptoms

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

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

We have more information on how these symptoms may be managed.

### **General symptoms**

You may have some general symptoms. These can include:

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

# In 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 <u>hormonal therapy</u> or the menopause. But it is important to tell your cancer doctor if your symptoms continue.

For more information, visit <u>macmillan.org.uk/menopausal-symptoms</u>

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

If you have secondary breast cancer in the bones, you 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 is called hypercalcaemia. It can cause symptoms such as:

- feeling very tired and thirsty
- feeling sick (nausea)
- passing more urine (pee) than usual
- constipation
- feeling confused.

Doctors can see an increase in calcium levels in a blood test before symptoms develop.

#### 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 in the spine, it may cause pressure on the spinal cord. This is called spinal cord compression (<u>page 94</u>).

Symptoms can include:

- unexplained pain in the back, neck, or down the arms and legs
- pain that may feel like a tight band around your body
- numbness or pins and needles in your arms, legs, toes, fingers, back, chest, tummy or buttocks
- a weakness in the arms or legs
- unsteadiness or difficulty walking
- problems controlling your bladder or bowel.

If you have any of these symptoms, it is very important to tell your cancer doctor or specialist nurse straight away. If spinal cord compression is diagnosed quickly, doctors can start treatment to prevent permanent damage to the spinal cord.

# In the lungs

The first symptom of a secondary cancer in the lungs may be:

- a cough that does not get better
- feeling breathless.

If cancer cells are in the tissues that cover the lungs (the pleura), it can lead to irritation. This causes fluid to build up and press on the lungs, making you breathless. This is called a <u>pleural effusion</u>.

## In the liver

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

Other symptoms can include:

- feeling sick (nausea)
- 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.

# In 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.

#### The meninges

Sometimes breast cancer cells spread to tissue that covers the brain and spinal cord. This tissue is called the meninges.

If cancer spreads to the meninges, it is called meningeal metastases or carcinomatous meningitis. It causes symptoms similar to secondary cancer in the brain or spinal cord compression.

# On or just below the skin

Secondary breast cancer can sometimes develop on or just below the skin.

Secondary cancer that affects the skin may be either:

- a firm painless lump on the skin
- many lumps of different sizes on the skin these are called skin secondaries
- an area of skin that is red, darker or 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 on other areas of skin, such as the scalp, neck, back and upper limbs.



# Diagnosing secondary breast cancer

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# How secondary breast cancer is diagnosed

If you have a new symptom, tell your GP, cancer doctor or specialist nurse. They will arrange tests or scans. These can be used to find out if there is a secondary cancer.

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

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

# **Blood tests**

Blood tests cannot diagnose secondary breast cancer. But they may show that you need further tests. You may have blood tests to:

- 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.

Tumour markers are proteins some cancers produce. The levels of them in your blood may be raised if you have cancer. But measuring them is not always reliable. Your doctor can tell you whether measuring tumour markers is helpful in your situation. "Macmillan has been there for me right from the start. As soon as I was diagnosed, my cancer nurse was there to provide information and point me in the right direction for help. At the time when I was most vulnerable, she was there to guide me through. And she is still here for me, at the end of the phone. "

Nicky, diagnosed with secondary breast cancer

"I developed pain in my right shoulder and it began to get a lot worse. I was having some physio but with no improvement. So I was sent for an ultrasound of the ligaments and tendons. I was in for a CT scan within a few days. I was told my pain was in fact the breast cancer cells moving to my bones.

Laura, diagnosed with secondary breast cancer

### **CT** scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan on our website. Visit <u>macmillan.org.uk/ct-scan</u>



### **Bone scan**

A bone scan looks for changes in the bones. It is more sensitive than an x-ray, as it shows any abnormal areas of bone more clearly.

#### Having a bone scan

The person who does the scan is called a radiographer. They inject a small amount of a radioactive substance through a cannula into a vein in your hand or arm. This is called a tracer. The amount of radiation used is small. It does not cause you any harm.

You need to wait for 2 to 3 hours between having the injection and having the scan. You may want to take something to help pass the time.

Areas of abnormal bone absorb more radiation than normal bone. This means the abnormal bone shows up more clearly on the scanner. The abnormal areas are sometimes called hot spots.

It is not always clear whether hot spots are caused by cancer or by other conditions, such as arthritis. Sometimes doctors also use a CT or MRI scan to help them decide. Some hospitals do an MRI scan of the whole skeleton instead of a bone scan. This is to check for signs of cancer in any other bones in the body.

#### After your bone scan

For the first 24 hours after your scan, you will be encouraged to drink plenty of fluids and pass urine (pee) often. The radiographer will explain if you need to take any precautions after the scan.

### 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 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 tissues on the outside of the lungs (the pleura). You will also usually have a <u>CT scan</u>.

# 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. They pass a small device over the area. The device is called an ultrasound probe. It gives off soundwaves. A computer changes the soundwaves into a picture.

You may have a <u>CT scan</u> of the liver rather than an ultrasound.

### **PET or PET-CT scan**

A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

If you are pregnant or breastfeeding, call the scanning department before the scan for advice.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about PET and PET-CT scans on our website. Visit macmillan.org.uk/pet-ct-scan

### **MRI scan**

An MRI scan uses magnetism to build up a detailed picture of areas of the body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about having an MRI scan on our website. Visit macmillan.org.uk/mri-scan

# **Biopsy**

A biopsy is when doctors remove a small piece of tissue or a sample of cells from an area of the body. This is then sent to be checked under a microscope. This is how doctors find out whether an abnormal area or lump (tumour) is cancerous (malignant) or non-cancerous (benign).

They can see if the cells have come from a cancer that started in the breast (primary breast cancer). A secondary breast cancer is always made up of breast cancer cells.

A biopsy gives doctors information about whether the secondary cancer has <u>receptors for hormones or for HER2</u>. These results may not be the same as for the primary breast cancer. It may mean your cancer doctor suggests different treatment.

Samples from the biopsy may be tested for gene changes, proteins or both. These results can help doctors decide which treatments may work for you. We have more information on <u>pages 38 to 40</u>.

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 scan results and symptoms. For example, you may have a biopsy taken from your lungs, liver or bone.

It is not always possible to do a biopsy. Sometimes the area is too difficult to reach. Or you may be too unwell. Your doctor will discuss this with you. If needed, they can arrange other tests instead.

#### 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 <u>CT scan</u> to help them guide the needle to the right place.

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.



# 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 to be ready. You may find it helpful to talk with your partner, your family or a close friend.

Your specialist nurse or <u>a support organisation</u> can also provide support. Or you can talk to one of our cancer support specialists on  $0808\ 808\ 00$  $00\ (7\ days\ a\ week,\ 8am\ to\ 8pm).$ 

It's so complicated, what I was going through. I felt depressed at one point. But the Macmillan Horizon Centre has been brilliant.

Lesley

# **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 into 4 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 that hormones or a protein called HER2 can attach to and encourage the cells to grow.

A doctor called a pathologist tests cancer cells for receptors. These cells are taken during a <u>biopsy</u> or surgery. The results help you and your doctor decide on the most effective treatment for you.

#### **HER2** receptors

Some breast cancer cells have too much of a certain kind of protein (receptor) called HER2. This type of breast cancer is called HER2 positive breast cancer. The extra HER2 protein encourages the cancer cells to divide and grow.

If you are diagnosed with breast cancer, you will have tests on the cancer to see if it is HER2 positive. Specific targeted therapy drugs are used to treat <u>HER2 positive breast cancer</u>. They do this by locking onto the HER2 protein to stop the cells dividing and growing.

#### Hormone receptors

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

Everyone has oestrogen in their body. But how much oestrogen your body produces can change. This depends on certain things. For example, oestrogen can be affected by your age and whether you have been through the menopause.

Breast cancers with receptors for oestrogen are called oestrogen receptor (ER) positive. The term ER is used because the American spelling of oestrogen is estrogen. Most breast cancers are ER positive. Hormonal therapy is usually used to treat ER positive breast cancer.

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.

### **Triple negative breast cancer**

Some breast cancers do not have receptors for HER2 or the hormones oestrogen and progesterone. This type of breast cancer is called triple negative breast cancer. We have more information on our website at <u>macmillan.org.uk/triple-negative-breast-cancer</u>

### Other tests before treatment

A pathologist can check cancer cells from your biopsy for certain gene changes. They can also check for certain proteins. These results help doctors plan your treatment.

For example, triple negative breast cancers can be checked for a protein called PD-L1. Drugs called <u>PD-L1 or PD-1 inhibitors</u> can then be used for this type of breast cancer.

You may be offered other tests as part of a clinical trial.

We have more information about cancer clinical trials on our website. Visit <u>macmillan.org.uk/clinical-trials</u>

# 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 <u>contact the</u> <u>cancer registry</u> in your country to opt out.




# Treating secondary breast cancer

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# **Treatment overview**

The aim of treatment for secondary breast cancer is to:

- keep the cancer under control
- improve your quality of life
- reduce the symptoms.

You may have single or combined treatments one after the other to keep the cancer under control. This is called lines of treatment. You usually have treatments in a specific order as the cancer progresses.

Your cancer doctor and specialist nurse will talk to you about your treatment options. Talk to them about what you prefer. They can also:

- help you make decisions about treatment
- offer more support if you need it
- refer you for more specialised help for coping with your emotions.

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

We have more information about cancer clinical trials on our website. Visit <u>macmillan.org.uk/clinical-trials</u>

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

- where the secondary cancer is in the body
- whether the cancer is <u>oestrogen receptor (ER) positive</u>
- whether the cancer is <u>HER2 positive</u>
- previous breast cancer treatments you have had, and how long ago you had them
- your symptoms
- your general health.

The main treatments to control secondary breast cancer are:

- <u>hormonal therapy</u>
- <u>chemotherapy</u>
- <u>targeted therapy</u>
- <u>immunotherapy</u> this is currently only used for triple negative breast cancer.

You may have some of these treatments together. This is called a combination of treatments. You may have other treatments to control symptoms. <u>Chemotherapy</u> is often used to treat secondary breast cancer.

If the cancer is ER positive and HER2 negative, your doctor will talk to you about having hormonal therapy with targeted therapy. There are different drugs and treatments that can be used.

If you have HER2 positive breast cancer, you will usually have targeted therapy. You may have it with chemotherapy. There are different drugs that can be used.

If you have triple negative secondary breast cancer, you may have immunotherapy, chemotherapy or targeted therapy. There are different treatments that can be used.

You may have <u>radiotherapy</u> to relieve pain from secondary breast cancer in the bone. 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. You can also have drugs to help strengthen bones.

Your doctor can refer you to a cancer doctor or specialist nurse who is an expert in symptom control. They can refer you at any time during or after treatment. These doctors or nurses are called palliative care experts. They help make sure that any difficult symptoms you have are controlled. You can see them in hospital, or nurses can visit you at home.

If at any point you decide not to have further treatment, they will support you and help to control your symptoms.

# Planning your treatment

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

# Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- an oncologist a doctor who treats people who have cancer
- a clinical nurse specialist (CNS) a nurse who gives information about cancer, and support before, during and after treatment
- a surgeon a doctor who does operations (surgery)
- a palliative care specialist a doctor or nurse who specialises in controlling symptoms
- a radiologist a doctor who looks at scans and x-rays to diagnose problems
- a pathologist a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include:

- a physiotherapist someone who gives advice about exercise and mobility
- a dietitian someone who gives information and advice about food and food supplements
- an occupational therapist (OT) someone who gives information, support and aids to help people with tasks such as washing and dressing
- a psychologist someone who gives advice about managing feelings and behaviours
- a social worker someone who can help sort out practical and financial problems
- a counsellor someone who is trained to listen to people's problems and help them find ways to cope.

# 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.

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 <u>0800 808 00 00</u>.

Usually, treatments for secondary breast cancer can help:

- control the cancer
- improve your quality of life
- reduce the symptoms.

Treatments for secondary breast cancer are advancing. This means people are able to live with the cancer for longer. If a treatment stops working, you can usually try another treatment that may work for a time.

There will be a time when the treatment you are offered will have little effect on the cancer, but you still get side effects. Deciding whether to have treatment in this situation is 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**

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. This is called a referral. The doctor giving the second opinion may review your medical notes and write to you. Or you may have to travel to another hospital to see them.

Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you are referred to gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit <u>macmillan.org.uk/second-opinion</u>

## **Giving your consent**

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected.

But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

For several months, I thought of myself as 'Angela who has cancer that could get worse'. This limited my mind on what I could do and achieve. I decided I did not want cancer to define me, and it is further in the background now.

Angela, diagnosed with secondary breast cancer

# Hormonal therapy

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 therapy drugs lower the level of oestrogen in the body. Or they block oestrogen from attaching to the breast cancer cells. They only work for breast cancer that is oestrogen receptor (ER) positive. We have more information on <u>page 32</u>.

Hormonal therapy is usually the first treatment for ER positive secondary breast cancer. Occasionally, people have chemotherapy (<u>pages 51 to 59</u>) before hormonal therapy.

The hormonal therapy you have depends on:

- whether you have been through the menopause
- whether you have had any hormonal therapy before
- how long ago you had hormonal therapy
- whether you are still having any hormonal therapy.

Your cancer doctor will explain which hormonal therapy treatments you need. You may have hormonal therapy with <u>targeted therapy</u>. Targeted therapy drugs interfere with signals that tell the cancer cells to grow. They make the hormonal therapy more effective.

It takes a few weeks before your doctors can tell how well hormonal therapy is working. Your cancer doctor will usually arrange for you to have a scan to check this. If 1 type of 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 therapy. You usually take hormonal therapy as tablets. Or you may have it as an injection under the skin.

The side effects are usually mild. They will depend on the drug you are having. We have more information on our website about the side effects of hormonal therapy drugs and how to cope with them. Visit <u>macmillan.org.uk/treatments-and-drugs</u>

If you have problems with side effects, talk to your specialist nurse or cancer doctor. They can usually help treat or manage any problems.

#### Aromatase inhibitors (AIs)

Aromatase inhibitors (AIs) stop oestrogen being made in the body.

There are different types of Als. These include:

- anastrozole
- letrozole
- exemestane.

You take them daily as a tablet. Side effects may include:

- tiredness
- joint and muscle pain
- hot flushes.

#### 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
- increased risk of a blood clot.

Symptoms of a blood clot include:

- pain, redness or swelling in a leg or arm
- breathlessness
- chest pain.

If you have any of these symptoms, contact a doctor straight away.

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**

Fulvestrant stops oestrogen reaching the breast cancer cells. This slows down or stops the growth of the cancer cells. Fulvestrant also reduces the number of receptors on the cancer cells.

You have fulvestrant as an injection into a muscle in the buttock. You have the first 3 injections 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 still have your ovaries and have not been through the menopause, you usually either have:

- drugs to stop your ovaries making oestrogen
- surgery to remove your ovaries (ovarian ablation).

You have these treatments along with an AI, tamoxifen or fulvestrant.

#### Drugs that stop the ovaries making oestrogen

The drugs goserelin and leuprorelin stop 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 these drugs, and your periods will stop within a few weeks.

The side effects are similar to menopausal symptoms. They include:

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

You have goserelin or leuprorelin as an injection under the skin of the tummy (abdomen). You have this injection once a month.

#### **Ovarian ablation**

Ovarian ablation is an operation to remove the ovaries. This reduces the amount of oestrogen in the body.

It can usually be done using keyhole surgery. The surgeon makes a small cut in the abdomen and inserts a thin tube with a small light and camera on the end. This is called a laparoscope. The surgeon uses it to help them remove the ovaries through the cut. You will be in hospital for a short stay. People usually recover quickly from this type of operation.

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



# 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 often used to treat secondary breast cancer.

# Chemotherapy drugs for secondary breast cancer

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®)
- nab-paclitaxel (Abraxane®)
- eribulin (Halaven®)
- vinorelbine (Navelbine®).

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. You will be involved in making decisions.

The drugs you have depends on any previous chemotherapy you have had.

### 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 1 of the following:

- a cannula a short, thin tube the nurse puts into a vein in your arm or hand
- a central line a fine tube that goes under the skin of your chest and into a vein close by
- a PICC line a fine tube that is put into a vein in your arm and goes up into a vein in your chest
- an implantable port (portacath) a disc that is put under the skin on your chest or arm and goes into a vein in your chest.

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

You usually have chemotherapy as a session of treatment. You then have 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 together make up a cycle of treatment. Your cancer doctor or specialist nurse will explain how many cycles of treatment you need.

### Side effects of chemotherapy

Chemotherapy drugs may cause side effects. But your cancer doctor or specialist nurse can give you drugs to help control some side effects. They can also give you advice about managing your side effects.

Not all drugs cause the same side effects. You may get some of the side effects we mention, but you are unlikely to get all of them. Some people have very few side effects. You can talk to your doctor or nurse about what to expect from your treatment.

We explain the most common side effects over the next few pages. We also discuss some ways to manage them.

#### **Risk of infection**

Chemotherapy 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 sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible.

Contact the hospital straight away on the 24-hour contact number you have been given 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
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

# It is important to follow any specific advice your cancer treatment team give 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 until your cell count increases.

You may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin. Talk to your doctor or nurse about possible side effects from this injection.

We have more information about G-CSF on our website. Visit <u>macmillan.org.uk/g-csf</u>



#### **Bruising and bleeding**

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

#### Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

#### Feeling sick or being sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

#### Tiredness (fatigue)

You are likely to become tired and have to take things slowly. Some people find that the more treatments they have, the more tired they feel. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

#### 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 cycle.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you if this is an option for you.

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.

#### Sore mouth and throat

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

If your mouth or throat 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 and throat.

#### Diarrhoea

Chemotherapy may cause diarrhoea. Diarrhoea means passing more stools than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3<sup>1</sup>/<sub>2</sub> pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

#### Constipation

Some chemotherapy drugs and anti-sickness medicines can cause constipation. Constipation means that you are not able to pass stools as often as you normally do.

Here are some tips that may help:

- 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.

#### Sore and red palms of hands and soles of feet

The skin on the palms of your hands and soles of your feet can become red and sore. The skin may also be shiny, cracked or peeling. This is called palmar-plantar or hand-foot syndrome.

Your doctor or nurse can give you advice and prescribe creams to improve the symptoms. 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)

Some chemotherapy drugs can cause numb or tingling hands or feet. These symptoms are caused by the effect of certain drugs on the nerves. You may 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.

#### Contraception

Your doctor will advise you not to get pregnant while having chemotherapy. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

#### Sex

If you have sex during a course of chemotherapy, you should use barrier protection such as a condom or dental dam. This will protect your partner if any of the drug is in your vaginal fluid.

## Electrochemotherapy

Electrochemotherapy may be used to treat skin tumours caused by secondary breast cancer. It uses chemotherapy and a small electrical current to destroy the cancer cells.

The doctor injects a low dose of chemotherapy into the tumour or into a vein (intravenously). After this, they put a probe called an electrode directly over the tumour to give the electrical pulse. The pulse changes the outside layer of the cells. This helps the chemotherapy get into the cancer cells and destroy them.

#### Side effects of electrochemotherapy

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. Your nurse or doctor will give you more information about side effects that may affect you.

# **Targeted therapy**

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

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

- HER2 negative and oestrogen receptor (ER) positive
- <u>HER2 positive</u>
- triple negative.

Your cancer doctor will explain which targeted therapy drugs are suitable for your situation. We have more information on our website at <u>macmillan.org.uk/targeted-therapies</u>



# HER2 negative and ER positive breast cancer

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

#### Abemaciclib, palbociclib and ribociclib

Abemaciclib (Verzenios®), palbociclib (Ibrance®) and ribociclib (Kisqali®) are given with hormonal therapy drugs. We have more information on our website at <u>macmillan.org.uk/treatment-and-drugs</u>

They are all a type of targeted therapy drug called a cancer growth inhibitor. They are sometimes called CDK4 and CDK6 inhibitors. CDK4 and CDK6 are proteins that tell cancer cells to grow and divide. These drugs block CDK4 and CDK6. This can slow or stop the growth of the cancer.

Abemaciclib comes in tablets that you take twice a day, every day without a break.

You take palbociclib and ribociclib 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
- anaemia.

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Other side effects may include:

- tiredness
- hair thinning
- changes in the way the liver and kidneys work
- diarrhoea
- effects on the heart
- inflammation of the lungs (pneumonitis).

We have more information about targeted therapy drugs. Visit <u>macmillan.org.uk/targeted-therapies</u>

#### Everolimus

Everolimus (Afinitor®) is a targeted therapy drug that you may have with the hormonal therapy drug exemestane. You need to have already had treatment with certain hormonal therapy drugs before you can have everolimus.

Everolimus is a cancer growth inhibitor. It can help slow down how quickly the cancer is growing. It also stops the cancer cells from making new blood vessels. This means it is an angiogenesis inhibitor. This may help shrink the cancer.

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

- a skin rash
- a sore mouth
- tiredness
- diarrhoea
- inflammation in the lungs (pneumonitis).

#### Alpelisib

Alpelisib (Piqray®) is a targeted therapy drug that is given with the hormonal therapy drug fulvestrant. You will only be offered alpelisib if both these things apply to you:

- The breast cancer has a PIK3CA gene change.
- You have already had hormonal therapy alongside a CDK4 or CDK6 inhibitor.

You take alpelisib as tablets once a day. You should take them after food at about the same time each day.

Common side effects include:

- raised blood sugar levels
- skin changes
- diarrhoea
- nausea and vomiting.

Your doctor or nurse will give you more detailed information about the side effects of this drug.

### **HER2 positive cancer**

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

- trastuzumab
- pertuzumab (Perjeta®)
- Phesgo® (trastuzumab and pertuzumab)
- trastuzumab emtansine (Kadcyla®)
- trastuzumab deruxtecan (Enhertu®)
- tucatinib (Tukysa®).

These drugs may cause changes to the way the heart works. You will have tests to check your heart before and during treatment.

If treatment causes any problems with the heart, your cancer doctor may prescribe you drugs or refer you to a doctor that is an expert in cancer and heart problems. They may advise you to stop taking targeted therapy drugs for a while.

#### Trastuzumab

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

You have trastuzumab every 3 weeks as a drip (infusion) or as an injection under the skin. You may have it with:

- pertuzumab and chemotherapy drugs, such as docetaxel (Taxotere®)
- chemotherapy drugs.

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

- flu-like symptoms
- diarrhoea
- headaches.

Some people have an allergic reaction, but this is less common.

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 drugs or radiotherapy (<u>pages 72 to 75</u>) to control the cancer in the central nervous system.

#### Pertuzumab

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

Pertuzumab is usually given with trastuzumab and either docetaxel or capecitabine. These are chemotherapy drugs. If you have not had targeted therapy or chemotherapy before, you may have pertuzumab with trastuzumab and either docetaxel or capecitabine as a first treatment.

You usually have pertuzumab as an injection under the skin. Side effects of pertuzumab include:

- feeling sick
- diarrhoea, which can be severe.

#### **Phesgo**®

Phesgo® is a combination of trastuzumab and pertuzumab. It is given as an injection under the skin (subcutaneously). The nurse gives you the injection every 3 weeks. You have this injection in the thigh.

#### Trastuzumab emtansine

Trastuzumab emtansine (Kadcyla®) is trastuzumab with the chemotherapy drug emtansine attached to it. Trastuzumab targets the cancer cells and delivers the chemotherapy to them.

You have it as an infusion every 3 weeks. Side effects include:

- a low white blood cell count, which increases the risk of infection
- a low platelet count, which increases the risk of bleeding
- a low red blood cell count (anaemia), which can make you tired
- a sore mouth
- diarrhoea
- effects on the liver you will have blood tests to check how well your liver is working.

#### Trastuzumab deruxtecan

Trastuzumab deruxtecan (Enhertu®) is trastuzumab with the chemotherapy drug deruxtecan attached to it. Trastuzumab targets the cancer cells and delivers the chemotherapy to them.

You have it as an infusion every 3 weeks. Side effects may include:

- feeling sick (nausea)
- diarrhoea
- constipation
- a low white blood cell count, which increases the risk of infection
- inflammation in the lungs (pneumonitis).

#### Tucatinib

Tucatinib (Tukysa®) belongs to a group of targeted therapy drugs called tyrosine kinase inhibitors (TKIs). It blocks the HER2 protein on cancer cells. This stops the cells from growing and dividing.

You usually have tucatinib in combination with trastuzumab and a chemotherapy drug called capecitabine.

You take tucatinib twice a day as tablets. You take it for as long as it is controlling the cancer and side effects are being managed.

Side effects may include:

- a low platelet count, which increases the risk of bleeding
- diarrhoea
- changes to the liver
- feeling sick.

### **Triple negative breast cancer**

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

#### Sacituzumab govitecan

Sacituzumab govitecan (Trodelvy®) is the targeted therapy drug sacituzumab with the chemotherapy drug SN-38 attached to it.

Sacituzumab is a cancer growth inhibitor. Some triple negative breast cancers have a protein called TROP2. This protein tells the cancer cells to grow and divide. Sacituzumab govitecan can block these proteins. This can slow or stop the growth of the cancer.

You usually have a course of several cycles of treatment. Each cycle of sacituzumab govitecan is 21 days (3 weeks). You have a drip into a vein (intravenous infusion) on days 1 and 8 of the cycle. You then have a rest from treatment for 1 week before the next cycle starts.

Ask your doctor or nurse for more information on side effects. Some may include:

- a low white blood cell count, which increases the risk of infection
- diarrhoea
- a sore mouth
- coughing
- breathlessness.

#### Olaparib

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

Olaparib blocks 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 include:

- feeling sick
- diarrhoea.

Olaparib is only available through the compassionate access scheme in the UK. Your cancer doctor can tell you more about this if they think this treatment is suitable for your situation. For more information about olaparib, visit <u>macmillan.org.uk/olaparib</u>

#### Anderson Wing



# Immunotherapy

Immunotherapy uses the body's immune system to find and attack cancer cells. It may be used to treat triple negative breast cancer that has PD-L1 proteins. PD-L1 proteins stop the immune system from attacking cells. This means it cannot attack cancer cells. This allows the cancer cells to grow.

Drugs called PD-L1 or PD-1 inhibitors can be used to treat triple negative breast cancer. They allow the immune system to attack the cancer cells.

## Atezolizumab

Atezolizumab is a PD-L1 inhibitor. You have it with the chemotherapy drug nab-paclitaxel (Abraxane®). You may have this treatment if you have not had any chemotherapy for secondary breast cancer.

You have atezolizumab twice in 28 days. It is given as a drip into a vein (intravenous infusion). You have nab-paclitaxel 3 times in 28 days, as an intravenous infusion. Your cancer doctor or specialist nurse will give you a treatment plan.

Side effects of atezolizumab include:

- effects on the lungs, liver and kidneys
- a skin rash, which can be severe
- diarrhoea and inflammation of the bowel, which can be severe
- a swollen pancreas
- hormonal changes.

If you have any side effects, it is important to tell your nurse or doctor straight away.
#### Pembrolizumab

Pembrolizumab (Keytruda®) is a PD-1 inhibitor. It can be given with paclitaxel or nab-paclitaxel.

You have pembrolizumab once every 3 weeks or once every 6 weeks. You have paclitaxel or nab-paclitaxel 3 times over 28 days. You have all these drugs as an intravenous infusion. Your doctor or nurse will give you a treatment plan.

Side effects of pembrolizumab include:

- diarrhoea
- inflammation of the lungs (pneumonitis)
- skin changes
- muscle and joint pain
- hormonal changes.

If you have any side effects, it is important to tell your nurse or doctor straight away.

We have more information about pembrolizumab on our website. Visit macmillan.org.uk/pembrolizumab



## Radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given, while doing as little harm as possible to normal cells.

The person who operates the radiotherapy machine is called a radiographer.

Radiotherapy can be used to treat secondary breast cancer. This is called palliative radiotherapy. It is used to relieve pain and other symptoms when breast cancer has spread to the bones, skin or brain. You often have between 1 and 5 sessions. Some people have more. Each treatment session will only take a few minutes.

Radiotherapy is not painful, but during treatment you have to lie in 1 position. Staying still in this position may be uncomfortable. Your cancer doctor may suggest that you take a painkiller half an hour (30 minutes) before having radiotherapy. This can help you be more comfortable.

Radiotherapy does not make you radioactive. You will not be a risk to anyone during the course of your treatment. This includes children.

If you have any questions about radiotherapy, you can ask your cancer doctor or the staff in the radiotherapy department.

We have more information about radiotherapy in our booklet <u>Understanding radiotherapy</u>.

#### Side effects of radiotherapy

You may have some mild side effects from radiotherapy.

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

Your cancer doctor, specialist nurse or radiographer will tell you what to expect. They will give you advice on what you can do to manage side effects.

If you have any new side effects or if side effects get worse, tell them straight away. Some side effects can be worse after treatment ends – for example, skin reactions. It may take about 1 week before they stop or begin to slowly improve.

#### Radiotherapy to the bones

Radiotherapy to the bones 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 keep 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. 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.

You may feel sick if the area treated is close to your tummy (abdomen) - for example, the ribs or spine. Your cancer doctor can prescribe anti-sickness drugs to help with this.

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

#### 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 and nerves. This is called spinal cord compression.

Spinal cord compression can cause different symptoms depending on the area that is affected. These include:

- unexplained pain in your back, neck, or down your arms or legs
- pain that may feel like a tight band around your body
- numbness or pins and needles in your arms, legs, toes, fingers, chest, back, tummy or buttocks
- weakness in your arms or legs
- unsteadiness or difficulty walking
- problems controlling your bladder or bowel.

Spinal cord compression is not common but needs to be treated quickly. This is to prevent permanent damage to the nerves. We have more information about <u>spinal cord compression</u>.

#### Radiotherapy to the brain

Radiotherapy to the brain can help shrink a secondary cancer in the brain and improve the symptoms.

For some people, a type of radiotherapy called stereotactic radiotherapy is suitable. It 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.

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 treatment ends, but it can sometimes stay 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 will give you advice on looking after the skin.

You may feel very tired 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, if you can. This can help 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.

## Surgery

Surgery is not usually used to treat secondary breast cancer. This is because the cancer is usually in more than 1 area. But surgery is sometimes used in certain situations.

## Surgery to strengthen a weakened bone

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

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

If 1 of your hip joints has been affected by the cancer, you may have surgery to replace the joint. This is called a hip replacement.

Surgery is also sometimes used to treat secondary breast cancer that has spread to the bones in the spine. Surgery can help strengthen the area of bone and relieve pressure on the spinal cord (<u>spinal cord</u> <u>compression</u>).

You have to stay in hospital for a week or longer after the operation so you can recover fully. But you can usually start walking 2 days after surgery. You usually have <u>radiotherapy to the bone</u> afterwards.

We have more information in our booklet <u>Understanding secondary</u> cancer in the bone.

#### Liver surgery

Sometimes it may be possible to remove a small cancer that is contained in only 1 part of the liver. If there is more than 1 tumour in the same area, it may be possible to remove them all. This is rare. It is major surgery that is done by a specialist liver surgeon.

A treatment called radiofrequency ablation may be used instead of surgery. The cancer doctor places needles in the liver tumour. Heat from a laser or microwave is then passed through the needle directly into the tumour to destroy cancer cells.

We have more information about secondary liver cancer in our booklet <u>Understanding secondary cancer of the liver</u>.

### **Brain surgery**

Some people may have surgery to the brain. This is usually if there is only 1 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 called a neurosurgeon. They will 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 1 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 <u>radiotherapy to the brain</u> after you have recovered from the operation.

#### Surgery to the primary cancer

Very rarely, it may be possible to have surgery to remove the primary cancer in the breast. This is usually only an option for people who have breast cancer that has only spread to 1 or 2 areas.

The cancer also needs to have responded well to treatment, and the response to treatment needs to be long lasting. Your cancer doctor or specialist nurse can explain if this may be suitable for you.



## Bone-strengthening drugs

If you have secondary breast cancer that has spread to the bones, you may be given bone-strengthening drugs. These may be bisphosphonates or a targeted therapy drug called denosumab (XGEVA®, Prolia®).

Denosumab is a type of targeted therapy called a monoclonal antibody. For more information, visit <u>macmillan.org.uk/denosumab</u>

These drugs also relieve bone pain and reduce the risk of a broken bone (fracture). Your cancer doctor may prescribe them to reduce the risk of developing further problems.

You usually have bisphosphonates as a drip (infusion) or as tablets. The main bisphosphonates used include:

- zoledronic acid (Zometa®) you have this as an infusion every 3 to 4 weeks
- pamidronate (Aredia®) you have this as an infusion every 3 to 4 weeks
- ibandronate (Bondronat®) you take this as a tablet once a day or have it as an infusion every 3 to 4 weeks.

Bisphosphonates can also be used to treat high levels of calcium in the blood. This is called hypercalcaemia.

Denosumab can 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 of bone-strengthening drugs. These will depend on the type of drug you have. Always tell your doctor or nurse 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 (this is more common if you take bisphosphonates as tablets)
- low calcium levels in the blood (hypocalcaemia)
- effects on the kidneys.

If you have bisphosphonates as an infusion, you may find the bone pain gets worse for a short time. Your cancer doctor can prescribe painkillers until this gets better.

#### Side effects of denosumab

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

- diarrhoea
- skin rashes
- pain in the muscles and joints
- low calcium levels in the blood (hypocalcaemia).

#### Jaw problems

Rarely, bone-strengthening drugs can damage the bone in the jaw. This is called 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 having 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

Steroids may be used to help control symptoms and help you to feel better.

They may be given:

- with certain chemotherapy drugs to prevent an allergic reaction or reduce sickness
- to reduce swelling and control pain caused by secondary cancer in the liver
- to reduce pressure and relieve headaches and sickness caused by secondary cancer in the brain
- to improve appetite and energy levels this is usually only for a short time
- to reduce <u>spinal cord compression</u> when the cancer has spread to the bones in the spine.

#### 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. If you have any side effects, tell your cancer doctor or specialist nurse.

Possible side effects include:

- indigestion or heartburn taking your steroids with food should help
- having more energy or feeling restless
- difficulty sleeping try taking your steroids earlier in the day
- increased appetite and weight gain
- a higher blood sugar level you may have blood or urine tests to check for this.

Sometimes steroids are given in high doses. The doses are gradually reduced after treatment ends. Having higher doses of steroids for a longer period of time may cause more side effects.

We have more information about steroids on our website. Visit <u>macmillan.org.uk/steroids</u>





### Managing secondary breast cancer symptoms

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## Managing symptoms

The symptoms of secondary breast cancer may improve 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.

There are also lots of other ways to control and manage symptoms. Always tell your cancer doctor or specialist nurse if you have new symptoms or if your symptoms get worse.

Sometimes you may be referred to a doctor or nurse who is an expert 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 we mention. Sometimes you may have very few symptoms.

## **Tiredness**

Feeling very tired is called fatigue. It is common. If it is caused by the cancer, treatments may help improve tiredness. You are likely to be tired during treatment, especially if you are having chemotherapy. But this should slowly improve once you finish chemotherapy.

If you are having ongoing treatment and are struggling with fatigue, tell your cancer doctor. They may suggest adjusting the dose of your treatment, if they think it may help.

Make sure you get enough rest. But try to balance this with some physical activity, such as short walks.

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 give you tablets to treat it. You may need to have a blood transfusion.

We have more information about fatigue in our booklet <u>Coping with</u> <u>fatigue (tiredness)</u>. It is also available as an audiobook.

We have more information about getting enough rest and managing fatigue on our website. Visit macmillan.org.uk/fatigue

## Feeling sick

There are different types of anti-sickness drugs that can help. You usually take them as tablets. But you can also have them as a skin patch, an injection into the skin or sometimes as a suppository (into the back passage).

Remember to:

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

I have learned to live life day by day, taking each day as it comes. Don't get me wrong – living with an incurable disease comes with its obstacles, but I will keep jumping over them for as long as I can.

Nicky, diagnosed with secondary breast cancer

## Constipation

This can be caused by:

- some chemotherapy drugs
- anti-sickness drugs
- painkillers.

Your cancer doctor or GP can prescribe a medicine called a laxative to help. Things you can do to help are:

- eating more fibre
- drinking plenty of fluids
- being more physically active if you can for example, going for short, regular walks.

We have more information about managing constipation on our website. Visit <u>macmillan.org.uk/</u> <u>constipation</u>



## Lymphoedema (swelling of the arm)

You may develop lymphoedema as a result of treatments such as surgery or radiotherapy to the armpit. It can also happen because the cancer is blocking lymph nodes in the armpit.

Ways of reducing the swelling and managing lymphoedema include:

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

If you notice any swelling in your arm or hand, tell your cancer doctor or specialist nurse as soon as possible. They may refer you to a lymphoedema specialist.



## Pain

There are many different painkillers. The painkiller you have depends on the type of pain you have. You may need more than 1 type of painkiller.

You usually have painkillers as tablets. You can also have them as:

- a skin patch
- an injection into the skin
- a suppository (into the back passage).

It is important to:

- take your painkillers regularly this will help give you constant pain control
- let your cancer doctor or specialist nurse know if the painkillers are not controlling your 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.

<u>Steroids</u> are used to reduce swelling and control pain. We have more information about managing cancer pain in our booklet <u>Managing cancer</u> pain.

We have more information about controlling pain on our website. Visit <u>macmillan.org.uk/pain</u>



## **Treating bone problems**

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 <u>surgery</u> to strengthen or repair the bone. This is usually done under a general anaesthetic. You may have radiotherapy before or after surgery. This can help repair the bone and treat the cancer cells in the area.

## Too much calcium in the blood (hypercalcaemia)

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

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

Tell your cancer doctor or specialist nurse straight away if you have these symptoms. They will give you a drip (infusion) of fluids to flush the extra calcium from your body.

They will also give you <u>bisphosphonates</u> 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 tumour is close to, or pressing on, the spinal cord and nerves.

It can happen as a first symptom of cancer. But it can also appear in people treated for early breast cancer in the past. Sometimes it can appear in people treated for breast cancer many years ago. It can happen if the breast cancer comes back and has spread to the bones in the spine.

It is important to tell your cancer doctor or specialist nurse straight away if you have any of the following symptoms. They will arrange an urgent scan to check your spinal cord.

Symptoms of spinal cord compression include:

- unexplained pain in your back, neck, or down your arms or legs
- pain that may feel like a tight band around the body
- numbness or pins and needles in your arms, legs, toes, fingers, chest, back, tummy or buttocks
- weakness in your arms or legs
- unsteadiness or difficulty walking
- problems controlling your bladder or bowel.

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.

We have more information about malignant spinal cord compression (MSCC) in our <u>MSCC alert kit</u>, which includes a leaflet and a fold-out patient alert card.

## **Breathlessness**

There are different things that can cause breathlessness. Tell your cancer doctor or specialist nurse if you feel breathless. They will check what is causing your breathlessness. They may arrange some tests or scans. They will give you advice on how to manage your breathlessness, and they may give you some medicines to help.

Sitting down when you are doing daily tasks such as washing, dressing or making food can help you to manage breathlessness. Controlled breathing or relaxation techniques may also help.

We have more information about managing breathlessness in our booklet <u>Managing breathlessness</u>.

### **Pleural effusion**

If cancer cells spread to the tissues that line the lungs (the pleura), it can cause fluid to build up. This is called a pleural effusion.

It can make you breathless. Your cancer doctor can treat this by passing a narrow tube into the 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. This allows you to drain the fluid into a bottle when you are at home.

Treating the cancer may also help to slow down or stop the fluid building up again.

#### Pleurodesis

To stop fluid build-up, your doctor may recommend a treatment that seals the 2 layers of the pleura together. This is called a pleurodesis. You will need to have a short stay in hospital

During a pleurodesis, you have a tube put into the 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 the chest. This is called a thoracoscope. The tube has a light and camera at the end, so the doctors can see into the 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 after the chest drain has been removed.

We have more information about pleural effusion on our website. Visit macmillan.org.uk/pleural-effusion



## Build-up of fluid in the tummy (ascites)

Ascites is a build-up of fluid between the 2 layers of the membrane that lines the tummy (abdomen). This membrane is called the peritoneum.

Ascites 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 manage 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 longer-term drain put in. This allows you to drain the fluid while you are at home.

Treating the cancer may also help to slow down or stop the fluid building up again.

For more information about ascites, visit <u>macmillan.org.uk/ascites</u>

## Treating secondary brain tumour symptoms

A secondary brain tumour can cause different symptoms, including headaches, sickness, vision problems or weakness in an area of the body. These can be frightening, but the symptoms may be controlled with:

- drugs called <u>steroids</u>, which reduce swelling in the brain caused by a tumour
- radiotherapy to the head or a specialised type of radiotherapy called stereotactic radiotherapy.
- surgery to reduce the pressure in the area of the brain.

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

I think you have to really listen to your body and do what is right for you when going through cancer. You have to be kind to yourself.

Nina, diagnosed with secondary breast cancer

## **Complementary** therapies

Some people 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 tell your cancer doctor if you are planning to start any complementary therapies. This includes taking supplements or other medicines. This is because some complementary therapies may interact with chemotherapy or other treatments.

We have more information about complementary therapies in our booklet <u>Cancer and complementary therapies</u>.

We have more information about complementary therapies on our website. Visit <u>macmillan.org.uk/</u> <u>complementary-therapies</u>



## After treatment for secondary breast cancer

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## **Clinic visits**

You will see your cancer doctor or specialist nurse regularly during your treatment. This helps make sure any problems can be managed. How often you see them will depend on your treatment plan.

You will have regular scans or x-rays to check how the cancer is responding to treatment. Contact your cancer doctor or nurse if you have any concerns or notice any new symptoms between appointments.

If you are having treatment such as chemotherapy, targeted therapy or immunotherapy, you will be given a number to call if you feel unwell.

It is natural to get anxious before appointments. It may help to get support from family, friends or a <u>support organisation</u>.

We have more information about tests and scans on our website. Visit <u>macmillan.org.uk/tests-scans</u>

"My nurses are strong, they are honest and they are all my friends now. They are special people. "

Lesley

## Living with secondary breast cancer

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

#### 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.

We have helpful tips on managing fatigue on our website. Visit

#### 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. You can try to slowly increase the amount you do. But be careful not to overdo it. Being active can also help look after your heart.

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.

# I have got a lot to live for, and I've still got stuff I can do. II Lesley

"I set up my living list, which is keeping me occupied with lots of activities to book and look forward to. I got married, and I co-founded Secondary Sisters with my friend Nicky, which has been a wonderful distraction. ,

Laura, diagnosed with secondary breast cancer
### Eat healthily

This can improve your general health. You will feel better and have more energy. If you gained weight during treatment, eating well can also help you manage weight gain.

There is no need to cut out certain types of foods from your diet. Try to eat a healthy balanced diet. This will help your energy levels.

Try to eat:

- plenty of fruit and vegetables each 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. Supplement drinks can 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 more information about managing weight gain in our booklet <u>Managing weight gain after cancer treatment</u>.

# Sex life

Cancer and its treatment may affect your sex life. 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. If you do not feel like having sex, there are other intimate and affectionate ways of showing how much you care for someone. Some people may find that their sex drive slowly improves over time.

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

Talking openly about any difficulties or concerns may help sort out any misunderstandings. For example, talking openly can reassure your partner that:

- sex will not harm you
- sex will not make the cancer worse
- they cannot catch the cancer by having sex.

We have more information about managing this type of problem in our booklet <u>Cancer and your sex life</u>.

Some cancer treatments can cause specific problems such as vaginal dryness and pain during sex.

There are treatments that may help with these side effects. Your cancer doctor or specialist nurse can give you advice.

Some people may find it helpful to talk to a sex therapist. You can contact a therapist through the <u>College of Sexual and Relationship</u> <u>Therapists</u>. You can also visit <u>cosrt.org.uk</u>

### Contraception

Your cancer doctor, specialist nurse or GP can give you advice on the best contraception for you to use. This may depend on the cancer treatments you are having.

Condoms, caps or non-hormonal coils are often the most suitable types of contraception to use. You may be advised not to use contraception that contains hormones. This includes the pill, implants or the coil (intrauterine contraception).

We have more information about sex and cancer on our website. Visit <u>macmillan.org.uk/sex-and-cancer</u>



# Early menopause and menopausal symptoms

If you have not been through the menopause, some cancer treatments can cause an early menopause or menopausal symptoms.

These treatments include:

- <u>chemotherapy</u> this can affect the ovaries and cause an early menopause
- <u>hormonal treatments</u> these affect the levels of hormones in the body and can cause menopausal symptoms or an early menopause.

Doctors do not usually advise taking hormone replacement therapy (HRT). This may be more likely if the cancer is oestrogen receptor (ER) positive. This is because HRT 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.

### 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 some anti-depressants can affect how tamoxifen works. An anti-depressant called venlafaxine can be given instead.

### **Vaginal dryness**

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

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 is absorbed by the body. It is important to talk to your cancer doctor or specialist nurse before you use any products containing oestrogen.

### **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. We have more information on our website. Visit <u>macmillan.org.uk/</u><u>menopausal-symptoms</u>



# Your feelings and relationships

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# **Emotional support**

You are likely to have different feelings to cope with during treatment. You may also be worried about practical issues such as work or finances.

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

- your healthcare team
- partners, family or friends
- support groups.

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

You may 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.

We have more information in our booklet <u>How are you feeling?</u> <u>The emotional effects of cancer</u>.

### 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 the Macmillan Support Line on <u>0808 808 00 00</u> or visit <u>macmillan.org.uk/supportgroups</u> 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 media sites, forums and blogs for people affected by cancer. You can use these to ask questions and share your experience.

You can talk to people in forums, blog your journey, make friends and join support groups on our Online Community at <u>macmillan.org.uk/</u><u>community</u>

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

Breast Cancer Now has specific services if you are under the age of 45. This includes events and a private Facebook page where you talk to other people going through the same thing.

Live Through This runs a peer support group for LGBTIQ+ people affected by cancer. This group focuses on LGBTIQ+ experiences of cancer and support, rather than on any cancer type.

We have more information about:

- Breast Cancer Now
- Live Through This.

"I have this extra group of friends through the cancer community. They are people that have had cancer and they just get it. I don't feel weird about talking about cancer. You can open up about something that is difficult to open up about. "

Hannah, diagnosed with secondary breast cancer

# **Your feelings**

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website at <u>macmillan.org.uk/emotions</u> and in our booklet <u>How are</u> <u>you feeling? The emotional effects of cancer</u>.

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on  $0808\ 808\ 00\ 00$  and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit <u>macmillan.org.uk/supportgroups</u>

Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about other ways we can help you.

# Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships on our website at macmillan.org.uk/relationships

We also have more information in our booklets:

- Talking about cancer
- <u>Cancer and relationships: support for partners,</u> <u>families and friends</u>.

### If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet <u>Talking with someone who has cancer</u>.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website at <u>macmillan.org.uk/carers</u>

We also have more information in our booklet <u>Looking after someone</u> with cancer.

### Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website <u>riprap.org.uk</u> offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet <u>Talking to children</u> and teenagers when an adult has cancer.



"I went for counselling when I first got diagnosed. So did my husband. He's living and breathing every step of the way with me. Counselling has given us a safe space to process what we're going through. "

Lesley

# 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. These may include meals on wheels, a home helper or money to help with hospital transport 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 called Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you are at a clinic or in hospital.

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

There is 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  $\underline{0808\ 808\ 00\ 00}$  can tell you more about counselling and can let you know about services in your area.



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# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have <u>information for carers</u>.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- <u>gov.uk</u> if you live in England or Wales
- <u>socialsecurity.gov.scot</u> if you live in Scotland
- <u>nidirect.gov.uk</u> if you live in Northern Ireland.

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 them by calling the Macmillan Support Line on <u>0808 808 00 00</u>. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from:

- <u>Citizens Advice</u> if you live in England, Scotland or Wales
- Advice NI if you live in Northern Ireland.

Our booklet <u>Help with the cost of cancer</u> has lots more information.

### **Macmillan Grants**

Macmillan Grants are small, 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 or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on <u>0808 808 00 00</u> or visit <u>macmillan.org.uk/grants</u>

#### Insurance

If you have or have had cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on <u>0808 808 00 00</u>.

We have information about insurance and cancer on our website. Visit <u>macmillan.org.uk/insurance</u>

We also have more information in our booklet <u>Travel and cancer</u>.

Our Online Community forum on travel insurance may also be helpful. Visit <u>macmillan.org.uk/community</u>

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on <u>0808 808 00 00</u>.



## 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 or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets have more information that may be helpful:

- Work and cancer
- Working while caring for someone with cancer
- Self-employment and cancer

You can also find out more about your employment rights in our booklet <u>Your rights at work when you are affected by cancer</u>.

There is also lots more information online at macmillan.org.uk/work

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on <u>0808 808 00 00</u>.

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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 booklets or leaflets like this one. Visit be.macmillan.org.uk or call us on <u>0808 808 00 00</u>.

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

#### **Online information**

All our information is also available online at <u>macmillan.org.uk/</u> <u>information-and-support</u> You can also find videos featuring 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

• interactive PDFs

- Braille
- British Sign Language
- large printtranslations.

• easy read booklets

Find out more at macmillan.org.uk/otherformats

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

#### The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary, we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

You can read more about how we produce our information at macmillan.org.uk/ourinfo

# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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. We 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on 0808 808 00 00. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to <u>macmillan.org.uk/</u> <u>talktous</u> If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call <u>0808 808 00 00</u> and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we will arrange for an interpreter to contact you.

#### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

#### Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

#### **Financial guidance**

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

#### Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <u>macmillan.org.uk/financialsupport</u> to find out more about how we can help you with your finances.

#### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

#### **Macmillan Grants**

Macmillan Grants are small, one-off payments to help people with the extra costs 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 travel to your appointments, you may be able to get a Macmillan Grant.

A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Call us on 0808 808 00 00 to find out more about Macmillan Grants.

#### Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit <u>macmillan.org.uk/work</u>

#### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on  $0808\ 808\ 00\ 00$  to speak to a work support adviser.

#### 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 is why we help bring people together in their communities and online.

#### Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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 <u>macmillan.org.uk/</u> <u>selfhelpandsupport</u>

#### **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

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support adviser or an information and support adviser any questions you have.

#### Macmillan healthcare professionals

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.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

#### Breast cancer support organisations

#### **Breast Cancer Haven**

#### Tel 0757 263 7588

#### www.breastcancerhaven.org.uk

Delivers one-to-one support sessions, healthy eating, exercise and stress reduction classes, and a range of self-help videos and resources. These can be accessed online.

#### **Breast Cancer Now**

#### Helpline **0808 800 6000**

#### www.breastcancernow.org

Provides information and practical and emotional support to people 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.

#### **UK Charity for TNBC**

#### www.ukcharityfortnbc.org

Provides support for people with triple negative breast cancer (TNBC).

#### General cancer support organisations

#### **Asian Women Cancer Group**

#### www.asianwomencancergroup.co.uk

Helps Asian women who have been affected by breast cancer. Provides emotional support and financial guidance.

#### **Black Women Rising**

#### www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

#### **Cancer Black Care**

#### Tel 0208 961 4151

#### www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

#### **Cancer Focus Northern Ireland**

#### Helpline **0800 783 3339**

www.cancerfocusni.org Offers a variety of services to people affected by cancer in Northern Ireland.

#### **Cancer Research UK**

#### Helpline 0808 800 4040

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

#### www.cancersupportscotland.org

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

#### Lymphoedema Support Network

#### Helpline 0207 351 4480

#### www.lymphoedema.org

Provides information about lymphoedema and what support you can get to help manage it.

#### **Macmillan Cancer Voices**

#### www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

#### Maggie's

#### Tel 0300 123 1801

#### www.maggies.org

Has a network of centres in many 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 300 0118**

#### www.pennybrohn.org.uk

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

#### Riprap

#### www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

#### Tenovus

#### Helpline **0808 808 1010**

#### www.tenovuscancercare.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

#### British Association for Counselling and Psychotherapy (BACP)

#### Tel 0145 588 3300

#### www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

#### UK Council for Psychotherapy (UKCP)

#### Tel 0207 014 9955

#### www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

#### Emotional and mental health support

#### Mind

#### Helpline 0300 123 3393

www.mind.org.uk Provides information, advice and support to anyone with

#### a mental health problem through its helpline and website.

#### Samaritans

#### Helpline **116 123** Email **jo@samaritans.org**

#### www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

#### Help with sexual well-being

#### **College of Sexual and Relationship Therapists**

#### Tel 0208 106 9635

www.cosrt.org.uk A national specialist charity for sex and relationship therapy. Provides information about sexual and relationship issues.

#### Financial support or legal advice and information

#### Advice NI

Helpline **0800 915 4604** Provides advice on a variety of issues including financial, legal, housing and employment issues.

#### **Benefit Enquiry Line Northern Ireland**

Helpline **0800 232 1271** Textphone **0289 031 1092** <u>www.nidirect.gov.uk/money-tax-and-benefits</u> Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

#### **Carer's Allowance Unit**

Tel **0800 731 0297** Textphone **0800 731 0317** www.gov.uk/carers-allowance

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

#### **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

#### England

Helpline **0800 144 8848** www.citizensadvice.org.uk

#### Scotland

Helpline **0800 028 1456** <u>www.cas.org.uk</u>

#### Wales

Helpline **0800 702 2020** www.citizensadvice.org.uk/wales

#### **Civil Legal Advice**

Helpline **0345 345 4345** 

Textphone 0345 609 6677

www.gov.uk/civil-legal-advice

Has a list of legal advice centres in England and Wales, and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

#### GOV.UK

#### www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

#### Jobs and Benefits Office Enquiry Line Northern Ireland

#### Helpline **0800 022 4250**

Textphone 0800 587 1297

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

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

#### Law Centres Network

#### www.lawcentres.org.uk

Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

#### Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction and education benefits, and for help from social services.

You should be able to find your local council's contact details online by visiting:

#### England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

#### Wales

www.gov.wales/find-your-local-authority

#### Macmillan Benefits Advice Service (Northern Ireland)

Tel 0300 123 3233

#### **StepChange Debt Charity**

#### Tel 0800 138 1111

www.stepchange.org

Provides free debt advice through the phone, email, the website and online through live chats with advisers.

#### Equipment and advice on living with a disability

#### **British Red Cross**

#### Tel 0344 871 11 11

#### www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

#### **Disability Rights UK**

#### Tel 0330 995 0400 (not an advice line)

#### www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

#### Living Made Easy

#### Helpline 0300 999 0004

www.livingmadeeasy.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

#### **Motability Scheme**

#### Tel **0300 456 4566**

The scheme enables disabled people to exchange mobility allowances they have as part of benefits to lease a new car, scooter or powered wheelchair.

#### Support for older people

#### Age UK

#### Helpline **0800 678 1602**

#### www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

#### LGBT-specific support

#### **LGBT Foundation**

#### Tel 0345 330 3030

#### 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.

#### Live Through This

#### www.livethroughthis.co.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBTIQ+ cancer experiences. LTT runs a peer support group with Maggie's Barts.

#### Advanced cancer and end of life care

#### **Hospice UK**

#### Tel 0207 520 8200

#### www.hospiceuk.org

Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

#### **Marie Curie**

#### Helpline 0800 090 2309

#### www.mariecurie.org.uk

Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

#### **Cancer registries**

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

#### England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

#### Scotland - Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-anddiseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/ overview

#### Wales - Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278** www.phw.nhs.wales/wcisu

#### Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028** www.gub.ac.uk/research-centres/nicr/AboutUs/Registry

## Your notes and questions


#### 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 Dr Rebecca Roylance, Consultant Medical Oncologist, and Professor Mike Dixon, Professor of Surgery and Consultant Surgeon.

With thanks to:

Susan Booker, Macmillan Clinical Nurse Specialist; Dr Russell Burcombe, Consultant Clinical Oncologist; Joyce Graham, Macmillan Nurse Consultant in Breast Care; Laura Lees, Macmillan Specialist Radiographer; Liz O'Riordan, Consultant Breast Surgeon; Dr Elsa Papadimitraki, Consultant Medical 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, please contact **cancerinformationteam@macmillan.org.uk** 

#### Sources

Below is a sample of the sources used in our understanding secondary breast cancer information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@ macmillan.org.uk** 

BMJ best practice. Metastatic breast cancer. https://bestpractice.bmj. com/topics/en-gb/718 [accessed November 2021].

National Institute for Health and Care Excellence (NICE). Advanced breast cancer: diagnosis and treatment. Clinical Guideline [CG81]. Updated 2017. https://www.nice.org.uk/guidance/cg81 [accessed November 2021].

### Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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.

#### 5 ways you can help someone with cancer

1. Share your cancer experience

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

#### 2. 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.

#### 3. 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?

#### 4. Raise money

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

#### 5. Give money

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

#### 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



### Do not 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 would rather donate online go to macmillan.org.uk/donate

Date /



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



When I first got diagnosed, it felt like jumping off a cliff. But I didn't hit the bottom because Macmillan caught me and stopped me from hitting the bottom.

Lesley, diagnosed with secondary breast cancer