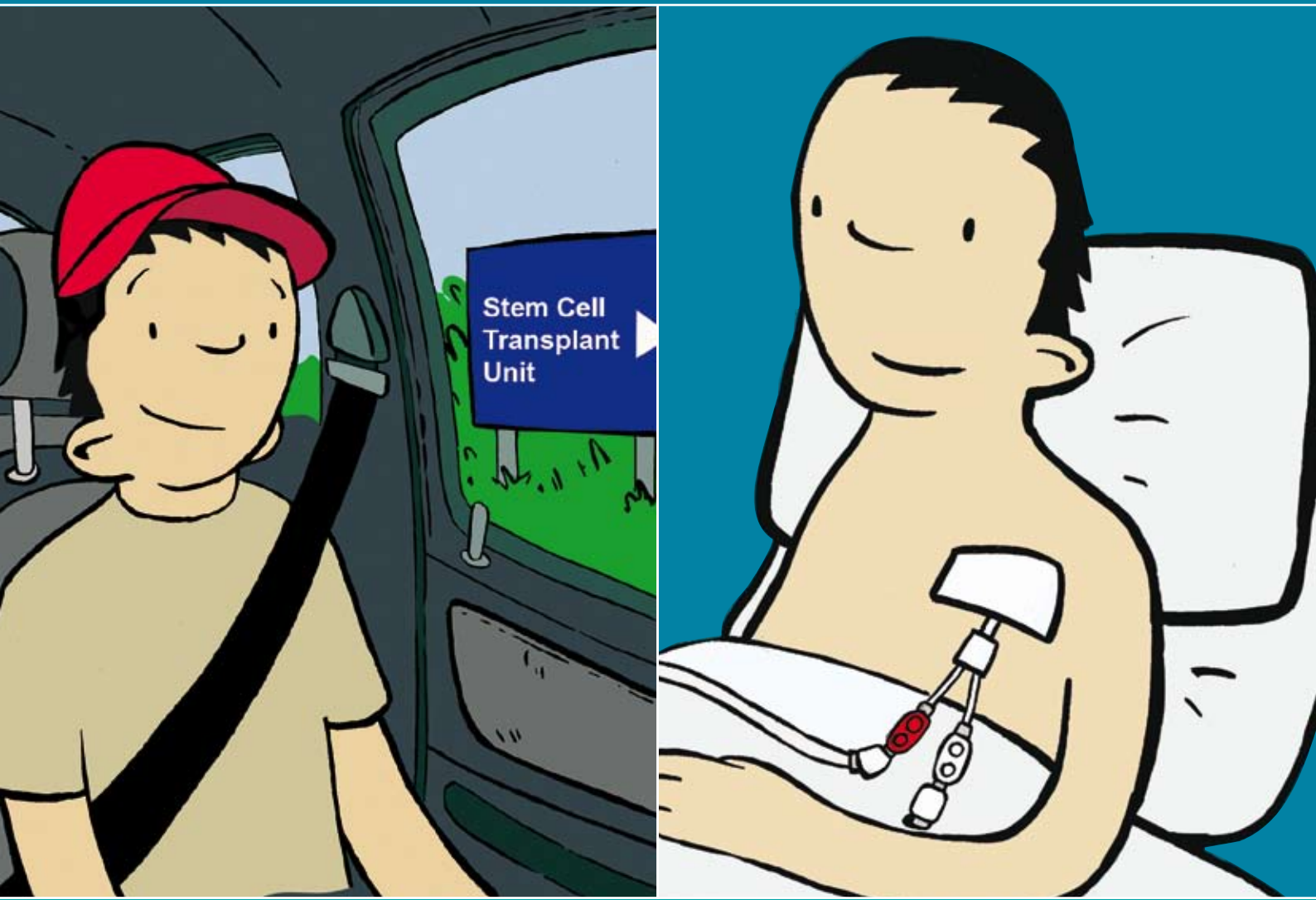
Stem cell Transplant

A guide to stem cell transplantation for teenagers and young adults



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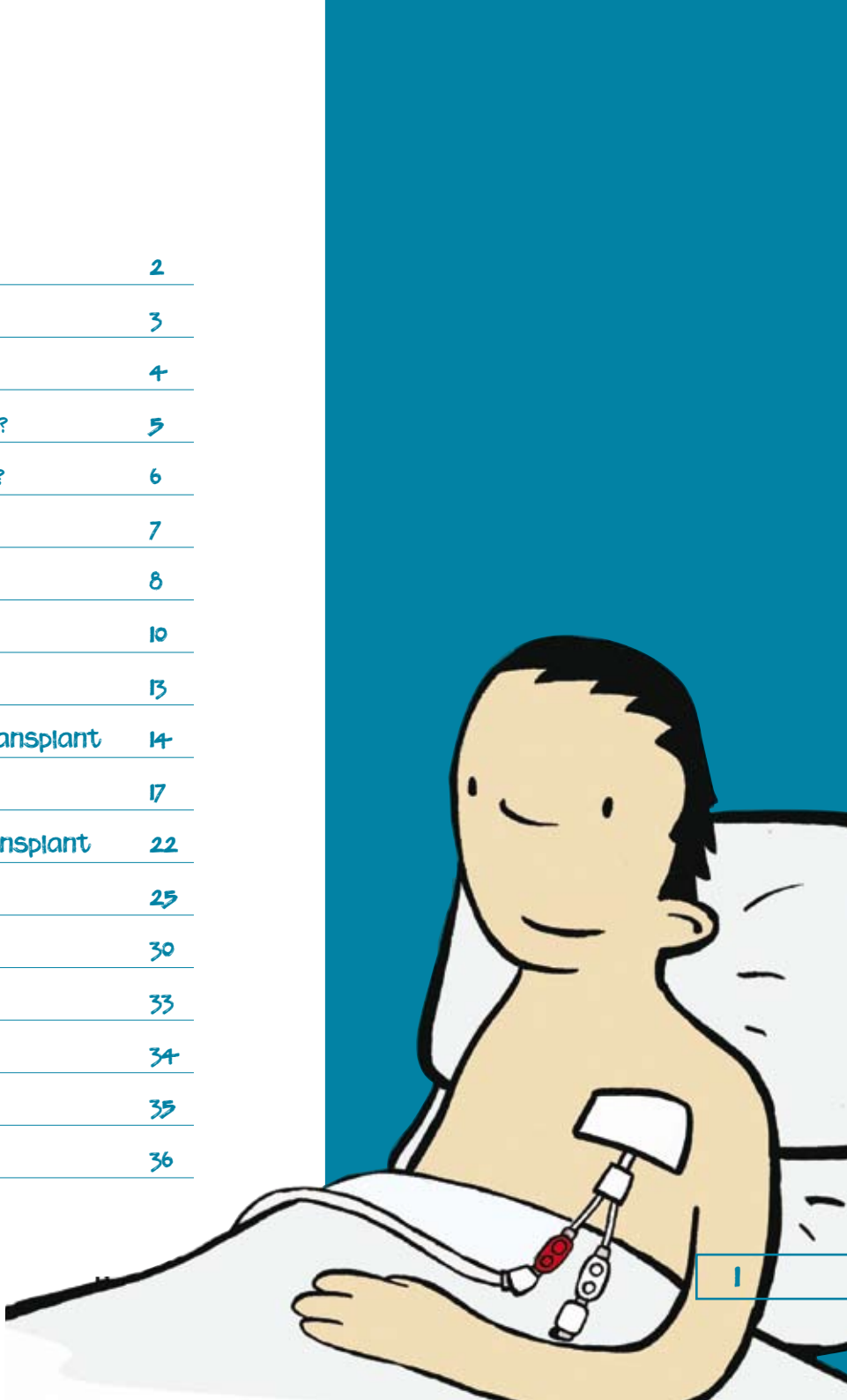
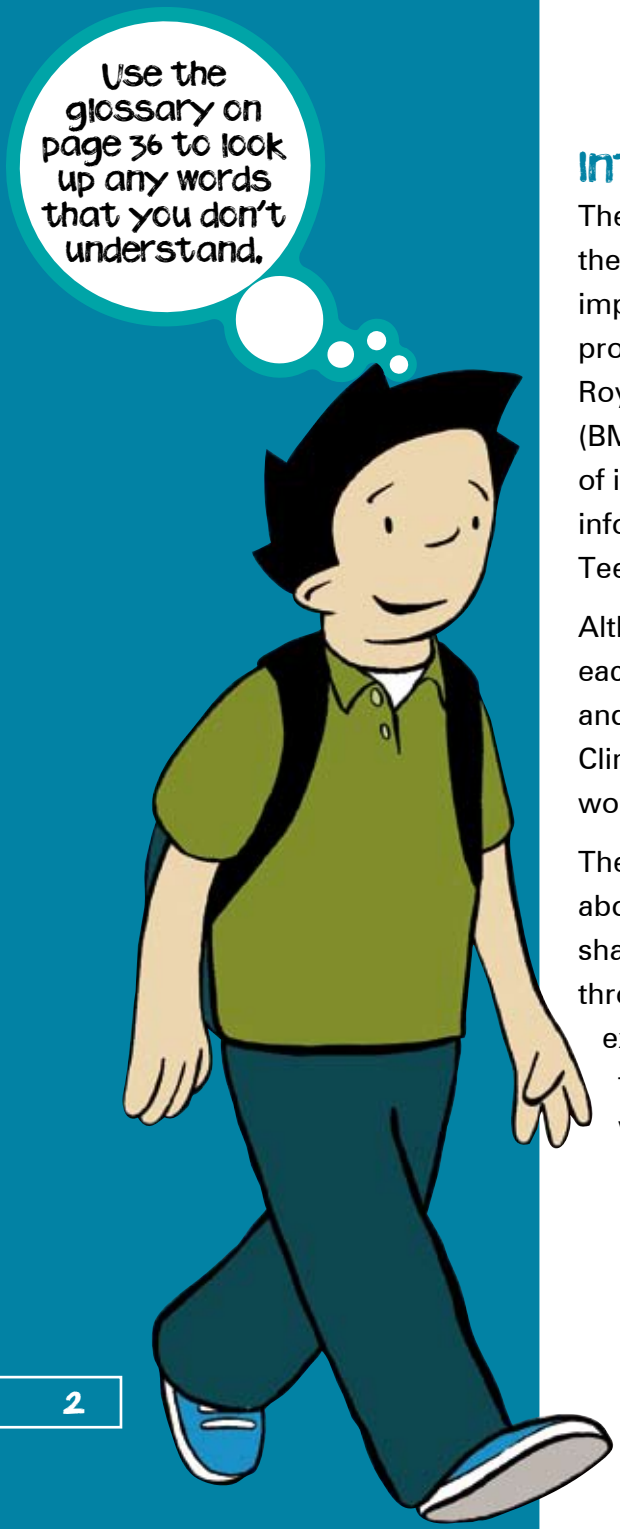




Introduction

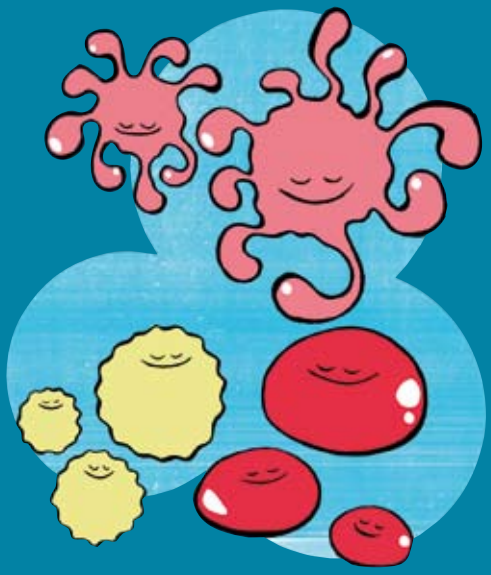
The stem cell transplantation process – from preparation for the transplant through to follow up – is long. It is extremely important that you understand why you need to undergo that process and what may happen to you along the way. The Royal College of Nursing Paediatric Bone Marrow Transplant (BMT) Nurses group have produced this guide as a source of information for teenagers and young adults. Additional information is available via Macmillan Cancer Support and the Teenage Cancer Trust.

Although we have tried to be as comprehensive as possible each transplant unit across the country will be slightly different and you should also ask your SCT Nurse Co-ordinator / Clinical Nurse Specialists, ward nurses and consultants if you would like further information.

The medical and nursing professions are continually learning about stem cell transplantation – their expertise is based on shared knowledge both nationally and internationally, gained through clinical trials and evidence-based practice. This expertise allows us to devise guidance on who is best suited to a transplant but generally your disease will determine when, and if, you require a transplant.

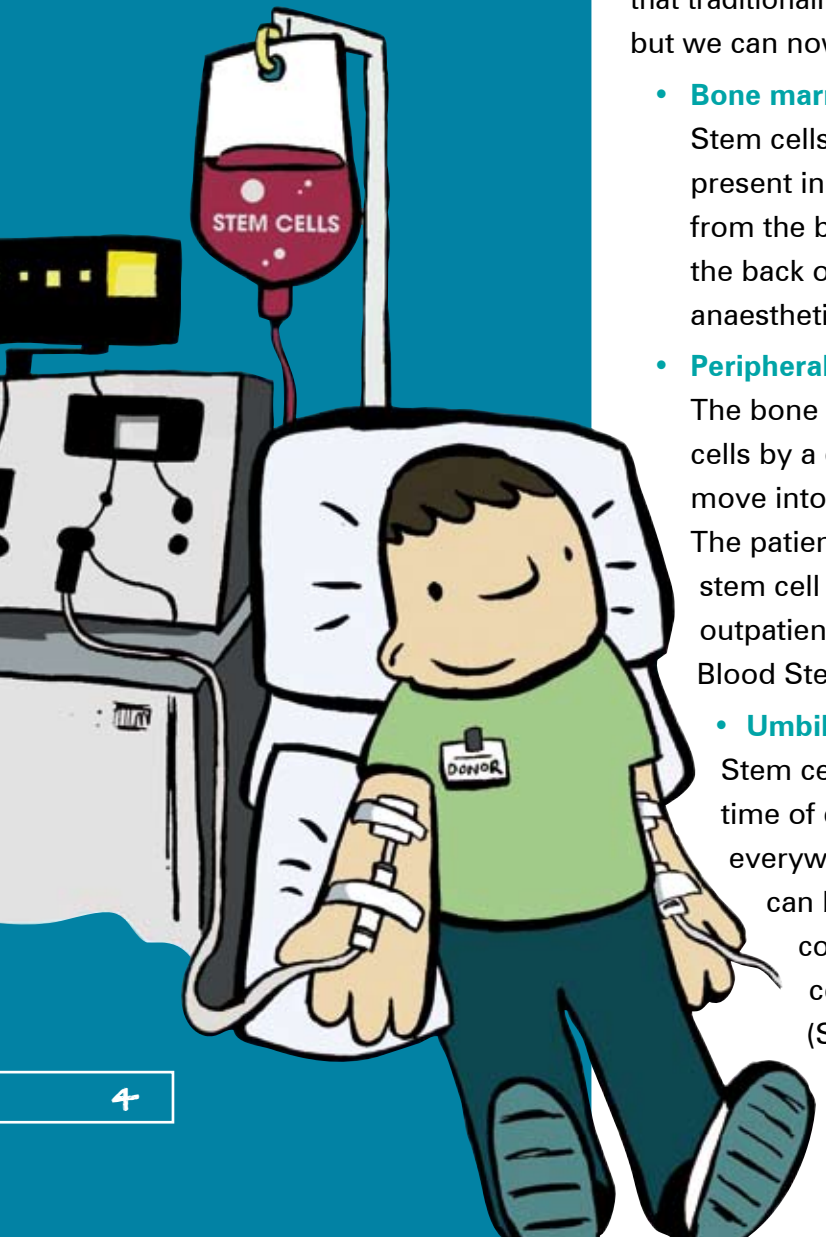
What are stem cells?

Bone marrow is spongy tissue found inside bones, particularly long flat bones such as the pelvis and breastbone. Stem cells are found in the bone marrow. They are blood cells in their very earliest stage of development that eventually develop into red blood cells, white blood cells and platelets.



What do blood cells do?

Blood cell	Function	Measured by	Symptoms if level low	Treatment
Red cells (RBC)	Contain haemoglobin which transports oxygen around the body	Haemoglobin (Hb) level – low level is called anaemia	Lack of appetite Lack of energy Pale skin Breathless Feeling cold Dizzy/headaches	Blood transfusion
White cells Many different types of white cells	Fight infection against bacteria, viruses and fungi Neutrophils are the most important type of white cell after transplant	White Blood Cell Count (WCC) Low neutrophil count is called neutropenia	If WCC falls – more likely to get infection	Observe for any signs of infection while WCC is low especially neutrophils and treat any symptoms
Platelets	Helps stop bleeding	Platelet count	Bruising Nose/gum bleeds Small bleeds under skin (petechiae)	Platelet transfusion



What is a stem cell transplant (SCT)?

A stem cell transplant is more commonly known as a bone marrow transplant (BMT). The reason we use different words is that traditionally the stem cells were obtained from bone marrow but we can now obtain the stem cells from 3 different sources:

- **Bone marrow**

  Stem cells can be found in the bone marrow, which is present in all long and flat bones. Stem cells can be taken from the bone marrow with a large needle – usually from the back of the pelvis while the patient is under a general anaesthetic. This is called a 'bone marrow harvest'.

- **Peripheral (or circulating) blood**

  The bone marrow is stimulated into producing extra stem cells by a growth factor – usually GCSF. The stem cells move into the circulating blood where they are collected. The patient has a cannula inserted and is attached to a stem cell collecting machine. This is usually done on an outpatient basis over 1-2 days. This is called a Peripheral Blood Stem Cell Harvest (PBSC Harvest).

- **Umbilical cord stem cells**

  Stem cells can be collected from umbilical cords at the time of delivery of a baby. This is not currently available everywhere in the UK but pre-arranged collections can be done where it is known that the baby is a compatible match for their affected sibling. Stem cells from unrelated cord units may also be used (See section on donors). Only a limited amount of stem cells can be collected from the cord

blood and therefore transplants using cord stem cells are usually limited to children but not always.

Stem cells can last for up to 72 hours if they are to be given fresh or they can be frozen and used at a later date.

Why have a stem cell transplant (SCT)?

The main reasons why someone may need a stem cell transplant are because:

- their own bone marrow/stem cells are diseased, leading to an imbalance in the production of blood cells, e.g. leukaemia where there are too many white cells
- the bone marrow is not functioning properly, e.g. aplastic anaemia, thalassaemia
- the bone marrow is suppressed, e.g. after chemotherapy or radiotherapy
- the immune system is not functioning properly, e.g. combined immune deficiency.

At the time of being told he would need a transplant:

"I was not prepared for this and I was upset as I didn't know what was going to happen"

Max age 12

What types of transplants are there?

Allogeneic transplant

Where stem cells are donated from a close relative or unrelated donor. This type of transplant is a complex procedure and can be subdivided into the following:

- **Sibling –** stem cells from a brother or sister. Each of your siblings has a 1 in 4 chance of being a match with you.
- **Syngeneic –** stem cells from an identical twin.
- **Haploididentical –** stem cells from a parent or sibling that will only be a 50% match. This is not a common type of transplant.
- **Umbilical cord –** stem cells taken from a related or unrelated umbilical cord.
- **Unrelated –** stem cells taken from a matched or partially mismatched donor that has been found on a donor panel and closely matches your tissue type.

Autologous transplant

Stem cells are the patient's own. This type of transplant is more likely to be done for solid tumours according to the treatment plan for the particular tumour. Stem cells can be collected by a bone marrow (BM) harvest or Peripheral Blood Stem Cell (PBSC) harvest and stored until the patient requires them, usually after high dose chemotherapy.

Donors

Finding a donor

Usually when it is decided that you need an allogeneic transplant your parents and siblings will be tissue typed to see if anyone is a match for you. Each sibling has a 1:4 chance of being a match with you. If no suitable family match is found an unrelated donor search will be initiated. The UK donor panels, which include the Anthony Nolan Trust (ANT), British Bone Marrow Registry (BBMR), and Welsh Bone Marrow Donor Registry (WBMDR), will be searched initially – if no suitable donor is found on these registries, international panels and cord banks are searched. The two largest international donor panels are the National Marrow Donor Panel (NMDP) in America and the German panel. There are approximately 10 million people/cord units on donor panels worldwide. It is often more difficult to find a donor if you are from a different ethnic background.

Tissue typing or Human Leukocyte Antigen (HLA) testing is done to best match patients with donors. HLAs are proteins found on most cell surfaces in your body and are genetic markers that make you an individual like fingerprints. Your immune system uses these proteins to recognize which cells belong in your body and which ones don't. They also help protect the body against organisms such as bacteria and viruses. That is why it is important to have a close HLA match between yourself and your donor so that your immune system does not attack the donor cells (graft rejection) or that your donor's immune cells attack your body after the transplant (Graft Versus Host Disease).

Pre-transplant preparation

Once a suitable donor is found we need to make sure that both you and your donor are fit and well before you have your transplant. The donor panel team will counsel and prepare the donor for the procedure and the transplant hospital team will look after you.

It is important before you have your transplant that you understand what is happening to you and that consent for treatment has been given. In the UK, teenagers/young adults between the ages of 16–18 years or their parents can consent for treatment, however it is important to include parents/guardians in decision making when undergoing complex treatment such as a transplant. Young adults who are aged 18 years and over can consent themselves. To give consent you should be given information on:

- The benefits and risks of treatment
- Implications of not having the transplant
- What the treatment will involve
- Whether there are any treatments other than transplant as a treatment option
- What the effect on your life will be of having, or not having, the transplant.

You will need to have all or some of the following tests:

Blood tests – this includes blood tests and virus testing.

ECHO – an ultrasound of the heart to check function.

Dental check – dental cavities can be a serious source of infection after your transplant so need to be treated before commencing conditioning.

Kidney function – A small amount of radioactive dye is injected into your line or cannula. A series of 4 blood samples are then taken over approximately a 4-hour period and a calculation on your kidney function is done on the results.

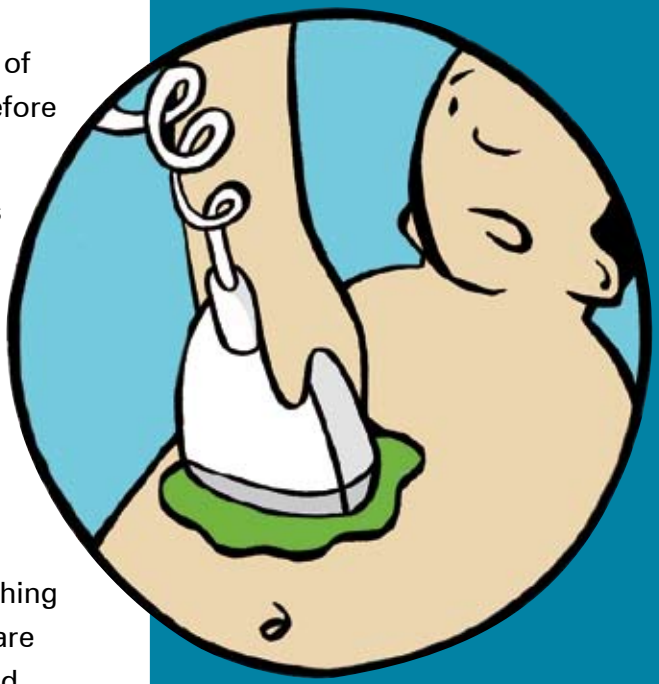
Bone marrow aspirate/trephine – to ensure that you are in remission going into the transplant.

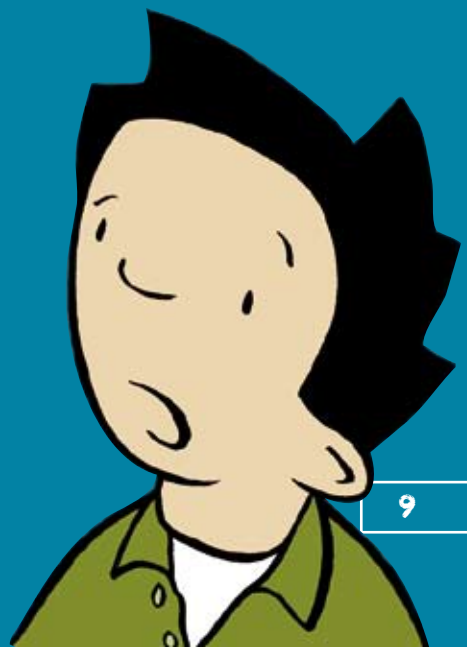
Lung function tests – you may need to undergo lung function tests pre-conditioning which will involve breathing into different machines to assess how well your lungs are working. Your kidney and lung function will be assessed pre-transplant and chemo prescribed accordingly to what your body can tolerate.

Hand X-ray – to assess bone age in relation to chronological age pre-transplant as a baseline, as some of the treatment may slow down your growth.

Pregnancy testing – females who have reached puberty will be asked to have a pregnancy test as part of routine pre-transplant preparation.

Sperm cryopreservation – males who are aged 13 years and over can discuss the possibility of sperm cryopreservation with their transplant consultant who will discuss if this is appropriate.





The transplant team

During a transplant there are many professionals involved in your care. These include the following but there may be others that are very important:

Consultants

Consultants are the doctors who are in overall charge of your care.

Specialist Registrar/Senior House Officer

These doctors look after your overall medical needs and report back to the consultant. You will be examined by one of these doctors each day.

Ward Manager

This is the nurse who is in charge of the Unit.

Stem Cell Transplant Co-ordinator/Nurse Specialist

This nurse will help prepare you and your family pre-transplant and follow your progress as an outpatient. The SCT Co-ordinator also provides a link between yourself, the hospital and your own local community (e.g. your G.P., shared care hospital, community nurse, school/college/work). S/he is available to give you support, information and guidance before, during and after transplant and in some centres can visit you at home if required.

Nurses

When you are admitted, you will be allocated a particular nurse, who on some units may be referred to as a named nurse, who is responsible for co-ordinating your nursing care during your admission and will care for you whenever possible. Sometimes you will have more than one named nurse.

"got to know the nurses better than the doctors - could chat to them and have a laugh. Easier to ask them questions than doctors especially on ward rounds as I felt that if I asked an easy question I would feel stupid in front if them"

Callum, age 13

Dietician

You will need to have a 'clean diet' during and following transplant. There are certain foods which cannot be eaten and care is required with preparation. The dietician will visit and explain this to you and help with any eating problems you may have before, during, and after transplant.

Social worker

The social worker can offer support and help you find ways to deal with some of the practical difficulties which may arise while you are in hospital. The social worker can also help you or your parents in finding out if you are eligible for a wide range of benefits.

Physiotherapist

The physiotherapist can help with any chest problems and any difficulties with your physical abilities and mobility. They will also suggest a range of exercises for you to do while you are in hospital.

Psychologist

You may find going into hospital worrying, although everything possible is done to prevent this. Bone marrow transplantation is a long process involving unpleasant treatments and side effects. In some centres, a psychologist will be available to help you cope and come to terms with this experience.

Teacher

If you are still at school / college the hospital teacher will spend some time working with you. S/he may also contact your school teacher to help keep up to date with the work as you may be facing exams. The teacher can liaise with external examination boards to arrange special considerations for examinations. If the hospital school is a recognised Exam Centre then some exams can be taken while in hospital. If required, the teacher can also arrange for a home tutor following transplant.

Activity co-ordinator/Play Specialist

Through activity and play, the specialist helps to bridge the gap between hospital and home. Using play and activities of different types s/he helps to prepare you for treatments, relieve your anxieties and fulfil social, emotional and developmental needs.

Ward clerk

The ward clerk is responsible for the administrative duties within the Unit, for example, arranging transport, dealing with telephone calls, and sorting out case notes.

Domestics/cleaners

The domestics are the cleaners on the Unit – keeping the Unit clean is extremely important. One of the domestics will clean your room each day. Other domestic issues will be discussed with you at a local level.

You will soon get to know all the different people involved in your care.

What to bring into hospital

When you are admitted for transplant you may not be sure what to bring in with you. Below are some suggestions, but if you have any questions please speak to your SCT Co-ordinator.

Medicines

Please bring with you any tablets or other medicines that you are taking and give them to the nurse in charge of the ward as soon as you arrive.

Activities and games

Most patients like to have something of their own to keep them occupied, so bring some of your favourite games, books, music, phone, laptop or ipad with you. There are also lots of activities and games provided in hospital as well.

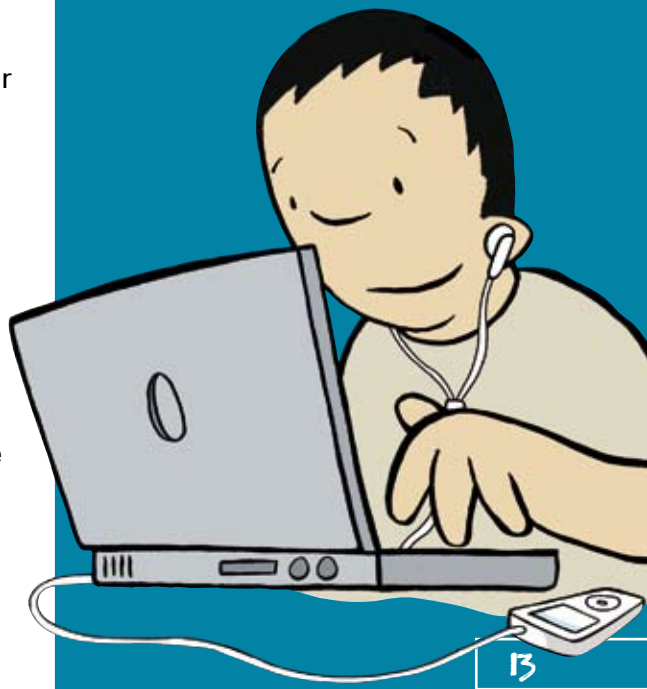
Some units may have WiFi, broadband dongles or a computer you can use to access e-mail/internet. They may also have game consoles and DVD's for your use. You may want to personalise your room with posters etc but check with your SCT Co-ordinator before admission.

Clothes

You will feel happier wearing your own clothes. You will need cool and comfortable nightwear and ordinary daywear, and a pair of slippers or soft shoes. Mark everything with your name if possible as the hospital cannot be responsible for any loss. Your clothes will need to be easily washed and tumble dried.

Toiletries

Please discuss what you will need to bring in with your SCT Co-ordinator.



"The central line is very useful as it doesn't hurt when blood is needed or drugs given. I was nervous that it would hurt a lot when it was first put in, but it quickly became part of me"

Maeve age 14

"Having a central line fitted was one of my biggest worries. I soon forgot about it and although changing the dressings is a pain it's much better than having a cannula or blood tests"

Alex age 18

Preparing to receive a bone marrow transplant

Before new bone marrow/stem cells can be properly accepted by the body the old bone marrow must be destroyed. The process by which this is done is known as conditioning treatment.

To allow us to take blood from you regularly, and support you with blood products as needed, and medication, it will be necessary for us to insert what is called a central line. Before you are admitted you will need to have a central line inserted so that we can give you your treatment and medications. The central line is inserted under a general anaesthetic, but in some centres certain types of central lines may be inserted under local anaesthetic. The line is a flexible catheter with 2 or 3 lumens. The line will reduce the need for needles and cannulas during your transplant. Your transplant co-ordinator will explain to you about the line if you do not already have one.

The conditioning treatment takes place approximately 7 – 10 days before receiving the stem cells, depending on whether you have a related or unrelated donor and require admission to the Stem Cell Transplant Unit. Strong chemotherapy drugs are given through the central line in order to destroy the old bone marrow.

Some young adults also have radiotherapy treatment to the whole of the body which also destroys the bone marrow – this is known as total body irradiation (TBI). This may be done at a different hospital as not all hospitals have a radiotherapy unit.

You will need to go to the radiotherapy department for your treatments this may be over one to four days. Each treatment

will be for about twenty minutes. Your SCT nurse will discuss your individual treatments with you.

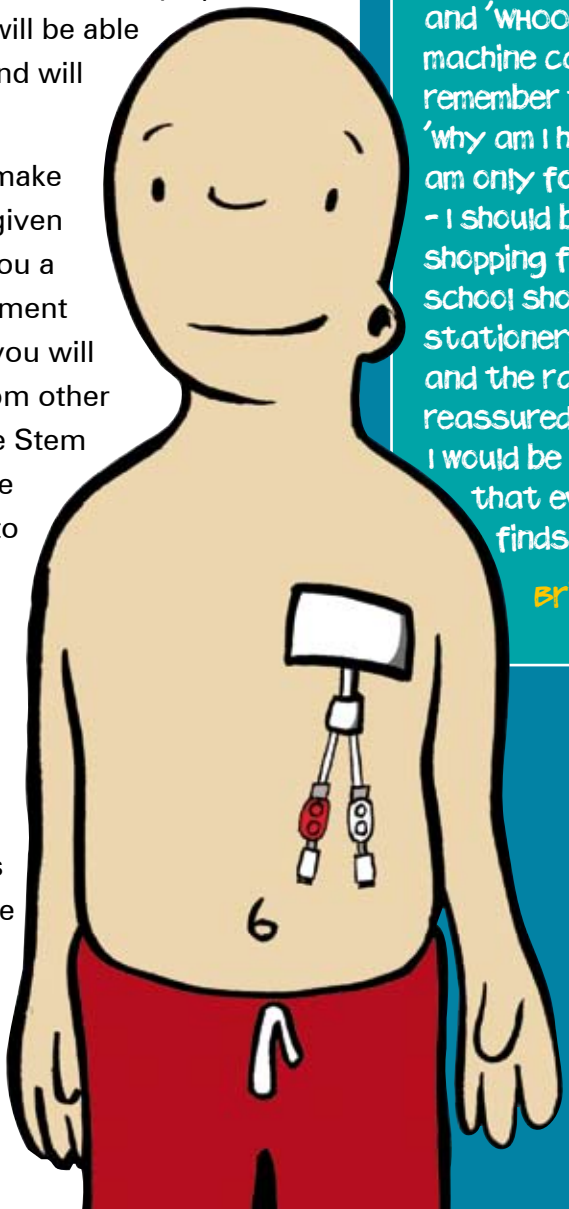
You will have to lie in the room alone and keep very still.

You can usually take music (phones, iPods or MP3 players) which may help to pass the time. You will be able to communicate with staff and family and will be closely monitored via CCTV.

The treatment does not hurt but may make you feel sick. Anti-sickness drugs are given to help prevent this. It may also give you a sore throat and diarrhoea. As the treatment affects the cells which fight infection, you will be nursed in a single room isolated from other patients on the ward. The rooms in the Stem Cell Transplant Unit have high pressure filters which clean the air and so help to prevent the spread of infection.

The exact treatment given before transplant varies and is individual to each person. It will be discussed with you by your doctors and nurses before transplant.

As the conditioning treatment destroys the bone marrow, it will no longer make the blood cells. Red cells and platelets can be replaced by transfusions through your central line. White blood



"The TBI was very daunting. I remember lying on the bed listening to music and 'WHOOSH' the machine came on. I remember thinking 'why am I here? I am only fourteen - I should be out shopping for my new school shoes and stationery', I cried and the radiographer reassured me that I would be fine and that everyone finds it scary."

Bridie age 14

cells are not routinely transfused post-transplant and, as they destroy germs, it is now important to protect you. You will be given medicines to help protect you from infection. However, most people do develop infections following stem cell transplant.

The conditioning treatment can also affect other cells in the body causing side effects of:

- Hair loss
- Nausea and vomiting
- Sore mouth (Mucositis)
- Diarrhoea
- Sensitive skin
- Infertility
- Inflammation of the liver (Veno-Occlusive Disease)
- Growth problems
- Inflammation of the bladder (Haemorrhagic Cystitis)

Measures are taken to prevent these side effects as much as possible and whilst some people may be affected mildly, others will feel extremely unwell. Unfortunately, these treatments are the only way to destroy the bone marrow effectively, which is important for the new marrow to work.

The transplant

The bone marrow/stem cells are given as a transfusion (just like a blood transfusion) through the central line and may take between fifteen minutes to two hours depending on the amount being given. The amount of bone marrow/stem cells needed is calculated from the weight of the person receiving the transplant.

You will have your blood pressure, pulse and temperature monitored during the transfusion to watch for an allergic reaction. This can be treated with drugs if it occurs.

The new cells enter the bloodstream and in the next few hours make their way to the empty bone marrow spaces in the bones produced by the conditioning treatment. Once they are in place they gradually begin to produce blood cells – this is known as engrafting.

The new cells will take two to four weeks before they make enough white cells to fight infection and there will not be enough to fight major infections, in particular viral infections, for at least six months. You may still need red blood cells and platelets even after discharge, but eventually the stem cells will produce enough blood cells of its own.

The whole transplant process from the beginning of onditioning treatment to the time when there are enough white cells to fight infection can take six to eight weeks, with a further three to six months before the bone marrow is working fully.

If you have had an allogeneic transplant recovery may take up to a year (see page 6).

"On the day of transplant when the nurse brought in the stem cells I thought my new life is in those bags... PLEASE DON'T DROP THEM!!!...that night when my door was locked I just thought how thankful I was to the donor and that things could only get better from here"

Bridie age 14

"When I said goodbye to my brothers before I was isolated it was really emotional. We all cried and my brother and I lay down on my bed for about an hour crying and hugging"

Bridie age 14

"Being in isolation was fine for me. I didn't want to leave the room much during the treatment anyway"

Alex age 18

Protective isolation (this may be more stringent for allogeneic transplants)

If you are not already in a single room on the day of transplant you will be moved into a specially cleaned single room. This is called 'isolation' and will protect you from infection.

The room has a filtered clean air system and anything taken into the room is cleaned first. The windows are closed to prevent unfiltered air getting into the room and the door is kept closed when not in use. Each day the room will be thoroughly cleaned and the bed linen changed. You will remain in the room until there are enough white cells to protect you from infection. This takes between about two and four weeks.

Visiting

During the time spent in isolation you will have limited contact with friends and family. Only the named visitors will be allowed to visit you in the cubicle, together with the Stem Cell Transplant Unit staff. Visiting restrictions vary from unit to unit.

The named visitors must be able to spend a lot of time with you. Very often they visit and stay in turn so that you can have a close relative/friend/partner with you as much as possible. Your named visitors should be adults – please ask your transplant co-ordinator who can advise accordingly on visitors. By taking turns with the other visitors your parents (or partners) can spend time with your brothers/sisters or have some time for themselves.

Some transplant units allow you to have other visitors, especially brothers and sisters, who do not enter the room but will be able to communicate with you. Brothers and sisters can only visit in this way during the period of isolation as they

may carry infections picked up from other children they are mixing with at nursery, school or college. You can still keep in contact with your friends at home if you are able to go online and you can also text.

Hand washing

Hand washing is the most important way to prevent the spread of infections. On entering the Unit your visitors must wash their hands thoroughly. Alcohol gels are now common in hospitals. The nursing staff at the hospital will explain good hand washing technique and the use of alcohol gel.

Identifying infection

Your temperature will be taken regularly and the doctor will examine you every day. A high temperature is often the first indication of infection. Infections can develop when the old marrow has been destroyed and the new marrow is not yet working. Despite all the measures taken, it is expected that all transplant patients will develop some infection, often caused by the normal bacteria living in the body, which in healthy people do not cause any problems. When infection occurs you will be given antibiotics through the central line. Urine and faeces specimens will be sent to the laboratory to check for infection as well.

The blood count

Blood is taken daily to check your 'Full Blood Count.' This is to examine how many red blood cells, white blood cells and platelets are in the blood.

If the red blood cells or platelets are low, a transfusion may be given. Red cells may only need transfusing a few times but platelets will need transfusing more often.

The white cells will not begin to develop until about fourteen days after transplant. When the white cells are high enough to protect you from infections, you will be allowed out of your room and will be discharged home if you are well enough.

When the white cell count is greater than 1 with 50% neutrophils on two days running then you will be allowed out of isolation. You may still have some isolation restrictions to protect you from infection for about 3-6 months (semi-isolation). This may not be necessary or may be much shorter if you have received your own bone marrow back.

The values for the blood count are much lower than normal following bone marrow transplant. The values will vary from day to day and for each person and will not return to normal for many months.

Medicines

You will need to take several medicines to help the new cells to work and to help prevent infection. Your doctor/nurse will explain what medicines you need and how they work. Medicines are usually given through a drip down the central line following the transplant and as you recover these medicines can be taken orally as tablets or syrup.

Mouth care

The mouth is a prime site for infection and you may be advised to be careful with oral hygiene during transplant.

Diet

While you are at risk from infection certain foods cannot be eaten and food and drink has to be specially prepared. Many

people do not feel like eating during the transplant process due to loss of appetite, nausea and sore mouth. This is to be expected and alternative methods can be used for feeding including a nasogastric tube (NG tube) or intravenous feeding (TPN) containing the necessary calories and nutrients can be given through the central line. It may be some time before you feel like eating as you did before the transplant.

Hair loss

Chemotherapy and radiotherapy cause the hair to fall out 2 – 3 weeks after the beginning of treatment. Your hair will grow back normally but can take some time. Some people are very upset by the loss, others cope extremely well. The nursing staff will help you with this as much as possible. Wigs can be provided but many people prefer to wear scarves and hats.

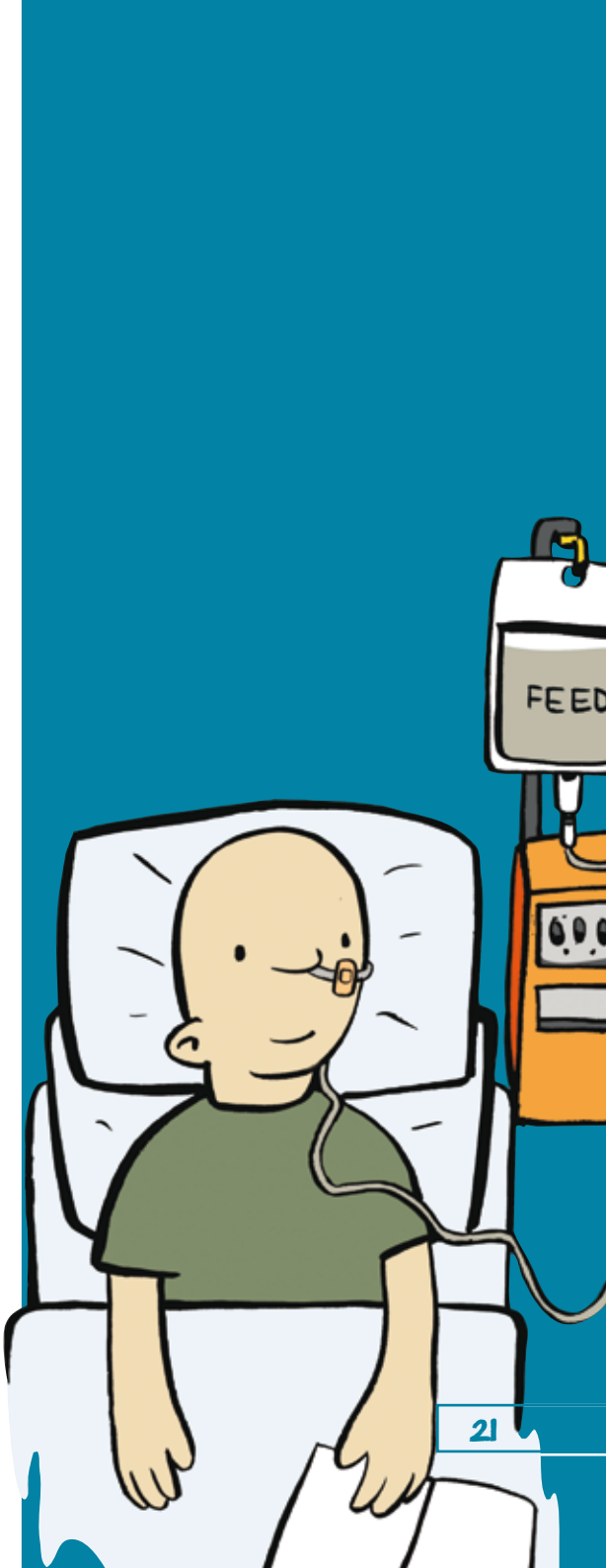
Mood swings

As you have to spend a long time in hospital feeling unwell and you are away from the secure and familiar environment of home with people you know around, you are likely to experience changes in your behaviour.

Some drugs can cause changes in mood: you may be angry, depressed, withdrawn and irritable.

This can all be extremely difficult for you and your family to cope with. Please discuss any problems or worries with the nursing staff who can help and guide you through any difficulties.

As you recover and life becomes more normal, you will find that these problems will get better, although it may take some time.



Side effects/complications during transplant

Stem cell transplant is an intensive form of treatment which can result in serious side effects and complications. These are outlined below and will be discussed with you fully when you speak to the Transplant Consultant and Transplant Co-ordinator/Clinical Nurse Specialist prior to admission. Some people are affected mildly and recover fully but others do experience problems and can be very ill during the transplant process. Occasionally admission to an Intensive Care Unit may be necessary to help support you through any difficult complications. Not all hospitals have Paediatric Intensive Care Units (PICU) the same as not all hospitals have Stem Cell Transplant Units. If there is no PICU in the hospital where you are having your transplant arrangements are in place for transfers to the nearest PICU, with specially trained teams coming to collect patients. Patients over the age of 18 years may go to an adult ITU.

Long-term side effects vary depending on the conditioning treatment given before transplant, which is different for each person, and will be explained to you.

Failure to engraft

This occurs very rarely and happens when the new marrow fails to grow. Drugs can be given to encourage the new marrow to grow. Occasionally, we need to request more cells from the donor or the back-up harvest which might help.

Graft rejection

This is where the new marrow is rejected by the body. This can happen anytime following transplant but the risk is higher during the first year. The risk reduces as time from transplant increases. If the transplant shows signs of rejection then drugs are given to try to prevent this happening.

Graft versus Host Disease (GVHD)

Graft Versus Host Disease can only occur if you have received bone marrow/stem cells from a donor (allogeneic transplant). As the stem cells begin to engraft, sometimes they recognise they are in a different body and react to this. This may cause redness of the skin on the palms of the hands and on the feet, diarrhoea and liver problems. This is known as Graft Versus Host Disease (GVHD), i.e. new donor stem cells versus recipient receiving stem cells. This is usually mild as drugs are given to prevent this occurring, but in some cases it can become very severe and even life threatening. If this occurs it does not mean that the transplant has failed and drugs are given to treat GVHD.

For further information, refer to the CCLG booket 'Graft Versus Host Disease (GvHD)' at www.cclg.org.uk.

Infection

You will be at risk of infection following stem cell transplant. These include bacterial, fungal and viral infections. Infection is a very common problem in SCT and can usually be easily treated with antibiotic, antiviral or antifungal drugs. Infection can be overwhelming, however, or difficult to treat. These circumstances can be life threatening but this is rare. All young adults undergoing SCT will be carefully monitored for infection until their immune system has recovered.

Sinusoidal obstructive syndrome (SOS)/ Veno-occlusive Disease (VOD)

This can be a serious complication, occurring usually within the first 30 days of the transplant, which affects the function of the liver. Drugs are given to prevent this if you are at risk. It only occurs with certain conditioning treatment and is rare.

Haemorrhagic cystitis

This is where there is blood present in the urine and can cause pain. This occurs with certain conditioning treatments or can be a result of various viruses and can happen anytime up to 3 or 4 months post-transplant. It can be treated.

Infertility

Some chemotherapy and radiotherapy treatments are highly likely to cause infertility, which means that you will be unable to have children. With males of pubertal age, sperm banking may be arranged. You will be referred to a specialist for help when you are ready to start a family.

Growth

Irradiation and chemotherapy can affect long term growth. This will be carefully monitored post-transplant. If necessary, growth hormone treatment can be given.

Cataracts

Radiotherapy can cause cataracts. This is blurring of the vision caused by clouding of the lens in your eye. This can be corrected by surgery and replacing the lens with a artificial one.

Getting ready to go home

The prospect of going home after a stem cell transplant is exciting but can also be quite worrying for you and your family. You will be able to go home when your transplant team feel you are medically fit/well enough after the transplant, your blood counts are recovering, and you can take all your food, fluid and medications either by mouth or a nasogastric tube.

Sometimes you and your family may feel frightened about going home but your team will prepare you as best they can and the hospital will be easily contactable if you need to call with any problems. It is also important that your whole family learns to live together again after the separation your hospitalisation has brought. If you need psychological or social work support after you have been discharged it is important to ask for this either on the phone or at clinic appointments.

Getting your home ready

As in hospital, good general hygiene and a clean environment are important when you return home. Floors and carpets should be cleaned at least weekly, kitchen surfaces cleaned before and after use, and crockery/cutlery washed in hot soapy water or dishwasher. Bathroom and toilet should be cleaned daily.

Clothes should be washed regularly and can be washed with the family's washing. Bedding and towels should be washed at least weekly.

As you will be immunosuppressed when you return home it is important that no building work is undertaken during

the first 12 months after returning home. This is because aspergillus spores can be found in bricks, concrete and dust and you could be at risk of fungal infections. Air conditioning can also harbour aspergillus (fungal) spores so it is best avoided.

Personal hygiene

While immunosuppressed common micro-organisms found on our skin may cause problems so it is important to wash daily either by having a shower, bath or strip wash, and to change underwear daily and clothes regularly. Mild hypo-allergenic moisturisers may be used on dry skin. It is also very important to wash your hands before meals and after going to the toilet.

Teeth should be cleaned twice daily. Toothbrushes should be changed monthly and stored separately from those used by other members of the family.

Body/ear piercing is not recommended for 6 – 12 months post-transplant. Tattoos should not be considered for at least 2 years post-transplant. Please check with your transplant team before having any body piercing or tattoos.

Protection from the sun

It is particularly important to protect your skin and head after a transplant especially if you have had TBI or GVHD. Where possible keep skin covered with clothes. You will be advised locally regarding what factor sun creams to use to protect your skin but it must have a UVA 5 star rating and be used as recommended on the bottle.

Skin care is important and you may be prone to dry skin/rashes. Any skin changes noted should be reported to your doctor.

Sleepiness

If you have had TBI it is not unusual to experience a period of sleepiness or lethargy – this is called somnolence. This can sometimes be accompanied by fever and headaches. This usually occurs 6 – 8 weeks after transplant and can last up to 2 weeks. It is important that you drink plenty of fluid during this period.

Clinic reviews

On discharge you will be advised when to return to clinic - you will require close monitoring initially and will probably be seen at least weekly until you stop your immunosuppressive drugs. During your clinic reviews the doctor will carefully examine you for any problems or signs of Graft Versus Host Disease if you have had an allogeneic transplant. Weight, temperature, blood pressure and pulse will be checked. In some centres your oxygen saturations may be checked particularly if you have any respiratory symptoms.

It is important, if you are taking Ciclosporin, MMF or Tacrolimus, that you do not take the morning doses until your blood has been taken for levels. If you are taking Ciclosporin avoid grapefruit or any foods containing grapefruit as this can affect levels.

In between clinic visits it is important to notify your transplant unit if you develop any of the following symptoms:

- Temperature of 38˚C or above/episodes of rigor or shaking
- Any bruising or petechiae (blood spots) or rashes
- Any redness, swelling or discharge from your central line
- Rigor or shaking after central line or Portacath is flushed

- Persistent/troublesome cough, shortness of breath
- Frequent diarrhoea or vomiting
- Abdominal pain or cramps
- Mouth ulcers or thrush
- Feeling unwell or off colour
- Any contact with chickenpox, measles, shingles.

Ask your transplant co-ordinator for a copy of 'What's the point of coming to the clinic?' or download it from www.cclg.org.uk.

contact with infectious diseases

It is important that you let your unit know if you have had any direct contact or show any symptoms of the following:

Chickenpox - The infectious period for catching chickenpox is 2 days before the spots have appeared until all the spots have crusted over. As you are immunosuppressed you will still be at risk of catching chickenpox even if you had it before your transplant. The length of time between your transplant and having contact with the disease will determine treatment but you may require readmission for intravenous Acyclovir.

Shingles - This is a reactivation of the chickenpox virus. It is usually seen as a rash on the head, neck or body and can be very painful. This sometimes requires readmission for intravenous Acyclovir.

Measles - Although now uncommon in the UK fewer people are now having the MMR vaccine so you may be at low risk. The first symptoms may be a fever or runny nose before a rash develops. You may need to be admitted for observation and antibiotics.

Reasons for possible readmission

- Infection – commonly central line related
- Reactivation of viruses – CMV (Ganciclovir)/Herpes zoster (Acyclovir)/adenovirus (Cidofovir)
- GVHD may cause nausea /vomiting/diarrhoea/weight loss
- Respiratory complications, e.g. pneumonia
- Weight loss/poor appetite

Common drugs on discharge

- Immunosuppressive drug(s) eg Ciclosporin, MMF, Tacrolimus +/- steroids
- Antifungal – usually Itraconazole
- Antiviral – usually Acyclovir
- PCP prophylaxis – Septrin/Pentamidine
- Lansoprazole – reflux/dyspepsia
- Penicillin – lifelong
- Loperamide – diarrhoea

Alternative drugs may be used if you are allergic or have difficulty tolerating a drug

Diet

A good diet is important to help your recovery post-transplant. While your transplant team understand that this may be difficult they will advise you on which foods you are allowed to eat while immunosuppressed and monitor your weight and gut symptoms during your recovery. If you have had TBI you may find that your mouth is dry for a few months after the transplant so you may need to drink more when eating. If you have had chemotherapy and TBI you might have changed ability to taste food.

"I would have liked to have been given more advice and information relating to the medications needed after transplant. I had problems with some tablets and I couldn't take Itraconazole liquid."

Max age 13

Getting back to normal

Most people feel tired after their transplant particularly if you do physical activity or try to concentrate. This generally improves with time, however, and it is important not to be too hard on yourself and rest when you need to. It may take up to 12 months to get your strength back to normal. Despite feeling tired it is important to try and exercise a little each day, gradually building up to help increase your stamina.

Emotional changes

Having been through a transplant and a lot of change it is not unusual to experience mood swings or feel depressed. It can be helpful to speak to your family or a member of the transplant team who can help you during this difficult time.

Central line

Each hospital may vary slightly but central lines are usually kept in for a minimum of 3 months post-transplant. This allows the team to monitor your bloods more easily without having to access veins and also to give blood and platelets if required. Once your line is no longer used regularly your transplant team will discuss removing the line with you. This will involve a short anaesthetic and minor procedure.

Returning to School or College

It is not unusual to have at least 6 months off before you are able to return to school or college. Home tuition is usually organised for you once you are discharged from hospital. It is likely that your attention span will be affected initially and you should start back for short periods, for example just a couple of hours per day building up to half days then full days.

Friendships

Allow yourself time to readjust and fit back in with your peer group. It is now easier than ever before to keep in touch with your friends via text, phone and social networking sites and it is helpful to maintain this contact.

Holidays

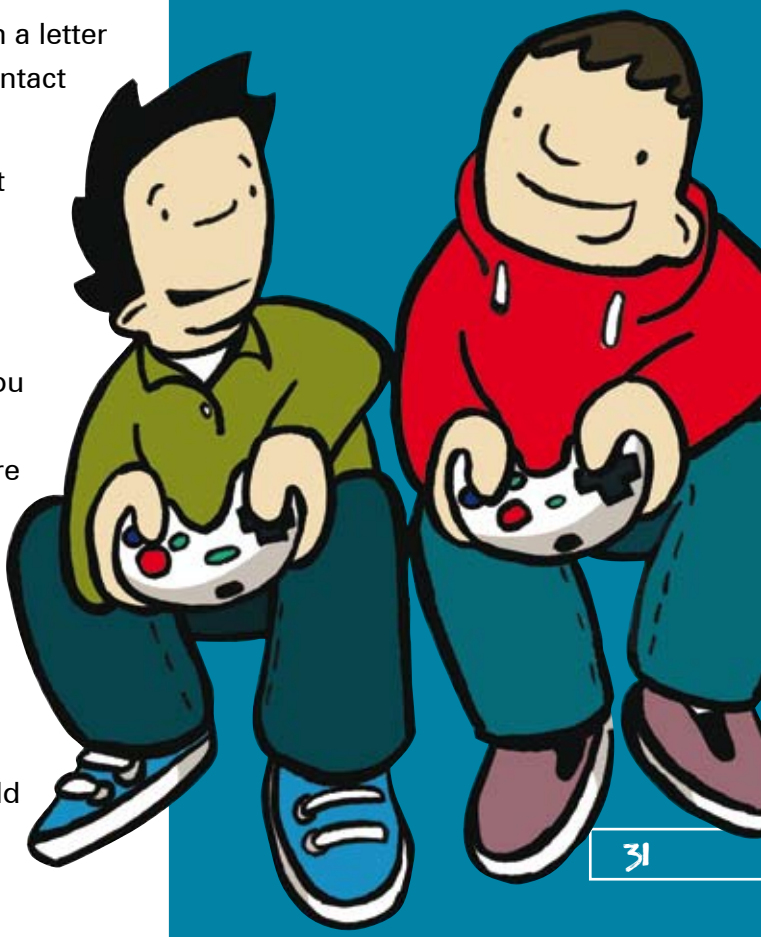
It is advisable not to fly within the first 6 months after transplant and to avoid tropical countries where vaccinations are required for at least 12 months. Holidays within the UK are usually not a problem but it is advisable to travel with a letter summarising your care to date, and to have made contact with a hospital near where you will be staying.

Please discuss any holiday plans with your transplant team or the consultant in charge of your care before booking.

Socialising

Many friends and family will probably want to visit you when you return home but it is important that any visitors do not have temperatures, coughs, colds, sore throats, vomiting, diarrhoea, cold sores or generally feeling unwell. Where possible have minimum contact with a family member who is unwell. Try to restrict the number of people visiting you at one time so that you don't get over tired.

Travelling on public transport and visits to crowded places, such as shopping centres and cinemas, should be avoided at peak times. Your transplant co-ordinator will advise regarding local guidelines.



Sex and sexuality

As teenagers and young adults cover a wide age range this topic may not be relevant for all patients and their families. Macmillan Cancer Support has produced an excellent booklet entitled 'Relationships, sex and fertility for young people affected by cancer'. Please ask your transplant co-ordinator to provide you with a copy if you would like further reading around this topic.

Revaccination

You will need to repeat all of your childhood vaccinations. Revaccination is usually necessary after both autologous and allogeneic transplants. After autologous transplants this usually commences 12 months post-transplant.

Pets

If your pet is healthy it is safe for it to remain in the home but avoid your pet scratching and licking you. Always wash your hands after contact with pets. The exceptions to the rule are reptiles and birds which are best avoided. Pets should not be kept in your bedroom and should be discouraged from sleeping on your bed. Do not clean out litter trays, rabbit hutches, aquariums etc.

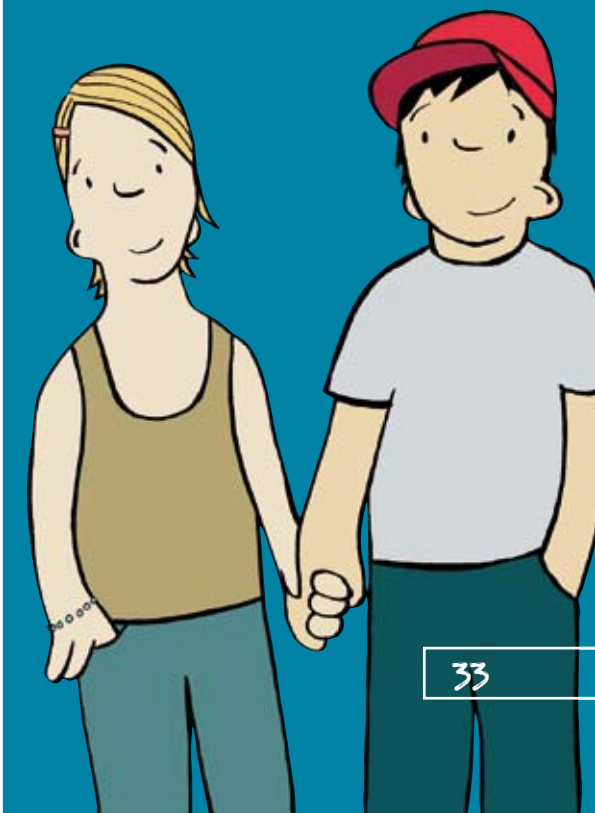
While you are immunosuppressed new pets should not be brought into the home.

For further information refer to the CCLG booklet 'Children with cancer and pets' at www.cclg.org.uk.

Things to think about for the future

It is important that patients who have had stem cell transplants are followed up regularly over the years.

Some survivors talk about experiencing job discrimination, or difficulties obtaining health or travel insurance. This may be because people know very little about stem cell transplants and are frightened about what is involved. Ask your transplant coordinator for a copy of 'After Cure' or download via www.cclg.org.uk.



contact numbers

Ward:

Transplant Co-ordinator:

Daycare:

Outpatients:

Dietician:

Clinical Psychology:

Local Hospital:

Other Numbers:

Useful organisations

The Anthony Nolan Trust
2 Heathgate Place
75-87 Agincourt Road
London, NW3 2NU
Tel: 0303 303 0303
Web: www.anthonynolan.org
National charity providing information regarding bone marrow donation.

The Aplastic Anaemia Trust
St. George's Hospital Medical School
Department of Haematology
Cranmer Terrace
Tooting
London SW17 ORE
Tel/Fax: 0870 487 0099
Web: www.theaat.org.uk
Funds research into the causes of aplastic anaemia and offers support and information for anybody suffering with the condition.

Cancer Research UK
Angel Building
407 St John Street
London EC1V 4AD
Tel: 020 7242 0200
Web: www.cancerresearchuk.org
National cancer charity devoted to the causes, treatment and prevention of cancer. Provides a range of information for anyone affected by cancer.

Children's Cancer and Leukaemia Group (CCLG)
3rd Floor Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH
Tel: 0116 2494460
Web: www.cclg.org.uk
National professional body for all healthcare professions who provide the best possible treatment for all children with cancer and leukaemia. Provides a range of information for patients and families affected by cancer in children and young adults.

CLIC Sargent
Horatio House
77-85 Fulham Palace Road
London W6 8JA
Tel: 0300 330 0803
Web: www.clicsargent.org.uk
A charity providing information and support for all family members affected by cancer in children and young people.

Leukaemia & Lymphoma Research
39-40 Eagle Street
London
WC1R 4TH
Tel: 020 7504 2200
Web: www.
leukaemialymphomaresearch.org.uk
National charity devoted to research into leukaemia, lymphoma and other serious blood disorders. Provides a range of information for all affected.

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Tel: 0808 808 0000
Web: www.macmillan.org.uk
UK charity offering support to people with cancer by providing expert care and practical support.

Teenage Cancer Trust
3rd floor
93 Newman Street
London W1T 3EZ
Tel: 020 7612 0370
Web: www.teenagecancertrust.org
National charity dealing with all issues of teenagers with cancer.

Glossary

Allogeneic Also called an allograft, stem cells are taken from a donor and given to a recipient

Alopecia Partial or complete hair loss, a side effect of chemotherapy

Anaemia Caused by low haemoglobin level in your blood, a side effect from chemotherapy, symptoms include tiredness, being pale and breathless

Antibody A naturally produced protein which destroys, neutralises or inhibits antigens such as specific infections

Antigen A substance which stimulates the body's defence to react by producing antibodies

Aplastic anaemia The bone marrow stops producing red and white blood cells and platelets

Autologous Stem cells are taken from the patient, stored and then given back to them

Bacteria Organisms which cause many types of infection, they are treated with antibiotics

Bone marrow The soft spongy tissue found in the centre of your bones, it produces all blood cells

Bone marrow aspirate A small sample of your bone marrow cells, taken under general anaesthetic usually from your pelvis

Bone marrow trephine A small sample of core tissue is taken for analysis

Cannula A small plastic tube inserted into the vein to allow fluid to be given and blood to be taken

Cells The individual units from which tissues of the body are formed

Chemotherapy Medication that is given to kill or stop the development of all abnormal/cancer cells

Central venous catheter (central line or portacath) A narrow plastic tube that goes into a large vein and used to give chemotherapy and other medication and to take blood samples.

Cord blood cells Blood obtained from the umbilical cord when a baby is born

Cryopreservation The process of cooling or storing cells, tissues or organs at very low or freezing temperatures to save them for future use

Cytomegalovirus A type of virus that is usually harmless in healthy people but can cause infection in patients having a stem cell transplant

Engraftment The process when the new bone marrow begins to grow in the patient

Fungal infection A type of infection usually from yeast or mould that can affect patients having a stem cell transplant

Graft Versus Host Disease A common complication, the donor's cells (graft) recognise the recipient (host) as foreign and attack them.

GCSF Granulocyte Cell Stimulating Factor, a drug given into your Hickman Line to boost your new white cells

Haematologist A doctor specialising in the diagnosis and treatment of blood disorders/diseases

Immunoglobulin Proteins which work as antibodies and may be given to help your immune system recover

Immunosuppression A reduction in the body's own defence system

Lumens Your Hickman Line will have two or three tubes these are called lumens and may be different colours

Mucositis Inflammation of the lining of the mouth, throat and gastrointestinal tract (stomach and intestines). It is a side effect of chemotherapy and can be very painful and cause diarrhoea

Neutropenia A reduction in the number of neutrophils in your blood

Neutrophil The most common type of white cell. This is what the medical team will look for when your new bone marrow begins to grow

Oncologist A specialist in the diagnosis and treatment of cancer

Pancytopenia When all blood cells are reduced in number

Petechiae Small red or purple spots on the skin caused by low platelets

Peripheral blood stem cell Stem cells in circulation on your blood

Platelets Tiny cells found in your blood which help to prevent and control bleeding

Prophylaxis Medication given as a precaution to try and prevent a infection or disease

Protocol A schedule or plan of treatment for a specific diagnosis or type of transplant

Red blood cells Cells which carry oxygen and haemoglobin

Remission Stage in your treatment where you have no evidence of disease

Sibling A brother or sister

Stem cells The first (primary) cell in the bone marrow from which all types of cells are made

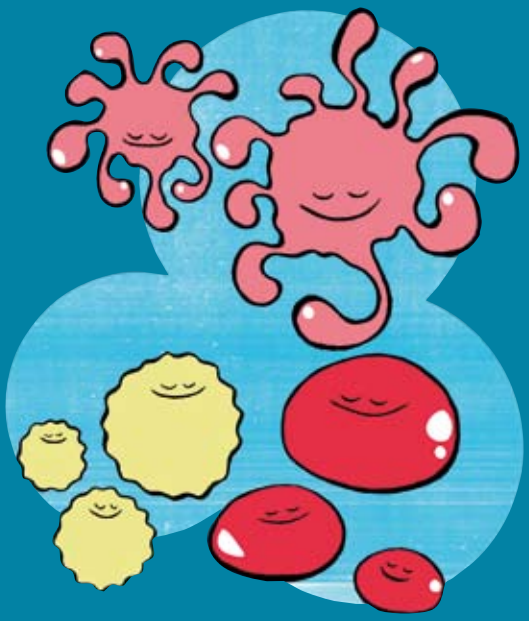
Tissue type Your blood (HLA-Human Leukocyte Antigen) is tested to find a donor match that is as similar to you as possible

Thalassaemia An inherited blood disorder affecting mainly people of Mediterranean, Asian or Middle Eastern origin. It is a kind of anaemia caused by not having enough haemoglobin in your blood.

T lymphocyte A type of white blood cell involved in controlling your immune reactions and helps to fight viral infections

Virus A type of infection affecting patients who are immunosuppressed, the main viral infections we screen for are CMV, Adenovirus and Epstein-Barr virus

White blood cells Cells that generally fight infection and are made up of different types of cells (granulocytes, lymphocytes and monocytes)



The CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

Children's Cancer and Leukaemia Group
3rd Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH
Tel: 0116 249 4460
Fax: 0116 249 4470
Email: info@cclg.org.uk
Website: www.cclg.org.uk
Registered Charity No: 286669

If you have any comments on this booklet, please contact us at the address above.

CCLG booklets are available to download from our website.