



## **Donating bone marrow or peripheral blood stem cells Information for the donor family**

### **Introduction**

This information has been written for you as a brother, sister or parent and potential bone marrow or stem cell donor, to guide you through each stage of the donation process. If you have any other questions, please speak to the transplant co-ordinators later.

### **Why are my stem cells or bone marrow needed?**

Stem cell transplants from a healthy donor to a patient can improve the chances of curing diseases, such as leukaemia, lymphoma, myeloma or aplastic anaemia. This treatment has been recommended for your relative.

### **What are bone marrow and stem cells?**

Bone marrow is a spongy tissue inside certain bones in the body. The main bones containing bone marrow are the sternum (breast bone), pelvis, femur (thigh bones) and ribs. All blood cells are produced in the bone marrow from specialist cells called stem cells. The stem cells are needed for transplantation.

### **What do blood cells do?**

There are three types of cell in the blood. Each type of cell does a different job.

- Red cells carry oxygen to all the tissues of the body. When these levels are low the patient feels more tired and may look pale.
- Platelets prevent bleeding and help the blood to clot. When these are low the patient can bruise more easily and may bleed from cuts for longer than usual.
- White blood cells help to protect the body against infection. There are several types of white cell and each has its own job. The one most commonly talked about is the neutrophil. This fights infection, kills bacteria and removes damaged tissue. When these are low the patient is more at risk of infection.

### **How do you match a donor to a recipient?**

We will take a blood sample from you and send this to the laboratory for tissue typing (the DNA of your white cell). We inherit certain characteristics from our parents, such as eye or hair colour, which are easily recognised. We also inherit the information which makes up most of the cells in our body. The test looks for proteins called human leucocyte antigens (HLA). Half of these human leukocyte antigens are inherited from the mother and half from the father. There are millions of different combinations of these antigens in the population.

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

- Statistically, there is a 1 in 4 (25%) chance of a brother or sister being a full match.
- It usually takes 3 weeks for the initial results of tissue typing to be available. If it looks like you may be matched then a second blood test will be taken to confirm this.
- Please note that your blood group does not need to match that of the recipient.

### **What if I am not a match?**

You may be disappointed or you may feel relieved that you do not have to be a donor. Please remember that there are other important ways that you can help support your relative as they go through their treatment. You may still find the following information helpful to understand what happens.

### **What if I am a match?**

If you are a suitable match then you will be given a choice whether you wish to proceed with donation or not.

### **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 are explained in more detail on pages 3 and 4.

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

The haematology doctor and transplant nurse will see you in clinic and both methods of stem cell collection will be discussed. Unless there are reasons that the collection could only be safely obtained using one method, you will be given the choice of collection procedure. Peripheral blood stem cell collection is the most common method of obtaining stem cells. However, some donors may opt for a bone marrow harvest. If you have no preference, the doctor will be happy to advise you about the method of donation.

### **What happens at the clinic appointment?**

- The doctor will ask you about your medical history such as any illnesses or operations you have had or any medical problems you are being treated for at the moment. They will also ask if you are on any medication either prescribed or bought over the counter. Please bring any medication with you for them to look at.
- The doctor will examine you and record your pulse, blood pressure and temperature.
- All donors need to have screening tests to ensure they are fit enough to have a stem cell collection. These tests are chest x-ray, ECG (heart tracing), pregnancy test (if applicable) and blood tests to look at your blood count, liver and kidney function and screen for infections.
- All stem cell donors are required to have a blood test looking for infections that may be transmitted in blood. This test needs to be performed within 30 days of collection and may need to be repeated. We will ask you to sign a consent form before this test is carried out. If

you have any questions about this, you should discuss this with the doctor and nurse you see in the clinic. The infections that are tested for are:

- Hepatitis B
- Hepatitis C
- Cytomegalovirus (CMV)
- Human Immunodeficiency Virus (HIV)
- Human T Cell Lymphotropic Virus types 1 and 2 (HTLV)
- Treponema Pallidum (syphilis)
- Varicella Zoster Virus (VZV)
- Herpes Simplex Virus (HSV)
- Epstein Barr Virus (EBV).

The results are usually available within a few days. The test results are confidential and we will inform you and your GP if these are positive. Some results may influence the treatment the patient needs at the time of transplant. Others are important because we would not want to transmit any infection from the donor to the patient.

- The doctor will explain the process of donating stem cells together with any risks. You will be given the opportunity to ask any questions.
- You can look around the outpatients unit where the stem cell collections are performed and one of the specialist nurses will speak to you about the process of stem cell donation.

### **Can I see the results of the tests? What if they are abnormal?**

Yes, you are entitled to see the results of all the tests performed. If any of the tests are abnormal, you will be contacted by one of the specialist nurses. This may mean you are not able to act as a stem cell donor. If you need any follow-up, this will normally be arranged via your GP.

### **How is the bone marrow harvest performed?**

- This type of harvest is carried out under a general anaesthetic. You will come into hospital the day before the harvest. You will need to have some blood tests and have an examination by a doctor. He or she 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 of the procedure we will ask you to shower and put on a hospital gown. Remove all your jewellery (except a wedding ring). When the theatre staff are ready for you, a porter and nurse will take you to theatre.
- The anaesthetist will insert a cannula (a plastic needle) into the back of your hand so you can have medication to put you to sleep.
- The doctor and nurses will harvest the bone marrow from the back of your hip bones (rarely this may also include the breast bone). He or she will put a needle into the bone and remove the bone marrow with a syringe and transfer this to a blood bag. The harvest takes about an hour to complete and about 1 to 1.5 litres of marrow will be removed. Your body can replace this in less than three weeks.

- A dressing is put over the puncture site to stop the site from bleeding and the staff will take you to the recovery room to 'wake up'.
- When you wake up you may have some fluids running from a drip 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 we will take you back to the ward.
- The staff on the ward will monitor you regularly and check the puncture sites, your blood pressure, temperature and pulse. They will also monitor your oxygen levels. You will be able to drink now and have some painkillers for the soreness in your back, hips and throat.
- If everything goes well, you can go home the next day with some painkillers to take and some iron tablets if you are slightly anaemic. We advise you to rest for the next few days and return to work the following week. If you need a sick note for work your 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 from the bone marrow. The donor will have injections of growth factors once a day for four days before the planned date of harvest.
- The growth factor used is called G-CSF (Granulocyte Colony Stimulating Factor). This is a natural hormone which stimulates the body to produce extra stem cells in the bone marrow and move them to the blood stream where they are collected. This can only be given by injections.
- The injections are given under your skin in your leg, arm or in your stomach. We can teach you to do the injections yourself or a family member can do them for you. If this is not possible, we can ask the district nurse to come to your home and give the injections. These injections are best given in the early evening. The syringes will need to be stored in the fridge. They should be taken out of the fridge about 30 minutes before they are used.
- Most donors are able to live normally whilst receiving the G-CSF injections. However everyone is different, so please discuss your personal circumstances with the specialist nurses and they can advise you accordingly.
- The most common side effects of the injections are flu-like symptoms (fever, aches and joint or back pain) and some discomfort or redness around the site of the injections. These symptoms are temporary and will disappear when the injections stop. You may take painkillers such as paracetamol or codeine which have no effect on the stem cells. We would advise that you do not take ibuprofen or similar products as they can affect your blood counts prior to undergoing the procedure. Taking a warm bath may also help with the symptoms.
- The doctor you see in the clinic will discuss the side effects of G-CSF in more detail when you come to the clinic.
- If you have any other side effects such as chest pain, stomach pain, leg swelling, or are concerned, it is important you speak to someone at the hospital. The Christie contacts are:
  - office hours tel: **0161 446 8011**
  - out of office hours contact The Christie Hotline on **0161 446 3658**.

- On the day of the collection, come to the haematology and transplant day unit at 8.30am. You can eat and drink normally during the procedure and use electronic devices. (It is difficult to read as you will only have one arm that is mobile). It is best to have someone to drive you; they can sit with you during the procedure. If your veins are suitable you will have a needle in the crook of one arm to remove blood and one in the back of your hand. Once you are attached to the machine you cannot be disconnected until the procedure is completed. This usually takes around four to five hours.
- The machine is called a stem cell separator. The blood flows out of the needle inserted into the crook of your arm and into the machine. You will not be able to move this arm. It is then spun through a centrifuge at high speed without damaging the cells, removing the stem cells into a bag. The remaining blood is returned to you through a needle in your other hand.
- Occasionally a donor may have poor veins and may need a femoral line. This is a larger plastic tube inserted into a vein at the top of your leg. This will be removed once all the procedures are completed, but you will need to be admitted to a ward overnight whilst it is in place. If it is likely that this will be required, then this will be discussed when you come to the clinic.
- We will record your blood pressure and pulse at the start and end of the procedure. You may feel dizzy or light-headed during the procedure and it is important to let your nurse know. This is because the machine is removing and replacing blood. It is a small amount at any one time but the change in blood volume can cause these side effects.
- The anticoagulant used in the machine to prevent the blood from clotting can cause your calcium level to drop. This may give you symptoms such as tingling around the lips, cheeks or fingertips, or palpitations. Let the nurse know if this happens, as they can give you a tablet or infusion of calcium into the cannula.
- There will be a nurse with you throughout the procedure.
- The collection is usually completed over one or two days. You may go home after the first day and we will tell you or telephone you if you need to return the next day. If so, you will need more G-CSF injections that evening.
- You will feel tired after donating your stem cells, and will require a few days rest before returning to work.
- Occasionally, we are unable to collect any or enough cells after three peripheral blood stem cell harvests. You may be asked to have a bone marrow harvest.
- Four to six weeks after the stem cell collection, we will ask you to have a blood check to ensure your blood counts have gone back to normal. This blood test can either be done here or at your GP surgery.

## Side effects of both procedures

G-CSF / Stem cell harvest	Bone Marrow Harvest
<ul style="list-style-type: none"> <li>• Injection site reactions.</li> <li>• Bone pain.</li> <li>• Flu like syndrome.</li> <li>• Venous thrombo-embolism (rare).</li> <li>• Splenic rupture (very rare).</li> <li>• Poor mobilisation – may require repeat harvest (5-10%) or bone marrow harvest (uncommon).</li> <li>• Insertion of temporary central venous catheter (femoral line) if peripheral venous access is inadequate.</li> <li>• Exceptionally rare but serious – capillary leak syndrome, symptoms include generalised swelling, puffiness, less frequent urination, difficulty breathing, abdominal swelling and extreme tiredness.</li> <li>• There are also theoretical concerns regarding the risk of developing leukaemia, although the available evidence indicates that donors treated with G-CSF are <b>not</b> at increased risk.</li> </ul>	<ul style="list-style-type: none"> <li>• General anaesthetic</li> <li>• Back pain</li> <li>• Anaemia – may require blood transfusion or iron supplementation</li> <li>• Infection at harvest site</li> <li>• Inadequate harvest that may require peripheral blood stem cell harvest.</li> </ul>

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

The collection is taken to the stem cell laboratory where the stem cells are counted to calculate exactly how many to give to the patient. They are taken to the transplant unit either the same or next day and given to the patient in the same way as a blood or platelet transfusion.

### What if the transplant does not work?

Sometimes the transplants are not successful. By donating your bone marrow or stem cells you have given the patient the best possible chance of a cure. Before having the transplant, the doctor will discuss the chances of a cure and all the risks with the patient.

Please discuss any concerns with the staff who will offer support and advice.

### **Can I donate my stem cells again?**

Occasionally, we may ask you to undergo a second procedure if the patient rejects the first transplant or shows signs of disease relapse. In the latter situation, you may be approached to donate lymphocytes which are used to try and treat relapsed disease. They are collected in the same way as stem cells, but you will not need to have any growth factor injections.

The lymphocytes are usually collected over one session of about four to five hours. They are then frozen and stored for use as needed.

### **Contacts**

If you have any questions please contact the transplant co-ordinators on **0161 446 8011** or **0161 918 7219** or via The Christie switchboard on **0161 446 3000**.

The Christie Hotline **0161 446 3658**

## **At home with G-CSF: A donor's guide to self-injection with G-CSF**

The type of injection you have depends on your weight. You may need two or three injections a day. These are best given at night.

### **NEUPOGEN**

This is stored in the fridge and is already pre-prepared. Remove the injection from the fridge and allow it to warm to room temperature. The neupogen injection is now ready

### **Giving yourself the injection**

1. For self-injection, the most convenient injection sites are the front or outer sides of the thighs and the front of your abdomen (tummy). To avoid the risk of soreness at the injection site, inject into a different place and alternate which side you inject each day.
2. Pick up the loaded syringe and remove the needle sheath.
3. Holding the syringe like a pen in one hand, use your other hand to pinch up a fold of skin at the chosen injection site.
4. Now push the needle quickly into the fold of skin at an angle of about 45 degrees.
5. Then slowly push the plunger of the syringe until the syringe contents have all been injected under the skin.
6. Now pull the needle out, keeping it at the same angle as when it went in. If there is any leakage from the puncture site, press it lightly for a few seconds with a clean tissue or piece of cotton wool.
7. Place the needle into the sharps bin.

### **Further information**

#### **Useful booklets**

Donating bone marrow or peripheral blood stem cells

Donating stem cells, what's involved?

Seven Steps

Bone marrow and stem cell transplantation

Histocompatibility testing for stem cell transplant patients

Chugai Pharma UK Ltd

Bloodwise

Bloodwise

Bloodwise

NHS Blood and Transplant service  
(INF258/1)

#### **Useful websites:**

**[NHBST.nhs.uk](http://NHBST.nhs.uk)**

**[Anthony Nolan.org](http://AnthonyNolan.org)**

**[Bloodwise.org.uk](http://Bloodwise.org.uk)**

**[HTS.gov.uk](http://HTS.gov.uk)**

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

Contact The Christie Hotline for  
urgent support and specialist advice

**The Christie Hotline:  
0161 446 3658**

Open 24 hours a day, 7 days a week

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

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The Christie Patient Information Service  
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