Irish Cancer Society

Your guide to dealing with cancer

For young people aged 16–24

This booklet has information on:

- ✓ Cancer treatments and side-effects
- ✓ What to expect in hospital
- ✓ Managing relationships when cancer comes along
- ✓ Dealing with changes in your body
- ✓ LGBTQIA+

Useful numbers

Specialist nurse	
Consultant	
Family doctor (GP)	
Medical social worker	
Psycho-oncology team	
Emergency	
Hospital records number (MRN)	

Contents

Clinical information

Practical information

Reading this booklet

Cancer is the last thing that anyone would invite into their lives. But now that it's here, having the right kind of help and information can make a big difference in dealing with it.

This book provides information that other young people and health professionals have found useful during and after treatment.

It's mainly aimed at young people who have recently been diagnosed with cancer. It will also be useful for young people who have had cancer for some time or who have had cancer in the past.

Your need for information will probably change before, during and after treatment. As a result, different sections of this book will be relevant to you at different times. We recommend that you just read the bits that are important to you now, then put it away to refer to another time.

This book is not a substitute for talking to your medical team. If you are confused or worried about anything, talk to your doctor or nurse. They know your medical history and your individual circumstances.

You can also talk to 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

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.

This booklet contains a lot of input from young people diagnosed with cancer. We thank them for sharing their experiences so generously.

Chapter 1

About cancer

What is cancer?

Cancer is a disease of the body's cells, which are the building blocks of your body. Cells grow and divide to make more cells when the body needs them. This ensures that damaged cells get replaced quickly. However, cancer cells are abnormal cells that grow without control.

Cancer can occur in different parts of the body. In fact, there are more than 200 different types of cancer, each with its own name and treatment.

Cancer can occur in organs of the body such as the brain or kidney. These are sometimes called solid tumours. Tumours can be either benign or malignant. Benign tumours are not cancerous and these do not spread to other parts of the body. However, they can keep on growing and cause problems by pressing on nearby organs.

A malignant tumour is cancerous. Cells can break away from the tumour and spread to nearby tissues. They may also spread further to other organs in the body through the bloodstream or lymphatic system.

When the cancer cells reach a new area, they may go on dividing and form a new tumour. This is known as a secondary cancer or metastasis.

Cancer can also occur in blood cells. When blood cancer occurs, normal blood cell development is affected by the uncontrolled growth of an abnormal kind of blood cell. Types of blood cancer include leukaemia and lymphoma.

What is 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.

It is made up of lymph nodes connected by tiny tubes called lymph vessels. Lymph nodes are found mainly in the neck, armpit, groin and tummy.

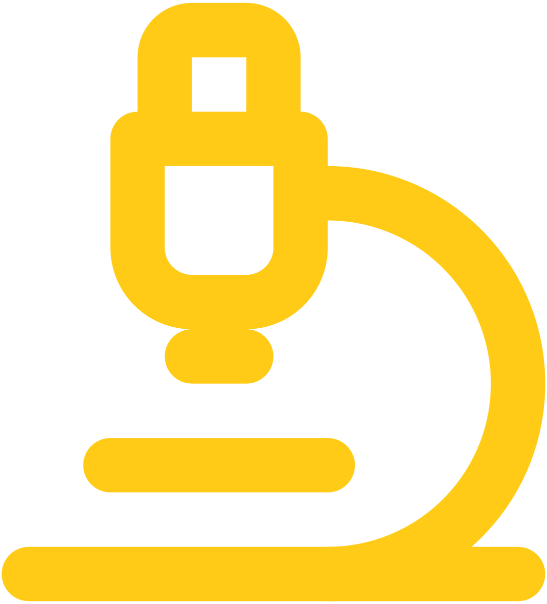
If cancer cells spread into lymph nodes or cancer starts in the lymph nodes, they can become swollen.

Why did I get cancer?

We don't know exactly what causes many cancers but research is ongoing. The main thing to remember is that it is not your fault. It's not because of anything you have done or not done.

Most cancers are not caused by an inherited faulty gene. It is very rare for brothers and sisters to develop cancer so they do not usually need to be tested.

Cancer is not infectious and cannot be passed on to anyone who comes into contact with you.



Survival rates

There have been huge improvements in cancer treatments in the past 50 years. As a result, more young people than ever are surviving cancer. Some forms of cancer are now completely curable.

Research is also continuing to improve treatments and reduce side-effects. Every person is different and your doctor will talk to you about your illness and the likely success of treatment.

Chapter 2

Diagnosis and further tests

How does the medical team know I have cancer?

You may have had some concern or symptom which led to you visiting your GP or emergency department. In order to work out what caused the problem, you would have had various tests and investigations. These tell your medical team more about your cancer and help them to decide on the best treatment for you.

Tests after diagnosis

You may need different types of tests when you have cancer. How much you want to know about these tests is up to you. Knowing what to expect can help some people to deal with any worries they may have, while others may prefer not to know. If you would rather not know about tests at this time, you can skip this section. You can always come back to this information another time.

Before you begin tests, your medical team will have a chat with you about your medical history. This includes talking about your general health and any illnesses or health problems you have had in the past. You will also be asked about your family's general health and if any members of your family have had any health problems such as cancer. You will be asked how long you have been feeling unwell for and what specific things are causing you concern. These questions will help guide your medical team to what tests they want you to have. This is a good time to mention any of the symptoms you are worried about, even if it might be a bit embarrassing.

These tests give your medical team more information about your cancer. Your doctors will put the results of all tests together, like the pieces of a jigsaw, to give them a picture of your cancer so that they can work out what treatment you need.

You may not need all of these tests. This will depend on your diagnosis. If you have any questions about tests, ask your doctor or nurse.

Blood tests

Blood tests can help to check your general health. They can also help your medical team to see if your organs are working properly, such as your kidneys and liver. Blood tests may also let your doctors know if your treatment is working or if there are any complications associated with your treatment, such as an imbalance in the salt levels in your body.

Biopsy

This is when a small amount of tissue is removed from your body to find out if cancer cells are present. A biopsy can also give your doctor information about the type of cancer you have and how it might grow. This information may be used by your doctors to makes decisions about your treatment.

Some types of biopsies require a local anaesthetic, which means that a small part of the body is numbed and you remain awake for the procedure. Other types involve a general anaesthetic, which means you are asleep for the procedure.

Scans

There are lots of different types of scanning machines that take pictures of your body in different ways. Your doctor may request that you have one or more different scans. These include:

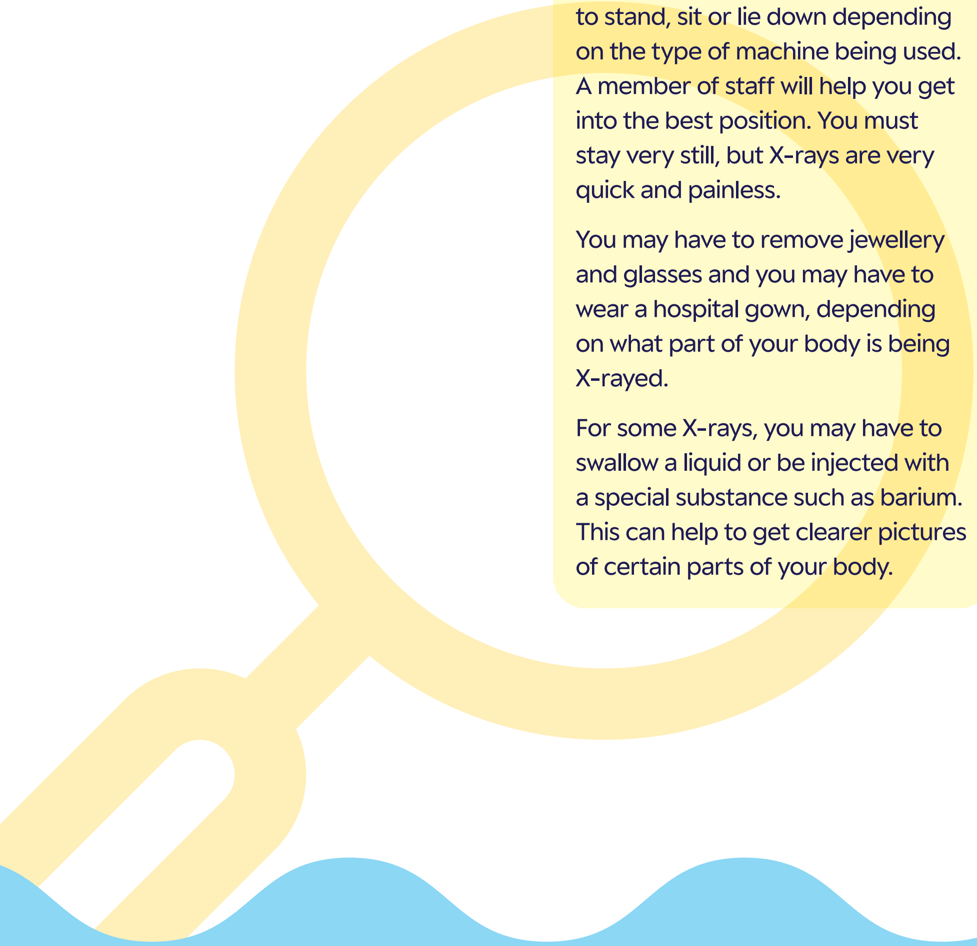
X-rays

X-rays use high-energy rays to take pictures of the inside of your body. They are usually quick and painless. They can check for bone and joint problems. They can also show changes in tissues and organs.

During an X-ray, you will be asked to stand, sit or lie down depending on the type of machine being used. A member of staff will help you get into the best position. You must stay very still, but X-rays are very quick and painless.

You may have to remove jewellery and glasses and you may have to wear a hospital gown, depending on what part of your body is being X-rayed.

For some X-rays, you may have to swallow a liquid or be injected with a special substance such as barium. This can help to get clearer pictures of certain parts of your body.



CT scan

A CT scan is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. It is sometimes known as a CAT scan. The scan allows your doctors to see exactly where your tumour is and how big it is.

For some CT scans, you might be asked to fast (not eat) for a few hours before the scan. For other types, you may need to swallow a liquid or have an injection of a special dye to give a clearer picture. 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 table will move forwards and backwards through the scanner until all the pictures are taken.

The scan is painless and takes between 10 and 30 minutes. If your appointment is just for this scan, you'll probably be able to go home as soon as it is over.

PET scan

This scan gives detailed 3D pictures of the inside of the body. It can show if any lumps you have are cancer or if your cancer has spread to other parts of your body. It can also show if your cancer treatment is working.

You will be asked to fast (not eat) for a few hours before the scan. You will get an injection of a low dose of a radioactive sugar. This can highlight cancer cells in your body. Around an hour after the injection, you will have your PET scan. You will lie on a table that moves through a scanning ring for up to 1 hour. You will not feel anything during the scan. You will be slightly radioactive after the 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.

You may have to travel to a different hospital from the one that you usually go to, as not all hospitals have these scanners.

MRI scan

This is a scan that uses magnetic energy and radio waves to build up a picture of the tissues inside your body. MRI scans can produce images from different angles all around the body.

You may have to fast (not eat) before the scan. You may also get an injection of a special dye before the scan to show up certain parts of your body.

During the scan, you cannot wear anything containing metal, such as metal jewellery, body piercings, hair clips, underwire bras or clothes with metal buttons and zips. You may not be able to have an MRI if you have certain medical devices in your body, such as fixed braces, a metal pin, a shunt in your brain or a pacemaker in your heart. Your doctors will decide if it is safe for you to have the scan.

You will lie on a bed which slides into a tunnel-like machine for about 30-60 minutes. It is important that you keep as still as possible during the scan.

Some people are afraid they will feel claustrophobic inside the tunnel. Tell the staff if you are feeling anxious.

An MRI is very noisy but you will be given earplugs to help block out the sound. The scan does not hurt and you can usually go home straight after.

Bone scan

Bone scans are sometimes used to look for bone cancer or to find out if cancer from other parts of your body has spread to your bones.

You will be injected with a tiny amount of a mildly radioactive dye. You will then have to wait around 2-3 hours to have the scan. Abnormal bone absorbs more of the radioactive dye than normal bone, so abnormal bones will appear as highlighted areas in the scan. These are known as 'hot spots'.

The scan lasts around 1 hour. You need to lie still while a camera moves around you, but you may also have to move positions during the scan. You should be able to go home straight after the scan.

While the level of radioactivity is very low and disappears within a few hours, you should avoid being around babies, young children and pregnant women until 24 hours after the scan.

Ultrasound

An ultrasound uses sound waves to create a picture or video of inside your body. During the ultrasound a radiographer will put a thin layer of jelly-like gel on your skin that lies over the area that is to be examined. The radiographer will then glide a handheld probe over this gel. Once they have enough images, they will wipe any remaining gel off your skin.

Depending on the type of ultrasound that is needed, you may be given different instructions to prepare for it. Some may require you to fast (not eat) for a few hours before, while others might need you to drink lots of water so that you have a full bladder (really need to pee).

It can take some time for the results of tests to come back, which can be frustrating. However, it is important that your medical team does all the investigations that they need to so that they know how best to treat you. There may be lots of images and test results that need to be reviewed by lots of different team members, but this is essential so that they can come up with the best treatment plan for you.

I have cancer, what now?

If you are under the care of CHI Crumlin, the oncology team will coordinate your care before the cancer has been confirmed. In adult hospitals, cancer needs to be confirmed before the oncology/haematology team takes over.

Once your medical team knows the type of cancer you have, they will meet you to discuss the treatment that you need. If you are under 18 years of age, your parent/guardian will have to attend this meeting with you. If you are 18 or older, you are still advised to bring a parent/guardian or significant other with you because it can be hard to remember everything that is said.

It is totally normal not to be able to absorb all of the information that you are given at this meeting, so ask the doctor or nurse to write down the important details.

If you are 18 years or older, you will have to sign a consent form to give your medical team permission to treat you. However, under Irish law, a person aged 16 and older can also give consent to surgical and medical treatments and it is not necessary to obtain consent for treatment from their parents/guardians. In other words, 16- and 17-year-olds have the same rights around consent to treatment as adults aged 18 and older.

Chapter 3

What to expect in hospital

Once you are diagnosed with cancer, hospitals will become a part of your life. Sometimes you may only need to attend an appointment, while other times you will need to be a day patient or have to stay for longer (inpatient). So what happens in hospital?

Checking in

When you are admitted, you will probably meet lots of administrative staff and different healthcare professionals like nursing staff, oncologists, haematologists, surgeons and medical social workers.

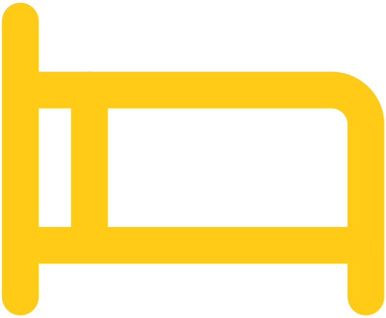
They may ask you to repeat your story several times. It can help to have someone with you if you're feeling unwell or overwhelmed.

They may ask personal questions. You can ask to speak with the doctors or nurses privately if you prefer. If you want to know how your information is stored or shared, ask your medical team.

Will I be in bed all day?

Depending on the type of cancer you have and the treatment you need, hospital stays can vary widely – from just a day in hospital to many weeks, or anywhere in between.

If you need to stay in hospital, your medical team will let you know how mobile you can be. For example, if you're having a chemotherapy infusion in a day unit, you may need to sit for some hours. After surgery, you may be encouraged to move around the ward to help you recover.



Other patients

Unfortunately, most hospitals are not designed for young people. As a result, the patients in hospital with you may be a lot older than you if you are in an adult hospital, or a lot younger than you if you are in a children's hospital. This can make hospital stays more challenging and isolating.

When you first get admitted, you will meet many other patients and their families in your day unit, ward or treatment centre. Some of the patients may be really sick and in different stages of their treatment. Some may be doing very well.

It can help to talk to other patients but remember everyone's cancer and treatment is different. You may notice that other people with the same type of cancer as you are not getting the same treatment as you. However, they may not be at the same stage as you so their treatment plan may be different.

What about visitors?

Each hospital will have different rules about who can visit, for how long and when. Ask your medical team about this. The rules may also be different if there are any restrictions in place, for example, if there is an outbreak of a vomiting bug.

In some cases, you may need to be in a room by yourself and the hospital might restrict who can visit you and when. Your visitors might also have to wear a mask, gloves and a hospital gown to enter your room.

If you live in a rural area

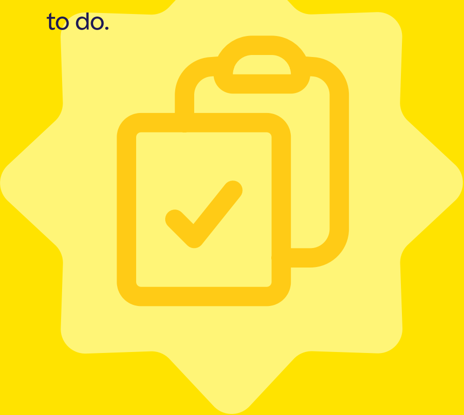
Cancer can hit you particularly hard if you live in a rural or remote area. If you are used to living in the country, having to travel to a big town or city for treatment might be really stressful.

You may be away from the support and comfort of your family and friends and miss your home, community, lifestyle and the food you usually eat. Being alone in an unfamiliar place is hard and you might feel lonely, frightened or uncomfortable.

If you are struggling, talk to a family member or friend. If you don’t feel you can talk to people you know, you can speak to one of our cancer nurses on Freephone 1800 200 700. You might also join an online community or contact an organisation aimed at adolescents and young adults. A list of useful organisations and websites can be found on pages 223-226.

Tips for long stays in hospital

- Use headphones and an eye mask to block out sound and light.
- Bring as much media as you can – phone, laptop or tablet, books and magazines. Watch shows and listen to music or podcasts.
- Pack your pillows, photos and other favourite stuff to make the hospital room feel more like your own space.
- Your friends may not realise you want them to visit you in hospital. Invite them to come and hang out if you want them there.
- Have video chats, watch shows or movies together or have a Zoom/Teams party.
- Make a visitor book or poster for visitors to sign and leave messages.
- Take pictures of people who visit.
- If you don't feel like talking to anyone, silence your phone or make a "Do not disturb" sign to let people know you're not up for visitors.
- Get to know the night nurses well. They'll save you from insanity when you can't sleep.
- Find your release – art, knitting, reading, puzzles, games, crosswords, listening to music.
- Make plans for things you will do when you get out of hospital. It helps to have something to look forward to.
- If you don't have enough energy to read, try an audiobook or podcast.
- Find out if there are other young people in the hospital and see if you can meet up with them.
- Get outside the hospital or ward if you are well enough. Some fresh air and sunshine can make a nice change.
- If you are in school or college, ask your friends or teachers to bring things from there for you to do.



> **Keep your mind busy and do the things you love. Listen to music, play games and watch movies. This is a time of your life where you can focus solely on yourself and your recovery.**
>
> Fiona, 22

Going home from hospital

If you have been in hospital for a long period, you may be really looking forward to going home. So why can it feel scary when the day actually arrives?

While you are in hospital, there are always people fussing over you, telling you what to do, when to wake up, what to eat and what treatments you will be having.

When you leave hospital, you might miss this routine. You might also miss people who understand your situation and the security of knowing you will be looked after if something goes wrong.

Re-adjusting to everyday life can be tough and people often need some support with this. Lean into your family, friends and community wherever you can. They are the ones who know you best.

Professional support will still be there for you after you leave the hospital, from your medical team, your GP and organisations like the Irish Cancer Society and CanTeen Ireland.

> **Going back into society is definitely hard when you have been in isolation for a while. For me, I went back out into the community with friends and family helping me, but it was too early. It's important to know when you're ready. Take your time in getting back out in society, even if it's a short trip to your local coffee shop for a takeaway coffee. You don't always need to keep up with friends. Go at your own pace and enjoy life.**
>
> Amy, 25

Preparing for regular hospital appointments

You may not always have to be admitted to hospital. Instead, you may just need to attend an appointment. Preparation is key to getting the most out of 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)
- 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 OK 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. You may be on your parents' policy
- 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 if you are on any, 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
- If you are on medication, 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, if you are not fasting
- Your phone and your phone number
- 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 contact details of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave, if required

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

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.

Who will be involved in my care?

There are many people who may be involved in your treatment. These can include:

Consultants: These are specialist doctors who are experts in different areas of medicine. These include:

- **Medical oncologist:** A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
- **Haematologist:** A doctor who specialises in diagnosing and treating patients with blood disorders, including blood cancer.
- **Radiation oncologist:** A doctor who specialises in treating cancer patients using radiotherapy.
- **Surgeon:** A doctor who specialises in surgery – removing tissue, including tumours, from the body.
- **Radiologist:** A doctor who specialises in interpreting X-rays and others scans, such as MRI and CT scans, to help diagnose cancer and plan your treatment.

Pathologist: A doctor who specialises in looking at cells under a microscope and diagnosing the cell type.

GP (family doctor): Your GP may have been the person who referred you for cancer tests in the first place. You will probably stay in contact with your GP but your hospital team will be your main point of contact.

Advanced nurse practitioner: Nurses with extensive knowledge and training who are skilled to a high level in the care of people with cancer.

Clinical nurse specialist: A specially trained nurse who works in a cancer care unit. They give information to you and your family at the time of your diagnosis and throughout your treatment.

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

Physiotherapist: A therapist who treats injury or illness with exercise and other physical treatments.

Occupational therapist: A therapist who provides help with everyday activities that you may be having problems with, such as getting dressed. Their aim is to improve the loss of any functions and manage fatigue (extreme tiredness) and energy loss.

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

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

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

Pharmacists: These may be based in hospital or your local pharmacy. They dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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

Questions to ask your doctor

Here are some questions that you may wish to ask. Never be shy about asking questions. It is always better to ask than to worry.

What treatment will I need?

Will treatment cure my cancer?

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

How long will my treatment take?

Do I have to stay in hospital for my treatment?

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

Is there anything I can do to help myself during treatment?

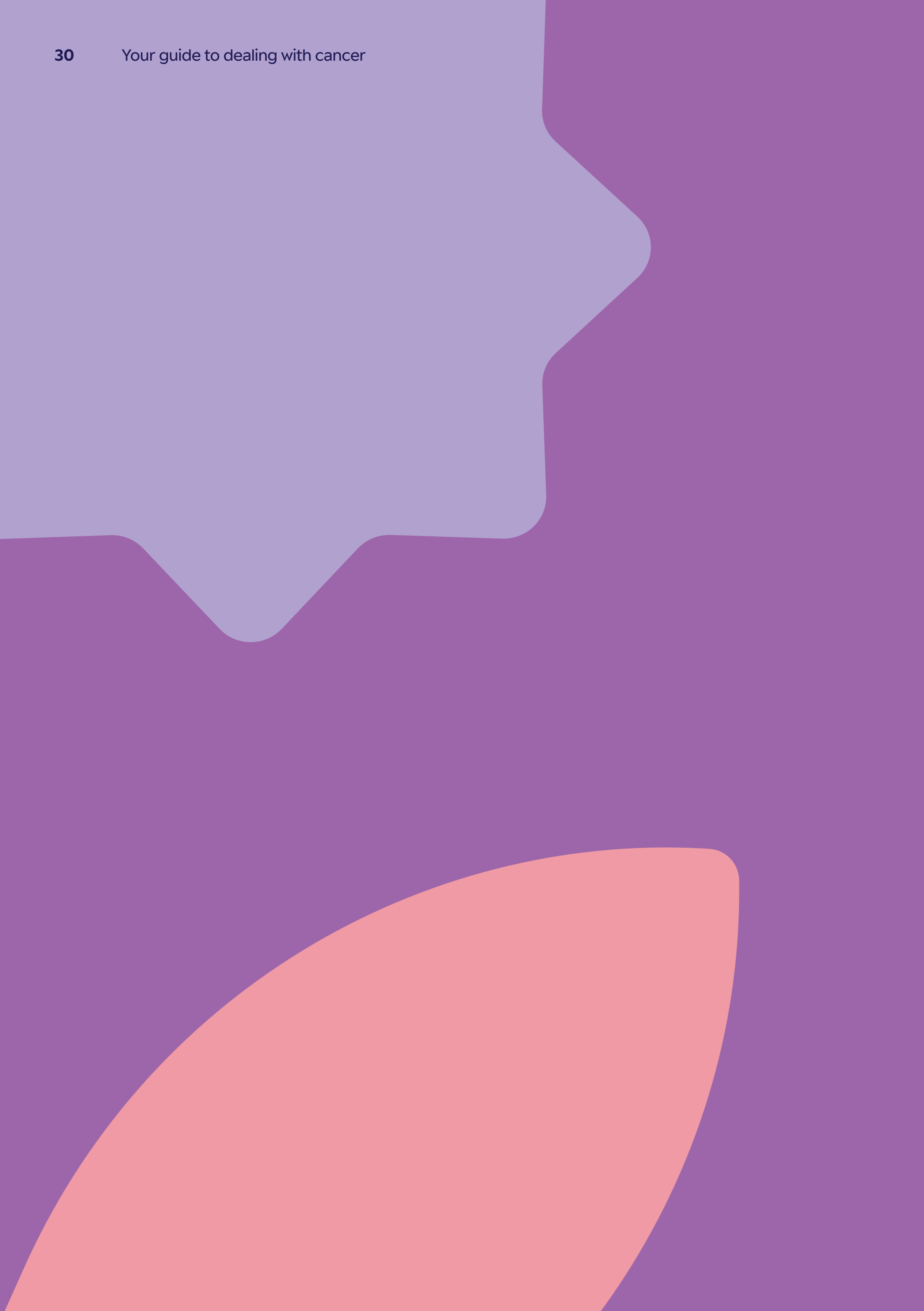
How soon after treatment can I have sex?

Will I be able to have children?

How often will I need check-ups?

Who do I contact if I have a problem when I go home?

What support services are available to help me cope with my cancer?



Chapter 4

Treatment

How is cancer treated?

There are lots of different ways that cancer can be treated. You may need one type of treatment or a mixture of different types. You may notice that some people with the same cancer as you are not getting the same treatment as you. Their cancer may be a different type to yours or they may be at a different stage of their treatment, so do not worry about this. Everyone’s treatment needs are different. If you have any questions about your treatment, always ask your medical team.

Chemotherapy

What is chemotherapy?

Chemotherapy is the name given to a special group of medicines that are used to kill cancer cells. There are lots of different chemotherapy medicines. Your doctor will decide which ones will work best against your type of cancer. You may be given more than one type as they all work in slightly different ways.

Chemotherapy can be used to:

- Help cure some cancers
- Shrink a cancer before surgery to make it easier to remove
- Kill any cancer cells that are still there after surgery
- Help radiotherapy to work better
- Help stop cancer from spreading, slow its growth or destroy cancer cells that have spread to other parts of your body
- Help to reduce the risk of the cancer returning (recurring) in the future
- Treat cancer that has come back after treatment

How is chemotherapy given?

Chemotherapy may be given:

- Directly into a vein as an injection under the skin or into muscle
- Through an intravenous infusion (by drip or pump)
- In tablet form or as a cream you put onto your skin (topical chemotherapy)

Depending on the type of chemotherapy you get, you may go to the day unit or you may need to stay in hospital overnight. Your medical team will explain this to you.

How often will I have chemotherapy?

Once your doctor knows what type of cancer you have, they will decide on what the plan for your treatment will be. This plan is called a protocol or course of treatment. The protocol is divided into sections called cycles. The protocol decides how many cycles of treatment you need and how long each cycle will take.

A cycle is the day or days of your treatment and this is followed by a rest period. This rest period allows your body time to recover from the side-effects of treatment.

What are the side-effects of chemotherapy?

As well as attacking cancer cells, chemotherapy also attacks other healthy cells. This is because chemotherapy cannot tell the difference between cancer and healthy cells. This can lead to side-effects which may include:

- Hair loss
- Nausea (feeling sick)
- Vomiting (getting sick)
- Weaker immune system (you will not be as good at fighting off an infection)
- Fatigue (extreme tiredness)
- Bruising and bleeding, such as nosebleeds
- Skin and nail changes, such as itchy skin and yellow nails
- Mouth problems, such as ulcers (sores) and gum infections
- Problems concentrating
- Changes in bowel patterns (constipation or diarrhoea)

These are some of the most common side-effects, but your medical team will go through all of the possible side-effects for the specific chemotherapy medicine that you will be receiving.

Sometimes, side-effects can happen very soon after treatment (a few days or weeks later). However sometimes, side-effects can happen months or even years later. These are known as late effects. You should tell your medical team about any side-effects you get. If there is anything you are worried about, always tell your medical team.

Radiotherapy

What is radiotherapy?

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

It can be used:

- Before surgery to shrink a tumour before it is taken out
- After surgery to treat any cancer cells that may have been left behind
- To help ease some of the symptoms of cancer
- As a treatment itself

Radiotherapy is sometimes given with chemotherapy. This is known as chemoradiation.

How is radiotherapy given?

Radiotherapy can be given in two ways:

- Internal radiotherapy: The radiation source is placed inside your body on or near your tumour using radioactive liquids, tablets, injections or implants.
- External beam radiotherapy: The radiation comes from machines which aim rays directly at your tumour or tumour site. You will have a CT scan to pinpoint the area to be treated. Marks will be put on your skin to pinpoint the exact treatment area. You will lie on a treatment table and the radiotherapy machine will move around you. Treatment usually only takes a few minutes.

Proton beam therapy is a type of external radiotherapy which can accurately target a tumour without affecting the healthy tissue around it too much. This treatment is not currently available in Ireland, but if your medical team thinks this is the best option for your tumour type, they will ask the HSE to fund it abroad.

How often will I have radiotherapy?

The amount of radiotherapy you need and the length of time treatment will take will depend on your diagnosis. A course of external radiotherapy can be several treatments over a number of days or weeks (6-8 weeks). For example, you may have to have treatment five days a week for six weeks. Radiotherapy is usually given as one session each day Monday to Friday, with a rest at the weekend. Treatment sessions take around 20 minutes and you usually do not have to stay overnight in hospital.

With internal radiotherapy, you may have to stay in hospital for a few days. Your medical team will let you know how long you need to stay.

What are the side-effects of radiotherapy?

Side-effects tend to only affect the parts of the body being treated. How severe those side-effects are will differ from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after treatment and get better within a few weeks. Late side-effects may develop some time after treatment.

Side-effects can include:

- Nausea (feeling sick)
- Vomiting (getting sick)
- Fatigue (extreme tiredness)
- Skin reactions in the treated area. Skin may become red, sore or itchy. It is very important that you do not apply any creams to the affected area if you have not discussed this first with the doctors or nurses at the radiotherapy centre. Some creams can interfere with how the radiotherapy works

- Bowel changes – constipation or diarrhoea
- Sore mouth
- Hair loss in the treated area

Always tell your radiation oncology team about any side-effects you get.

Can you be around other people after getting radiation?

People often wonder if it is OK to be around other people, or hug and touch them, after radiotherapy.

If you undergo external beam radiotherapy, there are no restrictions on contact with other people so you can be around them.

If you undergo internal beam radiotherapy, there may be some restrictions. You may have to stay away from others for a few days. Your medical team will talk to you about this.

Surgery

What is surgery?

Surgery is a procedure or operation that removes tissue from your body. It involves making a cut in your body. It may be done to:

- Take a sample of tissue from your body to help diagnose cancer (biopsy)
- Remove all or part of a tumour
- To repair or reconstruct a part of your body after surgery to remove a tumour

The aim of surgery to treat cancer is to remove the cancer from your body. The type of surgery you have will depend on your cancer type.

What does surgery to treat cancer involve?

If the cancer is only in one place, surgery may cure it. In general, the earlier a cancer is found, the easier it is to remove.

As well as the tumour, your surgeon will remove some tissue around it, in case any cancer cells have spread there. The area around the tumour is called the margin. Your surgeon may also remove lymph nodes around the tumour area. The cells from the margin and lymph nodes will be examined after surgery to see if they have cancer cells in them. If they do, more treatment may be required.

For your surgery, you may be given a general anaesthetic, which puts you to sleep. Or you may be given a local anaesthetic, which numbs the area but you remain awake. This will depend on the type of surgery you are having.

There are two main types of surgery:

- Open surgery: This means making a cut (incision) in your body. Your surgeon removes the tumour and other tissue through this cut.
- Keyhole surgery (laparoscopic surgery): Your surgeon will put a tube with a tiny telescope and light inside your body through a very small cut. Special instruments can then be used to remove the tumour. Recovery time tends to be quicker compared to open surgery, which means you may spend less time in hospital. However, keyhole surgery is not suitable in every case.

What happens after surgery?

You may spend a short time in an intensive care unit (ICU) or high-dependency unit (HDU) after your operation. However, not everybody needs to stay in ICU or HDU. When you wake up, you may have some tubes attached to your body. The type of tubes will depend on the type of surgery you had. Don't be worried as they are normal after surgery. They may include:

- Intravenous (IV) drip: This is a drip that is put into a vein in your arm. It gives you fluids until you are able to take fluids (drinks) by mouth again. You may also be given antibiotics in the drip to stop you from getting an 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 site of the operation to let your wound heal.

You will be encouraged to get up and about as soon as it is safe to do so. A physiotherapist may help you with exercises you can do, even when you are in bed. These exercises can help to prevent a blood clot.

In some cases, you may not have to stay in hospital overnight.

You may have to avoid certain types of activity, such as sport, for a few weeks or months after your operation.

What are the side-effects of surgery?

Side-effects depend on the type of operation you have. They can include:

- Pain
- Stiffness
- Fatigue (extreme tiredness)
- Loss of appetite
- Swelling at the site of surgery
- Bleeding from the wound
- Blood clots
- Infection at the site

Always tell your medical team about any side-effects you get.

Targeted therapies

What are targeted therapies?

Targeted drug therapies target certain parts of cancer cells that make them different from normal cells. The drugs go directly to the cancer cell and block the parts of it that allow the cancer to grow or survive. They can be used by themselves or in combination with other methods of treatment, such as chemotherapy.

Targeted therapies can:

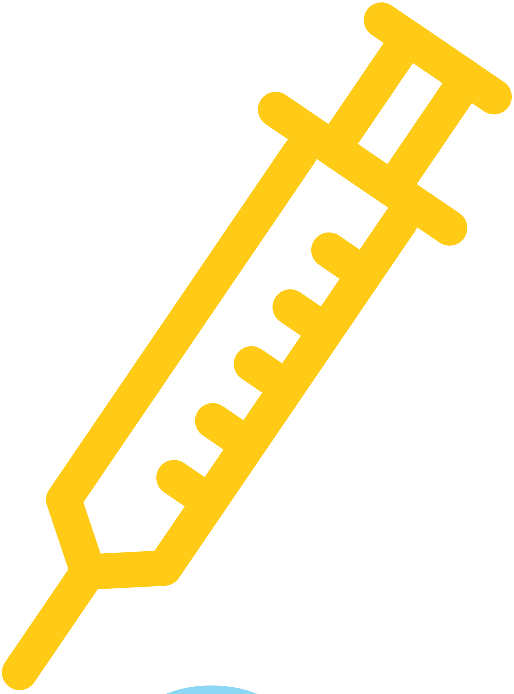
- Help stop cancer from spreading, slow its growth or destroy cancer cells that have spread to other parts of the body
- Treat cancer that has spread or come back (recurred) after treatment

Targeted therapies are not suitable for all types of cancer, but for some, such as chronic myeloid leukaemia (CML), they are one of the main treatments.

How are targeted therapies given?

Targeted therapies can be given in a drip through a vein. The drugs are diluted in a large bag of liquid and go into the body slowly over a number of hours.

They may also be given as an injection into the bloodstream, usually through a vein, or they may be given as tablets or capsules that are swallowed.



How often will I have targeted therapies?

Targeted therapies are usually given in a course of treatments. A course is made up of cycles. A cycle is the day or days of your treatment, followed by a rest period, when you have no treatment and your body is recovering. Your doctor will explain the number of cycles you need to treat the cancer. It will depend on your type of cancer and the drugs you are receiving.

What are the side-effects of targeted therapies?

You may develop side-effects after the first dose a bit like an allergic reaction, but they are often mild. Side-effects will depend on the drugs used and may include:

- Nausea (feeling sick)
- Diarrhoea
- Fatigue (extreme tiredness)
- Fever
- Headaches
- Muscle cramps
- Rashes or itching
- Chest or tummy pains
- Swelling of fingers, lower legs, face or eyelids

Always tell your medical team about any side-effects you get.

Immunotherapy

What is immunotherapy?

Immunotherapy helps your immune system to work better to fight cancer cells. The role of the immune system is to defend the body from infection. This system is made up of many parts of the body including cells, tissues and organs. These work together to recognise and fight against things like bacteria, viruses and abnormal cells.

Immunotherapy drugs help your immune system to recognise and fight against cancer cells.

Immunotherapy is not suitable for everyone.

Before you have immunotherapy, you may have to undergo tests to find out whether the treatment is likely to work.

How is immunotherapy given?

Most immunotherapies are given intravenously (through a vein). You may have a port or line (thin tube) inserted, which can be used to access your vein every time you have treatment.

Some immunotherapies are given as a tablet or injection.

How often will I have immunotherapy?

Immunotherapy is usually given in a course of treatments. This course can last weeks or months, depending on your cancer and the type of immunotherapy. A course is made up of cycles. A cycle is the day or days of your treatment and this is followed by a rest period. This rest period allows your body time to recover and respond to the treatment.

You may get a combination of immunotherapy treatments or have other treatments too, such as chemotherapy.

What are the side-effects of immunotherapy?

Side-effects depend on the drugs being used and they will vary from person to person. Because immunotherapy acts on the immune system, it can cause the immune system to incorrectly attack normal organs and cells in your body and affect the way they work. This can lead to an inflammation of any organ in your body or inflammatory conditions. The letters 'itis' at the end of a word often mean inflammation. For example, colitis (inflammation of the colon), pneumonitis (inflammation of the lungs), dermatitis (inflammation of the skin).

This effect – where the immune system attacks your own body (called an 'auto-immune effect') – can happen in any organ in the body, but tends to be more common in the skin, bowel, lungs and hormone-producing glands.

Other side-effects can include:

- Flu-like symptoms, such as chills, fever, headache and weakness
- Nausea (feeling sick)
- Muscle and joint pain
- Weight gain
- Skin changes such as rashes, blisters, itching or sensitivity to the sun
- Hair changes such as hair loss or extra hair growth

Side-effects from immunotherapy can sometimes be serious so always contact your medical team at the hospital if you have any. Do not self-medicate or ask for advice from your GP or pharmacist. Your hospital team is more familiar with immunotherapy side-effects and how to treat them. They may need to give you a course of steroids to settle the immune system back down.

Bone marrow (stem cell) transplant

What is bone marrow?

Bone marrow is the soft, spongy tissue found inside some of your bones, such as your hip bones. It contains stem cells. These are young cells that can grow into the different types of blood cells that the body needs – red blood cells, white blood cells and platelets. Bone marrow makes all of your body's blood cells.

What is a bone marrow (stem cell) transplant?

Cancer or cancer treatment can destroy these stem cells, meaning you don't have enough of the blood cells you need.

With a bone marrow (stem cell) transplant, your diseased or damaged stem cells are replaced with healthy stem cells. The stem cells given in a transplant can grow into new healthy blood cells in your bone marrow.

The stem cells that are transplanted can be collected from your body before treatment (autologous transplant) or from a donor (allogenic transplant).

If you are having an allogenic transplant, your medical team will decide which donor is your best match. They will often test some of your family members, especially siblings. Or they may use a database to find a donor who is not related to you, but is matched very closely to your bone marrow.

A bone marrow (stem cell) transplant may not be suitable for everyone. It will depend on things like your general health, the type of cancer you have and whether a suitable donor is available.

What are the side-effects of a bone marrow (stem cell) transplant?

You are likely to get some side-effects from your treatment. These may include:

- Infection: Your immune system will be less strong and you will be at high risk of infection, due to a lower number of infection-fighting white blood cells
- Anaemia: This is caused by a lack of red blood cells. It can cause you to feel tired and breathless
- Bleeding and bruising: A lack of platelets may lead to unexplained bleeding and bruising, such as nosebleeds
- Fatigue (extreme tiredness)
- Nausea (feeling sick) and vomiting (getting sick)
- Diarrhoea (loose, watery poos)
- Mouth problems, such as ulcers (sores)
- Hair loss

Always tell your medical team about any side-effects you get.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer or reducing side-effects. They can also help improve a person's quality of life when living with cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This includes adolescents and young adults.

Instead of the standard treatment, you may be given a drug that is only available as part of a clinical trial. 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. You will never receive treatment that is less effective than standard care.

You will be very closely monitored and may have extra tests and appointments.

Not everyone can take part in clinical trials. Your doctor can advise you about this.

For more information on cancer trials in Ireland, visit **www.cancertrials.ie**

Making treatment decisions

Since your diagnosis, there have probably been lots of people – medical staff, your parents and even the odd stranger – telling you what to do, when to do it and how to do it.

There will be times when you have to do what your medical team says whether you like it or not. But remember, they have carefully considered what treatment plan will work best for you to give you the best outcome.

Don't be afraid to ask whether you have any options for when and where you get treated. You might be able to be treated closer to home. Or maybe you can delay your next round of chemotherapy until after an exam or be allowed out of hospital for a special occasion. Speak up! If you don't ask, you'll never know.

Learning to speak up can be hard, but if it means you get to make decisions that are important to you, it's worth a try.

You may be happy to let your parent(s) make all the decisions about your care and treatment. That's fine – you've got enough to deal with.

Or you may want to have a bigger say in what is happening to you. In Irish law, people aged 16 and older can give consent for themselves to have medical and surgical treatment.

Some parents may find it hard to let go and you might start to feel that they are interfering when you don't want them to. Your parents only want what's best for you, but you have to be open with them about what you want. See the chapter on 'Managing relationships' on page 135 for tips on how to deal with this.

Chapter 5

Side-effects

You may develop side-effects while having treatment for cancer. These side-effects will depend on things like the type and amount of treatment you are getting, how long your treatment lasts and how cancer is affecting your body.

Side-effects may happen straight away, 7-10 days after treatment or even months or years later. Side-effects often go away after treatment has finished, but some can last for a long time. Some may even be permanent.

Side-effects that develop some time after you have finished your treatment are called late side-effects. You will need ongoing follow-up for them.

This booklet contains details about common side-effects. However, you should always tell your medical team about any side-effects you develop, even if they appear mild. It may help to keep a diary of any side-effects you experience, which you can then share with your medical team.

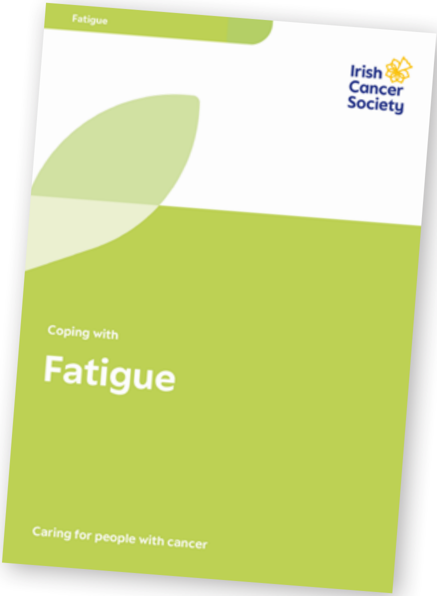
Fatigue

Fatigue means feeling extremely tired most or all of the time. Often, it is not relieved by rest. It is very common and can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Not sleeping well
- Emotional issues, such as feeling anxious or depressed

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

Our booklet ***Coping with Fatigue*** has more advice. Call our Support Line on 1800 200 700 for a free copy or download it from our website: **www.cancer.ie**



Hints and tips: **Fatigue**

- Try to do some exercise – ask your doctor, nurse, occupational therapist or physiotherapist for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Try to eat well and drink plenty of fluids. In order to work properly, your body needs energy from a healthy diet. When you are going through cancer treatment, your energy needs are higher than normal.
- Talk to family and friends about any worries you may have and take time to enjoy yourself.
- If you are not sleeping well, try to develop a good sleep routine. For example, avoid screens for at least an hour before you go to bed and avoid drinking stimulants, such as coffee or energy drinks, before bedtime. Try to go to bed and get up at the same time every day.
- Getting out in the fresh air will help with fatigue. Even just opening the curtains and windows will help as seeing daylight tends to wake us up a bit.
- Have some structure to your day. Get up, wash, brush your teeth, get dressed. Staying in bed all day with the curtains pulled will only make you feel worse.
- Set yourself achievable daily goals. For example, go for a short walk and try to go a little further each day. It is a good idea to track your progress. Sometimes you can lose sight of how far you have come.

Nausea and vomiting

Some cancer treatments, such as chemotherapy, can make you feel sick (nausea) or get sick (vomiting). Your doctor can prescribe anti-sickness medications to help prevent or lessen your sickness. If you feel these medications are not working, you should let your doctor know and they can try different medications or different ways to try and control your sickness.

Hints and tips: **Nausea**

- Keep a sick bag or bowl handy. For example, when you are travelling to and from hospital.
- Eat small meals and snacks often rather than 3 large meals.
- Chop up food into small pieces so it is easier to swallow.
- Try and find out if any foods make the nausea worse and avoid them. These may include greasy, spicy or strong-smelling foods.
- Eat with other people. This can help distract you if you are feeling sick.
- Once you recover from your ‘sick days’, it is important that you try to eat a good-quality diet. A dietitian can advise you about this.
- If you start to feel like you may be sick, take deep breaths.
- If you have been vomiting, try to drink water or other clear fluids. This will help you avoid dehydration. If the vomiting continues for more than 48 hours, contact your hospital.
- If you can’t take any medicines your medical team has prescribed for you because you feel too sick, contact your team. It is important that you don’t miss any medicines.

Infection

You may be more likely to pick up infections and even minor infections, such as a cold, could make you very ill.

This happens because cancer or cancer treatments, such as chemotherapy, can reduce the number of white blood cells in your blood. With fewer white blood cells, your immune system cannot fight infections properly. You will have regular blood tests to measure your number of white blood cells.

What symptoms should I watch out for?

- A sore throat
- A cough
- Stinging or burning when you pee
- Redness or swelling at the site of your central line
- A high or low temperature. Ask your hospital what temperature advice to follow
- Feeling shivery or unwell even if your temperature is normal

Ask your nurse about how to check your temperature and what to do if you are feeling unwell or have a high temperature. They will give you a number to call and tell you when you need to contact them.

What should I do if I have symptoms?

You, your parent/guardian or partner should contact the hospital straight away, even at night. Do not delay! Contact the acute oncology service, if this is available in your hospital, or the emergency department.

You may be asked not to take paracetamol or other medicines that will mask an infection while you are on treatment.

Hints and tips: **Avoiding infection**

- Avoid crowds.
- Avoid close contact, such as hugging or kissing, with people who have colds, flus or other infections like chickenpox or shingles. Let your doctor know if you have been in contact with these or any other infections.
- Ask your doctor about vaccinations available to protect you. Some vaccines are not suitable for people with low immune systems. Your doctor can advise you on this.
- Wash your hands often during the day, especially before you eat and after going to the toilet.
- Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.
- Avoid fast food or takeaway food.
- If you are considering getting a piercing or tattoo, speak to your medical team first.

How is an infection treated?

You will have tests carried out to find the source of the infection. These may include blood tests, a urine test or a chest x-ray. You may need antibiotics or other medication in hospital to treat the infection.

- Antibiotics: An antibiotic will bring an infection under control quickly. You may need antibiotics intravenously (into a vein).
- Growth factors and immunoglobulins: Growth factors can help your bone marrow to make more white blood cells quickly to prevent infection. These are given by injection. If you get serious recurrent infections, your doctor may decide to give you immunoglobulins (antibodies) into your vein.

You may develop other short-term side-effects such as bruising, dizziness, irritated skin and diarrhoea (watery bowel motions/poo). You should always tell your medical team if you get any side-effects, as there are treatments to help with most side-effects.

You should contact your doctor or nurse if:

- You feel you cannot cope well with your side-effects
- Your side-effects do not improve over time
- Your side-effects get worse
- You develop a new symptom that you are worried about

Eating difficulties and weight loss

Many things can affect your appetite when you have cancer. For example, feeling sick (nausea), having a sore mouth, food tasting different, anxiety or constipation (finding it difficult or painful to pass a bowel motion/poo).

When you are on treatment, you need more calories than normal because your body is working hard and using up extra calories all the time. If you do not eat well, you may lose weight. Eating well and avoiding weight loss can help you to:

- Keep up your energy
- Cope better with treatment
- Recover faster

Even if you are overweight or obese, you should try to maintain your weight during treatment unless you are specifically advised to lose weight by your medical team.

If you have any side-effects that are affecting your appetite, tell your medical team, as they may be able to help. For example, if you have nausea, they can give you anti-sickness medicines.

Hints and tips: **Eating difficulties and weight loss**

- If you can only eat a little, try to make everything as calorie-heavy as possible. Use full-fat options of foods.
- Try lots of different foods. Your tastes may change and you may like something you did not like before. Try to find out which foods taste best to you.
- Try eating or sucking pineapple as it will help with any strange tastes in your mouth caused by your treatment.
- Eat small meals and snacks throughout the day rather than 3 big meals.
- Eat foods that have a lot of calories, such as cheese and ice-cream.
- Eat foods that are high in protein, such as meat, fish, eggs and nuts.
- Getting fresh air and exercise may help your appetite.
- Talk to your dietitian who will have valuable advice about what to eat and supplement drinks that may help.
- For more information see our booklet, ***Understanding diet and cancer***. You can download this from **www.cancer.ie**

Sometimes, despite your best efforts, you may not be physically able to take in enough calories and you may need more nutritional support. This can be given by:

- **Nasogastric (NG) tube:** A soft tube is passed through the nose into the stomach. This is usually temporary and removed when eating is back to normal. The tube will be put in by your nurse while you are awake. It may feel unpleasant when going in and for a while afterwards, but people do get used to how the tube feels.
- **PEG tube:** A tube is passed through the wall of your abdomen into your stomach to give liquid food directly into your stomach. PEG tubes are usually temporary but can be left in permanently if needed. An operation is usually needed to have a PEG tube inserted.
- **Total parenteral nutrition (TPN):** This is when nutrition is given into a vein. A solution containing all the calories, proteins, vitamins and fluids that you need is given to you through a central line (a long thin flexible tube that is inserted into a vein leading to the heart).

Your dietitian and medical team will discuss with you what they think is best. It is normal to want to avoid any of these options, however it is essential that you get enough calories into your body. This will help you have more energy and tolerate treatment better.

Mouth problems

Some cancer treatments, such as chemotherapy and radiotherapy to the head and neck, can affect your mouth in different ways. You may develop issues such as:

- Sore/sensitive gums
- Dry mouth
- Jaw stiffness
- Problems with your teeth
- Taste changes

Your medical team can prescribe things to help with many of these problems. For example, there are many mouthwashes, gels and medications, such as painkillers, antiseptic or local anaesthetic gels or lozenges, which your doctor can prescribe if you have a sore mouth.

You should keep your mouth, teeth and gums very clean as this will reduce the risk of a mouth or throat infection. Brush your teeth regularly with a small, soft toothbrush and mild fluoride toothpaste. Use a mouthwash regularly if one has been prescribed to you. Only use mouthwashes recommended by your dentist, nurse or radiation therapist.

In some cases, your dentist can help by giving some low-level laser treatment to the sore areas of your mouth. Your medical team will decide if this is an option for you.

Eat soft, moist foods, such as soups, stews, mashed potato and yoghurts. Try to avoid crunchy foods and drinks that are very hot or very cold.

Changes to your bowel pattern

Constipation

Constipation is when you are finding it difficult or painful to poo. (You may also hear the terms bowel movements or passing stools.)

Constipation can be caused by some of the medications you are taking, changes to your diet or being less active.

If you have not had a bowel movement for three days or more, you need to tell your medical team.

If you are constipated, straining when pooing can cause a small tear in your anus. If you have any blood on your tissue, be careful about hygiene and tell your medical team.

Hints and tips: **Constipation**

- Drink plenty of water throughout the day. This will help keep your poo soft, making it easier to pass.
- Eat foods containing lots of fibre, such as fruit, vegetables and brown bread.
- Get moving. Even a short walk will help move your bowel.
- Toilet position. Sitting with your feet raised so that your knees are above your hips can help.
- Laxatives. Your medical team may prescribe you medicines that will help your bowels to open.

Diarrhoea

This is when you pass watery bowel motions (poo) more than three times in a day. You may also have stomach cramps.
It can be caused by certain drugs, infections and long-term constipation.

You should tell your medical team if your diarrhoea continues or gets worse, or if your poo is red or dark in colour.

Hints and tips: **Diarrhoea**

- Drink plenty of clear fluids (1.5-2 litres per day) to replace what you lose with diarrhoea.
- Eat small amounts of food during the day instead of 3 large meals.
- Watch what you eat and drink as some foods and drinks can make diarrhoea worse, such as fatty, greasy and fried foods, caffeine, fizzy drinks and citrus fruits like oranges and grapefruits.
- Avoid alcohol and tobacco.

Changes to body image

Some cancer treatments such as chemotherapy, radiotherapy and surgery can cause side-effects that can change how you look. It is normal to be upset about this as it can be a very public sign of your cancer. These changes can vary depending on the type of treatment that you need. Your medical team will talk to you in more detail about them. Some of the most common changes are listed on the following pages.

Hair loss

Not everyone loses their hair when they have cancer treatment, but if it happens, it can be very upsetting. Some treatments, such as chemotherapy, can damage the hair follicles. This is what causes the hair to fall out and prevents new hair from growing during treatment.

How much hair falls out depends on which treatment is being used, the dose and your reaction to it. The effects can include:

- Total hair loss: This includes the hair on your head, eyebrows, eyelashes, underarm and pubic hair
- Some hair loss: from a little thinning to quite a lot
- Little or no hair loss
- Damage to your hair: It may become dry and brittle

Your medical team will tell you before treatment if the drugs you are taking are likely to lead to hair loss. When hair loss happens, it is usually gradual. It may fall out in clumps when shampooing or brushing or you may find clumps of hair on your pillow.

Hair care during treatment

Your scalp may feel very sensitive to washing, combing or brushing during the short time when your hair is actually falling out.

Hints and tips:
Hair care during treatment

- Brush or comb your hair gently using a soft brush or a baby brush.
- Use gentle hair products.
- Use a gentle, unperfumed moisturiser on your scalp if it becomes dry or itchy. Natural oils such as olive oil are suitable.
- Avoid using heated products, such as a hair straightener or curling tongs. If using a hair dryer, keep it on a low to moderate heat only.
- Pat your hair gently after washing.
- It is best not to colour your hair during treatment or get a perm.
- Using a silk pillow case can help prevent your hair from clumping when it is falling out.

Will my hair grow back?

Your hair will usually start to grow again once treatment stops. It usually starts to grow within a few weeks of your treatment finishing. When it grows back, it may not feel the same as before. It might have changed colour, texture or style. It might be darker or lighter in colour, thinner, or it may be straight or curly when it wasn't before.

At first, fine downy hair will appear on your scalp and then stronger hair will develop. It grows at about one centimetre each month. You should have a full covering of hair on your head after 5 or 6 months.

Coping with hair loss

It's natural to feel upset at the thought of losing your hair. It can change the way you feel about yourself as it can be a visible sign that you have cancer. Try not to be afraid to talk to your medical team about your feelings. They will help you find ways to cope with your hair loss. Talk to your family and friends too.

Wearing a wig may help some people to cope with losing their hair, while others may prefer to wear hats, scarves or bandanas.

People will respond to your hair loss in different ways. Sometimes, their reactions will be hard to deal with. They may say things that are unhelpful or even hurtful without meaning to. However usually, most people will be supportive. Think about what you want to say and to whom. This decision may be affected by what type of headgear you choose, if any. For example, if you choose to wear a scarf instead of a wig, your hair loss will be more obvious. The decision is yours what to tell people, but try not to withdraw from friends and your social life because of your hair loss.

Weight changes

Some treatments, such as steroids, may cause you to gain weight. Or you may experience weight loss because of the cancer itself or because of eating difficulties caused by treatment, such as a reduced appetite or a sore mouth.

If you are having problems with your appetite, weight gain or weight loss, you can be referred to a dietitian. This is an expert on food and nutrition. They are trained to give advice on diet during illness and how to use your diet to help symptoms. For more on eating difficulties and weight loss, see page 57.

Scarring

Operations may leave physical scars. While scars will fade over time, it can take months or even years for this to happen. After your wound has healed, gentle massage can help improve circulation and reduce scar tissue build-up. There are some creams that may help. Your medical team will be able to advise you on this.

Skin changes

During your treatment, your skin may become very dry and flaky. Tips to help with this include:

- Gentle cleansing – use mild perfume-free, hypoallergenic products to clean your face. Avoid hot water
- Moisturise your skin daily to help prevent dryness. Try to use gentle non-fragranced products
- Protect your skin from the sun. Always use an SPF (sun protection factor) with the highest factor and cover up with clothing and hats. If you have lost your hair, be particularly careful to cover your head
- Stay well hydrated by drinking lots of fluids
- Avoid hot baths/showers as these will dry your skin out more. Opt for lukewarm instead
- Be gentle with your skin. Avoid scratching and wear soft clothes
- Talk to your medical team if you have any skin changes, rashes or discomfort. They may be able to suggest specific treatments to help

Nail changes

Nails often become very brittle, breaking easily during treatment. To help maintain your nail health:

- Keep your nails short as this will reduce the risk of them breaking
- Use gentle nail files if you are shaping your nails
- Use cuticle oils and hypoallergenic hand and nail creams to help moisturise
- If you want to wear nail polish, use non-toxic, hypoallergenic brands. Always use an acetone-free nail polish remover
- Mind your nails. Be careful not to open things with your nails. Wear gloves if you are doing housework or physical activities

Impact on sex

In Ireland, the age of consent for engaging in sexual activities is 17. If you are sexually active, there are some important things to consider while having treatment.

- It is always important to practise safe sex and this is especially important while having cancer treatment. Even if you are in a relationship, you are advised to use a condom for any penetrative sex or a latex barrier, such as a dental dam, for oral sex. This will help prevent infections and stop the passing of medications that may be in your bodily fluids to your partner. It will also act as contraception. You should not get pregnant while having cancer treatment as treatment can harm a developing baby. You should also wait a while after treatment before trying to get pregnant. You can discuss this further with your medical team.
- Some chemotherapies and radiotherapy can cause vaginal dryness so you should consider using a water-based lubricant to reduce discomfort during sexual activity. Check the one you use is safe to use with condoms.
- Try to maintain open and honest communication with your partner about your concerns, desires and any changes in your sexual function, such as erection problems.
- While sex at its best can often be spontaneous, this may not always be possible when you are having treatment. You may need to plan a bit more to make sure you are feeling your best.
- Cancer may affect how you feel about sex. It can be hard to relax when you have a lot of worries on your mind and you may be feeling tired from the effects of treatment. As a result, you may lose interest in sex. This is completely normal - there is no right or wrong way to feel about sex.

- Remember even if you don't feel like having sex, there are lots of other ways to be intimate with your partner, such as hugging, touching and massage.

Your medical team can discuss any concerns that you have. You do not need to be embarrassed talking about this – they have heard everything before.

Impact on fertility

Fertility is the ability to have children. When you are diagnosed with cancer at a young age, you might not want to think about this. However, even if having children is the last thing on your mind, you may feel differently in the future.

Your medical team can speak to you about how your cancer or cancer treatment may impact your fertility, as well as the options open to you. These options may include freezing eggs or sperm for use at a later date (see box on page 70).

You may also be able to avail of the Childhood Cancer Fertility Project, which is a partnership between the Irish Cancer Society and Merrion Fertility Clinic. It offers free fertility preservation and other services to young people with a cancer diagnosis, including:

- Children who have yet to reach adolescence
- Female survivors of childhood cancers aged between 18 and 27

For more information, speak to your medical team who can discuss this further with you, or contact our Support Line on 1800 200 700. You can also read more about the background and aims of the Childhood Cancer Fertility Project on our website, **www.cancer.ie**

Fertility is more likely to return in younger people, but it depends on the type of treatment you have and the dose. While some cancer treatments, such as chemotherapy and radiotherapy, can affect fertility, many people who have had these treatments have gone on to have children.

If you have ovaries, cancer treatment may affect your fertility in a few ways. For example, by affecting the hormones involved in reproduction or damaging the lining of the womb.

Treatment may also put you into early menopause, which is when your periods come to a complete stop. The average age to go into menopause is in the late 40s or early 50s. However, if your treatment affects your ovaries' production of eggs, you may go into menopause at an earlier age.

Your menstrual cycle or the pattern of your periods may also change during your treatment. Periods may become irregular or stop altogether while you are on treatment, or they may become heavier than usual. You should discuss any changes in your cycle with your medical team.

If you have testicles, cancer treatment may affect your fertility in a few ways. For example, it may affect your production of sperm or affect the hormones involved in reproduction.

Your medical team will be able to discuss all of these issues with you.

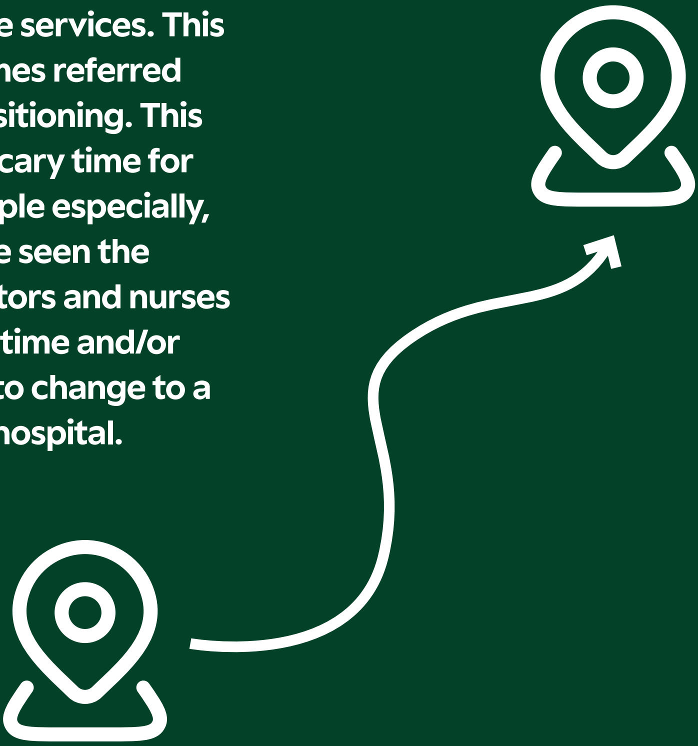
Egg and sperm freezing

- If egg or sperm freezing (sperm banking) are options for you and you are over 18, your consultant can refer you to SIMS IVF Clinic. This free service for cancer patients is funded by the clinic and the HSE.
- You can also use other fertility clinics for egg freezing and sperm banking, but there will be a fee.
- For more information, speak to your medical team or visit **www.sims.ie/oncology-patients**

Chapter 6

Moving to adult services

There may come a time when you have to move from child to adult healthcare services. This is sometimes referred to as transitioning. This can be a scary time for some people especially, if you have seen the same doctors and nurses for a long time and/or you have to change to a different hospital.



Thinking about moving to adult services

The move from child to adult services is something that should happen over time and not be rushed. It is very important that you understand what is happening and are comfortable with the changes you are facing. As a result, adolescents up to the age of 14 are encouraged to start thinking about moving, even though it won't happen for some time. There are a number of things you can do to get yourself thinking about the idea of moving to adult services. These include:

- Try to learn more about your cancer, medication and treatment.
- Use your phone to set reminders about hospital appointments, taking medications and treatment times.
- Talk to your parents/guardians about your medical history. This will help when you are older and you have to answer questions from your medical team.

Preparing for the move to adult services

You will likely move to adult services between the ages of 16 and 18. You should start to plan for your move to adult services up to the age of 16. Things you can do to prepare include:

- You should start learning more about your cancer, medications and treatment. For example, what medications do you take, how much do you need and how often?
- You should consider seeing your doctor or other healthcare professionals by yourself. You may be nervous about this but your medical team can answer any questions you have.
- Ask your medical team about the main differences between child and adult services. Are there any particular worries you have? If so, talk to your team about them.

Moving

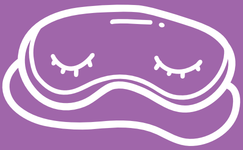
This will likely happen between the ages of 16 and 18. It will take you time to get used to your new service, but there are things you can do to make the process easier, including:

- Find out which adult service you will be moving to and try to arrange a visit or a phone call before your first official visit so that you will know what to expect.
- Try to find out as much as you can about your medical history, medications and treatments as you may be asked questions about these.
- Make a list of questions you would like to ask at your first appointment, including who to contact in case of an emergency.

It is totally normal to find the move to adult services daunting, so you can bring a parent/guardian or friend to your first appointment for support. The medical team will most likely address all their questions to you, which you may not be used to, so be prepared to talk about your cancer.

Adult medical teams may use words and terms that you are not familiar with. If you do not understand what they mean, always ask them to explain it. Remember, there are no stupid questions!

More general information about moving from child to adult services is available at **www.steppingup.ie**



Hints and tips: **How to feel more comfortable in hospital**

- Bring a duvet, blanket or pillow from home.
- Use front-opening pyjamas. Ones with buttons down the front can make accessing your port or Hickman line easier.
- Wear comfortable clothes. Some people like to get dressed during the day as it helps give structure to the day/night.
- Wear cosy socks and slippers or flipflops.
- Bring a dressing gown.
- Use a sleep mask. Lights on can make it difficult to fall asleep.
- Use ear plugs to block out unwanted noise.
- Don’t forget your phone and phone charger. Try to bring an extra-long cable as the available wall plugs can be located far away from your bedside.
- Bring toiletries, such as face and body wash, facial wipes and moisturising lotion.
- A small water spray may be refreshing as hospital wards can be very warm.

Chapter 7

Finding out

If you are reading this section, you may have been told you have cancer and suddenly your world has been turned upside down. How the doctors arrived at that diagnosis may be a bit of a blur, but it probably involved lots of tests and scans and waiting for results.

Everyone reacts to a diagnosis in their own way, but it's never easy. You may feel shocked or overwhelmed. Or you may not feel much emotion at all. Maybe you've been told there's a clear plan for treatment and you're getting ready to take the first steps. Or maybe there's still a lot to figure out.

The truth is that, right now, whatever you're feeling is fine. You may be numb, confused, angry, sad or scared. You may be feeling several or all of these emotions at once. You might feel blindsided or be asking 'why me?' So much has changed, so fast. It's going to take time. Be kind to yourself – your heart and mind are adjusting to a lot of news.

Things may start to move quickly. There will be lots of new words and terms, new people to meet, perhaps big decisions to make. But for now, go gently wherever you can – lean into the people you care about, write down questions when you think of them and ask for support.

> **Before being officially diagnosed, there was some small part of me still in denial that all those tests and scans I was having done would show something bad. Even hearing the words 'you have cancer' is a surreal experience for someone so young. I'm grateful that after hearing those words I suddenly had a team of medical professionals who helped me in every possible way, and helped my family and I get through such a difficult time.**
>
> Joe, 24

Do you feel like you have been holding your breath since you found out you had cancer? As hard as it might be to focus on anything, here are a few things that might help you get a better handle on the situation:

Most young people survive cancer

There have been huge improvements in cancer treatments for young people in the last 50 years. As a result, more young people than ever are surviving cancer. Some forms of cancer are now completely curable and research is also continuing to improve treatments and reduce side-effects.

Even though you may be overwhelmed, worried or feeling sick, remembering this may give you some hope during tough times.

You are not alone

Although no one will feel the exact same way as you, lots of other young people also live with cancer. It can help to know that others are experiencing similar things.

While your family and friends might give you lots of support, sometimes it might feel like they don't really get what you're going through. But you're not alone. You might decide to join an online community or an organisation aimed at people of your age, such as CanTeen Ireland.

The Irish Cancer Society also runs a Peer Support programme for people over the age of 18. Volunteers include people in their 20s and 30s who had cancer when they were teenagers and/or young adults. You can be put in contact with someone who has had a similar cancer experience to you. For more information, Freephone 1800 200 700 or email supportline@irishcancer.ie

It is not your fault

People sometimes blame themselves for their illness. You may think about things like your diet, lifestyle, drug use, environment or family history in search of a reason. However, doctors rarely know what has caused cancer, so there is no reason to blame yourself. It is better to focus on what you can do to make yourself feel more in control of your illness.

Remember, your cancer has nothing to do with anything you said, thought or did.

Knowledge is power

You may find yourself worrying about worst case scenarios, but things imagined can often feel worse than the reality. Having the correct information can be a big help. Learning about your particular cancer and its treatments from trustworthy sources, such as your medical team and the Irish Cancer Society, can take some of the fear out of it.

Be especially careful with online information. It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or your particular cancer type. Ask your medical team about recommended websites. See page 133 for more information on using the internet safely.

If you are wondering about anything at all, don't be afraid to ask your medical team. It is always better to ask than to worry. Remember, there is no such thing as a stupid question.

Positive emotions

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer. Being diagnosed with cancer can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions. Remember, this is your journey to manage. Be honest about how tough it might feel sometimes. Surround yourself with people who make you feel good and treat yourself with kindness and compassion. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

A cancer experience can also bring positive emotions. You may experience great love, affection and closeness from those around you. With that can come a sense of gratitude too.

The experience of cancer can also bring personal growth and knowledge. It may make you realise where your strengths lie and what, for you, is important in life.

Let your feelings out

Living with cancer is one of the hardest things you will ever have to do. Every person will react to the news and cope in their own way. Your thoughts and emotions can feel overwhelming, but they will come and go.

It is okay to feel scared, sad, frustrated and worried. But keeping it all inside or pretending that you are fine doesn't usually help. Try to notice the things that matter to you and make you feel good and try to be around people who you trust and feel comfortable sharing your feelings with.

If you're finding it hard to manage your emotions and feelings, or you're suffering with anxiety or depression, it's important to get help. Your mental health is as important as your physical health, so tell your medical team or another healthcare professional, such as your GP, if you need support.

You can also get advice and support from a cancer nurse by calling our Support Line on Freephone 1800 200 700 or email supportline@irishcancer.ie

Things usually get easier

Cancer can make your life really difficult. You have to deal with changes to your body as a result of your illness and its treatment.

Your school/college/work life will probably be interrupted. And there may be a big impact on your emotions and relationships. But over time, you will adjust to some of these changes and get used to some new routines.

Try to be patient and give yourself all the time you need. Always tell your medical team if you are finding it difficult to cope.

Everyone’s situation is different

It can be helpful to learn about what sorts of things might happen. But there is no substitute for talking to your medical team about what to expect in your case. Everyone’s cancer, treatment, prognosis and side-effects will be different. It will not help you to compare yourself with other people, as this may lead to you feeling worse about your situation.

For example, you may notice that people with your type of cancer are not getting the same treatment as you. However, their tumour may not be the same type or grade as yours, so their treatment will be different.

The way people react and deal with their feelings is also unique, so let yourself do it in your own way.

You can get answers and support

Even if your family and friends don't really understand what you're going through, there are people out there who do. Medical social workers and counsellors are really good at listening, linking you with support and helping you build skills to cope. You can talk to them in person, online and on the phone.

CanTeen Ireland provides access to counselling. For more information, call (01) 872 2012 or email info@canteen.ie

The Irish Cancer Society also funds professional one-to-one counselling (including telephone and video-call counselling) in communities across the country. For more information, or to speak to a cancer nurse, call our Support Line on Freephone 1800 200 700 or email supportline@irishcancer.ie

See also a list of helpful organisations and websites on pages 223-226.

> **I couldn't sleep the night I was diagnosed with cancer.**
> **I was so worried and concerned about the unknown. All I knew is that I would get through it, I had to.**
>
> Daniel, 22

Chapter 8

Talking about cancer

Cancer is a tough topic. You may have stuff that you want to know but you’re not sure how to ask or who to ask. You may have many fears and concerns but don’t want to worry or upset people.

Lots of websites and videos show families sitting around sharing their innermost thoughts, but the reality is that not all families talk openly and honestly about what is happening or how they feel. How your family communicates about cancer may depend on how you have always communicated and your situation. A cancer diagnosis isn’t going to miraculously change that.

You shouldn't go through this alone and you may be surprised about how much better it is when things are out in the open. The trick is to find the right time and the right way for you to talk about stuff.

Here are some key questions to think about before you tell others:

- What do you want them to know?
- What support do you need?
- Who else knows – who can they speak to?
- How would you like them to ask questions after the first conversation – what is the best way to stay in touch?

> **Deciding if and when I should tell people about my cancer is something I'm still figuring out years after finishing treatment. Most of the time I only bring it up with someone new if it naturally comes into conversation, and I've gotten used to every single person having a unique reaction to finding out.**
>
> Luke, 23

You've got what? Who to tell you have cancer

Talking about cancer with your family and closest friends can be challenging enough, but how do you tell people in your wider social circle, such as friends at school, college or work?

Who to tell and what to tell them can be a difficult area to navigate. You might be unsure of how people will react and afraid that they will treat you differently.

You may get several different reactions. A common reaction is shock. Some people may not know what to say and you may feel that some say too much. Some relationships may grow stronger with people stepping up and being a huge support while others may fade away.

Sometimes your treatment or side-effects might make it a bit hard not to say something, for example if you experience hair loss. But how much you tell and allow others to share about you is still up to you.

Ultimately, it is up to you how much information you share about your diagnosis and treatment. There will be different things to consider depending on your situation. For example, you may require support from your school/college/employer if you are going to be absent a lot as a result of treatment.

> **Telling people right away isn't for everyone. Sometimes you need to take your time and take in the information first.**
>
> Conor, 22

Reasons to tell:

- To get support from people you trust and who you know will be there for you.
- To take time off from study and work to attend treatment. If you tell your teachers or boss the real reason, they are more likely to offer to help you out. Classmates and colleagues you trust can also be helpful with keeping up or returning to study and work.
- If treatment affects your energy and concentration levels, it might be better for people to know there is a reason for this instead of them making one up. That doesn't mean you need to tell them everything.

Reasons not to tell:

- You may feel embarrassed talking about your diagnosis, as it may relate to private parts of your body (such as your breasts or testicles). You are in control of what information you provide, so you decide how much detail to give.
- You can't be bothered telling the same story and answering the same questions over and over.
- You may feel your life is now being dominated by an illness that you didn't ask to have. Maybe school/college/work is one of the only places where you can still be you without being defined by cancer.
- People may want to share their own cancer stories with you – good, bad and ugly. However, do not feel like you have to respond with your own story if you don't want to. You choose if and how you respond.

Who do you have to tell?

If you are a student, you do not have to tell your school or college about your cancer diagnosis. But if you think treatment and side-effects will affect your marks and ability to meet course requirements, it is a good idea to tell your teachers or go to the Students' Union to see if you can get any help with your workload or exams if necessary.

If you are working, you do not have to tell your employer that you have cancer, but you are strongly advised to, especially if your treatment involves taking time off. Your employer may also be able to help in other ways, such as reducing the number of hours you have to work or helping with physical access.

> **Sharing your cancer experience always starts with you – don't feel like it, don't have to.**
>
> Ezra, 21

How do you tell people?

Here are some tips for talking about cancer:

- Think about what you want to say before you start. It might help to write it down.
- It may be really hard to start and there may be lots of silent moments. That's OK.
- Try not to worry if you or other people get upset – keep going or try again later. You don't need to cover everything in one conversation.
- Talking can be easier if you are doing something else at the same time – like driving in the car or cleaning up in the kitchen – when the focus of attention isn't directly on you.
- Remember, it may take time for you to work out the best way of talking to others. This is a strange and scary time so take one step at a time.
- Go online and check out some blogs or forums and see how other people told those around them.
- Give permission to your friends, family or teachers to tell other people if you want them to know but don't want to tell them yourself. Make sure they understand if you want to keep the information private.
- Be prepared to deal with insensitive or silly questions. You can refer people to the Irish Cancer Society website at **www.cancer.ie** to learn more about your kind of cancer.
- If you don't know your teachers, lecturers or bosses very well, you may find it easier to email them.

> **The most challenging part at the start of my journey was telling my new friends. I never wanted to burden anyone with the news. I did individually call my close friends and then later shared the news on social media. It may be scary to tell people about this, but I got so much support when I did.**
>
> Fiona, 22

Sharing online

Some people use social media to let their broader network know they have cancer. But before you do, think about the impact of this approach. Once the news is 'out there', you can't take it back and it could be shared widely. Closed/private groups and accounts can be helpful.

It's a good idea to talk with those closest to you about how you want your diagnosis shared online – whether any updates and permissions come directly from you, or if a trusted partner or family member can do this for you. See page 149 for more about using social media to stay in touch with family and friends.

When talking is too hard

Some days you may not want to talk about cancer but still want to express your feelings, just for yourself, or to let your family, friends or partner know how you are feeling.

You can:

- Draw pictures
- Keep a journal – you can choose to keep it private or share it with your family or friends
- Write a letter, email or blog
- Play songs that say it for you or even write your own songs
- Send a text message
- Leave signs on your bedroom door

If you or your family really find it hard to talk to each other about cancer, it may help to speak to a counsellor or medical social worker. They can give you ideas about how to communicate with each other.

You can contact the Irish Cancer Society Support Line for information about free counselling services. Call 1800 200 700 or email supportline@irishcancer.ie

The Society also offers Creative Arts Therapy to young people up to the age of 24 years. This includes art therapy, dance-movement therapy, drama therapy and music therapy. Creative arts therapy is the purposeful and planned use of creative processes with a qualified therapist to support development, emotional expression, social interaction, physical improvements and cognitive goals. Sessions can take place:

- In-person or online
- One-to-one or in a group
- In your home or nearby

If you're interested in availing of creative art therapy support sessions, please email creativeartstherapy@irishcancer.ie and one of our team will be in touch.

Talking to children about cancer

If you have children or have younger brothers and sisters, telling them that you have cancer can be difficult. The younger the child, the longer it will take them to understand what is happening. They will probably be very worried about you but also concerned about what will happen to them.

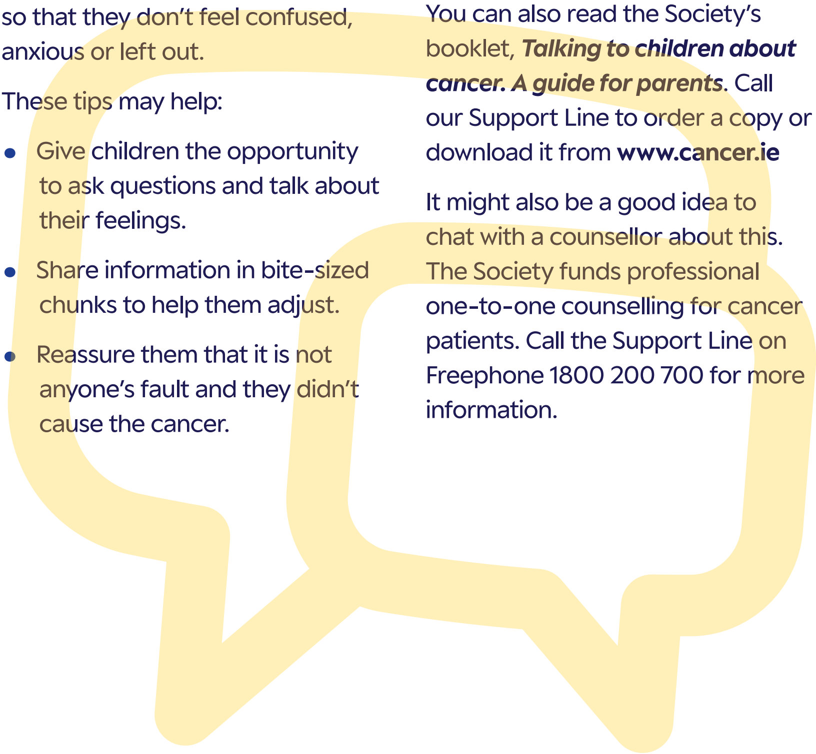
Children tend to know something is wrong so it is best to be honest so that they don't feel confused, anxious or left out.

These tips may help:

- Give children the opportunity to ask questions and talk about their feelings.
- Share information in bite-sized chunks to help them adjust.
- Reassure them that it is not anyone's fault and they didn't cause the cancer.
- Make sure they know cancer is not contagious and they can't "catch it".
- Ensure there is time for them to ask questions and make sure that they know it is OK to ask you anything.

If you feel uncertain about how to have this conversation with children, talk to your medical team, medical social worker or you can speak to a cancer nurse by calling the Irish Cancer Society Support Line on Freephone 1800 200 700. You can also read the Society's booklet, ***Talking to children about cancer. A guide for parents***. Call our Support Line to order a copy or download it from **www.cancer.ie**

It might also be a good idea to chat with a counsellor about this. The Society funds professional one-to-one counselling for cancer patients. Call the Support Line on Freephone 1800 200 700 for more information.



Chapter 9

Let's talk about feelings

Dealing with a cancer diagnosis can bring up all sorts of different feelings. Some of these feelings might come as a surprise to you. At times you may find it difficult to pinpoint what you are feeling and why. The main thing to remember is that there is no right or wrong way to feel.

Many young people describe having cancer as like being on an emotional rollercoaster. You feel like you are racing along with no control, while experiencing massive ups and downs on the way.

You might not be naturally comfortable with sharing your feelings and you may hope they will go away if you ignore them. Feelings are not good or bad – they are just feelings. Even if you keep them hidden or try to ignore them, they will still just be there.

When feelings get bottled up, they need to get out somehow and this can lead to emotional meltdowns, angry outbursts and unsafe behaviour. As hard as it may be, finding ways to express what you are feeling is important in helping you to deal with the stress of living with cancer.

Understanding grief and loss

Grief is a natural and normal reaction to a loss. You may have felt this sense of loss when you were told you had cancer, but it can also happen at other times during and after treatment. It can feel like everything has changed and that life will never be the same again.

You may feel like your body doesn't work the way it used to and you may look different because of your cancer. You may not feel as connected to your friends or you may need to stop going to school/college/work for a while to focus on your health. Some people may even drop out of education or quit their job. You may feel like you are missing out on having fun like other people your age or you may be longing for the life you used to have.

Grief and loss can have a big impact on so many parts of your life and while this is completely normal, that doesn't make it any easier. Grief affects everybody in different ways – there is no right or wrong way to respond to your diagnosis. The way you and your loved ones react may be similar or completely different.

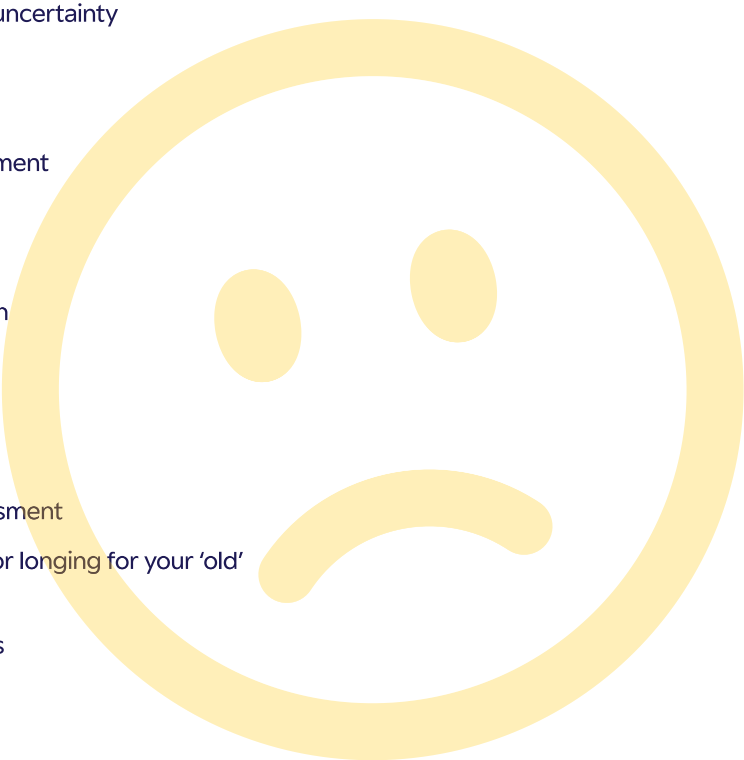
> **Cancer came into my life when I was transitioning from secondary school to university. It was unexpected to say the least and certainly not in the plan. Coping with this change wasn't easy, but having people by my side did make it a little easier.**
>
> Niamh, 22

For example, some people might take on a 'management role' and become practical in their thinking, choosing not to talk about their feelings very often. Others might openly express their feelings and cry.

Grief, emotions and thoughts

Remember, there is no right, wrong or 'normal' way to grieve. Many young people have described how they can sometimes feel many emotions all at once or feel just plain numb. You may feel some or all of the feelings listed below when you're grieving a loss.

- Shock and disbelief
- Fear and uncertainty
- Stress
- Regret
- Abandonment
- Anger
- Sadness
- Frustration
- Hope
- Clarity
- Guilt
- Embarrassment
- Jealousy or longing for your 'old' life
- Loneliness



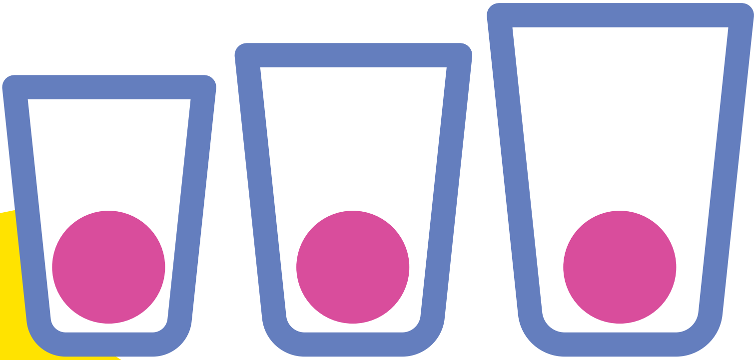
Emotions can happen at different times, sometimes months or years after treatment.

> **Through my cancer experience, my emotions were all over the place. I have many journals of my journey that record how I was feeling, whether I had a fantastic day or a not so good day. Having a journal helped me write about how people didn’t understand what I was going through. There were days where I hit impressive goals. Then there were days where I used foul language because I couldn’t go out or had trouble finding my words. I learnt to accept my feelings, cry, write them down and realise that your life is your life; you can’t always keep up with your friends. You choose your path.**
>
> Amy, 25

You may be experiencing difficult and complex feelings – life may not make sense to you anymore. You may have trouble staying focused or struggle to find a purpose or direction. You may also have no energy and stop doing things you once enjoyed.

Grief is not a single event. It can come and go in waves, so there will be good days and bad days. It may not feel like it now but it won't always feel this hard. In time, your grief will become more manageable.

People tend to believe that grief shrinks overtime



What really happens is that we grow around our grief

Finding a way through

It's important to find ways to take care of yourself and to develop healthy habits during this time. Sometimes when young people are going through tough times, they may deliberately hurt themselves or turn to alcohol or other drugs to get relief from the pain. Even though this might seem helpful at the time, this short-term 'fix' may cause more issues down the track, including having a negative impact on your health and relationships.

Feeling very up and down, as if you are on a rollercoaster ride, does not mean you are not coping. There are ways to live with the grief so that you can continue to move forward in your life and not get 'stuck'. Look for positive ways to get through the challenging feelings and situations you may experience. Finding strategies that work for you can help with the overwhelming feelings and grief you may feel at different points in your journey.

> **When I had brain surgery, I couldn't do much for months and it affected my emotional wellbeing. So I started a journal and wrote down what I felt and why. It helped my headspace. There were times when it didn't help and all I wanted to do was cry and scream, which I did.**
>
> Jenny, 24

Understanding your feelings and emotions can help you to learn how to cope better. Our booklet, ***Understanding the emotional effects of cancer***, can give you more information on your feelings. It may be hard to believe, but you may experience some positive feelings too. You may experience great love, affection, closeness or gratitude for those around you.

Things you can try:

- Write a journal or blog – it is up to you whether you share it with the world or keep it to yourself.
- Get organised – a weekly planner and to-do list can help things seem a bit more manageable. Be careful not to take on too much.
- Exercise – a walk, swim, yoga or bike ride a few times a week can reduce stress and help you to feel better. (Talk to your medical team first).
- Try something new. Have you ever wanted to learn to play guitar or paint? Learning something new might help to distract you from the worries of cancer and give you a sense of achievement.
- Meditate. This can reduce anxiety and stress.
- Hang out with positive and caring people.
- Try to keep doing the things you have always done. Connect with your family and friends, listen to your favourite music, keep up hobbies where possible.
- Rest and get plenty of sleep. When you're really tired, emotions and stress can be even harder to deal with.
- Join a support group – get in touch with people who understand what you're going through and can share tips, support and information. Contact CanTeen Ireland (**www.canteen.ie**) or call the Irish Cancer Society Support Line on 1800 200 700 for more information on supports available to you. You could also join an online support group.

Religious beliefs and spirituality

Living with cancer can make you start to think about your spiritual beliefs.

Spirituality is a broad term for how you make meaning in the world – through nature, people around you, culture, tradition and religious beliefs. Going through something like cancer will likely change how you feel about life, death and everything in between. That's generally because you're seeing things from a new perspective.

It's OK not to have the answers, to change your mind about things and to explore how you feel about life. In fact, it's an important part of being a young person. You can talk about these things with people you trust or look up to, or you can express yourself in others ways, such as through art and music. You may also like to go to places that mean something to you.

If religion plays a big part in your life, it can provide you with support and security as you deal with the experience of having cancer.

However, be prepared for your faith to be tested. You may start to question your religious beliefs. It is not uncommon for young people to do this anyway.

If you no longer want to participate in the customs and rituals of your family's religion, it might cause some conflict at home.

If you weren't particularly religious before, you might be drawn towards some sort of formal religion. If this gives you support and helps you deal with what is happening for you, it can be a very positive thing.

Belonging to a religious-based support group may also help you deal with some of the stuff you are going through.

Even if you are not into traditional religion, you might find that you develop an interest in other beliefs and types of spirituality. It can be a way to get some answers or find meaning in what is otherwise an unfair and tough situation.

Getting support

Dealing with cancer can be a difficult and isolating experience. You might struggle to cope with the feelings you're experiencing. It may affect how you cope at school, college or work. It may also affect your relationships. It's important to reach out to someone you trust who can listen and support you through it.

Although it's normal to have many reactions to your diagnosis, if you notice changes in your life that are getting difficult to manage and are affecting your daily activities, studies, work, relationships or self-esteem, it may be time to get extra support. Talk to your GP or medical team.

You can also call the Irish Cancer Society Support Line on 1800 200 700 or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Targeted life coaching programme

The Irish Cancer Society offers a targeted life coaching programme for young adults (18–24 years). People can avail of 6 one-to-one coaching sessions with an accredited coach to work on issues such as redefining your future after cancer and building up your confidence. For more information on this programme, see page 216.

Daffodil Centres are also located in 13 adult hospitals around the country. These are staffed by cancer nurses and trained volunteers. They provide face-to-face advice, support and information to anyone affected by cancer. This service is free and confidential.

The medical social worker in your hospital may also be able to help.

Managing other people’s expectations

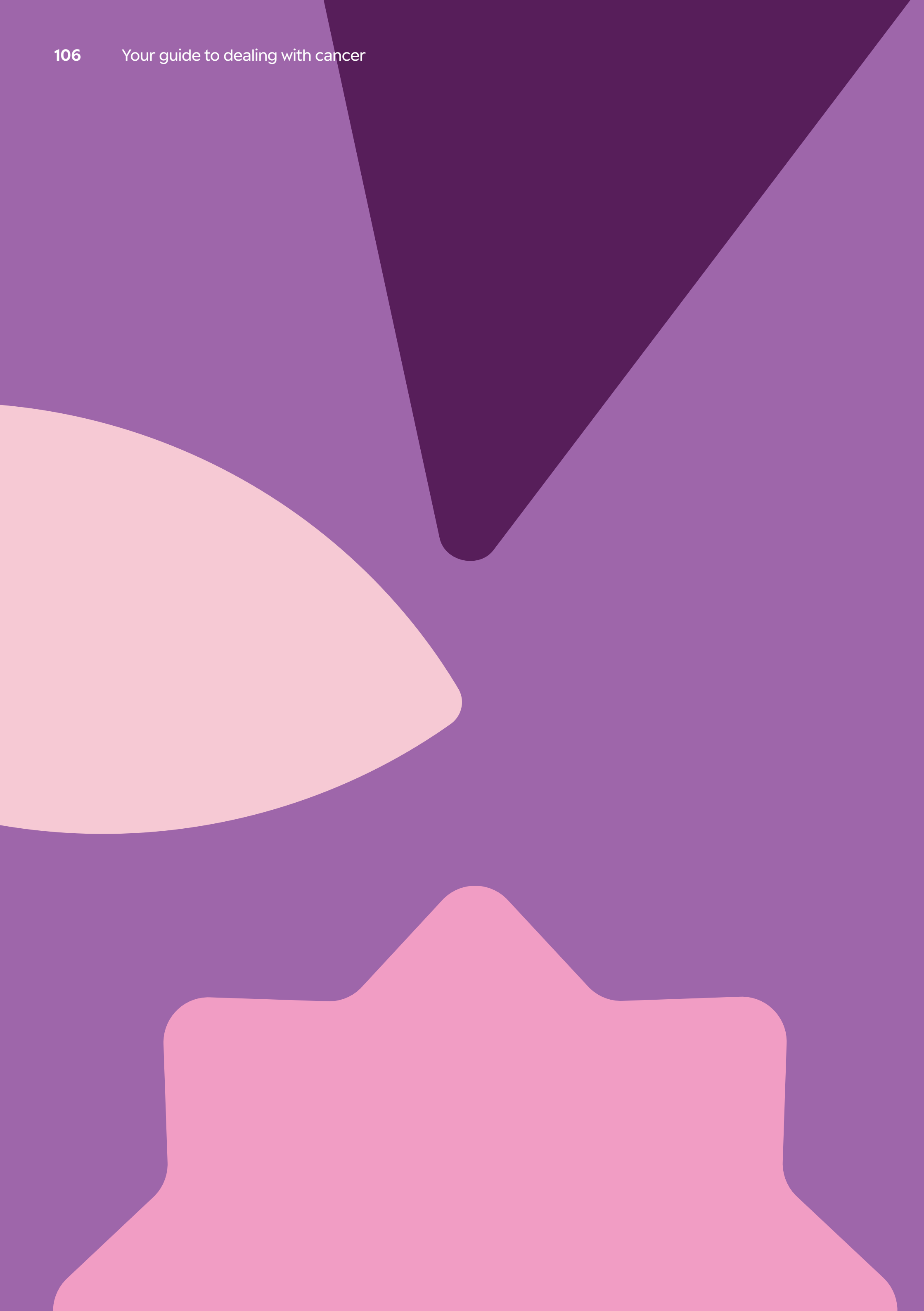
Many young people say that their cancer experience has taught them so much about themselves and life. It has also made them appreciate the little things and helped them to find a strength they didn’t know they had.

But staying positive and trying to remain composed and ‘chilled’ all the time can be a difficult expectation to live up to. You may feel pressure to ‘keep it together’. Some people in your life may have even said this to you.

Having cancer may be one of the biggest and scariest things that you ever face. It’s natural to be worried and upset and to show it when you are.

This is a reminder that it’s OK to:

- Get angry with the people you love and not be the perfect child, sibling, friend or partner
- Not feel brave all the time or think that the whole experience will be good for you
- Not feel positive all the time
- Not feel ‘lucky’ that the cancer has been cured
- Not feel like you’ve been through a life-altering transformation
- Not feel special



Chapter 10

When you're LGBTQIA+

Being diagnosed with cancer can be a shocking and scary experience. But if you are a member of the LGBTQIA+ community, you may have additional worries. LGBTQIA+ refers to lesbian, gay, bisexual, transgender, queer or questioning, intersex and asexual. The plus signs refers to people with other sexual orientations and gender identities. A glossary of LGBTQIA+ terms can be found on page 233.

As a young LGBTQIA+ person, you may wonder if you have to disclose your sexual orientation to your medical team. You may worry that if your gender identity is different to that assigned at birth, this may not be recognised by healthcare professionals. You may have already faced bullying or discrimination in the past because you are a member of the LGBTQIA+ community, so are nervous about this happening again. Or you may still be questioning your sexual or gender identity and feel overwhelmed about having to deal with this and cancer.

What is sexuality?

Sexuality describes how you express yourself in a sexual way. It is not just about the physical act of having sex. It includes how you see, feel and think about yourself as a sexual being. For example, how you view your own body and how you feel about close physical touch. It also includes your sexual feelings, thoughts, behaviours and attractions towards others.

Sexuality includes intimacy, which is a feeling of closeness or connection that develops between people in personal relationships. Examples of physical intimacy include kissing, cuddling, hugging and sex. Emotional intimacy can include feeling safe and secure enough to share your deepest feelings or worries with someone.

Sexuality also includes sexual orientation.

What is sexual orientation?

This describes who you are sexually, emotionally, spiritually, romantically and/or physically attracted to. Sexual orientations include heterosexual, gay, lesbian, bisexual, pansexual and asexual.

There are many different things that can influence your sexuality, such as:

- Age
- Gender or gender identity
- Upbringing
- Hormones
- Religious and cultural beliefs
- Self-esteem
- Personal sexual experiences

It can take time to figure out your sexual orientation and at times you might feel confused about it. Your sexual orientation can also change over time. This is all normal.

What is the difference between sex and gender?

Have you ever filled out a form that has asked you 'what is your sex?' or 'what is your gender?' These two terms are sometimes used interchangeably, however they are not the same.

Sex refers to the biological characteristics of males and females, such as reproductive organs and hormones. It is determined by biology and genetics and is usually assigned at birth based on a person's anatomy. For example, if a baby is born with a penis, they are assigned male.

Sex can include intersex, which is an umbrella term used to describe a wide range of natural bodily variations that do not fit the typical idea of male and female bodies. For example, a person may have reproductive organs that can be considered both male and female.

However, sex tends to be described in a binary way. Binary simply means that something is made up of two parts. In this case, the two parts are male and female.

Gender refers to characteristics of girls, boys, women and men that are socially constructed. This involves things like behaviours, norms, roles and stereotypes. For example, the idea that girls should wear pink and boys should wear blue. Or that women are more suited to caring jobs, such as nursing, while men are more suited to physically demanding jobs, such as construction.

Although these are common stereotypes in many societies, they can be harmful and limit people's beliefs and potential. For example, a person may fail to consider pursuing a particular career despite being well-suited to the position.

LGBTQIA+ language

Language is constantly changing and this includes the language around LGBTQIA+ people and identities. You may not use some of the terms that we use in this booklet. Or some of the terms that are commonly used now may be different from those used in the past.

The important thing is to recognise and respect everyone as the individuals they are.

A glossary of LGBTQIA+ terms can be found on page 233. However, here are a few terms that may be useful in the context of cancer treatment.

Gender identity

Gender identity refers to our internal sense of self and gender – how we feel inside. For many people, this may be the same as the sex assigned at birth. For example, you were assigned female at birth and you identify as a girl or woman.

When your gender identity matches your sex assigned at birth, this is known as cisgender. You may be referred to as a cisgender man, a cisgender woman or simply cis.

However, others may not identify with the sex they were assigned at birth. For example, a trans woman who was recorded as male at birth, but who identifies as a girl or woman.

If a person experiences discomfort, distress or unease because their gender identity differs from their sex assigned at birth, this is known as gender dysphoria. This can occur in a healthcare setting. For example, if you are undergoing cancer treatment and your doctor repeatedly uses the wrong pronouns for you.

Pronouns

This is how we identify ourselves apart from our name and affirm our gender identity. Examples include he/him, she/her and they/them. Using the wrong pronouns to refer to a person is known as misgendering. This can be distressing, particularly in a healthcare setting where you may already feel very vulnerable.

Gender-affirming healthcare

Gender-affirming healthcare includes social, psychological, behavioural or medical interventions that are designed to help transgender people align different parts of their lives – emotional, interpersonal and biological – with their gender identity.

These interventions can include counselling, changes in social expression (for example, using a new name or different pronouns) and medications, such as hormone therapy.

Gender-affirming hormonal therapy aims to help people who feel uncomfortable or distressed by the physical aspects of their assigned gender. For example, if you want to achieve a more feminine appearance, you may take oestrogen. If you want to achieve a more masculine appearance, you may take testosterone.

Gender-affirming surgery is a set of surgical procedures that change a person's physical appearance or the way their existing sexual characteristics work. If you are thinking about, or have already started gender-affirming healthcare, you may be concerned that this will affect your cancer treatment. Similarly, you may be concerned that your cancer treatment will affect your gender-affirming healthcare. You should speak to your medical team about any concerns that you have.

How you might feel after being diagnosed

A cancer diagnosis can be a huge shock for anyone. You will most likely feel a range of emotions from fear and anger to sadness and resentment. However, research suggests that members of the LGBTQIA+ community may face a higher risk of mental and emotional problems after a diagnosis of cancer. This can be due to lots of reasons, including:

- Anxiety around telling healthcare professionals that you are LGBTQIA+, especially if you haven't told many or any people yet
- Fear of being discriminated against by healthcare professionals
- Confusion if you are still questioning your sexual orientation or gender identity
- If you are transgender or intersex, you may worry that your healthcare professionals have little or no experience in this area

Everyone deals with their emotions in their own way. But if you are struggling with anxiety or depression, you should speak to your GP or medical team in the hospital. Counselling and medication may help.

The Irish Cancer Society offers free counselling to patients, either remotely (by telephone or video call) or in-person. You can also speak to a cancer nurse in confidence by calling our Support Line or by visiting a Daffodil Centre. Freephone 1800 200 700 for more information.

It may also help you to talk to an LGBTQIA+ organisation such as Outhouse LGBTQ+ Centre (**www.outhouse.ie**)
Belong To LGBT Youth Ireland (**www.belongto.org**),
LGBT Ireland (**www.lgbt.ie**) or Transgender Equality Network Ireland (**www.teni.ie**).

Speaking to family members and friends can also help. This is a very vulnerable time for you, so get support.

I'm not certain I'm LGBTQIA+

It's common for people to question and explore their identity, including their sexual orientation and gender. Having to deal with cancer on top of this can feel overwhelming. You might feel like you've always known that you were LGBTQIA+, or recently started to question or explore your identity. In either case, needing to have treatment can make figuring out your sexual orientation and identity more complicated.

Cancer can make you re-examine your identity. Some treatment side-effects, such as hair loss or loss of a body part, can be upsetting because they may change how you feel about yourself. Or the changes may help make you more certain about your identity. Whatever you're feeling, it's OK. This is a process that you should take at your own pace.

It may help you to talk to an LGBTQIA+ organisation such as Outhouse LGBTQ+ Centre (**www.outhouse.ie**) Belong To LGBT Youth Ireland (**www.belongto.org**), LGBT Ireland (**www.lgbt.ie**) or Transgender Equality Network Ireland (**www.teni.ie**).

Your GP and the medical social worker in the hospital may also be able to direct you to support services.

Hints and tips:
LGBTQIA+ friendly services

It can be reassuring to know that your hospital and medical team are LGBTQIA+ friendly. It can help you feel more accepted and less likely to worry about being discriminated against or receiving lesser care because of your sexual orientation and gender identity. Signs of an LGBTQIA+ service may include:

Signs of welcome – This can include LGBTQIA+ stickers, flags and posters on display or staff wearing rainbow lanyards.

Check forms – Do they include room to record non-binary gender options, your pronouns or your preferred name?

LGBTQIA+ training – You can ask if healthcare professionals and other staff have received inclusivity training. This training emphasises that everyone deserves to be treated with courtesy and respect regardless of sexual orientation and gender.

Inclusivity training is available to healthcare professionals working for the HSE, however, it is currently not mandatory. Training among private healthcare providers differs from one service to another.

Do I have to tell my medical team I am LGBTQIA+?

You do not have to tell your medical team if you are LGBTQIA+. However, if you feel comfortable and safe, you are strongly encouraged to. This is because your sexual orientation or gender identity may have an impact on your health needs and your medical care. For example, biological sex can have an impact on the way your body reacts to certain medications. So a trans man's body may react differently to medication than a cisgender man's body.

Some other benefits of sharing details about your sexual orientation or gender identity include:

- Improved trust and partnership with your medical team.
- Individualised, culturally sensitive medical care that meets your needs.
- Informing your medical team may make it easier if you want to ask questions about sex and sexually transmitted infections (STIs).
- Informing your medical team may make it easier if you want to discuss issues around fertility and pregnancy now or in the future.
- Inclusion of your partner in your medical appointments.

Telling your medical team may also reduce the risk of gender dysphoria, which is when people become distressed or uneasy because their gender identity differs from their sex assigned at birth. For example, if your team is not aware of your gender identity, they may misgender or deadname you, which could cause you distress.

However, it is the case that many people may choose not to tell their medical team that they are LGBTQIA+ because they worry that they will be treated differently to heterosexual, cisgender people.

What should I tell my medical team?

This is really up to you. Going through cancer treatment means seeing a lot of different healthcare professionals. Deciding whether to disclose your sexual orientation or gender identity to each of them can feel stressful and exhausting. You may want to just tell your team what your sexual orientation and/or gender identity is, or you may prefer to provide more details.

While it is not best practice, you might find that healthcare professionals assume that you're straight or cisgender. For example, if you attend hospital with your same-sex partner, they may assume the person is a friend or relative. Or hospital records might state your sex assigned at birth or a name that you were born with but no longer use. As a result, you may want to ask them to use specific pronouns when they address you or a name that is different to the one they may have recorded for you. You can simply say, 'my pronouns are they/them or my preferred name is …'

You should tell them about any relevant medical history, such as being on hormone blockers or any past surgeries. It is important to include any interventions that you may have had without medical supervision.

You may be nervous about telling your medical team you are LGBTQIA+, especially if you have had a bad experience with a healthcare professional before. However, if you are over the age of 18, anything you tell your medical team is confidential.

If you are aged 16 or 17 years, you can give consent to surgical and medical treatments without the consent of your parents/guardians. However, doctors are unable to promise complete confidentiality at this age because parents and guardians have the right to access their child's medical records. According to the Children's Rights Alliance, when it comes to disclosure of sensitive information such as LGBTQIA+ identity, healthcare professionals generally have a duty of confidentiality. However, exceptions may arise if there are significant concerns about the young person's wellbeing or if disclosure is necessary to protect their best interests.

For most young people, coming out is a gradual process. You can choose to just tell the healthcare professionals that you are comfortable with. If there is a particular healthcare professional who you feel more comfortable speaking to about this, you can seek them out.

Hints and tips: **Telling your medical team you are LGBTQIA+**

- Decide beforehand how much information you want to give and who you want to give it to. There may be a particular healthcare professional who you feel more comfortable speaking to about this.
- Write something down if you think this will help. You might use this to refer to while you speak or you may prefer to let your healthcare professional read it so you do not have to speak.
- It may help you to practise out loud what you want to say.
- Consider bringing someone with you, such as a friend or partner. They can provide support. They can also help you to make a complaint if the reaction is negative or discriminatory.
- If you are in a ward or other busy area, ask to speak in a private area where you won't be overheard.

What if I'm transgender?

Transitioning from the gender assigned to you at birth to a different gender that reflects your inner experience looks different for every trans person. It might include changing your name, pronouns, how you look, taking hormones and as you get older, surgery. You might be doing some or all of these things or you might be thinking about taking some of these steps.

Some people have legally changed their gender and have a gender recognition certificate. It is important to note that your right to medical care is not affected if you do not have a gender recognition certificate. (The United Nations and the World Health Organization recognise health as a basic fundamental right, irrespective of your gender identity.)

Do I have to tell my medical team I am trans?

You don't have to tell your medical team that you're trans, but knowing this will help them give you the information and care that is right for you. Your gender identity may have an impact on your health needs. For example, biological sex can have an effect on the way your body reacts to certain medications. So a trans man's body may react differently to medication than a cisgender man's body.

Informing your medical team may also make it easier if you want to ask questions about sex or fertility now or in the future.

Telling your medical team may also reduce your risk of experiencing gender dysphoria, which is when people become distressed or uneasy because their gender identity differs from their sex assigned at birth. For trans people, they may become very distressed at the thought of certain tests or procedures. For example, if a trans man has a cervix and needs to undergo a smear test. This can result in people delaying or failing to attend important appointments.

Research tells us that many healthcare professionals lack confidence or knowledge about trans bodies. However, they should always try to respect who you are and meet your individual needs. This includes providing the best information and care to you while also respecting your privacy and dignity.

Can I continue to take gender-affirming hormones while being treated for cancer?

It is usually possible to keep taking gender-affirming hormones while on cancer treatment.

However, in some cases your medical team may recommend that you reduce, pause or stop taking hormone treatment. For example, if you have been diagnosed with a cancer that is sensitive to hormones, your team may recommend pausing your hormone treatment while they carry out further tests.

The idea of pausing or stopping hormone treatment may be very distressing to you, so it is essential that you discuss all of the benefits and risks with your medical team.

Fertility

Your fertility may be affected by different types of cancer treatment, including chemotherapy and radiotherapy. Your chances of infertility depend on:

- Your fertility before cancer treatment. For example, if you had a low sperm count before treatment
- Your age. Fertility is most likely to return in younger people, although this depends on the type of treatment and the dose
- The type of cancer you have
- The type of treatment you have
- If you have any other health problems

Fertility is also affected by gender-affirming hormone therapy, so if you are having this type of therapy, you may experience reduced fertility.

It is currently unknown if the fertility of people on long-term gender-affirming hormone therapy will experience reduced fertility in the long-term. If fertility is important to you, it is important that you discuss this with your medical team and/or a fertility specialist.

Options that could be open to you include storing sperm (sperm banking) or freezing eggs.

Contraception

People having cancer treatment are advised to avoid pregnancy during this time, as treatment can harm a developing baby.

While some cancer treatments and gender-affirming hormone therapy can affect fertility, you should not assume you are infertile. It is important that you still use effective contraception when sexually active to protect yourself from sexually transmitted infections and to avoid pregnancy during this time. Speak to your medical team about the contraception options that are open to you.

Support

If you are trans and are struggling to deal with your cancer diagnosis or treatment, you could seek the support of family and friends. However, if you feel you can't speak openly to them, you should consider speaking to:

- A healthcare professional such as your GP or the medical social worker in your hospital, who may be able to direct you to relevant services or supports
- A professional counsellor. The Irish Cancer Society funds free counselling for patients, either remotely or in-person. Call 1800 200 700 for more information
- Our cancer nurses. Call our Support Line to speak to a cancer nurses in confidence. Freephone 1800 200 700. Or visit a Daffodil Centre
- An LGBTQIA+ organisation, such as Outhouse LGBTQ+ Centre (**www.outhouse.ie**), TENI (**www.teni.ie**), LGBT Ireland (**www.lgbt.ie**) or Belong To LGBT Youth Ireland (**www.belongto.org**). Supports offered by these groups include helplines, peer support for trans people and support for the families of trans people
- Online support groups

What if I’m intersex?

Intersex is when people are born with sex or reproductive characteristics that aren’t considered only male or female. For example, they may have reproductive organs that can be considered both male and female. This could include someone who appears female on the outside, but has internal testes instead of ovaries.

If someone is born intersex, this may be detected at the time of their birth. For example, if they appear to have both male and female genitalia. However, in some cases, the intersex variation is not obvious. For example, it may be at a hormonal level and does not become obvious until later, such as during puberty or when someone tries to have a baby.

Being intersex is about biological features not your gender. It’s also not about your sexual orientation – intersex people have many sexual orientations.

There are around 40 known variations of sex characteristics and these are estimated to occur in 1-2% of people globally.

Lack of understanding

Many people have never heard of intersex variations. As a result, there can be a lot of confusion about what being intersex means and what intersex people need.

If you have an intersex variation, you may have experienced a lack of understanding from healthcare professionals in the past. You might also have had procedures or treatments, such as genital surgeries, which may have been done when you were younger without your or your parents' consent. This can lead to distrust in the healthcare system or anxiety about having medical treatment in the future.

If your intersex variation was hidden from you for years, you might be angry about this secrecy. This can also lead to distrust in the healthcare system, as well as your own family.

It may be difficult to find a cancer specialist with experience of intersex variations. However, your medical team should always treat you with respect and ensure that you have enough information to make an informed decision about your cancer treatment.

Hormones

If you are intersex, you may have been prescribed hormone treatment. For example, to provide your body with sex hormones that it is not able to produce naturally. Or you may be on gender-affirming hormone therapy if the sex you were assigned at birth does not match your gender identity.

Your medical team will explain to you whether you can continue to take hormones. In some cases, they may recommend that you reduce, pause or stop taking hormone treatment. For example, if you have been diagnosed with a cancer that is sensitive to hormones, your team may recommend pausing your hormone treatment while they carry out further tests.

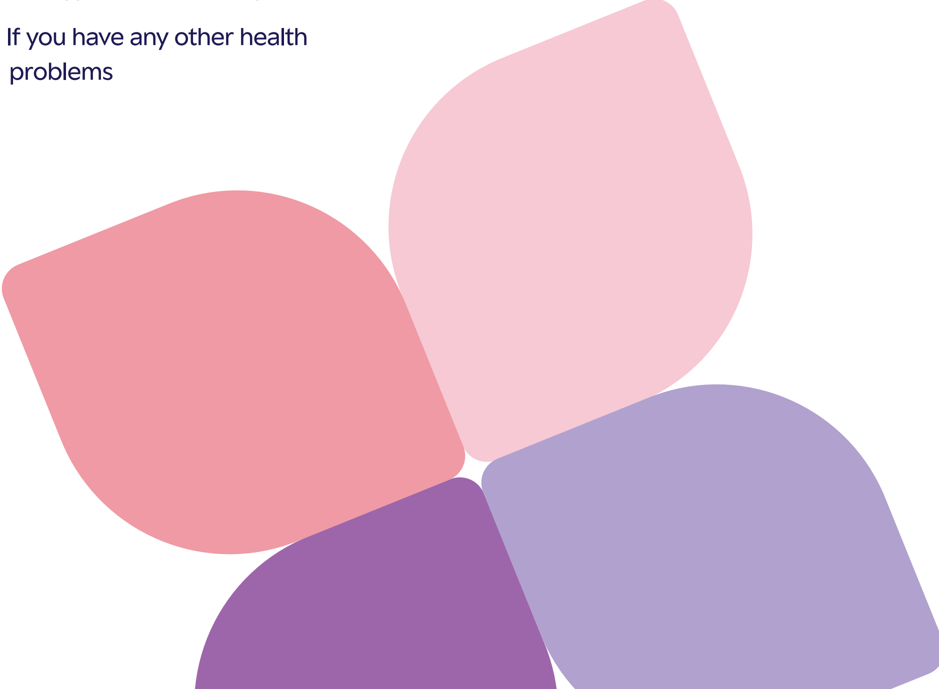
The idea of pausing or stopping hormone treatment for your intersex variation may be very distressing to you, so it is really important that you discuss all of the benefits and risks with your medical team.

Fertility

Your fertility may be affected by different types of cancer treatment, including chemotherapy and radiotherapy. Your chances of infertility depend on:

- Your fertility before cancer treatment. For example, if you had a low sperm count before treatment
- Your age. Fertility is most likely to return in younger people, although this depends on the type of treatment and the dose
- The type of cancer you have
- The type of treatment you have
- If you have any other health problems

Fertility may also be affected by your intersex variation, as well as any surgeries you may have had during childhood to remove ovaries or testicles. If fertility is important to you, you should discuss this with your medical team and/or a fertility specialist, before cancer treatment starts if possible.



Support

If you are intersex and are struggling to deal with your cancer diagnosis or treatment, you could seek the support of family and friends. However, if you feel you can't speak openly to them or that they don't understand, you should consider speaking to:

- A healthcare professional such as your GP or the medical social worker in your hospital, who may be able to direct you to relevant services or supports
- A professional counsellor. The Irish Cancer Society funds free counselling for patients, either remotely or in-person. Call 1800 200 700 for more information.
- An LGBTQIA+ organisation such as Intersex Ireland (email: intersex.ie@gmail.com), Outhouse LGBTQ+ Centre (**www.outhouse.ie**), LGBT Ireland (**www.lgbt.ie**), GOSHH (**www.goshh.ie**) or Belong To LGBT Youth Ireland (**www.belongto.org**)
- Online support groups

Discrimination

Some LGBTQIA+ people may be concerned that they will be discriminated against because of their sexual orientation or gender identity. In fact, some may already have been discriminated against by healthcare professionals in the past.

Discrimination is when someone treats you worse or less favourably than another person is, has been or would be treated, in a similar situation. In terms of healthcare and LGBTQIA+, discrimination can take many forms. It can include:

- Receiving a poorer standard of care due to your LBGTQIA+ status
- Having inappropriate or offensive comments made about you
- Having your partner(s) excluded from important discussions

Under Irish law, people are protected from these kinds of discrimination as part of the Equal Status Acts 2000-2018. The Equal Status Acts ban discrimination in certain situations, including when using public services, such as healthcare services.

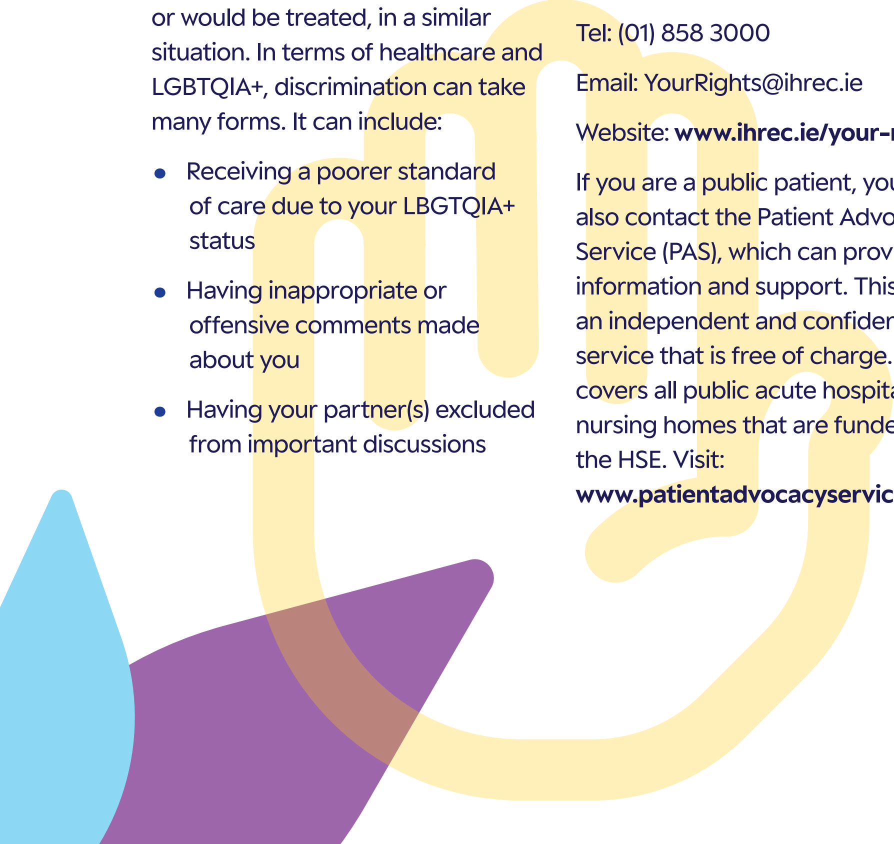
For more information on discrimination and your rights, contact the Irish Human Rights and Equality Commission's 'Your Rights' service:

Tel: (01) 858 3000

Email: YourRights@ihrec.ie

Website: **www.ihrec.ie/your-rights/**

If you are a public patient, you can also contact the Patient Advocacy Service (PAS), which can provide information and support. This is an independent and confidential service that is free of charge. It covers all public acute hospitals and nursing homes that are funded by the HSE. Visit: **www.patientadvocacyservice.ie**



Chapter 11

Getting the right information

Not knowing what's going on can be stressful. Ask your medical team as many questions as you like about anything you are curious or worried about. Remember – there is no such thing as a stupid question and it's better to ask than to worry.

You have a right to know what is happening to you and your body. Having the correct information is an important way to help you deal with your cancer. It might also help to give you a sense of control when everything else seems out of control.

You may not want all the information at the very beginning or you may not want it all at once. But as time goes by, you may be ready to ask more questions.

Some people like to know every little detail, while others only want to know things in a more general way. Whatever you choose is OK.

If you like, you can speak with your medical team without a parent or carer being present. People over the age of 16 are allowed to make their own decisions about medical and surgical treatment without their parent's consent.

Obviously, the decisions you need to make are serious and you need to think about them very carefully. Having the right information will help you to make decisions that are right for you.

What to ask

There are many questions you may want to ask your medical team throughout your cancer experience. Below are just a few suggestions to start with:

- What kind of cancer do I have?
- Where is the cancer? Has it spread to other parts of my body?
- How common is this type of cancer?
- What tests will I need and what do they involve?
- Where will the tests be performed?
- What are the pros and cons of each treatment option?
- Can someone stay in hospital with me, such as my parent or partner?
- What problems should I look out for and who do I contact if they occur?
- How will the cancer impact my everyday life?
- How much will treatment cost?

> **The emotional rollercoaster you get on when diagnosed with cancer isn’t talked about a lot. This ride doesn’t stop when treatment begins. I suggest trying to prepare mentally for treatment and talking to your doctors and family about any concerns you have. Never be afraid to ask questions.**
>
> Conor, 22

AGH! INFORMATION OVERLOAD!

When you are feeling stressed, upset or scared, it can be hard to understand all of the new information you are being told, especially at the beginning.

You will have lots of appointments with different doctors. They will probably use a lot of medical terms that might at first sound like a foreign language. But you will probably become very familiar with these terms later on.

Here are some tips on how to get the right information and ways to remember it:

- Write down your questions before appointments. Include any questions your family or partner might have.
- Write down the answers during the appointment or have someone with you who can do this. If there are any restrictions which mean you have to attend the appointment on your own, your support person could be on the phone or on video call. You can also ask to record the session.
- Ask people to repeat things if you don't understand them the first time. Some medical terms or types of treatment can be complex and they may need to be explained more than once before you understand. Ask the doctor or nurse to draw a picture or use an image to show you what they mean.
- Be careful with online information as it may be hard to understand or it may be incorrect. Ask your medical team for recommended websites and see the next page for advice on searchng the internet.

Dr Google

The internet is a great source of information and it may help you to get a better understanding of your cancer. But it can also contain incorrect, weird and even scary stuff. That's not helpful when you are trying to get accurate and useful information, especially when you may be feeling very vulnerable.

Here are a few tips for searching the internet:

Always check the source of the information

Lots of information online can be misleading. Look at where the information is coming from. Who is behind the website? Do they have expert medical knowledge? Can you find contact information for them? What is the purpose of the website – is it trying to provide information or is it trying to sell a product or service?

Who wrote the information?

Who has actually written the content you are reading? Are they a healthcare professional or expert in their field? If not, has the content been reviewed by a healthcare professional or expert?

Check when the information was written

Is the information on the website up to date? Is it reviewed regularly? Sometimes the date the information was written or last reviewed appears at the bottom of the page. Health services and treatments are changing all the time so ideally, you should be accessing the latest information.

Don’t believe it all

If the claims in an article seem too good to be true, they probably are. Be particularly cautious if a website claims to have a ‘cure’ or treatment for many different illnesses, or if a site is promoting unproven treatments. If a webpage is making money – for example by selling a ‘cure’ - there’s more reason for them to exaggerate or give misleading or incomplete information. It’s a good idea to check out claims made on the internet with your medical team.

Be suspicious if a claim is based on one person’s experience. Personal stories are interesting and may even be comforting to you, but one person’s experience is not a good basis for making decisions about your health. What works for one person may not work for another. This is why doctors use scientific evidence that has been carefully researched and reviewed to guide their decisions around your care.

Be careful with online information

It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or your particular cancer type. Ask your medical team for website recommendations.

The Irish Cancer Society website provides information on a range of topics, including cancer types, treatments and coping with cancer. Visit **www.cancer.ie**

There is also a list of useful websites on page 223.

Remember – the internet should never be a substitute for seeing your doctor. Your medical team knows your situation best and will carefully consider your treatment plan based on the latest scientific evidence.

Chapter 12

Managing relationships when cancer comes along

Cancer is tough for everyone and you may find relationships change.

What is happening to you will affect family, friends, partners, classmates and work colleagues in different ways. Their reactions might be due to concern about you, their own experience of cancer in their life, not seeing you as much and generally dealing with their own stuff.

This could mean changes in some of these relationships. Sometimes you'll grow closer, sometimes apart. Dealing with these changes takes patience, honesty and lots of communication. However, this can be hard when you are feeling sick, tired and worried.

Parents, carers and family

Families come in all shapes and sizes so there may be many different people who have a parental or caring role in your life right now. Hopefully, these connections can provide a safe space for you during this worrying time.

As a young person, you're often navigating changes in these parent-child relationships anyway – learning what is possible, changing roles at home, moving out. Add the stresses and challenges of cancer and these relationships can sometimes be put to the test. Your diagnosis can be just as overwhelming for your family as it is for you.

Your family may be dealing with a lot, including:

- Feeling guilty that this is their fault
- Shock, fear, anger and disbelief at your diagnosis
- Concern about you and the rest of your family
- Feeling helpless as they can't fix this for you or make it go away
- Becoming overprotective of you - trying to shield you from bad news and harsh realities
- Becoming distracted and not focusing on 'normal' things
- Feeling tired, stressed and short-tempered from thinking about everyone else all the time
- Trying to hide their feelings and put on a brave face for you
- Worrying about money and whether they can get time off work to look after you and your siblings
- Feeling isolated and lonely. Their friends might not know how to cope and so may avoid them. They might feel that no one else understands what they are going through
- Their own personal issues. The hard part is that life for other people doesn't stop. This can cause a lot of stress and difficulties when they're dealing with many things at once

It's important to know that you don't have to try to 'fix' any of this, but being aware can help you find common ground.

Support for parents

For parents, having a child diagnosed with cancer can have a huge impact. Common feelings and emotions on hearing the news can include shock, fear, sadness, denial, guilt, anger and stress. Along with worrying about their child, parents may also have practical issues that have to be taken care of, such as work, childcare and paying bills.

The Irish Cancer Society offers a number of supports to parents:

Support Line: Parents can call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. The Support Line is open Monday to Friday, 9am to 5pm. Freephone 1800 200 700. Parents can also email us on supportline@irishcancer.ie or visit our online community at **www.cancer.ie**

> **Having cancer brought me closer to my parents and family.**
>
> Steve, 24

Daffodil Centres: Daffodil Centres are located in 13 adult hospitals nationwide. These centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer, including the parents of young people with cancer.

Daffodil Centres are open to everyone and you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including cancer treatments, emotional support and entitlements. For more information on these centres, email daffodilcentreinfo@irishcancer.ie

Counselling: The Society funds professional one-to-one counselling. This can be remote (by telephone or video call) or in person at cancer support centres around the country. Counselling is available for the patient, but also their family members, so parents can avail of this. For more information, call Freephone 1800 200 700 or visit your nearest Daffodil Centre.

Peer Support: Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. As well as connecting people with cancer, we have trained parent peer supporters available to provide emotional and practical support to parents while their child is going through or has finished treatment. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Call our Support Line on Freephone 1800 200 700 for more information.

Publications and website information: We provide information on a range of topics including cancer types, treatments, side-effects and coping with cancer. Visit our website **www.cancer.ie** or call our Support Line for free copies of our publications.

Parents can also speak to the medical social worker in their child's hospital or their GP about supports that may be available.

If you're older

If you're already an adult, you've probably started taking on more responsibility and control of your life through big changes, such as starting college/work or moving out of the family home. This growing independence may have shifted your relationship with your parents.

> **Adjusting to life for me was difficult. I was diagnosed in my 20s when I could have been moving out of home.**
>
> Amy, 25

You might feel like you were capable of looking after yourself and enjoyed that freedom. A cancer diagnosis can change everything.

If your relationship with your parents was complicated before, cancer can change the dynamics of the relationship all over again.

You will most likely need and want the support of your parents or other family members. But while you may appreciate this help, it might not be easy to have parents and other family members so involved in your daily life again.

This can also be a very expensive time and you might need family members to help out with the financial costs. It can be hard to lose financial independence, particularly when your friends and siblings can still buy their own things.

It's likely your family is very worried and wants to make things easier for you. It is okay to have a mix of different feelings about this. Sometimes chatting with a healthcare professional, like the medical social worker in your hospital or a counsellor, can help you to see the situation more clearly. You may learn ways to navigate these new relationship dynamics.

> **I had just turned 18 and was trying to find my independence while living at home. When I was diagnosed, all that independence and control I had over my life disappeared. This was really difficult to deal with at the beginning as I had to rely on my parents. They were always there for me and were the support I really needed at the time.**
>
> Fiona, 22

Taking the reins

While you play a large part in making your own medical decisions, sometimes your parents may feel like they have more experience in making big decisions or that they know what's best for you. They might want to step in on your behalf and this could cause some friction.

It is important for you to maintain some independence and be included in the decision-making process, especially if you have different opinions about your treatment.

Accessing clear and accurate information and understanding what is happening to you can help you to feel more confident to make choices and regain some control over your life and body.

Parents

Whether you still live at home or moved out years ago, your parents may become very over protective of you after your diagnosis. They may try to take charge, even if this is not what you want.

It may be difficult but try to be honest with them about your feelings. Try to tell them clearly and calmly what you'd like from them. Let them know how they can help you and when you just want to be left alone.

Think about what matters to you and share this with your parents. For example, you may want more time with your friends or more privacy.

You may not want to tell your parents how scared, depressed or stressed you are because you are worried about upsetting them even more. But keeping your emotions hidden will only make you feel more stressed and alone.

You might feel like you are losing your independence, especially if you have to move home during treatment. But you may have to rely on your parents for some things during this time. Remind your parents how important it is for you to make your own decisions, but ask for help if you need it. As well as emotional and financial support, they may be able to help you with practical things such as making meals and arranging visits from family and friends.

Brothers and sisters

Best friends or sworn enemies? Probably both and it can move from one to the other in just a few seconds.

Being diagnosed with cancer won't make this go away. It's not like somebody waves a magic wand and says: "Now that cancer is here, you will all love each other deeply and never fight."

How you got on with your siblings before the cancer will affect how you get on now, but it's likely your relationships will change. You may stop arguing about the small stuff, but you will probably still argue about some things.

If you have had to move back to the family home, this may have a big impact on your siblings.

You might find that older siblings become protective of you. This can be OK, but it can be annoying to feel 'parented' by them.

Being in hospital for a long time can affect your relationship with your siblings. You might feel like you don't have as many things in common anymore. For example, going to school, hanging out with friends and playing sport. However, even if you often fought and annoyed each other, you might be surprised at how much you miss them.

Siblings can become a useful link between you and your friends at school, college and the rest of your world. You might also find that having cancer actually brings you closer together.

Don’t underestimate how your diagnosis will affect your siblings. They may feel a range of emotions, including fear, anger, jealousy, guilt and loneliness. There will naturally be lots of focus on you and your siblings may feel a bit left out. They may even resent you. This can show itself in various ways like not wanting to visit you in hospital, saying mean things, ignoring you or behaving badly.

Try not to blame yourself if your siblings are finding it hard to cope with your diagnosis. We all react differently to difficult situations and express our fears and pain in different ways. Understanding what is going on inside your sibling’s head may help you to understand why they behave like they do. Just sitting down and talking with them about how you are both feeling is a big first step that should help make things better.

The Irish Cancer Society has published a booklet, ***Supporting brothers and sisters of a child with cancer: A practical information guide.*** This can be downloaded from **www.cancer.ie** or you can call our Support Line on Freephone 1800 200 700 and ask for a free copy to be sent to you.

The Society also works with cancer support services all over the country. They have a range of services for cancer patients and their loved ones, including siblings. Many of these services are free, such as professional counselling and support groups. You can call our Support Line to find your nearest cancer support centre. Or go to **www.cancer.ie** and search ‘Find support’.

Friends

Your friends are really important. You may spend as much time with them, or more, as you do with your family.

Sometimes friends are amazing. They say the right things and are there to lean on when you have cancer. But other times, friendships get a bit complicated and confused.

There are all sorts of things happening to you that can mess with friendships, like:

- Feeling crappy and irritable while you are being treated
- Being in hospital a lot
- Not being able to do the same things as you used to
- Acting differently because of your diagnosis
- Looking different because of treatment

Sometimes friends can find all of this difficult to deal with.

It might seem like your friends are not calling you or inviting you out anymore. They might not visit you much or at all. They might make insensitive jokes or say unhelpful things. They might not want to talk about the 'C word' and just pretend that nothing is wrong.

The support of your close friends is probably really important to you. You might feel hurt or disappointed that they are not better at being there for you when you really need their support.

But this is new territory for everyone and your friends probably don't have much experience of dealing with someone with a serious illness.

It can help to think about the situation from their perspective. Some things to keep in mind include:

Friends sometimes don't know what to say

Your friends may be scared to say the wrong thing or to ask you a question. Often, they will just say nothing. It's not because they don't care. They simply may not know what to say. If you want to talk, you may have to start the ball rolling.

Friends won't say things to deliberately upset you

Sometimes your friends will say stuff that really annoys you and makes you angry. This can be really hard. But try not to be offended and keep in mind that they didn't set out to annoy you on purpose - it's just that they don't understand. It's OK to let them know how you feel and what you need from them.

There will probably be times when you are a bit snappy with your friends. That's OK as long as you talk to them afterwards and let them know how much they mean to you.

Friends may ask tough or silly questions

Be prepared for questions that may seem silly or strange – remember all the things that you didn't know before you got diagnosed? Sometimes you may not want to answer questions about your diagnosis or treatment. It is OK to let your friends know that you don't feel like talking right now.

Your friends have their own lives

Unfortunately, the world around you doesn't stop because you have been diagnosed with cancer. It may seem that your friends are just getting on with their lives without you and you may feel left out. Try to remember that they have their own lives too and they aren't dealing with the same things that you are.

Friends may change

Having positive people in your life is important. Some of your friends may become an amazing source of support, listening to your complaints, fears and wishes. These are true friends and you may become very close.

But not all of your friends will be able to handle it and some friendships will fade. Some people will find it hard to understand what you're going through. Some may even exclude you and you may decide that they are just not worth the hassle.

You may also change as cancer can make you have a different perspective on life. You may not relate to your old friends as well as you once did. You may want to find other people whose interests are more like yours.

> **I had friends who left and friends who stayed. I am very grateful for my friends who stayed and helped me through the ups and downs of my cancer journey.**
>
> Daniel, 24

You will find new friends

You may form new friendships. It can be really helpful to connect with other young people who are going through a similar thing. They might be easier to talk to about what is happening because they understand. Lots of young people say this is often the best support.

As unfair as it may seem, you may have to take the lead and help your friends handle what is happening to you.

Tips to help you stay in touch with your friends:

- Invite them to visit you in hospital or at home.
- Use social media to stay in touch.
- Ask them to keep calling, texting and messaging you. Explain to them that if you don't feel like talking, you just won't respond straight away.
- Ask them to keep inviting you to things and you'll go when you can.
- Remind your friends that you are still the same person.
- Tell your friends how they can help. Many will be happy to do whatever they can to show they care.

Connecting through social media

When you are having treatment for cancer, it can become incredibly hard to see and stay in contact with your friends as much as you would like. You might also be away from family members and other important people if you are in hospital for a while or are having treatment.

There are many ways that social media can be used in a positive way to help you manage the stresses of cancer. It is a great way to keep in contact with your friends when you might not be able to see them as much as you would like.

Sometimes you may get tired of answering the same questions over and over again. You (or a trusted family member or friend) can use social media and group chats to update friends and family about your treatment and other progress. You can send text or video messages (that you approve) to those you care about. This is a great way to avoid repeating information and to manage who you share updates with.

It can be helpful to set the expectation about what information is public and what is just for those closest to you. Using closed or private social media accounts can be a great way to journal your story. You might not even share it with anyone at the time, but it can be there just for you.

It's also a good idea to think carefully about how your name and image might be used in any personal fundraisers or updates at school, college or work. Think about what you are comfortable with. Remember, this information will remain searchable online in the future.

While social media can help you to stay in touch with your friends and family, at other times, it may not make you feel good. You may need to take a break from it.

Partners

Your relationship with your partner can change when you are dealing with cancer. Some couples find that going through something like this together strengthens their relationship and reinforces their closeness and commitment to each other.

But living with cancer places an enormous amount of pressure on everyone. Young people do not expect their partners to face a life-threatening illness. Like you, your partner is probably feeling scared, sad, worried, angry, overwhelmed and confused.

They might even struggle more than you do. They will want to make things better for you and might feel helpless and frustrated when they can't make it all go away.

With all the stress of what's happening, you might not be communicating as well as you used to. Sometimes when you are close to someone, you expect that they should be able to read your mind and know what you want. You might feel upset or angry if your partner doesn't know the best way to handle things.

Your relationship might change in different ways or it may not last. You may find that you have different priorities. Keep in mind that everyone responds to stress in a personal and sometimes unpredictable way.

Things that might happen:

- Your partner seems to be getting distant or is avoiding talking about your diagnosis. Some people cope by blocking out situations that are too painful to think about. This can hurt.
- Your partner may overwhelm you by trying to protect you and not let you do anything for yourself. This can leave you feeling frustrated or helpless.
- Your partner might not feel like they can handle the situation and give you what you need right now so you may find yourself alone.
- Your attitude towards things and your outlook on life changes because of your experience and this affects your relationship.
- You and your partner's feelings and attitudes about your diagnosis may not be in sync. One of you might feel hopeful while the other feels more pessimistic. This can make it hard for you to make decisions together about your treatment.
- You worry about how your partner will react to body changes such as scars, any sexual problems and potentially a loss of fertility. You may become shy or withdrawn.
- You feel guilty for burdening your partner with your illness or worry that they are just staying with you because they feel sorry for you.
- You feel that you just don't have the energy to put into a relationship as well as dealing with cancer treatment.

Whatever happens, it's important to remember that it's not your fault that you have cancer. Also, try to keep in mind that your partner has a choice to be there with you. If they are offering to look after you, then let them. You have enough to worry about. If you have any doubts about how your partner is feeling about your relationship, talk to them about it. In any relationship, you need to be open and honest.

Sharing is caring

Hiding emotions creates distance between partners. It is normal that you and your partner won't always feel the same way. Talk about your differences and respect each other's feelings without criticism or blame.

These tips can help:

- Try to still talk about everyday things. You don't always have to talk about cancer.
- Do something special for each other and plan time to be together.
- Find ways to get your partner involved because they may be feeling helpless.
- Laugh and cry together.
- Try to do things you used to enjoy as a couple, such as going to the movies. These activities might look different but use these times to remember what brought you together in the first place.
- If you are really struggling to communicate, couples counselling may help.

Starting new relationships

Dating and starting new relationships can be hard enough at the best of times. After a cancer diagnosis, it may seem almost impossible.

You may be feeling sick, exhausted and self-conscious about changes in your physical appearance. Going out and meeting new people can seem daunting.

But finding an opportunity to socialise and meet new people may boost your self-confidence and help you to feel like things are 'normal'.

You may like to try a new fitness class, book club, art class or join a dating or friendship app. These activities might help you to become more comfortable around new people, especially if you have physical signs of cancer, such as hair loss.

When to tell a new partner

At some point after your diagnosis, you may begin a new relationship. You may feel unsure about how and when to tell your new partner about your cancer. This may depend on whether you are just casually dating or getting more serious.

There is no right time to tell – it is really down to when you feel comfortable enough to talk about it. You may be happy to do this on a first date or much later on. Some people may want to move quickly in a relationship because they don't want to feel like they are wasting time after their diagnosis. Others will be happy to take it much slower. You might consider if the roles were reversed, when would you want to be told?

You may feel that you have to bring it up if there are visible signs of your illness, such as hair loss. But it is up to you how much information you give. You might just mention you have/had cancer early on and then go into more details at a later date. You may not be ready yet to talk at length about your cancer and that is OK.

You will probably be very nervous - it can be difficult to tell people that you've had cancer. It can also be difficult to tell people that you have had part of your body removed, like a breast or testicle. Deciding when to tell a new partner about your experience is a personal choice.

Here are some tips:

- You may want to wait until you think the relationship could become serious before sharing the information.
- Pick a time to talk to your partner when you are both relaxed.
- Try practising what to say beforehand.
- You could tell them about any physical changes, and show them, before any sexual activity. This will allow you both to get used to how that makes you feel.
- Be honest about your concerns and encourage your new partner to be honest about theirs.

Dealing with rejection

It is impossible to say how your partner or someone you are dating might react to the news. They may be very understanding and recognise that cancer is just one of your many life experiences.

If they are not as supportive as you would have liked, or appear to be struggling with the news, give them time to adjust. They may just need a little time to come to terms with the situation. If they really care about you, they should be able to recognise that cancer is just one part of your life.

Unfortunately, it may happen that a person does not want to be with you if they know you have/had cancer. They may feel they can't deal with it for a number of reasons. They may have no experience of cancer and feel this is just too much for them or they may have experienced a loved one's cancer diagnosis before and not want to go through it again. While this may hurt, there are supports available:

- Speak to family and/or friends about your relationship concerns
- Consider professional counselling. The Irish Cancer Society funds professional counselling, which can be done remotely (video or telephone calls) or in-person. Call 1800 200 700 for more information
- Speak to a counsellor or psychotherapist who specialises in relationships and/or sex-related issues. The Irish Association for Counselling and Psychotherapy (IACP) represents over 5,000 counsellors and psychotherapists around the country. You can find a counsellor or psychotherapist in your area on **www.iacp.ie**. There are fees involved
- Join in-person or online support groups. Sharing your story with people who have been through similar situations may help

- Try focusing on your social life if this is something you haven't been giving much attention to. You might reconnect with old friends or make new friends by, for example, taking up a new hobby
- Speak to the medical social worker in your hospital who may be able to direct you to support services in your area

Remember, lots of people return to the dating scene and find loving relationships after being diagnosed with cancer.

If you are single

Single people with cancer may have additional worries and concerns when dealing with a diagnosis of cancer. You may worry that you will not be able to find a partner in the future, especially if your sexual functioning or fertility has been impacted. Cancer may have come at a time when you would have normally been socialising and dating, such as during your college years. As a result, you may be particularly nervous about trying to navigate the dating scene.

When is the right time to start dating?

This is very much a personal choice. You may want to start dating as soon as possible as you don't want to 'waste time' after your diagnosis. You may also want to do 'normal' things that don't involve cancer.

Or you may be much more hesitant about dating. You may have little or no experience with sex and/or relationships. Or you may be dealing with the side-effects of treatment, which may make it difficult to be yourself on a date. You may have less energy or your appearance may have changed, impacting your self-esteem and confidence.

Some people may wait until their treatment is over and they have had a chance to recover, while others will try dating while having treatment. There is no right or wrong time. It is a personal decision.

How to share your cancer experience if you are dating

At some point during or after your diagnosis, you may begin dating or a new relationship. You may feel unsure about how and when to tell the person you are seeing about your cancer.

There is no right time to tell – it is really down to when you feel comfortable enough to talk about it. You may be happy to do this on a first date or much later on. Some people may want to move quickly in a relationship because they don't want to feel like they are wasting time after their diagnosis. Others will be happy to take it much slower. You might consider if the roles were reversed, when would you want to be told?

You may feel that you have to bring it up if there are visible signs of your illness, such as hair loss. But it is up to you how much information you give. You might just mention you have/had cancer early on and then go into more details at a later date. You may not be ready yet to talk at length about your cancer and that is OK.

You may be very nervous about sharing this news, so practising what you want to say or roleplaying the conversation with a friend might help. Choose a time to talk when both you and the person you are dating feel relaxed.

Give them the chance to respond. For example, after you tell them that you have/had cancer, ask them how they think that might affect the relationship or ask how them how they feel about it.

How will my date react?

It is impossible to say how the person you are dating might react to the news that you have/had cancer. They may be very understanding and recognise that cancer is just one of your many life experiences.

They may have many questions for you, so be prepared for this. You don't have to answer everything straight away, or you may not be able to answer all of their questions. It is OK if you want to give them the news first and then go into more details later.

If they are not as supportive as you would have liked, or appear to be struggling with the news, give them time to adjust. They may just need a little time to come to terms with the situation. If they really care about you, they should be able to recognise that cancer is just one part of your life.

Unfortunately, it may happen that a person does not want to be with you if they know you have/had cancer. They may feel they can't deal with it for a number of reasons. They may have no experience of cancer and feel this is just too much for them or they may have experienced a loved one's cancer diagnosis before and not want to go through it again. While this may hurt, there are supports available:

- Speak to family and/or friends about your relationship concerns
- Consider professional counselling. The Irish Cancer Society funds professional counselling, which can be done remotely (video or telephone calls) or in-person. Call 1800 200 700 for more information
- Speak to a counsellor or psychotherapist who specialises in relationships and/or sex-related issues. The Irish Association for Counselling and Psychotherapy (IACP) represents over 5,000 counsellors and psychotherapists around the country. You can find a

counsellor or psychotherapist in your area on **www.iacp.ie**. There are fees involved

- Join in-person or online support groups. Sharing your story with people who have been through similar situations may help
- Try focusing on your social life if this is something you haven't been giving much attention to. You might reconnect with old friends or make new friends by, for example, taking up a new hobby
- Speak to the medical social worker in your hospital who may be able to direct you to support services in your area

Remember, lots of people return to the dating scene and have a satisfying sex life after being diagnosed with cancer

Chapter 13

Dealing with changes to your body

At some point during your treatment, you might look in the mirror and think “who is that person?”

Everyone experiences confidence and body image issues at some time in their life, particularly as teenagers and young adults. But cancer can make things feel even worse. Cancer and its treatment can change how your body looks, feels and works.

Whether it’s changes to weight, loss of hair or scarring, your body may begin to look and feel like a foreign object that’s not even connected to you. You may be uncomfortable about your appearance and about looking different.

It is hard not to be affected by these changes. How you look is often tied up with how you feel about yourself. But many people find that with time, your appearance and feelings about your body will change. It may take time to get used to but it will become easier.

Dealing with unwanted changes to your looks can be really hard. But remember, underneath all of the changes, you are still you.

You might feel:

- Loss of confidence and self-esteem. You might be self-conscious of any physical changes and avoid doing things you used to enjoy like going to the beach, playing sport and wearing certain clothes.
- You may feel shy or withdrawn. You may not feel like hanging out with friends or going out in public.
- You may feel frustrated that your body doesn't work like it used to.
- You may feel angry. It is not fair that you have to go through this and that you have no control over the changes to your body.
- You may feel nervous that you will be laughed at or stared at.
- You may feel embarrassed or ashamed about the way you look now.
- You may experience grief over the loss of your 'old' body.
- You may feel scared that your friends, partners and workmates will treat you differently.
- You may feel worried about being less attractive and not being able to hook up with someone in the future.

> **When I was diagnosed, I had waist-length hair, so losing it had a massive impact on how I saw myself. It was also pretty daunting to have strangers ask why I'd shaved my head or even just stare at me in public. At first I wore hats and beanies and tried on a wig, which wasn't for me, but eventually I found my confidence in wearing bandanas and even learnt to embrace my baldness.**
>
> Marnie, 25

It doesn't make you vain or selfish to be worried about your body and how people see you.

Things that may help you cope with changes to your appearance include:

- Have a makeover. Experiment with a new look. A new wig or hat, some make-up or some clothes. Try this even if you don't feel like it.
- Talk about it. Your family and friends may not realise how much the change to your appearance is worrying you. People will understand.
- Try to treat your body with respect. It's been through hell and back already. Eat healthy foods, get enough sleep and try to get as much exercise as your body can handle.
- Hang out with people who make you feel good and accept you for the way you are.
- It may sound like a cliché but try to remember that you are still the same person and that your personality, interests and talents are still there. The cancer is not who you are.

> **I didn't lose my hair, but the surgeons needed to shave some of my hair. My hairdresser, whom I have known since I was a baby, offered to style my hair to help with my confidence with my scar, which I now always like to show off.**
>
> Amy, 25

> **When I lost my hair, I would find nice, fun studs and dangly earrings to make me look fun and different and not hide away my personality.**
>
> Lena, 24

After treatment – late effects

Late effects are side-effects that you may experience months or even years after your cancer treatment has finished. They do not mean that cancer has returned.

Not everyone who has cancer treatment will suffer from long-term or late effects. Even people who had the same type of treatment won't always suffer the same side-effects.

The potential effects depend on many different factors, including what kind of cancer you had, where it was in your body, how it was treated and how old you were. Late effects can affect any part of the body and include:

- Lung, heart, kidney or liver problems
- Developing another type of cancer
- Cataracts (clouding of the lens in the eye which can cause difficulty with vision)

- Fertility problems
- Bowel problems
- Thyroid problems
- Tooth decay
- Changes in bone density, which can lead to osteoporosis
- Memory and concentration problems

Managing late effects

Late effects may be hard to cope with, especially after dealing with all the tough stuff that cancer and its treatment has already thrown at you. It might seem like you will never escape from it. These tips might help:

- After finishing treatment, keep a detailed record of your diagnosis, treatments and ongoing plan of care. This will provide doctors you see in the future with a good knowledge of the type of cancer and treatment you received.
- Keep your follow-up appointments. Tell your doctor about any symptoms you have. It is always best to have them checked rather than to worry.
- Ask your healthcare team if you are at risk of developing late effects and what signs to look out for.

We aren't certain if we can prevent late effects, but it may still help to stay as healthy as you can. This includes protecting yourself in the sun, avoiding smoking and vaping, and exercising regularly.

For those old enough to drink alcohol (18+ years), if you're trying to feel as well as possible, physically and emotionally, it's best to avoid alcohol, or at least stay within the low-risk guidelines. According to the HSE, women should drink no more than 11 standard drinks in one week, while for men, it's no more than 17 standard drinks per week. A standard drink is a half pint of lager, a 100ml glass of wine or a pub measure of spirits. People are advised to have at least 2 alcohol-free days per week.

More information is available on the 'Managing side-effects after treatment' page on **www.cancer.ie**

If cancer returns

Living with the worry that cancer will return can be one of the hardest things to deal with. Although doctors will give you the very best treatment, there is a chance the cancer will come back. It is important to get as much information as possible and talk over your particular case with your medical team.

If your cancer returns, it may be because the first treatment didn't completely destroy all cancer cells. This doesn't mean that the treatment you received was wrong or that you have done anything wrong. It simply means that a small number of cancer cells survived the treatment. When cancer returns, it is known as recurrence.

It is possible to develop a new cancer that has nothing to do with your original cancer, but this doesn't happen very often.

When cancer comes back, it can return in the same place or near to the site of the original cancer. Or it can spread to another part of the body. This is known as secondary cancer or metastasis.

For more information, search 'Recurrence' on **www.cancer.ie**

How will I feel?

If the cancer does come back, it can feel like the end of the world. Your emotions may be intense and overwhelming. It might feel like all the treatment and side-effects you have been through have been for nothing. It can be especially challenging if you have been in remission for a long time. Remission means there are no more signs or symptoms of cancer in your body. There might still be some cancer cells in your body, but the number is so low that tests can't detect them. Or there may be too few cells to cause any symptoms.

It is not uncommon to wonder why this is happening to you. This is really unfair when you have been through so much already.

You may have many of the same emotions that you had when you were first diagnosed. These emotions may be more intense this time. But you have something now that you didn't have before – experience.

> **I still fear recurrence even after 3 years. There may be health scares in the future but knowing that you got through it once, you will be able to get through it again. I try to think of those thoughts as bubbles in my head and will pop them once they come into my mind. It can be hard to not dwell on these thoughts, but I encourage you to talk to someone about them, if these bubbles fill your head constantly.**
>
> Daniel, 24

Treatment decisions

Things may have changed since you were first diagnosed. Cancer researchers are constantly developing new treatments and ways to manage side-effects.

The treatment you are offered will depend on the type of cancer you have, where it is in your body and what treatment you had before.

Just like when you were first diagnosed, your medical team will talk you through your options.

Like all the other phases you have been through with cancer, getting the right information and the right support is really important. Ask people to be honest with you about what is happening.

Things to consider when making decisions about what treatment to have include:

- What impact will it have on your quality of life?
- What side-effects – both long- and short-term – can you expect?
- What are you prepared to go through again?
- Your prognosis. This is information about how your cancer is likely to progress. This includes average survival times or life expectancy.

Other people, such as your parents or partner, may have a big influence over your treatment decisions. There needs to be lots of open communication and negotiation, particularly if you and your loved ones have different ideas. It is important that you feel OK with your treatment decisions.

Chapter 14

Taking care of yourself

> **Even though cancer can make you feel sick, staying as healthy as you can will help your body to recover from treatment, giving you the best chance of coping with it all.**

Eating well

There will be times during your treatment when food is not exactly your best friend. But if you have cancer, your diet during and after treatment is very important. The goal is to maintain your weight. This will help you to keep up your energy and strength, tolerate your treatment better and recover faster. Some people may need to eat differently during or after treatment to get the right nutrients and to keep a healthy body weight.

Speak to the hospital dietitian. Dietitians are experts on food and nutrition. They are trained to give advice on diet during illness and how to use diet to help symptoms.

You can find more information on **www.cancer.ie**. Search for 'Diet advice for cancer patients'. The Irish Cancer Society also has a booklet, ***Understanding diet and cancer***, which can be downloaded from **www.cancer.ie** or call 1800 200 700 to order a free copy.

Physical activity

Getting out of bed or off the sofa may be a massive achievement when you are dealing with the physical effects of treatment. Exercise is probably the last thing you feel like doing. But physical activity is good for your body and your mind.

Exercise can help to:

- Heal your tissues and organs that have been damaged by treatment
- Give you more energy
- Ensure a better night's sleep
- Manage your weight better, especially if you are on steroids
- Keep your bones strong. Some treatments can reduce your bone density, making them more likely to break
- Improve your mood and cope with the stress of cancer and its treatment
- Feel better about yourself

According to guidelines from the HSE, adults over the age of 18 are recommended to get:

At least 2 hours and 30 minutes of **moderate intensity** aerobic physical activity each week

Or

At least 1 hour and 15 minutes of **vigorous intensity** physical activity each week.

Those aged 16 and 17 are recommended to get 60 minutes of moderate-to-vigorous activity per day.

Moderate intensity activities include brisk walking and cycling. Moderate intensity should cause you to breathe harder than usual but you should still be able to talk.

Vigorous intensity activities include running and playing a team sport such as Gaelic football or basketball. Vigorous intensity should see you unable to say more than a few words without having to stop to take a breath.

You are also advised to reduce sedentary activities, such as watching TV, looking at your phone or computer for long periods and driving for prolonged periods.

Talk to your doctor about becoming more physically active. These guidelines are for the general population and may not be suitable for you, depending on your cancer and treatment. Your doctor can advise you on what is safe and suitable for you and may be able to recommend a special exercise programme for people who have had cancer treatment.

Avoiding infection

Some cancer treatments, such as chemotherapy, can weaken your immune system and increase your risk of infections. A simple infection can quickly become serious when your immunity is low.

To reduce your chances of getting an infection you should:

- Stay away from people who are sick, even if they just have a cold
- Ask friends and relatives to tell you if they are sick or have been in contact with someone who is
- Wash your hands often and well
- Make sure your food has been washed and cooked properly
- Use sterile procedures when you clean your central lines

Avoiding infections

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

Getting enough sleep

Even though you may feel very tired a lot of the time, many people with cancer find it hard to sleep. You may toss and turn due to stress and worry. Pain, fevers, coughing, nausea and treatment drugs might also affect your sleep. It often doesn't help if you are in hospital and away from your own bed.

Not getting enough sleep can affect your mood and ability to concentrate and can make the stress of cancer even harder to deal with.

According to the Department of Health, people generally need between 5 and 9 hours of sleep a night. The ideal amount is around 8 hours but this can be different for everyone. If you are not sleeping well, here are some things you can try:

- Have a regular routine at bedtime. For example, do a few gentle breathing exercises first. Avoid screens for 1-2 hours before bed.
- Go to bed and get up at the same time every day.
- Have a warm milky drink before bed. Avoid coffee or tea as these are stimulants and may keep you awake.
- Have a warm bath with a few drops of lavender or geranium oil to soothe you or sprinkle a couple of drops of lavender oil on your pillow.
- Keep your bedroom quiet, dark and at a comfortable temperature – not too hot and not too cold.
- If you can't sleep, or wake up early, do something. Get up and read or listen to quiet music. Wait until you feel tired again and then go back to bed.
- Listen to relaxation tapes, audiobooks or podcasts to help you get back to sleep.
- Don't nap during the day if it affects your sleep at night. If naps help, try to keep them to less than an hour and have them earlier in the day.
- Get some exercise every day, if you can.

Drugs and alcohol

Drugs and alcohol don't mix well with cancer. To give your body the best chance to deal with your illness, it is important to be honest with your medical treatment team about what drugs you may be using or have used in the past. This includes illegal drugs (like cannabis, cocaine or ecstasy) and legal drugs (like alcohol, cigarettes and e-cigarettes).

Cancer and its treatment messes with your body. Your energy levels will be down and you may struggle to fight off infections. Drugs and alcohol will only make this harder. They can:

- Interfere with chemotherapy, radiotherapy or other treatments
- Increase the impact of side-effects
- Increase your chances of getting things like chest infections and other respiratory (breathing) problems
- Result in other infections, especially if you are injecting or sharing needles
- Affect your mood and behaviour, making it harder to deal with the physical and emotional challenges of cancer.

If you are still using drugs, it is important to do so safely and carefully. More information on drug use and supports for drug users can be found on the HSE website: **www.drugs.ie**

Sex and cancer

The age of consent in Ireland is 17 years. If you are old enough to have sex, you might wonder whether cancer will affect your ability to have sex. The good news is that unless your doctor tells you otherwise, it is okay to have sex while having treatment. But you need to practise safe sex - use STI (sexually transmitted infection) prevention methods and contraception during any sexual activity.

The bad news is that you may not have much energy or interest in sex for many months or even longer. You may feel unattractive or worry that you will never be able to be sexually active. The main thing to remember is that this will pass.

Chapter 15

Practical and legal stuff

School

Bet you never imagined that you would miss studying? School may take up a big chunk of your life and it can be scary thinking about what will happen to your studies while you are having treatment.

Many young people who have been through cancer treatment feel it's important to go back to school as soon as possible. But if you have been away for a long time, it's normal to feel nervous as well as excited about going back to school.

You may feel self-conscious about the changes in your life and how you look and unsure how others will deal with them. You may also be worried about catching up on the work you have missed, or maybe even having to repeat and being a year behind your friends.

Before you return:

- Ask your parent(s) to visit or call your school to let them know what to expect and what they can do to help.
- Your teachers might be able to tell everyone at the same time about what's going on. This means that everyone knows and won't be so shocked on your first day back.
- Get some work sent home to you or to the hospital. This might make you feel a bit more prepared before heading back.
- Find out if there is someone from the hospital who can visit your school to teach the teachers and students about cancer.

Friends at school

Be prepared – people at school might act a bit weird around you at first. People often avoid things they don't understand or are uncomfortable with. You can stop them whispering about you behind your back by telling them upfront what's going on and letting them know that it's OK to ask questions. However, it is entirely up to you who you tell and what you tell them. If you do not want to talk to people about your illness, that is your choice.

On the first day, it might help to have a friend meet you at school to walk in with you so that you have support.

Be prepared for comments and don't be shocked if you hear something dumb being said. People may even tease you but this is often because they are confused and don't know how to react. Avoid the temptation to tease back. Try to remember that it isn't your fault that someone is teasing you – they are responsible for what they do.

If this teasing becomes too much, it is important to tell a parent or teacher. If you are struggling with how you're being treated at school, it can help to talk to your tutor, year head, guidance counsellor or another trusted teacher.

Barretstown runs a School Education Programme, which aims to encourage young people to be supportive of their classmate with cancer in school. This reduces the likelihood of bullying, exclusion, confusion and anxiety. This free programme is available in secondary schools nationwide. Referral can come from the hospital, medical social worker, teacher or parent. For more information, email outreach@barretstown.org

Keeping up

Even if you have gone back to school, you may still miss out on a lot of classes because you need to go to appointments or have treatment.

You may also still get really tired and not feel 100%. This can make it hard to keep up.

You could:

- Ask a friend to share notes with you if you miss a class
- Get the teacher to email any work or assignments that you have missed, or they could send the work home to you with a friend or a sibling
- Work with your teacher to figure out what is a priority and then focus on that. This may be easier than trying to get it all done
- See if online classes are an option if you are missing a lot of classes due to treatment

If you are still in secondary school and are in hospital, Children's Health Ireland (CHI) runs schools in its 3 hospitals in Crumlin, Temple Street and Tallaght. This is for children right up to Leaving Cert age. Your hospital can provide more information about this.

Marks

You might feel ready to jump right back into school and make up for lost time. But don't be surprised if it is not as easy as that and your marks aren't what they used to be.

This might be because you were away a lot or because some of your treatment has made it harder to concentrate, understand or remember new information ('chemo brain'). You might feel like you have to work harder just to keep up. Or maybe your goals have changed.

Your health and getting better is the most important thing at this time. You and your teachers and parents might have to adjust your expectations for now.

Leaving Cert

When it comes to Leaving Certificate exams and applying for third level education (college), you may be eligible for extra supports, such as:

- **Reasonable Accommodations at Certificate Examinations (RACE):** This scheme is aimed at students with disabilities, such as a hearing impairment, mobility issues or learning difficulties, who are doing the Junior Cycle or Leaving Certificate. This may apply to you if your cancer or cancer treatment has left you with a disability. Reasonable accommodations can include taking your exam in a hospital bed or having a scribe (someone else to do the writing) during an examination. Applications for reasonable accommodations are made through your school to the State Examinations Commission (SEC).
- **Disability Access Route to Education (DARE):** This is an alternative admissions route to third level for students whose disability or ongoing illness has had a negative impact on their education in secondary school. DARE offers reduced points places to school leavers who have experienced additional challenges in secondary school as a result of their disability or ongoing illness. Childhood, adolescent and young adult cancer has been included in the scheme since 2023. For more information, visit **www.accesscollege.ie/dare/**

Third level

Your treatment and the side-effects of cancer may impact on your decision to enrol in, or continue with, further study at college. It might also affect your choice of course and method of study.

You might be worried about:

- Causing more stress to your body
- Not being able to meet the requirements of the assessments or falling behind
- The uncertainty of your health and being unable to predict how you will feel mentally or physically in the future
- Fitting in or receiving unwanted attention
- Lack of physical access, such as wheelchair access
- Not being able to complete particular types of exams, assessments, practical work or attend field trips

If you are concerned about face-to-face learning, distance learning might be an option for you. This means you could take courses online and study in your own time.

There are also support services on college campuses that can help you to make adjustments and cope.

Access and inclusion

If you're returning to study, there are often systems at college to help you adjust and make learning more accessible. You should speak to student services about this.

Accommodations might include:

- Extra time for exams
- Access to lecture notes before class
- Use of equipment and assistive technology
- Help with parking and physical access

Student services

Most campuses have a student services centre that provides support services such as:

- Counselling
- Financial assistance
- Tutoring
- Career advice
- Health services, housing services and childcare
- Employment services

> ”
>
> **I was able to continue studying part time while receiving treatment. My advice is to take the time you need and tell the relevant people at the university about your diagnosis. There are many support services and ways to make adjustments to your study/assessments.**
>
> Luke, 23

Work

Work is an important part of life and not just for money. Returning to work can help you to regain your confidence and independence and bring back a 'normal' routine that gives you something to focus on other than cancer.

But getting back to work can be hard. Giving yourself some time to prepare can help.

Going back to work

It is up to you to decide when you are ready to go back to work (and to talk about this decision with your medical team and your boss).

Before you return, here are some things you may want to consider:

- There is no legal obligation on you to disclose the nature of your illness to your employer. However, you are encouraged to tell them so that you can receive any necessary supports that you may need, such as more flexible working hours or assistive technology.
- Know your limits. Don't try to do too much too soon. Take regular breaks. You might need to change the type of tasks you're doing or the length of your shifts. You may have to work from home where possible. You might still be dealing with side-effects such as fatigue and changes to your concentration, so be kind to yourself.

- If it's relevant to your work roster, tell your boss about any follow-up appointments, scans and treatments ahead of time (including if you'll need rest days or travel time before or after these).
- Adjust your daily routine if possible, so you are doing certain tasks at times you feel the best. For example, you may have the most energy in the morning so this may be a better time to focus on certain work assignments.
- Decide how much and what you want to tell your workmates about having cancer. You are in control of this. You may only wish to tell your boss and/or direct supervisor, and even then, you may only want them to know limited details. It's up to you and what you feel comfortable with.

Getting a new job

Looking for a new job can be daunting for anyone. Add cancer into the mix and it might seem overwhelming.

Whether you're looking for your first job or have been inspired to make a change, you have many options and possibilities. Take your time to think about what is right for you.

If you are qualified for a job and physically able to do the work, your medical history should not affect your ability to get a job.

These tips may help:

- An employer cannot refuse to hire you because of your medical history.
- You are not legally obliged to tell a future employer about your diagnosis. It is a personal decision to tell or not.
- An employer must keep any information about your medical history confidential.
- An employer is allowed to ask you in an interview about your ability to perform tasks related to the job.

> **I got back into life as an adult via volunteering. Flash forward to current times, I landed myself a full-time position at a childcare centre.**
>
> Jenny, 24

- You may find it helpful to provide a potential employer with a letter from your doctor that explains your health status and ability to work.
- If you are worried about how to explain gaps in your CV because of treatment, think about organising it by experience and skills instead of date.
- A life or career coach can give you advice and help with CV writing and interview skills.

Life coaching

The Irish Cancer Society offers a targeted coaching programme for young adults (18–24 years) affected by cancer. We provide a dedicated programme of 6 one-to-one coaching sessions with an accredited coach. Topics covered include moving forward from diagnosis and treatment, setting new goals and building up your confidence. For more information, see page 216 or contact our Support Line on 1800 200 700.

Legal stuff

As a young adult or someone about to become a young adult, there are a number of legal topics that may be important to you at this time.

Age of consent (medical treatment)

If you are 18 years or older, you will have to sign a consent form to give your medical team permission to treat you.

If you are under 18, your family is mainly responsible for your care and protection. However, under Irish law, a person aged 16 and older can also give consent to surgical and medical treatments and it is not necessary to obtain consent for treatment from their parents/guardians. In other words, 16- and 17-year-olds have the same rights around consent to treatment as adults aged 18 and older.

This includes any procedure that is done for the purposes of diagnosis, such as a biopsy, and any procedure that is needed as part of a treatment, such as being given an anaesthetic.

Making a will

A will is a document that states what you want to happen to your money, possessions and children, if you have any, after you die. You can make a will from the age of 18. Every person over 18 should make a will, not just people who have cancer. You will have to get legal advice to do this.

If you are under 18, you cannot make a legal will. But you could still write down what you want to happen to all your stuff and ask your parents, friends or partner to keep it for you.

Disability discrimination

A disability is any physical, mental, cognitive or developmental condition that affects a person's ability to engage in certain actions or carry out normal daily activities or interactions. In other words, a disability makes it more difficult for the person to do certain activities and interact with the world around them.

Discrimination on the grounds of disability means being treated less favourably than someone who does not have a disability, or who does not have the same disability as you.

It might include:

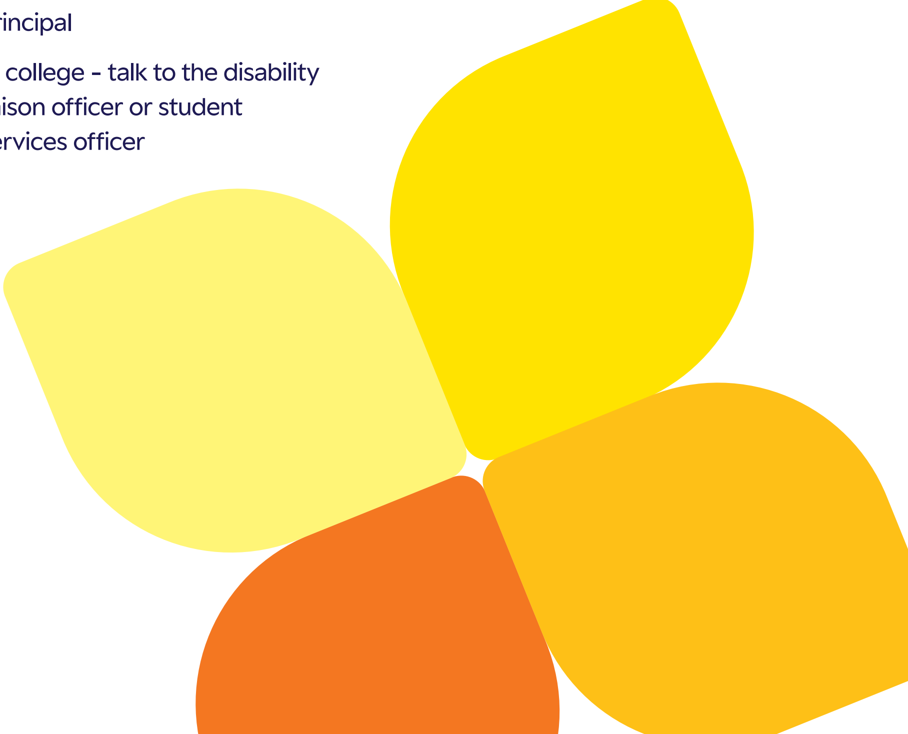
- Not being offered a job or being fired from your job
- Being treated unfairly at work
- Not being able to enrol in third level education
- Not being offered the same opportunities or choices as other people in your class or course

- Being unable to access public buildings such as libraries, hospitals and government offices
- Not being able to rent a house or room.

It is against the law for someone to treat you differently or unfairly because you've been diagnosed with cancer.

If you think you are being treated unfairly because of your condition, it is important that you bring it up:

- At school – talk to your tutor, year head, school counsellor or principal
- At college - talk to the disability liaison officer or student services officer
- At work – talk to your manager or HR. If they refuse to take the matter further, you can seek further advice from the Irish Human Rights and Equality Commission (IHREC). The IHREC's 'Your Rights Service' can only provide you with information. It cannot provide legal advice or comment on any individual case. If you think you need legal advice, you should talk to a solicitor. For more on the Your Rights Service, visit: **www.ihrec.ie/your-rights/**



Planning travel

You may worry that cancer will affect your ability to travel in the future. The good news is that you can still travel, it just may require more preparation than before. Things you may need to consider include:

Vaccinations

Depending on the type of cancer and treatments you've had, you might not be able to get the vaccinations you need to travel to some parts of the world. Check with your medical team.

Travelling with medications

If you are still taking medicines when you travel, it is important to make sure you have enough supplies to last the whole trip. You should also take extras just in case.

Some countries limit the amount of particular drugs that can be brought into that country. You need to check what rules apply to taking certain medications, such as prescribed drugs, out of Ireland and into the country you are visiting. For example, you may have to have a letter from your doctor or the original prescription.

You can check the rules of the country you are travelling to by contacting the Irish embassy in that country. Visit:
www.ireland.ie/en/dfa/embassies/

Useful information is also available from the International Narcotics Control Board. Visit:
www.incb.org/incb/en/travellers/

If you have to get drugs from a pharmacy in the country you are visiting, please note, your prescription is subject to the rules of the country where you are getting the medicine. For example, in some countries a prescription may only be accepted in the pharmacy for a certain period of time after it is written. You should also be aware that some medicines may not be authorised for sale or may not be available in the country you are visiting.

Medical records

It is a good idea to take printed and digital copies of medical files, in case you need to access treatment while you are away. A trusted family member can also hold a copy of these documents so they can email them to you if needed.

Flying

Unfortunately, there are some situations where you may not be able to fly because of oxygen levels and air pressure changes at certain altitudes.

You may have to wait to fly or find a place to go by car or train if you are breathless, anaemic, have had recent surgery or have a brain tumour and there is a chance of swelling in the brain. Check with your medical team if you are planning a trip that involves flying.

Travel insurance

Getting travel insurance when you've had cancer can be more difficult because you're more of a risk to the insurance company. They assume that you are more likely to:

- Get sick and need treatment while you're away
- Need to come home for treatment
- Cancel your trip because you fall ill before going

This doesn't mean you can't get insurance, but it might mean you have to shop around and/or it will be more expensive.

Generally, it's easier to get cover if you have finished your treatment and are cancer-free. But some insurance companies won't cover you until you've been free of cancer for a set period, or they may charge you a lot more if your treatment ended recently.

Sometimes an insurance company may cover you for medical expenses **apart from** any treatment or care related to your cancer. In this case, you would have to pay any cancer-related treatment costs yourself.

Make sure to read the fine print of your travel insurance policy.

For more information on this, search 'Travel insurance' on **www.cancer.ie**

Chapter 16

Beyond cancer

During cancer treatment, you might not have had the time or energy to think about much more than surviving. But when your treatment finally ends, what do you do now?

No matter how much you have been looking forward to returning to life after cancer treatment, it can still be weird, difficult and scary to leave the support of your healthcare team.

As you end active treatment, life can feel both exciting and confusing.

Figuring out what to do after cancer treatment is one of the hardest things to do. It's important that you give yourself time to adjust.

You may be affected by long-term impacts of cancer including:

- Health impacts, such as infertility
- Low self-esteem about the physical reminders of cancer treatment, such as scars
- Health anxiety, including fears that the cancer may come back
- Feeling that you are playing catch-up with your friends in terms of your education, career and romantic relationships
- Pressure to feel grateful that you ‘beat’ cancer while feeling that you have missed out on so much

> **However your ‘new normal’ feels, remember, it is totally normal. Cancer is a life-changing experience, but it never has to be your whole story.**
>
> Ezra, 21

Redefining your life plans

You and the people around you have faced a serious or life-threatening illness and overcome massive challenges.

When treatment ends, it might be a good time to redefine life rather than reconstruct it. Take some time to ease yourself back in and reflect on whether you want things to look the same as they did before.

Before you had cancer, you may have been working out what you wanted to do with your life and making plans for the future. During treatment, it might have felt like your life was put on hold. You may have missed a lot of school time or lost momentum in your study, training or career.

Now that treatment has ended, you may find that you can revisit and achieve some of your plans and goals, but others may need a rethink.

- Cancer may have left you with changes to your body, energy levels or emotional state that will prevent you from pursuing a particular job or fulfilling certain ambitions. This can be disappointing and upsetting and it may take some time to adjust.
- You may have changed your mind about the job or career you want. Sometimes survivors find that their cancer experience inspires them to pursue careers in the health profession or in organisations helping other people who are going through tough times.
- It is also possible that you have no clear idea what you want to do with your life. This is normal too. This is not an easy time of life for many young people. Having cancer may not be the only reason for your uncertainty.

Take some time to look into different options, write down a list of short-term and long-term plans. Talk to your family, friends, spiritual leaders, career advisors or medical social worker. There is no wrong or right way to deal with survivorship – doing what feels right for you is the most important thing.

> **Having had 3 different cancers in 18 years, I’ve mentally become stronger and allowed myself time to adjust to the different changes. There will always be struggles related to cancer in my life, but it’s how I handle those that will allow me to live life the best way possible. You realise how much life is worth when you get that second chance after surviving.**
>
> Lena, 24

What does it all mean?

Cancer is life changing and you may want to think more about the impact it has had on your life. You may want to search for the meaning or greater purpose behind your experience. You want to know and understand why it happened to you and what it means that you have survived.

But everybody is different and there is no 'right' way to feel. You may feel:

- That cancer has given you renewed strength and helped you to appreciate the smaller things in life.
- There is no need to search for deeper meaning in the experience of having cancer. You would rather just accept it and move on. That is OK too.
- Angry and frustrated that you had cancer and the unfairness of it all.
- Nothing!

Your identity

As a young person, you are probably just starting to gain a sense of who you are, how you see yourself and how you want others to see you. All of these things together make up your 'identity'.

Cancer may affect identities in different ways. Your identity may have changed or developed after your diagnosis and treatment, or you may feel confused about it. This might be because:

- Changes in your appearance, body image and sexuality have affected your self-esteem and confidence.
- Your role in your family, group of friends or romantic relationships may be different.
- You feel more mature and stronger than before and you think different things are important now.
- Even if you feel the same on the inside, people may treat you differently. Many young people find that cancer or 'being sick' starts to define their identity.

After cancer, it can take time to figure out a new identity. You might feel lost and confused for a while.

You may wish that everyone would treat you like they did before and not single you out as different. It can help if you spend as much time as possible doing the things you used to do – going to school, college or work, meeting new people, dating and hanging out with people your own age as much as possible.

Uncertainty and worry

It is common to worry that cancer might come back. Although this feeling is normal, it can still be hard to cope with. For some, the fear is so strong that it impacts their ability to enjoy life and make long-term plans.

It can also be exhausting to act as if you are fine all the time. You may have bad days when you feel down, sad and alone. Be kind to yourself and try to accept and work through your feelings rather than ignoring them.

> **I try to stay positive and not think of relapse. If you keep thinking of it, you're not going to live your life. Living my life is better than dwelling on the 'what ifs' of my health.**
>
> Conor, 22

You can speak to a cancer nurse in confidence by calling the Irish Cancer Society's Support Line on 1800 200 700 or emailing supportline@irishcancer.ie. You can also ask the nurses about counselling that is funded by the Society.

Relationships after cancer

Family

Many families expect everything to return to 'normal' when treatment ends. But be prepared – your family may have changed permanently.

Try to be patient with your family as they adjust. It may be hard for them to give you back your independence or to know how to talk about having cancer.

Spend some time experimenting with new routines and finding out what works for the whole family. Continue to work together and find ways to support each other.

Friends

Some friendships may have changed. You may feel closer to some of your friends, but you may feel more disconnected from others. You may feel like you can't relate to them as much anymore. Maybe you feel like you have been forced to grow up faster than them and now feel more mature. Or perhaps you have missed out on a lot of opportunities to hang out with people your age and you feel like your friends have moved on and left you behind.

You may find that you need to rethink and even end some friendships. This may have happened anyway – cancer or no cancer.

As you figure out what is important and interesting to you, give yourself opportunities to meet people who have similar values. You could consider joining a club or a team or connecting with people online.

Over time, you will develop your own unique identity and group of friends. Try to be honest with yourself about what kind of person you want to be and what kind of people you want to be around.

Partners

Dating and exploring your sexuality and sexual orientation is an important part of being a teenager and young adult. Cancer may have affected your confidence, self-esteem and appearance. Some people worry that they are less attractive and will find it difficult to form new relationships. Many wonder whether – and how – they will tell future partners about their cancer, particularly if their fertility has been affected.

If you want to begin a new relationship, consider:

- Getting involved in activities where you can meet people and practise your social skills
- Connecting with other survivors to talk about their experiences with dating
- Talking to your friends, family or counsellor about your emotional and body image concerns

For more information on maintaining relationships, see page 135.

Pressure to 'get over it'

You, your friends, your family or your employer may expect that life should just 'return to normal' now that cancer is gone from your body. You may hear statements such as "it's time to move on". But this isn't how things work.

Even when cancer treatment is over, its effects can remain. You may be processing what has happened to you and what it means for you and your future. If you feel others are pushing you, explain to them that the cancer experience is not over for you and that you need some space and time to cope with it in your own way.

It's OK not to feel totally positive after you finish treatment. The struggle to be positive can be really difficult.

If you feel like you aren't coping, it's OK to ask for help. Some things you may want to try include:

- Taking time to experiment with new routines and to find out what works for you and your family, partner or friends.
- Exploring new opportunities for personal and professional development. You may consider seeing someone like a life coach or career guidance counsellor.
- Acknowledging the emotions that come with survivorship through things like anniversaries of diagnosis or the deaths of other cancer patients.
- Focusing on any positive changes that have improved your life.
- Joining a cancer support group or programme to share your experiences and help other young people living with cancer.
- Acknowledging the amount of change, loss and grief you've experienced because of cancer.
- Focusing on living a healthy lifestyle by caring for and being aware of your body.

LACES education programme

The Irish Cancer Society runs the Life and Cancer – Enhancing Survivorship (LACES) programme for people over the age of 18 who have finished treatment. LACES can help you to adjust, live well and feel your best both physically and emotionally.

Our cancer nurses deliver LACES workshops online and face to face in some of our Daffodil Centres. To join a workshop, email patienteducation@irishcancer.ie

Or you can watch the programme videos on **www.cancer.ie/cancer-information-and-support/patient-education**

Chapter 17

When treatment doesn't work

Sometimes, treatment doesn’t work or stops working.

Being told that the cancer cannot be cured is probably the hardest thing you and your family will ever have to hear.

You have the right to deal with this news in your own way. There is no right or wrong way. It is important to find people you can trust and who will be honest with you. This may be family or friends, but sometimes it may be easier to talk to someone outside the family.

Making the most of life with a terminal illness often depends on how well your symptoms are under control. Palliative care is really important to relieve symptoms and treat any physical, emotional, social or spiritual concerns. If these are under control, you may find it easier to get on with doing what you want to do.

Palliative care

Palliative care is care that is designed to help manage your symptoms and improve your quality of life. It is for anyone with a life-limiting condition. This means a condition, illness or disease which is progressive and cannot be cured. While palliative care includes end-of-life care, your doctor may also recommend it to relieve symptoms earlier in your illness. Palliative care can include things like:

- Treatments such as radiotherapy or chemotherapy to improve symptoms like fatigue and nausea
- Help with keeping active and managing day-to-day life
- Physiotherapy
- Counselling
- Family support
- Spiritual support
- Complementary therapies, such as meditation or aromatherapy
- Advice about practical matters like financial entitlements
- End-of-life care

Palliative care is not designed to control or cure your illness, but rather to give you independence, comfort and support. It is free for all patients – you do not need a medical card or private health insurance.

Getting the right information

Getting the right information is so important. It can help you make decisions that are right for you and also help you to understand what is going to happen.

Questions you have could include:

- Why did this happen?
- How do you know that there are no more treatments to try?
- Can I get a second opinion?
- How long do I have?
- What will it feel like? Will it hurt?
- Will I be aware of what is happening?

There may be lots of other questions and remember, there is no such thing as a stupid question. Asking may be really hard, but not asking might be harder.

Finding people who will be honest in their answers might be tricky too. You can try your doctor, nurses, medical social worker or a family member.

In the advanced stages of cancer, there are usually difficult decisions that need to be made about treatment, such as:

- What sort of treatment you will be given (if any)
- Where you will have treatment
- When to stop treatment
- Whether to treat an infection with antibiotics or whether there should be resuscitation if breathing stops

These are all things that need to be discussed with your medical team and your family and loved ones. It's not easy, but it's important to talk about them and to make sure your medical team and family/partner know what you want. This can prevent more stress for them when decisions need to be made.

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 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 if you are 18 years or older. 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 if you are 18 years or older.
- Talking about what you want to your family, friends, carers and healthcare providers.
- Sorting financial affairs.

Think Ahead is a practical guide for advance care planning and end of life. It includes 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**

Making plans for now

After you have dealt with the initial shock and other intense emotions of finding out that your cancer cannot be cured, you may start to think about a lot of things that you want to do, say, sort out and get in order.

You may want to pack in as much as you can while you can, or you may want to just enjoy the time you have with the people you love.

The important thing is to find ways to communicate what it is that you want.

If you're able to talk openly about how you feel to your family and close friends, they will probably be relieved and able to respond.

You can choose who you want to talk to. You only need to share as much as you want and only when you are ready.

Some things to think about:

- Is there something that you have always wanted to do or see?
- Are there things you want to tell people who are close to you?
- Is there someone you would like to see or meet?
- Are there decisions that you want to make while you are still able to?
- Would you like to leave any letters or instructions for people, such as for special occasions?
- Have you made decisions about treatment at the end of your life? Is your family aware of these wishes?
- Do you want a funeral? What would you like this to look like? For example, would you like a church funeral or a humanist ceremony?
- Have you made a will?

Chapter 18

Support resources

Money matters

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

A diagnosis of cancer often means that you will have extra expenses, such as medication and travel costs when attending appointments. It may be harder for you to deal with your illness if you are worried about money.

Practical and financial advice from the Irish Cancer Society

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

- Understanding your welfare entitlements
- Telling your boss about your diagnosis if required

We can tell you about the 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 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.

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

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

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

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

Benefits and allowances

There are benefits that can help people who are ill and their families. For example, Illness Benefit, Disability Allowance, 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 photocopy completed forms before posting them.

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 217 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

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

- Support Line
- Daffodil Centres
- In-hospital support (for under-18s)
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Life Coaching
- Creative Arts Therapy
- Support in your area
- Transport Service
- Children's Fund (for under-18s)
- Fertility preservation
- Barretstown camps
- Night Nursing
- Publications and website information
- Practical support and financial solution services (see page 209)

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.

The Support Line 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, visit **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 adult 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 the 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 – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

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

In-hospital support (for under-18s)

Our children's cancer nurse is in Children's Health Ireland (CHI) at Crumlin one day a week to provide free, confidential advice, support and information to anyone affected by a child's cancer. She will be around the playrooms, wards and clinic areas. See the in-hospital posters for times and days.

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.

Parent Peer Support is also available for the parents of young people diagnosed with cancer. Parents can speak to a parent of a child who has gone through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone whose child is going through or finished their treatment. This service is also available to other adult family members, like grandparents, aunts and uncles. This programme is in partnership with Childhood Cancer Ireland and CanTeen Ireland.

To be referred to a Peer Support volunteer, call our Support Line on 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. Topics covered include chemotherapy, radiotherapy and immunotherapy.

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

Or you can watch the programme videos on **www.cancer.ie/cancer-information-and-support/patient-education**

Counselling

We fund professional one-to-one counselling for adults 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.

We also work with cancer support centres across the country to help provide services and support for adolescents with a cancer diagnosis. Many centres offer counselling services, creative therapies and practical support for those affected and their families. Telephone and video-call counselling is also available.

For more information on any of these supports, call our Support Line on Freephone 1800 200 700.

Life Coaching

We offer a targeted coaching programme for young adults (18-24 years) affected by cancer. This group faces very specific challenges after a cancer diagnosis and treatment, while they work with moving on with their lives. They face a lot of big life decisions and life stage transitions, such as finishing school, going to college or choosing a career path.

We provide a dedicated programme of 6 one-to-one coaching sessions with an accredited coach to work on these life stages and issues. Topics include moving forward from diagnosis and treatment, setting new goals, redefining your future and building up your confidence. For more information, contact our Support Line on 1800 200 700.

Creative Arts Therapy

Creative Arts Therapy includes art therapy, dance-movement therapy, drama therapy and music therapy. Creative arts therapy is the purposeful and planned use of creative processes with a qualified therapist to support development, emotional expression, social interaction, physical improvements and cognitive goals.

Creative Arts Therapy is available to all children, adolescents and young people (0-24 years) during or after their treatment. Creative arts therapy is also available to siblings of cancer patients. Sessions can take place:

- In-person or online
- One-to-one or in a group
- In your home, or nearby

If you're interested in availing of creative art therapy support sessions, please email creativeartstherapy@irishcancer.ie and one of our team will be in touch.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme (NCCP) to ensure cancer 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**, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Transport Service

We provide patient travel 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 Bons Secours Hospital, Cork.
- We have expanded our Transport Service to bring children, adolescents and young adults travelling from Dublin, Meath, Kildare and Wicklow to CHI at Crumlin for treatment.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite. Travel2Care is made available by the National Cancer Control Programme.

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

Children's Fund

For those under the age of 18, the Irish Cancer Society's Children's Fund offers financial support to the parents of children diagnosed with cancer. This is to help them with the unexpected expenses that a diagnosis brings, such as travel expenses to cancer treatment appointments, heating bills, childcare costs and home help.

This is a one-off grant of €3,000. It is not means tested. To qualify for the Children's Fund, the child:

- Must be under the age of 18
- Must have been diagnosed with cancer and is currently receiving treatment
- Must live permanently in Ireland

More information on this is available from the medical social worker in your child's hospital and on our website, **www.cancer.ie**

Fertility preservation

Sometimes, a young person's cancer treatment can affect their future fertility. The Childhood Cancer Fertility Project is a partnership between the Irish Cancer Society and Merrion Fertility Clinic. It offers free fertility preservation and other services to young people with a cancer diagnosis, including:

- Children who have yet to reach adolescence
- Female survivors of childhood cancers aged between 18 and 27

For more information, speak to your child's medical team who can discuss this further with you, or contact our Support Line on 1800 200 700. You can also read more about the background and aims of the Childhood Cancer Fertility Project on our website, **www.cancer.ie**

Barretstown Camps

Every year the Irish Cancer Society teams up with Barretstown to run a variety of camps specifically designed for children, adolescents and young adults living with cancer. These camps allow young people and their families to come together to enjoy new adventures, create magical moments, make new friends and find support. There are fun surprises around every corner and it's all for free.

- **Child and family camps**
  Enjoy a weekend away for all the family full of activities, adventure, creative play and relaxing family time together. This camp is for children up to 17 years of age and their family members.
- **Young adult camps**
  Young adult camps are for young people aged 18-24 years living with cancer. Spend the weekend in Barretstown meeting other young people who have been affected by cancer.

For more information, visit **www.cancer.ie** or **www.barretstown.org**

Night Nursing

We provide end-of-life care for cancer patients in their own homes. 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 healthcare professional looking after your loved one.

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 Freephone our Support Line on 1800 200 700 or call into your nearest Daffodil Centre for a free copy 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 families, partners and carers, during and after treatment, many of which are free. For example:

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

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

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'.

Chapter 19

Useful organisations and websites

Help and support in the Republic of Ireland

Irish Cancer Society

Tel: 01 231 0500
Support Line Freephone:
1800 200 700
Email: supportline@irishcancer.ie
Website:
www.cancer.ie

Go to www.cancer.ie/local-support for the most up-to-date information on support in your community.

CanTeen Ireland

A nationwide support group for young people aged between 12 and 25 who have or had cancer, and also for their siblings and friends.

Tel: 01 872 2012
Email: info@canteen.ie
www.canteen.ie

Cancer Fund for Children

This is a charity that offers families in the Republic and Northern Ireland free therapeutic short breaks at its centre, Daisy Lodge, in Co Down. Breaks are available to:

- Families with a child or young person (up to age 24) who has been diagnosed with cancer
- Young adults (aged 18-25) who have been diagnosed with cancer

Tel: 01 562 1580
Website:
www.cancerfundforchildren.com

SteppingUP.ie

Irish website with information and support for young people with long-term illnesses who are moving from child to adult health services.

Website:
www.steppingup.ie

DARE (Disability Access Route to Education)

This is an alternative admissions route to third level for students whose disability or ongoing illness has had a negative impact on their education in secondary school. It offers reduced points places to school leavers who have experienced additional challenges in secondary school as a result of their disability or ongoing illness.
Website:
www.accesscollege.ie/dare

Citizens Information

Statutory body provides comprehensive information on public services and on the entitlements of citizens in Ireland.
Tel: 0818 07 4000
Website:
www.citizensinformation.ie

Money Advice and Budgeting Service (MABS)

This is a free and confidential service for people who are having problems with money management and debt.
Helpline: 0818 07 2000
Email: helpline@mabs.ie
Website:
www.mabs.ie

Patient Advocacy Service (PAS)

This is a free, independent and confidential service available to patients who want to make a complaint about the care they received in an acute public hospital or nursing home.
Tel: 0818 293 003
Website:
www.patientadvocacyservice.ie

Jigsaw

An Irish charity that focuses on supporting the mental health needs of young people aged 12-25.
Website:
www.jigsaw.ie

Belong To

This is the national LGBTQIA+ organisation which advocates for young LGBTQIA+ people (up to age 24).
Tel: 01 670 6226
Website:
www.belongto.org

LGBT Ireland

LGBT Ireland is a national support service for lesbian, gay, bisexual and transgender people and their families and friends.
Tel: 1800 929 539
Website:
www.lgbt.ie

Outhouse LGBTQ+ Centre

Outhouse works to support people, spaces and issues that are important to LGBTQIA+ communities.
Tel: 01 873 4999
Email: info@outhouse.ie
Website:
www.outhouse.ie

Transgender Equality Network Ireland (TENI)

TENI works to improve the lives and advance the rights of trans people in Ireland.
Tel: 01 873 3575
Email: office@teni.ie
Website:
www.teni.ie

Useful websites outside the Republic of Ireland

Stupid Cancer

Global support community for adolescents and young adults with cancer.
Website:
www.stupidcancer.org

Teenage Cancer Trust UK

Cancer information and support forum for teenagers with cancer.
Website:
www.teenagecancertrust.org

Young Lives vs Cancer

UK charity aimed at people up to the age of 25.
Helpline: 0044 300 330 0803
Email: getsupport@younglivesvscancer.org.uk
Website:
www.younglivesvscancer.org.uk

Teenagers and Young Adults with Cancer (TYAC)

This UK organisation funds research and provides support for teenagers and young adults with cancer.
Email: info@tyac.org.uk
Website:
www.tyac.org.uk

Chapter 20

What does that word mean?

What does that word mean?

Acute Occurring suddenly over a short period of time.

Alopecia Hair loss.

Anaemia A reduced number of red blood cells.

Anaesthetic Drugs that put you to sleep (general anaesthetic) or that numb a part of your body (local anaesthetic).

Antibodies Proteins created by the immune system when exposed to toxins or other foreign substances such as viruses and bacteria. Antibodies recognise and latch onto the foreign substance, removing them from the body.

Benign Not cancer

Biopsy A small sample of tissue taken from the body to make a diagnosis.

Blood tests Doctors often examine blood samples to help them to diagnose cancer. Blood tests may be done when you are diagnosed, during treatment and afterwards at follow-up appointments.

Blood count A blood test to check the number of different cells in the blood. Sometimes it is called a full blood count or FBC.

Bone marrow The spongy material in the centre of large bones in the body, which makes blood cells.

Bone marrow aspirate/biopsy A test that takes a sample of bone marrow or bone using a needle. When a sample of semi-liquid bone marrow cells is taken, it is called an aspirate. When a piece of bone or solid marrow is taken, it is called a trephine biopsy.

Bone scan A test that can show if cancer is present in bones using a radioactive dye.

Cannula A short plastic tube put into a vein to deliver medication, fluids or a transfusion.

Cardio- To do with the heart

Catheter A thin, flexible tube used to give fluid into the body or to drain fluid from the body. For example, a urinary catheter or a central line, such as a Hickman line.

Central nervous system (CNS) This refers to the brain and spinal cord.

Cerebrospinal fluid (CSF) Fluid made in the brain that surrounds the brain and spinal cord.

Chemotherapy Drug treatment that kills cancer cells.

Chromosome Structure in the nucleus of the cell that contains the genetic make-up of the cell.

Chronic A condition that lasts a long time.

CT scan This special X-ray gives a detailed picture of the tissues inside your body. During the scan, you will lie on a table that passes through a doughnut-shaped machine. The scan is painless.

Cyst An abnormal sac or swelling that is filled with fluid or semisolid matter.

Cyto- To do with cells.

Cytogenetics The study of chromosomes in cells.

Dysfunctional Something not working properly.

Echocardiogram (Echo) This is an ultrasound scan of the heart. It checks how well the heart is working.

Electrocardiogram (ECG) This tests the electrical activity of the heart muscle. Electrical sensors are placed on your chest for the test.

Electroencephalogram (EEG) This tests the electrical activity of the brain. It is not painful but will involve electrical sensors being attached to your head.

Electrolytes The minerals and salts in the body. For example, sodium, potassium and calcium.

Endocrine To do with hormones.

Excision Cutting out.

GCSF (granulocyte colony-stimulating factor) This is a type of protein called a growth factor. It boosts the bone marrow to make more white blood cells, usually neutrophils, which are the most common type of white blood cell.

Genetic A condition caused by abnormal genes (may be inherited).

Glomerular filtration rate (GFR) is a test that shows how well the kidneys are working.

Haematology The study of blood and blood disorders.

Haemoglobin The substance in red blood cells that carries oxygen around the body.

Histopathology The study of body tissues.

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

Immune system The body's defence against infection, disease and foreign substances.

Immunology The study of the body's immune system, which fights infection.

Immunophenotyping A test to identify particular proteins in the cells to help find out which type of cell has become cancerous.

Immunosuppressive Lowering the body's ability to fight infection.

Intramuscular (IM) Into a muscle.

Intrathecal (IT) Into the spine, usually by lumbar puncture. See also lumbar puncture.

Intravenous (IV) Into a vein.

Lumbar puncture (LP) This test can be done to diagnose, prevent or treat disease. The fluid that surrounds the brain and spinal cord is called cerebrospinal fluid (CSF). During the test, some CSF is removed by putting a needle into the lower back and the fluid is then examined in the laboratory.

Lymph A clear fluid that is part of the body's defence against infection. It is carried around the body in a network of lymphatic vessels.

Lymphatic system Part of the circulatory system. It consists of a network of vessels that carry a clear fluid called lymph in the direction of the heart. Excess fluid (lymph) in the tissues is drained by the lymphatic system into the bloodstream. It also defends the immune system.

Lymph nodes Small bean-shaped structures found along vessels in the lymphatic system. They become enlarged due to infection or cancer.

Lymphocyte A type of white blood cell that fights infection.

Malignant Cancer.

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

Microbiology The study of microscopic organisms, such as bacteria and viruses.

MRI scan This uses radio waves and a powerful magnet linked to a computer to take detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.

Nausea Feeling sick.

Neuro- To do with the nerves or nervous system.

Neutrophils White blood cells that fight infection.

Oedema Swelling caused by fluid.

Oncology The study and treatment of cancer.

Ophthalmology The study of the eyes

Oral To do with the mouth.

Osteo- To do with the bones.

Palliative care Aims to control symptoms (for example, pain) and improve quality of life, rather than cure your illness.

PET scan This scan uses a low dose of radiotracer (radioactive sugar), which is injected into your arm. The PET scan uses the radiotracer to highlight cancer cells in the body.

Platelet A type of blood cell that helps the blood to clot.

Prognosis The expected outcome of a disease and its treatment.

Prosthesis An artificial replacement for a missing or damaged part of the body, such as a bone.

Pulmonary To do with the lungs.

Pulmonary function tests Tests that measure how well the lungs take in and breathe out air and also how well they move oxygen into the bloodstream.

Radiotherapy The use of high-energy X-rays to destroy cancer cells.

Red blood cells Blood cells that carry oxygen around the body. The part that contains iron called haemoglobin gives blood its red colour.

Refractory Resistant to treatment.

Relapse/recurrence The return of a disease after treatment.

Remission There is no evidence of the disease being present using the available tests.

Renal To do with the kidneys.

Sarcoma A tumour that forms in bone, muscle, fat or cartilage cells.

Stem cell Special cells that turn into many different types of cells.

Subcutaneous (SC) Under the skin.

Therapy Treatment.

Thrombocytopaenia Low levels of platelets in the blood leading to bruising and bleeding.

Total parenteral nutrition (TPN) Giving nutrients into a vein when a patient is unable to take food in the normal way (through the mouth).

Ultrasound A test that uses sound waves to examine the tissues inside the body.

White blood cells Blood cells that defend the body against infection.

X-ray An image that helps a doctor see the inside of the body.

Glossary of LGBTQIA+ terms

This list provides a short overview of commonly-used LGBTQIA+ terms and language. It is not exhaustive as LGBTQIA+ language is constantly changing. Also, it should be noted that some meanings can change over time.

Ally A person who believes in and fights for the equality of LGBTQIA+ people, despite not being a member of the LGBTQIA+ community.

Asexual Someone who feels a lack of sexual attraction to anyone.

Bisexual Someone who feels attracted to more than one gender.

Cisgender/cis Someone whose gender identity matches the sex they were assigned at birth.

Coming out When you share your sexual orientation or gender identity with people in your life.

Deadnaming Calling someone by their birth name after they have changed their name. For example, a trans person who has changed their name as part of their transition.

Gay Someone who is attracted to people of the same gender.

Gender-affirming healthcare This includes social, psychological, behavioural or medical interventions that are designed to support an individual's gender identity. Medical gender-affirming healthcare includes hormonal therapy and surgery.

Gender binary The idea that there are only 2 genders – male and female – and that everybody is either one or the other.

Gender dysphoria When people become distressed or uneasy because their gender identity differs from their sex assigned at birth.

Gender expression This is how a person shows their gender on the outside, for example, through their clothes, hairstyle or behaviours.

Gender fluid This is someone whose gender identity or gender expression is not fixed. It changes over time.

Gender identity This refers to our internal sense of self and gender – how we feel inside.

Heterosexual Someone who is attracted to people of the opposite sex.

Intersex When people are born with sex or reproductive characteristics that aren't considered only male or female. For example, they may have reproductive organs that can be considered both male and female.

Lesbian A woman who is attracted to other women. Some non-binary people may also identify with this term.

Misgender To refer to someone in a way that does not reflect their gender identity. For example, using the wrong pronouns.

Non-binary This refers to people whose gender identity falls outside of the typical binary of male and female. For example, someone may identify as both male and female. Or they may identify as neither male or female. Some believe their gender identity is fluid – changing at different times.

Outing The accidental or deliberate sharing of another person's sexual orientation or gender identity without their permission.

Pansexual Someone who is attracted to people of all genders.

Pronouns This is how we identify ourselves apart from our name and affirm our gender identity. Examples include he/him, she/her and they/them.

Queer A term used to describe people who are not heterosexual and/or cisgender. For a long time, queer was used as a slur against members of the LGBTQIA+ community and some people still use it as such. However, many LGBTQIA+ people have embraced the term in recent years.

Questioning This refers to someone who is still exploring or experimenting with their gender identity or sexual orientation.

Sexuality This describes how you express yourself in a sexual way. It is not just about the physical act of having sex. Rather it includes how you see, feel and think about yourself as a sexual being. For example, how you view your own body and how you feel about close physical touch. It also includes your sexual feelings, thoughts, behaviours and attractions towards others.

Sex assigned at birth This is a label you are given at birth – male or female – which is based on your anatomy (genitals and/or reproductive organs) or biology (chromosomes and/or hormones).

Sexual orientation This describes someone's attraction to others.

Transgender (trans) When your gender identity does not match the sex you were assigned at birth.

Trans man Someone who was assigned female at birth but who identifies as a man.

Trans woman Someone who was assigned male at birth but who identifies as a woman.

Transitioning This describes the process trans people go through to live as the gender they identify with, rather than the one they were assigned at birth. This can involve; medical changes, such as gender-affirming surgery; legal changes, such as changing their name and/or gender on official documents; social changes, such as telling family and friends.

Notes

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