

Understanding

Metastatic (secondary) breast cancer

Caring for people with cancer

Metastatic (secondary) breast cancer

This booklet has information on:

- Treatment for metastatic breast cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist breast nurse

Oncology liaison nurse

Oncology day ward

Family doctor (GP)

Breast surgeon

Medical oncologist

Radiation oncologist

Palliative care team

Medical social worker

Emergency

Medical records number (MRN)



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Fast facts

Can my cancer be treated?

Page 16

Yes. There are lots of different treatments for metastatic breast cancer. Metastatic breast cancer treatments are to keep the cancer under control, rather than to cure it. New treatments are being developed all the time.

What kind of treatment might I have? Page 39

Hormone therapy: Drugs used to treat breast cancers that are stimulated to grow by the hormones oestrogen and progesterone.

Targeted therapies: Drugs that find ways to stop breast cancer cells from dividing and growing.

Chemotherapy: Drugs that kill cancer cells, slowing down and controlling cancer growth.

Immunotherapy: Drugs that activate the immune system to kill cancer cells, slowing down and controlling cancer growth.

Radiotherapy: A course of X-ray treatments to control the disease and relieve symptoms.

Bisphosphonates: Drugs used to treat metastatic breast cancer in the bone.



Email: supportline@irishcancer.ie

How long will I live?

Page 36

Many people live a long time with metastatic breast cancer. What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things. The best thing to do is to ask your consultant about your own situation.

Clinical trials

Page 92

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

We're here for you

Page 149

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our Cancer Nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop in to a Daffodil Centre
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre
- Email us: supportline@irishcancer.ie

See page 149 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our Cancer Nurses:

- Call our Support Line on **Freephone 1800 200 700**
- Visit a **Daffodil Centre**
- Email the nurses at supportline@irishcancer.ie

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

We use gender-inclusive language. We sometimes use man/woman and male/female when they are needed to explain a person's treatment and care – for example, talking about hormones or body parts – and when needed to describe research or statistics.

Support Line Freephone 1800 200 700

About metastatic breast cancer

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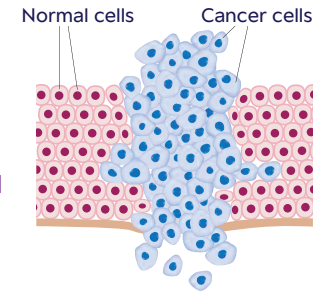
What is cancer?

Cancer is a disease of the body's cells.

Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

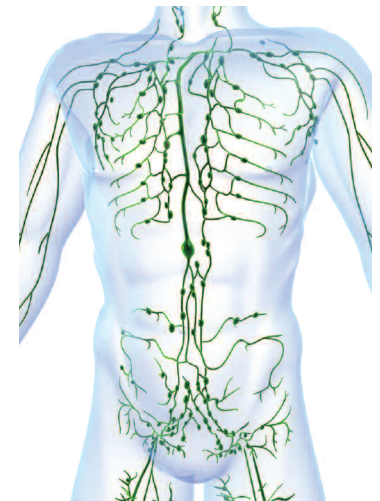
Cancers are named after the organ or cell where the cancer starts. Breast cancer starts in cells in the breast.

Cancers sometimes spread. If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new (secondary) tumour. This is called metastasis.



What is the lymphatic system?

- The lymphatic system is part of our immune system, which protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or if cancer starts in the lymph nodes they can feel swollen to touch.



What is primary breast cancer?

Primary breast cancer is when breast cancer cells grow in your breast. If you need information on primary breast cancer, please see our booklet, ***Understanding breast cancer***.

What is metastatic breast cancer?

Metastatic breast cancer is cancer that has spread from the first (primary) tumour in your breast to another part of your body. It is also known as secondary breast cancer, advanced breast cancer or stage 4 breast cancer.

What is de novo metastatic breast cancer?

Sometimes a patient's first diagnosis is metastatic breast cancer: their cancer has already spread by the time it is diagnosed. This is known as de novo metastatic breast cancer. 'De novo' means the breast cancer is metastatic 'from the start'.



Why does cancer spread?

Often primary breast cancer is cured, but sometimes treatment does not remove all the breast cancer cells. These breast cancer cells may be so small that they can't be picked up on scans. They may spread through the bloodstream or lymphatic system to other parts of the body, where they may eventually form another cancer (tumour).

Cells may also spread to another part of the body before treatment starts. The cells may be inactive for many years and then start to grow and divide to form a new tumour. Doctors and scientists do not know why this happens.

What parts of the body can be affected by metastatic breast cancer?

Metastatic breast cancer may affect one part of your body, but it can also affect more than one place. The most common places where breast cancer can spread are:

- Bones
- Lungs
- Skin
- Liver
- Brain
- Lymph nodes

Less commonly, it can spread to other parts of the body, such as the bone marrow, ovaries or lining of the abdomen (peritoneum). The metastatic cancer is made up of breast cancer cells. The metastatic cancer is still breast cancer, even if it is in another part of your body. For example, if breast cancer spreads to your lung, it is described as metastatic breast cancer in the lung, not lung cancer.

Email: supportline@irishcancer.ie

What are the symptoms of metastatic breast cancer?

The symptoms of metastatic breast cancer depend on where the breast cancer is found. Some patients have no symptoms. Or you might have general symptoms at first. This can include feeling more tired than usual or losing your appetite.

There can be specific symptoms, depending on which part of your body is affected. For example:

- Bone pain that does not go away
- Loss of power or weakness in your arms or legs
- Unexplained weight loss and loss of appetite
- A constant feeling of nausea
- Discomfort or swelling under your ribs or across your tummy
- Feeling constantly tired
- A dry cough or breathlessness
- Severe headaches

It is hard to list all the symptoms of metastatic breast cancer because different parts of your body may be affected. Tell your doctor about symptoms that are new, don't have an obvious cause and don't go away.

Cancer in the bone

A sign of metastatic breast cancer in your bone can be an ache in the affected bone. If you get a new pain that lasts longer than about 2 weeks, talk to your doctor. Not every new ache or pain means that breast cancer has spread to the bone, but all persistent pain needs to be checked.

If breast cancer spreads to your bone, it can damage the bone and weaken it. Sometimes breaking a bone (fracture) is the first sign of metastatic breast cancer. These fractures can happen after a minor injury because the bone is weakened.



The level of calcium in your blood can increase when bone is damaged. Too much calcium in your blood is called hypercalcaemia. It can cause symptoms such as tiredness, constipation, nausea, thirst and confusion. Often hypercalcaemia is found during blood tests before symptoms develop.

If the cancer spreads to the bones in your spine, it can press on your spinal cord and nerves. This is called spinal cord compression. It can cause symptoms such as pain, weakness or tingling in your leg and loss of bladder and bowel control. If this happens, visit your doctor immediately.

It is very important to treat spinal cord compression quickly.

Remember, metastatic breast cancer in a bone can be treated. For most people, treatment starts long before the bone becomes weak enough to break or cause a lot of pain.

Cancer in the liver

If breast cancer has spread to your liver, you might have loss of appetite, tiredness, nausea or discomfort on the right side of your tummy, where your liver is found.

The liver works by filtering blood from the digestive system, metabolising drugs, detoxifying chemicals and making bile to help digest food. If the cancer blocks the drainage tubes in your liver, bile can build up in your blood. This can cause jaundice and turn your skin and the whites of your eyes yellow. Your skin can feel itchy as a result. It can also make your urine darker and your poo paler.



Sometimes cancer can make your liver bigger or cause fluid to build up in your tummy. This fluid is called ascites and can make your tummy swell up. But your liver will continue to work when part of it, or even most of it, is out of action.

Cancer in the lungs

One of the first signs of metastatic breast cancer in the lungs is shortness of breath or a persistent dry cough. The space between your lungs and ribcage is called the pleural cavity. If cancer cells enter this space, they can cause fluid to build up and put pressure on your lungs.

Cancer in the brain

Symptoms of metastatic breast cancer in the brain can include headaches and nausea. Sometimes it causes changes in the part of your body controlled by that part of the brain. For example, your arm or leg may be weaker than usual or you may have a feeling of numbness, tingling or pins and needles, or changes to your vision. Cancer in the brain can also cause seizures and in rare cases, confusion or a change in personality.

Cancer on the skin

Cancer on the skin – sometimes called skin metastases – usually happens in areas close to where the original breast cancer was. It is different from local recurrence (see page 17). Symptoms of skin metastases include:

- Redness and inflammation in an area of skin
- A rash
- A firm, painless lump (or lumps) on or just below the skin

Skin metastases can also cause a swelling called lymphoedema (see page 103).

Cancer in the lymph nodes

Metastatic breast cancer can occur in more distant lymph nodes and is not considered local or regional spread (see page 17). It is considered metastatic if it spreads to lymph nodes in, for example, your abdomen or groin.

Can metastatic breast cancer be treated?

Yes, metastatic breast cancer can be treated, but not cured. The aim of treatment is to relieve your symptoms and improve your quality of life by slowing down the growth of the cancer. There are many treatments that can keep the cancer under control, sometimes for many years.



Your doctor will be very keen to ensure that any side-effects from your treatment are managed, to allow you live as full a life as possible. For some people, living with metastatic breast cancer is like living with a chronic (long-term) illness.

Your specialist will tell you about the likely progress of your cancer and what you might expect. See page 41 for more about treating metastatic breast cancer.

What are local and regional recurrences?

Local recurrence

Local recurrence is when breast cancer comes back in your chest or breast area. This means the cancer cells have stayed in the local area and have not spread to other parts of your body.

Regional recurrence

Regional recurrence is when breast cancer comes back in the tissues and lymph nodes close to the site of your first cancer. For example, in the tissues and lymph nodes around your chest, neck and under your breastbone.

Having a local or regional recurrence of breast cancer is different to having metastatic breast cancer. Even though these recurrences are not in the body's organs, your doctor usually recommends tests to check the cancer has not spread further.



Treatment for local or regional recurrence

Treatment for local and regional recurrence varies and will depend on the treatment you had previously. It may include surgery, radiotherapy and drug treatments. You can talk to one of our Cancer Nurses if you have any questions about local or regional recurrence or about metastatic breast cancer. Call our Support Line on 1800 200 700 or visit your local Daffodil Centre.



Preparing for your hospital appointments

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Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.



Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you aren't fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is okay to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one.
- Your private health insurance details, if you have insurance.
- The appointment letter from the hospital, if you got one.
- A referral letter or GP letter, if you got one.
- Your GP's name and contact details.
- Your medical history – remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand.
- Your list of questions.
- A notebook and pen to take notes. Some healthcare professionals may be happy for you to record the meeting, but make sure you ask for their permission first.
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medications. Hand-written lists can be hard to read or inaccurate.
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed.
- Medications and any medical supplies you may need that day, in case you are delayed.
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure.)
- Your phone and your phone number.
- Contact details of the person to call in an emergency.
- Your glasses and hearing aid, if you use them.
- A book or something to listen to (including headphones) to pass the time while you wait.

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know.
- Make sure you know what will happen next.
- Ask for the name and number of someone you can contact in case you have further questions.
- Ensure you are booked in for your follow-up appointment before you leave, if you need one.



After the appointment

- Arrange any tests before your next appointment as soon as you can. For example, a blood test, if your healthcare professional has asked for one.

It's important to go to your appointments

If you can't go to your appointment, contact the hospital as soon as possible and ask them for a new appointment. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Try not to be shy about asking questions. It is always better to ask than to worry.

- What tests do I need?
- How long will it take to get the test results?
- What type of metastatic breast cancer do I have?
- What treatment will I need?
- What is the goal of this treatment?
- What can I expect to happen if I choose not to have this treatment?
- What side-effects will I get from the treatment?
- Am I a candidate for a clinical trial?
- Is there anything I can do to help myself during treatment?
- Can my symptoms be controlled?
- How will I know if the treatment is working?
- On average, how long does this treatment usually work?
- What happens if the treatment stops working?
- What problems should I report to you?
- How will this treatment affect my lifestyle (family, work, leisure, sex life)?
- What is my prognosis?
- What support services are available to help me cope with my cancer?
- Do you recommend any complementary therapies?
- Where can I find out more about metastatic breast cancer?

Diagnosis and tests

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Being diagnosed with metastatic breast cancer

If your cancer has come back, or you have metastatic cancer as your first diagnosis, it can be hard to deal with your emotions. You may feel:

- **Upset** and **overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Angry** that this is happening to you

However you feel, you are not alone.

If you need to talk to someone or if you want support or advice:

- **Ask to speak to the cancer clinical nurse specialist (CNS) or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our Cancer Nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Peer Support volunteer** who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our Cancer Nurses can put you in touch with a volunteer.
- **Go to your local cancer support centre.** For more information, see page 158.

“ It is so difficult to describe the impact that such a diagnosis had on my life and that of my family. Devastation, pure and utter...a polite way of putting it. I almost instantly felt all hope vanish. But I want to tell you that I’m alive nearly 3 years later and I don’t feel or look like I’m at death’s door! Amazing! ”



Why was the cancer not picked up earlier?

You might wonder why the metastatic breast cancer was not picked up earlier during your check-up visits. Your doctor is unlikely to do scans or other tests routinely after breast cancer treatment. They will only do them if they suspect something is wrong. Having these tests regularly cannot stop cancer from spreading because the cancer cells may be so small they cannot be seen on scans.

Often your doctor may not want to expose you to the radiation involved in some tests, unless necessary. You might assume the tests are not done because they cost too much. But this is not true, even though many scans are expensive. You might find it hard to accept that certain scans and tests are not part of your routine check-up. Talk to your doctor for reassurance about this.

Having metastatic breast cancer as your first cancer diagnosis ('de novo' cancer)

Most people diagnosed with metastatic breast cancer were diagnosed with primary breast cancer previously. They have been through tests, treatments and side-effects. They are familiar with their healthcare team in the hospital and have learned how to cope with the disease.

Some people are diagnosed with metastatic breast cancer as their first cancer diagnosis – they have not had a previous diagnosis of breast cancer. 'De novo' means the breast cancer is metastatic 'from the start'.

Being diagnosed with metastatic breast cancer as your first cancer diagnosis is not common, but it can be incredibly overwhelming.

Your healthcare team will guide you through your diagnosis and treatment and we are here to help too. Our Cancer Nurses can support you and give you information on counselling and other services. Call our Support Line or visit a Daffodil Centre to talk to a nurse.

Email: supportline@irishcancer.ie

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure of how to break the news or need a little time to adjust. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a Cancer Nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer***. It can help you find ways to talk about your cancer and to ask for the help and support you need.



What tests will I have?

After being diagnosed with metastatic breast cancer, you may have more tests to find out about your cancer and your general health. Your doctor will tell you which tests they think you should have and why. Some tests will examine your bones, liver and lungs or sometimes your brain, as these are the most common places that breast cancer spreads to. Tests you may have include:

Blood tests

Blood tests can check your general health, including how well your kidneys and liver are working. Some cancers make chemicals that can be found in your bloodstream. These are called tumour markers. The CA 15-3 tumour marker blood test can monitor how well treatment is working and detect recurrence in some metastatic breast cancers. Blood tests can also check the amount of calcium in your blood (See page 13).

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help parts of your body show up on the scan. The injection may make you feel hot all over for a few minutes.



During the scan you will lie on a table that passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

For most scans you will be alone in the treatment room, but the medical team can still see you, hear you and speak to you. Just speak or raise your hand if you need anything.

Bone scan

For this test a tiny amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken of all the bones in your body. Because abnormal bone absorbs more of the radioactive substance than normal bone, the abnormal bone shows up as highlighted areas. After the injection you will have to wait about 3 hours before the scan can be taken. You may want to bring a book or magazine with you, or a friend to keep you company.

The level of radioactivity is very low and disappears within a few hours. But you should avoid babies, young children and anyone who is pregnant until the day after the test. This test is not recommended for people who are pregnant.

X-rays

X-rays use high-energy rays to take pictures of the inside of your body.

An X-ray of your bones can give a picture of the general condition of your bones. A chest X-ray may show if there is any breast cancer in your lungs. It might also look for a build-up of fluid in the space between your lungs and chest wall.



MRI scan

This is a scan that uses magnetic energy and radio waves to create a picture of the tissues inside your body.

An MRI can also be noisy, but you will be given earplugs or headphones to wear. You might get an injection before the scan to show up certain parts of your body. Sometimes patients feel like they need to pee after the injection, or it may make you feel hot all over. It is important that you keep as still as possible during the scan.



During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or metal pin, you may not be able to have this test.

During the test you will lie inside a tunnel-like machine. The length of time depends on the number of images that are needed and the area of the body being scanned. Some people are afraid they will feel anxious or claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

PET scan

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radiotracer (radioactive sugar) is injected into your arm. An hour or so later you will have a scan. The PET scan uses the radiotracer to highlight cancer cells in the body. Before the scan, you may have to fast (not eat) and drink only plain unflavoured water for a few hours. You may also be asked to avoid strenuous exercise the day before and the morning of the scan.



During the scan, you will lie on a table that moves through a scanning ring. The scan usually lasts between 20 and 60 minutes. You will be asked to stay still during the scan. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

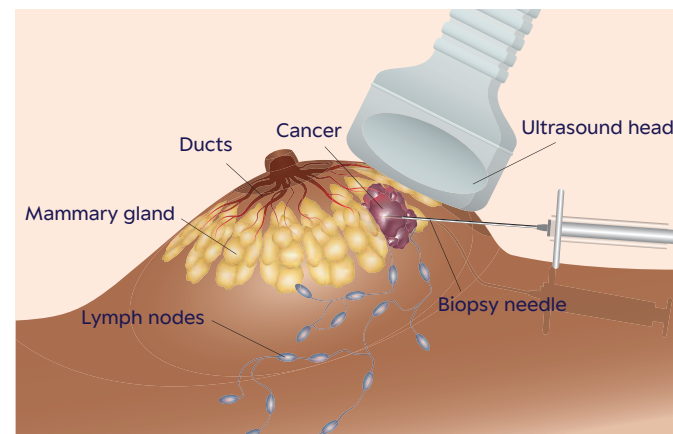
You will be slightly radioactive after the PET scan, so you should not have close contact with pregnant women, babies or young children for a few hours after the scan. Drink plenty of fluids and empty your bladder regularly after the scan; this can help flush the radiotracer from your body.

Biopsy

If metastatic breast cancer is your first diagnosis of cancer, your doctor will take a small piece of tissue from your breast to confirm your diagnosis. This procedure is called a biopsy. Biopsies can also help to find out whether the cancer cells have certain receptors that encourage the cancer cells to grow. For example, the hormone oestrogen (ER) or the HER2 protein.

If you have been diagnosed with breast cancer before, you might have a biopsy to see if the cancer is the same type as your first diagnosis. Tissue may be taken from the area where the metastatic cancer is, such as your bones or liver.

You usually have a biopsy under local anaesthetic so you will be awake for the procedure. The doctor uses an ultrasound or a CT scan to help them guide the biopsy needle to the right place.



Waiting for test results

It usually takes up to 2 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a Cancer Nurse.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy. It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.



Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on your prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor or nurse again after you have thought about everything.

If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, email supportline@irishcancer.ie or visit a Daffodil Centre. Our Cancer Nurses can give you support, information and advice. They can also tell you about free counselling and other services that may help you.

Email: supportline@irishcancer.ie



Treating metastatic breast cancer

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How is metastatic breast cancer treated?

The aim of treatment for metastatic breast cancer is to control the growth and spread of the cancer rather than cure it. Treatment can also help to relieve your symptoms and improve your quality of life. The best treatment for you will depend on:

- Where the metastatic cancer is in your body
- If your breast cancer cells are positive or negative for hormone receptors or the HER2 protein
- Your age and if you have gone through menopause or not
- Any previous cancer treatments and your response to those treatments
- How the cancer affects your everyday living and quality of life
- Your personal preference



Types of treatment

There is a range of treatments available to manage metastatic breast cancer. If one treatment doesn't work, or if the side-effects are difficult to manage, your doctor will look at other treatment options. You may receive more than one type. They include:

Hormone therapy

The female hormones oestrogen and progesterone can cause the growth of some breast cancer cells. Changing the level of these hormones in your body can slow down or stop the growth of metastatic breast cancer. Hormone therapy is suitable if you have oestrogen-receptor positive or progesterone-receptor positive cancer. It is usually used as the first treatment for metastatic breast cancer and may be used alone or with other treatments. See page 61 for more details.



Targeted therapies

These drugs work with your body to fight cancer. Different targeted therapies work in different ways. Those used for breast cancer usually work by stopping the breast cancer cells from dividing and growing. See page 70 for more details.

Immunotherapy

Immunotherapy helps the body's immune system recognise and attack cancer cells. Immunotherapy may be an option for some types of metastatic cancer. It is often given together with chemotherapy, but it's not helpful for all cancers. Tests on the tumour sample can show if immunotherapy is likely to be helpful for you. See page 70 for more.



Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. You may be offered chemotherapy if your metastatic breast cancer is growing quickly or is affecting the function of your liver or lungs. You might also have chemotherapy if you do not have positive hormone receptors on your breast cancer cells or if you have stopped responding to hormone therapies. See page 74 for more details.

Radiotherapy

Radiotherapy uses X-rays to destroy cancer cells. The aim of radiotherapy in metastatic breast cancer is to reduce the size of the cancer in some parts of your body and relieve symptoms such as pain. It is mostly used when the cancer has spread to your bones, lungs or brain. See page 83 for more details.

Bisphosphonates

Drugs called bisphosphonates are used to treat the effects of metastatic breast cancer in your bone. They work by relieving bone pain, reducing the risk of fractures and controlling the level of calcium in your blood. See page 87 for more details.

Surgery

Surgery is rarely an option for people with metastatic breast cancer. Drugs tend to be a better treatment option. Surgery is unlikely to remove all the cancer. If your cancer is confined to a small area, your doctor may consider surgery. See page 90 for more details.

Clinical trials

Ask your consultant if you are suitable for a clinical trial. For more information on clinical trials, see page 92.



Treatment of symptoms and palliative care

Some symptoms of metastatic breast cancer may need to be treated straight away. For example, bone pain or breathlessness. Treating symptoms is also called palliative care. Palliative care aims to control your symptoms and give you the best quality of life possible. It includes end-of-life care but it may be given at any stage to relieve symptoms such as pain and nausea. The palliative care team may be involved in your care at many different times. See page 118 for more details.

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a medical oncologist, radiation oncologist, radiologist, pathologist and breast care nurse. The team will meet to discuss your test results and your suggested treatment plan.



Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could also use the fill-in pages at the back of this booklet for your questions and answers.

If you do forget something or need more explanations, ask your specialist nurse or talk to one of our Cancer Nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor can refer you to another specialist for a second opinion if you feel this would be helpful.



Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

“ In relation to your healthcare team, ask them the medical questions you need answers to and make separate appointments if you feel they are rushed in the ward. ”

Email: supportline@irishcancer.ie

Who will be involved in my care?

Usually a team of health professionals will be involved in your treatment and care.

Consultant: An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Medical oncologist: A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Radiation oncologist: A doctor who specialises in treating cancer patients using radiotherapy.



Radiologist: A doctor who specialises in interpreting X-rays and scans, such as ultrasound, CT, MRI and PET.

Radiation therapist: A healthcare professional who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

Oncology liaison nurse/clinical nurse specialist (CNS): A specially trained nurse who works in a cancer care unit. They give information and support to you and your family from diagnosis and throughout treatment.

Surgeon: A doctor who specialises in surgery and who can remove a tumour from your body.

Pathologist: A specialist who examines tissue samples (biopsies) under a microscope to diagnose cancer and other diseases.

Medical social worker: A person trained to help you and your family with your emotional and practical needs. They can give advice on social welfare benefits, practical supports and services available to you, and financial and family matters.



GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

Dietitian: An expert on food and nutrition. They can advise you on diet during your illness and on how to use your diet to help symptoms.

Occupational therapist: A therapist who specialises in helping people who are ill or have disabilities learn to manage their condition and their daily activities, such as washing and dressing, housework, parenting, work and leisure activities.

Psycho-oncology team: These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist: A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.



Pharmacist: A healthcare professional who dispenses chemotherapy and other cancer drugs. Pharmacists may be based in hospitals or in local pharmacies. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Palliative care team: This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.



Community health services: This includes family doctors, public health nurses (who can visit you at home), community welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Individual treatment

You may notice that other people with metastatic breast cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak one of our Cancer Nurses.

While you're waiting for treatment, you might like to focus on your own health. This can help you prepare for your treatment and feel more in control.

Pre-treatment education workshops

Ask your specialist nurse, call our Support Line or visit a Daffodil Centre for information on our chemotherapy education group sessions. The sessions give information on what to expect and how to manage side-effects.

You can also learn about different treatments, such as targeted therapies, by watching our patient education videos at www.cancer.ie/our-services

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel as well as possible.

Eat well

Eating well when you have cancer can help you feel better. It can help you to:

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better, so you can finish your course of treatment
- Cope better with treatment side-effects
- Reduce your risk of infection and other complications
- Recover faster



Ask to talk to the dietitian at the hospital for advice on the best diet for you. We provide group online information sessions with an Oncology Dietitian, to support you to eat well during cancer treatment and beyond. You can also read our booklet ***Understanding diet and cancer***. For more information, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Stay active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you and may have information on exercise programmes and classes. Call our Support Line or visit a Daffodil Centre for information and support on how you can make exercise part of your everyday life. Ask about our free exercise classes to build strength and fitness in a supportive environment.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections.
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work.
- Not smoking can help you to heal better after surgery.
- Quitting reduces your chance of further illness.



If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Alcohol

Cut down on the amount of alcohol you drink. Alcohol can interfere with the way some drugs work, so you may need to stop completely. Your doctors and nurses will give you specific advice.



Our Cancer Nurses can give you more information about preparing for treatment, including free booklets. They can also connect you to our supports and services. Call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.



Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

Activities like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. There is help and support available if you are finding it hard to cope. Call into your nearest Daffodil Centre or call our Support Line on 1800 200 700.



Try to cope day by day

Some people find it helpful to concentrate the present and on getting through each day of tests or treatment. That may help you to cope with your illness, especially if you are worrying a lot about the future.



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Hormone therapy

- Hormone therapy only works for oestrogen and/or progesterone-receptor positive cancers.
- The choice of hormone therapy will depend on whether or not you have gone through menopause.
- Hormone therapy can cause some side-effects.

Hormone therapies are often used as the first treatment for metastatic breast cancer. They can be used alone or with other treatments.

How does hormone therapy work?

Some breast cancers are oestrogen receptor (ER) and progesterone receptor (PR) positive. This means they are encouraged to grow by the female hormone oestrogen. Oestrogen can be produced in 2 ways:

- The ovaries produce oestrogen.
- An enzyme called aromatase converts hormones called androgens into oestrogen.

All hormone therapies try to stop oestrogen from helping ER-positive breast cancer and PR-positive breast cancer to grow. Different types of hormone therapies work in different ways:

- Aromatase inhibitors stop aromatase from changing androgens into oestrogen. See page 63 for more about aromatase inhibitors.
- Anti-oestrogen drugs stop oestrogen from attaching to breast cancer cells and encouraging them to grow. See page 64.
- Ovarian treatments stop your ovaries from producing oestrogen. See page 65 for more about ovarian treatments.

If you had a hormone therapy to treat your primary breast cancer, you may need to have a different type to treat the metastatic cancer.

The benefits of hormone therapy can sometimes last for several years.



How does the menopause affect the choice of hormone therapy?

A natural menopause means you have not had a menstrual period for 12 months, where there is no other external cause for not having periods, such as medication. Whether you have reached menopause or not affects the choice of hormone therapy.

Before the menopause (pre-menopausal)

If you haven't been through the menopause, all types of hormone therapies are suitable for you. You may be given a combination of treatments, usually:

- An ovarian treatment to stop your ovaries from producing oestrogen
- An anti-oestrogen drug or an aromatase inhibitor to stop oestrogen from helping breast cancer cells to grow

After the menopause (post-menopausal)

After the menopause the ovaries stop producing oestrogen, so ovarian treatments are not helpful for you. You will most likely be treated with either:

- An aromatase inhibitor
- An anti-oestrogen drug



Types of hormone therapy

Aromatase inhibitors

Aromatase inhibitors block the enzyme aromatase, which changes hormones called androgens into oestrogen. Examples of aromatase inhibitors include anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®). They are given as tablets.

If your primary breast cancer was treated with an aromatase inhibitor, you may be given a different type to treat your metastatic cancer. Or you may be prescribed an anti-oestrogen drug like tamoxifen, which stops oestrogen from helping the cancer cells to grow. You might have several types of hormone therapies one after another to keep your disease under control.

Aromatase inhibitors can cause side-effects. They can cause vaginal dryness, nausea, and muscle and joint pain. Tell your medical team if you are bothered by any side-effects. Bone density scans may be done before starting treatment and regularly during treatment, as the drug can increase bone loss. There are treatments that can improve your bone strength.

Anti-oestrogen drugs

Anti-oestrogen drugs stop the hormone oestrogen from helping oestrogen-receptor positive cancer cells to grow. They do this by stopping oestrogen from attaching to the receptors on the cancer cells. Examples of anti-oestrogen drugs include tamoxifen or fulvestrant (Faslodex®). Tamoxifen can be given before or after the menopause. Fulvestrant is given to women who have been through the menopause.

What's the difference between hormone therapy and hormone replacement therapy (HRT)?

Although the names are similar, the cancer treatment hormone therapy and HRT are very different.

Hormone therapy is also called '**anti-hormone therapy**' because it works 'against' hormones. Hormone therapy drugs **reduce oestrogen** levels or **block oestrogen** from helping cancer cells to grow.

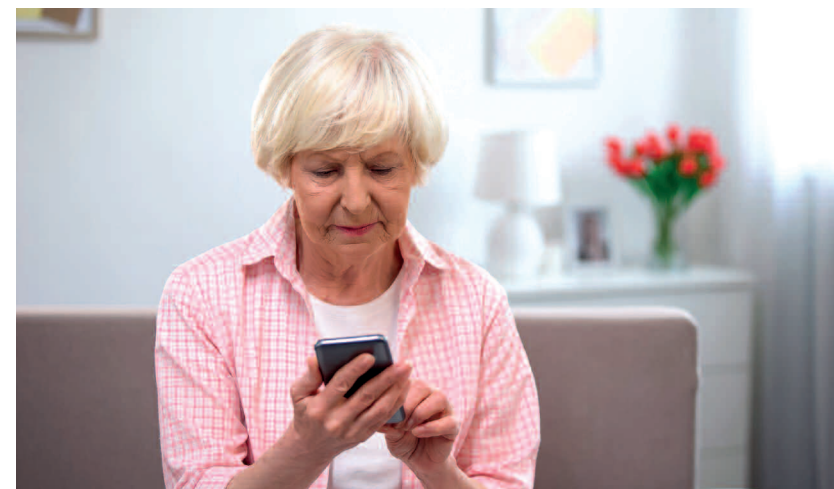
HRT **increases the level of oestrogen** in your body when levels are low because of the menopause. If hormones help your cancer to grow, you will probably be advised not to take HRT.

Ask your consultant about this.

Tumour flare

If you have metastatic breast cancer in a bone, you may find that tamoxifen makes the bone pain worse for the first few days. This is known as tumour flare, but it eases after a while. Let your doctor know if this happens. In general, the benefits of taking tamoxifen far outweigh the risks if your cancer is oestrogen-receptor positive.

If you would like more information on the different types of hormone drugs, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



Ovarian treatments

If you have not been through the menopause and your metastatic breast cancer is oestrogen-receptor positive, your doctor might suggest an ovarian treatment. Ovarian treatments stop your ovaries from making oestrogen. The treatments can be temporary (ovarian suppression) or permanent (ovarian ablation). You will usually have these treatments in combination with an aromatase inhibitor or an anti-oestrogen drug.

There are 3 ways to stop your ovaries from making oestrogen:

Drug treatment

Drugs are used to 'switch off' your ovaries temporarily. The drugs change the levels of the hormones released in your brain that control how your ovaries work. One example of this type of drug is goserelin (Zoladex®). When you stop taking the drug, your ovaries should start producing oestrogen again and your periods should return. If you are close to menopausal age, your periods may not return.



Surgery

Surgery involves removing your ovaries. Your periods will stop immediately if your ovaries are removed.

Radiotherapy

Radiotherapy uses high-energy X-rays to stop your periods so your ovaries will no longer produce oestrogen.

Surgery and radiotherapy are rarely used to stop the ovaries from making oestrogen. Most people will have drug treatment.

Both surgery and radiotherapy will permanently stop your ovaries from working, so you will no longer have periods.

What are the side-effects of hormone therapy?

Hormone therapy may cause short- or long-term side-effects. You should get an information sheet about your hormone therapy, which will tell you about possible side-effects. You can also ask your doctor or nurses.



As with all treatments, side-effects can vary. It also depends on whether or not you have gone through the menopause. Side-effects include:

- Menopausal symptoms
- Bone density loss
- Bone and joint pain
- Blood clots
- Thickened womb lining, which may cause changes to the timing of your period or the amount of period bleeds

If you are still having periods, hormone therapy may cause periods to become irregular, lighter or stop altogether. The physical effects of this may include menopausal symptoms like hot flushes, night sweats, anxiety, lowered sex drive, dry skin and dryness of your vagina.

Usually the side-effects are mild and may reduce over time. See page 109 for more about menopausal symptoms. You can also visit our website www.cancer.ie for more about ways to cope, or you can get information and support from a Cancer Nurse by visiting a Daffodil Centre or by calling our Support Line on 1800 200 700.



Infertility

Some hormone therapies can cause your periods to stop permanently, which means you will not be able to get pregnant naturally. It is not easy to come to terms with infertility. It can be very distressing if you are already coping with metastatic breast cancer. See page 115 for more about infertility.

Blood clotting

Some drugs slightly increase the risk of blood clotting. Tell your doctor if you have any chest pain, swelling, tenderness in your legs or arms or any new shortness of breath.

Thickened womb

Some drugs can cause the lining of your womb to become thickened or put you at a small risk of developing cancer of the womb. You should report any vaginal bleeding to your doctor.

Bone loss

Oestrogen helps to keep your bones strong and healthy. If your treatment lowers the amount of oestrogen in your body, there is a risk that your bones may become weaker and more likely to break. You may have regular scans to monitor your bone health during your treatment. You should also stop smoking, take regular exercise and eat calcium-rich foods. Ask your doctor about taking calcium supplements and about the best exercise for you. Some activities may not be recommended if your bones are weakened. Drugs may be prescribed if there is serious bone loss (osteopenia or osteoporosis). For more about bone health, see page 105.

Bone and joint pain

Some drugs may cause pains and aches in your muscles or bone joints.



Managing side-effects

Ask your doctor or nurse what side-effects you can expect and how to manage them. Usually these side-effects are mild and may reduce over time. If you continue to find them a problem, talk to your doctor or nurse. For more information about side-effects, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also find more information on our website, www.cancer.ie

Targeted therapies and immunotherapy

- Targeted therapies are drugs that target certain parts of the cancer cells that make them different from other cells.
- The drugs can be given by tablet or into a vein through a drip.
- Immunotherapy helps the body's immune system recognise and attack cancer cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies work with your body. They can help fight cancer, stop it spreading or control side-effects. Different types of targeted therapies work in different ways. For example:

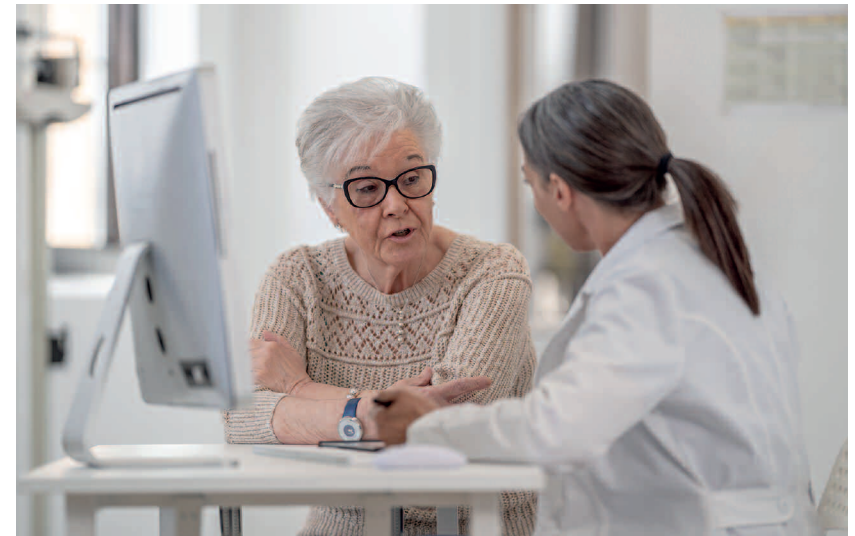
- Cancer growth inhibitors block the chemical signals that trigger cancer cells to divide and grow.
- Monoclonal antibodies trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.
- Angiogenesis inhibitors interfere with the blood supply to the cancer cells.
- Immunotherapy boosts your body's immune system to fight cancer.

Some targeted therapies fit into more than one of these categories. The targeted therapies used most often for metastatic breast cancer are:

Monoclonal antibodies, for example, trastuzumab (Herceptin®) and pertuzumab (Perjeta®). They target cancer cells that make too much of a protein called HER2. This protein is found on the surface of some cancer cells. The drugs work by attaching to the HER2 protein and slowing down or stopping the cancer cells' growth.

Antibody-drug conjugates, such as trastuzumab deruxtecan and sacituzumab govitecan, can also be used in HR-positive, HER-negative and triple-negative breast cancer. Antibody-drug conjugates combine a monoclonal antibody with an anti-cancer drug, for example a chemotherapy drug.

CDK4/6 inhibitors are designed to stop enzymes that help cancer cells grow. The types of CDK4/6 inhibitors commonly used to treat ER-positive, HER2-negative metastatic breast cancer are palbociclib (Ibrance®) and ribociclib (Kisqali®). Both of these drugs are usually given in combination with hormone therapy. Palbociclib and ribociclib are given as tablets.



PARP inhibitors can help stop cancer cells from repairing, so that they become too damaged to survive. You may be given a PARP inhibitor if your cancer is HER2 negative with an altered BRCA gene.

Cancer growth inhibitors, for example lapatinib (Tyverb®). Some drugs are given as tablets. Others are given into a vein through a drip.

How does my doctor decide which drugs to use?

Deciding which targeted therapy is best suited for you is determined in a number of ways. One of the main factors is the biology of the tumour – looking at the cells to see if they have receptors and proteins on their surface that a particular therapy can target. For example, the HER2 protein.

The cells are taken during a biopsy and looked at under a microscope. Biopsies from an area of secondary cancer may also be checked – it does not have to be breast biopsy.



Most people with ER-positive, HER2-negative cancers are treated with CDK4/6 inhibitors and hormonal therapy. About 1 in 5 people will have a HER2-positive breast cancer diagnosis and they will need different drug treatments.

If you had a HER2-positive breast cancer diagnosis and the cancer comes back, it may not be HER2-positive again. This is why biopsies on metastases are done, to check the biology of the tumour.

To decide which drugs to use, your doctor may also consider:

- Previous treatments you have had
- How well you have tolerated side-effects
- Any other underlying health issues you have

Side-effects of targeted therapies

Side-effects depend on the drugs being used and vary from person to person.

Common side-effects include:

- Allergic reaction
- Nausea
- Fatigue
- Flu-like symptoms
- Headaches
- fever and chills
- Diarrhoea

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you. For more information on targeted therapies and their side-effects, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Immunotherapy

Immunotherapy helps the body's immune system recognise and attack cancer cells. Immunotherapy drugs may be an option for some types of triple-negative breast cancer. A test on a sample of your cancer cells can measure how much of a protein called PD-L1 is on the cells. This test can tell your doctors if immunotherapy might be helpful for you. Immunotherapy is often combined with chemotherapy.

The most commonly used immunotherapy drugs are checkpoint inhibitors like pembrolizumab or atezolizumab. Immunotherapy is usually given as a drip into a vein in a hospital or day unit. Some drugs may be given as an injection just under the skin.

Often you will stay on immunotherapy for as long as it's working and any side-effects are manageable. Your treating team will go through possible side-effects with you.

New treatments

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 92). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Chemotherapy

- Chemotherapy is a treatment using drugs to control cancer growth.
- Chemotherapy can be given as tablets, directly into a vein as an injection or through a drip (infusion).
- The side-effects vary from person to person and depend on the drugs used.
- Some common side-effects are fatigue, nausea and vomiting, sore mouth and peripheral neuropathy.

Chemotherapy is a treatment using drugs to control the cancer. The doctor who specialises in chemotherapy is called a medical oncologist. The aim of chemotherapy for metastatic breast cancer is to slow down or stop the growth of the cancer. Chemotherapy is usually an option if you are not responding to hormone therapy or if your cancer is hormone negative. It might also be used for cancers that are growing quickly or affecting your liver or lungs.

Chemotherapy can relieve symptoms such as pain by controlling the growth of cancer and improve your quality of life. For some people, chemotherapy can make the cancer smaller and keep it under control. When your medical team is deciding your treatment

plan, your quality of life will be a very important consideration. The benefits of treatment with chemotherapy can sometimes last for years.

How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment.

The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection or through an intravenous infusion (drip). It may also be given as tablets. Usually your treatment will be given in the chemotherapy day unit.

You might receive your chemotherapy as part of a clinical trial. See page 92 for more details.



What kinds of drugs are used?

There are several chemotherapy drugs used to treat metastatic breast cancer. Chemotherapy drugs can be used on their own or in combination with each other. If one type doesn't work, there are usually more options. If you had chemotherapy to treat primary breast cancer, you will probably be given a different drug to treat your metastatic cancer. Your doctor or nurse will discuss your individual treatment plan with you.



Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you. If you know the name of a drug prescribed for you, visit the Health Products Regulatory Authority's website at www.hpra.ie for more information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our Cancer Nurses by calling our Support Line on 1800 200 700 or visiting a Daffodil Centre.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depends on the amount of chemotherapy you have and the drugs used.

Ask your doctor or nurse if you're worried about side-effects or have any questions.



Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

Fatigue

Fatigue is very common. It can make you feel tired and weak. For more information see page 107.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurse if they are not working well for you. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.

Risk of infection

Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine. If you have a high temperature or feel unwell (even with a normal temperature), it is very important to call the hospital straight away – never delay. Check with your hospital about the temperature advice to follow.

Anaemia

Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.



Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.



Menopausal symptoms

Chemotherapy can affect your ovaries, so you may experience symptoms of menopause, such as hot flushes. Sometimes chemotherapy brings on an early menopause. For more about managing menopausal symptoms see page 109.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will usually grow back 3 to 6 months after you stop chemotherapy. Some patients find attending a trichologist (hair specialist) after chemotherapy can be helpful for hair growth support. You can also talk to your nurse about hair care. For example, if you are thinking about perms or colouring your hair. Some treatments can cause permanent hair loss for some patients, but this is rare.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement (poo) often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help, if needed. Diarrhoea can be a sign of infection and you may also get dehydrated quickly when on chemotherapy, so let your medical team or GP know if you have diarrhoea while on chemotherapy.



Skin and nail changes

Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle. Tell your nurse if your fingertips have cracked or if your nailbed is sore – they may need to be examined.

Peripheral neuropathy

Some drugs can affect your nerve endings. It's important to tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Changes in kidney or liver function

Some drugs can irritate or damage kidney and liver cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

Allergy

On rare occasions people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath. Contact the hospital if you have these side-effects.

Blood clots

Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.



Changes in hearing

Some chemotherapy drugs can cause buzzing or ringing sounds in your ears. This is called tinnitus. Tinnitus can be very distressing. Let your doctor know if there is any change in your hearing.

Sore eyes

Some drugs can make you may feel as if you have grit in your eyes. Your doctor can prescribe suitable eye drops for you.

Feeling confused or memory problems

You might feel 'vague' or mildly confused or have memory problems while having chemotherapy. This is sometimes called 'chemo brain' or 'chemo fog'. Tell your doctor or nurse if you feel this way.



Effects on fertility

Chemotherapy can cause infertility. This is more likely if you are nearer to natural menopause. Infertility can be very hard to come to terms with. See page 115 for more.

If you have any symptoms that are troubling you or if you feel unwell, tell your doctor or nurse straight away. You will be given contact details of who to contact before you start your treatment.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, www.cancer.ie for tips on coping with different side-effects.

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- Side-effects affect the area of the body where the radiotherapy is aimed.
- Side-effects normally go once your treatment is over, but some can last a long time or develop later on.

Radiotherapy uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

Radiotherapy may help if the cancer has spread to your bone, skin, lymph nodes or parts of your brain. It is a localised treatment, which means it only treats the area of your body that it is aimed at.

If cancer has spread to your bones, the aim of radiotherapy is to improve your mobility, decrease pain and prevent any possible fractures or spinal cord compression. It should also make you feel more comfortable.

If the cancer has spread to other parts of your body, it can shrink the tumour and relieve pain or swelling.



How is radiotherapy given?

With external beam radiotherapy, the radiation comes from machines, which aim rays directly at your tumour or the tumour site. The machines are called linear accelerators. External radiotherapy does not make you radioactive. It is completely safe for you to mix with family and friends, including pregnant women and children.



Planning your treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells. You will have a CT scan to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day.

How much radiotherapy do I need?

Usually you will only need a short course of radiotherapy. You may have a single dose or a dose divided over a few days.



Side-effects of radiotherapy

Radiotherapy is given directly to the site of the cancer. This means any side-effects tend to affect the area of the body being treated. Because metastatic breast cancer usually only needs a short course of radiotherapy, most people have few side-effects. Some common side-effects are:

Nausea

Radiotherapy to your stomach area or brain may make you feel sick. This can be prevented or relieved by taking anti-sickness drugs before your treatment. Your doctor will prescribe these for you.

Fatigue

Fatigue or tiredness can build up over the course of your treatment. You may feel tired because of the treatment itself or perhaps because you are travelling long distances for treatment.

Rest as much as you need to. Regular gentle exercise such as walking can help to improve tiredness. See page 107 for more on fatigue.



Skin changes

You may get some redness of your skin on the treated area. But it is rare to have skin reactions. Ask the radiotherapy staff in your treatment centre for skin care advice and how to feel more comfortable.

Hair loss

You may lose body hair in the area being treated. If you have treatment to your brain, you are likely to have hair loss from your head. Hair usually starts to grow back within 2 to 3 months of treatment finishing.

Pain

Radiotherapy for metastatic bone cancer can cause a flare-up of pain in the treatment area for a few days and you may need to take painkillers to help.

How severe these side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment.

For more information on the side-effects of radiotherapy or a copy of the booklet ***Understanding radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Bisphosphonates for bone metastases

- Bisphosphonates can prevent bone damage in bones affected by metastatic breast cancer.
- They can help reduce pain that has not responded well to painkillers or is too widespread for local radiotherapy.
- Bisphosphonates can reduce high calcium levels in your blood.

If the metastatic breast cancer is affecting your bones, you might be treated with a group of drugs called bisphosphonates. These can slow down or prevent bone damage and may reduce the spread of cancer.

Bisphosphonates can also be used to lower calcium levels in your blood if you have a condition called hypercalcaemia. This occurs when too much calcium escapes from the damaged bone into your bloodstream. High calcium levels can cause problems, such as nausea, vomiting, thirst, constipation and drowsiness.

Bone can be seriously weakened by cancer. In this case, bisphosphonates can help to strengthen bone and reduce the risk of fractures. Bone pain can be reduced as well. In fact, the drug can help reduce pain that has not responded well to painkillers or is too widespread for local radiotherapy.

How are bisphosphonates given?

Bisphosphonates can be taken orally as tablets once a week or once a month. Some may be given as an injection into a vein, for example zoledronic acid (Zometa®) every 1 to 3 months. This happens either in the hospital or the community and takes about an hour.

Usually bisphosphonates are a long-term treatment and are given for as long as you are benefitting from them. It is extremely important to take bone-strengthening medications exactly as prescribed to get the best benefit.

What are the side-effects of bisphosphonates?

There are several possible side-effects to bisphosphonates but many people don't get any side-effects. Some mild side-effects happen at the start of treatment. For example, bone pain and flu-like symptoms. The tablets can sometimes cause diarrhoea, constipation and heartburn. Very rarely, bisphosphonates can cause jaw problems. Try to visit your dentist regularly and let them know that you are taking bisphosphonates.

Tell your doctor or dentist immediately if you develop any problems with your teeth or gums, or swelling, pain, heaviness or numbness of your jaw while you are taking bisphosphonates or targeted therapies.

Targeted therapies

A type of targeted therapy called a monoclonal antibody can also be used to prevent fractures and other cancer-related bone problems. An example is denosumab (Xgeva®, Prolia®). Tell your doctor or dentist immediately if you develop any problems with your teeth or gums, or swelling, pain, heaviness or numbness of your jaw while you are taking targeted therapies..



More about bone health

For more about bone health, see our website www.cancer.ie which has lots of information on bone-strengthening drugs, keeping bones healthy, avoiding falls, dental care and diet. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Surgery

Surgery is generally not an option for most people with metastatic breast cancer. It's unlikely to remove all the cancer and drug treatments tend to be better options. Surgery is mainly used to help control your disease and reduce your symptoms.



Your doctor might advise having surgery in the following situations:

First diagnosis

If metastatic breast cancer is your first diagnosis, you might need surgery to remove a sample of breast tissue (biopsy) to confirm your breast cancer diagnosis. Your surgeon may remove the primary breast cancer if the tumour is small. Your doctor will tell you if surgery to the breast is likely to be helpful in your situation.

Bone

If the cancer has spread to your bone, surgery can treat a fracture or replace a joint damaged by cancer.

Lungs

If the cancer has spread to the lining of the membrane outside your lungs (pleura), or to the lungs themselves, there are different types of surgery to manage the cancer.

Brain

If the cancer has spread to your brain, surgery can be used to remove small areas of cancer or drain fluid from your brain.

Liver

If the cancer has spread to your liver, it may be possible to operate to remove a small cancer in a single area of the liver.

Other reasons for having surgery

Surgery can help if the cancer has grown out through your skin or is pressing on nerves and causing pain or a blocked bowel.



What are the side-effects of surgery?

The side-effects of surgery will depend on the type of operation you have. Ask your surgeon or nurse to explain why the surgery is recommended for you and what will be involved.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Clinical trials

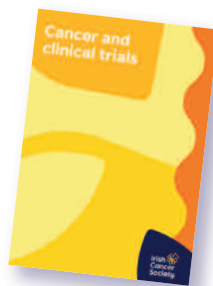
Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Patients with cancer are sometimes asked to consider taking part in a clinical trial. Clinical trials investigate new treatments and/or using existing treatments in different ways. For example, giving a different dose of a drug or using 2 treatments together.

If treatment is given as part of a clinical trial, you will be closely monitored and may have extra tests and appointments. Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial.

For more information, you can read our factsheet **Cancer and clinical trials**. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre. You can see a list of current cancer trials at www.cancertrials.ie



“Ask about drug trials, new combinations of drugs and research coming down the line. There is so much more hope for effective treatments now than when I was first diagnosed. I have friends on treatment for metastatic breast cancer for over 10 years who are living energetic lives!”

Managing side-effects and symptoms

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How can my symptoms be relieved?

Some symptoms of metastatic breast cancer can be linked to the cancer itself or you may have side-effects linked to treatment. Your symptoms will depend on how the metastatic breast cancer has affected you. You may experience:

- Pain
- Nausea and vomiting
- Breathing problems
- Difficulty sleeping
- Swelling of the arm (lymphoedema)
- High calcium levels in blood
- Bone pain and weakened bones
- Constipation
- Fatigue

If you have any symptoms that are troubling you, let your doctor or nurse know. Sometimes radiotherapy and chemotherapy can be used to help symptoms. But there are other treatments that can help to make your life easier too.



Pain

Lots of people worry about pain, however many people with metastatic breast cancer do not have pain. If you do get pain, it can be helped. Tell your doctor or nurse immediately if you are in pain. Your doctor will try to find out what is causing it so that you get the right treatment. Pain can also be due to other medical conditions that have nothing to do with your cancer.



Painkilling drugs

Your doctor will decide which painkiller is best suited to the type of pain you have. If the medication doesn't ease the pain, tell your doctor or nurse. There are lots of options, so if one medicine doesn't work, your doctor will try something else. A palliative care specialist who manages pain and other symptoms may also be able to help you. They can arrange for you to try out different painkillers to see which suits you best.

Support Line Freephone 1800 200 700

Other drugs

Besides painkillers, several other drugs can be helpful in reducing pain. If the pain is due to metastatic breast cancer in the bone, anti-inflammatory drugs can be helpful. Other drugs known as bisphosphonates can also help to relieve bone pain. See page 87 for more about bisphosphonates.



Radiotherapy

Radiotherapy is very good for treating bone pain from metastatic breast cancer. It can be given as a single dose or divided over a few days. It usually takes at least 2-3 weeks to work. For more information see page 83.

“Coping with side-effects often becomes a challenge and you need to speak clearly to the team involved in your care. Hospitals are such busy places and it can be difficult to get the help you require. Persevere, seek help from your GP and enquire about support centres.”

Hints and tips: Pain

If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain that you are in. There is no need to suffer in silence or play down the amount of pain that you have. Taking care of pain is important.

- **Describe the pain as clearly as you can.** Is it a dull or sharp sudden pain? Is it always there or does it come over you in waves? Is it mild or severe? Do you wake up in pain during the night?
- **Write down the times you get pain and what makes it better or worse.** You could show this record to your doctor or nurse – it may help to explain your problem and help you to see any patterns in when you have pain.
- **Try to score your pain on a scale of 0 to 10**, where 0 means no pain at all and 10 means the worst pain you can imagine.
- **Take your painkillers regularly as advised by your doctor**, even if you don't have pain at a particular time. They will help to keep your pain under control.
- **Even though your pain may be well controlled most of the time, you may notice that the pain is worse at night and wakes you up.** Discuss this with your doctor or nurse. You can get extra medication to help with this 'breakthrough pain'.

Side-effects of painkillers

Some painkillers have side-effects, especially the opioid-based ones. These side-effects may include constipation, feeling sick (nausea) and drowsiness.

If you have constipation, it's a good idea to take a laxative every day. Drinking plenty of fluids such as water and fruit juice between meals will also help keep your bowel habits regular. Tell your doctor or nurse if your bowels have not opened for 2 or 3 days. They may give you a different laxative.

If you are feeling sick (nausea), your doctor may give you anti-sickness tablets. Take them as instructed. This nausea often improves as you get used to your medication.

Drowsiness may happen with some painkillers. It usually wears off after a few days. Follow the instructions about operating machinery or driving if you are taking painkillers.



Nausea and vomiting

With metastatic breast cancer, you might be sick (vomit) or feel sick (nausea) at some point during your illness. This can make everyday life very difficult to cope with. If you are having problems with feeling sick or vomiting, tell your doctor or nurse. There are ways to control sickness, depending on what is causing it. Nausea can be due to:

- The cancer itself
- Side-effects of drugs such as painkillers
- Constipation
- Too much calcium in your blood
- Treatments such as chemotherapy

There are many anti-sickness drugs available to treat nausea and they work in different ways. If the drug you are taking is not working, let your doctor know and a different treatment can be prescribed. You may need a combination of drugs to help prevent nausea and vomiting.

Email: supportline@irishcancer.ie

Hints and tips: Nausea

- **Talk to your doctor if you're feeling sick.** There are medicines to help. Take them as directed.
- **Eat before you get hungry**, as hunger can make nausea worse.
- **If you are sensitive to the smell of cooking, try using ready meals or avoid being in the kitchen while food cooks.** Ask a friend or family member to help with cooking, if possible.
- **Eating little and often may help.** Eat slowly and chew food well.
- **Sip clear liquids** to avoid getting dehydrated between meals.
- **Take plenty of nourishing fluids** if you miss a meal or two.
- **Rest after your meals.**
- **Try the following foods and drinks**, as they might help:
 - Cold, bland foods like yogurt, desserts, boiled potatoes, rice, noodles, breakfast cereals or cheese
 - Dry food like toast, scones, crackers or breakfast cereals
 - Herbal teas like mint
 - Foods containing ginger, such as ginger ale or tea, ginger nut biscuits, ginger cake or fresh ginger in hot water
- **Some people find the following foods make nausea worse:**
 - Fatty, greasy or fried foods
 - Spicy foods
 - Very sugary foods
 - Foods with a strong smell, like onions and garlic.
- **Eat foods that you like or can tolerate.** When your nausea improves, try other foods for variety (if you can tolerate them).
- **Some people find relaxation exercises, acupuncture or meditation help with their nausea.** Check with your doctor if you're thinking of trying acupuncture, to make sure it's safe for you.

Breathing problems

Shortness of breath can be very uncomfortable and distressing. This symptom may be caused by a tumour in your lung or in the lining outside it. There are ways to relieve the problem causing shortness of breath. For example, you may have extra fluid on your lung that is making it hard for you to breathe in a relaxed way. This is known as a pleural effusion. By removing this fluid, your lung can re-expand and breathing becomes easier. It is done by putting a small tube into your chest under a local anaesthetic. The tube can then be removed once all the fluid has drained.



You may need to stay in hospital if you are having a chest drain procedure, so that your team can monitor your breathing. If the drainage improves your symptoms but the fluid starts to build up again, your doctor may recommend a pleurodesis. This is where medication is put into your chest through the chest tube to cause the linings of your lung to stick together. This prevents fluid from building up again. Your medical oncologist may consult with the specialist cardiothoracic team to help with your care. An alternative to pleurodesis is a permanent drain insertion, which can be managed by a community team of nurses and doctors.

If cancer has spread to the tissue of your lungs, the painkiller morphine can be used to relieve the breathlessness.

Breathing exercises may also ease shortness of breath. Your doctor may refer you to a physiotherapist who will teach you the exercises. For more information on breathlessness, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie



Difficulty sleeping

During your illness, there may be times when you find it difficult to sleep. Often this is because you are anxious about treatment or worried about the future. Not being able to fall asleep when you have a lot on your mind may be the hardest part. If you are feeling depressed, you may find that you wake early and then cannot get back to sleep. If you find it difficult to sleep at night, tell your doctor or nurse.

Hints and tips: Sleep problems

- **Have a regular routine at bedtime.**
- **Take a warm milky drink before bed**, but not coffee or tea.
- **Have a warm bath with a few drops of lavender oil in it** or sprinkle a few drops on your pillow.
- **Listen to music or the radio if you cannot sleep.** Or get up and watch TV or read a book.
- **Listen to audiobooks, relaxation tapes or apps** to help you get back to sleep.
- **Complementary therapies may also help.** For more information, see page 116.

Swelling of the arm (lymphoedema)

Lymphoedema is a swelling caused by a build-up of lymph fluid, when the lymphatic system isn't working properly to remove the fluid. This can happen if lymph nodes are removed during surgery or after radiotherapy to treat cancer.

If you notice swelling anywhere on your arm, hand or breast area, even if it comes and goes, you should tell your GP, oncologist or breast care nurse. This can happen soon after treatment or after some time. Other signs to watch out for are:

- A feeling of tightness when wearing clothing, bracelets, watches or rings.
- A full, heavy, achy or weak feeling in the arm.
- A tight feeling in the skin.
- Dry, flaky, rough or scaly skin, or changes to your skin colour.
- Trouble moving your arm.

Your doctor can refer you to a lymphoedema therapist who can recommend treatments to help keep it under control. The sooner you get treatment the better. Lymphoedema is easier to manage early on. There is more information on lymphoedema and tips on managing the condition on our website, www.cancer.ie



You can also get information and advice from a Cancer Nurse by calling our Support Line on 1800 200 700 or by visiting a Daffodil Centre.

High calcium levels in blood

With cancer in the bone, more calcium is absorbed into your bloodstream from your bone. A high level of calcium in your blood is called hypercalcaemia. It can cause excessive thirst, vomiting, drowsiness and confusion. To be treated, you will need to spend a day or 2 in hospital to get your calcium levels down. This is done by giving you intravenous fluids or drugs called bisphosphonates to stop further damage to your bone. Drinking plenty of fluids will help too. With treatment, you should feel much better after a few days.

Bone pain and weakened bones

Metastatic cancer in the bone can cause bone pain. It also makes your bones weaker, with a risk of fractures. Bisphosphonates and monoclonal antibodies can help to relieve bone pain and help to strengthen bones and reduce the risk of fractures. See page 87 for more information about bisphosphonates.



Radiotherapy is very good for treating bone pain due to metastatic breast cancer. The treatment can be given as a single dose or divided over a few days. It can take 2 to 3 weeks to work.

If a bone is very weak, you may need surgery to strengthen it. This is done in hospital under a general anaesthetic. Your surgeon will put a pin into the centre of the weakened bone and might fix a metal plate to hold the bone firm as well. You will need to stay in hospital for a week or so to recover after this surgery.

Hints and tips: Taking care of your bones

- **Make sure you take any supplements or medication prescribed for you.**
- **Take regular exercise.** For most people, weight-bearing exercise (exercise when you are standing upright) with some impact is helpful. This includes walking, running, dancing, jumping, climbing stairs, tennis and football. It's also good to build your muscle strength with exercise using weights, or exercise using your body weight, such as squats or lunges. Always check with your doctor about the best exercise for you and how to exercise safely, especially if your bone density is low.
- **Make sure your diet has plenty of calcium-rich foods** like cheese, milk, sardines, yogurt, tofu and green, leafy vegetables.
- **Vitamin D is also important.** Vitamin D is found in eggs, oily fish (such as salmon, mackerel, sardines), liver and foods with added vitamin D, such as fortified milk and cereals. Ask your doctor if you should take a vitamin D supplement.
- **Keep a healthy weight.**
- **Limit alcohol and caffeine. Stop smoking.**
- **Take precautions around the house** to avoid falls and accidents.
- **Take care of your teeth** and visit the dentist regularly.

Constipation

Some drugs, particularly certain painkillers, may cause constipation. This means you may find it painful or hard to poo or you may feel bloated or have nausea. If this happens, let your doctor or nurse know as soon as possible. They can give you tips to help and tell you if you need a laxative. Getting some exercise can help to move your bowels. For example, walking or yoga. Also try to drink more clear fluids and eat more fibre, found in raw fruit and vegetables and wholewheat cereals.

Fatigue

It's common to feel exhausted when you have cancer. This extreme tiredness (fatigue) can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well



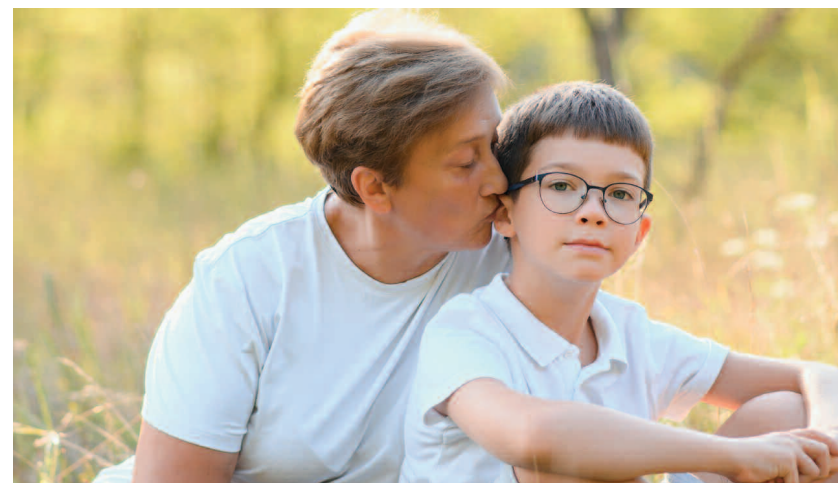
Tell your doctor or nurse if fatigue is affecting you, so that they can help you. Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help.

Our booklet ***Coping with fatigue*** has more advice. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. It's also on our website www.cancer.ie

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you. You can ask our nurses about free exercise classes. Call our Support Line or visit a Daffodil Centre to talk to a nurse.
- **Plan your days:** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet *Understanding diet and cancer* has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 131).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid alcohol and stimulants like caffeine in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** like meditation or acupuncture, if your doctor says they're safe for you.

“ Try to keep living your life. Enjoy the times with your kids and family, get out and exercise, get fresh air, eat well. I found eating well a way for me to take control in a world that was out of control. It helped me with symptoms and eased my fatigue. ”



How can I cope with early menopause?

The nearer you are to the menopause, the more likely that chemotherapy will stop your periods permanently. An early menopause can also be a side-effect of hormone therapy or ovarian ablation if you are fertile. Your periods may become irregular or stop altogether. This can lead to uncomfortable menopausal symptoms, including:

- Hot flushes
- Night sweats
- Generalised aches and pains
- Vaginal dryness
- Lower sex drive
- Mood swings
- Poor concentration

As the early menopause has been caused by treatment, any symptoms may appear far more suddenly than if it were a natural menopause. Symptoms can be quite severe in some cases and very mild in others. If you have a symptom and it concerns you, tell your doctor or nurse straight away.

Hints and tips: Menopausal symptoms

Menopausal symptoms can have a big impact on your day-to-day life, especially when you are trying to deal with cancer. Fortunately, there are lots of treatments to help with most menopausal symptoms and ways to help you cope better.

- **Prescription medications like hormone replacement therapy (HRT).** HRT is usually not suitable if you have hormone-sensitive breast cancer. Talk to your consultant about your options and about specialist menopause clinics, which may be able to help.
- **Complementary therapies such as reflexology, massage, meditation and aromatherapy** can help relieve menopausal symptoms for some people. Always discuss complementary therapies with your cancer specialist or GP before starting.
- **Relaxation techniques such as meditation and yoga.**
- **Cognitive behavioural therapy (CBT)** may help you to cope with menopausal symptoms, such as hot flushes, mood changes and sleep problems, and feel better in yourself.
- **Emotional support from counsellors and support groups.**
- * **Remember to check with your doctor if you are planning to use complementary therapies.** See page 116 for more about cancer and complementary therapies.

Coping with hot flushes

- **Avoid warm areas** and use an electric fan to lower your skin temperature.
- **Avoid spicy foods, caffeine, alcohol, sugar and hot drinks.**
- **Avoid hot baths or showers,** as they may trigger a hot flush.
- **Wear cotton or wicking-fabric clothing.** Cotton absorbs moisture and wicking fabrics take moisture away from the body to keep you dry and comfortable.
- **Have layers of clothing and bedding** so that you can remove or add layers as your body temperature changes.
- **Keep a cool gel pack under your pillow** at night.
- **Use sprays or moist wipes** to help lower your skin temperature.
- **Drink cold drinks.**
- **Taking regular exercise and being a healthy weight** may reduce symptoms.
- **Don't smoke.**
- **Ask your doctor about medication that may help.**



Coping with vaginal dryness

- Vaginal moisturisers can be used every few days to help with vaginal dryness.
- If you experience discomfort during sex, water-based lubricants may help. Ask your pharmacist, doctor or nurse about which products are suitable.
- Ask your doctor about oestrogen treatments, such as rings or tablets used inside your vagina. Oestrogen products may not be suitable for you if your cancer is hormone-receptor positive.

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have metastatic cancer can take quite a while. It can be hard to relax when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result. Or you may be coming to terms with changes in your appearance after treatment.



There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching and holding each other can help you to stay physically close.

There is no set time for you to be ready to have sex again. It varies from person to person.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again. You can also ask for a copy of our booklet, ***Understanding sex, sexuality and cancer***, or download it from www.cancer.ie

Some people fear that cancer can be passed on to a partner during sex. That is not true.



Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Some cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

It's important to discuss contraception with your doctor or nurse. If your cancer is hormone sensitive, they may advise you not to use a hormonal type of contraceptive, such as the pill. Ask your doctor's advice about contraception or for advice if you are thinking about having children.



Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a Cancer Nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. This may be temporary or permanent. It depends on the type and amount of treatment you have.

Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a Cancer Nurse.

Pregnancy and metastatic breast cancer

The issue of pregnancy for women with metastatic breast cancer is quite complex. You might worry about having a child for fear that you might not live long enough to raise the child. Or you may believe that even if you do die, you can still give your child the love and care they need in the meantime. Talk to your doctor if you are concerned about this issue. You can also talk to our Cancer Nurses – call 1800 200 700 or visit a Daffodil Centre.

Treatment during pregnancy

Controlling the cancer or cancer symptoms during pregnancy can be a challenge for your doctor. Some treatments are not suitable if you are pregnant when diagnosed with metastatic breast cancer. Talk to your doctor about your options and the timing of treatments.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, mindfulness, reflexology and aromatherapy. Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.



It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications or supplements. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective in treating cancer. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our Cancer Nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie

“ Everyone in the group had metastatic disease and I found it gave me a feeling of being more grounded and understood. It reduced the sense of isolation so many of us feel. ”

Palliative care

During or after your cancer treatment, your doctor may discuss palliative care with you. Palliative care includes physical, social and spiritual care. The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea. Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care also offers emotional support and comfort to patients and their families.

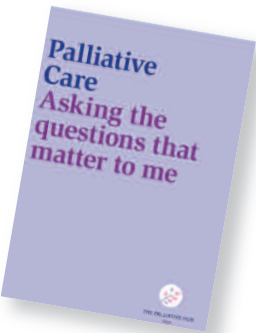
Palliative care includes end-of-life care, but your doctor may also recommend palliative care to manage symptoms and complications earlier in your illness, to empower you to have the best quality of life while living with a metastatic diagnosis.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer.

Palliative care teams work both in hospitals and in the community and sometimes visit patients at home. They may work along with your treating team. You may go to a hospice for a day or 2 to get treatment for your symptoms or you may stay at the hospice in the later stages of your illness.

For more information, including the booklet *Palliative care – Asking the questions that matter to me*, visit the Palliative Hub at www.adultpalliativehub.com. Talk to your doctor and nurse for more advice. If you do not feel well enough, your family can talk to them for you.



Living with metastatic breast cancer

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What follow-up will I need?

No matter what treatment you have, you will still need to have regular check-ups. This is called follow-up. At each outpatient visit, your doctor will examine you and blood tests may be done. Follow-up often includes scans and X-rays. Ask your doctor if these are needed and how often they'll be done.

“My scans have remained stable.
Treatment continues but the disease
doesn't. Good news is an understatement.”

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. It can help to write down what you want to say before you see the doctor, so you don't forget what you wanted to say.



It's important to attend your follow-up appointments as they will allow your doctor to help with any side-effects that you may have.

Your doctor can also check for signs of new side-effects that may develop. It is better to be aware of these as early as possible so that suitable treatment can be given.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.



If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

Support Line Freephone 1800 200 700

Living with metastatic breast cancer

It can take some time to adjust to life with metastatic cancer. You may need treatment at different times or you may need ongoing treatment with hormone therapy. There may be periods when the cancer is controlled and you are getting on with life. It isn't unusual, however, to sometimes feel quite low and lost. Feelings you may have include:

- **Fear about the future or how your disease may progress.**
This may be worse in the weeks leading up to a scan and while waiting for results. Living with fear for the future can be very challenging.
Ask your doctors or nurses for support. They can also advise you on other supports available. You can also call our Support Line on 1800 200 700.
- **Stress at having to deal with things that may have been on hold** – especially if you are on and off treatment – such as your finances, going back to work and family issues.
- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready.
- **Anxiety and self-doubt** about sexual and romantic relationships.
- **Anger** at what has happened and the effect on you and your loved ones.
- **Depression or sadness.**

There is more about how to cope with these feelings and adjusting to life with metastatic cancer on our website www.cancer.ie You can also call our Support Line or visit a Daffodil Centre to talk to a Cancer Nurse in confidence. See page 132 for other ways to get emotional support.

“ There is no right or wrong way to be or to feel when you are living with metastatic cancer. Everyone has their own approach. There is support to help you if you need it. ”

Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with any side-effects
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun



It's also important to have any vaccines recommended for you. For example, flu, COVID-19 and pneumonia. Some vaccinations may not be suitable, so check with your doctor which you should have and make sure you get them. Your medical team can also advise you on when to have your vaccinations.



If you want more information or advice on healthy living, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website www.cancer.ie for tips and publications.

How can exercise help?

Exercise is very helpful in lots of ways. It can:

- Give you more energy
- Improve fatigue
- Boost your mood
- Reduce stress
- Keep you fit

Exercise is safe and helpful for most people with cancer, but always get medical advice about exercising if you have metastatic cancer. For example, some activities may not be recommended if you have weakened bones.

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive**. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will**.
- **Talking about what you want** to your family, friends, carers and healthcare providers.
- **Sorting financial affairs**.

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at www.hospicefoundation.ie



Coping and emotions

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How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis. You may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Feelings like sadness, fear, grief, hopelessness and anger can happen at different times. Having metastatic cancer has been described as 'riding an emotional rollercoaster' – sometimes you may feel very low, while at other times you may feel very positive and hopeful. Most people come through the initial shock and upset and find a way to cope. See the next page for more about learning to cope.



“ Life takes on new dimensions with this uncertainty, not all entirely negative. It makes many previously troublesome issues seem unimportant. Focus on living life in the present moment, just do those things you've always wanted to do! ”

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the emotional effects of cancer***. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

While some treatments can have some unpleasant side-effects, people with metastatic cancer sometimes find their daily lives are not affected very much.

Often metastatic cancer can be treated like a long-term illness which causes problems from time to time.

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you, or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

“Get psychological support – talk to a counsellor as they can be invaluable. Ask for help. I found that hard but talking and getting help can be of huge benefit.”

Counselling

If you're feeling distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

The Irish Cancer Society funds professional one-to-one counselling, remotely and through some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700, visit a Daffodil Centre or email the nurses at supportline@irishcancer.ie.

“Counselling has helped me with every part of my life. I feel I have a future now.”



Ways to get emotional support

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 158 for more about local cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are in a similar situation and facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services if they are available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support.

Talk things through: It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our Cancer Nurses.

Seek spiritual support: For some people, spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop in to a Daffodil Centre.

“ Talking about cancer made it feel less awful and helped ease my fears. I learned to cope and understand myself better. ”

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.



“ I find information from conferences and literature a great crutch but I know others are more comfortable without detail. ”

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

“ I am very happy and content...even though I have to live with this. ”

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet ***Understanding the emotional effects of cancer*** can help you to find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our Cancer Nurses. Call us on 1800 200 700 or visit a Daffodil Centre.

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Talking to children and teenagers

If you have children, you may feel it's best not to tell them anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.



How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called **Talking to children about cancer: A guide for parents** gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.

Ask our Cancer Nurses if you would like a copy of the booklet. Our nurses can also support you if you have children and aren't sure what to say to them.



Supporting someone with cancer

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Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.



Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop in to a Daffodil Centre if you want to chat to a Cancer Nurse in confidence.



Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members, remotely and through many local cancer support centres. Talk to your GP or see page 131.

Find out about support for carers

Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer

When someone close to you has cancer, it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer***. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie

Support for you

Our Cancer Nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, ***Caring for someone with cancer***, has lots of information on:

- **Getting organised**
- **Managing and giving medications**
- **Giving personal care**
- **Practical and money matters**
- **Relationships with other people**
- **Looking after yourself**
- **Life after caring**

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie



Support resources

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Money matters

- If you have cancer, you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as medication, travel, heating and childcare costs.

If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with your illness if you are worried about money.



Our Welfare and Supports Service



Cancer can create additional challenges. Our Welfare and Supports team can help. We can advise on benefits, social welfare entitlements, public services, medical card applications, community support, legal entitlements, housing and mortgages, childcare or talking to your workplace about your diagnosis.

For more information or to be referred to our Welfare and Supports Service call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/welfare-and-supports

Medical expenses

Medical expenses that you might have include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs and incontinence products

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, regardless of your income.

If you don't have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment to check you're covered.



Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit and Carer's Leave.

If you want more information on benefits and allowances, contact:

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0818 074 000
- **Department of Social Protection** – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting them.

If you have money problems

If you are in debt or worried about getting into debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline on 0818 072 000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 155 for more details of our Transport Service and the Travel2Care fund.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Money and finances

Go to **www.cancer.ie** and see our Welfare and support page for information on:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

Our website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports team may also be able to help (see page 146).

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Telephone Interpreting Service**
- **Patient Education**
- **Peer Support**
- **Eating well information sessions**
- **Exercise information and support**
- **Counselling**
- **Transport Service**
- **Welfare and Supports Service** (see page 146)
- **Publications and online information**
- **Night Nursing**

Support Line Freephone 1800 200 700

Our Cancer Nurses offer confidential advice, support and information for anyone affected by cancer.

Our Support Line is open Monday to Friday, 9am to 5pm.

Email us on supportline@irishcancer.ie

The Support Line also offers video calls. From the comfort of your own home, you can meet a Cancer Nurse virtually and receive confidential advice, support and information on any aspect of cancer. To use this service, offered on the Microsoft Teams platform, visit **www.cancer.ie/Support-Line-Video-Calls**

One of our nursing team will email you with the time for your video call and instructions on how to access Microsoft Teams on your phone, tablet or computer.



Daffodil Centres

Our Daffodil Centres, located in 13 hospitals nationwide, are staffed by Cancer Nurses and trained volunteers who provide face-to-face advice, support and information for anyone affected by cancer. This service is free and confidential. This is a walk-in service; you do not need an appointment.

To see your nearest Daffodil Centre, contact details and opening hours visit www.cancer.ie/daffodil-centres



What information is available?

Our Cancer Nurses provide free and easy-to-understand information on:

- Screening, cancer prevention and early detection
- Cancer types
- Tests and investigations used to diagnose cancer
- Cancer treatments and side-effects
- Local cancer support services
- Life after cancer treatment
- Financial and practical supports
- End-of-life services

Our Cancer Nurses can also give you more information or refer you to any of our supports and services.

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Cancer Nurses in your own language through our Telephone Interpreting Service. To use the service:

- Tell us in English the language you would like.
- You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.
- We will connect you to an interpreter.
- The interpreter will help you to speak to us in your own language.



For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Patient Education

Chemotherapy Education is for cancer patients who are due to have chemotherapy. The aim of the session is to guide the patient through the treatment from beginning to end: what chemotherapy is, how it is given, managing side-effects and available supports.



Our after-treatment education workshop is called **Life and Cancer – Enhancing Survivorship (LACES)**. It was developed in partnership with the National Cancer Control Programme. **LACES** aims to improve the quality of patients' lives after active treatment has ended.

Patient education sessions take place online or in person in our 13 Daffodil Centres nationwide.

We also have pre-treatment video resources that you can watch in your own time. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre, visit www.cancer.ie/our-services or email patienteducation@irishcancer.ie

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. If you have a cancer diagnosis, you can be matched with a Peer Support volunteer who has had a similar cancer experience. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

More information on Peer Support is available at www.cancer.ie/our-services To be connected to a Peer Support volunteer, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.



Eating well information sessions

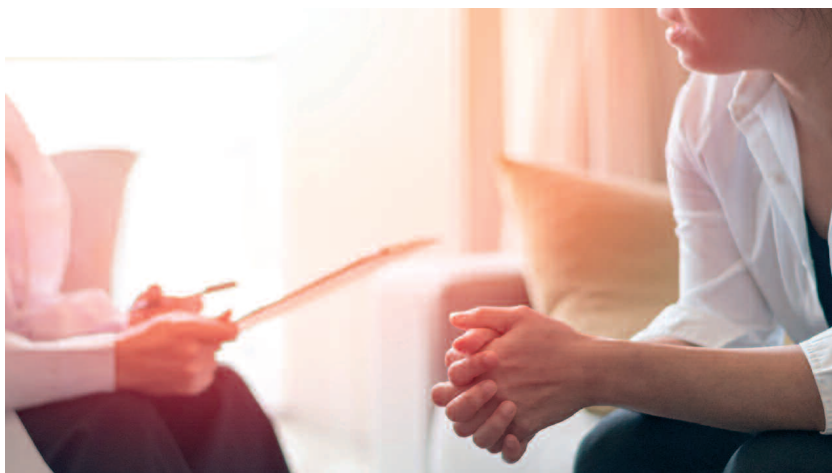
We provide group online information sessions with an Oncology Dietitian on the important role nutrition has for people with cancer. Using evidence-based specialist advice we can support you to eat well during cancer treatments and beyond.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Exercise information and support

Exercise before, during and after treatment can improve quality of life. We provide information and support on how you can make exercise part of your everyday life. We also offer free exercise classes, to help people with cancer to improve fatigue, quality of life, reduce anxiety and build strength and fitness in a fun and supportive environment.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services



Counselling

We fund professional one-to-one counselling for anyone affected by cancer – the person diagnosed with cancer, family members and close friends. Counselling sessions are available remotely (over the telephone/online) or in person in certain cancer support centres around the country.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Transport Service

We provide transport and limited financial grants for patients in need who are in cancer treatment.

Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments. We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.



Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they travel over 50 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme (NCCP).

To access this support, please contact your hospital healthcare professional. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Publications and online information

We provide information on a range of topics, including cancer types, treatments, side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.



Night Nursing

Our service supports patients to remain at home for the last days of their lives, surrounded by their families and loved ones. We offer up to 10 nights of end-of-life care free of charge for cancer patients. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am. To access this service please contact the healthcare professional looking after your loved one. For more information visit **www.cancer.ie/our-services**

To find out more about the Irish Cancer Society's services and programmes:

Visit us at www.cancer.ie

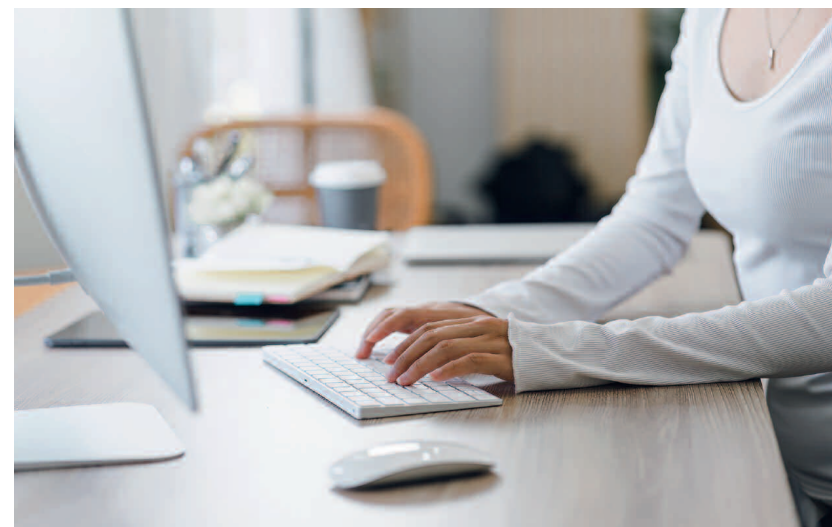
Speak with one of our Cancer Nurses:

- **Call our Support Line on Freephone 1800 200 700**
- **Visit one of our 13 Daffodil Centres in hospitals nationwide**

Email the nurses at supportline@irishcancer.ie

Follow us on:

- **Facebook [@IrishCancerSociety](https://www.facebook.com/IrishCancerSociety)**
- **X [@IrishCancerSoc](https://twitter.com/IrishCancerSoc)**
- **Instagram [@irishcancersociety](https://www.instagram.com/irishcancersociety)**
- **LinkedIn [@irish-cancer-society](https://www.linkedin.com/company/irish-cancer-society)**



Local cancer support centres

Local cancer support centres have a range of services for cancer patients, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds one-to-one counselling through many local support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting, and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

Visit www.hse.ie to find a cancer support centre in your area.

Our Cancer Nurses can also help you to find support and services. Call our Support Line on 1800 200 700 or visit a Daffodil Centre to talk to a nurse.

Support Line Freephone 1800 200 700

What does that word mean?

Alopecia: Loss of hair. No hair where you normally have hair.

Antibody: A protein that attacks and kills organisms, such as bacteria and viruses, or cells that cause disease.

Anti-emetic: A tablet, injection or suppository to stop you feeling sick or vomiting.

Ascites: An abnormal amount of fluid in your abdominal peritoneal cavity (tummy area).

Biopsy: Removing a small amount of tissue from your body to find out if cancer cells are present.

Bisphosphonate: A drug used to treat osteoporosis and bone disease in cancer patients.

Cells: The building blocks that make up your body. They are tiny and can only be seen under a microscope.

Chemotherapy: Treatment using drugs that cure or control cancer.

Enzymes: Proteins that cause chemical reactions in the body.

Fatigue: Ongoing tiredness often not helped by rest.

HER2: A protein on a cell that allows a growth factor to bind to the cell, causing the cell to grow and divide.

Hormone: A substance made by a gland and carried in the bloodstream to parts of the body where it has a specific effect on the way the body works.

Hypercalcaemia: A high level of calcium in your blood.

Immunotherapy: Treatment that helps your immune system work better to fight cancer cells.

Intravenous: Into a vein.

Lymph: A yellow fluid containing cells called lymphocytes which fight disease and infection.

Lymph nodes: Small glands scattered along vessels of your lymphatic system. They may become enlarged due to infection or cancer cells.

Lymphoedema: Swelling in your arm that can sometimes develop after treatment for breast cancer.

Malignant: Cancer. A tumour that can spread.

Medical oncologist: A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Metastasis: The spread of cancer from one part of your body to other tissues and organs.

Nausea: Feeling sick or wanting to be sick.

Oncologist: A doctor specialising in treating cancer.

Oncology: The study of cancer.

Palliative care team: A team of doctors and other healthcare professionals who are trained in managing pain and other symptoms caused by cancer. They will also help cope with any emotional distress.

Prognosis: The expected outcome of a disease.

Radiation oncologist: A doctor who specialises in treating cancer patients using radiotherapy.

Radiotherapy: The treatment of cancer using high-energy X-rays.

Recurrence: When cancer comes back after treatment. It can come back in the same place as the original one or in a different part of your body.

Targeted therapies: Drugs that target specific genes and proteins that are involved in the growth and survival of cancer cells.

Spinal cord compression: If the cancer spreads to the bones in your spine, it can press on your spinal cord and nerves. This can lead to paralysis, incontinence and numbness.

Staging: Tests that measure the size and extent of cancer.

Notes/Questions

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Acknowledgments

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The following sources were used in the publication of this booklet:

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit www.cancer.ie if you want to get involved.

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate directly
- Take part in one of our fundraising events or challenges
- Organise your own event

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie



Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
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- Contact your nearest Daffodil Centre