



Donating your stem cells to your brother or sister

A guide to stem cell (bone marrow) donation
for teenagers and young adults



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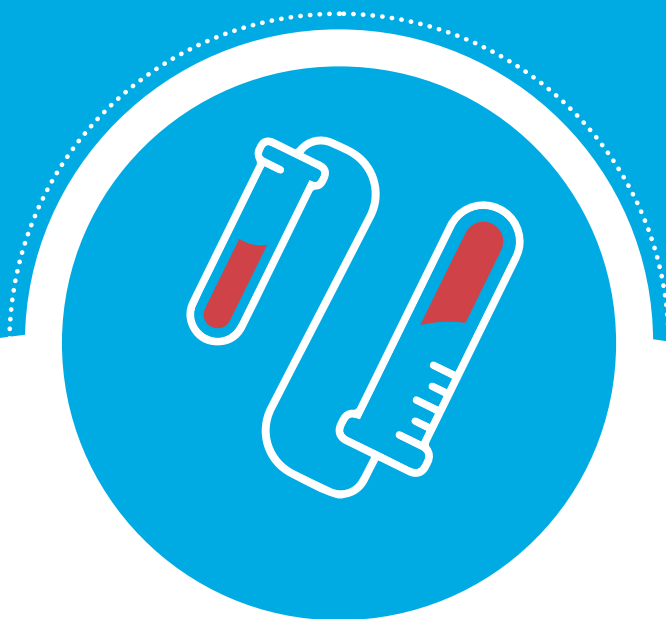


About stem cell transplants

This booklet helps explain about being a stem cell donor for your brother or sister, and describes some of the things that you may experience. It is important that you understand what will happen if you are selected to be a donor.

We give as much information as we can although each transplant unit across the country will be slightly different. You should always ask a member of the hospital team if you would like any further information.

Use the glossary on pages 19-20 to help explain any words that you are not familiar with.



What are stem cells?

Stem cells are blood cells in their very earliest stage of development which will eventually become red blood cells, white blood cells and platelets (see page 5).

Stem cells begin in the spongy tissue found inside your bones. This tissue is called bone marrow. Long flat bones such as the pelvis and breastbone have a lot of bone marrow in them.

What is a stem cell transplant (SCT)?

During a stem cell transplant, new healthy stem cells will be put into your brother's or sister's bloodstream. In time, they will attach to their bone marrow (called engraftment) and start to make new blood cells.

A stem cell transplant is sometimes called a bone marrow transplant (BMT). This is because stem cells used to be taken from bone marrow, but now we can obtain them from different sources (see page 6).

Why have a stem cell transplant?

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

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



What do blood cells do?

Your blood is made up of cells called red blood cells, white blood cells and platelets which are carried around the body in a liquid called blood plasma. Each type of blood cell has a specific job to do.



Red blood cells

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

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

Platelets

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

White blood cells

There are many different types of white blood cells such as leukocytes, lymphocytes and neutrophils. They fight infection against bacteria, viruses and fungi in the body.

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) and a low neutrophil count is called neutropenia.

A low WCC means a person may be more likely to get infections so they will be closely monitored by the hospital team.

Sources of stem cells for donor transplants

Stem cells can be donated from a close relative like yourself or an unrelated donor. This is the type of transplant your brother or sister will be having and is called an 'allogeneic' transplant.

If your stem cells are identified as a match for your brother or sister, and you agree to be their donor, your stem cells will be collected and subsequently given to your brother or sister, in the same way as a blood transfusion. If your donated stem cells 'engraft', they will begin producing healthy blood cells in your brother's or sister's body. Your donated stem cells will form a new immune system for them too.

From the bone marrow

Stem cells are 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 needle – usually from the back of the pelvis while the donor is asleep under a general anaesthetic. This is called a 'bone marrow harvest'.

From circulating blood

Your bone marrow is stimulated into making extra stem cells by taking a drug called a 'growth factor'. The stem cells move into the circulating blood where they are then collected using a machine. This is usually done on an out-patient basis over 1-2 days. This is called a peripheral blood stem cell harvest (PBSC harvest).

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



Finding a donor

Usually, when it is decided that a patient needs a transplant, close family relatives will be checked first to see if they are a match for the patient. This is called tissue typing. Each sibling has a one in four chance of being a match with the patient.

This is because children inherit their tissue type from their parents in the same way that they inherit their eye or hair colour. Half of your tissue type is inherited from your mother and the other half from your father.

Tissue typing is done to best match patients with donors.

Proteins called HLAs are found on most cell surfaces in your body and are genetic markers that make you an individual, like fingerprints. Your immune system uses these proteins to recognize which cells belong in your body and which ones don't. They also help protect your body against bacteria and viruses. This is why it is important to have a close HLA genetic match between the patient and donor, so that there is less chance that the donor's immune system will attack the patient's cells (called graft versus host disease or GVHD), or that the patient's immune cells do not attack donated stem cells after the transplant (called graft rejection).



Testing to see if you can be a donor

A sample of your blood will be taken from a vein in your hand or arm. Anaesthetic cream or spray can be used to help numb the skin before taking the blood. This is usually a quick procedure and takes around two weeks for the results.

This waiting time can be a good time to think more about your feelings on becoming a donor. You may feel a bit nervous or scared so it is important to ask as many questions as you can to help you think things through. If you have any worries, there is always support from the hospital team, your parents and friends and your brother or sister, so you are not alone. Often people forget their questions when they are actually in the room with the doctor or nurse, so try to write questions down as you think of them.

Many children/teenagers have mixed feelings about whether or not they want to be a donor. Take your time to make the decision and think carefully about what would happen if you did, or did not, donate your cells and what this might mean to your brother or sister. This is why it is so important to talk it through with someone you trust.

You only have a 1 in 4 chance of your stem cells matching your brother or sister's and it can be frustrating to find out that you are not a match. But it is not your fault if your tissue type does not match your brother or sister. It is just part of nature and happens often so it is nothing to feel bad about.



What happens if you are selected as a donor?

Depending on your age, there are two different donor options. Usually, a donor under the age of 16 will have their stem cells collected with a bone marrow harvest. Donors over 16 years of age will usually be given the choice of either a bone marrow harvest or peripheral blood stem cell collection. In this case, you will be given information on both options to help you make a final choice.

Three to four weeks before collecting your stem cells, you will be asked to attend the hospital for a medical examination to check that you are fit and healthy.

You and your parents will be asked questions about any illnesses you've had in the past, about any illnesses in the family, and your health now. You will also be asked if you are taking any medication so please make a note of any tablets you are taking, or bring them with you. You will also have a physical examination, and some tests to check your heart.

Another blood sample will be taken to check there are no viruses in your blood that may be transferred to your brother or sister during the transplant. It is not possible to be a donor if you are pregnant so you will be asked to take a pregnancy test if appropriate.

During the medical checks, you can talk about the donation process in more detail and ask any questions that you may have. If you are unhappy with anything during this time, please do talk to a doctor or nurse.

You may feel different emotions, and this will vary depending on whether or not you have decided to donate. If you have decided to donate, then many people feel excited that they can play a part in helping their brother or sister to get better. Some people feel a little worried about what they will need to do, and what will happen both to them and to their brother or sister.

You will have a very detailed explanation about what will happen, and lots of opportunities to ask questions.



What happens if you are not a suitable match?

Although you may be feeling frustrated or disappointed that you are not a match for your brother or sister, it is not your fault.

However, there are other ways that you can support them as they go through their treatment which are still very important. You may still find the information which follows helpful in order to help understand what is happening to other members of your family.

You may also decide to become a registered voluntary donor (if you are over the age of 16 years and in good health). This may be done by contacting Anthony Nolan, the UK stem cell registry. This means your tissue type will be kept on a database and you may be a match for another person needing a transplant in the future.

If no suitable family match is found for your brother or sister, a national search for an unrelated donor will be carried out. If no suitable donor is found in the UK, international registries and cord banks are then searched.



Giving your consent

If you are under 16 years old, your parents will be asked to sign a consent form at the medical examination. This is where they agree for you to donate stem cells. You can sign this form as well if you would like to.

If you are between 16-18 years old, you can sign the consent form yourself if you feel you have been given the right information and you understand all the information you need to make your decision – this is known as informed consent. Your parents can sign this as well. You can read through the consent forms before the medical check-up.

Once you or your parents have signed the consent form, you can still withdraw your consent or agreement at any time.

Although donors always have the right to withdraw consent at any time, it is important for you to feel happy about donating your stem cells before your brother or sister begins his or her pre-transplant conditioning treatment.

This is because your brother or sister will start conditioning treatment about 7-10 days before you donate your stem cells so that their body is prepared. This involves their own blood stem cells being wiped out by chemotherapy and radiotherapy to get rid of cancer cells. This means that your brother or sister will have no immune system or bone marrow after the conditioning, whilst awaiting your stem cells.

Once your donor cells are given, they start work straight away in your brother or sister's body by producing blood cells to carry oxygen and fight infection.



Human Tissue Authority (HTA) assessment

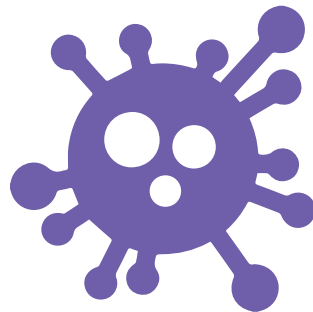
Donating stem cells for transplant in the UK is regulated by the Human Tissue Authority (HTA) who check that all donors have had the information they need and are happy to proceed.

Depending on your age, you may see an HTA assessor or a consultant who is part of your team and qualified in HTA assessments who will talk with you to make sure that you understand what will happen. If they are happy that you have made an informed decision, they will then give the go ahead to the hospital to collect your stem cells.

What if you don't want to be a donor?

If you are a match, but don't want to be a donor, remember that no-one can force you to do anything that you don't want to. If you are worried about any part of the procedure, then talking it through with your parents, medical and nursing staff can help you to feel more confident and prepared to be a donor.

You don't have to do it if you really don't want to, but it is important that you have talked to someone about how you feel, and discussed why.



Having the stem cell (or bone marrow) harvest

What to bring into hospital

When you go into hospital to donate your stem cells, you may not be sure what to bring in with you. Usually you will need to stay in hospital for two nights. Below are some suggestions, but if you have any questions please speak to the nurse.

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 to keep you occupied

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 tablet with you. There are also lots of activities and games in hospital as well including game consoles and DVDs. There may even be free WiFi.

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 in case anything is lost.



What happens in hospital

The day before

- You may need to come into the hospital the day before the operation where the ward team will look after you.

On the day

- You will have your last meal six hours before the bone marrow harvest and your last drink of water two hours before.
- You will be asked to shower, put on a hospital gown and remove any jewellery.
- A porter and nurse will come to the ward and take you on the bed down to the operating theatre. Your parents can go with you as well.
- A tube will be inserted into the back of your hand so that a doctor called an anaesthetist can give you medication called a general anaesthetic so that you will go to sleep.
- Once asleep, bone marrow or stem cells will be taken from the back of your hip bones. You will not feel anything at all. A sterile needle and syringe is used to make a small puncture hole through the skin and into the hip bone. These all heal quickly and no cuts or stitches will be made.
- The bone marrow harvest takes about one hour.
- Once over, a dressing is put over the small puncture sites to stop any bleeding.
- You will be taken to the recovery room and you may have hydration fluids running into the tube in your hand. This is to help replace some of the fluid that has been taken during the bone marrow harvest procedure.
- When you are properly awake, your parents will be waiting with you and you will be taken back to the ward.
- You will be monitored regularly and ward staff will check the sites where the needles went in, your blood pressure, temperature and pulse. They will also monitor your oxygen levels as some people need to have a small amount of oxygen after having a general anaesthetic.
- You will be able to drink again and can have painkillers for any discomfort or pain you may have in your back and hips.

The day after

- Most donors feel well enough to leave the hospital 24 hours after the harvest.
- Your blood counts will be checked before you leave. If your haemoglobin level (see page 5) is a little low after the procedure, you may need to take iron tablets for a couple of months.
- You will be seen by a member of the hospital team before you can leave hospital.
- You may be given a prescription for painkillers to take at home.

Did you know?

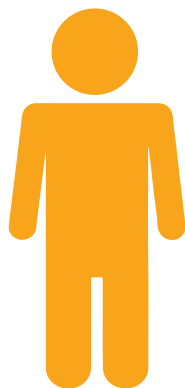
Depending on your size, up to 1.5 litres of bone marrow can be taken from your hip bones. This sounds a lot but your bone marrow can quickly regenerate and make new stem cells. This is only a small amount of your total bone marrow.

Will it hurt?

You may worry that the stem cell harvest will hurt. Other previous donors say that it is not a painful procedure and you will be asleep for the whole time but you may have some back pain afterwards.

Things to know after the procedure

- You might feel some discomfort and stiffness for a while at the sites where the stem cells were taken. Back pain can sometimes happen too.
- Most donors feel tired after the harvest so it is best to have the rest of the week away from school, college, work, or energetic physical activity, to help you fully recover.
- It will take a few weeks for your own body to replace the blood stem cells that have been taken out. This is normal and will not cause any harmful effects.



After the stem cell harvest

What happens to the stem cells after they have been collected?

Once your stem cells are collected, they will either be taken to the stem cell laboratory at the hospital or they will be sent by courier to the hospital where your brother or sister is having their transplant.

They are then given to your brother or sister in much the same way as a blood transfusion.

What happens if the transplant is successful?

If the transplant is successful, you can expect your brother or sister to be in hospital for around four to six weeks.

After this they can go home. At first, they will need to attend the hospital frequently for check-ups but gradually the number of visits will reduce and life will return to a more normal routine.



What happens if the transplant does not work?

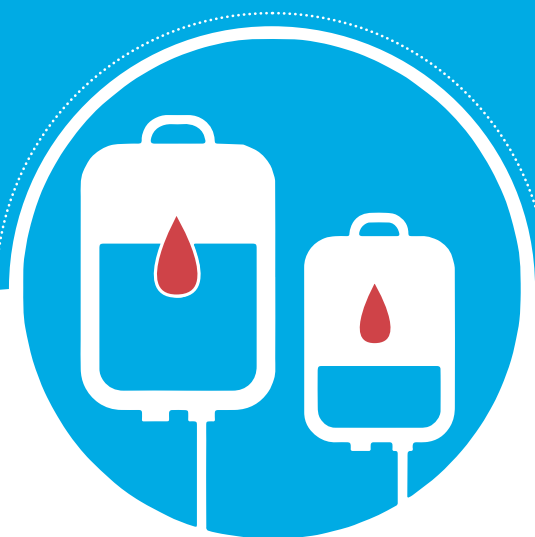
Sometimes, treatments are not successful. For example, the transplant fails to engraft in your brother or sister's body so new marrow doesn't grow, or they are not able to cope with the side effects of having a transplant, or their original disease comes back.

If any of these happen, it is important to realise that it is not your fault and you are not to blame. Sadly, we cannot always make people better. By donating your stem cells you have given your brother or sister the best possible chance of a cure. Support will always be available for you from hospital staff and your parents and friends.

Please ask any questions or to talk about any fears or feelings you are experiencing.

Will you be asked to donate again?

Occasionally, a second stem cell collection or harvest may be requested if the first one doesn't work. However, this is unusual.



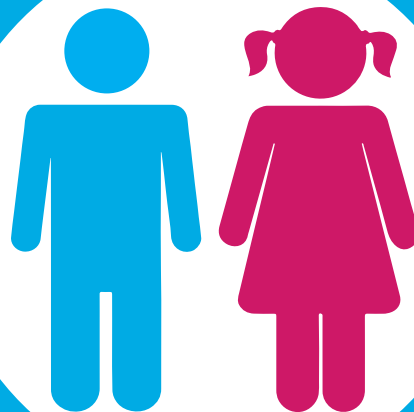
Will your relationship with your brother or sister change?

Many brothers or sisters feel they become closer because they have had a shared experience through the donation process. Some feel exactly the same as before.

Some donors ask if their brother or sister will become more like them, because they are receiving something from the donor's body. As far as we know, the bone marrow or stem cells do not carry any influence on male/female characteristics, personalities or physical features. You will only be giving your brother or sister the chance to have new blood cells and immune system, and not anything else.

Please do remember that you are volunteering and it's your choice to be a donor. If there are any questions that remain unanswered please speak to the medical or nursing team about your concerns. You may find that by doing this you are less worried about undergoing the procedure and are better prepared to be a donor.

Thank you for taking the time to read this and for considering being a stem cell donor for your brother or sister.



Glossary

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

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

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

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.

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.

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.

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

Immunosuppression: A reduction in the body's own defence system.

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 brother or sister's new bone marrow begins to grow.

Oncologist: A specialist in the diagnosis and treatment of cancer.

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.

Red blood cells: Cells which carry oxygen and haemoglobin.

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 ensure a donor and recipient are as closely matched 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.

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.

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, post-mortem 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.

Macmillan Cancer Support

www.macmillan.org.uk

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

NHS Choices

www.nhs.uk

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



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  TYACancerPro

Registered charity in England and Wales (1182637) and Scotland (SC049948).



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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 ChildrensCLG   CCLG_UK

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