Irish Cancer Society

Understanding

Autologous stem cell transplants

Caring for people with cancer

Understanding

Autologous stem cell transplants

This booklet has information on:

- Preparing for a stem cell transplant
- Having a stem cell transplant
- What happens after a transplant, including possible side-effects

Useful numbers

Haematology nurse specialist

Haematology transplant coordinator

Family doctor (GP)

Haematologist

Medical oncologist

Medical social worker

Emergency number

Hospital records number (MRN)

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Fast facts

What is an autologous stem cell transplant? Page 10

An autologous stem cell transplant allows you to have higher doses of chemotherapy than usual to treat your disease. The high-dose treatment will destroy your bone marrow. An autologous stem cell transplant uses healthy blood stem cells from your own body to replace your damaged bone marrow.

What are the stages of an autologous stem cell transplant? Page 12

1. **Collecting your stem cells.** Before your stem cells are collected you will be given drugs to move your stem cells from your bone marrow into your blood. When you have enough stem cells, they are collected using a special machine.
2. **High-dose treatment.** You will be admitted to a special hospital ward to receive your treatment. How much chemotherapy you need will depend on your condition.
3. **Getting your stem cells back.** Your stem cells are usually given back to you 1–3 days after the chemotherapy has finished.
4. **Waiting for new blood cells to grow.** After your stem cells are given back to you, they find their way to your bone marrow and start to grow and make healthy new blood cells. After the transplant you will be looked after in isolation to protect you from infection. Usually after 10–21 days, your blood counts will start to recover.

Are there side-effects? Page 50

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

There are treatments to help with most side-effects, so tell your treating team if you have any. Don't suffer in silence.

We're here for you Page 79

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 to speak to a nurse. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 79 for more about our services.

Reading this booklet

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

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

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

About our information

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

You should always talk to 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.

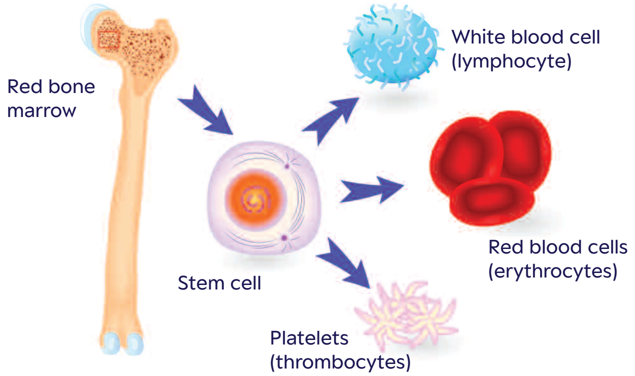
About stem cell transplants

What are stem cells?

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

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

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



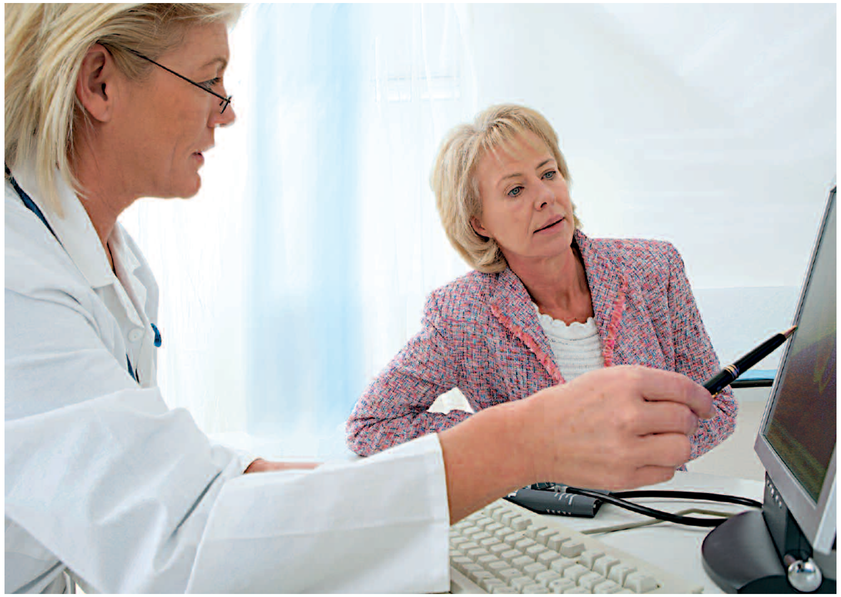
What is an autologous stem cell transplant?

A stem cell transplant allows you to have higher doses of chemotherapy than usual to treat your disease. But the high dose of treatment will also destroy your bone marrow.

Because of this, you have some of your stem cells taken and stored before having high-dose treatment. After the treatment, they are given back to you so they can grow new, healthy blood cells.

When you donate the stem cells yourself, it is called an autologous transplant. Autologous means something that comes from your own tissue or DNA. It can also be called an autograft or autologous peripheral blood stem cell transplant.

The word transplant can sometimes be confusing when used to talk about blood and bone marrow diseases. It is not a transplant like an organ transplant, such as a kidney transplant. It refers to getting stem cells from your blood or bone marrow and returning them to you.



Why do I need a transplant?

An autologous stem cell transplant allows you to receive high doses of chemotherapy. The chemotherapy will destroy the cells causing your cancer.

But chemotherapy cannot tell the difference between normal and diseased cells. As a result, it will also destroy the healthy cells in your bone marrow. 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 your stem cells are given back to you through a drip (infusion), they will ‘rescue’ you from this high dose of chemotherapy. Your 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.

What are the stages of an autologous stem cell transplant?

There are four stages to an autologous stem cell transplant or autograft. These are:

1. Reducing your disease to as low a level as possible using chemotherapy or radiotherapy.
2. Collecting your healthy stem cells from your blood using mobilisation chemotherapy (cell mobilisation), by a procedure called peripheral blood stem cell harvest (see page 23).
3. Treating you with high-dose chemotherapy (conditioning chemotherapy). Because the chemotherapy cannot tell the difference between cancer and healthy cells, your bone marrow cells will also be killed (see page 37).
4. Giving you back your stem cells (reinfusion), which will grow and make new red blood cells, white blood cells and platelets. The reinfusion of the stem cells is the transplant (see page 43).

What are the risks of transplants?

The main risks happen when your bone marrow is recovering. This is the first 2 weeks after your transplant. At this time, you are at risk from infections and bleeding. See page 50 for more about side-effects of transplants.

Where does the transplant take place?

The transplant will take place at a highly-specialised transplant centre. Before your stem cells are collected, you will be asked to attend the transplant centre. 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 your visit. So it's important to bring along your partner or a family member when you visit. You will also be asked to sign a consent form allowing for the transplant to go ahead.

If you like, you can also phone the transplant centre after your visit in case there were any questions you forgot to ask. 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 close contact with you to arrange visits and what to do if you need injections, tests or anything else.

Fertility and stem cell transplants

High-dose chemotherapy often causes infertility, so you may not be able to have children after treatment. If you want start a family or have more children in the future, ask your doctor about how your treatment may affect your fertility before treatment starts. They can advise you about your options.

Questions to ask your doctor

Here are some questions that you may wish to ask your doctor. There is also some space at the back of this booklet for you to write down your own questions Never be shy about asking questions. It is always better to ask than to worry.

- What is an autologous stem cell transplant?
- What difference will it make to my condition?
- What tests do I need beforehand?
- What are the risks or side-effects of a transplant?
- When are the stem cells collected?
- How do I prepare for the cells to be collected?
- How are the stem cells moved into my bloodstream?
- What happens if you cannot collect enough stem cells?
- What happens after the stem cells are collected?

> “Throughout my stem cell transplant, the care I received was seamless. The nurses and doctors looking after me made me as comfortable as possible and always found the time to answer my questions.”

Preparing for the transplant

What tests do I need beforehand?

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. Some of these tests include:

- Blood tests
- 24-hour urine collection
- Lung function tests
- Chest X-ray
- ECG (heart test)
- Echocardiogram (ECHO)
- Dental check-up
- Extra scans or biopsies, if your transplant is for lymphoma.

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

24-hour urine collection: This test checks how well your kidneys are 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 stream of urine in the toilet as normal and note the time. Write this time on the bottle. From then on start collecting all of the urine you pass. Your collection finishes exactly 24 hours after the time you wrote on the bottle. It is important to collect all the urine you pass in the bottle. If you forget to pass urine in the bottle, the test will have to be repeated. To measure the results, you will need a blood test taken when you return the urine collection to the hospital.

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

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

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

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

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 infections, which are not usually harmful but may cause problems 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. Because your veins will be used to collect the stem cells, a nurse will check if they are suitable for the type of needles put in to collect the cells.

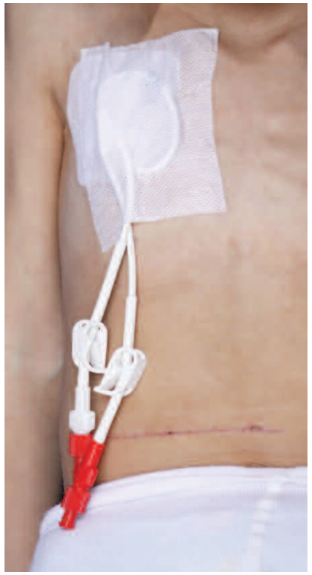
If you are pregnant, the high-dose chemotherapy could harm the foetus. If there's any chance you could be pregnant, you will have a pregnancy test before treatment.

You may need a bone marrow biopsy and a lumbar puncture. Your doctor or transplant coordinator will explain these in more detail. Extra tests may be needed, depending on your condition and medical history.

Putting in a central line

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

Skin-tunnelled central line

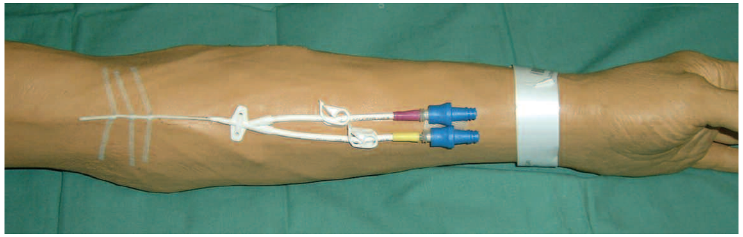


This line is put into your vein in the X-ray department under local anaesthetic. It is a hollow plastic tube that is put in through a small cut (incision) near your collarbone.

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

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

PICC line



PICC stands for peripherally inserted central catheter. This is the type of line most commonly used for an autologous transplant. The 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 two thin tubes come out from your arm. The PICC line can remain in place throughout your transplant. It will be held in place by stitches, which will remain there while the line is in.

Getting organised before your transplant

The time you spend in hospital before, during and after your stem cell transplant will vary from person to person. But your treatment may impact significantly on your life. Before you begin your treatment, you may want to:

- Organise your finances, including any social welfare benefits you may be entitled to
- Talk to your employer about sick leave
- Organise childcare
- 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.

Collecting the stem cells

Before your stem cells are collected

Before your stem cells are collected, you will be introduced to the team of nurses who will take care of you. They are known as the apheresis team. You will also get a chance to ask any questions and clear up any concerns. It is a good idea to prepare any questions you may have before your appointment and take a notebook with you to take notes. The staff will explain in detail what is involved. You will also be asked to sign a consent form allowing them to go ahead and organise the moving and collection of the stem cells.

> “My doctor explained that that the potential benefits of a stem cell transplant far outweighed the negatives.”

How are the stem cells moved into my bloodstream?

The first part of collecting stem cells from the blood is making them move from the bone marrow into the blood. This is called mobilising the stem cells. There are several ways that this can be done. The method will be decided by your doctor, depending on your condition. The most common ways are:

- **Giving growth factors (G-CSF)**
- **Giving chemotherapy and growth factors (G-CSF)**

Growth factors (G-CSF)

Growth factors stimulate the bone marrow and increase the number of stem cells in the blood. The most common one is G-CSF, which stands for granulocyte-colony stimulating factor. When given by injection, G-CSF causes blood stem cells to be released from your bone marrow into your bloodstream. These stem cells can then be collected from your bloodstream.

The growth factors are given as a daily injection under your skin for several days. This is done until enough stem cells have been collected. It is important that the injection is given in the evening at roughly the same time each day. Remember the injections must be given every day and only stopped when the transplant team tells you to do so. The haematology team will discuss how to give the injection with you. A family member, partner, or public health nurse can be organised to give the injections. If you wish, you can also give the injections yourself.

Side-effects

The most common side-effect of these injections is bone pain. This usually happens in the chest, back and hip area and is a spasmodic type of pain. The pain is usually relieved by simple painkillers such as paracetamol. However, paracetamol may mask or hide a fever. If you feel unwell in any way, the best advice is to contact your hospital.

Other side-effects include flu-like symptoms, tiredness, headache, sleeplessness and irritability. Occasionally, a slight tingling sensation, redness and bruising may occur at the injection site. Sometimes G-CSF can cause allergic reactions, which can be easily treated.

> "After the growth factor injections, I'd have quite a bad pain in my back. My doctor told me this was common. It meant the growth factor was working and that the bone marrow was making more white blood cells."

Chemotherapy and growth factors (G-CSF)

A course of chemotherapy may be given to you before starting the G-CSF injections. This is given both to treat your condition and to increase the number of stem cells mobilised. Some chemotherapy courses may be given as an inpatient, while others are given as an outpatient. Your doctors and nurses will discuss with you the chemotherapy you might receive.

When are the stem cells collected?

The ideal time to collect stem cells is when your white blood cells begin to rise rapidly. For this reason the transplant team will check your full blood count regularly. Your blood must also be tested for a special protein called the CD34 level. This level reads the number of stem cells in your bloodstream. Based on this result, the transplant team will know when your stem cells are ready to be collected. When checking this level, blood samples need to be taken over a number of days to find out the ideal day to start collecting the stem cells. Your nurse will let you know at what time this blood sample will be taken each day.

There is a chance that your blood count may not ever rise to the level needed to collect the stem cells. There is also the chance that the number of stem cells collected is not enough to allow for future use. If this happens, other options will be discussed with you.

How are the stem cells collected?

Collecting the stem cells is called harvesting. The stem cells are collected using a machine called a cell separator. It is also known as an apheresis machine. This machine spins your blood at high speed to separate out the stem cells. You will notice on the day of your harvest that the machine makes a low humming noise like a washing machine spinning. The spinning allows your blood to separate into layers.

> “On the day of my stem cell collection I sat in a comfortable seat and was hooked up to the machine beside me. It took about 3 hours and it went very fast. I didn’t feel anything at all.”

The layer with the stem cells is collected into a sterile bag by the machine. Also, the machine will remove some of your plasma each day, usually about 400mls. Plasma is the name given to the pale yellow liquid part of blood minus the blood cells.

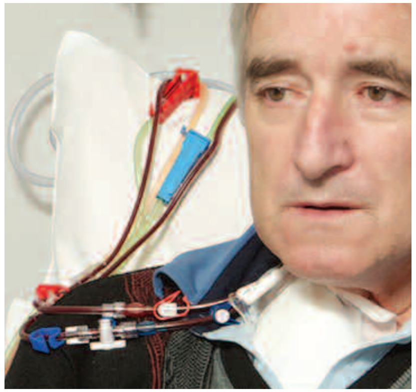
All of the remaining blood is then returned to your system. All the kits used in the machine containing the lines and bag are disposable, so no blood actually comes in contact with the inside of the machine.

Apheresis machine

Putting in needles

To collect the stem cells, a special needle must be put in the bend of both your arms. One of these needles helps to take the blood from you and into the machine. The other is to allow the blood that is no longer needed to be returned to you.

During the collection, you cannot move your arms freely and will need to stay in one place. This is to prevent the needles moving or dislodging. But your arms will be placed in a comfortable, supported position beforehand. Once the stem cells are collected, the needles will be removed. You may notice some bruising and tenderness around the needle area but this should clear up within a few days.



If your veins are too small or not suitable, you may need to have a temporary line put into a large vein. This line or tube is sometimes called a catheter or vascath. The vein can be located in your neck, upper chest or groin. A local anaesthetic is given first and X-rays are taken to guide the line into your vein.

The line will be left in place until all the stem cells are collected and will then be removed. Once removed, the area around the line may be tender and may also bruise. But this should clear up within a few days. Some lines can be left in place to allow for any further chemotherapy and your transplant. The transplant coordinator will discuss this with you.

Will I feel anything while connected to the machine?

Once you are connected to the machine you should not feel anything. Your nurse will stay with you for the entire time. Certain side-effects can occur and are mainly due to:

- A change in the amount of blood in your system
- The anticoagulant used

Side-effects can include:

- Feeling light-headed
- Feeling dizzy
- Nausea
- A sour taste in your mouth
- Tingling around your lips, fingertips and other sensitive areas
- Bleeding or bruising
- Tiredness

Amount of blood in your system: Usually about 200mls of blood is spinning through the machine at any one time. Having slightly less blood in your system may cause you to feel light-headed, dizzy or nauseated. If these side-effects occur, tell your nurse, as they can be easily treated.

Anticoagulant used: Once blood leaves your body it will start to clot after a time. To prevent the blood in the machine from clotting, an anti-clotting (anticoagulant) drug is added. As blood is returned to you, so will some of this anticoagulant. The anticoagulant may drop the calcium level in your body, causing a sour or metallic taste in your mouth. You might also notice some tingling around your lips, fingertips and other areas with sensitive nerve endings. Other symptoms include nausea or feeling cold and shivery. These can be treated simply with a glass of milk or a calcium tablet drink or drip.

Bleeding or bruising: Some red cells and platelets may be unavoidably removed when collecting the stem cells. This may reduce your platelet count. As a result, you may be more likely to bleed or bruise. Within days the platelets will rise to the normal level naturally, but if your count is very low you may need a platelet transfusion. This will be discussed with you in more detail if needed.

Tiredness: You will probably feel quite tired afterwards, but this should ease off once you have rested.

How long does the collection take?

In general, each session takes around 3–5 hours. It may take a few sessions to collect enough, so this will happen over a few days. Afterwards you will be asked to stay on for about half an hour to make sure you are feeling well. During this time you will be offered a light snack.

What if there are not enough stem cells?

Sometimes you may not have enough stem cells on the first try. This can happen for many reasons. Some people's stem cells are simply stubborn and will not release well into the bloodstream. More often it is because the patient has had chemotherapy or radiotherapy to the bones as part of previous treatment. If you do not have enough cells the first time, your doctors and nurses may need to try a different approach. For example, giving another drug to help G-CSF release the stem cells into your blood. See page 26 for more information on G-CSF.

What happens once the cells are collected?

Once the collection is over, the bag of stem cells will be removed from the machine. About 200–300mls of stem cells are collected per day. You will get the chance to see the stem cells if you wish. From there the cells are brought to the laboratory where the number of stem cells in the bag are counted. The stem cells are then mixed with a preservative called DMSO and frozen. This freezing is known as cryopreservation.

Once frozen, the stem cells can be stored for several years. On the evening of your harvest, one of the haematology team will contact you to tell you if you will need a second or third day of harvesting. You may be admitted to hospital until your stem cells are collected, particularly if a line has been inserted to collect your cells.

This routine will be the same on each day of harvesting. No more than 3 days of harvesting will be done. If you need another day of harvesting, then it is important to keep taking your growth factor (G-CSF) injections.

> “After the harvest I had something to eat and was free to go home. My stem cells were taken away to be frozen.”

Hints and tips: What can I do to help?

- **Do not take aspirin or tablets containing aspirin 2 weeks before your stem cell collection.** Your transplant team will discuss this with you. If you are taking any anti-coagulant (blood-thinning) medication, talk to your doctor or transplant coordinator about stopping this medication for a time.
- **Make sure you have a milky breakfast on the morning(s) of your harvest** to boost your calcium level. If you prefer, you can eat yoghurt or cheese instead.
- **Wear or bring a short-sleeved top** to allow easy access to your arms.
- **If the day is cold, wrap up well.** Keeping warm will help enlarge your veins and make it easier to put in the needles.
- **Use the bathroom before you are connected to the machine.** As you will be 3 to 4 hours on the machine, it may be difficult to use the toilet.
- **Often the time on the machine can be quite boring. Ask the transplant team if it is OK to bring a companion along if the hospital,** if you would like company. You could bring something to listen to, if you wish. It is best not to bring reading materials as your movements will be restricted. Most units have a television for your entertainment.
- **Do not drive after the harvesting.** It is a good idea to have someone collect you afterwards.
- **Avoid strenuous activity on the days of harvesting.** Rest for the evening.
- **Avoid smoking for at least 2 hours after the harvest.**
- **You can return to work the day after your last harvest** if you wish.

High-dose treatment

When will I go to hospital for high-dose treatment?

If your stem cells have been successfully collected, the transplant coordinator or specialist nurse will contact your doctor and nurse with dates for your admission and transplant.

You will then be admitted to a special hospital ward or unit. The ward is specially designed to look after patients needing a stem cell or bone marrow transplant. Each patient usually has a single room with ensuite bathroom and a television. The air in the ward is specially filtered, which helps to prevent or reduce the risk of airborne infections. The system also allows the air temperature of your room to be changed as needed.

During your stay, you will be asked to remain within the ward but you can leave your room and walk around the ward, unless your white blood cell count is low. At some point during your transplant, you may be brought out of the ward to the X-ray department if scans or X-rays are needed.

Hints and tips: What to bring to hospital

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

How many days of treatment will I need?

Usually you start high-dose chemotherapy the day after you are admitted to the ward. How much chemotherapy you need and for how long will depend on your condition. It may last one or more days. But your transplant coordinator or specialist nurse will discuss this with you in more detail. Giving high-dose chemotherapy is also known as conditioning your bone marrow. All the bone marrow cells are killed off so you can receive new stem cells.

All of the chemotherapy will be given into a vein through a central line. You will need to drink lots of fluids to flush out any harmful toxins and waste products afterwards. If you don’t feel well enough, you can be given fluids through a drip. Your doctor and nurse will explain this to you in more detail. Once the chemotherapy is completed, you will have at least a 24-hour gap before your stem cells are given back to you.

The high-dose chemotherapy will cause your blood count to fall about 5 days after treatment. In particular, your white blood cells will be very low. This means your immune system will be less strong and you will be at risk of infection. This is why you will be nursed in isolation in a special ward or single room. You are likely to experience some side-effects of chemotherapy. See page 50 for more details.

Having the transplant

When are the stem cells given back to me?

Once you have finished the chemotherapy, replacing your stem cells is quite simple. This happens 1–3 days after the chemotherapy has finished. The stem cells are first defrosted and then given through a drip into your central line.

Giving your stem cells back to you is known as reinfusing the stem cells.

The day you receive the stem cells is known as Day 0 (zero). This is because the staff measure your recovery starting from this day.

Defrosting the stem cells

The reinfusion is usually in the early afternoon, but the staff will let you know when the reinfusion is planned. One of the laboratory staff will come to your room about 1 hour beforehand to set up a water bath. Your stem cells will be defrosted in a special container in this water bath.

> On the morning my stem cells were given back to me, they arrived in my room in a portable freezer. They were then thawed out in hot water and put back into my body through my PICC line.

Reinfusing the stem cells

Once they are thawed, the stem cells are reinfused through your central line. Before the reinfusion you will be given an antihistamine and steroid injection. This is given to prevent you having any allergic reaction to the preservative used to store the stem cells. You don't need to worry as your nurses and doctors will watch you closely. The injection may make you feel slightly sleepy.

Receiving the cells is like having a blood transfusion, but there may be a number of bags to infuse. If you have more than 4–6 bags of stem cells, you might receive them over 2 days. If a large number of cells have been collected, only some of them might be given back to you. The rest will stay in storage. Usually the infusion lasts under an hour. A nurse and member of the laboratory staff will be in the room with you during the infusion. You should not feel anything while the stem cells are being reinfused.

Will I feel anything after receiving the stem cells?

You may notice a strange taste and smell after the infusion. The smell is like garlic or boiled sweet corn. This is due to DMSO, which is a preservative used to protect the cells while in storage. You may not notice this smell but your relatives and visitors may notice it. It is nothing to worry about and the smell and taste will clear within a day or two.

You might also feel some nausea. Your urine might turn red after the return of the stem cells as well. This will disappear within a few hours.

What happens after I receive the stem cells?

After your stem cells are reinfused, you will start G-CSF injections. This is a growth factor that will boost the growth of the infused stem cells and help them mature. The day on which these injections start will vary, depending on your treatment plan. You will remain on this injection until your blood counts have recovered.

You will need to wait for the stem cells to move into your bone marrow. This happens gradually and is called engraftment. During this time, your blood counts will be low and you may need transfusions and antibiotics. Usually after 10 to 21 days, your white bloods cells will start to recover.

Daily blood tests will be done, especially to check the number of white cells, in particular, neutrophils. These neutrophils fight infection. Your transplant team will try to protect you from possible infection so you will be looked after in a special ward or single room during this time. This is sometimes called protective isolation.

What happens when I'm in isolation?

Once the stem cells have been given back to you, you will be looked after in isolation, to protect you from infection. You will be closely watched and checked for signs of infection.

Visitors

In general, visiting is restricted while you are in isolation. 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. If you are not feeling well after chemotherapy, you could ask your relatives not to visit that day.

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.

Handwashing 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. For your protection, staff and visitors will be asked to wear plastic aprons before seeing you. Your room and its contents will also be cleaned every day.

> "Visitors were limited and everyone who came into my room had to wear gowns and wash their hands thoroughly."

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.

Moving around

It can be hard having to stay in a small room all the time. But it is important to be as mobile as possible and keep your muscles working. It's also important for your lungs. 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.

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 overcome these difficulties and will make your stay as easy as possible. They can arrange for you to talk to a clinical psychologist or psycho-oncology nurse to explore your feelings and try to help you cope.

> "I made sure I had plenty to keep me entertained during my hospital stay. I didn't mind being in isolation. My wife would visit me and I read a lot."

Are there side-effects to the transplant?

Your doctor and nurse will discuss any likely side-effects with you beforehand. Any side-effects you experience are due to the high-dose chemotherapy.

Many of the chemotherapy drugs that are used have different actions. Also, different drugs are used for different conditions. Your doctor and nurses will let you know about these drugs in more detail. There is no way of knowing in advance how many side-effects you will get. Each person is different; some will get all of the side-effects, while others just a few.

The main side-effects happen because the blood cells produced by the bone marrow (red cells, white cells and platelets) are affected by the treatment. Lack of red cells can cause anaemia, lack of white cells can increase your risk of infection and lack of platelet cells can cause bleeding and bruising.

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.

Infection

Once your white blood cell level drops, you will become more at risk of infections. For example, the bacteria normally present on your skin can cause problems such as central line and skin infections. There are many precautions taken to prevent infection, including nursing you in a single room. Despite these precautions, it's likely you will develop a temperature or infection at some point during your hospital stay.

Your nurses will monitor you very closely for signs of infection. Signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine. The nurses will check your temperature regularly along with your pulse and blood pressure, particularly when your white cell count remains low.

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

When you have a fever, your doctor will examine you and will probably prescribe intravenous antibiotics. These are antibiotics that are given 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 and are used until the cause of your fever is identified or your temperature returns to normal. If you still have a temperature after 24 or 48 hours, doctors may repeat the blood test and change the antibiotics.

Occasionally people can become very ill with infection and develop a condition called sepsis. Sepsis can result in low blood pressure or difficulty breathing and can even require admission to the intensive care unit for closer monitoring.

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.
- **Drink sterile water or canned soft drinks** – these will all be provided for you during your time in hospital.
- **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.**

If you are unsure about any of these hints and tips, ask your nurses for more advice.

Bleeding and bruising

Once your platelet count falls, you will become more likely to bleed and bruise and may need platelet transfusions. The usual places to notice bleeding are in your gums and from your nose.

Hints and tips: Bleeding

- **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.

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, the dietitian may advise that you have nutrition through a vein. For this, you will receive a bag of liquid nutrients, usually overnight, 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 ease off gradually.

If you get diarrhoea, hygiene is very important. Creams will also be given to you 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 take extra fluids to replace those that 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**

> “After the high-dose chemotherapy, I was bloated and nauseous and I had diarrhoea… but with every day, I felt a little bit better.”

Inflamed mouth

Mucositis is the name for an inflamed or irritated mouth. Your mouth might feel sore, and ulcers can develop. Chemotherapy 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 get this problem. As a result, your mouth or throat may begin to get sore a couple of days after the transplant. It can begin slowly, then you may notice that your tongue looks white and the lining of your mouth becomes tender. Your saliva might also become thick. You might notice that your throat is sore and you cannot swallow as normal. If you notice black or white spots on your tongue, tell your doctor or nurse.

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

Hints 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.

Poor appetite

This happens quite often when chemotherapy is given. You might have no wish to eat anything for a few days. Even drinking fluids might be difficult for you. If this happens, then you may need to get fluids in a drip. The hospital dietitian can also offer you advice on what to eat.

Hair loss (alopecia)

Chemotherapy often causes hair loss. Loss of body hair occurs at first from your head and then from your eyebrows, eyelashes, underarm and pubic area. It can affect your confidence and make you feel self-conscious about your cancer. The amount of hair loss differs in individuals. For example, you might get severe hair thinning or total hair loss. This can be very distressing. Some people prefer to have their hair cut up short or completely shaven 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.

Remember the hair loss is temporary and hair will return. Regrowth usually begins any time from 2 months after the chemotherapy but it 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 but applying olive oil can relieve this. Avoid strong sun and wear a sunblock if you expose your scalp. For more advice call our Support Line on 1800 200 700 or see our website **www.cancer.ie**

Veno-occlusive disease

This is an extremely rare problem if you have an autologous stem cell transplant. It is a disease where the blood flow through the small veins in your liver is partly blocked by clots. It causes weight gain due to fluid retention, jaundice (yellowing of the eyes and skin) and swelling of your tummy. Usually it is very mild but sometimes can be severe. You may be given a drug to prevent it happening. If it does occur, it usually happens within 3 weeks of having chemotherapy. It is treated with drugs to try to dissolve the clots.

Infertility

Due to the high-dose chemotherapy, you are likely to become infertile, but this may not always happen. For many people, 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. 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 is of childbearing age.

Fatigue

Fatigue is very common. It can make you feel tired and weak. For more information see page 66.

Skin and nail changes

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

Peripheral neuropathy

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

Changes in kidney or liver function

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

Blood clots

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

Other side-effects

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

Talking to your medical team

It is important that you talk to your nurses and doctors if there is anything troubling you. For example, a sore mouth, being unable to eat or if you are feeling down. All of your worries and concerns are important to them. If you don't understand something you have been told, ask them to repeat it. They won't mind explaining it again.

How long will I be in hospital?

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 10–21 days after the transplant. But everyone is different and the time period can vary depending on your recovery. Overall, you could spend 3 to 4 weeks in hospital – from the time you are admitted until you go home.

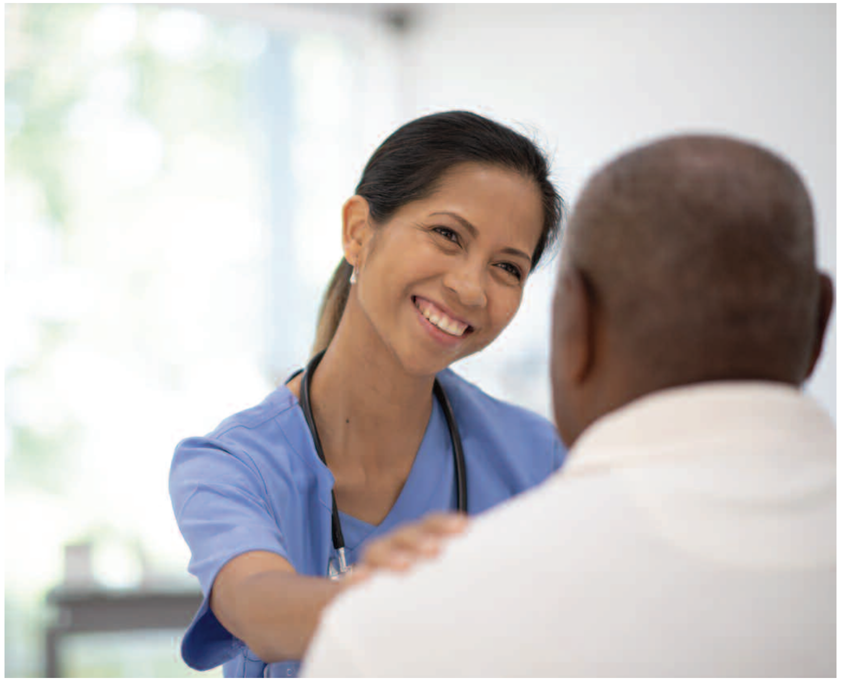
If you have been referred from another hospital, after your discharge you will be referred back to your original doctor for follow-up care. Before you go home the transplant coordinator or specialist nurse will tell you if you need any further check-ups at the transplant centre.

> “I was well enough to go home 15 days after I received my stem cells back. I went back to the hospital a week later and then 2 weeks after that to make sure my bloods were OK.”

Feelings about going home

Going home after your transplant can be difficult for you and your family. You have had a very intensive and often stressful procedure.

You may feel excited but you may also feel anxious about leaving behind the care you received in hospital. This is all perfectly normal and there is no right way or wrong way to feel. In the days before you leave hospital, your nurses will help you with your plans for going home. Do talk to them about any worries you have. If you have any questions after you go home, you can always call the transplant unit. It may be reassuring to hear a familiar voice.



It is very common for patients to be re-admitted to hospital in the weeks or months following discharge. For example, you may develop an infection or experience vomiting or diarrhoea. Try not to worry or be disappointed if this happens to you.

What happens after I leave hospital?

Outpatient visits

For the first few weeks after your transplant you may have to return to the day ward for blood tests. This is to check your blood counts and to make sure your liver, kidney and bones are working well. In general, your blood tests will come back to normal quickly after discharge. You might need a blood, platelet or magnesium or potassium infusion in the weeks after the transplant. Once your blood counts are stable and your strength is improving, you will have fewer visits to the hospital.

Your doctor will decide how often you need to be seen. These check-ups after treatment are called follow-up. It is likely that you will need follow-up for a long time after your transplant. This will depend on your original disease but you may need blood tests, bone marrow tests or scans. In some cases you may start consolidation or maintenance treatment once you have recovered from your transplant. These are treatments with anti-cancer drugs for a few weeks (consolidation treatment) or longer term (maintenance treatment) to kill any remaining cancer cells and / or to try to increase the length of a remission.

Central line

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

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, redness or pus around your line

Bowels

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

Urine

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

Skin

- Any kind of a rash
- Itching or a sore

Temperature/shivering

- Temperature over 37.5ºC, 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 the urine or stools (poo)
- Persistent nosebleed

Cough or breathlessness

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

Contact the hospital straight away if…

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

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

How will I know if the new cells are working?

The first sign that the transplant has worked is when your blood counts increase. A special follow-up visit happens about 100 days (3 months) after the transplant. At this visit, your doctor will check how your disease is behaving. Depending on your diagnosis, this visit may take place at the transplant centre or at your referring hospital.

Your doctor might do tests to see what stage your disease is at now. This might include blood tests, a CT scan or perhaps a bone marrow biopsy. You will also need blood tests to check your hormone levels, thyroid function and immunity levels. Your transplant coordinator will organise these with you or your referring hospital.

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 listed below:

- 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, it may mean you develop an infection and will need to go back to hospital.

Coping with fatigue

For the first few weeks after the transplant your energy levels will be quite low. Fatigue is a common and unpleasant side-effect of chemotherapy.

You will probably find you have no energy and do not feel like doing anything at first. Often 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. Remember to be realistic about how much you can achieve.

This tiredness can last for a few months but sometimes can take longer to overcome. It might take about 6 months before you feel back to normal.

> Once I got back home, I began to get back to myself almost immediately. It took a while to get my energy levels back up but they got there eventually. I took it easy and had everyone running around after me so I could rest as much as possible.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. 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.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 88).
- **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.

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

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 getting back to your 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** until your next visit to the day ward.
- **Avoid people with infections.**
- **Avoid areas that are overcrowded.**
- **Avoid close contact with pets, especially birds,** in the first few weeks.
- **Avoid swimming** if you go home with your central line in place.
- **Keep your fridge clean.**

Appetite and diet

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

It can help to eat small meals regularly, as large ones might 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 taking supplements. Sometimes you might need to go back to hospital if there are problems with eating and drinking.

Aim to drink 2 to 3 litres of fluid a day to speed up your recovery. Sip small amounts throughout the day rather than taking large amounts in one go, especially if your appetite is small, as fluids might fill you up.

Your mouth may continue to feel dry after your transplant so drinking plenty of fluids will also help with this. Often it is best to avoid alcohol after your transplant but you can resume drinking gradually, if your doctor allows it. Talk to your doctor for more advice about alcohol.

Getting back to everyday life

Social life

Once your white blood cell count has increased and you feel well enough, there is no reason why you cannot resume your social life. Going out can help you feel you are getting back to everyday life. But remember you will be more at risk of infections. Avoid visiting people who have colds, sore throats or flu. It is best to stay out of very crowded spaces for the first few months to reduce the risk of infection. For example, shopping centres or crowded pubs, cinemas, clubs or concert venues.

> “When I went home, I felt flat for about 3 weeks. I would go for a walk every day at my own pace, but I was very tired. I went back to bed at 1 pm for 2 or 3 hours and I'd be in bed again by 9 pm. You have to listen to your body.”

Returning to work or studies

Once your blood counts are stable, you can think about returning to work, school or college. But you might not feel able for this for a couple of months after your transplant. As a rough guide, it is best to wait until at least 3 months after your transplant. Committing yourself to full-time work and all its pressures is often not a good idea.

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 discuss it with your doctor.

> “Now I am better than I've ever been. I'm back at work and back to normal, everyday life.”

Your sex life

When you have sex again often depends on how you feel. It is likely that after your transplant your sex life will be affected in some way. For example, 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 offer you help and support with issues affecting your sex life or close relationships.

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

Skin and nail care

After high-dose chemotherapy your skin may be extra sensitive, especially to sunlight. Continue to use non-perfumed soaps and bodywashes for the first few weeks after the transplant. Take care in the sun. Cover up, wear a total sunblock (at least factor 50) and hat to avoid sunburn for at least 6 months after the transplant.

Wearing a hat until your hair regrows to avoid direct sun to your scalp is important, as this area will burn very quickly. You may also notice that your nails are ridged or drier than usual. This is a side-effect of your chemotherapy and will clear up soon.

Going on holiday

Getting away, even for a day or two, can be good for you. If you are planning a holiday or have one planned already, let your nurses know. In the immediate 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 vaccinations are not suitable after having a stem cell transplant. Always ask your doctor and nurse for advice. For any holidays abroad 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. Do 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.

Coping and emotions

How can I cope with my emotions?

It can be a difficult journey going from diagnosis and early treatment to stem cell collection and transplant. Not only can it be hard physically but also emotionally. Remember your emotional wellbeing is 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 a new experience and can often be traumatic

You might have mixed emotions – both highs and lows. Returning the stem cells can feel like an anticlimax after all the preparations. 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 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. You might also be afraid that your bone marrow won't recover well enough or your blood counts won't improve. You might feel helpless and insecure. Other fears include the fear of cancer coming back (recurrence) or other cancers developing, that your appearance or sex life might be affected, distress about your family, uncertainty about the future, and worries about a delayed return to work life or college. But this does not mean that you cannot cope.

Being well prepared can make you feel less anxious and afraid. It can help to find out as much information as possible from your nurses. If you feel overwhelmed by your emotions it can help to speak to a trained counsellor or clinical psychologist. 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.

Depression and distress

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

You might also be feeling lonely or be worried about getting infections, about dying or your quality of life, or 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 and your medical team can advise you further.

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.

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

Cancer diagnosis

If you are finding it particularly hard to cope with your cancer diagnosis, seek professional advice early. 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 nurses can also put you in touch with cancer support centres and counsellors if you feel that would help. You can also visit a Daffodil Centre if one is located in your hospital.

> “My local cancer support centre was wonderful. The first time we went, my wife and I spent hours chatting to the lady who welcomed us. We laughed and we cried. We found it so uplifting.”

Support resources

Money matters

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

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

Practical and financial solutions from the Irish Cancer Society

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

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

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Benefits and allowances

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

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

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential.
Call the MABS Helpline 0818 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 89 for more details of our **Transport Service** and the **Travel2Care** fund.

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

Money and finances

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

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

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

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Practical and financial solutions (see page 82)

Support Line Freephone 1800 200 700

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

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

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

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

Daffodil Centres

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

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

Who can use the Daffodil Centres?

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

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

Telephone Interpreting Service

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

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

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

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

Peer Support

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

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

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

Patient Education

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

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

Counselling

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

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

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

Support in your area

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

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

Transport Service

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

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

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

Night Nursing

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

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

> “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.”

Publications and website information

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

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

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

Local cancer support services

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

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

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

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

What does that word mean?

Allogeneic: The use of someone else's tissue for a transplant.

Allograft: A transplant using matched donated tissue.

Anaemia: A shortage of red blood cells in your blood.

Antibody: A protein that kills off cells that cause disease or infection.

Autologous: The use of your own tissues for a transplant.

Autograft: A transplant using your own tissue.

Blood count: A blood test that counts all the different types of cells in your blood. This includes red blood cells, white blood cells and platelets.

Bone marrow: The spongy material at the centre of long bones that makes your body's blood cells.

Central line: A flexible tube put into a large vein in your chest. It allows chemotherapy to be given and blood to be taken through the same line.

Fatigue: Ongoing tiredness often not helped by rest.

G-CSF: A protein called a growth factor. It stimulates the bone marrow to make white blood cells. It stands for granulocyte colony stimulating factor.

Haematologist: A doctor specialising in diseases of the blood and bone marrow.

Histology: The study and description of cells.

Immune system: The parts of your body that fight off and prevent infection.

Intravenous: Into a vein.

Lymph: The straw-coloured fluid that circulates material through the lymphatic system.

Lymphatic vessels: The tubes that carry lymph and connect with your lymph nodes.

Lymph node: A gland that forms a sieve in your lymphatic system and which is involved in fighting infection.

Neutropenia: A shortage of neutrophils in your blood.

Neutrophils: A type of white blood cell that fights bacteria.

Oncologist: A doctor specialising in the treatment of cancer.

Plasma: The pale yellow liquid part of blood minus the blood cells.

Stem cells: Immature cells that develop into different types of mature cells in your blood.

Subcutaneous: Underneath your skin.

Thrombocytopaenia: A shortage of platelets in your blood. Platelets help to stop bleeding.

Transplant coordinator: A clinical nurse specialist with particular knowledge of stem cell transplants.

Notes/questions

Chemotherapy date:

G-CSF date:

Harvest date:

Admission date (if applicable):

Notes/questions

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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Join the Irish Cancer Society team

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

Irish Cancer Society

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