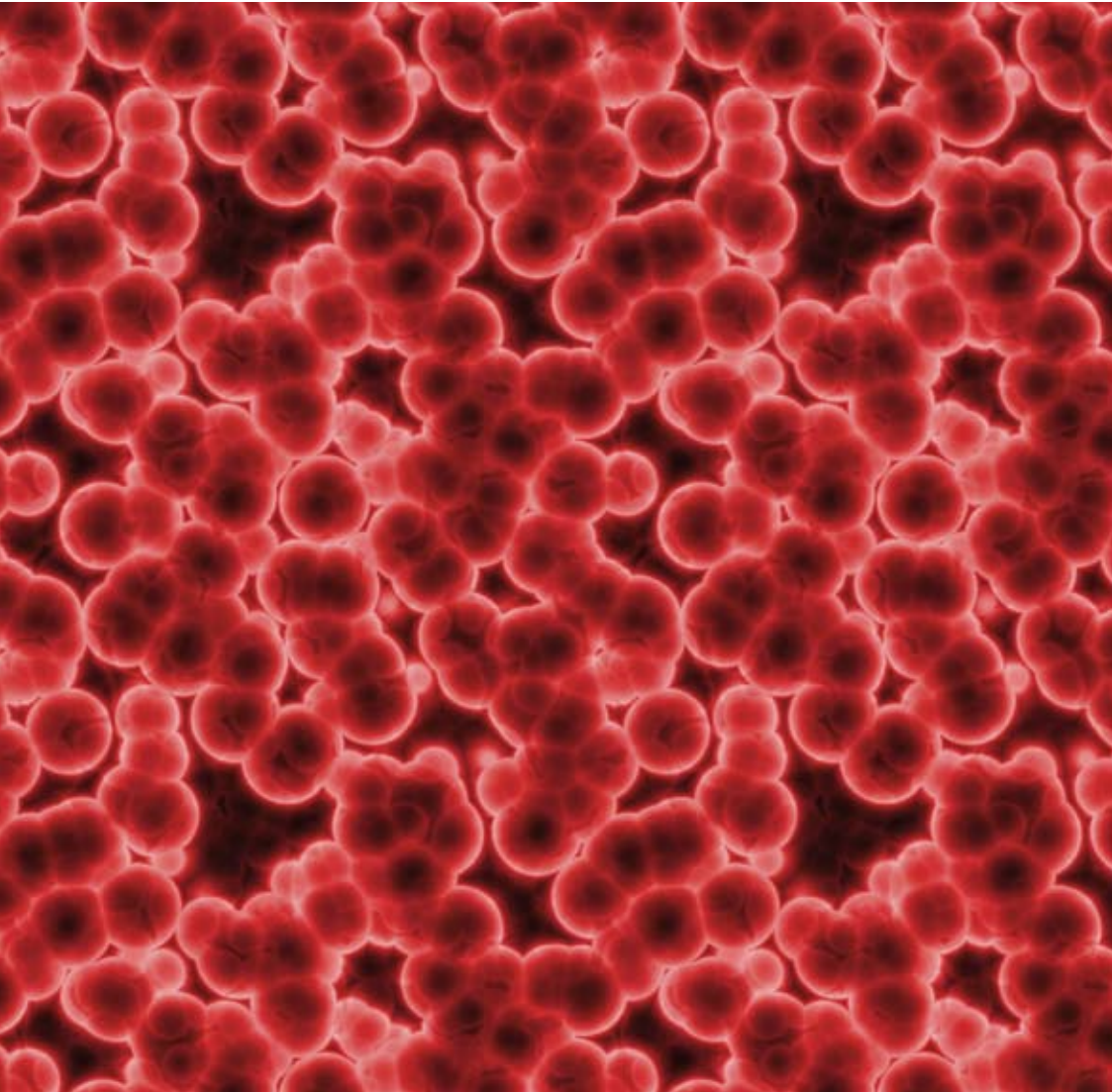


# **Undergoing high dose therapy and autologous stem cell transplant**



The diagnosis of a blood cancer can be a devastating event for patients, families and friends. It is therefore vital for everyone to have access to reputable and understandable information to help cope with the illness. Whenever possible our booklets are written in line with national guidelines for the treatment of patients with a blood cancer. The information in our booklets is more detailed than in many others but is written in a clear style with all scientific terms explained for the general reader.

We recognise that the amount and level of information needed is a personal decision and can change over time. Particularly at the time of diagnosis, patients may prefer less detailed information. A number of alternative sources of information are available which complement our publications.

The booklets in this series are intended to provide general information about the topics they describe. In many cases the treatment of individual patients will differ from that described in the booklets.

**At all times patients should rely on the advice of their specialist who is the only person with full information about their diagnosis and medical history.**

**For further advice contact the clinical information team on 020 7269 9060.**

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It is important to understand that details of procedures may vary from hospital to hospital and between patients. This book was written to provide information about the typical experience of a patient receiving a stem cell transplant.

Patients should always rely on the advice of their specialist doctors and nurses who are the only people with full information about their diagnosis and medical history.

For further advice contact the clinical information team on 020 7269 9060.

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# Introduction

## About the booklet

**This booklet has been written to tell you what is involved when you agree to have a stem cell or bone marrow transplant using your own cells, and to guide you through the transplant process. Hopefully, it will go some way to answering the many questions you may have. If there are questions that remain unanswered please speak to the transplant doctor and/or transplant coordinator nurse.**

## What is bone marrow?

Bone marrow is a spongy tissue found within certain bones in the body. The main bones it is found in are the pelvis, sternum (breast bone), limb bones and ribs. All blood cells are produced in the bone marrow.

## What is a stem cell?

A stem cell is the 'mother' cell capable of dividing many times to form the three main types of cells found in the blood. These are the red blood cells, the white blood cells and the platelets.

Red blood cells — these carry oxygen from the lungs to all the tissues of the body. When the numbers of red blood cells are low (anaemia) you may feel more tired and may look pale.

White blood cells — these help to protect the body against infection from bacteria and viruses. One type of white blood cell (the neutrophil) is very important in fighting infection from bacteria and fungi. When neutrophils are low (neutropenia) you are at greater risk of infection.

Platelets — these cells form blood clots and therefore help control bleeding. When they are low (thrombocytopenia) you can bruise more easily and may take longer to stop bleeding if you cut yourself.

# Considering the options

**The process begins by assessing your treatment options. You will have an appointment with the haematology transplant consultant, usually with a specialist nurse present. The consultant will discuss the whole procedure with you in detail, including risks and benefits.**

## What are the benefits?

The benefits are the chances of the transplant either curing your disease, or prolonging the time that your disease is controlled for. We already know that for some diseases the transplant is not curative but may offer control for a longer period of time than by just giving chemotherapy. Similarly, whilst transplant can cure some diseases it is never a 100% guarantee. Your consultant will be able to tell you the chances of curing your disease if this is possible.

## What are the risks?

Although the risks of autologous transplants are lower than those of donor transplants, there may be side effects occurring at the time of the transplant; rarely, these can be fatal. Your specialist will discuss this with you in detail before you make a final decision about undergoing a transplant. The longer term risks include the possibility that the transplant may not be successful; again this will be explained in detail.

As a result of your consultation you may be advised to have your stem cells collected for future use but that a transplant at the moment is not necessary. Similarly it may be that the consultant advises you to have a transplant to consolidate your treatment. Either way this is the first opportunity to ask questions but you should be given details of a 'key worker'. This is usually the transplant coordinator nurse or another specialist nurse who you can contact if you have any further questions, or you may wish to come back and see the consultant again.

Before you leave this appointment, you should have the details and dates of what is going to happen i.e date of the stem cell collection and potential date of admission. These may change if your current chemotherapy treatment is delayed for some reason or if you do not collect enough stem cells the first time round. Ideally you should have also been shown around the ward or unit where the transplant will take place. If you would like to look around the ward or unit but haven't been given the opportunity, give your key worker a call and they should be able to arrange this.

If you are happy with all of the information you are given you may be asked to sign a consent form for the transplant. If you are not happy or are in any way unsure you do not have to sign straight away.

# What is a stem cell/ bone marrow transplant?

**A blood stem cell or bone marrow transplant allows you to have much higher doses of chemotherapy, sometimes with radiotherapy, to improve the chances of curing the cancer or remaining in remission for longer dependent on the type of cancer you have.**

Some of your own stem cells or bone marrow are taken and stored before you have high doses of treatment. Then, high dose treatment (the conditioning regimen) is given to destroy the cells in your bone marrow. Your own stem cells or, less commonly, bone marrow are then used to 'rescue' you from this intensive treatment. This means that healthy blood cell production can restart, allowing the bone marrow to recover and produce new blood cells.

# How are the cells collected and stored?

**There are two different ways to collect stem cells:**

- **bone marrow harvest (BMH)**
- **peripheral blood stem cell (PBSC) collection**

These two procedures are very different and will be explained in more detail over the next few pages. PBSC collection is currently the more commonly used method.

Whichever procedure is performed you will need to have routine infection screening performed before the collection takes place. These are blood tests that look for particular viruses you may have been exposed to in the past. This is done as a safety measure to prevent cross infection when the cells are cryopreserved (frozen) and stored in vats.

The infections tested for are:  
Hepatitis B and C, Human Immunodeficiency Virus (HIV) and syphilis.

It is a requirement that these tests are discussed with you before they are performed and that you sign a consent form agreeing to have the tests done. The results are usually available within a few days. All results are confidential and a copy will only be sent to the GP if positive. If any results are positive that could have implications e.g. the HIV test, you will be called back to the clinic to discuss them.

## Stem cells

The stem cells are collected by moving or 'mobilising' them into the blood, often using growth factors. The growth factor used is called G-CSF, which stands for Granulocyte Colony Stimulating Factor. This is a synthetic version

of one of our naturally produced chemicals, which stimulates the body to produce extra stem cells in the bone marrow and move to the blood stream where they are collected. This can be done in a number of ways. If you are undergoing chemotherapy, it is sometimes possible to collect stem cells as your blood counts recover. We know after chemotherapy that your white counts will go down and after around ten days start to increase in number again as they recover from the effects of chemotherapy.

Approximately five days following completion of chemotherapy, G-CSF injections are commenced daily and these help to accelerate the white count recovery. Stem cell numbers in the marrow and blood also increase and therefore can be collected. The hospital will monitor your blood counts on a daily or alternate day basis and will collect your stem cells when the white count is high. Alternatively, growth factors can be administered without prior chemotherapy. Injections are given once or twice a day, generally starting four days before the date of the harvest.

You can be taught to give the injections to yourself or a family member can do this for you. If this is not possible for any reason, a district nurse can be asked to visit your home to give the injections. If you are receiving daily injections, these will usually be given in the early evening around the same time each day. If you are having twice daily injections it is important to have the injections eight hours apart. They should be stored in the fridge and taken out about 30 minutes before they are to be given.

The most common side effects of the injections are a flu-like feeling (including fever and aches) and bone pain. These symptoms are temporary and will disappear when the injections stop. It may be necessary to take painkillers such as paracetamol. The painkillers will have no effect on the stem cells, although aspirin or similar products should be avoided as they may cause an increased risk of bleeding when you are disconnected from the machine after the procedure. Taking a warm bath may also help with the symptoms.

If you experience any other side effects such as chest pain or stomach pain it is important that you speak to someone at the hospital that prescribed the injections. Contact telephone numbers should be given to you at your clinic appointment.

You will be asked to sign a consent form before the procedure is carried out. By signing this form you are agreeing that the procedure has been explained to you and that you understand any risks involved. If you are unsure about any aspect of the treatment proposed you must ask.

You will be told what time to attend the hospital on the day of collection. You can eat and drink normally during the procedure and can read a book or magazine. It is not advisable to drive yourself and whoever brings you can usually sit with you during the procedure. If you have a central line in, such as a Hickman™ line, this can be used for the procedure. A needle will also need to be placed in a vein in one arm, and connected to the machine. If you do not have a central line you will be attached to the machine using needles in both arms. Rarely, if the veins in the arms are not large enough, a line will have to be placed in one of the larger veins in the body (usually in the groin or in the neck). This line will be removed when the collection procedures have finished. Once you are attached to the machine you cannot be disconnected until the procedure is completed which is usually around 3-4 hours.

You are attached to a machine called a cell separator. The blood flows out of one line and into the machine; it is then centrifuged in the machine at high speed without damaging the cells. The stem cells collect in a bag and the remaining blood cells are returned to your bloodstream.

Your blood pressure and pulse will be recorded during the procedure. You may feel dizzy or light headed during the procedure and it is important to let the nurse or doctor know. This is because the machine is removing and replacing blood and although this is only a small amount at any one time (about a teacupful), some people can be sensitive to the change in blood volume.

There is an anticoagulant used in the machine to prevent the blood from clotting. For about 10% of patients, this may cause a sour taste in the mouth or tingling around the lips, cheeks or fingertips due to a fall in calcium levels. Giving you a tablet called Calcichew or a glass of milk can easily treat this, so it is important to let the nurse or doctor know if you get these symptoms.

The collection is usually completed in one or two days. Occasionally you will be collected a third day if more stem cells are required to make up the number for transplant. You may go home after the first day and will be told or telephoned if you need to return the next day, in which case you will require more G-CSF injections that evening.

## **Bone marrow harvest**

This type of harvest is carried out in theatre under a general anaesthetic. You are usually admitted to hospital the day before the harvest. You may need to have some blood tests and be examined by a doctor who will discuss the procedure with you again and ask you to sign the consent form agreeing to the procedure.

You are not allowed to eat or drink anything from midnight the night before theatre. On the day you will be asked to shower and put on a hospital gown. All jewellery must be removed except a wedding ring. When the theatre staff are ready for you a porter and nurse will take you to theatre.

You will have a cannula (a plastic needle) inserted into the back of your hand so the anaesthetist can give you the medication to put you to sleep.

Bone marrow is harvested from the back of the hipbones; very rarely, the breast bone may be used in addition. A needle is put into the bone and the bone marrow is sucked out with a syringe and transferred into a blood bag. The harvest takes around an hour to complete and about 1-1.5 litres of marrow is removed. It sounds a lot but your body can replace this in less than three weeks.

Once complete, a dressing is put over the puncture site to stop the site from bleeding and you are taken to the recovery room to 'wake up'. When you come round you may have fluids running into the cannula in your hand. This is to replace some of the fluid that has been taken during theatre. When you are properly awake you will be taken back to the ward.

It may be necessary to give you a blood transfusion; the doctors will inform you of this if it is needed.

The staff on the ward will monitor you regularly checking the puncture sites, your blood pressure, temperature and pulse. They will also monitor your oxygen levels when you return to the ward to recover. You will be allowed to drink now and given painkillers for the soreness you can experience to your back and hips.

If everything goes well you will be discharged the next day with some painkillers to take at home and some iron tablets if you are slightly anaemic. It is advisable to rest for the next few days.

## **Storage of cells**

After collection the stem cells are carefully labelled and taken to the processing laboratory in the hospital. The stem cells are then frozen and placed in special bags before being stored in liquid nitrogen. A chemical called DMSO is mixed with the stem cells in the blood or bone marrow before freezing. DMSO prevents the water in the cells forming ice crystals that would permanently damage them during the freezing process. Once frozen the cells can be stored for up to ten years if needed and do not have to be immediately transplanted.

## **What if there aren't enough cells collected?**

There are occasions when we do not collect enough stem cells. You are able to undergo the procedure of Peripheral Blood Stem Cell collection again,

although there needs to be a gap of around two months to give your bone marrow time to recover from the previous collection. If there are still not enough stem cells, it is possible to give you a single dose of chemotherapy to boost the stem cell production. However, sometimes it is the case that no matter what is done we are unable to collect sufficient stem cells, usually due to the amount and type of treatment you have received for your cancer. The options open to you can then be discussed with your consultant.

# Preparing for your transplant

## Tests

**There are a number of investigations and tests that are carried out before the transplant; these are to ensure you are generally fit and well. Usually these tests can be done in one day either at your local hospital or the transplant centre. Sometimes you may need to make more than one visit to get all the tests done.**

### ∴ Blood tests

Blood count, blood group, tests of kidney, liver and bone function, clotting, glucose and ferritin (iron level). Some patients will also need immunoglobulins or a paraprotein.

### ∴ Kidney function

There are several ways of measuring kidney function.

#### EDTA clearance

For this test you go to the Nuclear Medicine Department at the hospital. A radioactive dye is injected into one of the veins in your arm. After this a series of blood tests are taken, usually two, three and four hours after the initial injection. These timings may be different if you are having dialysis. If you have a central line in situ, this can be used to take the blood samples. The dye will not cause any side effects and is not harmful.

#### 24-hour urine collection

This can be done instead of the EDTA clearance. You will be given a large bottle to collect all the urine you pass in 24 hours. To start the collection you pass your first stream of urine straight into the toilet, but write the time on the bottle. From then on you collect all your urine in the bottle. You finish

collecting the next day at the same time you started. If you forget to collect any urine you will need to start the whole thing again. To be able to calculate the results when you take the bottle back to the hospital you will need to have a sample of blood taken. You need to take the bottle back to the hospital on the day you finish the collection.

## ⚡ Lung function

This tests how well your lungs work. It involves you breathing into different machines, breathing deeply, as hard as you can and for as long as you can. The technician who performs the test will explain what you need to do. If you normally take inhalers for breathing try not to take them for four hours before the test is carried out, but if you have to take them make sure you tell the technician. Make sure you take a list of any medication you are taking.

## ⚡ Heart function

There are different ways of measuring heart function (how well your heart pumps) that are commonly used. You will only need one of these tests as they provide the same information.

## MUGA

These are scans to check your heart. A MUGA scan is performed in the Nuclear Medicine Department. The test involves two small injections in your arm of radioactive dye. After the first injection there is a wait of approximately 30 minutes before the second injection is given. A series of pictures of your heart can then be recorded. The whole test takes around an hour to complete. The dye will not cause any side effects and is not harmful.

## ECHO

If you have an ECHO you will be asked to undress to the waist, and to lie on a couch firstly on your back and then on your side. A gel will be put on your skin around your heart which allows a probe to be moved around your skin

and produce an image of your heart on a monitor which can then be printed off. This test is not painful, but you may be asked to lie still at times.

## **ECG**

An ECG is a trace of your heart rhythm. This is done by placing a series of electrodes, that stick to your skin, on your wrists, ankles and on your chest around your heart. A graph of your heart rhythm is printed on a piece of paper. This test is not painful, but you will be asked to lie still while breathing normally.

## **Dental appointment**

Before being admitted for transplant it is a good idea to see your dentist for a check up, if you have not been recently. This would also be a good time to have any minor dental work done that is needed as you will be at risk of infection immediately post transplant and do not want to have problems with your teeth. Patients should be warned against having any major dental treatment performed immediately before the transplant as time needed for sufficient cavity healing may delay the procedure. The dentist should contact the transplant centre if radical work or extractions are proposed.

## **Wig/toupee referral**

Due to the radiotherapy and/or chemotherapy you will lose your hair, if this has not already happened as part of your chemotherapy treatment. This is usually a gradual process that occurs one to two weeks after having chemotherapy. If you have long hair it is advisable to get it cut shorter prior to admission to make it easier when it is falling out. Alternatively you may want to get your head shaved by the nursing staff when it starts to fall out.

Not washing or combing your hair when it is starting to fall out will not stop it from happening. When receiving treatment as part of the NHS you are entitled to a free wig/toupee or vouchers for a wig/toupee if there is no service at your hospital. It is advisable to organise your wig/toupee

before you lose your hair so it can be matched to the colour, length and style. You will also be shown how to look after it and fit it correctly.

Most importantly your hair will grow back! You may start to feel that your head is itching; this is the commonest sign that your hair is on its way, and usually occurs a couple of months after the transplant. When your hair comes back it is usually soft at first but can quickly become thicker, wavy and coarse feeling; this will change as it gets longer. Be aware though that your hair may not be quite the same as it was prior to transplant. It may be curly where before it was straight and vice versa. If you were starting to go grey you may find your hair grows back completely grey.

## **Fertility referral**

It is highly likely that you will be infertile post high-dose therapy and stem cell transplant although this is not 100% and there have been a few reported cases of conceptions and births following transplant. It is therefore advisable to continue to use contraception after the transplant if you or your partner are of child-bearing age and do not wish to have children. The effects of chemotherapy on fertility may have already been discussed with you at your referring centre as you may have had chemotherapy that affects fertility to some extent.

For men, the main fertility option is semen storage prior to starting treatment. For women, options remain limited, and can be more difficult to organise prior to initial treatment chemotherapy as they are time consuming. Pre transplant it may be that you can be referred to a fertility service for advice as to the options available. This should be discussed with your consultant.

## **Insertion of central line**

You may already have a central line in place; this may be a Hickman™ line or a PICC line. Hickman™ lines are inserted under general anaesthetic

in theatre or under local anaesthetic in an x-ray department. PICC lines are generally inserted on the ward or unit under local anaesthetic. Each transplant centre has their preferred type of central lines.

A Hickman™ line is a catheter or hollow tube that is inserted into a large vein in the neck and tunnelled under the skin. One end sits in a large vein that feeds into the heart, the other end stays outside the body and can be used to give drugs and fluids or administer stem cells and collect blood samples. This type of line can stay in place for months if needed.

A PICC line is a long, fine tube inserted into a vein in the crook of your arm but ends in a large vein in the heart with the other end remaining outside the body as the Hickman™ line does. This type of line is usually only kept in for the time of the transplant and can be taken out before you go home.

## Going in to hospital

You may be admitted into a single room, twin room or a bay of patients undergoing transplant. Each transplant centre is laid out differently. At your initial consultation, or when shown around the ward or unit, you will be made aware of where transplant patients are nursed. As your blood counts fall, it is advisable that you are cared for in a single room and some centres do have isolation rooms for this type of transplant. Although the risk of infection is greater than if you had chemotherapy prior to transplant, the general risk is still low. See section on infection in 'Side effects of treatment'.

Storage space will probably be limited so think carefully about what you are taking with you. Average admission is 3-4 weeks; the easiest way is to imagine you are taking a long vacation. Take comfortable clothes for the daytime remembering the nurses will need to access your central line. Take nightclothes and a dressing gown and something comfortable to wear on your feet i.e. slippers. Ask your relatives to take your bags and coat home so you have less to store. Ensure you have toiletries with you but towels will be provided by the

hospital. You will also need to keep yourself occupied although there will be a period of time where you don't feel well enough to do anything. If you enjoy reading take in a couple of books to read or if you enjoy sewing or knitting you can take this in with you.

The doctors and nurses on the ward are all experienced members of staff and should be able to answer any questions you may have. You may feel anxious and unsure during your time in for transplant. This is not unusual, particularly if you are being treated in a hospital you are not used to. Talk to the nurses and doctors and let them know your fears. Similarly your key worker may see you while you are in to provide support and answer any questions.

Some transplant centres have access to a psychologist or psychotherapist who is experienced in listening to transplant patients who are worried or anxious about their time in hospital. They can provide expert support and ways of coping with your feelings and anxieties. Sometimes just saying what is on your mind is enough to make you feel better.

# Conditioning therapy

**Before receiving a transplant, patients are given chemotherapy drugs and sometimes radiation therapy to kill off the existing bone marrow. In the case of an autologous transplant the purpose of this is to ensure any remaining disease cells are destroyed before the healthy stem cells are returned to the body. This is known as conditioning treatment. Side effects are covered later in the book.**

## Radiotherapy

This radiotherapy is called Total Body Irradiation (TBI). The majority of patients having their own cells back do not have radiotherapy as part of their transplant. If you need TBI you will meet a consultant or registrar from the radiotherapy department who will go through the procedure, risks and benefits. You will be given written information and be asked to sign a consent form just for the radiotherapy. You will then meet a radiographer who will take some measurements i.e. height and weight, and show you the room where the radiotherapy is carried out.

Radiotherapy is administered in 'fractions' each lasting no more than ten minutes. How many fractions you need will depend on the transplant guidelines but usually it is twice a day, early morning and late afternoon, for three or four days. For the TBI you are either sat in a chair or lying on a couch. The radiographers will explain fully what you need to do. Once everything is set up the radiographers will leave the room but you will be able to talk to each other.

## Chemotherapy

This is the use of cytotoxic (anti-cancer) drugs to destroy cancer cells. You may well have had some chemotherapy as part of your original treatment, and so may have some idea as to what to expect.

The chemotherapy will be given through your central line along with plenty of fluids. It is given as a single infusion, or a series of infusions over a few days. It usually depends on your disease as to which chemotherapy schedule you have. Some schedules contain a mixture of chemotherapy infusions and chemotherapy tablets.

You will also be given a lot of tablets to take. These are to help reduce any side effects you will experience. Normally you will receive tablets to help with sickness and indigestion and to reduce the chance of infections.

## Return of your stem cells

**This day is known as 'Day 0', and is usually a day or more after completing your conditioning therapy. Your stem cells will be brought to your bedside in a vat containing liquid nitrogen. Each bag will be defrosted individually in a water bath and infused through your central line over 10-15 minutes each. You will be given intravenous fluids before the cells and also an injection of hydrocortisone and Piriton to stop any reactions. This is because you can react to the DMSO, the preservative used to keep the cells safe when frozen.**

You will have your temperature, pulse and blood pressure recorded regularly during the procedure to monitor for reactions. You may also experience nausea or sickness from the preservative. You will already have had anti-sickness tablets to prevent this but may need an injection if it persists.

When passing urine you may notice your urine is a red colour. This is normal and is nothing to worry about. When you had your stem cells collected a small number of red cells would have been caught up in the process and frozen with the cells. These cells die when defrosted and it is these cells you are passing in your urine, hence the red colour.

Due to the preservative we can only give a maximum of eight bags of cells back in one day. Sometimes, you may have more than eight bags, especially if you were collected more than once in order to get enough cells for the transplant. If this is the case your cells may be given over more than one day.

# Side effects of treatment

**These side effects are not in any particular order but are all the side effects you may experience. You may have some or all of these effects.**

## Mucositis

The conditioning therapy affects fast dividing cells. Whilst the target of this treatment is cancer cells, other fast dividing cells include those that line the mouth and gut. These cells are called mucosal cells; they become thin and break easily forming ulceration and inflammation affecting your mouth, stomach and bowel.

This may start off as soreness in the mouth and throat. It may begin to look white and feel rougher than usual. It may become so painful that you are unable to eat and drink. The nursing staff will check your mouth daily and be able to give you painkillers when needed. It may be that you need painkillers as strong as morphine; often given in a 24-hour continuous infusion through your central line, or in the form of patient controlled analgesia (PCA) where you push a button on a hand-held pump when you are experiencing pain.

Mouth care is extremely important throughout this time. You will be given mouthwashes to help keep your mouth clean. You should also continue to keep your teeth clean using a soft or baby toothbrush and toothpaste for as long as possible, although this may become difficult. It is important to try and do your mouth care after meals and before bedtime, or four times daily.

## ∴ Nausea and vomiting

This is a known side effect of conditioning therapy. You will automatically be given anti-sickness medications while you are receiving treatment. If you still feel sick or are physically sick make sure you let the staff know as you may need your anti-sickness medication changing.

Nausea and vomiting may also be caused by the mucositis. Again anti-sickness medication should help and can also be given as a 24-hour infusion.

## Diarrhoea

Damage to the mucosal cells also affects the bowel causing abdominal discomfort and diarrhoea. This can be an unpleasant and distressing experience which can be helped by using a drug called loperamide. The staff will ask for a specimen of diarrhoea to make sure you do not have an infection as a cause for the diarrhoea.

It is important to keep yourself clean and dry after each episode of diarrhoea. Ask staff to help you if you need to.

## Neutropenia and infection

During your admission, your white count will fall to zero, so you will be neutropenic for a period of 7-14 days. This means you will be at increased risk of infection. These infections normally come from you rather than someone else. Bacteria live quite happily on your skin and in your stomach and bowel and do not present a problem until you become neutropenic. It is then that the bacteria can multiply and cause infections. As discussed earlier you may be nursed in a single room at this time.

It is important to have a daily shower to keep your skin clean and make sure you dry your skin thoroughly. Also ensure you wash your hands after going to the toilet and before eating your meals. Your bed linen will be changed daily to help reduce infection. If you are too tired and weak to shower ask a member of staff for help.

Most hospitals do not allow food to be brought in from home because of the increased risk of food poisoning. You will be on a 'clean diet'. An information sheet should be available for you so you know what the restrictions are. All visitors should maintain hygiene precautions. They should wash their

hands, and follow any procedures the nursing staff request (such as wearing a plastic apron). It is important that no visitors have a cough or cold or have been in contact with anyone with an infection.

## **Anaemia**

The conditioning therapy affects all cells so you may become anaemic. This can make you feel tired but you can be given a blood transfusion to rectify this.

## **Bleeding and bruising**

Similarly your platelets will be affected and you may find you bruise more easily. If you cut yourself or blow your nose too hard it may bleed and take some time to stop. If this is the case make sure you tell the nurses and doctors and you may be given a platelet transfusion.

## **Hair loss (alopecia)**

As discussed earlier, you will lose your hair but it will grow back.

## **Tiredness**

This is due to the conditioning therapy and is a common side effect. You may find you sleep more, even during the day but this is normal. If you are not sleeping properly at night then it may be possible for the doctors to prescribe a sleeping tablet.

## **Reduced or altered taste**

Conditioning therapy can alter your taste and smell. You may find that foods do not taste the same or that you are sensitive to certain food smells. This is a common side effect that will resolve slowly and may still be a problem when you first go home.

# Engraftment

**Once the stem cells are put back into the blood stream, they travel to the bone marrow, where they settle and develop into new blood cells. This is known as engraftment. You may be given growth factor injections, the same drug you would have received as part of the stem cell collection. These injections help to stimulate your bone marrow.**

Between 10 and 14 days after the cells have been infused, your white count will slowly start to come up. Your mouth will start to feel better and you should recover from any infections you have. Once your white count is high enough and you are able to eat and drink normally you will be allowed to go home.

# Discharge

When you are discharged you should be given an outpatient appointment, tablets to take home with you, and emergency contact numbers in case you are unwell at home.

It is important that you continue to take any medication prescribed until told otherwise and take your tablets or a list with you to your first outpatient appointment. At the appointment, your bloods will be checked and your medication will be looked at. How often you are seen initially depends on how well you are, if you had any complications during your transplant and how good your blood results are. You will be referred back to your local haematologist for routine appointments and monitoring once your transplant consultant is happy your condition is stable.

If you feel unwell it is important that you contact the hospital whatever time of day or night, as you are still at risk of infections. If you have been discharged back to your local haematologist then you must contact a member of their team or the haematology ward at your local centre. If you are still under the care of the transplant team then you must contact them to be assessed. It is important you contact them as soon as you feel unwell so infections can be caught early and treated properly.

## Life after transplant

### ∴ Eating and drinking

It can take anywhere between two and six months to return to normal after transplant. For the first few months while your immune system is returning to normal it is helpful to try to eat a healthy and balanced diet and avoid possible risks of infection from food. This means eating freshly cooked food and avoiding reheating food<sup>1</sup>. Eat foods well within the sell-by date and only store frozen foods for the recommended length of time.

<sup>1</sup>There is a separate publication on dietary advice for patients with neutropenia available from Leukaemia Research

It is important that you continue to drink well when you go home. Try to drink at least two litres of fluid daily.

### ⌘ Socialising

In order to reduce the risk of infection, you should avoid crowded places such as cinemas and pubs until your white blood cells return to normal. Your doctor can tell you what your blood count is and when you can relax these restrictions.

### ⌘ Exercising

Regular gentle exercise such as walking is a good way of building up your strength, similarly a gentle cycle on an exercise bike if you have one. Gradually build up the exercise, don't rush.

### ⌘ Sex

Your physical ability to have sex should not be affected and once your blood counts return to normal there is no reason why you and your partner cannot continue a physical relationship. However you may find your sex drive is reduced for some months after transplant while your body generally recovers.

You need not feel guilty or embarrassed about asking for professional advice if you are having sexual problems. Your doctor may be able to help directly or may refer you to a specialist for advice.

### ⌘ Working

You may be uncertain about when you should return to work. It may be possible to go back to work sooner if you have a sitting or desk job, or if you are able to start back on a part-time basis. Your doctor will be able to advise when this is feasible although it is usually at least three months after transplant.

## **Holidays**

Holidays are important and there is no reason why they cannot continue. You should discuss destinations with your doctor before booking; holidays abroad are not recommended in the first six months. When you are on holiday it is important to use adequate skin protection and avoid sunburn as your skin will be more sensitive after transplant, especially if you have had TBI.

# Notes



The following patient information booklets are available free of charge from Leukaemia Research. You can download them from our website or request copies by phone or post (see form inside):

## Leukaemia and Related Diseases

Acute Promyelocytic  
Leukaemia (APL)

Adult Acute  
Lymphoblastic Leukaemia (ALL)

Adult Acute  
Myeloid Leukaemia (AML)

Childhood Acute  
Lymphoblastic Leukaemia (ALL)

Childhood Acute  
Myeloid Leukaemia (AML)

Chronic Lymphocytic  
Leukaemia (CLL)

Chronic Myeloid Leukaemia (CML)

Aplastic Anaemia (AA)

The Myelodysplastic  
Syndromes (MDS)

The Myeloproliferative  
Disorders (MPD)

Multiple Myeloma (MM)

Hodgkin's Lymphoma (HL)

Non-Hodgkin's Lymphoma (NHL)

**Leaflets on a range of associated  
blood disorders are also available  
from Leukaemia Research**

Bone Marrow and Stem Cell  
Transplantation (BMT)  
– for children and adults

Donating stem cells  
– what's involved?

Donor Lymphocyte Infusion (DLI) –  
what's involved?

The Seven Steps – Blood & bone  
marrow transplantation

Undergoing high dose therapy and  
autologous stem cell transplant

Chemotherapy  
– what do I need to know?

Clinical Trials

Complementary and  
Alternative Medicine (CAM)

Dietary advice for patients  
with neutropenia

Supportive care

Treatment decisions

Watch and wait

Young adults with a blood cancer –  
what do I need to know?

Jack's Diary: an illustrated children's  
book to help young patients  
understand and deal with blood  
cancers, treatment and life changes

**Leukaemia Research, 43 Great Ormond Street, London WC1N 3JJ**

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