Irish Cancer Society

Understanding

Sarcoma

Caring for people with cancer

Understanding

Sarcoma

This booklet has information on:

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

Useful numbers

Specialist nurse

Family doctor (GP)

Surgeon

Medical oncologist

Radiation oncologist

Medical social worker

Emergency:

Hospital medical records number (MRN)

Contents

Fast facts

Can my sarcoma be treated? Page 39

Surgery plays a pivotal role in treating sarcoma. Its aim is to remove the entire tumour. Chemotherapy and radiotherapy may be used alone or in combination before or after surgery to reduce the chance of the sarcoma coming back.

Will I be OK? Page 37

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things and everyone's prognosis is different. The best thing to do is ask your medical team about your situation.

Are there side-effects from treatment? Page 59

Your medical team will talk to you about possible side-effects. You can also read about the different treatments to find out about possible side-effects. There are treatments to help with most side-effects, so tell your doctor. Don't suffer in silence!

Clinical trials Page 85

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. You can also see a list of current cancer trials at **www.cancertrials.ie**

We're here for you Page 131

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

Ways to get in touch

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

See page 131 for more about our services.

Reading this booklet

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

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

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

About our information

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

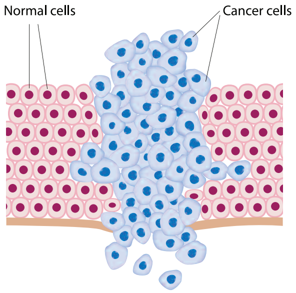
You should always talk to your own team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About sarcoma

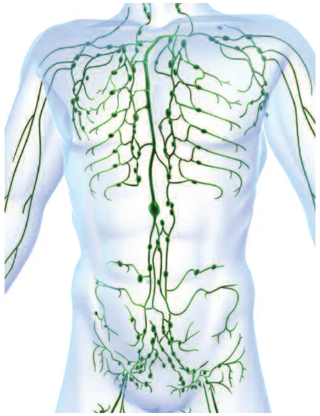
What is cancer?

- **Cancer is a disease of the body's cells**
  All the cells in our body are constantly growing, dividing, dying and being replaced in a controlled way. Cancer occurs when cells grow and change in an abnormal and uncontrolled way.

  When groups of these cancer cells continue to grow, they can form a lump called a tumour.



- **Cancers sometimes spread**
  If a tumour does develop and it is cancerous (malignant), it can spread to other parts of the body through the blood stream or the lymphatic system. The lymphatic system is part of our immune system. It protects us from infection and disease and removes extra fluid and waste from the body's tissues.



If the primary tumour spreads to other parts of the body and forms a new tumour, this is known as secondary cancer or metastasis. Secondary cancers are made up of the same type of cancer cells found in the primary cancer. For example, if bowel cancer spreads (metastasises) to the lungs, it is still treated as bowel cancer, not lung cancer. It may be called metastatic bowel cancer.

What is sarcoma?

Sarcoma is a type of cancer that starts in the tissues that support and connect the body's organs. These include bones, connective tissues, muscles, fat, nerves, and blood vessels.

There are many different subtypes of sarcoma, but they are most easily divided into 2 main groups: soft-tissue sarcomas and bone sarcomas.

Soft tissue sarcoma

Soft tissue sarcomas affect tissues such as muscles, fat, nerves and blood vessels. 4 out of 5 sarcomas are soft tissue sarcomas.

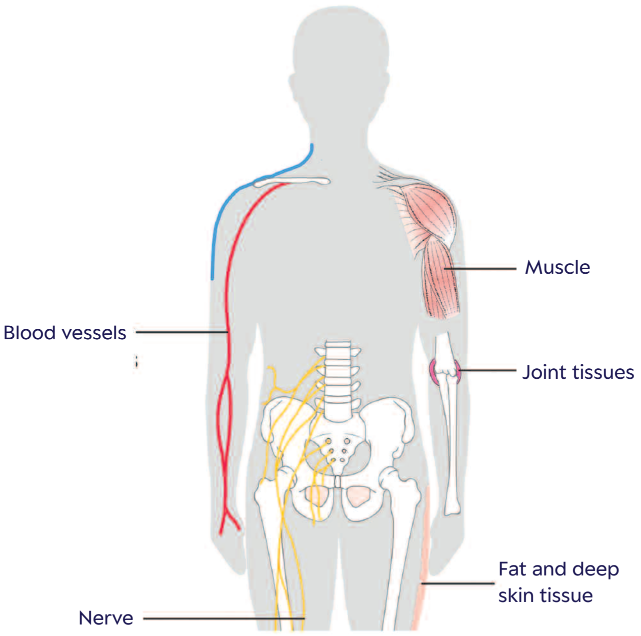


Image courtesy of CRUK / Wikimedia Commons

Bone sarcoma (primary bone cancer)

Bone sarcoma is a cancer that starts in the bone.

How common is sarcoma?

Less than 1 in 100 cancers are sarcomas and about 280 people are diagnosed each year in Ireland with some type of sarcoma.

What are the types of sarcoma?

There are many different types of sarcoma. The main ones are listed on pages 12–19, but there are many subtypes of sarcoma, some of which are very rare. You may be told about the grade and stage of your sarcoma. Grading describes how the cells look under a microscope – how fast they might grow, how they might respond to treatment and if the cancer might spread. Staging refers to the size of the tumour, where it is in the body and if it has spread. See page 36 for more about staging and grading.

Ask your medical team to explain your type of sarcoma, its stage and grade and what this means for your treatment plan.

Types of soft-tissue sarcoma

Liposarcoma

Liposarcoma is the most common type of soft tissue sarcoma. They are most common in adults aged between 30 and 60 years old and are slightly more common in males.

These tumours usually develop in the deep fatty tissue. They are most commonly found in the upper leg, behind the knee, the groin, the buttock area or behind the organs in the belly (abdominal cavity).

They usually feel solid and bumpy to touch.

There are different types of liposarcoma, which include:

- **Well-differentiated liposarcoma** (usually a large tumour in the deep tissues of the abdominal cavity, chest and groin region).
- **De-differentiated liposarcoma** (found in similar places to well-differentiated liposarcoma but the tumour is of higher grade).
- **Pleomorphic liposarcoma** (most commonly seen on the lower limbs and feet; high grade).
- **Myxoid liposarcoma** (most commonly seen in the deep soft tissue of limbs, especially around the knee).

Myxofibrosarcoma (fibrous tissue)

Myxofibrosarcomas are sarcomas in fibrous tissue (mainly muscles). They are usually found in the arms or legs or on the trunk of the body but can occur in any fibrous tissue. They are more commonly seen in people over the age of 60.

Dermatofibrosarcoma protuberens (DFSP)

This is a sarcoma of superficial soft tissues, usually involving the skin. It is most common in people aged between 20 and 50, although a small percentage can occur in children. Most commonly it affects the head and neck area, trunk and upper arms and legs.

Synovial sarcoma

Synovial sarcoma is usually found in young adults. It is most commonly found in the arms or legs next to a joint (where two bones meet). They are usually found around the joint capsule but rarely spread into the joint itself. The most common sites are around the knee and near the foot, ankle or hand.

Unlike other soft tissue sarcomas, synovial sarcomas are occasionally painful.

Epithelioid sarcomas

Epithelioid sarcoma is divided into classical and proximal types. Classical epithelioid sarcomas are usually found in the hand or foot of young adults. Proximal type epithelioid sarcoma is usually found on the trunk and upper arm and leg areas. They appear like small lumps, which sometimes join. This cancer will spread to lymph nodes in about 1 in 5 cases.

Perivascular epithelioid cell tumours (PEComa)

These are a rare type of soft tissue tumour, which may be found in the lung, intra-abdominal cavity or female pelvis. The majority of these tumours are benign (not cancer), but some show cancerous features and behave more aggressively.

Rhabdomyosarcomas (striated muscle tumour)

These cancerous muscle tumours are one of the more common types of soft tissue sarcoma in children. About half of all soft tissue sarcomas found in children are rhabdomyosarcoma. There are several different types, including embryonal, alveolar, botryoid and pleomorphic.

Embryonal rhabdomyosarcoma

This is the most common type of rhabdomyosarcoma. It is diagnosed most often in children under the age of 10. It can be found anywhere in the body, but it is more often found in the head and neck area, especially around the eye.

Alveolar rhabdomyosarcoma

This tumour is generally fast growing and usually occurs in teenagers and young adults.

Pleomorphic rhabdomyosarcoma

This tumour is rare and occurs most commonly in people over 60. Because it grows in the muscle, it is usually below the skin surface. Tumours can grow in many different areas within the same muscle and tend to grow fast. The tumour can spread to other parts of the body in the blood or through other vessels in the body.

Leiomyosarcoma (smooth muscle tumour) and uterine sarcoma

Leiomyosarcomas are another type of muscle tumour which usually occur in the leg, bowel or womb. Symptoms of bowel or womb leiomyosarcomas can include bleeding and pain.

Gastrointestinal sarcoma – otherwise known as gastrointestinal stromal tumour (GIST)

GIST develops in tissue around the stomach and intestines. These are relatively common. They are usually treated with surgery alone, but some people require drug treatment before or (more frequently) after they are removed.

Solitary fibrous tumour (SFT)

SFT is a tumour of soft tissues that can affect any site in the body including the lining of the lung (pleura), and soft tissues of the limbs, trunk and within the abdominal cavity. Some grow slowly and don't spread. Others are more aggressive – they grow faster and may spread to other parts of the body.

Vascular sarcomas (containing many blood vessels)

Hemangioendothelioma

Epithelioid hemangioendotheliomas are very rare tumours of the blood vessels, which can be cancerous. They rarely affect children. They may be found in the skin, liver or bone

Angiosarcomas

Angiosarcomas are rare and about a third of the cases occur on the skin and a quarter are found in the soft tissue or organs such as breast, liver, heart and lungs.

Malignant peripheral nerve sheath tumours

Malignant peripheral nerve sheath tumours are usually found in young to middle-aged adults and are more common in males. They occur in the nerves which are not in the brain or spinal cord. These tumours spread to the surrounding soft tissue forming a lumpy tumour. These tumours can be painful and tender and may occur in patients who have a syndrome known as neurofibromatosis.

Alveolar soft-part sarcoma

This is a very rare tumour that typically occurs in adolescents and young adults. It is usually a slow-growing tumour found in the arms and legs.

Types of bone sarcoma

There are several different types of bone sarcoma.

Many cancers that start in the bone (primary bone cancers) are sarcomas. Cancer can also spread to the bone from other parts of your body. This is called secondary or metastatic cancer.

Ewing's sarcoma

Ewing's sarcoma is actually several types of sarcomas known as the Ewing's family of tumours. In Ireland, there are about 20 cases diagnosed each year, generally in children and young adults under the age of 30. It can be found in any bone but is most common in the bones of the lower body such as the pelvis, tibia (shin), fibula (shin) and femur (thigh).

Chondrosarcoma

Chondrosarcoma develops from the cells that produce cartilage. Less than one-third of bone sarcomas are chondrosarcomas. It is more commonly found among older people than children. Unlike the other bone cancers chondrosarcoma is more often found in the spine and pelvis than in the legs or arms.

Types of chondrosarcoma include low/intermediate grade, high grade, de-differentiated and extra skeletal myxoid.

Osteosarcoma

Osteosarcoma mainly occurs in adolescents and young adults. It usually affects the large bones of the upper arm and the leg. It is most common around the knee. It is slightly more common in males than females. Although osteosarcoma is a common malignant bone tumour, it is still rare, with fewer than 30 new cases each year in Ireland.

Benign sarcomas

Benign sarcomas are non-cancerous growths that develop in the soft tissues of the body, such as muscles, tendons, fat, nerves, and blood vessels. Although they are not cancerous, benign sarcomas can still cause symptoms depending on their size and location. They may need to be removed if they cause pain, discomfort or other complications. Benign sarcomas generally do not invade nearby tissues or spread to other parts of the body.

Lipomas

A lipoma is a benign (non-cancerous) growth of fat cells that forms a lump under the skin. Lipomas are usually soft to the touch, movable, and typically painless. They can develop anywhere on the body where there are fat cells, but they are most commonly found on the shoulders, neck, chest, arms, back, or thighs.

Lipomas are generally harmless and do not usually require treatment unless they cause discomfort, pain, or other symptoms. In some cases, a healthcare provider may recommend removal if the lipoma is large, bothersome or cosmetically undesirable. However, lipomas are not a serious medical condition and are typically considered a cosmetic concern.

Desmoid tumours

These tumours are usually slow-growing tumours. They tend to spread to nearby tissues but not to other parts of your body. Desmoid tumours may occur on their own without any other known condition (sporadic desmoid) or may occur in association with an underlying genetic condition known as Familial Adenomatosis Polyposis syndrome (hereditary desmoid). Patients with this syndrome may also be at risk for tumours in the lower digestive tract. Treatment for desmoid tumours includes cytotoxic chemotherapy, tyrosine kinase inhibitors, radiation therapy or cryoablation. Surveillance is sometimes recommended as about a quarter of these tumours can shrink without treatment. Surgery is only occasionally advised.

Myxoma

Myxomas occur in adults around the age of 50. They are usually found in the arms and legs. Tumours can be small lumps or very large tumours. They are benign and do not spread to other parts of the body but they can spread to tissue close to the tumour.

Giant cell tumours

Giant cell tumours (GCTs), also known as giant cell tumour of bone, are relatively rare tumours that typically occur in the bones. These tumours are usually benign, meaning they are non-cancerous, but in some cases, they can be locally aggressive and have the potential to recur.

These tumours most commonly occur in the long bones, such as the distal femur (thigh bone) and the proximal tibia (shin bone), but they can also occur in other bones.

PVNS (Pigmented Villonodular Synovitis)

PVNS affects the synovium, which is a thin layer of tissue that lines the joints and tendon sheaths. PVNS typically affects the knee, but it can also occur in other joints such as the hip, ankle or shoulder. It can grow and affect surrounding tissues and bones.

Preparing for your hospital appointments

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

Before your appointment

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

What to take to your appointment

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

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

Before leaving the appointment

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

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

Note: If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

Questions to ask your doctor

What type of sarcoma do I have?

What stage is my cancer?

What treatment do you recommend and why?

Are there other treatment options? Why is this one best for me?

Where will I have treatment?

How long will my treatment take?

Will surgery cure my cancer?

What care will I need after surgery?

Am I suitable for a clinical trial?

What side-effects or after-effects will I get?

How often will I need check-ups after treatment?

If the cancer comes back, how will I know?

Diagnosis and further tests

Being diagnosed with sarcoma

Hearing that you have sarcoma can be a huge shock.
You may be feeling:

- **Upset and overwhelmed** by your emotions
- **Confused** about why this happened
- **Worried** about what will happen next
- **Angry** that this is happening to you

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

- Ask to speak to the clinical nurse specialist at the hospital. They can help you and you and your family to cope with your feelings and advise you about practical matters and support available. They may also refer you to a medical social worker.
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Go to your local cancer support centre. For more information, see page 137.

> “However you feel, you are not alone.”

Feeling alone

Being diagnosed with sarcoma can feel isolating. With so many different types, it may be hard to find someone who has the same diagnosis as you. You may feel that no one understands what you are going through. However, many cancer patients say they find it helpful to talk to others, even if they have a different type of cancer.

Sarcoma Cancer Ireland offers monthly online support groups, as well as one-to-one counselling and a financial support grant. See **www.sarcoma.ie** for more.

You may find a support group specific to your type of sarcoma, although this may be outside Ireland, if your type of sarcoma is rare. Remember that everyone is different and treatments in other countries may vary. Always check any medical advice or information with your treating team.

You can also join our online community at **www.cancer.ie/community**

Telling people about your diagnosis

A diagnosis of sarcoma can be hard to talk about, as people may not have heard of sarcoma, and each diagnosis is very individual. It may be hard for you to explain, especially when it is new to you too. You can ask your medical team if your friends and family have questions you don't know the answer to.

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

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

What tests might I have?

Sarcomas are most commonly suspected following an ultrasound, MRI or CT scan (see below). However, the only way to confirm the tumour is a type of sarcoma is with a biopsy (tissue sample) analysed by a specialist pathologist.

Once the diagnosis of sarcoma is confirmed, further tests will be performed to determine if the sarcoma has travelled to other parts of the body. These most frequently include a CT scan of your chest, abdomen and pelvis (if not already done), a bone scan (in the case of bone sarcoma), occasionally a PET-CT and rarely a scan of your head (unless the tumour started there or you have symptoms that make your doctors feel such a scan is necessary).

You will also have tests to check your response to treatment and monitor your health as part of your surveillance (see page 101).

Ultrasound scan

This uses sound waves to create a picture of the inside of your body on a computer. Ultrasound scans may be used to investigate lumps. A gel will be spread over your skin, over the area the doctors are checking. A small handheld device like a microphone is moved back and forth over your skin to take the scan.

MRI scan

MRI scans are often used to examine the part of the body in which the sarcoma has started. They may help with diagnosis, staging or be part of your follow-up care.

MRIs use magnetic energy to build up a picture of the tissues inside your body. During the scan you will lie inside a tunnel-like machine. The length of time you are in the machine depends on the number of images that are needed and the area of the body being scanned.

Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious. You will be asked to remove metal jewellery before the scan.

If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the scan.

You might get an injection of dye/contrast before the scan to show up certain parts of your body. An MRI can be noisy, but you will be given earplugs/headphones to wear. Usually you can go home soon after the scan.

CT scan

A CT scan is type of X-ray that gives a detailed 3D picture of the tissues inside your body.

Depending on where the sarcoma is this, may be of your chest, abdomen or pelvis (or all 3) or a bone (in the case of bone sarcoma). CT scans are used to stage sarcoma and may also be part of your surveillance care after treatment.

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.

Biopsy (taking tissue samples)

The biopsy sample will be examined by an expert sarcoma pathologist. By examining the cells under a microscope, the pathologist can give your doctor information about your type of sarcoma, its grade and if there are features of the sarcoma that might respond to certain treatments.

Plain X-ray

X-rays use high-energy rays to take pictures of the inside of your body. X-rays are very simple imaging tests. You may have an X-ray as part of your diagnosis but usually only if you have a bone sarcoma or bone pain. Chest x-rays are more commonly performed as part of the surveillance following sarcoma treatment. This is because, though not common, the most common area in which the sarcoma can return is the chest (lung).

PET or PET-CT scan

A PET scan combines a CT scan with an injection of a radioactive substance (radiotracer) that can highlight cancer cells on the scan. These scans are not commonly used in the investigation (or follow up) of sarcomas. The main situation in which they may be used is if the radiologists feel they might add additional information to that obtained by the CT scan.

You will be slightly radioactive after the PET scan, so you will be advised not to have close contact with pregnant women, babies or young children for a few hours after the scan.

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

Other tests

You may have other tests, depending on the type of sarcoma you have. Your team will explain them to you. Ask any questions you have, including what the test is for. You can also speak to our nurses by calling Freephone 1800 200 700 or by visiting a Daffodil Centre. There is also information on cancer tests on our website, **www.cancer.ie**

Waiting for test results

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

Grading and staging sarcoma

Grading and staging are ways to describe your sarcoma, to help your team plan the best treatment for you.

- Grading describes how the cells look under a microscope – how fast they are likely to grow, how they might respond to treatment and if the cancer might spread. The cells are taken during a biopsy.
- Staging refers to the size of the tumour, where it is in the body and if it has spread.

Grading sarcoma

Low-grade – the cancer cells are slow-growing, look quite similar to normal cells, are less aggressive and are less likely to spread

Intermediate-grade – the cancer cells are growing slightly faster and look more abnormal

High-grade – the cancer cells are fast growing, look very abnormal, are more aggressive and are more likely to spread

Staging sarcoma

Staging sarcoma looks at:

- Where the tumour is
- The size of the tumour
- How aggressive the cancer cells are (the grade)
- If the cancer has spread to lymph nodes or other parts of the body

Always ask any questions you have, including what the grade and stage mean for you and your treatment. For example, which treatment is most suitable and if treatment will aim to cure the cancer or to stabilise the disease and improve any symptoms.

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:

Get the information from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information you are being give and answer any questions you have.

Ask a friend or family member to go with you if you would like some support.

Be careful with online information. It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation, especially as there are so many different types of sarcoma. Ask your doctor or nurse specialist for recommended websites.

Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.

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

Treatment overview

How is sarcoma treated?

- Surgery is the main treatment for most types of sarcoma. Sometimes radiotherapy (and occasionally chemotherapy) is given before or after surgery. Radiotherapy or chemotherapy can also be used alone if surgery is not possible or surgery cannot remove all the cancer.
- A team of specialists will be looking after you (multidisciplinary team).

Your treatment will depend on a number of things including:

- The type of sarcoma
- Where in the body it is
- Whether it has spread and how far (its stage)
- Your general health

Because there are many different subtypes of sarcoma, treatment plans are very individual. For example, some types do not respond well to chemotherapy, so radiotherapy may be a better option for your sarcoma.

Soft tissue sarcoma

Surgery to remove the cancer and radiotherapy are often used in combination for soft tissue sarcoma. Chemotherapy may also be used for types of soft tissue sarcoma known to respond to chemotherapy.

Bone sarcoma

Surgery to remove the cancer and chemotherapy before or after surgery are the main treatments for bone sarcoma. Radiotherapy may be used for some types.

Types of treatment

Surgery

Surgery is used to try to remove the sarcoma, along with surrounding healthy tissue. Surgery can also be used for recurrent or metastatic sarcoma (see page 61).

Radiotherapy

Radiotherapy is the use of high-energy rays to kill the cancer cells. External radiotherapy is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour. Radiotherapy may be used:

- Before surgery to shrink the tumour, making it easier to remove.
- After surgery to try to kill any remaining cancer cells, to prevent the cancer coming back.
- To help with symptoms and/or to control the cancer, if surgery isn’t possible or it can’t remove all the tumour.

See page 72 for more about radiotherapy.

Chemotherapy

Chemotherapy is the use of drugs to kill or control the growth of cancer cells. It can be used:

- Before surgery to reduce the tumour, making it easier to remove.
- After surgery to try to prevent the cancer coming back.
- To control the cancer, if surgery isn’t possible or it can’t remove all the tumour.

Chemotherapy is used most often with bone sarcomas, as not all types of soft-tissue sarcomas respond to chemotherapy. See page 75 for more about chemotherapy.

Targeted therapy drugs

Some subtypes of sarcoma can be treated with targeted therapy drugs. These therapies work by specifically targeting genetic mutations or abnormalities in cancer cells, to control their growth and spread. See page 82 for more details

Immunotherapy

Immunotherapy helps boost the body's immune system to recognise and attack cancer cells. Although it is not a standard treatment for all sarcomas, it may be used in certain cases or as part of clinical trials.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. See page 85 for more about clinical trials.

Treatment for recurrent or metastatic sarcoma

If the sarcoma has spread (metastatic disease) or comes back again after treatment (recurs), treatment will aim to keep the cancer under control. See page 84 for more.

Will treatment cure my sarcoma?

Many sarcomas can be treated successfully. The success of treatment is higher if the sarcoma is diagnosed at an early stage, for example, when it's small and before it has developed the ability to travel to other parts of the body.

Doctors don't generally use the term 'cure' when talking about sarcoma – as it can come back again (recur). You may hear the terms 'remission' or 'no evidence of disease'.

If a sarcoma is going to recur or travel to another part of the body, this generally happens within the first 2-5 years after treatment. After 5 years the chance of recurrence reduces greatly.

Worrying about the cancer coming back

It is normal to feel anxious about the cancer coming back. There are there are things that may help you to cope with this uncertainty. See page 103 for more about coping with uncertainty.

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. The MDT works together to plan the best treatment for you.

The National Sarcoma Multidisciplinary Team (MDT) is based in St Vincent's University Hospital, Dublin 4, but the members of that team may recommend treatment in other hospitals around the country. The MDT is made up of specialists in different areas of medicine who have expertise in planning and delivering treatment for sarcoma patients. For example, sarcoma surgeons, medical oncologists, radiation oncologists, radiologists, pathologists and specialist nurses. There is also a specialist team in Cork University Hospital (CUH).

Depending on the type of sarcoma you have it may be possible for you to be treated in one of the other cancer centres around the country.

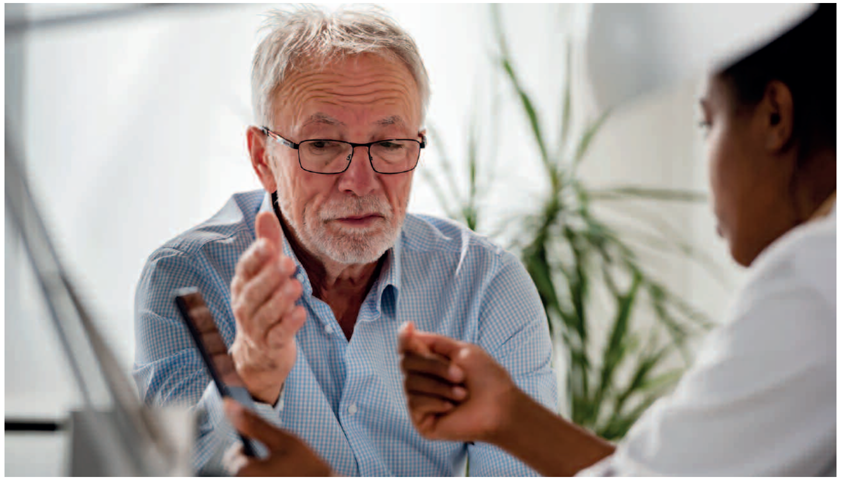
Your treatment plan

- **The treatment or treatments your doctors recommend for you are based on the latest research and international guidelines** about the best way to treat sarcoma.
- **Your team may also consult with international sarcoma specialists about the sarcoma subtype,** to ensure the best treatment can be recommended.
- **Your doctor and nurse will explain your treatment options.**
- **You may notice that other people with sarcoma and not getting the same treatment as you.** Their cancer may not be the same type or at the same stage as yours. Every patient is different and the same treatment plan may not work with different people.
- **Talk to your doctor if you have any questions** about your treatment plan.
- **You could use the fill-in page at the back of this booklet to write down your questions.** Ask as many questions as you like. If you forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses. Call our Support Line on 1800 200 700.

Specialist cancer centres

There is not a single sarcoma hospital in Ireland, but people diagnosed with sarcoma should have their case discussed at a specialised sarcoma MDT meeting where an individual treatment plan is decided. The National Adult Sarcoma MDT is hosted by St Vincent's University Hospital, which works alongside Cappagh National Orthopaedic Hospital, Tallaght University Hospital and the St Luke's Radiation Oncology Network. Most adults will have their sarcoma treated in one of these hospitals but, in certain situations, another cancer centre may be involved in all or some of the treatment. There is also a regular MDT meeting held in Cork University Hospital.

You may be referred to a specialist hospital, which may be different from the one where you received your diagnosis, or a sarcoma specialist from one of these centres may be consulted for their opinion on your treatment plan.



Tests and treatment abroad

Some types of sarcoma are best treated outside of Ireland. For example, with pelvic or spinal bone sarcoma, surgery may be planned and take place in the Royal Orthopaedic Hospital, Birmingham, with rehabilitation in Ireland afterwards. Some types of sarcoma are better treated with proton radiotherapy and this takes place in either the UK or Germany.

The cost of treatment is covered by the Treatment Abroad Scheme from the HSE. For more information and details of what is covered, see the HSE website or ask your treating team.

Understanding your treatment

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

The treatments the doctors in Ireland recommend are based on the latest research and international best practice. But you might find it reassuring to have another medical opinion to help you decide about your treatment.

If you want to contact a doctor abroad, talk to your team and they will arrange an external opinion for you. Getting a second opinion abroad may take time and you will need to pay privately for this.

Accepting treatment

You have the right to find out what a treatment option means for you. You also have the right to accept or refuse treatment. 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.

Who will be involved in my care?

Some of the following professionals may be involved in your care:

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

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

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

Radiologist: A doctor who specialises in interpreting X-rays and scans such as ultrasound, CT, MRI and PET and also undertakes biopsies under image-guidance.

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

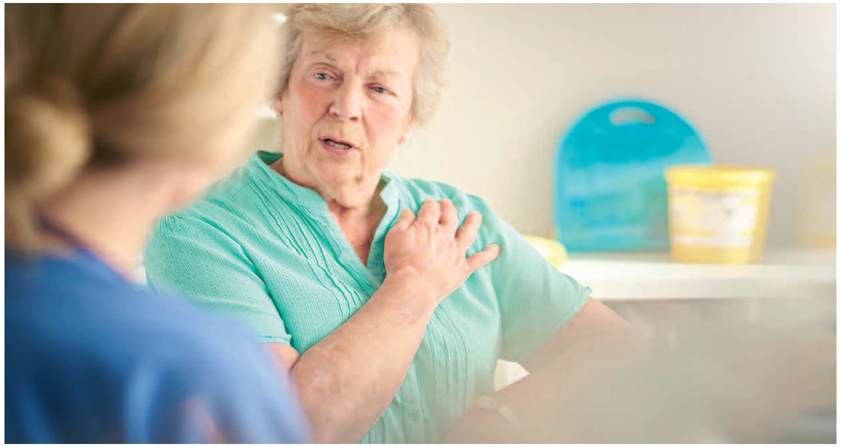
Advanced nurse practitioner (ANP): A specialist nurse who has advanced qualifications, experience and training. They can clinically assess, diagnose, refer and treat patients. For example, sarcoma ANPs can carry out tests such as core biopsies and can prescribe medications.

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

Rehab team: This team includes specialists who can help you to recover after your treatment. Your team may include physiotherapists, occupational therapists, psychiatrists and prosthetists.

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments related to the illness. They can help you with strength and mobility in your muscles and joints after treatment, to help you be as active as possible. They can also provide any exercises or equipment you need for your recovery.

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



Prosthetist: A false limb specialist. They can fit artificial limbs and will help you to wear and use them.

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

Psychiatrist: A specialist in the diagnosis and treatment of mental health conditions. They provide talk therapy and can also prescribe medication.

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

Dietitian: An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms

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 and what side-effects to expect. They can also advise on possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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

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

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

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you.

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 the 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.

Talk to your doctor or nurse if you have any worries about your treatment plan. You can still change your mind after you have started treatment.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread even more during this time.

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

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

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on cancer treatments, including what to expect and how to manage side-effects.

How can I help myself?

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

Eat well

Eating as well as possible can help you during your treatment. It can help you to:

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

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Understanding Diet and Cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it from our website **www.cancer.ie**

Keep active

If you are able, it can really help to stay active. Keeping up or increasing your activity levels can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Improve your mobility and strengthen your muscles, joints and bones. This may also help your recovery if you are having surgery. For example, if you might need to use crutches or a walking aid, increasing your fitness and upper body strength can make things easier. Your physiotherapist can advise you about this.
- Reduce the risk of other health issues

Talk to your doctor, nurse or physiotherapist before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe and beneficial for you, considering your general health, diagnosis and treatment plan.

Quit smoking

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

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

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit www.QUIT.ie or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

You will have a better quality of life if you give up smoking.

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. Make sure you get your information from trustworthy sources like your medical team, the National Sarcoma Network website **www.stvincentssarcomanetworkireland.com** and the Irish Cancer Society.

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, childminding 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 that they have to 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

Surgery

- Surgery aims to remove cancer from the body.
- You may need to have plastic surgery or a prosthesis (implant) to repair the area.
- Surgery can also be used to relieve symptoms.

Surgery aims to remove the cancer. Your surgeon will try to remove all the cancer and an area (margin) of healthy tissue around the tumour, to reduce the risk of the cancer returning. The type of surgery and how much tissue is removed depends on the size of the cancer, where it is and if it has spread.

Surgery for soft tissue sarcoma

The type of surgery for soft tissue sarcoma and how much tissue needs to be removed depends on the size of the cancer and where it is.

You may have radiotherapy before surgery to reduce the size of the cancer to make it easier to remove and afterwards to reduce the risk of the cancer coming back. Sometimes chemotherapy may be used, depending on the type of sarcoma.

If a large amount of tissue needs to be removed, you might need to have a plastic surgeon involved to reconstruct the area. For example, some people have a skin graft. This means taking a thin layer of skin from another part of your body (often the upper thigh) and using it to repair the area where the tumour was removed. Your team will try to ensure that you will look and function as well as possible after the surgery to remove your cancer.

Surgery for sarcoma in other areas of the body, such as retroperitoneal sarcomas (inside the tummy (abdomen)) usually need more complicated surgery.

Retroperitoneal surgery

The retroperitoneum is an area deep in the abdomen (tummy area). The retroperitoneum contains a number of organs, such as the adrenal glands, kidneys, oesophagus, ureters, pancreas, rectum and parts of the stomach and colon. If sarcomas develop in this area of the body, removing the tumour and the area around it may mean that organs or parts of organs may need to be removed as well, if they are close to the tumour. For example, some people may have a kidney removed. Your kidney function will be checked with a DSMA scan before surgery. This is a test that uses an injection of a radioactive substance to show your kidneys on a scan. This is to ensure that your remaining kidney will function well for you after surgery.

Your surgeon will explain your surgery to you and what it might mean for your recovery.

Surgery for bone sarcoma

The aim of surgery is to remove the affected bone and an area around it, to remove any remaining cancer cells to try to stop the cancer coming back. The bone removed is often replaced with an implant (prothesis).

The type of surgery and how much tissue needs to be removed depends on the size of the cancer and where it is. Most bone sarcomas are in the arms or legs. If you have sarcoma affecting another part of the body, the surgery may be different. Ask your surgeon about this.

It is likely you will have chemotherapy before surgery to reduce the size of the cancer to make it easier to remove and afterwards to reduce the risk of the cancer coming back. Sometimes radiotherapy may be used, depending on the type of sarcoma.

Your team will try to ensure that you will look and function as well as possible after the surgery to remove your cancer. Depending on how much bone is removed, you may need other procedures. Your surgeon will discuss these with you.

Amputation surgery

This means removing the affected limb or part of the limb when soft tissue or bone sarcoma affects the arms or legs. Amputations are not common - surgeons will usually try to save the limb, but rarely amputation might be necessary if limb-sparing surgery won't remove all the cancer or it might cause long-term problems with pain or movement.

Your surgeon will explain your surgery to you.

Understanding your surgery

Sarcoma surgery can be complicated and recovery can take a while. If you are having an arm or leg removed, it may have a bigger impact on you, both physically and emotionally. Your team will be there to support you.

Before your operation your surgeon will explain what will happen during and after surgery, as well as explaining any possible risks or complications.

Try to think about what you want to ask them so that you have as much information as you want. For example, how long you will be in hospital, how you will be affected and what kind of support you will have.

Meeting the rehabilitation team

You might meet some of the rehabilitation team too. This team will help you to recover and adjust after your surgery. This team includes physiotherapists, occupational therapists and the prosthetic and orthotic service. This service can provide artificial limbs (prostheses) to people who have had amputations and other devices you may need, such as splints and supports.

The physiotherapist may recommend exercises you can do before your surgery to strengthen your muscles and help with your recovery.

Coping with your feelings about surgery

Talk to your team about any worries or if you are feeling overwhelmed or are finding it hard to deal with your feelings. Your team may also be able to refer you to a psycho-oncology service, who can give you emotional support and help you to cope. You can also call our cancer nurses on Freephone 1800 200 700 or visit a Daffodil Centre.

Preparing for surgery

It might also help to look after your own health while you are preparing for surgery – for example, stopping smoking can help you to recover and reduce the risk of complications, exercising to build strength and muscle mass can make it easier for you to cope physically with rehabilitation after surgery. See page 54 for more about preparing for treatment.

After surgery

You may spend a short time in intensive care after your operation. You will be closely watched before returning to the ward.

Drips, drains and tubes

You may have some drips, drains or tubes attached to you after your operation. For example:

- **Intravenous (IV) drip:** A drip will be put into a vein in your arm. This will give you fluids until you are able to take fluids by mouth again. You may also be given antibiotics to prevent infection.
- **Drains:** One or more thin tubes called drains may be attached to you near your wound. These help to drain blood and fluid from the operation site to let your wound heal. They are usually removed after a couple of days.
- **Epidural:** You may have a thin tube called an epidural in your back. This is to deliver medication to relieve any pain you might have.

Wound

The wound will be covered with a dressing at first. Your nurses will look after the wound while you are in hospital. If you will need wound care after you leave hospital, your ward nurses will arrange this with your local community health centre before you go.

Pain relief

You may have some pain after the operation. Your nurse can give you medicine to control the pain, if you need it. You may have an epidural tube in your back to relieve pain after the surgery or a patient-controlled analgesia pump (PCA), which releases pain relief when you press a button. Your nurse will show you how to use it. Always ask for help before the pain gets too bad.

Phantom pain after amputation

Sometimes people feel pain in the area that has been amputated. This is called phantom pain. There is medication to help with this type of pain, so let your team know if you experience phantom pain.

Infection

After surgery, there is a risk you may get an infection. Your nurse will check your wound and the tubes twice a day. Let them know if any leakage, swelling or redness happens at the wound or tube sites or if you feel hot or unwell.

Seroma

Sometimes fluid builds up and forms a lump (seroma) after surgery. This fluid may be reabsorbed by the body or it may may need to be drained by your surgical team. If you notice a build-up of fluid or any swelling contact your surgical team or nurse specialist who will arrange a clinic appointment for this to be assessed.

Getting up and about

A physiotherapist will visit you regularly and recommend breathing and other exercises for you. Doing the exercises can help to prevent blood clots and chest infections.

Even when you are in bed you will be encouraged to move and do deep breathing exercises at least once an hour.

If you are in pain, you may not feel able to do your breathing or movement exercises, so let your nurse or doctor know if you need medication to help with pain. The physiotherapist can also show you any other exercises that will help you to recover after surgery.

Rehabilitation after surgery

After sarcoma surgery your rehabilitation team will work with you to help you recover movement and function and return to your daily activities. Rehabilitation can happen at different times after surgery, depending on the type of surgery you have had and if you are having more treatment after surgery. For example, you may need to keep a limb still while it heals, and you may have a sling or a brace for some time.

Physiotherapy

The physiotherapist will show you exercises to help you to regain movement in the affected limb and to use it again. If you have had an amputation, your physiotherapist will give you exercises to help you recover and to prepare you for an artificial limb, if you are having one.

It’s important to continue with your physiotherapy to make sure you recover as well as possible. If you had surgery to your leg, you may use crutches or a walking aid at first or you may have an immobilisation device such as cast or brace.

Your surgeon will decide if you need physiotherapy after you leave hospital.

Occupational therapy

The occupational therapist will help you to adjust so that you can carry on your daily activities. This may include washing and dressing, housework, parenting, work and leisure activities. They can advise on and organise any equipment you might need to help you.

Psychological support

Adjusting to life after sarcoma surgery can be a challenge, and rehabilitation may take a lot out of you. You may also be dealing with your feelings about your cancer diagnosis and your surgery. If you have had an amputation you may have difficult emotions relating to the loss of your limb.

See page 71 for more about feelings after surgery. If you need help to cope with your feelings, tell your medical team. They may be able to refer you to a psycho-oncology service. You can also talk to our cancer nurses on 1800 200 700 or by visiting a Daffodil Centre. They can give you advice and support and refer you to free counselling and other supports.

Going home after surgery

The amount of time you will stay in hospital depends on the operation you have had and your recovery. You may feel nervous about going home or worry how you will manage. Your team, including your specialist nurse, physiotherapist and occupational therapist, will work with you to prepare you and organise any support you might need. For example, you might need a wheelchair, other equipment or you may need changes to your home. Let your team know if you have any concerns about managing at home so that they can help you.

Artificial limb (prosthesis)

Some patients may be suitable for an artificial limb (prosthesis). Your surgical team will discuss this prior to your operation. Some types of prosthesis look like the limb they are replacing but they do not move. Others move to help you do some of the things the amputated body part used to do.

It can take some time to get used wearing and using a prosthesis. A specialist called a prosthetist will help you. They will take measurements or a cast of the area where your arm or leg was removed. They use these to make a socket that fits over the area. The prosthesis will be made to fit into this socket.

When your prosthesis is ready you will have appointments to fit the prosthesis and make sure you can attach and remove it. A physiotherapist or occupational therapist will work with you to make sure you can use it.

You will have regular check-ups with this team to make sure your prosthesis is comfortable and working well for you.

Feelings after surgery

Depending on the operation you have and the impact it has on you, you may find it difficult to cope emotionally. You may feel angry, frustrated, powerless or self-conscious about your appearance.

Amputation and your emotions

Losing a body part and adjusting to the physical challenges it creates can be difficult to cope with. You may experience a range of emotions after having an amputation – you may feel a sense of grief over the loss of your limb and the loss of your previous life or identity.

Getting support

It's important to acknowledge how you are feeling and get help if you are finding it hard to cope. Your medical team can support you and they may also refer you to specialist psycho-oncology services. You can also talk to our cancer nurses by calling 1800 200 700 or by visiting a Daffodil Centre. They can support and advise you and tell you about free counselling and other services. See page 115 for more about getting support.

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- Radiotherapy is painless and only takes a few minutes.
- The treatment is usually just a few short sessions.

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

Radiotherapy may be given:

- Before surgery to shrink the cancer. This makes it easier to remove. This is called neo-adjuvant treatment.
- After surgery to destroy small amounts of the cancer that may be left. This is called adjuvant therapy.
- To control and relieve symptoms, such as pain, bleeding and shortness of breath. This is called palliative radiotherapy.

External radiotherapy is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour.

Planning your external radiotherapy treatment

Radiotherapy is usually given as external beam radiation. This is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour.

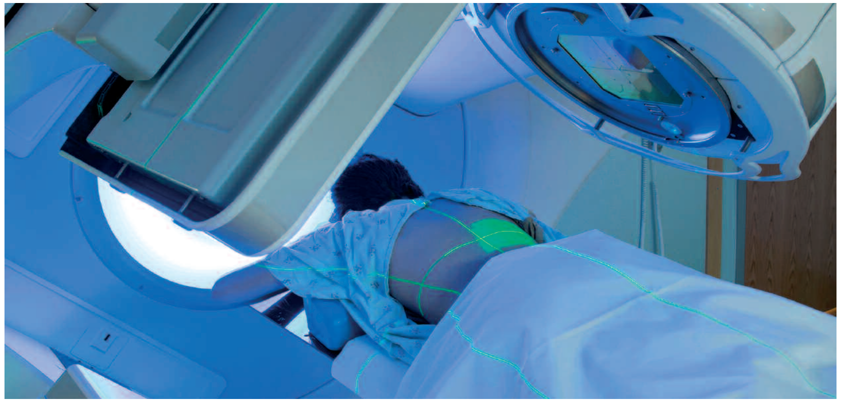
Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby areas.

You will have a planning (simulation) appointment, which includes 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 a few minutes and is painless.

Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different department or hospital from where you had chemotherapy or other treatment.



How much radiotherapy do I need?

Radiotherapy given before surgery usually involves 5 weeks of treatment (25 sessions or fractions). Radiotherapy given after surgery (once the wound has healed) usually involves 6 weeks (30 sessions or fractions) of treatment. You will get a break at the weekend. Radiotherapy given to alleviate symptoms of sarcoma when cure is not possible usually involves 1 to 10 treatments.

External beam radiotherapy does not make you radioactive. It's safe for you to mix with family and friends, including pregnant women and children.

For more information on radiotherapy, or to order a copy of our booklet ***Understanding Radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Side-effects of radiotherapy

Side-effects will depend on the area of the body that is being treated and the dose of radiation you are given. Side-effects can include:

- Nausea (feeling sick), but usually only if the head or abdomen is treated
- Fatigue (extreme tiredness)
- Skin problems. The skin around the treatment area may become red, dry or itchy and it may be sensitive to touch
- Eating-related issues. Radiotherapy to the head or neck area can cause problems such as swallowing difficulties, sore mouth and changes to your sense of taste
- Hair loss. Radiotherapy causes hair loss only in the area that is being treated. If you need radiotherapy to the brain, the hair on your head will fall out

How severe side-effects are varies from person to person. Most side-effects develop during or shortly after your treatment and can usually be managed with simple medications. Most side-effects improve or go away in the weeks after you have finished treatment.

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

Proton radiotherapy

Proton radiotherapy is a type of radiotherapy that uses high-energy proton beams rather than high-energy photon radiation beams to deliver a dose of radiotherapy. This technology is most helpful when treating sarcomas around the head, neck and spine area and in children. It is usually no more beneficial than photon radiotherapy in other parts of the body. If your treating team feels proton beam therapy might be helpful for you, you will be referred to a hospital in the UK or Germany.

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Chemotherapy can cause a range of side-effects.
- Side-effects normally go after treatment ends.

Chemotherapy is a treatment that uses drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy may be given:

- As a treatment on its own.
- Before surgery to shrink the cancer and make it easier to remove. This is called neo-adjuvant treatment.
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- For cancer that has spread or come back after treatment to control the cancer, slow its growth, reduce the side-effects of cancer and improve quality of life.

Chemotherapy is used more often with bone sarcoma, as not all types of soft-tissue sarcoma respond to chemotherapy drugs.

How often will I have chemotherapy?

Chemotherapy is 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 treatments and cycles can vary, depending on things like how well you are responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given in tablet form. Often it is given through a portacath. This is a thin, soft plastic tube with a rubber disc (port) at the end.

The tube is inserted into a vein until its tip sits just above your heart and the port lies under the skin on your upper chest. The port can be put in under a general or local anaesthetic.

A special needle called a huber needle is put into the port in the hospital to allow the drugs to be given through the port. Blood can also be taken from the vein through the port. This saves you having repeated injections.

Usually your treatment will be given in the oncology day ward.

What kinds of drugs are used?

There are several types of chemotherapy drugs that may be used to treat sarcoma. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or you may have more than one type together.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your drug, you can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on Freephone 1800 200 700.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depends on the amount of chemotherapy you have and the drugs used. Ask your doctor or nurse if you're worried about side-effects or if you have any questions.

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

Fatigue

Fatigue is very common. It can make you feel weak and tired. For more information, see page 91.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurses if they are not working well for you. Thinking or talking about the treatment can also make you feel sick.

This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.

Risk of infection

Chemotherapy drugs make you more likely to get infections. You will be given a number to call for advice if you have signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine.

Avoiding infections

If you have a high temperature or feel unwell (even with a normal temperature), it is very important to call the number you have been given straight away – never delay. Check with your hospital about the temperature advice to follow.

Anaemia

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

Bleeding and bruising

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

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you. You will also be told about how to look after your mouth during treatment to try to prevent mouth problems.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back 3-6 months after you stop chemotherapy.

Constipation and diarrhoea

Chemotherapy can cause constipation. This is when you don't have a bowel movement (poo) often enough. It can also cause diarrhoea. This is when you have frequent loose or watery bowel movements. Your doctor can give you medication to help, if needed.

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

Changes in kidney or liver function

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

Allergy

On rare occasions people can have a reaction to certain chemotherapy drugs. Reactions can include a rash, itching, low blood pressure and shortness of breath. Tell your team if you have these reactions.

Blood clots

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

Loss of appetite

It is often hard to eat well due to cancer and the effects of treatment. But do try to eat as well as you can to keep your strength up. Eat smaller amounts more often. Getting some fresh air and exercise may help to boost your appetite.

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

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

Targeted therapies

- Targeted therapies target certain parts of cancer cells that make them different from cancer cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells.

Different targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cell to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

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

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 85). 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

Side-effects depend on the drugs being used and vary from person to person. Common side-effects can include:

- Fatigue (extreme tiredness)
- Nausea (feeling sick)
- Vomiting (getting sick)
- Dizziness
- Diarrhoea

Your doctor and nurse will explain your treatment to you in more details 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 side-effects or symptoms that are troubling you.

For more information on targeted therapies and their side-effects, or to order a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Treatment for cancer that has spread (metastasis) or come back (recurrence)

If the cancer spreads to another part of your body, it is called metastatic or secondary cancer. If it comes back after treatment it is called recurrent cancer.

If your cancer has spread or come back it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. There are a range of treatment options for most advanced cancers, and new treatments are being developed all the time.

Surgery may be used if the sarcoma comes back in a similar area. You may also have surgery if it spreads to the lung, depending on the size and position of the tumour.

Often metastatic or recurrent cancer is treated with chemotherapy and sometimes with targeted therapies, radiotherapy or immunotherapy.

There may also be treatments that you can have as part of a clinical trial (see the next page).

Thanks to recent advances in research and treatments, many people are living longer with cancer and with a better quality of life.

You can also have treatment to help with any symptoms. You may be referred to the palliative care team, who are experts in managing the symptoms of cancer.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects.

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of, or as well as, the standard treatment, you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

Because the drugs are still in trial, you'll be closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment. You may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet ***Cancer and Clinical Trials***. It's available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at **www.cancertrials.ie**

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to manage symptoms and complications earlier in your illness. The palliative care team are the experts in symptom management and control. They may be involved in your care from the beginning of treatment to assist and guide management of symptoms.

Palliative care includes physical, psychosocial and spiritual care. The team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellor. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. Palliative care teams work both in hospitals and in the community and sometimes visit patients at home. They may work along with your treating team.

For more information on palliative care visit the Palliative Hub at **www.adultpalliativehub.com**.

Managing side-effects and symptoms

Symptoms and side-effects can vary from person to person. Most can be treated and some can be prevented. You should always tell your medical team about any symptoms or side-effects you are experiencing.

Pain

Taking care of pain is important. Pain can make you feel depressed and affect your ability to move, work, do activities you enjoy and sleep. Controlling pain is also important if you have had surgery, so that you can continue with any physiotherapy recommended for you and stay active.

Tell your doctor and nurse if you have pain, as there are ways to treat it. There are also a lot of good painkillers (analgesia) available today – some over the counter and others your doctor can prescribe. Your doctor will decide which painkiller is best suited to the type of pain you have. There are other ways to treat pain such as nerve blocks and epidural injections. You may also be referred to doctors who specialise in pain relief.

Describing your pain

Be honest about the level of pain that you are in. Describing how you're feeling and how the pain is affecting you as fully as possible can help your medical team to work out the best way to treat your pain. There is no need to suffer in silence or play down the amount of pain that you have.

Hints and tips: Taking pain medication

- **Take your painkillers regularly as advised**, even if you don't have pain at a particular time. They will help to keep your pain under control.
- **If one doesn't work, tell your doctor or nurse so they can try something else.** They may arrange for you to try out different painkillers to find out what suits you best.
- **Tell your doctor or pharmacist if you're bothered by side-effects.** Some painkillers have side-effects, especially the strong ones. These side-effects may include constipation, feeling sick (nausea) and drowsiness. They may recommend medication to help.
- **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, talk to your doctor or nurse.** They may suggest you take a laxative every day. Drink plenty of fluids such as water and fruit juice to keep your bowel habits regular. Your doctor or nurse will give you something stronger if your bowels have not opened for 2 or 3 days.
- **Don't drive or work machinery if you feel drowsy.**

Phantom pain

If you have had a limb amputated, you may experience phantom pain. This is pain in the area that has been amputated. Let your medical team know if you have this type of pain.

Fatigue

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Usually, fatigue starts to improve once treatment is over but it can carry on for some people. 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 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.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy,
- **Ask for help at work or home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Diet and Cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 113).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night. Try to have naps in the earlier part of the day.
- **Try complementary therapies** like meditation or acupuncture, if your doctor says they are safe for you.

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

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 cancer can take quite a while. It can be hard to relax when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

If you have had surgery that affects the movement and function of your limbs or other body parts, it may take time for you to recover and then to adjust to any limitations you have. You may also feel self-conscious about the way your body looks or feel less attractive. If you are struggling with these issues, try to talk openly with your partner. Your medical team can also refer you to psycho-oncology services, if they are available at your hospital.

There is no right or wrong way to feel about your sexuality and sex life. If you do not feel like having sex or cannot have sex, touching and holding each other can help you to stay physically close and keep a close and loving relationship with your partner.

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

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

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

Ask your doctor's advice about contraception or if you are thinking about having children in the future.

Asking for advice

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

Will treatment affect my fertility?

Your fertility may be affected by chemotherapy, targeted therapies or radiotherapy and some types of surgery. Your team will discuss this with you and tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. Call our Support Line on 1800 200 700 for more information on counselling or to speak to a cancer nurse in confidence.

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, meditation, acupuncture and aromatherapy.

Complementary therapies can't treat or cure cancer. But some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. 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 treating cancer. An unproven alternative could harm tour health, or you might miss out on a treatment that could really help you.

More information

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

After treatment

What follow-up will I need?

After your cancer treatment has ended, you will still need to go back to the hospital for regular check-ups. This is called follow-up or surveillance. Sarcomas can come back again after treatment, so it's important to always go to your follow-up.

For some patients, follow-up may involve consultations over the phone. For others, they may need to go to the hospital for clinical assessment. Follow-up tests can include blood tests and imaging tests such as X-rays, MRI scans or CT scans. There may be a combination of phone consultations and outpatient visits.

Your medical team will discuss your follow-up with you. How often and the type of follow-up you have will depend on your treatment plan.

The purpose of follow-up is to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the cancer coming back (recurrence)

You can tell 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. For example, if you are struggling with mobility challenges after surgery or if you are finding it hard to cope with your emotions, feeling depressed or finding it difficult to adjust to a changed body image. It may help to write down what you want to say before you see the doctor, so you don't forget anything.

Symptoms to watch out for

- Any new lump
- Pain – particularly at night – that carries on
- Shortness of breath, a bad cough or coughing up blood

You will be monitored after your treatment, but it is important to report any symptoms to your medical team between appointments. Having symptoms doesn't mean that your cancer has come back, but it's important to report any symptoms so they can be checked.

If you have any symptoms or problems between appointments, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary. Go to your GP if you're unwell and you can't contact the hospital team or attend the hospital's emergency department, if necessary.

Will the cancer come back? Coping with uncertainty

It can be very hard to live with uncertainty and worries about the cancer coming back. Everyone will cope differently, but there is support available that might help you. It may help to focus on the present and the things that you can control. This may help you to feel more positive and think less about what might happen in the future.

- **Talk about how you're feeling –** share your worries with a friend or family member or try counselling (see page 113)
- **Join a support group –** visit your local cancer support centre, where you can meet other people and learn techniques to help you relax
- **Get information about your sarcoma,** such as your follow-up schedule, signs to look out for and ways to take care of yourself
- **Tell your GP or medical team if you're finding it hard to cope** and feel you need extra support.

Life after treatment

It can take some time to adjust to life after treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

- Fear of the sarcoma coming back and worrying about every small symptom
- Loneliness without the company and support of your medical team and fellow patients
- Stress at having to deal with things that may have been on hold during your 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
- Depression or sadness
- Relief that treatment is over and a new phase in your life can begin

There is more about how to cope with these feelings and adjusting to life after treatment on our website www.cancer.ie

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 115 for more ways to get emotional support.

After-treatment workshops

You might like to join our free **Life and Cancer – Enhancing Survivorship (LACES)** workshops when you have completed treatment or have started maintenance therapy. Developed in partnership with the National Cancer Control Programme, LACES covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

Living a healthy lifestyle

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

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

A healthy lifestyle includes:

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

It's also important to have any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so check with your doctor which you should have and make sure you get them.

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

Adjusting to changes in how your body looks and works

If you have had surgery that affects the way your body works or looks, you may find it takes a long time to adjust. Most people do learn to adjust in time, but it's important to get support if you are finding things difficult. You can tell your treating team if you need support.

It may help to talk to someone who has had a similar surgery. Sarcoma Ireland has monthly online support groups. See page 30 for more.

You can also speak to our cancer nurses by calling Freephone 1800 200 700 or visiting a Daffodil Centre. They can also give you details of local cancer support centres, free counselling and other supports.

Planning ahead

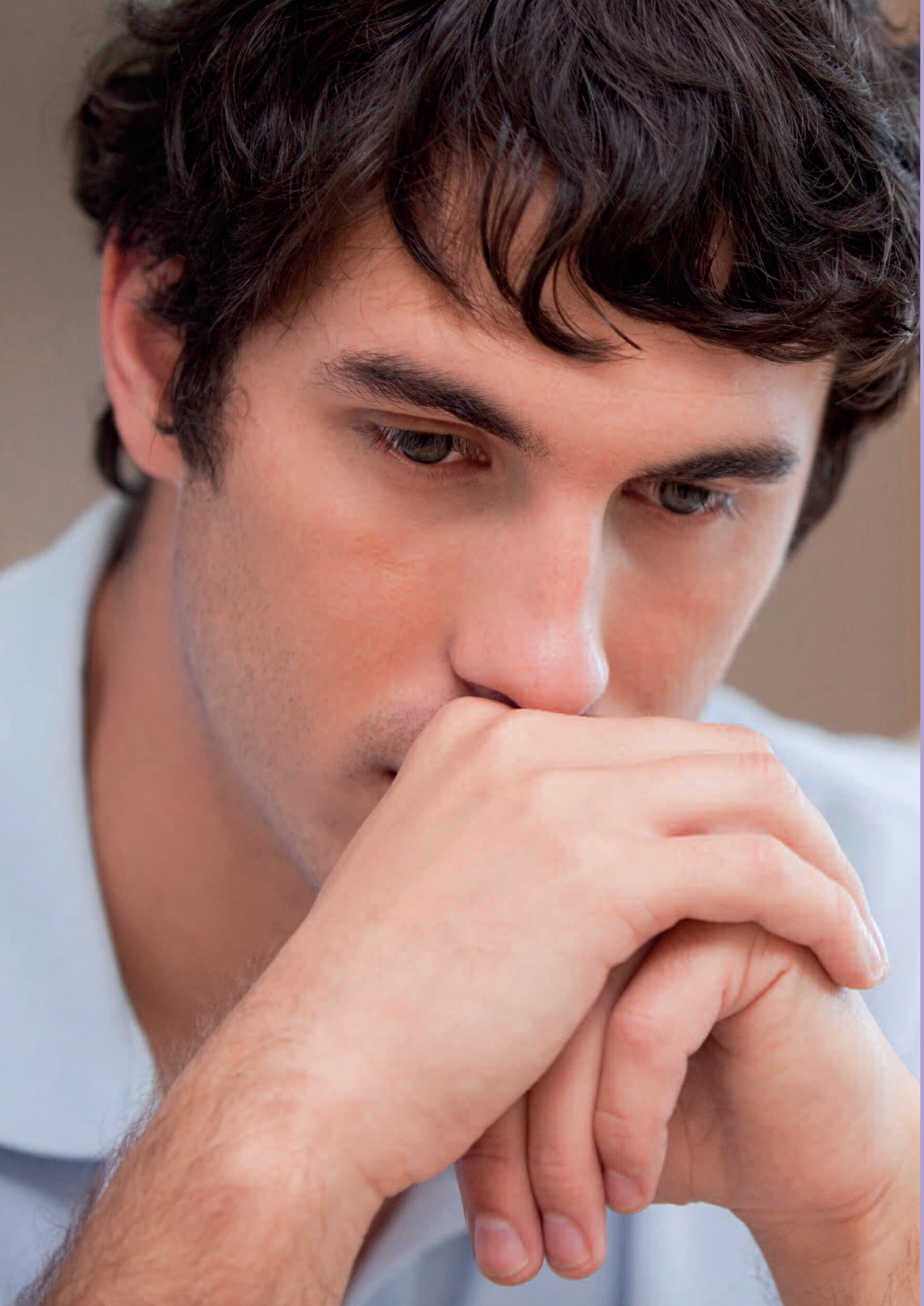
Many people find it puts their mind at rest to have medical plans in place and to sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead enables people to concentrate on their illness and its treatments knowing that their wishes and desires are clearly documented should a need arise.

Planning ahead might include:

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

Who can help me plan?

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



Coping and emotions

How can I cope with my feelings?

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

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

Feelings like sadness, fear, grief, hopelessness, anxiety and anger can happen at different times, sometimes months or years after treatment.

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

With sarcoma, you may also be dealing with feelings about the impact surgery has had on your life. You may be facing difficult physical challenges. You may be mourning the loss of your previous life, especially if things you enjoyed before your diagnosis are now difficult or no longer possible. If treatment has changed the way your body looks, this can also be difficult to come to terms with, although most people do adjust in time.

It's important to recognise these feelings and get plenty of support. Tell your medical team about any emotional difficulties you are having. You can also call our cancer nurses for support, advice and information on services and supports, such as counselling. There are other ways to get support on page 115.

> Being diagnosed with cancer can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions and get help if you need it.

Anxiety and depression

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

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

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

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.

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

> Counselling has helped me with every part of my life.

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that their diagnosis brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

> "I am very happy and content…even though I have to live with this."

Ways to get emotional support

Find out about 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 137 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer. Sarcoma Cancer Ireland has monthly online support groups. See **www.sarcoma.ie** for more.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

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

You and your family

Every family deals with illness 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 illness 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 and find out how they 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.

Supporting someone with cancer

How you can help

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 them, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

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

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members remotely and at many local cancer support centres. Talk to your GP or see page 113.

Find out about support for carers

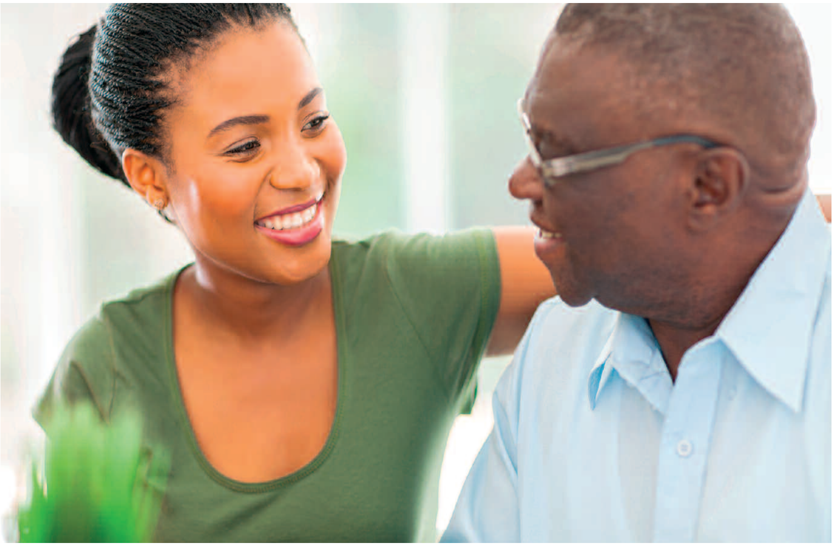
Find out about groups and organisations for carers. Many local cancer support centres have services for carers too.

Support for you

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

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

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



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 illness. Or you may be afraid of saying the wrong thing. Often what people want most is someone to listen to them.

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

> “The emotional support I got made a huge difference to me.”

Support resources

Money matters

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

A diagnosis of cancer often means that you will have extra expenses, such as 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 are worried about money.

Practical and financial solutions from the Irish Cancer Society

We provide individualised financial support and practical solutions for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**

We can tell you about public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having a Practical and Financial Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Practical and Financial Officers might help.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to 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 tests or 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: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

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 0818 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 135 for more details of our **Transport Service** and the **Travel2Care** fund.

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

Money and finances

Go to **www.cancer.ie** and see our **Managing money** page for information on:

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

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Practical and financial solutions (see page 128)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm. You can also email us any time on supportline@irishcancer.ie or visit our Online Community at **www.cancer.ie/community**

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of the service, please go to **https://www.cancer.ie/Support-Line-Video-Form.**

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – 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

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

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

We will connect you to an interpreter.

The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person, in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our patient education workshops, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them.

For more information about what's available near you, visit **www.cancer.ie/local-support**, contact your nearest Daffodil Centre or call our Support Line on Freephone 1800 200 700.

Transport Service

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

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and the Bons Secours Hospital, Cork.
- Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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 a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

For more information, please contact the health professional who is looking after your loved one.

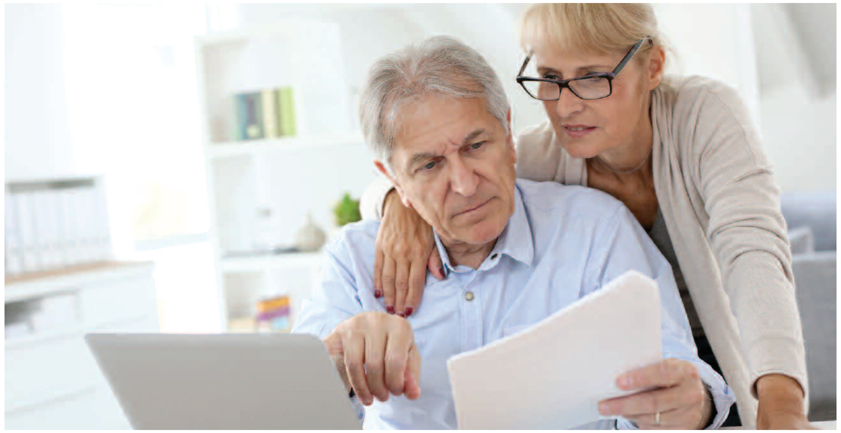
> “Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.”

Publications and website information

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

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

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**
    Facebook
    X
    Instagram
    LinkedIn



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, their partners, families and carers, during and after treatment, many of which are free. For example:

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

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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

What does that word mean?

Anaemia When there are fewer than normal red blood cells in your blood. This can cause tiredness, weakness and shortness of breath.

Benign Not cancer. A tumour that does not spread.

Biopsy The removal of a small amount of tissue from your body to find out if abnormal 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 that uses drugs to cure or control cancer.

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

Intravenous Into a vein.

Lymph node A small oval or round gland found along lymphatic vessels that removes bacteria and foreign particles from your body.

Malignant Cancer. A tumour that can spread.

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

Oncology The study of cancer.

Palliative care This aims to control your symptoms and improve your quality of life, rather than cure your illness.

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

Pathology The study of tissues/cells to determine their exact nature

Primary The area in which the tumour first started.

Prognosis The expected outcome of a disease.

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

Secondary cancer If cells break away from the primary cancer and spread to another part of the body, they may form a new tumour. This is a secondary cancer. It is the same type of cancer as the primary tumour. For example, colon cancer cells that have spread to the lungs are still colon cancer cells (not lung cancer cells).

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

Tumour A mass formed by the overgrowth of abnormal cells.

Notes/questions

Notes/questions

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Acknowledgments

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.

SARCOMA ADVISERS
Prof Charles Gillham , Consultant Radiation Oncologist
Prof Mark Doherty, Consultant Medical Oncologist
Prof Alan Molloy, Consultant Orthopaedic Surgeon
Ms Hazel Murray, Advanced Nurse Practitioner
Ms Una Hayden, Advanced Nurse Practitioner

EDITOR
Sarah Lane

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

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The Irish Cancer Society is a registered charity, number CHY5863.

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Did you like this booklet?

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

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie