

Understanding

Autologous Stem Cell Transplants

Caring for people with cancer



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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.



Haematology nurse specialist Tel:

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Haematologist Tel:

Medical oncologist Tel:

Medical social worker Tel:

Emergency number Tel:

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services of 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.

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- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (ed), 9th edn. Lippincott Williams & Wilkins, 2011.
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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, known as an allogeneic transplant, call the National Cancer Helpline on 1800 200 700.

Naturally, you and those close to you might feel daunted at this process, and it can be a stressful time. This booklet aims to help and guide you through each stage of the process. Transplants can be complicated things 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 any queries you may have, so just ask. At the end of the booklet, you will find a list of websites and special groups to help and support you at this time.

If you would like information on how stem cells are collected, a useful booklet called *Understanding Stem Cell Collection* is available. Call the National Cancer Helpline on 1800 200 700 for a free copy.



Reading this booklet

Remember you do not need to know everything about stem cell transplants straight away. First read a section about a particular item as it happens. Then when you feel relaxed and want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline on Freefone 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. Or if you wish, you can also visit a Daffodil Centre if one is located in your hospital. See page 37 for more about Daffodil Centres.



About stem cell transplants

What is an autologous stem cell transplant?

A stem cell transplant is when healthy stem cells are given to replace damaged or diseased stem cells in your body. The stem cells can be donated by yourself or another person. If you donate the stem cells yourself, it is called an autologous transplant. Autologous means something that comes from your own tissue or DNA.

When your own cells are involved, it can be called an autograft, autologous transplant or 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 marrow and returning them to you.

A stem cell transplant may be done for the following reasons:

- If high-dose chemotherapy or radiotherapy is given to treat blood disorders such as leukaemia, lymphoma or myeloma, or other cancers.
- If your bone marrow stops working and doesn't make enough healthy stem cells.
- To help your body make enough healthy white blood cells, red blood cells or platelets. This can reduce your risk of serious infection, anaemia and bleeding.

Why do I need a transplant?

If you are reading this booklet now, more than likely your stem cells or bone marrow have already been collected or harvested. They have been frozen and stored for some time.

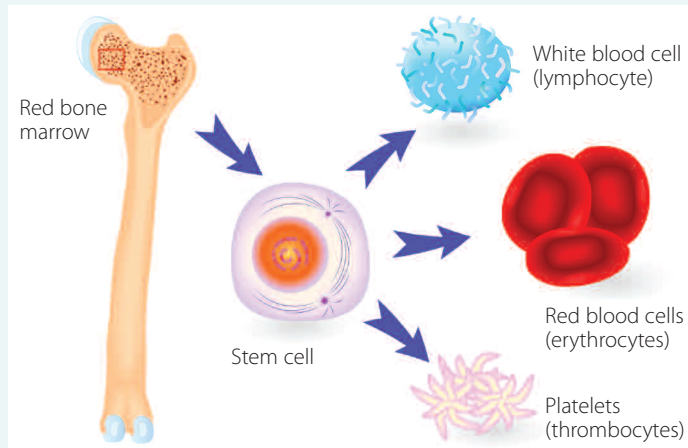
By having a transplant, it can allow you to receive high doses of chemotherapy or radiation. This chemotherapy, which is given before

your stem cells are returned to you, will destroy the cells causing your cancer. But remember 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 in turn increases your risk of bleeding, infection and anaemia.

Reinfusing your stem cells will protect or 'rescue' you from this high dose of chemotherapy. The infused 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 immature or at the earliest stage of development. They can develop into mature red cells, white 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 stem cells either by a bone marrow harvest or a peripheral blood stem cell harvest.
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. Reinfusing your stem cells, which will grow and make new red blood cells, white blood cells and platelets.

This booklet focuses on the third and fourth stages of the autograft process. For more information on how stem cells are collected, call the National Cancer Helpline on 1800 200 700 for a free booklet called *Understanding Stem Cell Collection*. Or you can also visit a Daffodil Centre if one is located in your hospital.

What are the risks of transplants?

The main risks occur 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 18 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 in cancer designated hospitals in Ireland. More than likely you will be familiar with the transplant centre, especially if your stem cells were collected or harvested there. You will get a chance to meet all the haematology team again, including the doctors, nurses and transplant co-ordinators. Naturally, there will be a lot of information to

discuss during your visit. So do bring along your partner or family member when you visit. You can ask questions and get any concerns or queries cleared up. It can help to write down these questions beforehand so they all get answered. All of the staff will explain in detail what is involved. 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. She will keep in close contact with you to arrange visits and what to do if you need injections, tests or anything else.



Preparing for the transplant

What tests do I need beforehand?

Before the transplant you will receive high dose chemotherapy. But before this happens some tests are needed 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 complete 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: These blood tests will check your blood count, blood group, clotting and iron levels as well as seeing how well your kidneys, liver and bones work.

24-hour urine collection: This test checks how well your kidneys are working and 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. 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. They can tell if the transplant is having an effect on your lungs or not.

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. It is like the one pregnant women have to picture the baby on a screen. 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.

Extra tests

Extra tests may be needed, depending on your condition and medical history. These extra tests may be used as a baseline to check your response to the treatment. Sometimes a bone marrow test may be done.

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. There are different types of central lines. For example, Hickman line or PICC line. You may already have a line in place from your stem cell harvest. If not, you will have one of these two lines put in, but not both. You might hear the line called a catheter by your nurses and doctors.

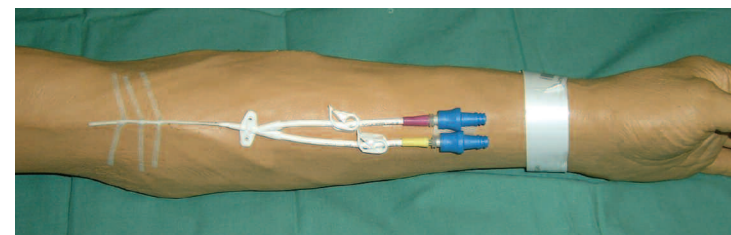
Hickman line

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 near your collarbone. The line is tunnelled under your skin from your collarbone and will exit at either the right or left side of your chest. It will have either two or three lumens or arms coming from the line, which you can see. The tip of the line will sit in one of the large veins that leads to your heart. 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.



PICC line

This line is put into one of your arms above the bend in your arm. PICC stands for peripherally inserted central catheter. Again, this line will be put into your vein in the X-ray department under local anaesthetic. The tip of the line will sit in one of the large veins near your heart. It has two arms or lumens, which will exit 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.



When will I be admitted to the hospital?

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. These dates depend on the results of your tests and if the laboratory staff say your stored stem cells are suitable to use.

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 and DVD player. 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.



Hints & 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 special 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, DVDs, iPod, MP3 player, CD player, etc.
- Mobile phone and charger – these can all be used on the ward.



Do ask your nurses what else you can bring in. It is best to leave valuables at home.

How many days of chemotherapy 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 before admission. 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 a 1 or 2 day rest period to allow the chemotherapy to be excreted from your body.

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 is less strong and you are 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 18 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.

Defrosting the stem cells

Your stem cells, which have been frozen, will be given back to you. These cells are stored in a special liquid nitrogen freezer at -180°C in sterile containers until they are needed.

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 infused 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 present in the room with you during the infusion. You should not feel anything while the stem cells are being reinfused. You might feel the infusion is no different to a blood transfusion.

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 a slight reaction to the DMSO preservative. There is no cause for worry as your nurses and doctors will watch you closely.



What happens after I receive the stem cells?

After your stem cells are returned 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 settle into your bone marrow. This happens gradually and is called engraftment. This might take 8–12 days. Usually after 14 to 21 days, your white blood cells will have recovered. Daily blood tests will be done, especially to check the number of white cells known as neutrophils. These neutrophils fight bacteria in particular.

What happens when I'm in isolation?

During your transplant, 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. Visiting hours are not restricted. 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. Remember children under 14 years of age are not allowed to visit because they are more prone to picking up infections and bugs. Please discuss this with the nurse manager if it is an issue for you. For your protection, staff and visitors will be asked to wash their hands and wear plastic aprons before seeing you. Your room and its contents will also be cleaned every day.

Fresh flowers: In general these are not allowed in the ward as they can carry fungal germs.

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 have a proper intake of food for as long as possible, 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. Naturally, there will be days when you will not feel like eating. If this continues for some time, you might need to have nutrition through a vein.

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. Do get up and walk around the room at least a few times a day. Even getting up 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 32 for more about dealing with this.

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

Remember 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 occur 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 admission. 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.



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.

If you are unsure about any of these hints and tips, do ask your nurses for more advice. The hospital dietitian can give also you advice on what foods to avoid.

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.



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
- Inflamed mouth and gut
- Poor appetite
- Hair loss (alopecia)
- Venous-occlusive disease
- 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 do 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 the booklet *Diet and Cancer*. Call the National Cancer Helpline 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 will 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 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 remember caring for your mouth at this stage is vital because infections are most likely to occur then.



Hints & Tips – mouth care



- Use a toothbrush with soft bristles.
- Keep your lips moist with Vaseline® or a 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 pineapple 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 receive 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 will lose your hair. This is a side-effect of some chemotherapy drugs that are used. You might have experienced it if you had previous chemotherapy.

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 a number of companies providing a variety of 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 return 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. You can also call the National Cancer Helpline on 1800 200 700 and ask for a copy of the factsheet, *Hair Loss and Cancer Treatment*, or download it from www.cancer.ie

Veno-occlusive disease: This can be a rare problem if you receive an autograft. 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. You may hear your doctors and nurses referring to it as VOD. 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 receiving 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 a copy of the factsheet, *Managing Menopausal*

Symptoms, call the National Cancer Helpline 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. This is done at the HARI Unit in the Rotunda Hospital in Dublin. See page 40 for contact details. If you are female, do discuss your options with your doctor.

Other side-effects

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

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 10–14 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 advise you if you need any further check-ups at the transplant centre.

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 a few times a week for blood tests. This is to check your blood counts and to make sure your liver, kidney and bones are working well. 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 gradually have less and less visits to the hospital.

Your doctor will decide how often you need to be seen. These check-ups 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 the central line
- Nausea, vomiting or diarrhoea
- An unusual or itchy rash or sore

A skin rash might be shingles, but like all infections it can be treated.

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.

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:

- Motilium® - anti-sickness medication, but you may not experience nausea or vomiting at all.
- Antacid - to treat heartburn.
- Septrin® - an antibiotic that protects against a particular strain of pneumonia.
- Valtrex® - an anti-viral that protects 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 be readmitted 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 the booklet *Coping with Fatigue*. Call the National Cancer Helpline on 1800 200 700 for a free copy or download it from www.cancer.ie or visit a Daffodil Centre.

Avoiding infection

Even if your blood counts are stable, 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 be readmitted 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. Do ask your doctor for more advice about alcohol.

Getting back to everyday life

Social life

Once your white cell count has increased and you feel well enough, there is no reason why you cannot resume your 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. Do avoid visiting people who have colds, sore throats or flu. It is best to stay out of very crowded spaces for the first few months to reduce the risk of infection. For example, shopping centres, or crowded pubs, cinemas, clubs or concert venues.

Returning to work

Once your blood counts are stable, you can think about returning to work, school or college. But you might not feel able for this for a couple of months after your transplant. As a rough guide, it is best to wait at least 3 months after your transplant before returning. 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.

Sexual activity

Resuming sexual activity 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. Do discuss them with him or her.

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. With this in mind, do use a reliable form of contraception such as condoms. This will also reduce the risk of infection. Do talk to your nurse and doctor for more advice.

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 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. Special holiday insurance may be needed in some cases. Depending on where you intend to travel, certain vaccinations may be

needed. But remember there are some types of vaccinations that are not suitable after having a stem cell transplant. Do 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.

Financial issues

You might have some financial issues during or after your transplant. For example, you might worry about the cost of treatment or if you are entitled to any benefits. Do speak to the medical social worker at your hospital. They can give advice on practical and financial supports and services available when you go home. A useful booklet is available called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. Call the National Cancer Helpline on 1800 200 700 for a free copy or download one from www.cancer.ie or visit a Daffodil Centre.



If you have financial worries...



A diagnosis of cancer and having a transplant can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 38 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 40 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 46 for more information.

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 the National Cancer Helpline 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 well-being 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 rise. 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 body image 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. Do ask your nurses for advice.

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.

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 about these, if they are 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 tailor your care to your 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. In this case, your doctor might prescribe antidepressants if he or she thinks 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 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. Do expect good days and bad days. It will take time but life can begin to feel normal after a while.

Cancer diagnosis

Your emotions might also be linked to your cancer diagnosis and especially if your treatment is hard going. If you are finding it particularly hard to cope, 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 the National Cancer Helpline on 1800 200 700 for a free copy or download one from www.cancer.ie

The helpline 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 the National Cancer Helpline 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.

Support resources

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:

087 787 5089

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's.ie /
m.connell2@st-vincent's.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



Irish Cancer Society services

The Irish Cancer Society funds a range of support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project



Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a discussion space on our website (**www.cancer.ie**) to share your stories, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.
- Find us on Facebook and follow us on Twitter (**@IrishCancerSoc**).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 41–45 for more details.

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms

with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. The booklets and factsheets are available free of charge from the Irish Cancer Society by contacting 1800 200 700. They can also be picked up at a Daffodil Centre or downloaded from www.cancer.ie



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website www.cancer.ie or a Daffodil Centre.

Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline Freefone: 1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2920
Freefone: 1800 240 724
Email: info@carersireland.com
Website: www.carersireland.com

Citizens Information

Citizen Information Phone Service:
0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

HARI: The National Fertility Centre

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline: 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

AVIVA Health (formerly VIVAS Health)

PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare (formerly Quinn)

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
Local: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres

Dublin and Cork (see pages 42 and 43).

CanTeen Ireland

Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

I've Got What?!

[Support for young adults affected by cancer]

c/o Cross Cause Charity Shop
Blackrock
Co Louth
Tel: 086 339 5690

Lakelands Area Retreat & Cancer Centre

Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Connaught support groups & centres

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080

Ballinasloe Cancer Support Centre

Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloecancer@yahoo.co.uk

Cancer Care West

Inis Aoibhinn
University Hospital Galway
Costello Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590
Email: caraiorrais@gmail.com

East Galway Cancer Support Centre

The Family Centre
John Dunne Avenue
Ballinasloe
Co Galway
Tel: 087 984 5574 / 087 945 2300
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group

The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220
Email: gcsupport@eircom.net
Website: www.gortcs.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sligo Cancer Support Centre

44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support groups & centres**ARC Cancer Support Centre**

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group

25 Kingshill
Arklow
Co Wicklow
Tel: 085 110 0066
Email: arklowcancersupport@gmail.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Balbriggan
Co Dublin
Tel: 087 353 2872

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: info@cuislecentre.com
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Éist Cancer Support Centre Carlow

The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100 / 086 817 2473
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

Haven Cancer Support and Therapy Group

Haven House
68 Hazelwood
Gorey
Co Wexford
Tel: 053 942 0707 / 086 250 1452
Email: info@thehavengroup.ie
Website: www.thehavengroup.ie

HOPE Cancer Support Centre

22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Kilkenny Cancer Support Services

Walkin Street
Kilkenny City
Tel: 085 721 9280
Email: info@kilkennycancersupport.com
Website: www.kilkennycancersupport.com

Lakelands Area Retreat & Cancer Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Midlands Myeloma Support Group

c/o ROHDU
Tullamore General Hospital
Tullamore
Co Offaly
Tel: 086 780 4007 / 057 932 1501 (Bleep 317)
Email: info@dochasoffaly.ie / Maryb.Kelly@hse.ie
Website: www.mymyeloma.ie

Rathdrum Cancer Support Centre

34 Main Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Stillorgan Cancer Support

c/o Marsham Court
Stillorgan
Co Dublin
Tel: 01 288 5725

Tallaght Cancer Support Group

Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486
Email: ctallaght@yahoo.ie

Wicklow Cancer Support Centre

1 Morton's Lane
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support groups & centres**Cancer Information & Support Centre**

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: cancersupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Kerry Cancer Support Group

124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.org

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation

Solas Centre
7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.secf.ie

Suimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email:
suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Youghal Cancer Support Group

161 North Main Street
Youghal
Co Cork
Tel: 024 92353 / 087 273 1121

West Cork Cancer Support

Community Work Department
HSE Skibbereen
Co Cork
Tel: 027 53485 / 086 862 5417

Ulster support groups & centres**Cancer Support and Social Club**

Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965

The Forge Cancer Support Group

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924

Good and New Cancer Drop In Centre

Unit 1, Portlink Business Park
Port Road
Letterkenny
Co Donegal
Tel: 074 911 3437

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Living Beyond Cancer

Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477

Solace: Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

Yana Cancer Support Centre

Belturbet
Co Cavan
Tel: 087 994 7360

For other support groups or centres
in your area, call 1800 200 700.

Useful contacts outside Republic of Ireland**Action Cancer**

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

Website: www.cancer.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Network Buddies

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

Healthtalkonline

Website: www.healthtalkonline.org

Leukaemia and Lymphoma Research

39-40 Eagle Street
London WC1R 4TH
Tel: 0044 20 7405 0101
Email: info@beatbloodcancers.org
Website: www.beatbloodcancers.org

Lymphoma Association

Website: www.lymphomas.org.uk

Macmillan Cancer Support (UK)

Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77-81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net

MDS Foundation (European Branch)

King's College Hospital
Denmark Hill
London SE5 9RS
Email:
eupatientliaison@mds-foundation.org

Myeloma UK

Broughton House
31 Dunedin Street
Edinburgh EH7 4JG
Scotland
Tel: 0044 131 557 3332
Email: myelomauk@myeloma.org.uk
Website: www.myeloma.org.uk

National Cancer Institute (US)

Website: www.nci.nih.gov

TC-Cancer: Testicular Cancer Resource Network

Website: www.tc-cancer.com

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Stem Cell Collection*
- *Understanding Acute Lymphoblastic Leukaemia*
- *Understanding Acute Myeloid Leukaemia*
- *Understanding Chronic Lymphocytic Leukaemia*
- *Understanding Myeloma*
- *Understanding Hodgkin Lymphoma*
- *Understanding Non-Hodgkin Lymphoma*
- *Understanding Testicular Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *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*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*
- *A Time to Care: Caring for Someone Seriously Ill at Home*



Autologous Stem Cell Transplant

Lymphoma Association, 2011
ISBN 978-0956475558
[For more details, see
www.lymphomas.org.uk]

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul
Partnership/Limerick VEC/Safefood, 1998
ISBN 187407514X
[For more details, see www.mabs.ie]

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.
Thrombocytopenia	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?
- 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?
- What precautions should I take at home?
- 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



Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet:

Haematology staff, St James's Hospital, Dublin

Sheila McCrorie, Clinical Nurse Manager in Cancer Services

Karen Mulhall, Haematology Clinical Nurse Specialist

Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet, or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes patient education booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life with three programme areas to achieve them: advocacy, cancer services and research.

