

Understanding

Autologous Stem Cell Transplants

Caring for people with cancer

Understanding

Autologous Stem Cell Transplants

This booklet has been written to help you understand more about stem cell transplants. It has been prepared and checked by cancer doctors and nurses, and the information is an agreed view on stem cell transplants.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information you may need.



Name	Telephone
Haematology nurse specialist	
Family doctor (GP)	
Haematologist	
Medical oncologist	
Medical social worker	
Emergency number	



This booklet has been produced by the Irish Cancer Society and the haematology staff of St James's Hospital, Dublin 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.

STEM CELL ADVISERS

Dr Liam Smyth, Consultant Haematologist

Michelle Connell, Haematology Clinical Nurse Specialist

Joy Lewis, Haematology Clinical Nurse Specialist

COMPILED BY

Liz Higgins, Transplant Co-ordinator

CONTRIBUTORS

Deirdre Colton, Cancer Nurse Nurse

Olivia Merrigan, Daffodil Centre Nurse

EDITOR

Tara Droog

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

- Stem cell transplantation in Europe: trends and prospects. SS Tan, CA Uyl de-Groot, PC Huijgens & WE Fibbe. *European Journal of Cancer* 2007; 43: 2359–65.
- Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation: joint recommendations of the European Group for Blood and Marrow Transplantation. Rizzo JD et al. Center for International Blood and Marrow Transplant Research, and the American Society for Blood and Marrow Transplantation EBMT/CIBMTR/ASBMT. *Biology of Blood and Marrow Transplantation*, 2006; 12(2): 138–151.
- DeVita, Hellman, and Rosenberg's *Cancer: Principles and Practice of Oncology*. R Govindan (ed), 9th edn. Lippincott Williams & Wilkins, 2011.
- *Cancer Nursing: Principles and Practice*. CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society 2013. Revised 2018.

Next revision: 2020

Product or brand names that appear in this booklet are for example only. The Irish Cancer Society does not endorse any specific product or brand.

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

Contents

About stem cell transplants

Page 7 ▶▶

Preparing for the transplant

Page 11 ▶▶

Collecting the stem cells

Page 17 ▶▶

High-dose treatments

Page 27 ▶▶

Having the transplant

Page 31 ▶▶

Coping and emotions

Page 49 ▶▶

Support resources

Page 55 ▶▶

Quick facts

What is an autologous stem cell transplant? Page 8 ▶▶

An autologous stem cell transplant allows you to have higher doses of chemotherapy than usual to treat your disease. But such 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 9 ▶▶

There are 4 main stages:

- 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. See pages 18 to 25.
- 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. See pages 28 to 29.
- 3 **Getting your stem cells back.** Your stem cells are usually given back to you 1–3 days after the chemotherapy has finished. See pages 32 to 33.
- 4 **Waiting for new blood cells to grow.** After your stem cells are given back to you, you will be looked after in isolation to protect you from infection. Usually after 10–21 days, your blood counts will start to recover. See page 34.

Are there side-effects from treatment? Page 35 ▶▶

All treatments, particularly high-dose chemotherapy, can cause side-effects. But these are usually temporary. See pages 35 to 40.

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

We're here for you Page 59 ▶▶

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 Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 59 for more about our services.



Cancer Nurseline Freephone 1800 200 700

Introduction

This booklet has been written to help you and your family understand more about stem cell transplants when you donate the stem cells yourself. This is called an autologous stem cell transplant. The booklet only deals with stem cells donated by yourself for yourself. For information about other people donating stem cells, ask for a copy of our booklet *Understanding Allogeneic Stem Cell Transplants* by calling our Cancer Nurseline on Freephone 1800 200 700 or visiting a Daffodil Centre.

Having a stem cell transplant can be a stressful time for you and those close to you. This booklet aims to help and guide you through each stage of the process. Transplants can be complicated to explain and no doubt you will have many questions and concerns of your own.

We hope this booklet answers some of those questions and encourages you to discuss them with your doctors and nurses. They are more than willing to answer your queries, so just ask.



Reading this booklet

Remember you do not need to know everything about stem cell transplants straight away. Read a section that you are interested in. Then read another section when you want to know more



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie

You can also visit a Daffodil Centre. See page 59 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

Email: cancernurseline@irishcancer.ie

About stem cell transplants

What is an autologous stem cell transplant?	8
Why do I need a transplant?	8
What are the stages of an autologous stem cell transplant?	9
What are the risks of transplants?	10
Where does the transplant take place?	10

What is an autologous stem cell transplant?

A stem cell transplant allows you to have higher doses of chemotherapy or radiation therapy than usual to treat your disease. But such high-dose treatment will also destroy your bone marrow. Because of this, you have some of your stem cells taken and stored (see pages 17 to 24) before having high-dose treatment. After the treatment, they are given back to you.

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.

Strictly speaking, it is not a transplant. It is very different from getting a transplant like a kidney transplant for example. The word transplant can sometimes be confusing when used to talk about blood and bone marrow diseases. It really refers to getting stem cells from your blood or bone marrow and returning them to you.

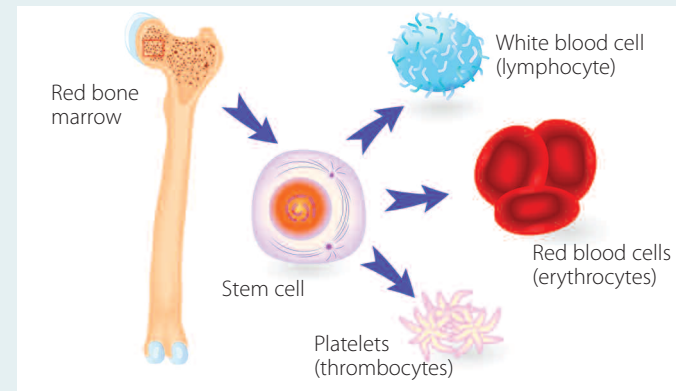
Why do I need a transplant?

An autologous stem cell transplant allows you to receive high doses of chemotherapy. This chemotherapy, which is given before your stem cells are returned to you, 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 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 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 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, while platelets help blood to clot and prevent bleeding. These stem cells are found in your bone marrow, which is a spongy tissue found within bone, in particular your hip bones. Bone marrow makes all of your body's blood cells.



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 by a peripheral blood stem cell harvest (see page 20). Rarely, stem cells may be collected from the bone marrow.
- 3 Treating you with high-dose chemotherapy. Because the chemotherapy cannot tell the difference between cancer and healthy cells, your bone marrow cells will also be killed.
- 4 Giving you back your stem cells, which will grow and make new red blood cells, white blood cells and platelets.

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 33 for more about side-effects of transplants.

Where does the transplant take place?

The transplant will take place at a transplant centre. These are highly specialised centres. Before your stem cells are collected, you will be asked to attend the transplant centre for a number of reasons. 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.

6 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. 9

Preparing for the transplant

What tests do I need beforehand?	12
Putting in a central line	14
Other things to consider	15

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
- Echocardiogram (ECHO)
- Dental check-up

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

24-hour urine collection: This test checks how well your kidneys are working at clearing waste products from your body. You will be given a large plastic bottle to bring home with you to collect your urine. You will be asked to collect all the urine you pass in a 24-hour period. It is best to start the collection in the morning. When you wake up, pass your first 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 to complete.

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

Other tests

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

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

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.

You will also have a pregnancy test if you are a woman and can still have children.

You may need a bone marrow biopsy and a lumbar puncture. Your doctor or transplant co-ordinator will explain these in more detail.

Extra tests may be needed, depending on your condition and medical history.

Putting in a central line

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

Skin-tunnelled central line

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

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

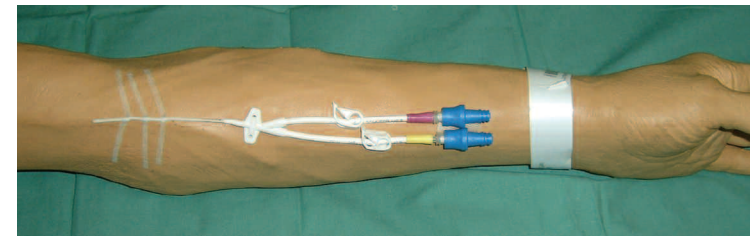
Your doctor will gently thread the line under your skin into a large vein in your chest. You will be able to see a thin tube come out of your chest. It may divide into 2 or 3 tubes so you can have different treatments at the same time.

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



PICC line

PICC stands for peripherally inserted central catheter. This line is put into one of your arms above the bend in your elbow. Again, this line will be put into your vein in the X-ray department under local anaesthetic. It is threaded through the vein until it sits in one of the large veins near the heart. You will see one or two thin tubes come out from your arm. The PICC line can remain in place throughout



your transplant. It will be held in place by stitches, which will remain there while the line is in.

Other things to consider

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 will be able to assist you with some of these issues.



Collecting the stem cells

Before your stem cells are collected	18
How are the stem cells moved into my bloodstream?	18
When are the stem cells collected?	20
How are the stem cells collected?	20
How long does the collection take?	23
What happens once the cells are collected?	24
Is there anything I can do to help?	25

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 journal with you to take notes. All 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)
- or
- 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.

- 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. 🙄

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.

The layer with the stem cells is selected and 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 the 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 co-ordinator 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, do tell your nurse as they can be easily treated.

Anticoagulant used: Once blood leaves your body it will clot in a matter of time. To prevent the blood in the machine from clotting, an anti-clotting drug is added. As blood is returned to you so too 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 prone to bleeding or bruising. 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: Afterwards you will probably feel quite tired, but again this should ease off once you have rested.

How long does the collection take?

In general each session takes around 3–5 hours. 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 blood stream. But 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 18 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.



Stem cells

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

Is there anything I can do to help?

Yes! There are many things that you can do to help:



Tips & Hints – 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.
- 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.
- Do bring a companion along. Often the time on the machine can be quite boring. Feel free to 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. Do 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 be admitted to the hospital? 28

How many days of treatment will I need? 29

When will I be admitted to the hospital for high-dose treatment?

If your stem cells have been successfully collected, the transplant co-ordinator 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 facilities 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, if you wish. But 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.



Tips & Hints – 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.
- Do ask your nurses what else you can bring in. 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 co-ordinator 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. Again, 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. 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 35 for more details.

If you are having total body radiation, your team will discuss with you how many days of treatment is needed. This is not commonly used for autologous stem cell transplants.



Having the transplant

When are the stem cells given back to me?	32
Will I feel anything after receiving the stem cells?	33
What happens after I receive the stem cells?	33
What happens when I'm in isolation?	34
Are there side-effects to the transplant?	35
How long will I be in hospital?	41
What happens after I leave the hospital?	42
Getting back to everyday life	45

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.

Defrosting the stem cells

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. 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.

Reinfusing the stem cells

Once they are thawed the stem cells are reinfused through your central line. 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.

👉 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. 🙄

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. 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. You will be given an antihistamine and steroid injection before the reinfusion, so this may make you feel slightly sleepy. This is given to prevent you having any reaction to the DMSO preservative. You don't need to worry as your nurses and doctors will watch you closely.

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 which these injections start will vary, depending on the type of treatment you are receiving. 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 blood 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 bacteria.

What happens when I'm in isolation?

Once the stem cells have been given back to you, you will be looked after in isolation. This means that you will be in a special ward or single room to protect you from infection. You will be closely watched and checked for signs of infection.

Visitors to the ward: 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 two 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.

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 prone to picking 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.

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. Do get up and walk around the room at least a few times a day. Even getting up to go to the toilet and to wash yourself helps with your recovery.

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

Coping with isolation: Being in isolation can be quite difficult. See page 49 for more about dealing with this.

6 Visitors were limited and everyone who came into my room had to wear gowns and wash their hands thoroughly. 9

Are there any 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. The main issue is bone marrow problems.

Bone marrow problems

All types of high-dose chemotherapy you receive will destroy your bone marrow. This in turn will affect your red cells, white cells and platelets. As a result you may be:

- Anaemic
- More prone to infection
- More prone to bleeding

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 cell levels. It is best to balance periods of rest and activity. Do keep active to avoid problems that can happen due to staying in bed for long periods, such as pneumonia. But on the other hand, do rest often during the day.

More prone to infection: Once your white cell level drops, you will become more prone to infection and fevers. 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, more than likely you will develop a temperature or infection at some point during your hospital stay.

If your symptoms suggest an infection, blood tests and other tests like a chest X-ray or lung scan will be taken. You will then be given antibiotics through a vein. This process might happen several times during your admission. On rare occasions, patients with serious infections will be transferred to the intensive care unit (ICU). This is to allow nurses and doctors to monitor you more closely.

>>> Hints & 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 during your transplant as they may contain harmful bacteria.
- Talk to the dietitian about avoiding foods that may be harmful to you.
- Tell your nurses if you have an intrauterine contraceptive device 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, do ask your nurses for more advice.

More prone to bleeding: Once your platelet count falls, you will become more prone to bleeding and bruising and may need platelet transfusions. The usual places to notice bleeding are in your gums and from your nose.



Hints & 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 urine or stool or any unusual bleeding.

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

Common side-effects of 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. Some of the common side-effects of chemotherapy are listed below. 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.

- | | |
|----------------------------------|--------------------------|
| ▪ Nausea, vomiting and diarrhoea | ▪ Hair loss (alopecia) |
| ▪ Inflamed mouth and gut | ▪ Veno-occlusive disease |
| ▪ Poor appetite | ▪ Infertility |

Nausea, vomiting and diarrhoea: These are common problems after getting chemotherapy drugs. But you will be given anti-sickness medication to control any nausea and vomiting you have. It can help too 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 not lose weight.

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 haemorrhoids, do 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 *Diet and Cancer*. Call our Cancer Nurseline on 1800 200 700 for a free copy or download it from www.cancer.ie

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

The stronger your treatment, the more likely you are to 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, do 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.

Email: cancernurseline@irishcancer.ie



Hints & Tips – mouth care



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

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): Due to the high-dose chemotherapy, you may lose your hair.

Loss of body hair occurs at first from your head and then from your eyebrows, eyelashes, underarm and pubic area. The amount of hair loss differs in individuals. For example, you might get severe hair thinning or total hair loss. Naturally, the loss of hair can be distressing for you. It often falls out in clumps from your head when brushed or is rubbed off on your pillow. 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.

Fortunately, there are now lots of companies providing wigs, turbans, hats and hairpieces. Your nurse or medical social worker can give you the contact numbers and arrange a visit if you are interested. Remember the hair loss is temporary and will return. Regrowth usually begins any time from 2 months after the chemotherapy, but may take longer. Your hair might grow back a different shade or be curly. These differences often disappear as your hair continues to grow.

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 Cancer Nurseline 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 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 but if it does occur, it is usually 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, it will mean that they cannot have children. For women, 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. For men, you may stop making sperm after high-dose chemotherapy. While most chemotherapy drugs cause infertility, some do not. Do discuss the chance of getting this side-effect with your doctors or nurses. Remember to still use a condom if you or your partner is of childbearing age.

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

Other side-effects

If you have any other problems, especially those not listed above, do talk to your nurse and doctor. For more about side-effects of chemotherapy, see the booklet *Understanding Drug Therapies*. Call our Cancer Nurseline 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.

“ 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. ”

Communicating with those caring for you

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. The team will want to make you as comfortable as possible and put your mind at rest. 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 at all having to explain 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 remember 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 co-ordinator or specialist nurse will tell you if you need any further check-ups at the transplant centre.

Cancer Nurseline Freephone 1800 200 700

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. But 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 less 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 visits for a long time after your transplant. This will depend very much on your original disease but you may need blood tests, bone marrow tests or scans. Do contact the team at the transplant centre or your referring hospital if you have any of the following problems at home.



Hints & Tips – watch out for these symptoms at home



- A fever of more than 37.5°C
- Uncontrolled shivering
- A runny nose or flu or a cold
- Red or tender areas, or yellow/green ooze, around your central line
- Nausea, vomiting or diarrhoea
- An unusual or itchy rash or sore
- Bleeding or bruising. For example, blood in your urine, coughing up blood or nose bleeds
- A persistent headache

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.

Some special tests will be needed for this check-up, as your doctor might wish to see what stage your disease is now at. 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.

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.

Medications

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

Exercise and fatigue

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

You will probably find you have no energy and do not feel like doing anything at first. Regular gentle exercise can help with fatigue. But try to balance activity and rest. Often getting up, washed and dressed can be a major feat in the first few weeks. Start off gently. 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. It might take about 6 months before you feel back to normal. For more about tiredness and fatigue, see our booklet *Coping with Fatigue*. Call our Cancer Nurseline on 1800 200 700 for a free copy or download it from www.cancer.ie or visit a Daffodil Centre.

“ 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. ”

Avoiding infection

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



Hints & Tips – avoiding infection

- Continue to shower every day and be strict about your personal hygiene.
- Continue your mouthwashes 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.

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.

Appetite and diet

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

It can help to eat small meals regularly as large ones might look difficult to manage. Also try tasty foods to stimulate your taste buds. If you are not gaining weight as expected the hospital dietitian can advise you about 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. 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 cell count has increased and you feel well enough, there is no reason why you cannot resume your previous social life. Going out as you normally would can help you feel you are getting back to everyday life. But remember you will be more prone to infection. Avoid visiting people who have colds, sore throats or flu. It is best to stay out of very crowded spaces for the first few months to reduce the risk of infection. For example, shopping centres, or crowded pubs, cinemas, clubs or concert venues.

6 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. 9

Returning to work

Once your blood counts are stable, you can think about returning to work, school or college. But you might not feel able for this for a 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 do discuss it with your doctor.

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 too will your sex drive (libido). If your platelets or white cells are low, do 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 the high-dose chemotherapy, there is no guarantee that it will happen. Research suggests that a small number of patients can recover fertility after a transplant. It is important to use reliable contraception such as a condom after chemotherapy to avoid pregnancy. This is because the drugs might harm a developing baby. Your doctor or nurse will advise you to use reliable contraception for a few months afterwards.

Skin care

After high-dose chemotherapy your skin may be extra sensitive, especially to sunlight. Continue to use non-perfumed soaps and bodywashes for the first few weeks after the transplant. Also, do 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. Until your hair regrows avoid direct sun to your scalp, as this area will burn very quickly. You may also notice that your nails are ridged or drier than usual. Again, this is a side-effect of your chemotherapy and will clear up soon.

Going on holiday

Getting away, even for a day or two, can be good for you. If you are planning a holiday or have one planned already, do let your nurses know. In the 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 remember there are some types of vaccinations that are not suitable after having a stem cell transplant. Always ask your doctor and nurse for advice. For any holidays 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 sit at home worrying. You can also call our Cancer Nurseline on 1800 200 700 for advice or visit a Daffodil Centre.

6 Now I am better than I've ever been. I'm back at work and back to normal, everyday life. 9



Coping and emotions

How can I cope with my emotions? 50

What am I likely to feel before and after the transplant? 50

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

For much of the time you might have mixed emotions – both highs and lows. Returning the stem cells can feel like an anticlimax 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. Do make a list of any concerns you have and discuss them with your doctor or nurse. They can also refer you to a counsellor or clinical psychologist for further help and support.

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

Fear and anxiety

It is normal to feel anxious and daunted by the transplant process. It might make you feel helpless and insecure as a result. But remember this does not mean that you cannot cope. You might also be afraid that your bone marrow won't recover well enough or your blood counts won't improve. It can help to find out as much information as possible from your nurses. By being well prepared, it can make you feel less anxious and afraid. Other fears might include the fear of recurrence or other cancers, that your appearance or sex life might be affected, distress about your family, uncertainty about the future, and worries about a delayed return to work life or college. It can help to speak to a trained counsellor or clinical psychologist if you feel overwhelmed by your emotions. Some relaxation techniques can be useful in reducing anxiety. Ask your nurses for advice.

👉 I didn't mind being in isolation. My wife would visit me and I read a lot. 🙄

Coping with isolation

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

👉 I made sure I had plenty to keep me entertained during my hospital stay. 🙄

Frustration and disappointment

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

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

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. Do 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 worry too much 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 indeed so might those close to you. Even when you're at home, you might also feel separate or apart from your family and friends, but this is natural at this time. Remember you have just had an intense treatment and are leaving the security of the hospital. Naturally, you can feel anxious and afraid as a result. But planning and advice from your doctors and nurses can help to reduce those feelings and help you adapt. Expect good days and bad days. It will take time but life can begin to feel normal after a while.

Cancer diagnosis

If you are finding it particularly hard to cope with your cancer diagnosis, do seek professional advice early. A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy or download one from www.cancer.ie. Our Nurseline can also put you in touch with cancer support centres and counsellors if you feel that would help. Or if you wish, you can visit a Daffodil Centre if one is located in your hospital.

Express yourself



It can help to write down any issues that are troubling you or any strong emotions you have. Call our Cancer Nurseline on 1800 200 700 for a free copy of *Journey Journal: Keeping Track of Your Cancer Treatment*. Not only can you keep track of your thoughts and emotions but also any physical side-effects you are having.

- 6 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

Contact details of stem cell transplant centres	56
Coping with the financial impact of cancer	57
Irish Cancer Society services	59
Local cancer support services	61
Helpful books	62
What does that word mean?	63
Questions to ask your doctor	65
Your own questions	66
Notes	67

Contact details of stem cell transplant centres

St James's Hospital, Dublin

Ms Liz Higgins, Transplant Co-ordinator.

St James's Hospital

James's Street

Dublin 8

Tel: 01 410 3000 Bleep 187

Mobile: 087 6672005

Email: ehiggins@stjames.ie

St James's Hospital: 01 410 3000

Denis Burkitt Unit (inpatient ward): 01 416 2271 / 01 416 2265

Please use at weekends and out of hours.

Haematology Day Ward: 01 410 3970 / 01 416 2168

St Vincent's University Hospital, Dublin

Ms Joy Lewis/Ms Michelle Connell, Haematology Clinical Nurse Specialists.

St Vincent's University Hospital

Elm Park

Dublin 4

Direct Tel: 01 221 4373

Tel: 01 221 4000 Bleep 656

Email: j.lewis@st-vincent.ie /

m.connell2@st-vincent.ie

Main hospital: 01 221 4000

St Anne's Ward/Haematology Day Ward: 01 221 6692 / 221 6687

University Hospital Galway

The service is co-ordinated by medical consultants and clinical nurse specialists.

University Hospital Galway

Newcastle Road

Galway

Tel: 091 524 222 Bleep 214 / 730

St Joseph's Ward: 091 544 430

St Patrick's Ward: 091 544 759

Haematology Day Ward: 091 544 610

Email: cancernurseline@irishcancer.ie

Coping with the financial impact of cancer

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

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Medicines
- Visits to hospital
- Appliances, like wigs
- Overnight stays in hospital

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 do not 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.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

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

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

If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 58 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

For more information go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

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

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

Irish Cancer Society services

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

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

- **Our Cancer Nurseline Freephone 1800 200 700.** Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

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

- **Our Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- **Our Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 59 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the National

Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.

- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

- **Our publications and website information.**

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.



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

Local cancer support services

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

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

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

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue



Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Taking About Your Cancer

Talking to Children about Cancer: A Guide for Parents

A Time to Care: Caring for Someone Seriously Ill at Home

Caring for someone with cancer

Managing the Financial Impact of Cancer. A Guide for Patients and their Families



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 special type of 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	are a type of white blood cell that fight 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 co-ordinator	A clinical nurse specialist with particular knowledge of stem cell transplants.

Questions to ask your doctor

Here is a list of questions that you may wish to ask your doctor. There is also some space for you to write down your own questions if you like. 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?
- How much chemotherapy do I need?
- When will my stem cells be returned to me?
- 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 get more support?

Your own questions

1 _____

Answer _____

2 _____

Answer _____

3 _____

Answer _____

4 _____

Answer _____

5 _____

Answer _____

6 _____

Answer _____



Notes



Chemotherapy date: _____

G-CSF date: _____

Harvest date: _____

Admission date (if applicable): _____

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre..

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Email: cancernurseline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

