

Understanding

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# Allogeneic Stem Cell Transplants

Caring for people with cancer

## Understanding

# Allogeneic (donor) stem cell transplants

This booklet has information on:

- A transplant using stem cells (early blood cells) from another person (a donor)
- Recovering after your transplant
- Coping with the emotional side of a stem cell transplant

### Useful numbers

Transplant co-ordinator

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Haematology nurse specialist

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Family doctor (GP)

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Haematologist

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Medical oncologist

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Medical social worker

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Emergency number



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## Fast facts

### What is an allogeneic (donor) stem cell transplant?

An allogeneic (donor) stem cell transplant allows you to have higher doses of chemotherapy and/or radiation therapy to destroy your bone marrow and replaces your bone marrow that is no longer working properly with healthy stem cells from your donor. Your donor may be a family member or an unrelated donor.

### Are there side-effects from treatment? Page 37

All treatments, particularly high-dose chemotherapy, can cause side-effects. But these are usually temporary. **There are treatments to help with most side-effects, so tell your doctor. Don't suffer in silence!**

### We're here for you Page 76

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

#### Ways to get in touch

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

### What are the stages of an allogeneic stem cell transplant?

There are 5 main stages:

- 1 **Preparing for the transplant.** You have tests to check your general health, and are given advice on preparing for the treatment. Doctors will look for a donor whose cells match yours. See page 13.
- 2 **Conditioning treatment.** You have a combination of drugs including chemotherapy and/or radiation and drugs to suppress your immune system to destroy your bone marrow and immune system. This prepares your body to accept your donor's cells. See page 25.
- 3 **Having the transplant.** You are given your donor's stem cells through a drip after the conditioning treatment has finished. See page 29.
- 4 **Waiting for new blood cells to grow.** Your donor's stem cells find their way to your bone marrow and start to grow and make healthy new blood cells. This is called engraftment. You will be looked after in isolation and you will need lots of medical and nursing support while the stem cells engraft. See page 33.
- 5 **Recovering after the transplant.** When your blood cells have recovered and you are well enough, you can go home. Your doctor or nurse will give you advice about avoiding infection. You will have regular follow-up appointments at the hospital to check your recovery. See page 51.

## Reading this booklet



This booklet is to help you throughout your stem cell transplant and afterwards. You will probably find different sections useful at different times, so keep it for reference. It is best to read this booklet along with our information about your particular cancer type.

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

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

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



Support Line Freephone 1800 200 700

# About allogeneic stem cell transplants

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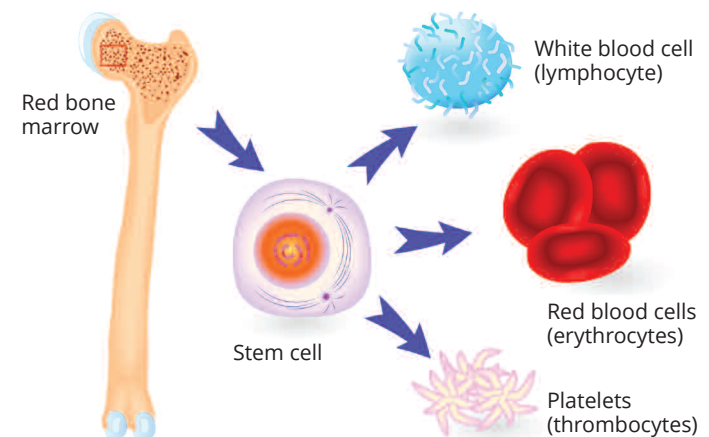
## Stem cells and bone marrow

To understand a stem cell transplant, it helps to know about stem cells and bone marrow.

Stem cells are blood cells that are at the earliest stage of their development. They can develop into red blood cells, white blood cells and platelets:

- **Red cells** carry oxygen around your body
- **White cells** help to fight infection. There are 2 main types of white cell. These are called neutrophils and lymphocytes. Neutrophils are the most common. You will hear your doctor or nurse talk about your neutrophil count during your treatment
- **Platelets** help blood to clot and prevent bleeding

Stem cells are found in your bone marrow, which is a spongy tissue found within bone, in particular your hip bones. Bone marrow makes millions of new blood cells every day to replace blood cells as they are needed.



## What is an allogeneic stem cell transplant?

An allogeneic (donor) stem cell transplant allows you to have higher doses of chemotherapy and/or radiation therapy to destroy your bone marrow and replaces your bone marrow that is no longer working properly with healthy stem cells from your donor. The goal of the transplant is to cure your underlying disease.

## Why do I need a transplant?

An allogeneic stem cell transplant allows you to receive high doses of chemotherapy and/or radiotherapy called conditioning therapy. This conditioning therapy will destroy the cells causing your cancer. But as conditioning therapy cannot tell the difference between normal and diseased cells it will also destroy the healthy cells in your bone marrow, causing a drop in your normal blood counts. This means you will have low numbers of red blood cells, white blood cells and platelets in your blood. This will increase your risk of bleeding, infection and anaemia.

When you receive donor stem cells through a drip (infusion), they will 'rescue' you from this high dose of chemotherapy. The stem cells will travel to your bone marrow, where they will grow and begin to make new blood cells. Your doctor or nurse might call this engraftment, which means the stem cells have settled in your bone marrow and are now growing. The transplant also gives you your donor's immune system (white blood cells). This helps your body to get rid of any remaining cancer cells.

Email: [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

## What are the stages of an allogeneic stem cell transplant?

- 1 **Preparing** for the transplant
- 2 **Conditioning** treatment
- 3 **Having** the transplant
- 4 **Waiting** for engraftment (new blood cells to grow)
- 5 **Recovering** after your transplant

## Where will I have the transplant?

The transplant will take place at the transplant centre in St James's Hospital, Dublin, which is a highly specialised centre.

Before your treatment and transplant, you will be asked to attend the transplant centre a number of times. First, you will meet the haematology team, including the doctors, nurses and transplant co-ordinators. This visit gives you a chance to ask questions and get to know the transplant centre. There will be a lot of information to discuss during these visits, so it's important to bring someone with you such as your partner, a family member or a friend.

You will need to think about the benefits and risks of this treatment very carefully before you decide. A donor stem cell transplant may increase the chance of being cured, or of getting you into remission more than any other treatment. But you will need to consider this against the risks. When you and the transplant team decide that you are suitable for transplant, you will be asked to sign a consent form allowing it to go ahead.

The transplant co-ordinator or specialist nurse will give you details about when you need to come into hospital for the transplant. They will keep in contact with you to arrange visits and to tell you what to do if you need tests or anything else. If you are being referred for transplant from another hospital, these tests will be done locally.



## Preparing for the transplant

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## Finding a donor

You will first have a blood test to find your tissue type. Your tissue type is the combination of proteins called human leukocyte antigen (HLA) markers on the surface of your cells. Doctors use your tissue type to match you with a donor. Your donor does not need to have the same blood group as you.

When you have the blood test, a small sample of blood is taken from a vein in your arm. This sample is sent to the laboratory. The results are usually available in about 2 weeks.

### Possible donors

There are different types of donors:

- **Sibling** – a brother or sister
- **Alternative family donor** – a parent, cousin or child
- **MUD** – a volunteer matched unrelated donor

When selecting a donor, doctors look to see if their tissue type is the same as yours (a match). Having the best possible match means less risk of:

- Your body rejecting the new stem cells
- The new immune cells reacting against your other body cells.

When a donor search is started, a patient's brothers and sisters are tested first to see if they might be a suitable match.

Our tissue type is a combination of both parents. Not every combination will be the same. Brothers or sisters (siblings) each have a 1 in 4 chance of having the same tissue type as you and being a match. So not every sibling will be a close enough match to be a donor.

If you do not have a close match in your family, your doctors will carry out a search of bone marrow donor registries to find you the best possible donor. There are several million volunteers around the world who are registered as potential bone marrow donors.

People from black, Asian and minority ethnic groups often have difficulties finding a good match from volunteer registries. Organisations and charities are working to increase the number of registered donors from all these groups, so this is slowly improving.

All donors will need a physical check-up to make sure that they are fit and healthy. This includes a physical examination by a doctor, blood tests, a heart trace (ECG) and a chest X-ray.

## Getting ready for your transplant

### Timing

Your transplant will be scheduled around your treatment schedule and donor availability. If you are concerned about the timing of your transplant, talk to your transplant team.

You can expect to be in hospital for about 6 weeks. If you live more than an hour from the transplant centre, you will need to stay in the Dublin area for around another 6 weeks. A family member or carer will also need to stay with you during this time.

After this, you will have regular appointments at the outpatient department to check your recovery. It varies from patient to patient but these regular appointments can continue for some months.

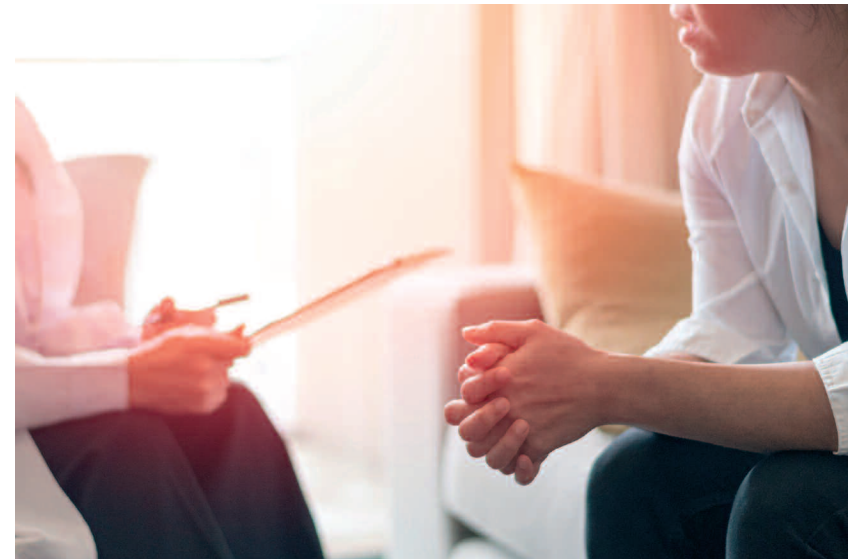
There are likely to be times when you feel very unwell. It can take 6 months to a year or more before you fully recover.

### Other things to consider

Having an allogeneic stem cell transplant will impact significantly on your life. Before you begin your treatment, you may want to:

- Organise your finances, including any social welfare benefits you may be entitled to
- Talk to your employer about sick leave
- Organise childcare
- Organise a family member or carer to stay with you for 6 weeks after you leave hospital
- Ask a close friend or family member to provide updates to everyone else
- Organise help for when you are discharged from hospital

You can ask to speak with the medical social worker in your hospital who will be able to assist you with some of these issues.



## Fertility

High-dose chemotherapy often causes infertility, so you may not be able to have children after treatment. If you had considered starting a family or having more children, ask your doctor about how your treatment may affect your fertility. Before starting high-dose chemotherapy, it may be possible to store sperm if you are male. Rotunda IVF at the Rotunda Hospital in Dublin provides this service. If you are female, talk to your doctor about your options. See page 47 for more about fertility.

## Planning ahead



It can be hard to think about what might happen in the future when you have cancer and are receiving treatment. It might make you feel worried, scared or upset to think about the end of your life. Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

### Who can help me plan?

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



## Ways to help yourself



### Gather information about your stem cell transplant:

Understanding your treatment and knowing what to expect can help to relieve anxiety and stress for some people.

**Involve your family and close friends:** Don't keep your worries or any physical problems secret from the people closest to you.

**Use your support network:** Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need.

### Try relaxation and stress management techniques:

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

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

**Try to cope day by day:** Don't think about the future too much. Concentrate on the present and getting through each day. That way, you may find it easier to cope with your illness.

## What tests do I need beforehand?

Having an allogeneic stem cell transplant can be very physically demanding. Before your transplant you will have tests to make sure you are fit enough for the treatment. These tests may be done in your local hospital or at the transplant centre. Your nurse will let you know about these tests and arrange them for you. You might need more than one visit to the hospital to have all the tests you need.

Some of these tests include:

- Blood tests
- 24-hour urine collection
- Lung function tests
- Chest X-ray
- ECG
- Echocardiogram (Echo)
- Dental check-up

### Blood tests

Doctors measure the numbers of different blood cells by taking a blood test. This is called a blood count or full blood count. They will check your blood count often before, during and after treatment. This is because the treatment will affect the levels of your blood cells. Before treatment, doctors will also check your blood group, clotting and iron levels and how well your kidneys, liver and bones work. They will also check for viruses, for example, HIV, hepatitis A, B and C, and syphilis.



### 24-hour urine collection

This test checks how well your kidneys are working at clearing waste products from your body. You will be given a large plastic bottle to bring home with you to collect your urine. You will be asked to collect all the urine you pass in a 24-hour period. It is best to start the collection in the morning. When you wake up, pass your first urine in the toilet as normal and note the time. Write this time on the bottle. From then on start collecting all of the urine you pass. Your collection finishes exactly 24 hours after the time you wrote on the bottle. It is important to collect all the urine you pass in the bottle. If you forget to pass urine in the bottle, the test will have to be repeated. To measure the results, you will need a blood test taken when you return the urine collection to the hospital.

### Lung function tests

These tests show how well your lungs are working. For example, one test involves blowing into a machine. If you take inhalers, please try not to take them for 3 hours before the test. Of course, if you feel breathless, then take your inhalers as normal.

### Chest X-ray

This is a simple X-ray of your chest. It will act as a baseline for your doctors during your treatment. It will also check for any lung problems you might already have.

### ECG

This is a tracing of your heart rhythm. Small sticky electrodes will be placed on your chest, arms and legs first and then the machine will read your heart rhythm, tracing it on paper.

### Echocardiogram (Echo)

This test is an ultrasound of your heart. A small amount of gel will be placed on your chest and a probe will be moved around your skin near your heart. You can see the pictures of your heart on the screen. This test takes about 20 minutes to complete.

## Dental check-up

Before you have the high-dose chemotherapy, a dentist needs to check your teeth. This visit might include having an X-ray of your teeth. Decaying teeth can cause a serious infection during your transplant. You can visit your own dentist for this check-up. Your doctors will need a letter from your dentist saying that you are dentally fit for the transplant.

## Other tests

You will need to be checked for certain bacteria, which are not usually harmful, but may cause infection after high-dose chemotherapy. This will help your doctor choose the correct antibiotics if you do become unwell.

You will have your height and weight measured, and your blood pressure, pulse and oxygen saturation level will also be recorded.

You will also have a pregnancy test if you are a woman and up to the age of 55 years. You may need a bone marrow biopsy and a lumbar puncture. Your doctor or transplant co-ordinator will explain these in more detail. Extra tests may be needed, depending on your condition and medical history.

## Putting in a central line

Before you receive the high-dose chemotherapy, you will need a special line placed in a large vein. This is so that you can receive all your treatment during your transplant. Having this special line means there is no need for needles in your arms each time and it will save your veins from trauma. You might hear the line called a catheter by your nurses and doctors. There are different types of central lines available:

## Skin-tunnelled central line

This line is put into your vein in the X-ray department under local anaesthetic.

It is a hollow plastic tube that is put in through a small cut (incision) near your collarbone.

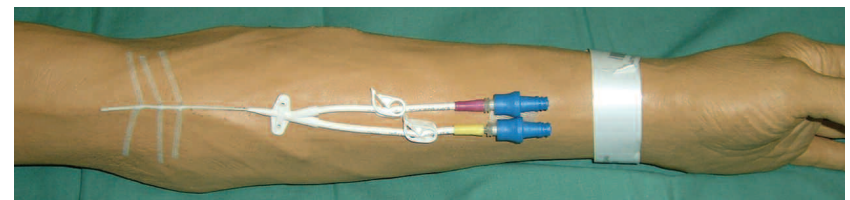
Your doctor will gently thread the line under your skin into a large vein in your chest. You will be able to see a thin tube come out of your chest. It may divide into 2 or 3 tubes so you can have different treatments at the same time.



A cuff under the skin stops the line from falling out. At first, the line will be stitched into place but these stitches will be removed later. While in hospital, you will be taught how to care for this line. A central line may be called by its brand name. For example, Hickman®.

## PICC line

If you can't have a central line, your doctors may arrange for you to have a peripherally inserted central catheter (PICC) line. This line is put into one of your arms above the bend in your elbow. Again, this line will be put into your vein in the X-ray department under local anaesthetic. It is threaded through the vein until it sits in one of the large veins near the heart. You will see one or two thin tubes come out from your arm. The PICC line can remain in place throughout your transplant. It will be held in place by stitches, which will remain there while the line is in.





## Conditioning treatment

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## Things to take into hospital

When you go into hospital for your transplant, you can take some personal belongings with you. Please bear in mind that the rooms in transplant units are usually small.

### Tips & Hints – what to bring to hospital

- Nightdresses or pyjamas, dressing gown, slippers, soft towel.
- Comfortable loose clothes like tops, pyjamas or tracksuit bottoms.
- A soft toothbrush and toiletries – check with your nurses about using any creams and lotions.
- Personal items like photos of your family, friends or pets, or a child's drawing.
- Personal items to occupy your time – card games, books, magazines, tablet, etc.
- Mobile phone and charger – these can be used on the ward.
- Ask your nurses what else you can bring in. It's best to leave valuables at home.

Support Line Freephone 1800 200 700

## Having conditioning treatment

Before you have your transplant, your existing bone marrow and immune system need to be treated and prepared, to make way for your donor's cells.

This means having chemotherapy or radiotherapy, or a combination of the two. You may also have drugs that will work on your immune system. This is called conditioning treatment.

Not all patients have radiotherapy. Your transplant team will give you more information on radiotherapy if this is part of your treatment.

Almost all patients have chemotherapy. This can either be given in tablet form or into your vein (intravenously). Intravenous chemotherapy is given through your line (see page 22), infused over an hour or a number of hours. It can also be given by injection.

You usually begin conditioning treatment the day after you go into hospital. It can take anything from 5 to 12 days. Your doctor will talk to you about the type of conditioning treatment that is best for you.

Most patients have their transplant the day after they finish conditioning treatment. But this can vary depending on the treatment and the type of transplant.

### Reduced-intensity conditioning (RIC)



Reduced-intensity conditioning (RIC) uses fewer or lower doses of chemotherapy. This should make the side-effects less severe and reduce the risk of transplant complications. RIC is becoming more widely used. If you have any questions about RIC, talk to your nurse or doctor.

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## Your transplant

The day of the transplant is often a very exciting one as it signifies a new beginning. This day is referred to as day zero, with the days following referred to as plus days. The day after your transplant is day plus one, two days after is plus two, and so on.

The cells are infused through your line in the same way as a blood transfusion is given through the line.

The transplant is only the first step in your recovery. Your medical team will support you after your transplant.

## Before the infusion

Just before the infusion of the cells, your nurse gives you some medication through your line, and also starts a saline drip. The medication, an anti-histamine, and sometimes a small dose of steroid, is given to prevent any allergic reaction during the infusion. Your nurse also checks your temperature, pulse and blood pressure.

## Having the infusion

The actual infusion of the donor cells can seem a little bit of an anti-climax as it is just like having a blood transfusion.

The length of time for the infusion depends on how the stem cells are collected from your donor. The cells can be collected:

- Directly from the bone marrow – a **bone marrow harvest**
- From the blood – a **peripheral blood stem cell harvest**

**A bone marrow harvest** gives a volume of approximately 1 to 1.5 litres. The harvest from the marrow contains lots of red blood cells. If the donor and recipient blood groups are different the red blood cells are removed and the volume will be smaller. Bone marrow cells are given fresh and usually take two to four hours to infuse.

**With a peripheral blood stem cell harvest** it can take up to 2 days to collect enough stem cells from your donor's blood. You may have the collected cells infused in one session, or

you may receive one bag on the first day of collection and one on the second. Each bag usually takes about 30 minutes to infuse.

Occasionally bone marrow and peripheral blood stem cells that have been collected may be frozen. They have a preservative added to them, so that the freezing process does not damage the cells. This preservative carries a smell, often described as being 'like boiled sweetcorn'. You may not be able to pick this smell out at all, but your relatives and visitors may well pass a comment. You excrete the preservative through your skin and in your bodily fluids (in a similar way to excreting garlic) for about 24 hours after the transplant.

## After the infusion

After the infusion, your nurse flushes the drip with saline and then takes it down. You have your observations re-checked and then the transplant infusion is finished.



# Waiting for engraftment (for your new blood cells to grow)

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## What is engraftment?

Your donor's stem cells will travel through your blood to your bone marrow, where they will start to grow and mature into new blood cells. This is called engraftment. You will need blood and platelet transfusions until you begin to produce your new blood cells.

Engraftment happens over 2 to 3 weeks, but can sometimes take longer. The first sign is often a rise in your white blood cell count. This rise can sometimes be unsteady, so don't worry if your count goes up and down a little at the start.

You may be given a drug called a growth factor as an injection. This will boost the growth of the stem cells and help them mature.

The number of white blood cells (your neutrophils) will be very low for some time. This is called being neutropenic. Neutrophils are very important in fighting infection. Your transplant team will try to protect you from possible infection so during this time, you will be looked after in a single room. This is sometimes called protective isolation.

## What happens when I'm in isolation?

You will be looked after in a single room with the door closed. The room will have a special air conditioning system to keep the air in your room very clean. You will be closely watched and checked for signs of infection.

### Visitors

It is best that only your close family and friends visit you during your stay. This is to reduce the chance of you and other patients picking up an infection. The best advice is that no more than two people visit you at any one time.

Your visitors should remove their outdoor coats and put on a plastic apron before they visit you. Fresh flowers and plants are not allowed inside your room as they may increase your risk of infection.

## Hand washing and hygiene

There are strict guidelines about handwashing for all visitors. A staff member on the ward will advise them about this. Visitors who have signs of active infection like a cough, cold or rash must not enter the ward. This is particularly important if they have been in contact with someone who has an infectious disease like chickenpox or shingles. Children under 14 are not allowed to visit because they are more prone to picking up infections. Please discuss this with the nurse manager if it is an issue for you. Your room and its contents will also be cleaned every day.

## Coping with isolation

Being in isolation after the transplant can be stressful. Naturally you might find it difficult being on your own without other patients around you. Your nurses can help you overcome these difficulties and will make your stay as non-traumatic as possible. They can arrange for you to talk to a clinical psychologist to explore your feelings and try to help you cope.

## Moving around

It can be hard having to stay in a small room all the time. But it is important to be as mobile as possible and keep your muscles working. It's also important for your lungs. Do get up and walk around the room at least a few times a day. Even getting up to go to the toilet and to wash yourself helps with your recovery.

You will be allowed to exercise and the occupational therapist or physiotherapist may plan an activity programme for you. You may be allowed out of the room for short periods when your blood count has started to rise.

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## Infection

Your nurses will monitor you very closely for signs of infection. They will check your temperature regularly along with your pulse and blood pressure, particularly when your white cell count remains low.

Fever is the most common sign of infection. Some patients can feel cold and start shivering (known as a rigor) before a fever. Let your nurse know straight away if this happens to you.

When you have a fever, your doctor will examine you and will probably prescribe intravenous antibiotics. These are antibiotics that are given to you through your line. Your nurse will also take a blood sample from you and send it to the laboratory to see if they can find out the cause of your fever. They may also take samples of your urine or stools (poo).

Quite often, the laboratory cannot find the source of the infection. This is why doctors use a broad range of antibiotics to treat you. These antibiotics are effective against many organisms and bacteria and are used until the cause of your fever is identified or your temperature returns to normal.

If you still have a temperature after 24 or 48 hours, doctors may repeat the blood test and change the antibiotics. Occasionally people can become very ill with infection and develop a condition called sepsis. Sepsis can result in low blood pressure or difficulty breathing and can even require admission to the intensive care unit for closer monitoring.

When you no longer have a fever and you're feeling better, the antibiotic treatment is stopped. It is common for patients to have several fevers and 'rounds' of antibiotics after their transplant.

Support Line Freephone 1800 200 700

## Nausea, vomiting and diarrhoea

These are common problems after getting chemotherapy drugs. But you will be given anti-sickness medication to control any nausea and vomiting you have. It can help to eat small portions often rather than big meals. If you cannot tolerate food, you may need to have nutrition through a vein. For this, you will receive a bag of liquid nutrients to make sure you get all the essential vitamins and minerals you need and to not lose weight. Your sense of taste and smell might also change, but this will improve gradually.

If you get diarrhoea, hygiene is very important. You will also be given creams to prevent any discomfort that may occur as a result. If you have existing piles (haemorrhoids), tell the staff, as these may become painful if you are having diarrhoea.

You will also need to drink more to replace fluids you have lost. For more about coping with nausea, vomiting and diarrhoea, see our booklet *Diet and Cancer*. Call our Support Line on 1800 200 700 for a free copy or download it from [www.cancer.ie](http://www.cancer.ie)



## Inflamed mouth and gut

Mucositis is the name for an inflamed or irritated mouth and gut. Your mouth might feel sore and ulcers can develop, often after receiving chemotherapy drugs. These drugs kill all fast-growing cells, which include the cells in your mouth and gut. How much mucositis you get can vary with the different drugs.



The stronger your treatment, the more likely you are to develop mucositis. As a result, your mouth or throat may begin to get sore a couple of days after the transplant. It can begin slowly, then you may notice that your tongue looks white and the lining of your mouth becomes tender. Your saliva might also become thick. You might notice that your throat is sore and you cannot swallow as normal. If you notice black or white spots on your tongue, tell your doctor or nurse.

A sore mouth can stop you eating properly. Regular painkillers can be given to relieve the pain, while special mouthwashes with local anaesthetic can also be used. You will be offered morphine in a liquid or infusion form, as this is the best painkiller for this type of pain. Remember this problem will ease off and heal once your stem cells begin to mature. Often it becomes hard to look after your mouth because it is so painful. But caring for your mouth at this stage is vital because it's when infections are most likely to happen. Your nurse will talk to you about caring for your mouth.

### Hints & Tips – mouth care



- Use a toothbrush with soft bristles.
- Keep your lips moist with lip balm.
- Use regular mouthwashes as advised by your nurses.
- Use mouth sponges instead of a toothbrush if your mouth becomes sore.
- Avoid dental floss.
- Suck ice or watermelon chunks if your saliva is thick.
- Remove your dentures if you get mouth ulcers.

## Kidney problems and urinary problems

Mild kidney problems are common following a bone marrow transplant. Your nurse and doctor will keep a close eye on your kidney function. Always let your nurse or doctor know if you have any blood in your urine, pain in your lower tummy or pain when passing urine.

## Fluid gain

During conditioning treatment, you may find that you put on weight. This is often because of a build-up of the fluid that is given with chemotherapy. This kind of fluid gain can be easily resolved with diuretics. These are drugs that make you pass more urine.

## Hair loss

Due to the high-dose chemotherapy, you will probably lose your hair. Loss of body hair occurs at first from your head and then from your eyebrows, eyelashes, underarm and pubic area. Losing your hair is also called alopecia. The amount of hair loss differs for everyone. For example, you might get severe hair thinning or total hair loss. This can be very upsetting. Some people prefer to have their hair cut short or shaved as it starts to fall out. A family member, nursing staff or a hair liaison expert can help you with this.

There are now lots of companies providing wigs, turbans, hats and hairpieces. Your nurse or medical social worker can give you the contact numbers and arrange a visit if you are interested. You can also call our cancer nurses on 1800 200 700 for information and support.

*Choosing a wig before your hair falls out means you can match the style and colour to your own hair.*

Remember, the hair loss is temporary. Hair regrowth usually begins any time from 2 months after the chemotherapy, but may take longer. Your hair might grow back a different shade or be curly. These differences often disappear as your hair continues to grow.

## Bleeding

The conditioning treatment you have before your transplant will affect your bone marrow's ability to produce red blood and platelet cells. Red blood cells help transport oxygen around the body. Platelets help your blood to clot and stop bleeding. With fewer platelets you may bleed or bruise very easily for a few weeks after the transfusion. For example, you may get nosebleeds, bleeding gums or unexplained bruising. You may need a blood transfusion or a transfusion of platelets to help with this until your bone marrow has recovered and can start making platelets again. You will also need to be careful to avoid injuries and cuts.

## Fatigue

Fatigue means feeling extremely tired. Fatigue is a very common problem after a transplant. Patients often find it difficult to read a book, watch television or even hold a conversation.

You may well find that activities such as showering or bathing are exhausting.

You may find that your sleep and rest patterns change. A good night's sleep is important to prepare you for the day ahead. Getting to sleep at night can be difficult. You may be resting too much during the day. Remember the things that you do at home that help you to go to sleep. For example, reading, listening to the radio, hot milky drinks. Try to do the same while you are in hospital.

If you are having problems sleeping, talk to your nurse or doctor. For more on fatigue, see page 57.

## Graft versus host disease (GvHD)

After a donor cell transplant, the new stem cells may attack your own. This is called graft versus host disease (GvHD). GvHD can range from mild to severe. It may even be life-threatening. It mainly affects the skin, mouth, liver, stomach and bowel.

You will have treatment with drugs before and after your transplant to reduce the risk of GvHD.

There are 2 different types of GvHD: acute and chronic.

### Acute graft versus host disease

Acute GvHD usually happens within the first 100 days of your transplant. It mainly affects the cells of the skin, causing a rash. It may also attack the cells of the liver and gut. Around 2 to 3 weeks after your transplant (when your donor's stem cells are expected to engraft), your doctors will seem particularly interested in the palms of your hands and the soles of your feet. They will check them daily for any signs of GvHD, such as redness or itching. They will also monitor your gut and bowel and ask you if you have diarrhoea.

### Chronic graft versus host disease

Chronic GvHD starts more than 100 days after your transplant. It can develop from acute GvHD or happen on its own. It may affect your:

- Skin
- Gut
- Mouth
- Joints
- Liver
- Eyes
- Lungs

Chronic GvHD is mainly treated with immunosuppressive drugs. These drugs help stop your donor's cells attacking your body's tissues. Sometimes chronic GvHD can be difficult to treat. In this case, your doctors will try different treatments. After a time the condition often improves.



## Graft versus disease effect

In donor transplants, the same cells which cause GvHD may also attack any remaining leukaemia cells. This is a positive and powerful effect. It can also happen in other diseases such as lymphoma and myeloma, but does not tend to be as effective. Some patients may receive a donor lymphocyte infusion (DLI) to help with this effect.

### Donor lymphocyte infusion

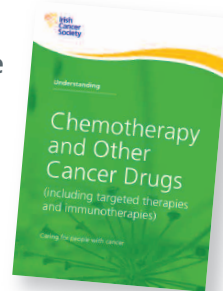
DLI means having an infusion of donor lymphocyte cells into your blood. This is done if blood tests show that you have a mixture of your own and your donor's blood and bone marrow cells after the transplant. This is called mixed chimerism. Mixed chimerism can improve on its own, but sometimes a DLI is needed to destroy any of your own cells that survive.

The aim of DLIs is to reduce the risk of the cancer coming back. Usually you will receive only a small number of donor cells, to reduce the risk of developing graft versus host disease (GvHD). You can have more DLIs if you need them.

You may also have DLIs along with chemotherapy if the cancer comes back after your transplant (relapse).

### Other side-effects

If you have any other problems, especially those not listed above, do talk to your nurse and doctor. For more about side-effects of chemotherapy, see the booklet *Understanding chemotherapy and other cancer drugs*. Call our Support Line on 1800 200 700 for a free copy or download it from [www.cancer.ie](http://www.cancer.ie). You can also visit a Daffodil Centre for advice if one is located in your hospital.



## Fertility problems

Due to the high-dose chemotherapy, you are likely to become infertile, but this does not always happen. For many people, treatment will mean that they cannot have children.

For women, your periods may stop or become irregular. You may experience early menopause with symptoms such as hot flushes or vaginal dryness, but your hormone levels will be checked to make sure. For more information, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

For men, you may stop making sperm after high-dose chemotherapy. While most chemotherapy drugs cause infertility, some do not. Talk to your doctors and nurses about the chance of getting this side-effect. Remember to still use a condom if you or your partner is of childbearing age and ask your medical team about how long you need to use contraception for.

Before starting high-dose chemotherapy, it may be possible to store sperm if you are male. Rotunda IVF at the Rotunda Hospital in Dublin provides this service. If you are female, talk to your doctor about your options.



## Other problems

There are some other less common problems that may happen after the transplant. Your doctors and nurses will monitor you closely for any of these complications.

### Cytomegalovirus (CMV)

Most people will have had CMV by the time they are an adult. CMV is a viral infection. It stays in your body and your immune system keeps it under control. It generally isn't serious, perhaps causing mild flu-like symptoms.

It usually only becomes a problem in patients with a weakened immune system. It is particularly dangerous in patients who have had a bone marrow transplant.

Significant progress has been made in preventing CMV infections, especially in patients who already carry the virus.

In the months after your transplant, you will have regular blood tests to check for CMV.



### Veno-occlusive disease (VOD)

Veno-occlusive disease (VOD) happens when the blood flow through the small veins of the liver is partially blocked. This can cause pain or swelling in your tummy and jaundice (yellowing of the eyes and skin). It can also cause a build-up of fluid in your legs and ankles.

VOD can be a very serious problem and you will be given treatment immediately. Recovery is helped by the liver's great ability to repair itself.

### Graft rejection

Graft rejection can happen in donor transplants. It is when the donor cells do not engraft properly, and are unable to produce new and healthy blood cells. Graft rejection can happen for a number of reasons but it is not very common.

### Relapse

The goal of the transplant is to cure your underlying disease. Unfortunately in some patients, the underlying disease can return after a transplant. This is always a very serious problem and treatment options may be limited depending on the previous treatments you have already received.





## What happens after I leave hospital?

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## Going home

Going home after your transplant can be difficult for you and your family. You have had a very intensive and often stressful procedure. You may feel excited, but you may also feel anxious about leaving behind the care you received in hospital. This is all perfectly normal and there is no right way or wrong way to feel.

In the days before you leave hospital, your nurses will help you with your plans for going home. Do talk to them about any worries you have. If you have any questions after you go home, you can always call the transplant unit. It may be reassuring to hear a familiar voice.

It is very common for patients to be re-admitted to hospital in the weeks or months following discharge. Do not be worried or disappointed if this happens to you. Common reasons for re-admission are:

- Infection (see page 39)
- Nausea, vomiting or diarrhoea (see page 40)
- Graft versus host disease (see page 45)



## Things to look out for at home

You need to contact the hospital immediately if you develop any of the following symptoms:

### Central line

- Shivering episode after flushing your line
- Swelling, tenderness or pus around your line

### Bowels

- Persistent diarrhoea or constipation
- Change in the colour or consistency of your stools (poo)
- Cramps

### Urine

- Change in colour
- Pain or burning sensation
- Red urine, clots or difficulty passing urine

### Skin

- Any kind of a rash
- Itching

### Temperature/shivering

- Temperature over 38°C, with or without shivering
- Shivering with or without a temperature

### Pain

- A persistent headache that does not respond to paracetamol
- Stomach ache
- Gut cramps
- Joint pain
- Mouth ulcers or a sore throat

### Nausea or vomiting

Let the hospital know if this is new or is preventing you from drinking or taking your medication

### Medicine

Let the hospital know if you're unable to take your medication for any reason

### Bleeding

- Any signs of bleeding or bruising. For example bleeding gums, or blood in the urine or stools (poo)
- Persistent nosebleed

### Cough or breathlessness

- A new or persistent or worsening cough
- Shortness of breath or increasing shortness of breath

### Contact the hospital straight away if...



You must also contact the hospital if you have contact with anyone who has chickenpox, measles or shingles.

This above list is a rough guide. If you feel unwell in any way, it is really important to call the hospital straight away.

Email: [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

## Outpatient visits

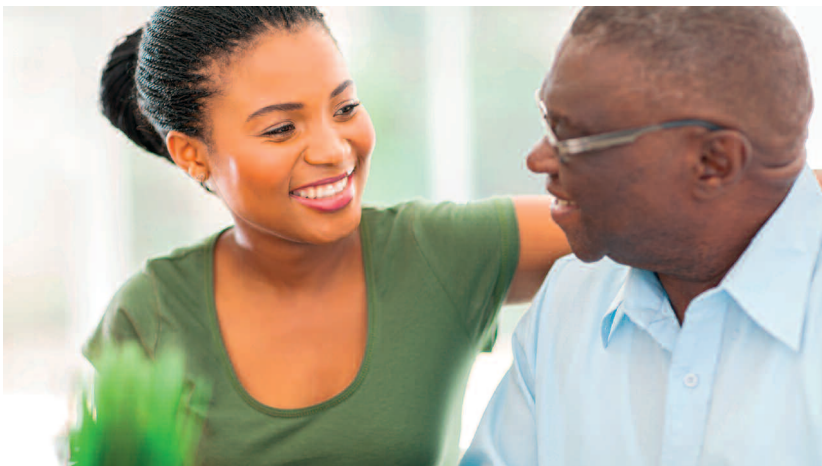
For the first few weeks after your transplant you will have to return to the day ward regularly, often daily at first.

You might need regular blood or platelet transfusions. Once your blood counts are stable and your strength is improving, you will have fewer visits to the hospital.

After this, your doctor will decide how often you need to be seen. Check-ups after treatment are called follow-up. It is likely that you will need follow-up appointments for a long time after your transplant. This will depend very much on your original disease but you may need blood tests, bone marrow tests or scans.

## Central line

In general your central line will be left in place if it is not causing problems. It can stay in until your blood counts are high enough to allow it to be removed. If the line needs to stay in place, you or a family member will be shown how to care for it at home. It will also need to be cared for weekly with a flush and dressing change in the day unit.



## Medications

You will be discharged home on certain medications. Often these include anti-sickness drugs as well as medication to protect you from certain infections. Some of the common ones are:

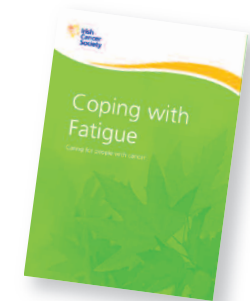
- Anti-sickness medication, but you may not experience nausea or vomiting at all
- Antacid – to treat heartburn
- Antibiotics to protect against a particular strain of pneumonia
- Anti-viral drugs to protect against the cold sore and shingles virus

You might also have other medications to take, but these will all be explained to you before you go home. Continue to take these medications until your doctor decides to stop them. If you decide not to take them, you may develop an infection and will need to go back to hospital.

## Exercise and fatigue

For the first few weeks after the transplant your energy levels will be very low. Fatigue can be a frequent and unpleasant side-effect. You will probably find you have no energy and do not feel like doing anything at first. Just getting up, washed and dressed can be a challenge in the first few weeks. Don't be expect too much from yourself – take one day at a time.

This tiredness can last for a few months but sometimes can take longer to overcome. For more about tiredness and fatigue, see our booklet *Coping with Fatigue*. Call our Support Line on 1800 200 700 for a free copy or download it from [www.cancer.ie](http://www.cancer.ie) or visit a Daffodil Centre.



## Hints & Tips – Fatigue



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



## Avoiding infection

Even if your blood counts are back to normal, your immune system takes a little longer to recover. Remember to be cautious and avoid obvious sources of infection while resuming a normal life.

### Hints & Tips – Avoiding infection

- Continue to shower every day and be strict about your personal hygiene.
- Continue your mouth care (see page 42).
- Avoid people with infections.
- Avoid areas that are overcrowded.
- Avoid close contact with pets, especially birds, in the first few weeks.
- Avoid swimming if you go home with your central line in place.
- Keep your fridge clean.

## Appetite and diet

Often during your transplant your appetite will be reduced. This might continue for some time at home and your taste and sense of smell could change too. Foods that you loved before might now begin to taste and smell different. Try not to worry, as your appetite and taste will gradually improve. Sweet tastes often return first, followed by sour ones.

It can help to eat small meals regularly, as large ones might look difficult to manage. Also try tasty foods to stimulate your taste buds. If you are not gaining weight as expected, the hospital dietitian can advise you about your diet and other things that can help you to put on weight. Sometimes you might need to go back to hospital if there are problems with eating and drinking.

Aim to drink 2 to 3 litres of fluid a day to speed up your recovery. Your mouth may continue to feel dry after your transplant so drinking plenty of fluids will also help with this. Often it is best to avoid alcohol for a time after your transplant. Ask your doctor for more advice about alcohol.

## Getting back to everyday life

### Social life

Once your white cell count has increased and you feel well enough, there is no reason why you cannot resume your social life.

Going out again can help you feel you are getting back to everyday life. But remember you will be more vulnerable to infection. Avoid visiting people who have colds, sore throats or flu. It is best to stay out of very crowded spaces for the first few months to reduce the risk of infection. For example, shopping centres, or crowded pubs, cinemas, clubs or concert venues.

### Returning to work

Once your blood counts are stable, you can think about returning to work, school or college. But you might not feel able for this for a few months after your transplant. As a rough guide, you will probably need 4 to 6 months off work.

If possible, consider returning on a part-time basis at first to ease yourself gently back to normal life. Returning to work, school or college is a big step, so do discuss it with your doctor.

### Your sex life

It is likely that after your transplant your sex life will be affected in some way. Tiredness, anxiety and lack of interest can often be the reason. It is likely that once your energy levels return to normal so too will your sex drive (libido). If your platelets or white cells are low, ask your nurse for advice about having sex. Your nurse can help and support with issues affecting your sex life or close relationships.

Even though you are likely to be infertile after the high-dose chemotherapy, there is no guarantee that it will happen. Research suggests that a small number of patients can recover fertility after a transplant. It is important to use reliable contraception such as a condom after chemotherapy to avoid pregnancy. This is because the drugs might harm a developing baby. Your doctor or nurse will advise you to use reliable contraception for a few months afterwards.



### Skin care

After high-dose chemotherapy your skin may be extra sensitive, especially to sunlight. Continue to use non-perfumed soaps and bodywashes for the first few weeks after the transplant. Take care in the sun: Cover up, wear a total sunblock (at least factor 50) and hat to avoid sunburn for at least 6 months after the transplant. Wearing a hat until your hair regrows is also important to protect your scalp, as this area will burn very quickly. You may also notice that your nails are ridged or drier than usual. Again, this is a side-effect of your chemotherapy and will clear up soon.



## Going on holiday

Getting away, even for a day or two, can be good for you. If you are planning a holiday or have one planned already, do let your nurses know. In the period after your transplant, it is best not to plan a foreign holiday. Any foreign travel should be discussed first with your doctor. You may need special holiday insurance in some cases. Depending on where you intend to travel, you may need certain vaccinations. But remember there are some types of vaccinations that are not suitable after having a stem cell transplant. Always ask your doctor and nurse for advice. For any holidays it is best to carry a letter giving details of your medical history and the hospital phone number in case of emergency.

## Other issues

More than likely you will have other issues that this booklet has not discussed. Talk to your nurses if you have any concerns or questions that need answering. No matter how small or trivial you think the question, the staff will be happy to help you. It is always better to ask than to sit at home worrying. You can also call our Support Line on 1800 200 700 for advice or visit a Daffodil Centre.



## Long-term recovery

The length of time it takes for you to fully recover from the transplant is a very individual thing and depends on the type of transplant that you have had.

Getting back to your previous routine may not be exactly what you want at this stage. You may need to make some adjustments to your personal and professional life.

It is common to feel that your life has been put on hold by your ill health. Preparing to go back to work and family life can be difficult.

In getting your control back, you may be surprised that your views and attitudes to many things may have changed. Many patients feel that their quality of life is better than before their illness, and are often surprised that they value things in life with renewed enthusiasm.

Although the transplant is a serious time, most patients are happy with the results of their treatment and are very positive about their future.

It is possible for the cancer to come back again (relapse) after a stem cell transplant. This is more likely in the first 2 years after transplant, after this time the risk of relapse reduces. If your cancer comes back, your consultant will discuss your treatment options with you, taking into account your medical history and your general health.

## Recovery of the immune system and vaccinations

Following donor transplants, it can take up to a year or even longer for your new immune system to recover. As part of this type of transplant, you lose your immunity to all of the diseases that you were vaccinated against as a child. After the first year you will see your doctor and he will let you know when you are ready to have your vaccinations. These include measles, mumps, rubella and the non-live polio vaccine.

## Possible late side-effects

### Infection

In the first year after your transplant, you may get viral infections. These include cytomegalovirus (CMV) as well as the chickenpox (Herpes zoster) virus.

For more information on CMV, see page 48. If you have CMV, it may be necessary to admit you to the hospital for a number of weeks of treatment.

The infection which results from the chickenpox virus is called shingles. This can be painful and can cause scarring. You often need to be admitted to hospital for treatment into a vein (intravenous) with anti-viral drugs.

You may also be vulnerable to chest infections and you should report any symptoms such as fever, cough and difficulty breathing to your doctor straight away.

### Chronic graft versus host disease

If you have had a donor transplant, around day 100 is the time that you can develop chronic graft versus host disease (GvHD). For more information, see page 45.



## Coping and emotions

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## How can I cope with my emotions?

Remember your emotional wellbeing is just as important as your physical health. Throughout the transplant you may have a wide range of emotions. Naturally, there will be times when you are frightened and anxious. After all, it is a new experience and can often be traumatic. It is normal to have emotional difficulties at this time and you will need the support of others.

For much of the time you might have mixed emotions – both highs and lows. Getting the stem cells can feel like an anti-climax after all the preparations beforehand. There will be the lows of feeling unwell to the highs of when your blood counts begin to recover. It can help to talk about your feelings to those close to you as well or to someone who is a good listener. Make a list of any concerns you have and discuss them with your doctor or nurse. They can also refer you to a counsellor or clinical psychologist for further help and support.



## What am I likely to feel before and after a transplant?

### Fear and anxiety

It is normal to feel anxious and daunted by the transplant process. It might make you feel helpless and insecure. But remember this does not mean that you cannot cope. You might also be afraid that your bone marrow won't recover well enough or your blood counts won't improve.

It can help to find out as much information as possible from your nurses. Being well prepared can make you feel less anxious and afraid.

Other fears might include the fear of recurrence or other cancers, that your appearance or sex life might be affected, distress about your family, uncertainty about the future, and worries about a delayed return to work life or college. It can help to speak to a trained counsellor or clinical psychologist if you feel overwhelmed by your emotions. You can call our cancer nurses on 1800 200 700 for information on free, professional one-to-one counselling (including telephone and video-call counselling) funded by the Irish Cancer Society. Some relaxation techniques can be useful in reducing anxiety. Ask your nurses for advice.

### Frustration and disappointment

There are many things that can give rise to frustration and disappointment at this time. For example, if your blood counts are improving only very slowly. If you develop symptoms or side-effects and need to be readmitted to hospital, this might upset you as well. The fact that you are not getting better as quickly as you would like might disappoint you too. You may also find it frustrating if you need frequent check-ups or trips to the day unit after you come home.

You might find the ongoing tiredness and fatigue the worst thing to bear. It might get you down that you have no energy for doing the things you enjoy. Remember some things take time to improve and this includes fatigue and blood counts. Talk to your doctors and nurses if this is getting you down.

**Express yourself:** It can help to write down any issues that are troubling you or any strong emotions you have.

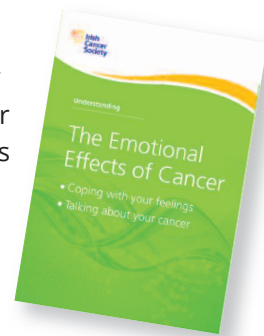
### Depression and distress

It is common to feel very low after the transplant is over, especially in the early stages. It can help to have support from your family and friends at this time. Talk to your nurses if you feel low or distressed. The distress can often happen because of the intensive treatment. Each patient has a very different experience and your nurses will care for your particular needs. It can also help to join a cancer support group so you can express your emotions and worries at this time. See page 82 for more about support centres. Your nurses can arrange for you to talk to a clinical psychologist if you are feeling distressed or depressed.

You might also be feeling lonely or feel very worried about getting infections, about dying, about your quality of life, or about any ongoing health concerns. Sometimes your doctor might prescribe antidepressants if they think it might be helpful. Your treatment can also be a difficult time for your partner or for those who care for you. Support is also available for them. Your medical team can advise you about this. Our cancer nurses on our Support Line and in our Daffodil Centres are also there to support your loved ones.

## Cancer diagnosis

If you are finding it particularly hard to cope with your cancer diagnosis, don't be afraid to get professional help. You can talk to your GP, doctors and nurses or a counsellor. A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call our Support Line on 1800 200 700 for a free copy or download one from [www.cancer.ie](http://www.cancer.ie). Our nurses can also put you in touch with cancer support centres and counsellors if you feel that would help. Or you can talk to a nurse in one of our hospital-based Daffodil Centres.



## Adjusting to home life

Once you are discharged, it can be hard to readjust to home life at first. You may feel a bit scared about going home and indeed so might those close to you. Even when you're at home, you might also feel separate or apart from your family and friends, but this is natural at this time.


Remember you have just had an intense treatment and are leaving the security of the hospital. Naturally, you can feel anxious and afraid as a result. But planning and advice from your doctors and nurses can help to reduce those feelings and help you adapt. Expect good days and bad days. It will take time but life can begin to feel normal after a while.

Email: [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

# Support resources

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## Coping with the financial impact of cancer

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

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

### Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

## Benefits and allowances

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



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

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

## If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 79 for more details of our Volunteer Driver 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.

## More information

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

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



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

## Irish Cancer Society services

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

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

### Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.

The Support Line is open Monday–Friday, 9am to 5pm. You can also email us at any time on [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie) or visit our Online Community at [www.cancer.ie](http://www.cancer.ie)

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



## Daffodil Centres

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



### Who can use the Daffodil Centres?

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

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

You can email [daffodilcentreinfo@irishcancer.ie](mailto:daffodilcentreinfo@irishcancer.ie) or visit [www.cancer.ie](http://www.cancer.ie) to find your local Daffodil Centre.



## Survivor Support



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

### Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to [www.cancer.ie](http://www.cancer.ie) and search 'Find support'.

## Patient travel and financial support services



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

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

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

## Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

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

Email: [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

## Publications and website information



We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Support Line for free copies of our publications.

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

## Local cancer support services

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

For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)



- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics



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

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

## What does that word mean?

**Anaemia** Deficiency in the oxygen-carrying pigment haemoglobin in the blood. Causes pale skin, tiredness and breathlessness.

**Antibodies** Naturally produced substances in the blood which destroy or neutralise specific toxins or 'foreign bodies', for example viruses. They are produced by the white blood cells known as lymphocytes in response to exposure to antigens.

**Antigen** A substance which stimulates cells of the body's defence system to react by producing antibodies.

**Aplasia** Failure of production of blood cells in the bone marrow because of a lack of stem cells. Usually this condition affects all types of blood cells and is called aplastic anaemia.

**Auto-immune disease** Diseases caused by an individual's immune system producing antibodies against tissues of its own body.

**Bacteria** Microscopic organisms which cause many types of infectious disease, for example pneumonia. Patients have a reduced ability to fight infections following chemotherapy or bone marrow transplantation. This may mean that even harmless bacteria, for example those which are normally found on the skin, may cause serious illness.

**Benign** Non-cancerous growths that may or may not need to be surgically removed.

**Biopsy** A small sample of fresh tissue, for example lymph node or bone marrow, removed for laboratory analysis to establish or confirm an exact diagnosis of disease.

**Bone marrow aspirate** A small volume of liquid bone marrow removed under local or general anaesthetic from either the hip (pelvis) or breastbone (sternum). The cells in the sample can then be examined under the microscope to identify any abnormality in the developing blood cells. A trephine biopsy, where a small 'core' of bone marrow tissue is removed under local anaesthetic, may be taken at the same time.

**Candida** A type of fungus. Candida infection in the mouth (oral thrush) is a common problem for immune suppressed patients.

**Cannula** A tube inserted into the body, usually into a vein, via a sharp needle-type fitting which is then withdrawn from the cannula to allow fluids to pass through the tube.

**CAT scan (CT scan)** Computer assisted tomography (CAT) is a sophisticated X-ray technique used to produce detailed internal images of the body, particularly the chest and abdomen. The patient lies on a couch, which gradually moves through the X-ray machine and the image is built up by a computer as a cross-section through the body.

**Catheter** A hollow tube inserted into organs of the body. Catheters can be used to remove urine from the bladder.

**Cells** The individual units from which tissues of the body are formed.

**Central nervous system (CNS)** The brain and spinal cord.

**Cerebrospinal fluid (CSF)** This fluid surrounds and protects the brain and spinal cord. Samples can be obtained by lumbar puncture.

**Clotting factors** A group of chemical constituents of the blood (factors I to XIII) which interact to make the blood clot.

**CNS-leukaemia** Invasion of the brain or spinal cord by leukaemic cells. This may be diagnosed by examination of the surrounding cerebrospinal fluid.

**Coagulation** Clotting of the blood. A complex reaction depending on a series of biochemical components (clotting factors) and platelets in the blood.

**Consolidation treatment** A course of treatment with anti-cancer drugs, given to the patient whilst in remission with the aim of killing any remaining cancerous cells.

**Contrast** A medium or fluid that is used in certain tests to show up or highlight organs or parts of the body.

**Cord blood** Blood obtained from the umbilical cord at the time of birth, which derives from the baby.

**Cord blood stem cells** Stem cells recovered from cord blood which have been shown to have the capability to re-populate bone marrow and produce blood cells.

**Cytogenetics** The study of the structure of chromosomes. Cytogenetic tests are carried out on samples of blood and bone marrow taken from leukaemia patients to detect any chromosomal abnormalities associated with the disease. These help in the diagnosis and selection of optimal treatment.

**Cytopenia** A reduction in the number of cells circulating in the blood.

**DNA** Deoxyribonucleic acid (DNA) provides the essential building block for storing genetic material. There are four different chemical components of DNA (bases) arranged in a coded sequence as genes, which determine an individual's inherited characteristics.

**Fungus** An infective agent such as a mould or yeast, causing particular problems in immune suppressed patients, for example candida.

**Granulocyte** A type of white blood cell. They protect the body against infection by seeking out and killing microorganisms. Neutrophils, a type of granulocyte.

**Haploidentical** 'Half-matched'. Term used in tissue-typing.

**Haematologist** A doctor specialising in the diagnosis and treatment of blood diseases.

**Haematopoiesis or haemopoiesis** Term to describe the production and maturation of blood cells from very primitive stem cells. This takes place in the bone marrow, which is a spongy tissue in the middle of bones.

**Haemoglobin** The iron-containing pigment in red blood cells which carries oxygen around the body. Lack of haemoglobin is called anaemia. Normal values are 13.5 to 17.5 g/100ml of blood in males, 11.5 to 15.5 g/100ml in females.

**Haemorrhage** Bleeding either to the outside through the skin or internally.

**Hepatitis** Inflammation of the liver.

**Hepatomegaly** Enlargement of the liver.

**Hickman™ line** A narrow plastic tube or catheter, which is inserted, into a major blood vessel in the chest under anaesthetic. It provides a route for taking blood samples and administering drugs without repeated needle puncture of a vein.

**Immune compromised/Immunocompromised** Impaired ability of the body's defence system.

**Immunoglobulins** Proteins in the blood plasma which function as antibodies and play an important part in controlling infections.

**Intramuscular injection** Injection into the muscle.

**Intrathecal injection** Injection of drugs into the spinal fluid to prevent or treat CNS leukaemia or lymphoma.

**Late effects** Results of chemotherapy and/or radiotherapy which only become apparent with long-term monitoring of the patient over a period of years. These are of particular concern in patients below the age of puberty.

**Leukocytes** Collective term for white blood cells.

**Lumbar puncture** A procedure for removing spinal fluid from around the spinal cord using a fine needle in the lower part of the back. Samples are analysed for evidence of any CNS-leukaemia. Also used to administer anti-cancer drugs to either prevent or cure CNS-disease.

**Lymph nodes or glands** Small structures found throughout the body, for example, neck, groin, armpits, abdomen, which contain both mature and immature lymphocytes.

**Lymphatic system** This consists of the spleen, lymph nodes and areas of lymphoid tissue such as the tonsils. It plays a major part of the body's immune response.

**Lymphoid** Referring to the lymphatic system including lymphocytes and lymph nodes.

**Magnetic resonance imaging (MRI)** A body scanning technique which uses an intense magnetic field to generate images of the internal organs. Properties of normal and cancerous tissue differ, allowing malignant tumours to be visualised by computer processing of the signals detected.

**Mucositis** Inflammation of the mouth and throat which may be caused by anti-leukaemia drugs.

**Myeloid** Collective term for the non-lymphocyte groups of white blood cells. It includes cells from the granulocyte, monocyte, red cell and platelet lineages.

**Neuropathy** Damage to the nerves which may occur as a complication of anti-leukaemia treatment. It usually affects the peripheral nerves (nerves to the arms and legs) and may be reversible when treatment is stopped or reduced.

**Oncologist** A specialist in the diagnosis and treatment of cancer.

**Palliative care** Treatment aimed at relieving symptoms and pain rather than curing the disease.

**Pancytopenia** Condition in which there are reduced numbers of all types of blood cells.

**Paraprotein** A form of antibody characteristic of, and produced by, a clone of cells of the B cell type, for example in multiple myeloma. Its presence in the blood acts as an important marker of disease.

**Pathologist** A doctor who specialises in the cause and diagnosis of disease and how disease affects the organs of a body.

**Peripheral blood stem cell transplant** The use of peripheral blood stem cells as an alternative to bone marrow transplantation. The stem cells are obtained by using growth factors given to the donor to increase numbers in the circulation to a level where they can be harvested.

**Petechiae/purpura** Small red or purple pin-head spots on the skin, usually the result of a shortage of platelets.

**Plasma cells** Large cells derived from the lymphocytes that form antibodies. These are normally found in bone marrow and lymph nodes.

**Plateau phase** Stable stage of disease in multiple myeloma following good response to anti-cancer treatment.

**Platelets or thrombocytes** They are tiny cell-like bodies derived from megakaryocytes in the bone marrow. Platelets circulate in the blood and play an important role in the prevention and control of bleeding. Normal values are 150-400 x 10<sup>9</sup> per litre.

**Portacath™** A form of central venous line in which the whole of the line is surgically implanted within the body, unlike a Hickman™ line. A membrane just below the skin gives access by a simple skin puncture to a line running straight into one of the main blood vessels. This simplifies the administration of chemotherapy.

**Prognosis** An assessment of the likely course of disease for a patient, particularly concerning the chances of cure and complete recovery or length of survival.

**Protocol** A schedule of treatment. For example, the number, frequency and timing of administration of a course of anti-cancer drugs.

**Pruritis** Itching, sometimes severe, which may be a significant problem in lymphoma.

**Radiotherapy** The use of X rays and other forms of radiation in treatment. Radiotherapy kills cancer cells in the area of the body being treated and is therefore an effective treatment for localised disease, particularly in lymphoma and multiple myeloma. Side-effects vary according to the type of treatment and will be discussed with the patient by the hospital staff.

**Red blood cells or erythrocytes** The cells of the blood which contain the red pigment haemoglobin and carry oxygen to all the tissues of the body. Normal red cell count in the blood is  $4.5\text{-}5.0 \times 10^{12}$  per litre.

**Remission** When the blood, bone marrow and general health of the patient are returned to normal after treatment.

**Remission induction or induction treatment** The initial course of treatment given to patients on admission to hospital to remove all clinically detectable cancer.

**Septicaemia** This is a general term to describe serious bacterial infection of the blood stream. Often causes a high fever.

**Serum** The part of the blood which remains after cells, platelets and fibrinogen have been removed.

**Specimen** A sample of tissue, blood, urine etc., taken for examination.

**Sinuses** A large channel between the brain and skull.

**Spleen** The spleen acts as a filter for your blood. It can remove old red blood cells and bacteria and other foreign bodies. The spleen also acts as a store for platelets. It is often enlarged in leukaemia.

**Splenectomy** Surgical removal of the spleen. This is sometimes done in leukaemia or lymphoma as part of a patient's treatment.

**Splenomegaly** Enlargement of the spleen.

**Staging** Seeing how much a disease has spread through the body, for example in lymphoma. Knowing the stage helps your doctors decide on the best treatment for you.

**Subcutaneous injection** An injection into tissue immediately under the skin.

**Syngeneic** Literally 'sharing the same genes'. It refers to bone marrow or peripheral blood stem cell transplants between identical twins.

**T-lymphocyte (T-cell)** A type of white blood cell derived from the thymus (hence T-cells) involved in controlling immune reactions and in fighting viral infections. Uncontrolled proliferation of this type of cell gives rise to T-cell leukaemia/lymphoma.

**Thrombocytopenia** Shortage of platelets, leading to problems with bleeding.

**Thrombosis** The development of a clot in a blood vessel, usually in a vein but sometimes in an artery. It is potentially life-threatening if left untreated.

**Total body irradiation (TBI)** Radiotherapy often given in several doses before a bone marrow transplant. It aims to kill any leukaemia in the patient. It is used together with high-dose anti-cancer drugs.

**Virus** A tiny living thing that causes disease and sickness.

**White blood cells (leukocytes)** There are 3 main types of white blood cells: granulocytes (mainly consisting of neutrophils), lymphocytes and monocytes. They are formed in the bone marrow and it is their uncontrolled proliferation, which leads to leukaemia. Normal values are within the range  $4.5\text{-}11.0 \times 10^9$  per litre.

## Questions to ask your doctor

Here is a list of questions that you might like to ask. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

What is a stem cell transplant?

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What difference will it make to my condition?

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What are the risks or side-effects of a transplant?

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How much chemotherapy do I need?

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What happens after I get the stem cells?

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How long will I stay in hospital?

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What follow-up care do I need and how long will it take to recover?

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What precautions should I take at home?

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What are the short- and long-term side effects of this treatment?

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How will my lifestyle be affected?

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Where can I go for support?

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## Your own questions

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## Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

### Support people affected by cancer

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

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

### Share your experiences

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

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

### Raise money

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

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

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

### Did you like this booklet?

We would love to hear your comments or suggestions.  
Please email [reviewers@irishcancer.ie](mailto:reviewers@irishcancer.ie)

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