



Stem cell transplant

A guide to donor (allogeneic) stem cell transplantation for teenagers and young adults



Edited by the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer, in partnership with the National Paediatric Stem Cell Transplant Nurses Group. The original version of this booklet was edited by Lynne Barnes, Penny Owens and Joanne Page on behalf of the The National Paediatric SCT Nurses Group in collaboration with the CCLG Publications Committee.

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Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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An introduction to stem cell transplants

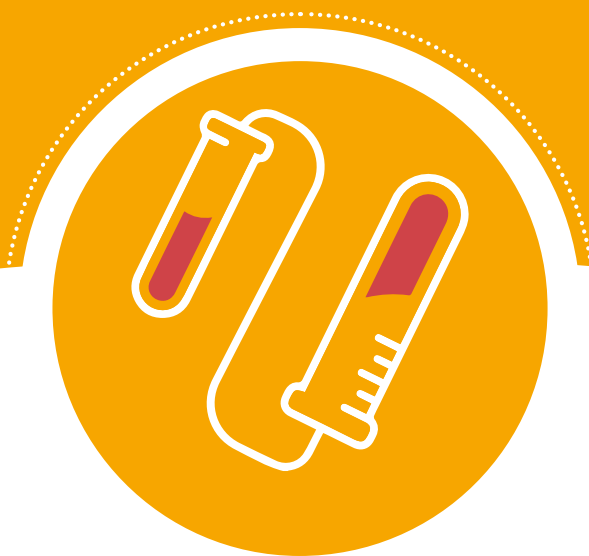
The stem cell transplantation process – from preparation for the transplant through to follow up – is long. It is extremely important that you understand why you need to undergo this process and what may happen to you along the way.

We have produced this guide as a source of information for teenagers and young adults. 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 stem cell transplant nurse coordinator / 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.

You can use the glossary on pages 28-29 to look up any words you are not familiar with.

Your transplant team will be happy to answer any questions that you have, and will provide you with any information specific to the unit where you are being treated.



What are stem cells?

Stem cells are blood cells in their very earliest stage of development that will eventually become red blood cells, white blood cells and platelets (see below).

What is a stem cell transplant (SCT)?

During a stem cell transplant (SCT), your medical team will put new, healthy stem cells into your bloodstream. After a period of time they will attach to your bone marrow (engraftment) and start to make new blood cells. A stem cell transplant is sometimes called a bone marrow transplant (BMT). This is because traditionally the stem cells were obtained from bone marrow, but now we can obtain them from three different sources (see page 5).

Why have a stem cell transplant?

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.

What do blood cells do?

Your blood is composed of blood cells (red blood cells, white blood cells and platelets) carried in a liquid called blood plasma. Each type of blood cell has a specific function.

Red blood cells

Red blood cells (RBC) contain haemoglobin (Hb), which transports oxygen around the body. Your red blood cell levels are measured by your Hb level - a low Hb level is called anaemia.

Symptoms of low RBC level include a lack of appetite, lack of energy, pale skin, breathlessness, feeling cold, feeling dizzy and having headaches. Treatment for a low RBC level is a blood transfusion.

White blood cells

There are many different types of white blood cell, including leukocytes, lymphocytes and neutrophils. White blood cells fight infection against bacteria, viruses and fungi. Neutrophils are the most important type of white blood cell after a transplant. Your white blood cells levels are measured by a 'white cell count' (WCC) - a low neutrophil count is called neutropenia.

A low WCC means you are more likely to get infections. If you have a low WCC, you'll be observed closely for any signs of infection, and any symptoms will be treated.

Platelets

Platelets help to stop bleeding. They are measured by 'platelet count'. If you have a low platelet count, you may experience bruising, nose or gum bleeds, and small bleeds under your skin (petechiae). If you have a low platelet count, this can be treated with a platelet transfusion.

Sources of stem cells for transplant

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 donor 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 drug called a ‘growth factor’. The stem cells move into the circulating blood where they are collected. The donor 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).

Allogeneic (donor) transplants

This is 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

The donor stem cells are from a brother or sister. Each of your siblings has a 1 in 4 chance of being a match with you.

Syngeneic

The donor stem cells are from an identical twin.

Umbilical cord

The donor stem cells are taken from a related or unrelated umbilical cord.

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 (but not always) limited to children.

Download or order our free factsheet on peripheral blood stem cell harvesting from www.cclg.org.uk/publications.



Haploidentical

The donor stem cells are from a parent or sibling that will only be a 50% match. This is not a common type of transplant.

Unrelated

Stem cells are taken from a matched or partially mismatched donor that has been found on a donor panel and closely matches your tissue type.

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.

Autologous transplant

In an 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.

This booklet is about allogeneic transplants. You can find more information about autologous transplants on our website, www.cclg.org.uk



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 in 4 chance of being a match with you.

If no suitable family match is found, the United Kingdom donor panel, run by the charity Anthony Nolan, will be searched for a potential match.

If no suitable donor from the UK is found, Anthony Nolan will search the international donor registries.

It is often more difficult to find a donor if you are from a black, asian or minority 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 recognise which cells belong in your body and which ones don't. They also help protect the body against organisms such as bacteria and viruses. 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) and your donor's immune cells do not attack your body after the transplant (graft versus host disease).

Getting ready for your transplant

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.

Consent

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 options other than a stem cell transplant
- What the effect on your life will be of having, or not having, the transplant.



Tests and scans

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

Blood tests

This includes virus testing.



Bone marrow aspirate/trephine

To ensure that you are in remission going into the transplant.



Echocardiogram (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 treatment.



Kidney function

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



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 chemotherapy prescribed according 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.

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 coordinating your nursing care during your admission and will care for you whenever possible. Sometimes you will have more than one named nurse.

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.

Ward manager

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

Stem cell transplant coordinator/ Nurse specialist

This nurse will help prepare you and your family pre-transplant and follow your progress as an outpatient.

The SCT coordinator also provides a link between yourself, the hospital and your own local community (e.g. your GP, 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.

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.

Dietitian

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 dietitian 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.

Psychologist

You may find going into hospital worrying, although everything possible is done to prevent this. Stem cell 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.

Activity coordinator/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.

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.

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.

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 coordinator.

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 emails and the internet. They may also have game consoles and DVDs for your use. You may want to personalise your room with posters etc but check with your SCT coordinator 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 coordinator.



Having a central line

To allow your team to take blood from you regularly, and support you with blood products and medication as needed, it will be necessary for you to have what is called a central line inserted.

You will need to have this before you are admitted for transplant so that your team can give you your treatment and medications.

The central line is usually 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 two or three lumens. The line will reduce the need for needles and cannulas during your transplant. Your transplant coordinator will tell you about the line if you do not already have one.

Conditioning treatment

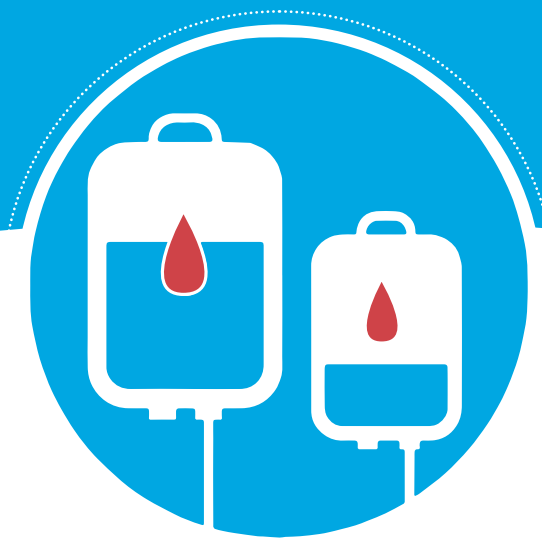
The conditioning treatment takes place approximately 7–10 days before receiving the stem cells, depending on whether you have a related or unrelated donor and require admission to the stem cell transplant unit.

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 which 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.

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



Having your stem cell transplant

The stem cells are given as a transfusion (just like a blood transfusion) through the central line.

This may take between fifteen minutes and 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 transfusions of 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 conditioning 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. For an allogeneic transplant, recovery may take up to a year.



Protective isolation

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 coordinator who can advise accordingly on visitors. By taking turns with the other visitors your parents (or partner) 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.

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

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).

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 two to three 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.

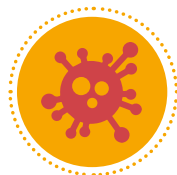
Please discuss any problems or worries with the nursing staff who can help and guide you through any difficulties. As you recover and life becomes more normal, you will find that these problems will get better, although it may take some time.



Side effects and 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 coordinator/clinical nurse specialist prior to admission.



Graft versus host disease (GvHD)

GvHD can only occur if you have received 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 more information, download or order our free factsheet on graft versus host disease from www.cclg.org.uk/publications.

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.

Infections can be more difficult to treat, and may in some instances be life threatening, but this is rare.

Growth

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

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.

For more information, download or order our free factsheet on veno-occlusive disease from www.cclg.org.uk/publications.

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 three or four 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.

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 an artificial one.

After your stem cell transplant

Getting ready to go home

You will be able to go home when your transplant team feel you are medically fit and 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. Bathrooms and toilets 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 (fungal) spores can be found in bricks, concrete and dust and you could be at risk of fungal infections. Air conditioning can also harbour aspergillus spores so it is best avoided.



Personal hygiene

While immunosuppressed common microorganisms 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 two 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.

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 two 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.

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 two 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.

Possible readmission

You may have to be readmitted (return to hospital as an inpatient) for the following reasons:

- 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

When you leave the hospital, you will have a number of medications that you will need to continue to take. Full instructions will be given by your SCT team.

The drugs are likely to include:

- Immunosuppressive drug(s) e.g. ciclosporin, MMF, tacrolimus, with or without steroids
- Antifungal medication – usually itraconazole
- Antiviral medication – usually acyclovir
- PCP prophylaxis – septrin/pentamidine
- Lansoprazole – to treat reflux/dyspepsia
- Penicillin – lifelong
- Loperamide – to treat diarrhoea

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, some foods may taste different.

Most people feel tired after their transplant particularly if they do physical activity or try to concentrate. This generally improves with time, 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.



Getting back to normal

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 three 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 six 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 six 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 coordinator will advise regarding local guidelines.

Sex and sexuality

As this booklet covers 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 'Sex and relationships: support for young people affected by cancer'. Please ask your transplant coordinator 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.



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. New pets should not be brought into the home while you are immunosuppressed.

For more information about pets and animals during cancer treatment, download or order a free copy of our booklet 'Handling animals and pets' from www.cclg.org.uk/publications.

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.

You'll continue to have regular clinic appointments to ensure your recovery is going as expected. Many people find it helpful to keep a diary (or use a smartphone app) to keep track of everything they need to remember, such as clinic appointments, medication reminders or any questions you want to ask your medical team.

Going through a stem cell transplant and the recovery period afterwards can be difficult to cope with. You may experience a range of emotions, and this is natural - there is no 'right' or 'wrong' way to feel.

It's important that you have someone to talk to about your worries - this may be a family member or friend, or a professional from your medical team or a charity that provides emotional support. The team at your

hospital can provide you with information about the support services available locally.

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. If you're starting or returning to work following your transplant, it's illegal for employers to discriminate against you. There are also specialist insurers who will help you to get travel insurance. You can find out more on the CLIC Sargent website.

If you were working when you were diagnosed with cancer, you may be worried about your financial situation. You should speak to your employer about the support available, including statutory sick pay. There are a number of organisations that may be able to provide financial support or advice about finances, including CLIC Sargent, Macmillan Cancer Support and Maggie's Centres.

CCLG has produced a range of resources called 'Aftercure' for teenage and young adult survivors of childhood cancer. The Aftercure booklet covers a variety of useful topics including future care, education, jobs, finances, travel and more. Accompanying factsheets are available with information about specific late effects of cancer treatment.

For more information, or to download or order the free Aftercure booklet and factsheets, visit www.aftercure.org

We hope that you have found this booklet useful. Don't forget, your transplant team will be happy to answer any questions that you have, and will provide you with any information specific to the unit where you are being treated.

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 is 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 (GvHD):** 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 central line to boost your new white cells.
- Haematologist:** A doctor specialising in the diagnosis and treatment of blood disorders/diseases.

Glossary

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 blood 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 in 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 an 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.

Tlymphocyte: A type of white blood cell involved in controlling your immune reactions and helping 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).

Useful organisations

Anthony Nolan

www.anthonynolan.org

National charity that runs one of the main stem cell donor registers in the UK, matching stem cell donors with those in need of a transplant. Also provides a range of information about stem cell transplantation for patients and families.

The Aplastic Anaemia Trust

www.theaat.org.uk

Funds research into the causes of aplastic anaemia and offers support and information for anybody suffering with the condition.

Bloodwise

www.bloodwise.org.uk

National charity devoted to research into leukaemia, lymphoma and other blood cancers. Provides a range of information for all those affected.

Cancer Research UK

www.cancerresearchuk.org

National research charity that also provides a wide range of information about cancer.

Children's Cancer and Leukaemia Group (CCLG)

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, teenagers and young adults.

CLIC Sargent

www.clicsargent.org.uk

A charity providing information and support for all family members affected by cancer in children and young people.

Healthtalk.org

www.healthtalk.org

Information about a wide range of health conditions, including cancer, from the perspective of patients.

JTV Cancer Support

www.jtvcancersupport.com

JTV Cancer Support is a project for teenagers and young adults who have been affected by cancer. Using all aspects of media it enables young people to explore and express their feelings, and make some sense of their very personal journeys from diagnosis onwards.

Little Princess Trust

www.littleprincesses.org.uk

Provides real hair wigs, free of charge, to children and young people who have lost their hair as a result of cancer treatment.

Macmillan Cancer Support

www.macmillan.org.uk

UK charity offering support to people with cancer by providing expert care and practical support.

Maggie's Centres

www.maggiescentres.org

A network of drop-in centres for cancer information and support. Also provides an online support group.

NHS Choices

www.nhs.uk

Information about symptoms, conditions, medicines and treatments from the NHS.

Teenage Cancer Trust

www.teenagecancertrust.org

National charity providing information, services and support for teenagers and young adults with cancer.

Trekstock

www.trekstock.com

Practical and emotional support for young adults (in their 20s and 30s) living with and beyond cancer.

Youth Cancer Trust

www.youthcancertrust.org

Provides support and free activity-based holidays for young people living with cancer.



Teenagers and Young Adults with Cancer




Having cancer is hard at any age, but for a teenager or young adult it's unthinkable.

'Normal life' suddenly stops and young people find themselves thrown into a scary unknown world of hospitals and cancer treatment. This has a devastating impact at a time when they are already coping with changes in how they think and feel as adolescents.

Teenagers and Young Adults with Cancer (TYAC) recognises that teenagers and young adults (ages 13-24) have different and specific needs. This is why we work tirelessly to make sure that every teenager and young adult with cancer is treated and cared for in a sensitive and age-appropriate way with the right to fast diagnosis and best treatment, no matter where they live.

TYAC is the UK's professional association for those involved in the treatment, care and support of teenagers and young adults with cancer. By providing information on best practice and new developments, training and support to our members, and through funding and supporting research into teenage and young adult cancer, we aim to improve the quality of life and likelihood of survival for young people with cancer. TYAC is part of Children's Cancer and Leukaemia Group (CCLG).

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 TYACancerOrg
 TYACancerOrg
 TYACancerPro



Children's Cancer and Leukaemia Group

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.




If you have any comments on this booklet, please contact us. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

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