

Understanding

Metastatic (secondary) breast cancer

Caring for people with cancer

Understanding

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

Liaison nurse

Oncology day ward

Family doctor (GP)

Breast surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Hospital records number (MRN)



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Fast facts



Can my cancer be treated? Page 17

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

How long will I live? Page 27

Many women 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.

What kind of treatment might I have? Page 29

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

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

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

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

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

Will I get side-effects/symptoms? Page 69

You may get side-effects and symptoms from treatment or the cancer itself. Read about the treatments to learn more about their side-effects. There are treatments to help with most side-effects and symptoms, so tell your doctor. Don't suffer in silence!

Clinical trials Page 66

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We're here for you Page 114

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 Cancer Nurseline on 1800 200 700
- Drop in to a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 114 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 Cancer Nurseline on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at cancernurseline@irishcancer.ie

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.



Cancer Nurseline Freephone 1800 200 700

Rhona's story

'I am married with three adult children. I've been living with secondary breast cancer for 13 years and lead a full, active life.

I was first diagnosed with primary breast cancer in my mid-forties. Having just completed treatment for that, I was diagnosed with secondary breast cancer ...

I was devastated. Unlike primary breast cancer there was no longer a prospect of a cure. My prognosis was poor. I had overwhelming feelings of shock, disbelief, sadness, fear and anxiety. I grieved for all the things I thought the cancer would take from me, and the future I had imagined. But I had three young children so I was determined to beat the odds.

I started back on treatment – chemotherapy and Herceptin. I attended cognitive behaviour therapy and mindfulness sessions in the hospital to help me cope with the diagnosis, and the uncertainty of treatment and ongoing scans. I sought information on treatment, clinical trials, management of side-effects, nutrition, and exercise. I attended Arc Cancer Support for reflexology, relaxation and stress management classes – all of which helped to get my life back on track.

My first follow-up scans showed a huge improvement and to date the cancer has remained stable, for which I am very grateful. I am well and living a full, active life. I work part time, and also volunteer with the Irish Cancer Society and Arc Cancer Support. I am a member of the Plurabelle Paddlers, a breast cancer dragon boat team, and we have competed and won medals internationally. I have a deep appreciation of life and enjoy the simple things and spending time with family and friends.

While everybody is different and needs to find what works for them, these are the things I found helpful:

- **Good communication with and trust** in my medical team.
- **Nurturing my mind, body and spirit** with good nutrition, exercise, counselling, relaxation, meditation, music, and the beauty of nature.
- **Embracing the good days** and being kind to myself on the bad days.
- **Prioritising what is important to me** and accepting any help offered. Fatigue can be an issue so let family and friends help you in practical ways.
- **Continuing to hope!** There are huge advances in treatment and metastatic patients are living much longer with improved quality of life. A new drug or a clinical trial may totally change things for you. I am alive because of one such drug.'

RHONA



About metastatic breast cancer

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What is cancer?

- **Cancer is a disease of the body's cells**

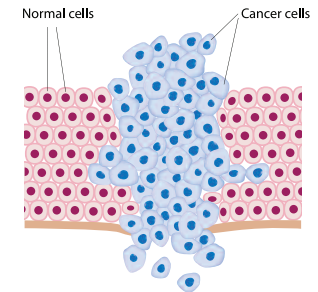
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

- **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 tumour. This is called metastasis.



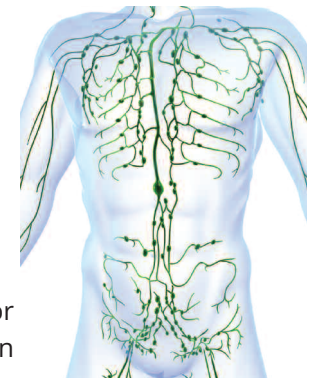
What is the lymphatic system?

- The lymphatic system 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 cancer starts in the lymph nodes they can become swollen.



What is primary breast cancer?

Primary breast cancer is when breast cancer cells grow in your breast.

What is metastatic (secondary) 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 cancer. Metastatic cancer can happen months or years after your first breast cancer diagnosis. Occasionally, women are diagnosed with metastatic cancer at the same time as the primary breast cancer is found. This is sometimes called 'de novo' metastatic breast cancer, meaning the breast cancer is metastatic from the start.

Why did the 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 tiny and 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 or 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 for breast cancer to spread to are the:

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

However, 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.



Cancer Nurseline Freephone 1800 200 700

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 pains need be checked out.

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 complain of loss of appetite, tiredness, nausea and discomfort on the right side of your tummy. This is 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 stools paler in colour.

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 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, an arm or a leg may be weaker than usual or there may be 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 of the skin – sometimes called skin metastases – most commonly occur in areas close to where the original breast cancer was. It is different, however, to 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 lymphoedema (see page 77).

Cancer in the lymph nodes

Metastatic breast cancer can occur in more distant lymph nodes and is not considered local or regional spread (see next page). 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 women, 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 29 for more about treating metastatic breast cancer.

What are local and regional recurrence?

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.

Local recurrence

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

Regional recurrence

Regional recurrence is when breast cancer comes back beyond your breast and armpit lymph nodes. It can occur in the tissues and lymph nodes around your chest, neck and under your breastbone.

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/or 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 Cancer Nurseline on 1800 200 700 or visit your local Daffodil Centre.



Diagnosis and tests

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Being diagnosed with metastatic breast cancer

You may find the news that cancer has come back more upsetting than your original diagnosis. But remember, nothing you have done is to blame. Even the experts don't fully understand what triggers some breast cancers to spread.

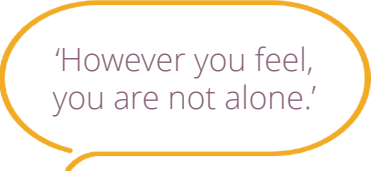
On hearing that you have metastatic breast cancer, you may feel:

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

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 (oncology) liaison nurse 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 Cancer Nurseline on 1800 200 700. You can email the nurses at cancernurseline@irishcancer.ie
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community
- Go to your local cancer support centre. For more information, see page 120.



'However you feel,
you are not alone.'

'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!'

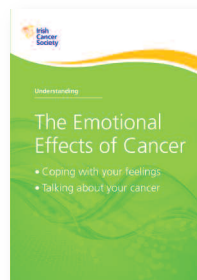
Telling people about your diagnosis



It can be hard to tell other people the news that you have been diagnosed with metastatic cancer.

You may want to talk about your diagnosis or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet ***Understanding The Emotional Effects of Cancer***. This booklet 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 a diagnosis of metastatic breast cancer, you may have blood tests, a CT scan, bone scan, X-rays, MRI, PET scan and breast biopsy.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.



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. Blood tests can show the level of tumour markers in your blood. Blood tests can also check the amount of calcium in your blood.

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 show up parts of your body 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 which 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.



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 do avoid babies, young children and pregnant women until the day after the test. The test is not recommended for pregnant women.

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 to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs/headphones to wear. You might get an injection before the scan to show up certain parts of your body.

During the scan you cannot wear metal jewellery. If you have a medical device in your body, like a pacemaker or metal pin, you may not be suitable for the test. Usually you can go home soon after the scan.

PET scan

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into a vein in your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

PET is safe to use and there are no side-effects. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

Breast biopsy

If metastatic breast cancer is your first diagnosis of cancer, your doctor will take a small piece of tissue (biopsy) from your breast. This can confirm your diagnosis. The biopsy will also help to find out whether the cancer cells have certain receptors which encourage the cancer cells to grow. For example, the hormone oestrogen (ER) or HER2. You usually have a biopsy under local anaesthetic. The doctor uses an ultrasound or a CT scan to help them guide the needle to the right place. If you have been diagnosed with breast cancer before, you might have a repeat biopsy to test for changes in receptors.

Waiting for test results



It usually takes over a week 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

'It is a difficult and dark place when diagnosed with a life-threatening illness. I found meeting people with a similar diagnosis through the Irish Cancer Society's Living Life programme a huge benefit. Friends and family are amazing but it's hard to talk about your deep and dark fears with them.'

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 to your cancer specialist. Remember 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 about this for reassurance.

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 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 even incorrect. Also, it might not really apply to your situation or to your particular cancer type. Ask your doctor or specialist nurse for advice and 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 again after you have thought about everything.
- **Get emotional support if you need it.** 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 Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.


Cancer Nurseline Freephone 1800 200 700

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 HER2.
 - Your age and if you have gone through menopause or not
 - Your previous cancer treatments and 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 45 for more details.

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. It might also be given if you do not have hormone receptors on your breast cancer cells or if you have stopped responding to hormone therapies. You may have chemotherapy on its own or with other treatments. See page 51 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. Or it may be given to control the cancer coming back in your skin or armpit. See page 56 for more details.

Targeted therapies

These drugs work with your body to fight cancer. Different targeted therapies work in different ways. The type used for breast cancer usually work by stopping the breast cancer cells from dividing and growing. See page 59 for more details.



'There are a number of treatment options open to me if it does come back so I would feel very positive about the treatment of metastatic disease these days.'

MARIAN

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 62 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 64 for more details.

Treatment of symptoms and palliative care

Some of your symptoms of metastatic breast cancer may need to be treated straightaway. For example, bone pain or breathlessness. See page 71 for more details. 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 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 87 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, 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. If you do forget to ask a question or need more explanations, call our Cancer Nurseline 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 treating doctor or your GP 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.

Clinical trials

Ask your consultant if you are suitable for a clinical trial. For more information on clinical trials, see page 66.

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.' MARIAN

Who will be involved in my care?

Some of the following may be involved in your care at the hospital. Usually a team of specialists (multi-disciplinary team) will decide your treatment.

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

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.



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

Oncology liaison nurse/clinical nurse specialist 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 social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on supports and services available to you when you go home.

GP (family doctor) You can talk to your GP about your medication and any side-effects you have. You can also 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.

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.

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. 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 specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.

Counsellor A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Community health services This includes family doctors, public health nurses (who can visit you at home), 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. 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control.

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 better.



Eat well

Eating as well as possible can help you to:

- Reduce any weight loss
- Cope better with the side-effects of treatment
- Recover better

Ask to talk to the dietitian at the hospital for advice on the best diet for you.

You can also read our booklet *Diet and Cancer*. To get a copy, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or download it on our website www.cancer.ie

Be active

Being active has many benefits. It 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.

Be careful not to overdo it at the beginning – build up gradually.



Quit smoking

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

- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal better after surgery
- Not smoking or drinking reduces the risk of other illnesses

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have smoking cessation officers who can help and support you.



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. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

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

Therapies 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.

Be aware that there will be ups and downs

Sometimes people feel they must be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day

Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.



Types of treatment

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Hormone therapy



- Hormone therapy only works for women who have oestrogen-receptor positive (ER+) cancers.
- The choice of hormone therapy will depend on whether you have gone through menopause or not.
- Hormones tend to cause just mild 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 47 for more about aromatase inhibitors.
- Anti-oestrogen drugs stop oestrogen from attaching to breast cancer cells and encouraging them to grow. See page 47.
- Ovarian treatments stop your ovaries from producing oestrogen. See page 48 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?

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 or
- 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 usually given in tablet form.

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 usually cause few side-effects. They can cause vaginal dryness, nausea, and muscle and joint pain. Side-effects tend to be mild if they do occur. Bone density scans may be done before starting treatment and regularly during treatment, as the drug can increase bone loss. Treatments are also available 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.

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 Cancer Nurseline on 1800 200 700.

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 making oestrogen. They can be temporary (ovarian suppression) or permanent (ovarian ablation). These treatments are usually given in combination with an aromatase inhibitor or an anti-oestrogen drug. There are three ways to stop your ovaries 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.

The operation to remove your ovaries is called an oophorectomy. It may be done using keyhole surgery usually under general anaesthetic.

Your surgeon uses a thin flexible tube with a light and magnifying lens at the tip to look into your tummy (abdomen). A few small cuts are first made in the skin and muscle of your tummy and the tube is put in. You may need to stay in hospital for a day or two.

Radiotherapy

Radiotherapy uses X-rays to stop your ovaries from working to produce oestrogen. Normally you have one more period, which may be heavy, and then your periods stop completely.

Both surgery and radiotherapy will stop your ovaries working permanently, 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. As with all treatments, side-effects can vary. It also depends on whether you have gone through the menopause or not. Side-effects include:

- Changes to periods and menopausal symptoms
- Osteoporosis
- Blood clotting
- Thickened womb
- Bone loss and pain

Changes to periods and menopausal symptoms

For women who 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 81 for more about menopausal symptoms. You can also visit our website www.cancer.ie for more about ways to cope or get information and support from a cancer nurse by visiting a Daffodil Centre or by calling our Cancer Nurseline on 1800 200 700.

Infertility

Some hormone therapies can cause a permanent menopause. 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 84 for more about infertility.

Osteoporosis

Oestrogen helps to keep bones healthy. If you have hormone treatment to reduce the amount of oestrogen in your body, there is a risk that your bones may become weaker and more likely to break. This is called osteoporosis. There is medicine that can help with osteoporosis. For more about bone health, see page 78.

Blood clotting

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

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. For this reason, you should report any vaginal bleeding to your doctor.

Bone loss and pain

Some drugs may increase bone loss and cause pains and aches in your muscle or bone joints. As a result, bone density scans may be done before starting treatment and regularly during it. You should also stop smoking, take regular exercise, and eat calcium-rich foods. Ask your doctor about taking calcium supplements. Drugs may be prescribed if there is serious bone loss (osteopenia or osteoporosis).

There are also other ways to lessen the side-effects of hormone treatments.

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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also find more information on our website, www.cancer.ie

Chemotherapy



- Chemotherapy is a treatment using drugs to control cancer growth.
- Chemotherapy can be given in tablet form, 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 in tablet form. Usually your treatment will be given in the chemotherapy day care unit. You might receive your chemotherapy as part of a clinical trial. See page 66 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. If you had chemotherapy to treat primary breast cancer, you will probably be given a different drug to treat your metastatic cancer. 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 have any questions or need any more information, you can speak to our cancer nurses by calling our Cancer Nurseline on 1800 200 700.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.



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 where you feel tired and weak and rest does not seem to help. For more information see page 79.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Infection

Chemotherapy drugs make you more likely to get infections. You will be told how to watch out for signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough, or pain passing urine.

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.

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 the symptoms of menopause, such as hot flushes. Sometimes chemotherapy brings on an early menopause. For more about managing menopausal symptoms see page 81.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your reaction to it. Hair will grow back after you stop chemo.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Skin and nail changes

Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

Peripheral neuropathy

Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Changes in kidney function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

Changes in hearing

Some chemotherapy drugs can cause buzzing or ringing sounds in your ears. This is called tinnitus. These 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

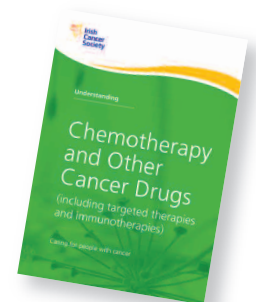
You might feel 'vague' or mildly confused or have memory problems while having chemotherapy. This is sometimes called 'chemo brain' or 'chemo fog'. Tell your doctor or nurse if you feel this way.

Effects on fertility

Chemotherapy can cause infertility. This is more likely in women who are nearer their natural menopause. Infertility can be very hard to come to terms with. See page 84 for more.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding Chemotherapy and Other Cancer Drugs***, call our Cancer Nurseline 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 women 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 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 79 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 to your head. The hair usually starts to grow back within 2 to 3 months of the 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Targeted therapies



- Targeted therapies are drugs that target certain parts of the cancer cells that make them different from other cells.
- They can help to control cancer that has spread.
- The drugs can be given by tablet or into a vein through a drip.
- Some side-effects include fever and chills, headache, rashes.

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:

- Cancer growth inhibitors, for example Lapatinib (Tyverb®)
- Monoclonal antibodies, for example, Trastuzumab (Herceptin®), Pertuzumab (Perjeta®) and antibody-drug conjugate Trastuzumab emtansine. These drugs may be suitable if you have HER2-positive breast cancer. They target cancer cells that 'overproduce' or 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 growing.
- **CDK4/6 inhibitors** are designed to interrupt enzymes that promote the growth of cancer cells. Types of CDK4/6 inhibitors commonly used in treating ER-positive, HER2-negative metastatic breast cancer are Palbociclib (Ibrance), and Ribociclib (Kisqali). Both of these drugs can be given in combination with hormone therapy. Palbociclib and Ribociclib are given in tablet form.

A sample of breast cancer cells can be tested for the presence of HER2. It usually takes 3 weeks to get the results. About 1 in 5 women with breast cancer is HER2 positive. These cancers tend to grow faster than those that are HER2 negative and like many breast cancers, can recur. Remember if you had cancer before, the HER2 receptors on your cancer cells can change. Your doctor will not know if they have changed until they do a new biopsy.

Some drugs are given in tablet form. Others are given into a vein through a drip.



New developments

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 66). 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.

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 – fever and chills
- Headaches
- Flu-like symptoms
- Diarrhoea
- Nausea
- Fatigue

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 Cancer Nurseline 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 the 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, or as an injection into a vein, for example Zoledronic acid (Zometa ®) every 1-3 months. This happens in the hospital day ward and takes a couple of hours. Usually bisphosphonates are a long-term treatment and given as long as you are benefiting 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 women 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.

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

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®). For more information on targeted therapies, see page 59.

Email: cancernurseline@irishcancer.ie

Surgery

- Surgery is rarely an option for most people with metastatic breast cancer.
- 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.

Surgery is generally not an option for most people with metastatic breast cancer. It is 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

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. Do ask your surgeon or nurse to explain why the surgery is recommended for you and what will be involved. You can also call our Cancer Nurseline 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 or diagnosing cancer or reducing side-effects.

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of, or in addition to, the standard treatment, you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Drugs that are used in a clinical trial have been through years of testing before they are given to patients. However, because the drugs are still in trial, patients taking part will be monitored even more closely than normal 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 Cancer Nurseline 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 ten years who are living energetic lives!'

SARAH





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 may occur as a result of treatment. Your symptoms will depend on how the metastatic breast cancer has affected you. You may experience symptoms such as:

- 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

It is very unlikely that you will have all of these symptoms or even most of them. 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. In fact, 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

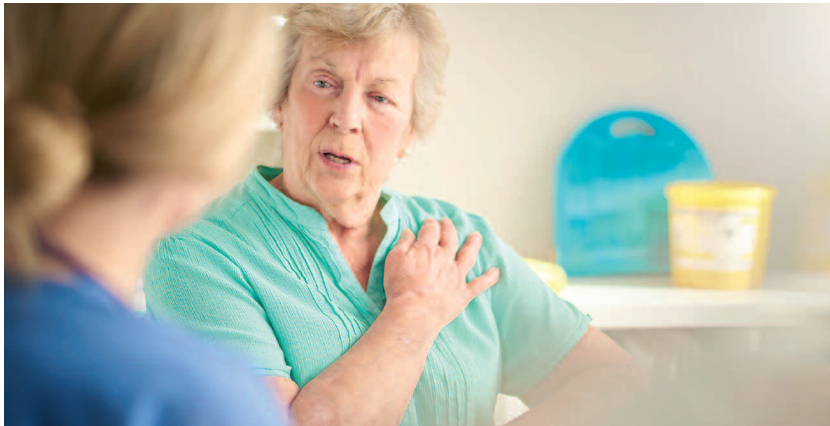
Your doctor will decide which painkiller is best suited to the type of pain you have. If the medication doesn't ease the pain, tell your doctor or nurse. There are lots of options, so if one medicine doesn't work, your doctor will try something else. A palliative care specialist who manages pain and 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.

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 62 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 56.



‘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.’

SARAH

Tips and Hints: pain



- If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain you are in.
- 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? It may help to write down the times you get pain and what makes it better or worse.
- 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.
- If you only have pain from time to time, take the painkillers when you need them. But if the pain is there most or all of the time, take your painkillers regularly.
- Discuss with your doctor or nurse if the pain is worse at night and wakes you up or if you have times when the pain ‘flares up’ and isn’t controlled by your usual pain relief. You can get extra medication to help with this ‘breakthrough pain’.
- If you are constipated from the painkillers, take a laxative every day. Drink plenty of clear fluids such as water and fruit juice to keep your bowel habit regular. Your doctor or nurse will give you something stronger if your bowels have not opened for 2 or 3 days.
- If you are feeling sick, your doctor may give you anti-sickness tablets. The nausea often improves as you get used to your medication. Do not drive or work machinery if you feel drowsy.

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.

Tips and Hints: nausea



- Eat small amounts of food regularly.
- Avoid fatty foods.
- Avoid foods that make you feel sick.
- Avoid taking a lot of fluid just before you eat.
- Take ginger or peppermint to ease the nausea.
- Take plenty of fluids in small amounts throughout the day.
- Try a complementary therapy, like acupuncture. It may help nausea. Ask your doctor for advice first.
- Ask your doctor if you can take a regular anti-sickness drug.

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.

If the drainage improves your symptoms but the fluid starts to build up again, your doctor may decide to do 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 building up again.

If cancer has spread to the tissue of your lungs, the painkiller morphine can be used to relieve the breathlessness. Another way to ease the shortness of breath can be through breathing exercises.

Your doctor may refer you to a physiotherapist who will teach you the exercises. For more information on breathlessness see our website, www.cancer.ie. You can also talk to a cancer nurse by calling our Cancer Nurseline on 1800 200 700 or visiting a Daffodil Centre.

Email: cancernurseline@irishcancer.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.

Tips and Hints: 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 85.

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 Cancer Nurseline 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 two 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 as well as help strengthen them and reduce the risk of fractures. See page 62 for more information.

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 2–3 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.

Tips and Hints: taking care of your bones

- Take any medication prescribed for you.
- Get regular exercise.
- Make sure you are getting enough calcium in your diet. Good sources are cheese, yogurt, green leafy vegetables and sardines.
- Stay a healthy weight.
- Don't smoke.
- Avoid caffeine and alcohol.
- Take precautions around the house to avoid falls and accidents.
- Take good care of your teeth and visit the dentist regularly.

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

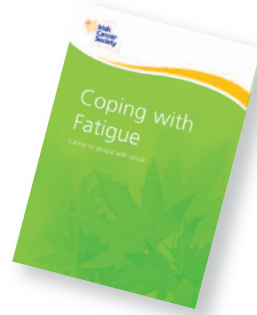
Fatigue when you have cancer can be caused by many things, including:

- 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
- Symptoms like pain, breathlessness or fluid retention



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 you.

Our booklet ***Coping with Fatigue*** has more advice. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy. It's also on our website www.cancer.ie



Tips and Hints: fatigue



- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants such as caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

'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.'

MARIAN

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. Some symptoms can be quite severe in some women and very mild in others. If you have a symptom and it concerns you, tell your doctor or nurse straight away.

Remember to check with your doctor if you are planning to use complementary therapies. See page 85 for more about cancer and complementary therapies.

Tips and Hints: menopausal symptoms

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

- Prescription medications such as hormone replacement therapy (HRT) – your doctor will tell you if this is suitable
- Complementary therapies such as acupuncture and aromatherapy
- Relaxation techniques like meditation and yoga
- Emotional support from counsellors and support groups

Remember to check with your doctor if you are planning to use complementary therapies. See page 85 for more about cancer and complementary therapies.



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 as well 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.

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. Try other forms of closeness, such as touching, caressing and holding each other. 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. He or she may refer you for specialist relationship counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. If you have any queries about how treatment may affect your sex life, do talk to your doctor. Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

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. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

It's important to discuss contraception with your doctor or nurse. If your cancer is hormone sensitive, it is best not to use a hormone type of contraceptive, such as the pill. Ask your doctor's advice about contraception or 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. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor and nurse are well used to talking about these matters and will give you advice. You can also call our Cancer Nurseline 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 cancernurseline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you will not be able to get pregnant.

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

Dealing with infertility may not be easy, depending on your age and if you have had children. It can bring feelings of sadness, anger and loss of identity. Infertility is especially hard if you had plans to start a family, or to have more children. It can help to share your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

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. Do talk to your doctors about your options at this time and the timing of treatments.

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 else 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.

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, massage, counselling and acupuncture.

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. 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 at keeping cancer under control. 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 Cancer Nurseline 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.'

SARAH

Palliative care

During or after your anti-cancer treatment, your doctor may discuss palliative care with you. The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea.

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 earlier in your illness, to help to manage your symptoms and improve your quality of life.

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.

You do not need health insurance. Palliative care can be given in a hospice or community hospital or in your own home.

You may go to a hospice for a day or two to get treatment for your symptoms or you may stay at the hospice in the later stages of your illness.

For more information on palliative care including a booklet called *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. Or if you do not feel well enough, your family can do so.



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 go back to the hospital for 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.'

MARIAN

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. Sometimes it helps 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. He or she 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.

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:

- **Loneliness**
- **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 after cancer on our website

www.cancer.ie/coping/life-aftercancer-treatment

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 99 for other ways to get emotional support.

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 side-effects
- Keep up your energy and strength

A healthy lifestyle includes:

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

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

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

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.

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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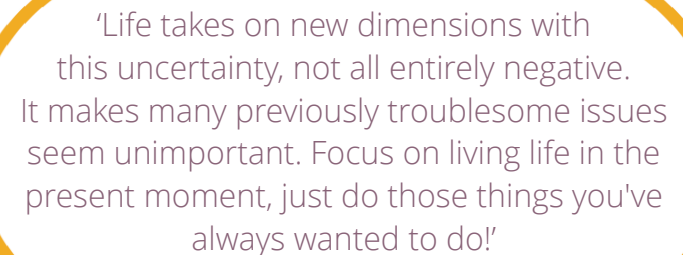
How can I cope with my feelings?

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.

Emotions 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!'

SARAH

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the Emotional Effects of Cancer***. Call our Cancer Nurseline 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

Sometimes a diagnosis of metastatic cancer can cause 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 antidepressants or anti-anxiety medication can work well. Professional counselling can also be very helpful.

'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.'

MARIAN

Counselling

If you're feeling very 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.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

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 120 for more about 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 the same 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.

Survivor Support

Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Get online support

Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

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 Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

'I find information from conferences and literature a great crutch but I know others are more comfortable without detail. There is no correct way of coping.'

SARAH

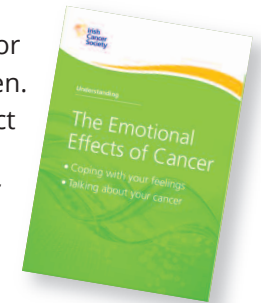
Positive feelings

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.

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 to you find ways to talk about your cancer and to ask for the help and support you need.



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.

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. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.

'I am honest when talking to my family, but I don't overburden them with detail.'

SARAH



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 Cancer Nurseline 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 Cancer Nurseline on 1800 200 700 or drop into 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. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 99.

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.

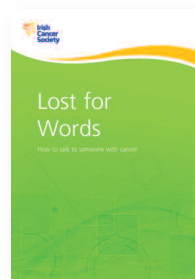
How to talk to someone with cancer



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 Cancer Nurseline on 1800 200 700.

Ask for a copy of our booklet ***Lost for Words*** – ***How to talk to 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.irishcancer.ie



Support for you



Our cancer nurses are there to support you. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@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 Cancer Nurseline, or download it from our website www.cancer.ie





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Coping with the financial impact of cancer



- 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, like car parking during hospital visits, 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 cancer if you're worried about money.

Medical expenses

Medical expenses that you might have to pay include:

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

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, irrespective 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, 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: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 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 photocopy completed forms before posting them.

If you have money problems

If you are getting into debt or you are in 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 0761 07 2000 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 117 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

Go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer*. This explains:

- **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**



The booklet also has lots of other information to help you manage. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living-at-home and nursing home supports.



Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

Cancer Nurseline Freephone 1800 200 700

Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday–Friday, 9am to 5pm. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie



Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

Survivor Support



Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support, including counselling. See page 120 for more information.

Patient travel and financial support services



We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for free copies of our publications.



If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses



- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **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 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.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

What does that word mean?

Adjuvant treatment	Treatment for cancer given soon after surgery.
Ascites	An abnormal amount of fluid in your abdominal peritoneal cavity.
Alopecia	Loss of hair. No hair where you normally have hair.
Anti-emetic	A tablet, injection or suppository to stop you feeling sick or vomiting.
Benign	Not cancer. A tumour that does not spread.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
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.
HER2	A protein on a cell that allows a growth factor to bind to the cell, causing the cell to grow and divide.
Hypercalcaemia	A high level of calcium in your blood.
Fatigue	Ongoing tiredness often not helped by rest.
Lymphoedema	Swelling in your arm that can sometimes develop after treatment for breast cancer.
Malignant	Cancer. A tumour that spreads.

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.
Neo-adjuvant treatment	Treatment such as chemotherapy or radiotherapy that is given before surgery to shrink a tumour.
Oncology	The study of cancer.
Palliative care team	A team of doctors and nurses 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.
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.

Questions to ask your doctor

Here is a list of questions that you might like to ask. There is also some space for you to write down your own questions if you wish. Never 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 complementary therapies?
- Where can I find out more about metastatic breast cancer?

Your own questions

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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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!

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 Survivor 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 direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

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