Irish Cancer Society

Understanding

Allogeneic stem cell transplants

Caring for people with cancer

Understanding

Allogeneic 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

The information in this booklet describes treatment for patients aged over 16.

Useful numbers

Transplant co-ordinator

Haematology nurse specialist

Family doctor (GP)

Haematologist

Medical oncologist

Medical social worker

Emergency number

Contents

Fast facts

What is an allogeneic (donor) stem cell transplant? Page 10

- When you have an allogeneic stem cell transplant, you will receive healthy stem cells that were donated by a person who may be either related or unrelated to you.
- Before receiving an allogeneic stem cell transplant you will be treated with either a high dose of chemotherapy or radiation therapy. Sometimes both treatments are used.
- These treatments are used to destroy any remaining cancer cells in the body.
- They also destroy your bone marrow and weaken your immune system so that you do not reject the healthy donor stem cells.
- Your bone marrow that is no longer working properly is replaced with healthy stem cells from your donor.

Are there side-effects from treatment? Page 43

All treatments, particularly high-dose chemotherapy, can cause side-effects. They are usually temporary.

There are treatments to help with side-effects, so it is very important that you contact your nurse or doctor if you are experiencing side-effects or are unwell.

What are the stages of an allogeneic stem cell transplant? Page 11

1 **Preparing for the transplant.** You will have tests to check your general health and you will receive advice on preparing for the treatment. Doctors will look for a donor whose cells match yours. See page 15.

2 **Conditioning treatment.** You will receive a combination of drugs including chemotherapy and drugs to suppress your immune system and/or radiotherapy. These treatments are given to you to destroy your bone marrow and immune system. This prepares your body to accept your donor's cells. See page 27.

3 **Having the transplant.** You are given your donor's stem cells through a drip after the conditioning treatment has finished. See page 31.

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 37.

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 61.

Helplines Partnership Member

We're here for you Page 97

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

Ways to get in touch

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

See page 97 for more about our services.

Reading this booklet

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

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

About our information

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

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

About allogeneic stem cell transplants

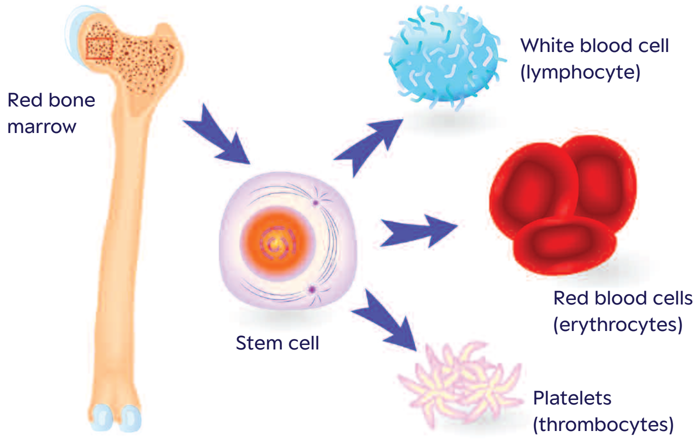
Stem cells and bone marrow

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 - 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 most bones, particularly in your hip bones. A healthy bone marrow makes over 600 billion 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 (conditioning therapy) to destroy your bone marrow. It then replaces your bone marrow that is no longer working properly with healthy stem cells from your donor.

Why do I need a transplant?

- The goal of the transplant is to cure your underlying disease.
- The conditioning therapy is given to destroy the cells causing your cancer.
- 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 the high doses of conditioning treatment.
- 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.

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.

Meeting the team: 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.

Benefits and risks: 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.

Giving consent: 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.

Planning your treatment: 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.

Questions to ask your doctor

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

What is a stem cell transplant?

What difference will it make to my condition?

What are the risks of a transplant?

How much chemotherapy do I need?

What happens after I get the stem cells?

How long will I stay in hospital?

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

What precautions should I take at home?

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

How will my lifestyle be affected?

Where can I go for support?

Preparing for the transplant

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 your 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 of 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. These regular appointments can continue for some months. It varies from patient to patient.

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 have a big impact 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 can help you with some of these issues. Our Welfare and Supports team can also help you (see page 94). To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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 treatment starts. They can advise you about your options. See page 57 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**

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. Your team 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. This is also referred to as virology testing.

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. 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 pads (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.

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 infections 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. Your blood pressure, pulse and oxygen saturation level will also be recorded.

If you are pregnant, the high-dose chemotherapy could harm the foetus. If there's any chance you could be pregnant, you will have a pregnancy test before treatment.

Most patients also need a bone marrow aspirate and biopsy and may need to have a lumbar puncture with a small dose of chemotherapy given at that time. Your doctor or transplant co-ordinator will explain these in more detail.

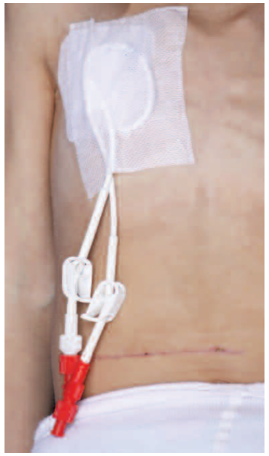
You may need to have a CT scan or PET scan before a transplant to assess your response to treatment, particularly if you have lymphoma.

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 (thin tube) placed in a large vein, which stays in place for as long as it is needed. Having this line means there is no need to put needles into the veins in your arms each time. You might hear the line called a catheter by your nurses and doctors. There are different types of central lines available, but most patients will have a skin-tunnelled central line.

Skin-tunnelled central line



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

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. 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 2 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. PICC lines are rarely used for allogeneic (donor) transplants.

Conditioning treatment

Hints and tips: 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.
- **Things to occupy your time** such as card games, books, magazines, a tablet.
- **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.

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 a high dose of chemotherapy or radiotherapy, or a combination of the 2. You may also have drugs that will work on your immune system. This is called conditioning treatment. Your doctor will talk to you about the type of conditioning treatment that is best for you.

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 26) and is infused in a drip over an hour or a number of hours. It can also be given by injection.

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

Conditioning treatment usually begins the day after you go into hospital. It can take anything from 5 to 12 days. Most patients have their transplant the day after they finish conditioning treatment. 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 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.

The stem cell transplant

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 following days referred to as plus days. The day after your transplant is plus one, 2 days after is plus 2, and so on.

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

> “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 will give you some medication through your line and will also start a saline drip. The medication, an anti-histamine and sometimes a small dose of steroids are given to prevent any allergic reaction during the infusion. Your nurse will also record 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 will depend on how the stem cells were 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

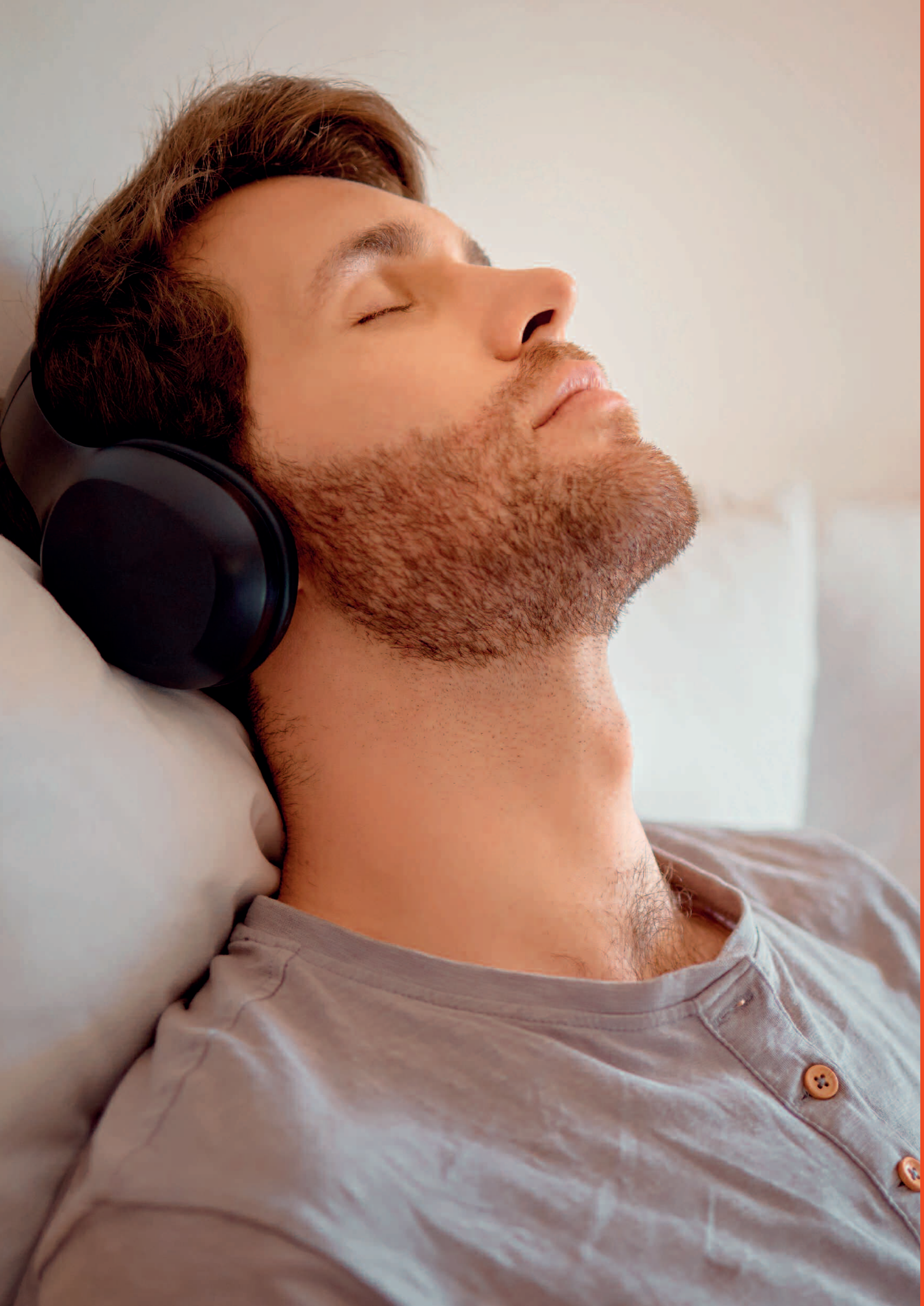
A bone marrow harvest gives a volume of approximately 1 to 1.5 litres. The harvest from the marrow contains lots of red blood cells. If the donor and recipient blood groups are different, the red blood cells are removed and the volume will be smaller. Bone marrow cells are given fresh and usually take 2 to 4 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 notice this smell but your relatives and visitors may notice it. 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 your new blood cells to grow (engraftment)

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 take longer sometimes. 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 receive a drug called a growth factor as an injection. This will boost the growth of the stem cells and help them to mature.

The number of your white blood cells (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 cared for 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 monitored 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 2 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 likely to pick 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. You might find it difficult being on your own without other patients around you. Your nurses can help you to overcome these difficulties and will do all that they can to make your stay as easy as possible. They can arrange for you to talk to someone from the psycho-oncology team to explore your feelings and try to help you cope. This may be a psychiatrist, clinical psychologist or psycho-oncology nurse specialist.

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 to keep your muscles working. This is also important for your lungs. 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. 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.

Your diet

A healthy diet is important when having a transplant. Good nutrition can help to prevent you picking up any infections. That is why you should try to eat, even if you have nausea or lose your appetite. The hospital dietitian can discuss the best way to deal with these problems if they arise. You may be given a special diet to limit your exposure to bacteria in food. This is called a low microbial diet.

How long will I be in hospital?

You will be in hospital for around 6 weeks from the time you are admitted until you go home. Once your blood counts have returned to normal levels and you are eating and drinking well, you will be allowed to go home. This is usually about 14-28 days after the transplant, depending on the type of donor and conditioning you have had for your transplant. But everyone is different and the time period can vary depending on your recovery.

If you have been referred from another hospital, your care may be shared with your referring hospital when your condition allows.

Side-effects

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.

Signs of infection include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine.

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 into a vein 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. The antibiotics 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.

Hints and tips: Preventing infection

- **Take a shower every day** and be strict about your personal hygiene.
- **Take care of your mouth** as advised by your nurses.
- **It is advisable to choose fresh running tap water, water that has been boiled and cooled or bottled carbonated (fizzy/sparkling) water.** Do not drink tap water from storage tanks or wells, water from coolers/fountains, bottled still mineral water, ice cubes made with unsafe water.
- **Avoid foods like salads, fruits, cream and uncooked eggs** – they may contain harmful bacteria.
- **Always eat freshly cooked foods.** Do not eat reheated food.
- **Ask the dietitian what foods to avoid** that may be harmful to you.
- **Tell your nurses if you have an intrauterine contraceptive device** ('coil') in place.
- **Do not to use tampons while in hospital.**
- **Remove all body piercings while in hospital.**
- **Tell your visitors not to come if they are unwell** or have been in contact with sick people.
- **Let your nurse know if you notice any signs of infection** such as pus, redness or tenderness around your central line or any wounds you may have.
- **Tell your nurse or doctor if you have a history of haemorrhoids.**

Anaemia

This is a lack of red blood cells in your body. It may cause you to feel tired, breathless and lack energy. While waiting for the new stem cells to mature, you may need some blood transfusions to boost your red blood cell levels. It is best to balance periods of rest and activity. Keep active to avoid problems that can happen due to staying in bed for long periods, such as pneumonia. But get plenty of rest during the day too.

Bleeding (thrombocytopenia)

The conditioning treatment you have before your transplant will affect your bone marrow's ability to produce platelet cells. 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.

Hints and tips: Bleeding and bruising

- **Use a soft baby toothbrush** to avoid damage to your gums.
- **When shaving, use an electric razor** to avoid bleeding.
- **Avoid blowing your nose too hard** while your platelets are low.
- **Tell a member of staff if you notice bleeding, bruising or a skin rash.** Look out for any traces of blood in your pee or poo, or any unusual bleeding.

Inflamed mouth and gut (mucositis)

Mucositis is the name for an inflamed or irritated mouth and gut (digestive system). These problems happen because tissues in the mouth, stomach and intestines are sensitive to the drugs used in the conditioning therapy. These drugs kill all fast-growing cells, which include the cells in your mouth and gut. How much mucositis you get can vary with different drugs. The stronger your treatment, the more likely you are to develop mucositis.

Mouth problems

Your mouth might feel sore, and ulcers can develop, often after receiving chemotherapy drugs.

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.

Your healthcare team may give you special mouthwashes or lozenges and pain medicines for a sore mouth. 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 healthcare team will talk to you about good mouth care during and after treatment.

Hints and 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.

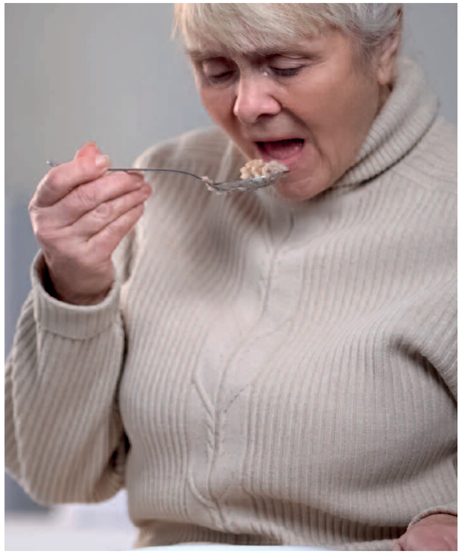
Digestive system problems

Digestive system problems often occur shortly after a stem cell transplant. Mucositis can cause these problems. Digestive problems can also be caused by infection or graft versus host disease (GvHD). Digestive system problems can include:

- Nausea
- Vomiting
- Loss of appetite
- Weight loss
- Diarrhoea

Digestive problems can be managed in different ways. There are some tips below on coping with nausea and diarrhoea. Your healthcare team may also prescribe medicines to control diarrhoea, nausea and vomiting.

Eating difficulties



Digestive problems and a sore mouth can make it hard for you to eat properly. If you have digestive problems, try to eat small meals and snacks. The healthcare team may also suggest nutritional or food supplements if you have trouble eating. If you are not managing to eat enough, you may be given a special fluid through the central venous catheter to make sure you get enough nutrition. This is called parenteral nutrition or total parenteral nutrition (TPN).

Nausea, vomiting and diarrhoea

These are common problems after getting chemotherapy drugs. 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 avoid weight loss. 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 ***Understanding diet and cancer***. Call our Support Line on 1800 200 700 for a free copy or download it from **www.cancer.ie**

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. Diuretics 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. It can affect your confidence and make you feel self-conscious about your cancer.

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.

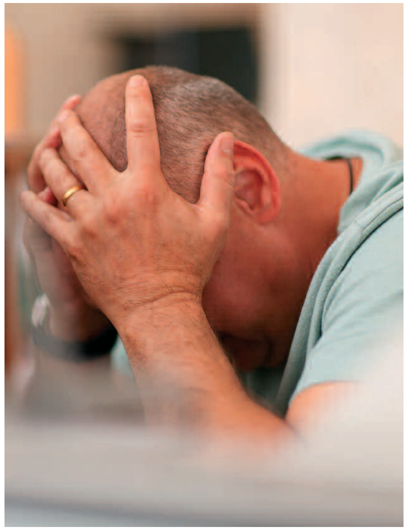
There are lots of companies providing wigs, turbans, hats and hairpieces. Your nurse or medical social worker can give you the contact numbers and arrange a visit if you are interested. You can also call our cancer nurses on 1800 200 700 for information and support.

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 when it wasn't before. These differences often disappear as your hair continues to grow.

Until your hair regrows it is important to look after your scalp. Often the skin can be dry. Applying olive oil can relieve this. Avoid strong sun and wear a hat to protect your scalp from the sun. Wear a total sunblock if you expose your scalp outside. For more advice call our Support Line on 1800 200 700 or see our website **www.cancer.ie**

Fatigue



Fatigue means feeling extremely tired. Fatigue is very common after a transplant. Patients often find it difficult to read a book, watch television or even hold a conversation. You may 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 or a podcast, 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 67.

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

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. See page 76 for more about chronic GvHD.

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)

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 the side-effects of chemotherapy, see our 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**. You can also visit a Daffodil Centre for advice.

Fertility problems

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

- Periods: Your periods may stop or become irregular. You may get an early menopause with some 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.
- Sperm count: You may stop making sperm after high-dose chemotherapy.

While most chemotherapy drugs cause infertility, some do not. Discuss the chance of getting this side-effect with your doctors or nurses. They can advise you about your options if you might want to have children in the future. For example, it may be possible to store sperm before starting high-dose chemotherapy.

Remember to still use a condom during and for a time after treatment if you or your partner are of childbearing age.

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?

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. 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. Try not to worry or be disappointed if this happens to you. Common reasons for re-admission are:

- Infection (see page 45)
- Nausea, vomiting or diarrhoea (see page 52)
- Graft versus host disease (see page 55)

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, passing blood clots or difficulty passing urine

Skin

- Any kind of a rash
- Itching or soreness

Temperature/shivering

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

Pain

- A persistent headache
- 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 or bruising

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

Cough or breathlessness

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

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

Contact the hospital straight away if...

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

Outpatient visits

For the first few weeks after your transplant you will have to return to the day ward regularly, maybe 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-up visits after treatment are called follow-up visits. It is likely that you will need follow-up appointments for a long time after your transplant. This will depend on your original disease, but you may need to have 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. This will be arranged by the hospital depending on where you are in your treatment.

Medications

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

- Immunosuppressants (anti-rejection drugs) before, during and for some time after the transplant to help to reduce the risk of GvHD. These drugs also help to reduce the risk of the donor's stem cells being rejected by your body
- 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. 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, washing and dressing can be a challenge in the first few weeks. Don’t expect too much from yourself, take one day at a time.

Regular gentle exercise can help with fatigue. But try to balance activity and rest. Start off gently as you become more active. Gradually build up the amount of exercise you take until you can resume normal activities. Remember to be realistic about how much you can achieve, taking 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** or visit a Daffodil Centre.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Start off gently as you become more active. Gradually build up the amount of exercise you take until you can resume normal activities. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Understanding diet and cancer*** has tips to help.
- **Mind your mental health.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 100).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** if your doctor says they're safe for you.

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 you're getting back to everyday life.

Sometimes you might need to be readmitted to hospital if there is a problem with infection. It is best to stop smoking too as it increases your risk of infection. Ask your nurse or doctor for advice if you would like to quit.

Hints and tips: Avoiding infection

- **Continue to shower every day** and be strict about your personal hygiene.
- **Continue the mouthcare prescribed by your hospital team.**
- **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 meals might feel 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. See our booklet ***Understanding diet and cancer*** for further information and tips.

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. If your appetite is decreased and/or you feel full more easily, avoid drinking large amounts of fluids before or during meals. 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, crowded pubs, cinemas, clubs or concert venues.

Returning to work or studies

Once your blood counts are stable, you can think about returning to work, school or college. 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 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 time afterwards.

Skin and nail care

After high-dose chemotherapy your skin may be extra sensitive, especially to sunlight. Continue to use non-perfumed soaps, body washes and moisturisers 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. You will get sunburn very easily for at least 6 months after the transplant. Wearing a hat to protect your scalp until your hair regrows is also important, 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. Moisturise your skin regularly using non-perfumed creams and lotions.

Going on holiday

Getting away, even for a day or 2, can be good for you. If you are planning a holiday or have one planned already, 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 some types of vaccinations 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 worry. 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 find that your views and attitudes to many things 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) and the chickenpox (herpes zoster) virus. For more information on CMV, see page 58. 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 treatment) 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.

Other late effects

There are other health conditions that can happen some time after a transplant. It is important to go to your follow-up appointments so your team can identify any late effects and manage them.

Chronic graft versus host disease (GvHD)

Chronic GvHD can appear at any time after an allogeneic transplant. It happens most commonly in the first 2 years after your transplant.

Chronic GvHD can present in many ways in addition to the skin, liver and gut symptoms experienced in acute GvHD. It can affect the eyes, mouth, lungs, neuromuscular system or genitourinary tract. It mainly affects the skin, causing a skin rash, which can cause the skin to become thickened and scarred over time. It can also affect:

- The eyes, making them dry and itchy
- The mouth, causing dryness and mouth ulcers
- The gut, causing weight loss and problems absorbing nutrients

GvHD can affect the lungs in 5-10% of people. This usually causes difficulty in emptying all the air from the lungs when you breathe out, which means air is left in the lungs. It can be a serious long-term problem. The healthcare team will monitor you for lung problems. They may take chest X-rays and check lung function tests. They may also prescribe medicines to prevent infection right after a stem cell transplant or to treat certain lung conditions.

Like acute GvHD, chronic GvHD is usually treated with immunosuppressive drugs, which may need to be taken for a prolonged period of time.

Important note about graft versus host disease

While GvHD can deeply impact your quality of life, it does have some benefit. The same immune response responsible for attacking your normal cells is also monitoring and destroying any surviving cancer cells. This is called the graft versus tumour effect. Patients who develop GvHD have lower disease relapse rates.

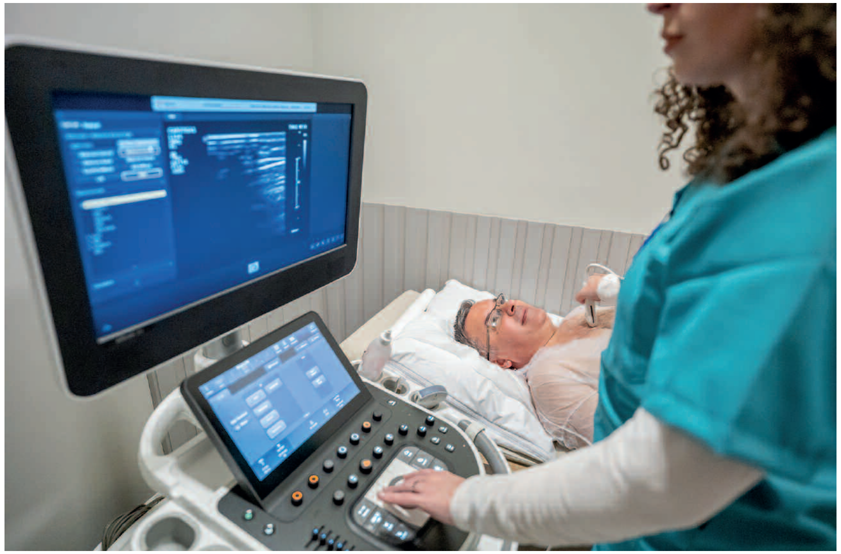
Heart problems

Heart (cardiac) problems are not common after stem cell transplants, but they can happen. Certain chemotherapy drugs, such as cyclophosphamide, can cause the heart to work less efficiently. They can also cause inflammation of the tissue around the heart (pericarditis).

If you develop cardiac problems, you may have extra heart tests, such as a repeat echocardiogram.

Chemotherapy drugs that are less damaging to the heart may be used during conditioning if there is a concern from your pre-transplant evaluation.

Studies have shown that long-term survivors of stem cell transplantation are at increased risk of having high blood pressure and high cholesterol levels, which may need treatment. This will be monitored as part of your follow-up care.

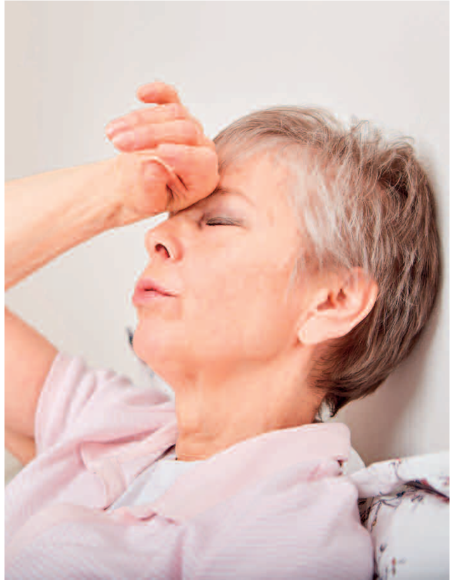


Eye problems

Some people can develop eye problems, mainly cataracts, after a stem cell transplant. A cataract clouds the lens of the eye and can cause vision loss. Eye problems can occur in people who received total body irradiation (TBI). Chemotherapy and steroids may also increase the chance of developing cataracts. The chance of developing cataracts also increases with age. Cataracts can be successfully treated by minor eye surgery.

Some patients also experience dry eyes as part of GvHD, which can be troublesome. Eye problems usually develop a year after a stem cell transplant, but they can also happen several years later. Stem cell transplant recipients are encouraged to have regular eye exams.

Thyroid problems



The risk of developing thyroid problems is quite high when total body irradiation (TBI) is used as part of the treatment. An underactive thyroid (hypothyroidism) is the most common thyroid problem. This is a condition in which the thyroid does not make enough thyroid hormone. Symptoms of hypothyroidism include fatigue, weight gain, hair loss, brittle nails, dry skin and feeling cold. For adults, thyroid function may be checked each year after a stem cell transplant. Some people may need thyroid hormone replacement therapy if the thyroid doesn't make enough thyroid hormone.

Bladder problems

Bladder problems can occur when chemotherapy drugs used during conditioning or intensive therapy scar the bladder wall. This can lead to frequent urination or blood in the urine. Sometimes patients may experience difficulty passing urine or have blood in the urine as a result of a viral infection in the urinary tract. Drugs that suppress the immune system can make this problem worse. Medicines may be needed to treat bladder problems.

Bone health

There are 2 main problems that can affect your bones: osteoporosis and avascular necrosis. The risk of these conditions is higher if you needed long-term steroids before your transplant or to treat GvHD afterwards.

Osteoporosis (or thinning of the bones) is a common problem for many people as they get older, but it's more likely to happen after a stem cell transplant.

Although it's generally not painful, your bones become weaker and could fracture (break) easily. A special type of X-ray called a DEXA scan is usually carried out about a year after your transplant and shows whether you are at risk of osteoporosis.

Fortunately, osteoporosis is often reversible. Being physically active and taking calcium and vitamin D supplements can help to prevent and treat it. Your doctor may prescribe medication called bisphosphonates that will help too.

Avascular necrosis is when bones in the joints break because of poor blood flow. It's much less common and mainly affects hip joints, but can also happen in shoulders, wrists, knees or ankles. It can be very painful and can make walking and other activities more difficult. Medication can help with the pain but many people with avascular necrosis will need surgery.

Central nervous system problems

The central nervous system (CNS) is made up of the brain and spinal cord. Several parts of the stem cell transplant process can affect brain tissue, including:

- Chemotherapy used in conditioning or intensive therapy
- Radiation therapy to the brain
- Chronic GvHD
- Infection
- Cancer that comes back (recurs)

CNS problems can include damage to the brain (called leukoencephalopathy) and problems with mental or cognitive function (processing information). Although rare, CNS problems can result in seizures. More commonly, patients experience cognitive problems during treatment. This may continue for months after finishing treatment. For some patients, CNS problems can develop months or years after a stem cell transplant.

Signs and symptoms of cognitive problems include:

- Trouble concentrating, focusing or paying attention
- Mental fog or disorientation
- Memory loss or forgetting certain things, especially names, dates or phone numbers
- Problems with understanding
- Difficulties with judgment and reasoning
- Not being able to organise thoughts or find the right word
- Processing information slower
- Behavioural and emotional changes. This includes irrational behaviour, mood swings, intense anger or crying, or socially unsuitable behaviour
- Severe confusion

It is important to report changes in your mental function to the healthcare team. They may refer you for neurological assessment or counselling. Many people deal with cognitive changes by learning ways to better cope with poor attention span, short-term memory and management of information.

Mental health and psychological problems

Mental health can be affected by the transplant procedure, which can be very stressful. The chemotherapy, radiation and long periods of time in isolation can have an impact on mental health. Some chemotherapy drugs, most commonly steroids, can cause severe mood disturbances such as depression or difficulty sleeping. In other people, steroids can induce a feeling of being very happy despite the events and associated illness of the transplant procedure. The healthcare team work closely with the psychiatry team in the hospital and frequently ask for an assessment before, during and after the transplant procedure.

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.

Second cancers

Other cancers can develop because of the amount of chemotherapy and radiation therapy given during conditioning or intensive therapy. These cancers can include:

- Acute leukaemia
- Melanoma
- Other skin cancers
- Head and neck cancers
- Brain cancer
- Liver cancer
- Bone cancer
- Sarcoma
- Lymphoma (particularly B-cell lymphoma)

Conditioning or intensive therapy can also cause myelodysplastic syndrome (MDS) later in life. MDS is a group of disorders that affect the bone marrow so it does not make enough healthy mature blood cells.

Coping and emotions

How can I cope with my emotions?

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.

It is normal to have emotional difficulties at this time and you will need the support of others.

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 about the transplant process. It might make you feel helpless and insecure. But 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 the cancer coming back.
- The fear that your appearance might change, which might affect the way that you feel about yourself.
- That your ability to have and enjoy a normal sex life may be affected.
- Worries about changes in your role within your family and maybe relationship changes.
- Worries about your finances.
- Uncertainty about the future.
- Worries about a delayed return to work or college life.

It can help to speak to a trained counsellor or clinical psychologist if you feel overwhelmed by your emotions. Your nurse or doctor can arrange a referral for you.

You can also talk to our cancer nurses on our Support Line and in our Daffodil Centres. They can also give you information on free professional one-to-one counselling.

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. For example:

- Your blood counts are improving very slowly.
- You develop symptoms or side-effects and need to be readmitted to hospital.
- You are not getting better as quickly as you would like.
- You need frequent check-ups or trips to the day unit after you come home.
- Ongoing tiredness and fatigue mean that you have no energy for doing the things you enjoy.

Talk to your doctors and nurses if things are getting you down and remember that things such as fatigue and blood counts take time to improve. Our booklet ***Coping with fatigue*** has advice to help. Call our Support Line for a free copy or read or download it on our website **www.cancer.ie**

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. 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 104 for more about support centres. Your nurses can arrange for you to talk to a clinical psychologist if you are feeling distressed or depressed.

It is normal to experience many different emotions.
You may be feeling lonely or you may 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 the Support Line and in the Daffodil Centres are also there to support you and your loved ones.

Cancer diagnosis

If you are finding it particularly hard to cope with your cancer diagnosis, seek professional advice early. You can talk to your GP, your hospital team or a counsellor.

Our booklet ***Understanding the emotional effects of cancer*** has advice to help. Call our cancer nurses on 1800 200 700 for a free copy or download one from **www.cancer.ie** Our cancer nurses can also put you in touch with cancer support centres and counsellors if you feel that would help. You can also 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 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.

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.

Support resources

Money matters

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

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

Irish Cancer Society Welfare and Supports Team

We provide appropriate supports and advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis/returning to work**
- **Housing and homelessness issues**

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 an Irish Cancer Society Welfare Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

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

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: 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 101 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.

Money and finances

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

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

Our website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Team may also be able to help (see page 94).

Email: supportline@irishcancer.ie

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:

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Welfare and Supports Team (see page 94)

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

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

You can also email us at any time on supportline@irishcancer.ie

Daffodil Centres

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

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

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone. Just call in if you want to talk or need information on any aspect of cancer including:

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

Telephone Interpreting Service

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

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

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

We will connect you to an interpreter.

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

Peer Support

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

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

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

Patient Education

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

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

Counselling

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

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

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

Support in your area

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

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

Transport Service

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

- The Irish Cancer Society Volunteer Driver Service is available mainly to patients undergoing 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 radiotherapy patients attending University Hospital Cork and the Bon Secours Hospital, Cork 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 the fund if they are travelling over 50km one way to a national designated cancer centre or approved satellite centre. Travel2Care is made available by the National Cancer Control Programme.

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

Night Nursing

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

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

> “We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.”

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

Email: supportline@irishcancer.ie

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line or visit 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 partners, families and carers, during and after treatment, many of which are free. For example:

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

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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie/local-support**

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 axial 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. Urinary 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 involving 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 comes 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 the most suitable 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 are 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 men and people assigned male at birth, 11.5 to 15.5 g/100ml in women and people assigned female at birth.

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-cancer 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-cancer treatment. It usually affects the 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 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 109 per litre.

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 4.5-5.0 x 1012 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: Outlining 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 - 11.0 x 109 per litre.

Notes/Questions

Notes/Questions

Acknowledgments

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

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

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Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Did you like this booklet?

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

Our cancer nurses are here for you:

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

Irish Cancer Society

www.cancer.ie