CCLG The Children & Young People's Cancer Association

A guide to donor stem cell transplants

Information for parents, carers and young patients about having a donor (allogeneic) transplant

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This version was edited by the CCLG information team and reviewed by Craig Baillie, Stem Cell Transplant Clinical Nurse Specialist, Glasgow, on behalf of the National Paediatric Stem Cell Transplant Nurses Group, and the CCLG Information Advisory Group, comprising parents, survivors and multiprofessional experts in the field of children and young people's cancer.

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Patient Information Forum

About this guide

This guide has been written with the help of experts, patients, parents and carers. It gives information for teenagers and young adults, and their families, about stem cell transplants from donors (allogeneic transplant) and what to expect when having a transplant.

Although we have tried to be as comprehensive as possible, each transplant unit across the country will be slightly different. If you would like more information talk to your stem cell transplant nurse coordinator or medical team.

Doctors and nurses are continually learning about stem cell transplantation. Their expertise is based on knowledge shared nationally and internationally, gained through clinical trials and evidence-based practice. This helps them to decide who is best suited to a transplant but generally the disease will determine when, and if, a transplant is needed.

There is a lot of information in this guide, and it may be helpful to read it in small sections. There is a glossary on pages 28-30 to help explain medical terms you may come across. We hope this guide will help to answer some of your questions. It is important to remember that everyone is an individual, and information in this guide cannot replace that from your own doctor and medical team.

Your transplant team will be happy to answer any questions that you have and will provide you with any information specific to your stem cell transplant unit.

> “Knowing that you need a stem cell transplant is an anxious time. It feels scary and unknown. Support from your medical team as well as your family and friends is very important. We hope this booklet helps you to understand what to expect and answers many of the questions you may have"
>
> *Craig Baillie, Stem Cell Transplant Clinical Nurse Specialist*

Contents

About stem cell transplants

The stem cell transplant process is long – from preparation through to follow up. It is important to understand why this is needed as part of the treatment plan and what may happen along the way.

What are stem cells?

Stem cells are blood cells in their earliest stage of development. They will eventually become red blood cells, white blood cells and platelets. Stem cells are produced in the bone marrow (the soft spongy part inside of the bones).

What is a stem cell transplant (SCT)?

During a stem cell transplant (SCT), new healthy stem cells are put into the bloodstream. After a period of time, they will attach to the bone marrow (engraftment) and start to make new healthy 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 other sources within the body.

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 imbalanced production of blood cells, e.g. leukaemia where there are too many white cells
- the bone marrow is not working properly, e.g. aplastic anaemia, thalassaemia
- the bone marrow is suppressed, e.g. after chemotherapy or radiotherapy
- the immune system is not working properly, e.g. combined immune deficiency

Where in the body are stem cells taken from the donor?

Bone marrow

Stem cells can be found in the bone marrow, which is 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 donor is given a drug called a 'growth factor' to trigger the bone marrow to produce extra stem cells. The stem cells move into the circulating blood. Using a cannula, the donor is attached to a machine which collects the stem cells from the blood. This is usually done over 1-2 days as an outpatient. 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.

See our free factsheet on peripheral blood stem cell harvesting from **www.cclg.org.uk/publications.**

About blood cells

Our 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 (RBC) — contain haemoglobin (Hb), which transports oxygen around the body. Red blood cell levels are measured by our Hb level — a low Hb level is called anaemia. Low RBC levels can cause 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. White blood cell levels are measured by a 'white cell count' (WCC) — a low neutrophil count is called neutropenia. A low WCC means a person is more likely to get infections, so it is important to watch closely for any signs of infection.

Platelets — platelets help to stop bleeding. They are measured by 'platelet count'. If a person has a low platelet count, they may have bruising, nose or gum bleeds, and small bleeds under the skin (petechiae). A low platelet count can be treated with a platelet transfusion.

What are the different types of transplants?

There are different types of transplants. The type of transplant recommended will depend on the disease type and treatment plan.

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 divided into the following:

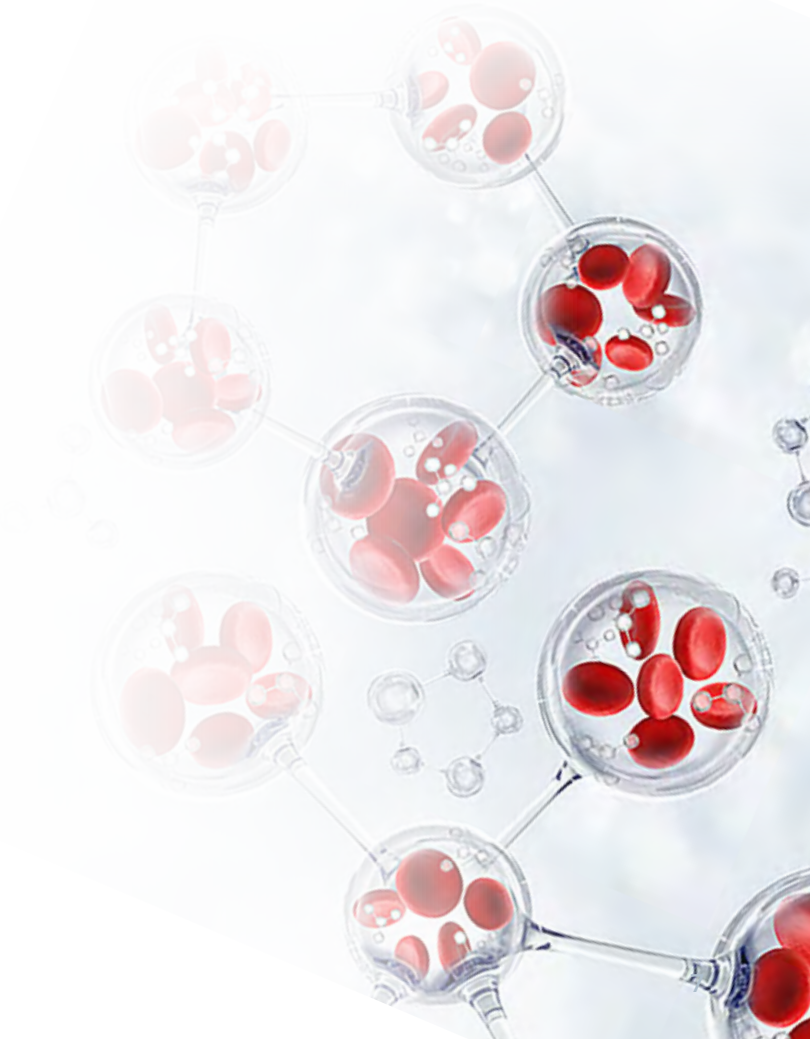
- **Sibling** — the donor stem cells are from a brother or sister. A sibling has a 1 in 4 chance of being a match for their brother or sister.
- **Syngeneic** — the donor stem cells are from an identical twin.
- **Umbilical cord** — the donor stem cells are taken from a related or unrelated umbilical cord.
- **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 the tissue type needed.

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 (own cells) transplants

In an autologous transplant, stem cells are collected from the patient's own body and reintroduced after intensive cancer treatment.

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



Finding a donor

Who can be a donor?

Usually, when an allogeneic transplant is needed, parents and siblings will be tested to see if their tissue type is a match. Each sibling has a 1 in 4 chance of being a match.

If no suitable match is found within the family, the charity Anthony Nolan will search for a potential donor match. This search will include the UK stem cell register, which the Anthony Nolan charity runs, as well as international donor registries.

How the matching works

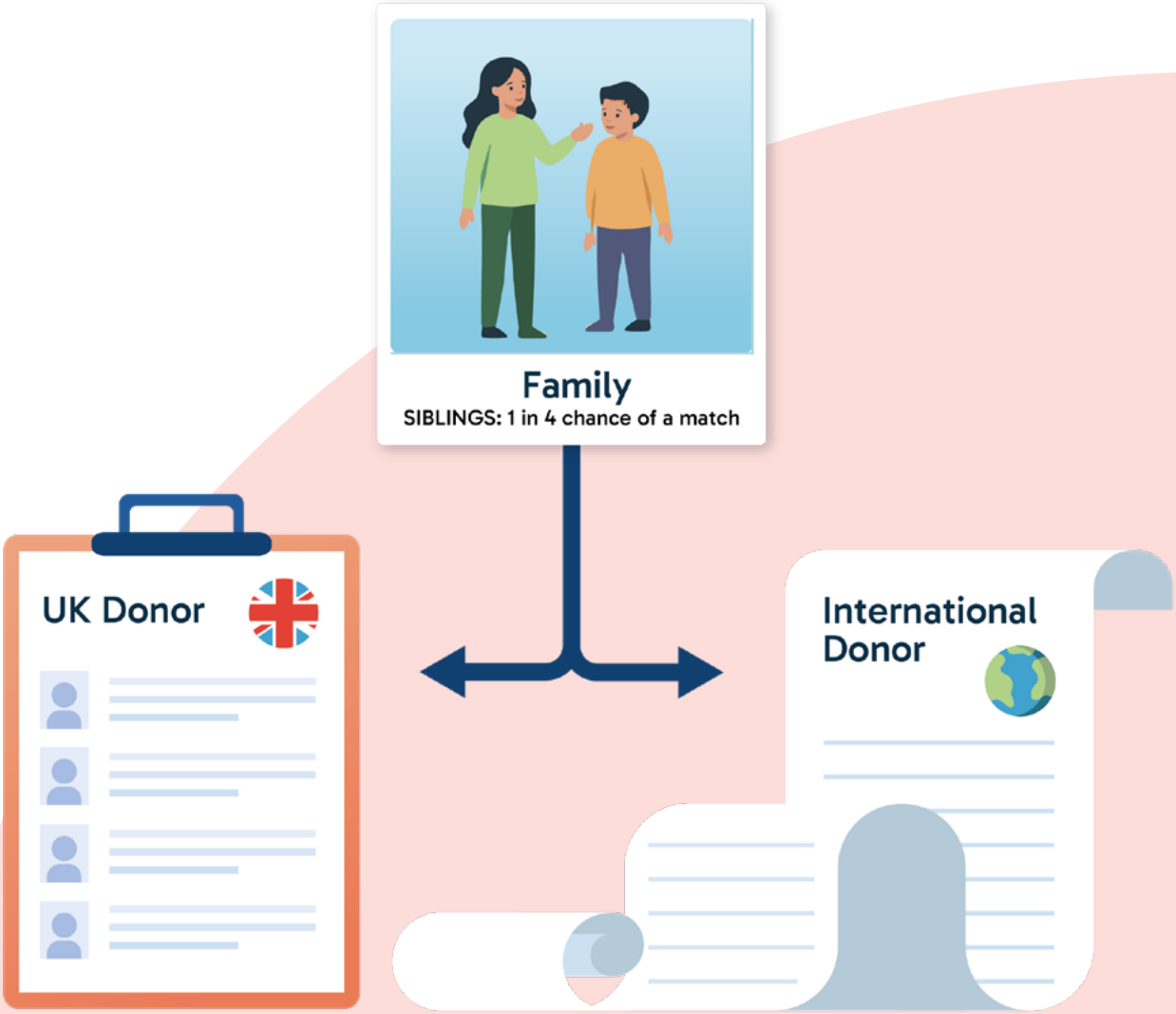
Tissue typing or human leukocyte antigen (HLA) testing is done to match patients with donors. HLAs are proteins found on most cell surfaces in the body. They are genetic markers which make you an individual, like fingerprints.

The immune system uses HLAs to recognise which cells belong in our bodies 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 with the donor so that the immune system does not attack the donor cells (graft rejection) and the donor's immune cells do not attack the recipient's body after the transplant (graft versus host disease).

It may be harder to find a match for a rare tissue type. It is more likely to find a donor from someone with a similar ethnic background. But it is possible to find a donor from someone from any ethnic background.

At the moment, there are less people from black, asian and minority ethnic backgrounds on the stem cell register, so it can be more difficult for people from these backgrounds to find a donor. Stem cell registries are working hard to encourage people from minority ethnic backgrounds to join their country's stem cell registers.

Finding a donor match:



Who's who in transplant care

During a transplant many professionals are involved with the care of a patient. These include the following, but there may be others that are very important:

Consultants	Consultants are doctors who are in overall charge of care.
Specialist registrars	These doctors look after overall medical needs and report back to the consultant. Every transplant patient is examined by one of these doctors each day.
Stem cell transplant coordinators/ Specialist nurses	This nurse helps prepare patients and their families pre-transplant and follows their progress after discharge. The SCT coordinator provides a link between the patient, the hospital and local community (e.g. GP, shared care hospital, community nurse, school/ college/work). They give support, information and guidance before, during and after transplant. In some centres they can carry out home visits if required.
Ward nurses	At the time of admittance, every patient is given a particular nurse (also called a named nurse) who is responsible for coordinating daily care during their admission. Sometimes more than one named nurse will be allocated.
Ward manager	This nurse is in charge of the unit.
Play specialists	Play specialists help prepare children and young people for treatments using play and different types of activities to reduce fear and anxiety and provide distraction.

Domestic assistants	Domestic assistants clean the unit, which is extremely important. Every transplant patient's room is cleaned each day.
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.
Dietitians	A ‘clean diet’ must be followed during and after transplant. There are certain foods which cannot be eaten and care is required with preparation. The dietitian will explain this and help with any eating problems before, during, and after a transplant.
Physiotherapists	Physiotherapists can help with physical ability and mobility difficulties, as well as any chest issues. They will also suggest a range of exercises to do while in hospital.
Occupational therapists	Occupational therapists can help with young children's development of gross and fine motor skills. They can provide facilities or equipment needed to aid daily activities, and help with planning for home.
Psychologists	It is understandable to find going into hospital for a transplant worrying, although everything possible is done to help make this easier. Stem cell transplantation is a long process involving unpleasant treatments and side effects. In some centres, a psychologist will be available to give support through this experience.
Social workers	Social workers can offer support and help find ways to deal with some of the practical problems which may arise from staying in hospital for a long period. They can also help to find out if you or your family are eligible for benefits.
Hospital teachers	Hospital teachers will spend some time working with children and young people who are still at school or college. They may liaise with schools and colleges to help keep up to date with the work set. They 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.

Getting ready for a transplant

Once a suitable donor is found, both the patient and donor need to have checks to make sure they are fit and well enough for the transplant. The donor panel team will counsel and prepare the donor for the procedure and the transplant hospital team will look after the patient.

Giving consent

Before a transplant can start, it is important to understand what is going to happen, and consent for the treatment must be given.

In the UK, teenagers aged 16–17 years, or their parents, can consent for treatment. However, it is important to include parents and carers in decision making when undergoing complex treatment such as a transplant.

Young adults who are aged 18 years and over can consent themselves.

Before giving consent, information should be given on:

- the benefits and risks of treatment
- implications of not having the transplant
- what the treatment will involve
- whether there are any other treatment options
- what the longer-term effects will be of having, or not having, the transplant

Having a central line

Before having a transplant, a central line is needed. This allows blood to be taken regularly, and blood products and medication to be given as needed. It reduces the need for needles and cannulas. The central line is a flexible catheter which is placed into a vein. It is usually inserted under a general anaesthetic. It has two or three ends, called 'lumens'. Certain types of central lines may be inserted under local anaesthetic. Your SCT coordinator will tell you about the line if one is not already in place.

Prehabilitation

There may be ways to prepare for a transplant by improving general health through nutrition and exercise. This is called prehabilitation. What may suitable for each person will be different, depending on their disease type and stage, what treatment they have already had, and symptoms and side effects experienced. Please talk to your team if you would like to find out more about this.

What tests and scans are needed?

The following tests are needed before the transplant takes place:

Blood tests

This includes virus testing.

Bone marrow aspirate/trephine

To check disease status going into transplant.

Echocardiogram (Echo)

An ultrasound of the heart to check function.

Dental check

Dental cavities can be a serious source of infection after transplant so need to be treated before starting conditioning treatment.

Kidney function

A small amount of radioactive dye is injected into the line or cannula. Four blood samples are then taken over a four-hour period and kidney function is calculated from the results.

Lung function tests

Tests involve breathing into a machine to assess how well the lungs are working.

Hand x-ray

To assess bone age in relation to chronological age as a baseline, as some of the treatment may slow down 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 sperm cryopreservation with their transplant consultant.

What to bring into hospital?

It is normal to wonder what to bring when staying in hospital for a transplant. Below are some suggestions, but ask your SCT coordinator if you have any questions about what is allowed.

Medicines

Bring any medicines being taken and give them to the nurse in charge of the ward when you arrive.

Activities and games

Most patients like to have their own things, so bring favourite games, books, music, phone, laptop or iPad. There are also lots of activities and games provided in hospital. Some units have WiFi or broadband dongles and may also have game consoles and DVDs. Some units allow rooms to be personalised with posters or other items.

Clothing and toiletries

Clothes from home will be most comfortable. Cool and comfortable nightwear, ordinary daywear and slippers or soft shoes are recommended. Make sure everything is named and can be easily washed and tumble dried. Talk to your SCT coordinator about what toiletries are best to use during your stay.

Having stem cell transplant treatment

Stem cell transplant treatment includes 'conditioning treatment' which is given first to prepare the body to receive the stem cells from a donor. The donor cells are then given. It takes several weeks for the new stem cells to begin working.

Having conditioning treatment

The conditioning treatment takes place approximately 7–10 days before receiving the stem cells, depending on whether the donor is related or unrelated, and will mean being an inpatient in the stem cell transplant unit.

Strong chemotherapy drugs are given through the central line in order to destroy the bone marrow. Kidney and lung function are assessed pre-transplant so that chemotherapy can be given accordingly.

Some people also have radiotherapy treatment to the whole of the body to destroy 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. Your SCT nurse will discuss an individual treatment plan with you.

The radiotherapy treatment takes place over one to four days. Each treatment takes about 20 minutes. During each session it is necessary to lie in the room alone and keep very still. Music and audio is usually allowed which may help to pass the time.

The radiotherapy team closely monitor what is happening on a screen and through audio. Staff and family members can communicate through CCTV.

The radiotherapy treatment does not hurt but may cause nausea (feeling sick). Anti-sickness drugs are given to help prevent this. It may also cause a sore throat and diarrhoea.

As the conditioning treatment affects the cells which fight infection, it is necessary to stay 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.

When the bone marrow is destroyed by the conditioning treatment, it cannot make blood cells. Red cells and platelets can be replaced by transfusions through the central line. White blood cells are not routinely transfused post-transplant so, as they destroy germs, it is important to stay protected during this stage. Medicines are given to help protect from

infection. Most people do develop infections following stem cell transplant, but all patients are closely monitored so that any infections can be treated quickly.

The conditioning treatment can also affect other cells in the body causing side effects (pages 18–20). 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.

Although these treatments can have significant side effects, they are the only way to destroy the bone marrow effectively, which is important for the new cells to work.

Receiving the donor cells

Before being given the stem cells, the central line will be checked and medicines to prevent nausea and an allergic reaction may be given.

The stem cells are given as a transfusion (just like a blood transfusion) through the central line. This may take between 15 minutes and two hours depending on the amount being given. The amount of stem cells needed is calculated from the weight of the person receiving the transplant. Blood pressure, pulse and temperature are 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 created 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. There will not be enough to fight major infections, in particular viral infections, for at least six months.

Transfusions of red blood cells and platelets may still be needed even after going home, 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.

During transplant treatment

Staying in isolation

All transplant patients stay in a single room that has been specially cleaned. This is called ‘isolation’ and will help to protect 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. It is important to remain in the room until there are enough white cells in the blood to protect from infection. This takes between about two and four weeks.

Visiting from friends and family

During the time spent in isolation there will be limited contact with friends and family. Only named visitors will be allowed to visit, together with the stem cell transplant unit staff. Visiting restrictions vary from unit to unit.

Named visitors spend a lot of time in the hospital, often taking it in turns so that a close relative, friend or partner stays as much as possible. Named visitors should be adults but if you are unsure, ask your SCT coordinator. By taking turns with other named visitors, parents (or other relatives) can have a break and spend time with siblings.

Some transplant units allow other visitors, especially brothers and sisters, who do not enter the room but will be able to communicate from outside. Brothers and sisters can only visit in this way during the period of isolation as they may carry infections picked up from other children at nursery, school or college.

Keeping in touch with friends and family via messaging, phone and social media during the time in hospital will help to reduce feelings of isolation. It is now easier than ever before to keep in touch with friends via text, phone and social networking sites and it is helpful to maintain this contact.

Hand washing

Hand washing is the most important way to prevent the spread of infections. On entering the unit, visitors must wash their hands thoroughly. The nursing staff at the hospital will explain good hand washing technique and the use of alcohol gel.

Looking out for infection

Regular checks will be made by the doctors and nurses to monitor for signs of infection. 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 happens, antibiotics will be given through the central line. Urine and poo specimens will be sent to the laboratory to check for infection as well.

> "Don't be scared to cancel social visits if you're not feeling up to it. Your health has to come first and friends and family should understand"

Monitoring blood counts

If 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 provide protection from infections, isolation rules can be relaxed and when well enough, discharge to home will be organised.

When the white cell count is greater than 1 with 50% neutrophils on two days running, isolation to one room is no longer required. Some isolation restrictions to protect from infection may continue for about 3-6 months (semi-isolation).

Blood counts are much lower than normal following transplant. The values will vary from day to day, and for each person, and will not return to normal for many months.

Other medicines to help

Several medicines will be needed to help the new cells work and help prevent infection. Your doctor or nurse will explain what medicines are needed and how they work. Medicines are usually given through a drip down the central line following the transplant but can be taken orally as tablets or syrup on going home.

Looking after the mouth

The mouth is a prime site for infection so it is important to be careful with oral hygiene during transplant. The mouth needs to be checked regularly so that any problems can be treated as quickly as possible. See page 19 for more information about mucositis.

Diet and eating

While infection risk is high, certain foods cannot be eaten and food and drink must be specially prepared. Many people do not feel like eating due to loss of appetite, nausea and sore mouth. This is common and other feeding methods containing necessary calories and nutrients can be used, such as a nasogastric tube (NG tube), or intravenous feeding (TPN). It may take time for appetite to return to normal.

Emotional issues

Behaviour and mood often change during a stem cell transplant. Feeling unwell and being away from the secure and familiar environment of home will add to this. Some drugs can cause changes in mood: feelings of anger, depression, irritability and being withdrawn are common. This can be very difficult for the patient and family to cope with. Talk to your team about any problems or worries so that they can help and give guidance. As recovery progresses and life becomes more normal, these issues generally get better, although it may take some time.

> "I spent several months in hospital due to loads of complications, but I tried my best to remain positive and think of where I would be in a year's time"

Side effects and complications

A 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.

Nausea (feeling sick) and vomiting (being sick)	The conditioning treatment may cause nausea and vomiting. This can be helped with anti-sickness medicines. Tell the team if the sickness persists, as changing the medicine often helps.
Hair loss	Chemotherapy and radiotherapy cause the hair to fall out two to three weeks after the beginning of treatment. Hair will grow back normally but can take some time. Some people are very upset by hair loss; others cope extremely well. The nursing staff will help with this as much as possible. Wigs can be provided, some people want to wear scarves or hats and others prefer not to cover their head.
Diarrhoea	Some drugs may cause diarrhoea, and anti-diarrhoea medicine may be needed. It is important to drink plenty of fluids to avoid becoming dehydrated.
Haemorrhagic cystitis	This is where there is blood present in wee, 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.

Infection	Risk of infection is high following a stem cell transplant. This includes bacterial, fungal and viral infections. Infection is a very common problem in stem cell transplant treatment and can usually be treated with antibiotic, antiviral or antifungal drugs. At this time, some infections can be difficult to treat, and may be life threatening, but this is rare.
Mucositis	Chemotherapy drugs can affect all the cells in the digestive tract – from inside the mouth (causing soreness and ulcers), right through the gut (causing abdominal cramps) and down to the rectum (causing a sore bottom). This condition is called 'mucositis'. This happens because the cells in the protective lining reproduce quickly, so they are targeted by chemotherapy. This makes them irritated, inflamed and swollen, sometimes with patches of pus where it becomes infected. Symptoms in the mouth can be prevented, or reduced, with good oral hygiene. That's why mouth care is very important during transplant. Mouthwashes, numbing sprays, protective gels and painkillers can help. Some hospitals offer photobiomodulation. This is a type of light or laser treatment that can help prevent or reduce the severity of mucositis. It is important to check the mouth regularly so that any problems are treated as quickly as possible.
Sensitive skin	Conditioning treatments can cause skin rashes, sore patches or a change in skin colour. They may also make the skin more sensitive to products like scented soaps or body wash. Skin will also be more sensitive to the sun. It's important to always protect skin by wearing a hat, loose clothing and sunglasses. Use sunscreen with at least sun protection factor 50 (SPF50) on any exposed areas. Your SCT team can advise on how best to care for skin rashes or sore patches.
Growth	Irradiation and chemotherapy can affect long term growth. This will be carefully monitored post-transplant. If necessary, growth hormone treatment can be given.

Graft versus host disease (GvHD)	GvHD sometimes occurs when stem cells are received from a donor (allogeneic transplant). As the stem cells begin to engraft, they sometimes 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 be severe and even life-threatening. If this occurs, drugs are given to treat the GvHD, it does not mean that the transplant has failed.
Sinusoidal obstructive syndrome (SOS)/ Veno-occlusive disease (VOD)	This can be a serious complication that can be caused by some conditioning treatments and affects the how the liver works. It usually happens within the first 30 days of the transplant. It is not common. It is usually a temporary problem, but it can cause long-term issues. There are several circumstances which may make it more likely for VOD to occur. Doctors will assess individual risk and, if necessary, give drugs to prevent it.
Cataracts	Radiotherapy can cause cataracts, which is blurred vision caused by clouding of the eye lens. This can be corrected by surgery and replacing the lens with an artificial one.
Fertility	Some chemotherapy and radiotherapy treatments are likely to affect fertility. For females, this means that it may be harder for them to become pregnant in the future. For males, this means that their sperm is less fertile, which can affect their chance of having children in the future. There may be some treatments available which aim to maintain fertility, including sperm banking and eggs, embryos or ovarian tissue storage. If you would like more information about these, please discuss with your medical team. Referral to a fertility specialist will be available in the future, when thinking about starting a family.

After transplant

The transplant team decides when a patient is medically fit to be able to go home. This will depend on blood counts, and being able to take fluid, food and medicines either by mouth or NG tube.

Getting ready to go home

It is normal to feel anxious and frightened about going home. The medical team will prepare you as best they can and arrange for you to be able to call the hospital easily with any problems.

It is also important that the whole family learns to live together again after the separation that hospitalisation has brought. Psychological or social work support may be needed after discharge, so 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 at home. Bathrooms and toilets should be cleaned daily. Floors and carpets should be cleaned at least weekly. Kitchen surfaces should be cleaned before and after use, and crockery and cutlery washed in a dishwasher or hot soapy water.

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

The risk of certain infections continues for some time. 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. Air conditioning can also harbour aspergillus spores so it is best avoided.

> "There's a common misconception that when you go home you are better and everything is back to normal. I had to explain to my friends lots of times that I still had restrictions about what I ate and where I went because my body was still at risk of infection"

Personal hygiene

While immunosuppressed, common microorganisms found on our skin may cause problems. It is important to wash daily, by having a shower, bath or strip wash. Mild hypo-allergenic moisturisers may be used on dry skin. It is also very important to wash 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.

Underwear should be changed daily and clothes changed regularly.

Body or 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 the skin and head after a transplant especially after having had TBI or GvHD. Where possible, keep skin covered with clothes. Always use a sunscreen SPF factor 50 with a UVA 5-star rating and use as recommended.

Contact with infectious diseases

It is important to let your SCT team know about any direct contact with, or 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. Due to being immunosuppressed, there is still a risk of catching chickenpox even if it has been had previously. The length of time between transplant and having contact with the disease will decide any treatment needed, but it may be necessary to go into hospital for IV antiviral medication.

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 IV antiviral medication.

Measles

Although uncommon in the UK, fewer people are now having the MMR vaccine so there may be a low risk. The first symptoms may be a fever or runny nose before a rash develops. It may be necessary to be admitted to hospital for observation and antibiotics.

Sleepiness after radiation

After having TBI, it is not unusual to experience a period of sleepiness or lethargy, sometimes with fever and headaches as well. This is called somnolence and usually occurs 6–8 weeks after transplant, lasting up to two weeks. It is important to drink plenty of fluids during this period.

What to eat

After transplant, it is important to have a good diet to help recovery.

Your transplant team understands that this may be difficult and will advise which foods are allowed to be eaten while immunosuppressed. They will also monitor weight and gut symptoms during recovery.

Having TBI as part of the transplant process can cause a dry mouth for a few months, so drinking more is important when eating. Having chemotherapy and TBI can cause some foods to taste different.

Feeling tired

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 to take things slowly and rest when needed. It may take up to 12 months to get strength back to normal. Despite feeling tired, it is important to try and exercise a little each day, gradually building up to increase stamina.

Medicines to take at home

After leaving hospital, there will be several medications 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 – to protect from infection
- loperamide – to treat diarrhoea

Going back into hospital

It may be necessary to go back into hospital for a while 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

Clinic appointments

When being discharged, you will be told when to return to clinic. Close monitoring is needed initially, and appointments will probably be at least weekly until immunosuppressive drugs are stopped.

At clinic reviews, the doctor will check for any problems or signs of graft versus host disease. Weight, blood pressure, temperature and pulse will be checked. Sometimes oxygen saturations will be checked, particularly if there are any respiratory symptoms.

Do not take ciclosporin, MMF or tacrolimus, in the morning until blood has been taken to check levels. Avoid grapefruit or any foods containing grapefruit when taking ciclosporin as this can affect levels.

Things to watch for

In between clinic visits, it is important to tell your transplant unit if any of the following develop:

- temperature of 38˚C or above
- episodes of shivering (rigor) or shaking
- any bruising or petechiae (blood spots) or rashes
- any redness, swelling or discharge from the central line
- shivering (rigor) or shaking after central line or Portacath is flushed
- persistent or 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

Getting back to normal

Following a donor cell stem transplant, it can take a long time for full immunity to return. This period is very individual. Your team will be able to tell you when it is safe to return to normal activities.

What happens with central lines?

Each hospital may vary but central lines are usually kept in for a minimum of three months post-transplant.

This allows the team to monitor bloods without having to access veins and also to give blood and platelets if required. Once the line is no longer used regularly, the transplant team will discuss removing the line with you. This will involve a short anaesthetic and minor procedure.

Seeing friends and family

Many friends and family will probably want to visit but it is important that any visitors do not have a high temperature, coughs, colds, sore throats, vomiting, diarrhoea, cold sores or generally feel unwell. It is best to have minimum contact with a family member who is unwell. It may help to restrict the number of people visiting at one time.

Travelling on public transport and visits to crowded places, such as shopping centres and cinemas, should be avoided at peak times. Your SCT coordinator can give more advice about this.

Returning to school or college

It is not unusual to have at least six months off before returning to school or college. Home tuition is usually organised after discharge from hospital.

It is likely that attention span will be affected initially and it is helpful to return gradually, for example, just a couple of hours per day, building up to half days, then full days.

> "I find it helps me to talk about my experiences, whether that's to consultants, colleagues, friends or family. It helps to alleviate some of the pressure I feel from time to time. It's important that people know how I am feeling, and to get help and support when I need it."

For young adults returning to work

If you're starting or returning to work following your transplant, it's illegal for employers to discriminate against you.

If you were working when you were diagnosed with cancer, you may be worried about your financial situation. There are organisations that may be able to provide support or advice about finances and employment, including Young Lives vs Cancer, Macmillan Cancer Support and Maggie's Centres.

Revaccination

Childhood vaccinations will need to be done again so revaccination is usually necessary after both autologous and allogeneic transplants. Your team will tell you what you need to do about this.

Being around pets

If a pet is healthy, it is safe for it to stay in the home. The exceptions to the rule are reptiles and birds, which are best avoided. New pets should not be brought into the home of someone who is immunosuppressed. Always wash hands after contact with pets and avoid scratching and licking from them. Pets should not be kept in the bedroom and should not sleep on the bed. Immunosuppressed people should not clean out litter trays, rabbit hutches, aquariums etc.

See our booklet 'Handling animals and pets' for more information **www.cclg.org.uk/publications**

Holidays

Flying is not recommended within the first six months after transplant, and tropical countries where vaccinations are required should be avoided for at least 12 months. There are specialist insurers who will help you get travel insurance.

Holidays within the UK are usually not a problem but it is a good idea to travel with a letter summarising care to date, and to contact 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.

Daily life

Young people may find the CCLG website section about living with cancer helpful. This covers relationships, body changes, mental health, school, work and money.

For more information visit **www.cclg.org.uk/about-cancer/young-people-and-cancer/living-with-cancer**

"There are good days and bad days. Don't be hard on yourself; recovery is a slow process."

Moving forward

Getting to go home after having a transplant is a positive time. But for many people it can be an anxious time too. The impact of this experience can sometimes hit weeks, months or even years later.

Emotions and feelings

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

For some, a transplant may be only part of the treatment plan. More tests, scans and treatment may follow which can bring further anxiety and uncertainty. It is not unusual to experience mood swings or feel depressed.

It is important for both patients and parents/carers to have someone to talk to — this may be a family member or friend, a professional from your medical team, or a charity that provides emotional support. Try to find people who will let you be very open and honest about how you are feeling. Talking or writing your feelings down can also help to make your own thoughts clearer.

Everyone has difficult days. If you find that your feelings are becoming stronger, you feel more anxious or you are struggling to cope with each day, then it might help to talk to someone who can support you better such as the hospital psychology team, your GP, or a counsellor.

The team at your local hospital can provide information about the support services available locally.

Follow-up care

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

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

> "Don't try and pretend to be OK. Counselling helped me a lot. I was also able to meet other young people with similar experiences; this helped me to feel less isolated, offering a safe space for socialising because of our shared understanding."

Things to think about for the future

There are now over 45,000 survivors of childhood cancer in the UK who are supported with specialist health care and advice.

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.

CCLG has produced a range of resources called ‘Living beyond cancer’ for teenage and young adult survivors of childhood cancer. The 'What happens next?' booklet for teenagers and 'Living beyond cancer' booklet for young adults cover 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 visit **www.cclg.org.uk/about-cancer/living-beyond-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 the blood. It is a side effect from chemotherapy, symptoms include tiredness, being pale, and breathless.

Antibody

A naturally-produced protein which destroys, inhibits or neutralises 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 our bones, it produces all blood cells.

Bone marrow aspirate

A small sample of bone marrow cells, taken under general anaesthetic usually from the 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(CMV)

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 in donor transplant patients. The donor's cells (graft) recognise the recipient (host) as foreign and attack them.

GCSF

Granulocyte Cell Stimulating Factor, a drug given to boost the growth of new white cells.

Haematologist

A doctor specialising in the diagnosis and treatment of blood disorders and diseases, including blood cancer.

Human leukocyte antigen (HLA)

HLAs are proteins found on most cell surfaces in the body. They are genetic markers which make you an individual, like fingerprints.

Immunoglobulin

Proteins which work as antibodies and may be given to help the immune system recover.

Immunosuppression

A reduction in the body's own defence system.

Lumens

A 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 the blood.

Neutrophil

The most common type of white blood cell. This is what the medical team look for when 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

The standard schedule or plan of treatment for a specific diagnosis or condition.

Red blood cells

Cells which carry oxygen and haemoglobin.

Remission

Stage in 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 typing

Human leukocyte antigen (HLA) is tested to find a donor match that is as similar to the patient as possible.

Thalassaemia

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

T lymphocyte

A type of white blood cell involved in controlling 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 phone numbers

Ward:	
Transplant coordinator:	
Daycare:	
Outpatients:	
Dietitian:	
Clinical psychology:	
Local hospital:	
Other numbers:	

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.

Blood Cancer UK
www.bloodcancer.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
Information and statistics on all cancer types and a funder of research into cancer.

CCLG: The Children & Young People's Cancer Association
www.cclg.org.uk
Information and guidance, funding of research, and a full range of award-winning patient information resources, including Contact magazine for families of children and young people with cancer.

Scan to order or download this booklet or any other CCLG publications FREE of charge:
www.cclg.org.uk/publications

Ellen MacArthur Cancer Trust
www.ellenmacarthurcancertrust.org
Supporting young people after cancer treatment to inspire them to believe in a brighter future through free sailing and outdoor adventures.

Human Tissue Authority
www.hta.gov.uk
The UK regulator for human tissue and organs. The HTA regulates organisations that remove, store and use human tissue for research, medical treatment, postmortem examination, education and training. They give approval for organ and bone marrow donations from living people.

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.

Leukaemia Care
www.leukaemiacare.org.uk
Support, information and services for anyone affected by blood cancer.

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
Practical, financial and emotional support for anyone affected by cancer.

Maggie's Centres
www.maggiescentres.org
A network of drop-in centres for cancer information and support. Also provides an online support group.

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

Teenage Cancer Trust
www.teenagecancertrust.org
Support for teenagers and young adults with cancer.

Teens Unite
www.teensunite.org
Activities and breaks for teenagers and young people (13-24 years) during cancer treatment and beyond.

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.

Young Lives vs Cancer
www.younglivesvscancer.org.uk
Provides advice and support for all family members affected by cancer in children and young people.

Notes/questions:

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The Children & Young People's Cancer Association

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We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care, and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Our work is funded by donations. If you would like to help, visit **www.cclg.org.uk/donate** or text '**CCLG**' to **70085** to donate **£3.** You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.

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