The ROYAL MARSDEN
NHS Foundation Trust

Donating stem cells for a relative

Patient Information

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Introduction

This booklet has been written to help close relatives, who are over the age of 16 years to understand what is involved in the stem cell donation process. It also aims to guide you through each stage of the process if you are found to be a match for your relative and consent to donation. There is a glossary (page 16) to explain some of the medical terms used.

What are stem cells?

Stem cells are immature cells that are found in the bone marrow, which is the 'factory' where new blood cells are made. Stem cells can grow and divide into mature red blood cells needed to carry oxygen, white blood cells needed to fight infection, or platelets to help blood clot. The type of blood cell a stem cell develops into is determined by the needs of your body, and through the action of substances called growth factors.

Why does my relative need my stem cells?

Most often, a patient needs a stem cell transplant to replace their own diseased bone marrow or immune system. Immediately before the stem cell transplant, the patient will receive chemotherapy, radiation or a combination of both to destroy their own bone marrow. If all goes well, your donated cells will engraft which means they will begin producing healthy cells in your relative.

How do you know that I will be a suitable donor for my relative?

We will carry out a test on a sample of your blood. This is done by putting a small needle into a vein in your arm to take the blood sample. The blood sample is then sent to the tissue-typing laboratory.

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. A donor is chosen according to how similar their tissue type is to that of the patient. There is a 1 in 4 chance (25%) of a brother or sister being a full match and it usually takes around two weeks for the results to be available.

When testing, we are not looking at blood group compatibility (this does not have to match), but rather at proteins called human leukocyte antigens (HLA). Tissue typing or 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 do not. They also help protect the body against organisms such as bacteria and viruses.

It is important to have as close a HLA match between you and your relative so that your relative's immune system accepts your stem cells to enable engraftment. If the immune system of the patient tries to reject the transplanted cells, this can lead to possible graft failure. The new donor immune system can also recognise parts of the recipient's body as foreign and may mount a response called graft-versus-host disease. This may need treatment with medication to suppress the immune system. However, graft-versus-host disease is usually also associated with a strong reaction against the recipient's original disease and may therefore help prevent relapse.

In addition, we will ask for your consent to test for infectious diseases that may be transmitted to your relative through a stem cell donation. These include tests for antibodies to Hepatitis B, C and Human Immunodeficiency Virus (HIV) viruses.

Please read carefully and consider the health screen information (page 3), which is designed for the protection of both you and your relative.

Health screen

There is a chance that you will not be able to be a stem cell donor if:

- You are above or below a certain weight
- You have severe lung disease, such as asthma, emphysema or lung fibrosis
- You have uncontrolled high blood pressure, abnormal heart rhythm, or other heart problems
- You have ever had cancer
- You have ever had a stroke, heart attack, heart failure, angina, heart bypass operation or heart valve replacement
- You have an autoimmune condition
- You are receiving treatment for epilepsy or have certain other neurological conditions
- You are at risk of contracting hepatitis C, HIV, malaria and other infections – for example, through high-risk sexual behaviour, intravenous drug use, travelling in areas of high risk for infectious diseases or tattooing
- You have anaemia, sickle cell disease or thalassaemia
- You have ever been diagnosed with HIV, hepatitis C or Human T cell lymphotropic virus (HTLV), or you currently have hepatitis B
- You have ever had a clot on the lung (pulmonary embolus)
- You have haemophilia
- You are currently pregnant
- You have injected yourself, with illegal or non-prescription drugs including body building drugs in recent years.

Please remember, you may be at ongoing risk of HIV or Hepatitis B or C after sex with:

- Any individual you think may be HIV, HTLV positive or a Hepatitis B or C carrier
- Any individual who has participated in high-risk sexual activities including unprotected sex with multiple partners in recent years
- Any individual who has ever injected, or has been injected with illegal or non-prescription drugs
- Any individual who has had unprotected sex with partners from areas of the world where AIDS and HIV is very common, including countries in Africa.

Please inform your transplant coordinator if you have any of the above health conditions or risk factors before your blood is tested to see whether you are a match.

If after reading this information you do not want to be a donor for your relative, please inform your transplant coordinator as soon as possible. This information will be treated with strict confidence and your relative would only be informed that you are not a suitable donor.

Any information you give us about health conditions or lifestyle risk factors will be treated in strict confidence.

What happens if I am not a suitable match for my relative?

The fact that you gave blood to be tested is very much appreciated. Remember there are other ways that you can support your relative as they go through their treatment which are equally 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 on the Anthony Nolan (AN) register – this means your tissue type will be kept on a computer database at the registry and you may be a match for another person needing a transplant in the future. You can find out more information about registering with AN at *www.anthonynolan.org*.

What happens if I am selected as the donor for my relative?

If your stem cells are identified as a match for your relative and you agree to be their donor, your stem cells will be collected from your blood stream (peripheral blood stem cell {PBSC} collection). They are then given to your relative in much the same way as a blood transfusion. If all goes well your donated cells will engraft.

We will ask you to attend the hospital three to four weeks before the pre-arranged stem cell donation date for a medical examination. The purpose of the medical is to confirm your general health and to assess the suitability of your veins for a peripheral blood stem cell collection. We will take an account of your medical history and that of your family, as well as the present state of your health. We will also ask if you are taking any medication so please make a note of any tablets or medicines you take, either prescribed or over the counter (including complementary therapies and supplements) or bring them with you. We will carry out a comprehensive physical examination including blood tests and an electrocardiogram (ECG).

All donors need to have routine blood tests for infection screening 30 days before the collection takes place even if this was done when you were tissue typed. The infections tested for include hepatitis B and C, cytomegalovirus (CMV), herpes simplex virus (HSV), human immunodeficiency virus (HIV), human T cell lymphotropic virus (HTLV) and syphilis. The results are usually available within a few days. It is necessary that we discuss these tests with you before they are carried out and you must give your consent agreeing to have the HIV test.

If any of these test results are positive, there could be implications for your health or the donation and we will call you back to the clinic to discuss them. All results are confidential. A copy will only be sent to your GP with your permission.

It is not possible to be a donor if you are pregnant and therefore women who have reached puberty and are still of child bearing age will be asked to have a pregnancy test as part of routine stem cell donation preparation.

The medical examination also provides the opportunity to discuss the donation process in more detail and answer any questions that you may have. Please read the rest of this booklet to find out more about the choices available for the donation procedure.

How is the peripheral blood stem cell (PBSC) collection performed?

To collect stem cells from the peripheral blood, the stem cells have to be encouraged to move from the bone marrow into the circulating bloodstream. This is known as ‘mobilisation’. During the four days before the collection, the donor receives daily injections of a growth factor called granulocyte-colony stimulating factor (G-CSF).

G-CSF also occurs naturally in the body and is one of a number of human growth factors that stimulate and regulate the production of new blood cells in the body. A short course of additional G-CSF stimulates the stem cells to divide rapidly in the bone marrow and move into the peripheral blood in sufficient quantity to be collected. G-CSF can be manufactured synthetically in a form identical to the natural human variety and has been licensed for use in healthy donors.

Very infrequently, in less than 1% of cases, an inadequate number of stem cells are in the peripheral blood after giving G-CSF and there may be too few stem cells collected to allow the patient to engraft. In this unlikely event, you may also be asked to consider a bone marrow harvest.

How is G-CSF given?

G-CSF is given as an injection just under the skin, at approximately the same time each day for four days. The first injections can be given at The Royal Marsden or arranged with your GP surgery. After this you can administer the injections yourself or we can arrange administration.

What are the risks and side effects of G-CSF?

G-CSF is administered to volunteer donors as a short course lasting four to five days and has a high safety record. More than 20,000 volunteer unrelated donors and many more donors related to patients have received short courses of G-CSF in the last 20 years without evidence of serious harm except on very rare occasions.

The most common short-term side effect associated with G-CSF is bone and muscle pain. This can range from mild to painful and can be controlled with over the counter painkillers such as paracetamol, taken regularly.

Important note: aspirin and anti-inflammatory medication such as ibuprofen (Nurofen) can affect the clotting ability of blood. They must not be used for pain relief during the donation process.

Less common side effects of G-CSF include:

- Insomnia
- Headaches
- Fatigue
- Nausea and vomiting
- Flu-like symptoms including night sweats and fever.

There have been some rare reports (less than one in one thousand patients) of allergic reactions, which is why we monitor you after the first injection. These reactions include temporary changes in the way the liver works, and skin rashes;

this occurs in a very small number of patients and usually after prolonged treatment with G-CSF. Of the thousands of donors who have donated in this way, there are a few reported cases of donors in the USA who have had a ruptured spleen requiring surgery.

Safety data from large follow up studies of volunteer donors show no evidence of any long-term medical problems. Nevertheless, we continue to follow up all donors for 10 years post-donation to ensure we detect any possible long-term side effects in people who have received G-CSF. There is also collaboration with other blood stem cell collection centres in Europe.

We believe that the risk of giving G-CSF to healthy individuals is exceedingly low. However, we have a responsibility to ensure that the procedure of collecting blood stem cells from donors is as safe as it possibly can be, both in the short and long-term. If any significant new data emerges, we will inform past and future donors.

More information is available from Anthony Nolan
www.anthonynolan.org

What actually happens during a PBSC collection?

On day five after the G-CSF injections begin, you will attend The Royal Marsden Apheresis Unit at the agreed time (usually 8.30am). Usually all collections are carried out on the day as planned.

The procedure for collecting stem cells from the peripheral blood is known as ‘apheresis’ and is carried out as an outpatient procedure on one or two days, lasting approximately four to six hours each day. 80% of donor collections are performed in one day but others will be required to return for a second day. There will be a nurse nearby throughout the collection procedure.

The collection is made using a machine called a blood cell separator. A needle is put into a vein in your arm to draw blood out into a sterile plastic circuit connected to the cell separator.

The blood is mixed with a blood thinner while in the circuit to stop it from clotting. The blood is spun in a special machine (centrifuge) to separate the stem cells from the other parts of the whole blood. The stem cells are then collected into a sterile bag. The rest of the blood continues through the circuit and is returned through a needle into a vein in your other arm.

What can I do during the collection?

You will be lying or sitting on a reclining chair and can do anything calm (for example, read, or watch the television) during the procedure. You can eat breakfast on the morning of the procedure (foods rich in calcium may help such as milk, yoghurt, cheese) and you will be able to have refreshments once the collection is underway. You should use the toilet before the procedure starts. If you require the toilet during the procedure, the nurse will help you with a bottle or a commode. You can have someone to come and stay with you during the PBSC collection if you wish.

What happens after the collection?

You will need to wait after the first collection for us to take a stem cell count to see whether enough stem cells have been collected for your relative's transplant. If a second collection is necessary you will receive another dose of G-CSF before going home. You will then need to return to The Royal Marsden on day six for the second collection.

After the collections, you may feel tired for a short time. Most people find that two or three days should be plenty to allow for recovery. These are only guidelines and you may find that you do not need any time off work, or that you need longer.

What are the risks and side effects of apheresis?

- Bruising at the needle insertion sites.
- Feeling faint; let the nurse know if you have a history of fainting during blood tests.

- Temporary tingling around the mouth, face, fingers and toes, a sense of bodily vibrations, nausea, chills, and cramps can occur because of decreased calcium levels caused by the blood thinner. This can be resolved effectively and quickly with calcium supplements.
- Sometimes platelets (blood cells involved in clotting) are collected with the stem cells, causing an increased chance of bruising and bleeding. A blood test is taken after each collection to check the blood and platelet counts. You may also be advised not to fly until your platelets have recovered, which is usually within a day or two after the collection. The apheresis team will advise you to avoid strenuous activity and alcohol consumption if your platelet count has temporarily lowered.

What happens if my peripheral veins are not suitable for the PBSC collection?

An important part of the pre-donation medical examination is to assess the suitability of your veins. We need to be able to gain good access to your veins for PBSC collection. This is usually possible using the veins in your arms. If you do not appear to have suitable peripheral veins, the options of using a central venous catheter (a soft plastic tube that is inserted into a large vein in your neck or groin) to collect your stem cells will be discussed. However, it is not always possible to predict a problem with venous access from the arms and if this arises at the start of the collection, we will offer you a central catheter then. Less than 5% of donors (5 in 100 people) need to have a central catheter.

A central venous catheter is only needed for one or two days. If it needs to stay in for a second day, you will be admitted to the hospital overnight between the collections. A member of the healthcare team will insert the central catheter and will use a local anaesthetic to numb the skin at the point of insertion. The procedure can be uncomfortable and there may be some bruising.

What are the risks of having a central venous catheter?

Risks are rare, but occasionally the central catheter does not function properly or becomes blocked. This is not a serious complication and can usually be corrected easily.

Other very uncommon risks are local bleeding, infection and blood clot formation.

What happens after stem cell donation?

We will telephone you one week after donation to check on your general health and wellbeing. We will then send you a health questionnaire via post or email. You will receive this annually for 10 years as part of our long-term donor follow up.

Donating stem cells should be as stress free as possible and we are keen to receive feedback on all aspects of donor care. Please contact us if you experience any difficulties that may be related to the donation.

What happens to the cells after they have been collected?

The stem cells are taken to the stem cell laboratory at The Royal Marsden where they are counted to calculate exactly how many will be given to your relative. They are then taken to the transplant unit either the same or next day. They are infused into your relative in much the same way as a blood transfusion. If you are unavailable to donate your stem cells around the time we need to do the transplant, we can discuss the possibility of collecting your stem cells earlier and freezing them until they are needed.

If your stem cell collection has produced a higher number of stem cells than needed for the transplant, we may decide to freeze and store the surplus in varying amounts to be used as donor lymphocyte infusions (DLI). A donor lymphocyte infusion may be needed if the patient appears to be losing their graft or has a relapse of their disease after transplant.

We will ask for your consent for this at the time of your medical examination.

What happens if the transplant does not work?

Sometimes the treatments we offer our patients are not successful. A stem cell transplant is an intensive treatment with a long recovery period and a number of serious side effects including a high risk of infections in the early transplant period. Although a transplant offers a patient who needs one the best chance of long-term cure, some patients do relapse to their original disease and treatment options at this point may be very limited.

Another complication is graft-versus-host disease (GVHD). A stem cell transplant works by the new donor immune system recognising any remaining disease cells in the recipient as foreign and destroying them (the graft-versus-disease effect). However, this process can also lead to the new immune system recognising normal patient tissue as foreign causing GVHD. This most commonly causes an itchy skin rash or gut or liver problems which may need treatment with immune suppression and if severe, can be serious for the patient.

If any of these complications occur, you are in no way to blame and there are no changes that you can make to your lifestyle that would make any difference to the outcome for your relative. By donating your stem cells you give your relative the best possible chance of a cure. Before undergoing the transplant, your relative will have been told the chances of curing them and will know the risks they are taking. Support will be available for you from nurses, doctors, family and friends. Please discuss any fears or feelings you are experiencing and contact the transplant coordinator at any time after your donation if you are having problems.

What happens if the transplant is successful?

If the transplant is successful and everything goes smoothly you can expect your relative to be in hospital for four to six weeks. Once home again they will need to attend the hospital frequently for check-ups and review, but gradually the frequency of visits should reduce and life should return to a more normal routine. Things may never seem quite the same again but hopefully the experience of being a donor will be a positive one.

Will I be asked to donate again?

We may approach you to discuss a second donation if a further infusion is felt to represent the best treatment for your recipient's care. This happens most commonly if your relative rejects the first transplant, has an incomplete acceptance of the new immune system or for treatment or prevention of relapse. Approximately 10% of donors (10 in 100 people) are asked for a second donation.

A second donation may either involve a single apheresis procedure to collect lymphocytes, without the need for G-CSF or may involve a repeat stem cell collection like your first donation. You would always undergo a repeat donor evaluation and consent prior to any further donation with a full explanation of the procedure.

The consent to donate process

We will ask you to sign a form at the medical examination whereby you consent to donate peripheral blood stem cells. Copies of these consent forms are available on request if you wish to read them before your medical appointment. Informed consent is approached as an ongoing process and not an isolated event. Even once you have signed the consent form you are still entitled to withdraw your consent.

We encourage you to write down any questions you may have to remind you to ask the doctors or nurses who will be caring for you.

Although donors always have the right to withdraw consent at any time, it is essential that you satisfy yourself that you do wish to proceed with the harvest or collection before your relative begins their pre-transplant conditioning treatment. This treatment begins seven to ten days before the harvest or collection and consists of the patient's own blood stem cells being destroyed by chemotherapy and radiation, with the intention, in the case of leukaemia, of destroying all the leukaemic cells. The patient is then dependent on the infusion of donor stem cells to engraft and to start producing the necessary blood cells to carry oxygen and fight infection.

The law on consent

For a comprehensive summary of the law on consent see the Department of Health's Reference guide to consent for examination or treatment (also available at *www.gov.uk*).

See Human Tissue Authority (HTA) Codes of Practice on (1) Consent (2) Donation of organs, tissue and cells for transplantation and (6) Donation of Allogeneic bone marrow and peripheral blood stem cells for transplantation.

These codes give practical guidance to those carrying out activities which lie within the HTA's remit and lay down standards expected (also available at *www.hta.gov.uk*).

See Human Tissue (Quality and Safety for Human Application) Regulations 2007 (available at *www.hta.gov.uk*).

Remember you are volunteering and it is your choice to be a donor. If there are any questions that remain unanswered, please speak to the healthcare 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.

Contact details

Transplant coordinators

Tel: 020 8661 3785 and 020 8915 4091 and 020 3186 5583

Bud Flanagan apheresis unit

Monday to Thursday (8am – 5pm)

Tel: 020 8642 6011 ext 4258

After hours, weekends and bank holidays

Ask for the senior nurse on bleep 017

Tel: 020 8642 6011 via switchboard

Alternatively, please call:

The Royal Marsden Hotline: 020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Useful websites

Anthony Nolan	*www.anthonynolan.org*
World Marrow Donors Association	*www.wmda.info*
Be The Match	*www.bethematch.org*
British Heart Foundation	*www.bhf.org.uk*

Glossary

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells (including leukaemia, lymphoma and myeloma). Chemotherapy may be used alone to treat some types of cancer. It may also be used with other types of treatment such as surgery, radiotherapy, hormonal therapy, biological therapies, or a combination of these.

Cytomegalovirus (CMV)

CMV is a virus which can be passed on by breathing in the droplets from the coughs and sneezes of an infected person. It can also be caught through having unprotected sex with a person who has the virus, or having donated organs or blood transfusions from someone with CMV. Once you have CMV, it remains in your body for life. If you have got a strong immune system, you may have mild side effects. But if your immune system becomes weak later in life, for example if you have chemotherapy, the virus may be activated.

Electrocardiogram (ECG)

An ECG records the rhythm and electrical activity of the heart. An ECG is a simple and useful test. Small sticky patches called electrodes are put onto the arms, legs and chest. These are connected to an ECG recording machine which picks up the electrical signals that make the heart beat. The machine records a few beats from each set of electrodes onto paper. The test only takes a few minutes.

Epstein-Barr Virus (EBV)

EBV is a common virus that causes glandular fever, although most people develop immunity to it.

Graft

A graft is another word for transplant and in this situation, means taking stem cells from one person and putting them into another. When these stem cells begin producing healthy blood cells, this is known as engraftment.

Graft-Versus-Host Disease (GVHD)

Sometimes the donor stem cells react against remaining immunity in the recipient. The patient (the recipient) may most commonly experience skin, gut or liver symptoms. However, GVHD can affect a wide range of organs and tissues.

Hepatitis B (HBV)

HBV is a virus which spreads through the blood and bodily fluids of an infected person. The hepatitis B virus can go on to cause a chronic (long-term) illness, which may follow an acute infection. This is very common in babies and young children, but it can also occur in adults. If you develop chronic hepatitis B, you may remain well, but you may pass on the virus because you are a carrier. Symptoms may come and go, or you may develop serious liver damage.

Hepatitis C (HCV)

HCV is a blood-borne viral infection. It can also be passed on in other bodily fluids, such as semen. Drug users sharing needles are at particularly high risk, but also anyone whose blood has come into contact with the blood of someone infected with hepatitis C. The virus is not transmitted through normal social contact, such as hugging, kissing, sharing kitchen utensils or toilet seats. Approximately 20 per cent of people will fight the infection and naturally clear it from their bodies within two to six months. Of the rest some will remain well, and never develop liver damage but many will develop mild to moderate liver damage (with or without symptoms). A further 20 per cent will progress to cirrhosis (scarring of the liver) over a period of 20 to 30 years. Excessive drinking of alcohol is often associated with increased likelihood of progression to severe liver complications.

Herpes Simplex Virus (HSV)

HSV, or cold sore virus, is highly contagious, and it can be easily passed from person to person by close direct contact.

Human Immunodeficiency Virus (HIV)

HIV is a sexually transmitted virus that attacks the body's immune system, which provides a natural defence system against disease and infection.

Human T cell lymphotropic virus (HTLV)

HTLV is a virus which can be transmitted from a mother to her baby through unprotected sex, a blood transfusion or the sharing or re-use of needles and syringes to inject drugs. HTLV is quite rare in the UK, with only an average of 50 new cases occurring each year. Further information can be obtained from the National Centre for Human Retrovirology: *www.htlv.eu*

Radiotherapy

Radiotherapy is the use of high energy x-rays and similar rays (such as electrons) to treat cancer including leukaemia, lymphoma and myeloma. Many people with cancer will have radiotherapy as part of their treatment. Radiotherapy works by destroying the cancer cells in the treated area. Although normal cells can also be damaged by the radiotherapy, they can usually repair themselves.

Syphilis

Syphilis is a bacterial infection that is most often passed through sexual contact. However, it can be passed on by intravenous drug use (injecting drugs directly into the vein), blood transfusions and from an infected mother to her unborn child. The latter is known as congenital syphilis.

Varicella Zoster Virus (VZV)

VZV is the virus that causes chicken pox. After a chickenpox infection, the virus stays in the body's nerve tissues (remains dormant). It does not do any harm because it is kept under control by the immune system; the part of the body that fights infection. At any time later in life, but usually when you are an adult, the virus can be reactivated (come back), causing a different form of the virus, known as shingles.

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone:	Chelsea	020 7811 8438 / 020 7808 2083
	Sutton	020 8661 3759 / 3951
Email:	patientcentre@rmh.nhs.uk	

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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