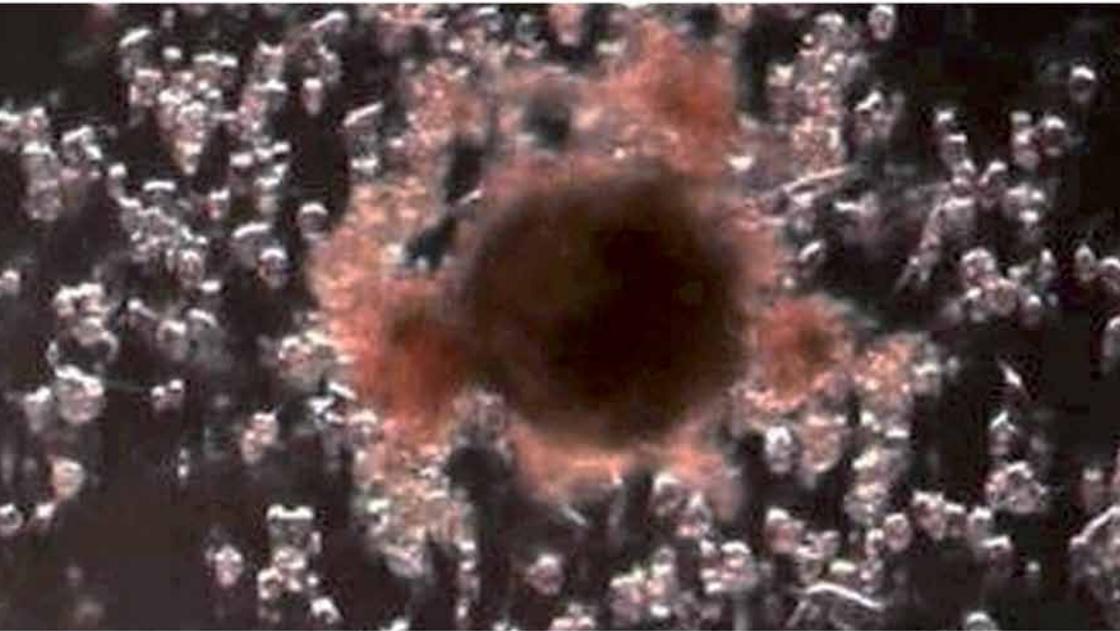


Donating stem cells



What's involved?

The diagnosis of a blood cancer can be a devastating event for patients, families and friends. It is therefore vital for everyone to have access to reputable and understandable information to help cope with the illness. Whenever possible our booklets are written in line with national guidelines for the treatment of patients with a blood cancer. The information in our booklets is more detailed than in many others but is written in a clear style with all scientific terms explained for the general reader.

We recognise that the amount and level of information needed is a personal decision and can change over time. Particularly at the time of diagnosis, patients may prefer less detailed information. A number of alternative sources of information are available which complement our publications.

The booklets in this series are intended to provide general information about the topics they describe. In many cases the treatment of individual patients will differ from that described in the booklets.

At all times patients should rely on the advice of their specialist who is the only person with full information about their diagnosis and medical history.

For further information please contact the patient information team on 020 7504 2200.

The information contained in this booklet is correct at the time of going to print (February 2012).

**Leukaemia & Lymphoma Research,
39-40 Eagle Street, London, WC1R 4TH**
T: 020 7504 2200
E: info@beatingbloodcancers.org.uk
W: beatingbloodcancers.org.uk

Series compiled by Ken Campbell MSc, reprinted February 2012.

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Being a stem cell or bone marrow donor

This booklet has been written to tell you what is involved when you agree to be a stem cell or bone marrow donor and to guide you through each stage of the donation process.

Hopefully, it will go some way to answering the many questions you may have. If there are questions that remain unanswered please speak to the transplant doctor and/or transplant co-ordinator nurse. Remember, they are not only there for the patient but also for you.

Why are my stem cells or bone marrow needed?

When treating some types of leukaemia, lymphoma, myeloma or other diseases, donor stem cells or bone marrow are used to improve the chances of curing the disease. A transplant can be done early in the disease process or when the patient is in remission following chemotherapy.

What is bone marrow?

Bone marrow is a spongy tissue found within certain bones in the body. The main bones it is found in are the pelvis, sternum (breastbone), limb bones and ribs. All blood cells are produced in the bone marrow.

What is a stem cell?

A stem cell is the ‘mother’ cell in that it divides to form the three main types of cells found in the blood. These are the red blood cells, the white blood cells and the platelets.

Red blood cells carry oxygen from the lungs to all the tissues of the body. When these are low (anaemia) the patient feels more tired and may look pale.

White blood cells help to protect the body against infection from bacteria and viruses. The one most talked about is the neutrophil. When these white cells are low (neutropenia) the patient is more at risk of infection.

Platelets form blood clots and help control bleeding. When these are low (thrombocytopenia) the patient can bruise more easily and may take longer to stop bleeding if they cut themselves.

Why am I the donor?

The test to see if you are a suitable donor requires a sample of blood to be taken and sent to the tissue-typing laboratory. When testing they are not looking at the blood group as this does not have to match, they are looking for proteins called Human Leucocyte Antigens (HLA).

A donor is chosen according to how similar the HLA type is to the patient.

Statistically, there is a 1 in 4 chance of a brother or sister being a full match.

It usually takes two weeks for the results of tissue typing to be available.

Remember you are volunteering, it is your choice to be a donor.

If you are worried about being a donor then it may help to talk to a member of nursing or medical staff about your concerns. You may find that by doing this you are less worried about undergoing the procedure and are prepared to be a donor.

How are stem cells collected?

There are two different ways to collect stem cells:

- Bone marrow harvest
- Peripheral Blood Stem Cell collection

These two procedures are very different and will be explained in more detail over the next few pages.

Will I have to decide which way to collect the cells?

The possible procedures will be discussed with you at your clinic appointment with the haematology doctor and transplant nurse. The way the cells are collected will depend on what is best for the patient and you as the donor.

Collecting stem cells from the peripheral blood, rather than the bone marrow, has now become the most common method of obtaining stem cells. However some donors, particularly unrelated donors, may opt for a bone marrow harvest.

What happens at the clinic appointment?

The doctor will ask about your medical history such as any illnesses you have had, operations you have gone through or any medical problems you are being treated for at the moment. They will also ask if you are on any medication so it might be an idea to bring any tablets with you for them to look at.

The doctor will examine you and your blood pressure will be recorded.

All donors need to have routine infection screening performed 30 days before the collection takes place. These are blood tests that look for particular viruses you have been exposed to in the past. This is done to prevent cross infection when the cells are given to the patient.

The infections tested for are:

- Hepatitis B and C
- Cytomegalovirus (CMV)
- Human Immunodeficiency Virus (HIV)
- Human T cell Lymphotropic Virus (HTLV)
- Syphilis.

The results are usually available within a few days. It is a requirement that these tests are discussed with you before they are performed and you sign a consent form agreeing to have the tests done. All results are confidential and a copy will be sent to the GP only if positive. If any of the results are positive that could have implications i.e. the HIV test,

you will be called back to the clinic to discuss the results. If you are CMV positive this is not a risk to you but something the team need to know about before you donate your cells. Therefore you would not necessarily be called back to discuss this result.

You will be asked to sign a consent form before the procedure is carried out. By signing this form you are agreeing that the procedure has been explained to you and that you understand any risks involved. If you are unsure about any aspect of the treatment proposed you must ask.

So that the cells can be given fresh, the harvest or collection is performed when the patient has received most or all of their chemotherapy and/or radiotherapy that he or she needs.

How is the bone marrow harvest performed?

This type of harvest is carried out in theatre under a general anaesthetic. You are usually admitted to hospital the day before the harvest. You may need to have some blood tests and be examined by a doctor who will discuss the procedure with you again and ask you to sign the consent form agreeing to the procedure.

You are not allowed to eat or drink anything from midnight the night before theatre. On the day you will be asked to shower and put on a hospital gown. All jewellery must be removed except a wedding ring. When the theatre staff are ready for you a porter and nurse will take you to theatre.

You will have a cannula (a plastic needle) inserted into the back of your hand so the anaesthetist can give you the medication to put you to sleep.

Bone marrow is harvested from the back of the hip bones; very rarely the breast bone may be used in addition. A needle is put into the bone and the bone marrow is sucked out with a syringe and transferred into a blood bag. The harvest takes about an hour to complete and about 1 to 1.5 litres of marrow is removed.

It sounds like a lot but your body can replace this in less than three weeks.

Once complete a dressing is put over the puncture site to stop the site from bleeding and you are taken to the recovery room to 'wake up'.

When you wake up you may have fluids running into the cannula in your hand. This is to replace some of the fluid that has been taken during theatre. When you are properly awake you will be taken back to the ward.

It may be necessary to give you a blood transfusion. Up to a month before the procedure you would have been asked to donate one or two units of your own blood and this would be returned to you at the time of the harvest.

The staff on the ward will monitor you regularly - checking the puncture sites, your blood pressure, temperature and pulse. They will also monitor your oxygen levels when you return to the ward to recover. You will be allowed to drink now and given painkillers for the soreness you can experience to your back and hips.

If everything goes well you will be discharged the next day with some painkillers to take at home and some iron tablets if you are slightly anaemic. It is advisable to rest for the next few days and return to work the following week.

If you need a sick note for work the hospital doctor can fill one in for you.

How is the Peripheral Blood Stem Cell collection performed?

The stem cells are collected by moving or 'mobilising' them into the blood. This is done by administering growth factors in the form of injections once, possibly twice, a day starting four days before the date of harvest.

The growth factor used is called G-CSF, which stands for Granulocyte Colony Stimulating Factor, and is a naturally produced hormone, which stimulates the body to produce extra stem cells in the bone marrow and move to the blood stream where they are collected.

You can be taught to do the injections yourself or a family member can do them for you. If this is not possible for any reason the district nurse can be asked to come to your home to give the injections. If you are receiving daily injections these will be given in the early evening around the same time each day. If you are having twice daily injections it is important to have the injections eight hours apart. They should be stored in the fridge and taken out about 30 minutes before they are to be given.

The most common side effect of the injections is a flu-like feeling (fever, aches and joint or back pain). This symptom is temporary and will disappear when the injections stop. It may be necessary to take painkillers such as paracetamol or ibuprofen. Whatever painkillers you take will have no effect on the stem cells, although we would not advise you to take aspirin or similar products as they may cause an increased

risk of bleeding when you are disconnected from the machine after the procedure. Taking a warm bath may also help with the symptoms.

If you experience any other side effects such as chest pain or stomach pain it is important you speak to someone at the hospital that prescribed the injections. Contact telephone numbers should be given to you at your clinic appointment.

You will be told what time you need to attend the hospital on the day of collection. You can eat and drink normally during the procedure and can read a book or magazine. It is not advisable to drive yourself and whoever brings you can usually sit with you during the procedure. If your veins are suitable you will have a needle in one arm and one in the back of your hand. Once you are attached to the machine you cannot be disconnected until the procedure is completed, which is usually around four hours.

You are attached to a machine called a cell separator. The blood flows out of the needle and into the machine; it is then spun through a centrifuge that spins the blood at high speed without damaging the cells, removes the stem cells into a bag and then returns the remaining blood through the needle in your hand.

Occasionally a donor may have poor veins and may require the insertion of a central line, usually in the x-ray department.

Your blood pressure and pulse will be recorded during the procedure. You may feel dizzy or light headed during the procedure and it is important to let the nurse or doctor know. This is because the machine is removing and replacing blood and although this is only a small amount at any one time (about a teacupful) the change in blood volume can cause these side effects.

There is an anticoagulant used in the machine to prevent the blood from clotting. This may cause a sour taste in your mouth or tingling around the lips, cheeks or fingertips as your calcium level can drop. Giving you

a tablet called Calcichew or a glass of milk can easily treat this, again you should let the nurse or doctor know. This only occurs in approximately 10% of patients going on the machine but if you experience these side effects you need to let the doctor or nurse know.

The collection is usually completed in one or two days. You may go home after the first day and will be told or telephoned if you need to return the next day, in which case you will require more G-CSF injections that evening.

In rare cases it is not possible to collect sufficient cells even after three peripheral blood stem cell harvests. It would then be necessary to complete a bone marrow harvest.

You will feel tired after donating your stem cells but should be able to return to work the next day.

What happens to the cells after they have been collected?

They are taken to the stem cell laboratory where the stem cells are counted to calculate exactly how many are given to the patient, and then they are taken to the transplant unit either the same or next day.

They are then given to the patient in the same way as they would have a blood or platelet transfusion.

What if the transplant does not work?

If the transplant does not work it is not your fault. Sometimes the treatments on offer to patients are not successful although they are the best treatments available for them. By donating your bone marrow or stem cells you are giving the patient the best possible chance of a cure. Before undergoing the transplant the patient will have been told the chances of curing them and will know the risks they are taking.

Support will be available to you from nurses, doctors, family and friends. Please discuss any fears or feelings you are experiencing.

Can I donate my stem cells again?

Occasionally, a second stem cell or bone marrow harvest may be requested. This could happen if the patient rejects the first transplant. However, this is an unusual occurrence.

In some instances a further collection is taken from the blood of the donor. The cells that are collected are called lymphocytes and these are used to try and help prevent or treat relapse of disease.

The cells are obtained in the same way as the peripheral blood stem cell harvest but this time injections are not needed. The cells being collected are circulating in the bloodstream.

The lymphocytes are usually collected over one or two sessions of approximately three hours each. They are then frozen and stored in varying amounts for use as needed. This is known as a Donor Lymphocyte Infusion (DLI). This does not work in all types of disease or forms of relapse. The doctor will contact you if they need to collect cells for DLI.

Notes

Notes

Two further publications by Leukaemia & Lymphoma Research are available should you require further information about the transplant procedure itself:

- Seven Steps
- Bone Marrow and Stem Cell Transplantation.

Copies can be ordered online at
www.beatingbloodcancers.org.uk/order-patient-information
or by calling us on 020 7504 2200.

Useful web addresses

www.blood.co.uk/about-blood/information-for-patients/

www.ebmt.org

The following patient information booklets are available free of charge from Leukaemia & Lymphoma Research. You can download them from our website or request copies by phone.

Acute Promyelocytic
Leukaemia (APL)

Adult Acute
Lymphoblastic Leukaemia (ALL)

Adult Acute
Myeloid Leukaemia (AML)

Childhood Acute
Lymphoblastic Leukaemia (ALL)

Childhood Acute
Myeloid Leukaemia (AML)

Chronic Lymphocytic
Leukaemia (CLL)

Chronic Myeloid Leukaemia (CML)

Aplastic Anaemia (AA)

The Myelodysplastic
Syndromes (MDS)

The Myeloproliferative
Neoplasms (MPN)

Multiple Myeloma (MM)

Hodgkin Lymphoma (HL)

Non-Hodgkin Lymphoma (NHL)

**Leaflets on a range of
associated blood disorders are
also available from Leukaemia &
Lymphoma Research**

Bone Marrow and Stem Cell
Transplantation (BMT)
– for children and adults

Donating stem cells
– what's involved?

Donor Lymphocyte Infusion (DLI) –
what's involved?

The Seven Steps – Blood & bone
marrow transplantation

Undergoing high dose therapy and
autologous stem cell transplant

Chemotherapy
– what do I need to know?

Clinical Trials

Complementary and
Alternative Medicine (CAM)

Dietary advice for patients
with neutropenia

Supportive care

Treatment decisions

Watch and wait

Young adults with a blood cancer –
what do I need to know?

Jack's Diary: an illustrated children's
book to help young patients
understand and deal with blood
cancers, treatment and life changes

Wiggly's World: a colourful A-Z
illustrated booklet, designed to take
the anxiety out of treatment for
children and their parents

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E: info@beatingbloodcancers.org.uk • W: beatingbloodcancers.org.uk

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