Donating peripheral blood stem cells

Answering some of the questions you may have about donating stem cells to the Welsh Blood Service
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You recently provided a blood sample to confirm your suitability as a donor. Doctors at the transplant centre have chosen you as the best donor for their patient. This booklet answers some of the questions you may have about donating peripheral blood stem cells. We have also included a booklet about donating bone marrow to help you decide whether you would rather donate peripheral blood stem cells or bone marrow.

Donating peripheral blood stem cells involves having blood stem cells taken from a vein in your arm using a cell separator machine (this is known as ‘apheresis’). This usually takes place in a private hospital in Newport.

What happens before I donate?

A registry nurse will arrange to meet you to explain everything about donating blood stem cells and answer any questions you may have. It is a good idea to have a relative or friend with you at counselling for support.

If you agree to be a donor, you will need to sign a consent form to confirm this. We will then arrange for an independent doctor to examine you to make sure you are fit enough to undergo the procedure. This will include a full physical check-up as well as some blood and urine tests. You will also have a chest X-ray and an electrocardiogram (ECG) to check your heart.

The doctor will also assess whether your veins are suitable for the procedure. If your veins are not suitable, donating peripheral blood stem cells would not be an option for you.
If you can donate peripheral blood stem cells, you will need to start a course of injections four days before you donate your stem cells.

**What are the injections?**
The drug we use is called Granulocyte Colony Stimulating Factor (G-CSF). This is prescribed by our medical consultant. This drug is similar to a chemical produced naturally in the body and it makes the bone marrow produce more blood stem cells, which then spill over into the bloodstream so we can collect them. You will need to have these injections for four or five days in a row before the donation procedure. A nurse from Healthcare at Home usually gives the first three injections and a registry nurse will give the fourth injection.

**Are there any risks or side effects of G-CSF?**
G-CSF often causes side effects. Most people experience some mild to moderate bone pain in the breastbone (sternum), lower back, arms and legs because of the drug stimulating the bone marrow. Taking paracetamol usually reduces the pain. It is normal to get flu-like symptoms, including weakness, aching muscles, tiredness, headaches and a mild fever. Other side effects include insomnia (difficulty in sleeping), loss of appetite, nausea (feeling sick), vomiting, diarrhoea, nosebleeds or inflammation (redness and swelling) and itching at the area where the needle was inserted. Rare side effects include urinary problems (pain when passing urine, or blood in your urine), a low platelet count (platelets are blood cells that help stop bleeding), low blood pressure, osteoporosis and worsening of rheumatoid arthritis. Most symptoms usually disappear within 24 hours of stopping the injections.

Do not take aspirin or medicines containing aspirin from two weeks before the start of the first injection and for two weeks after your donation.
Some rare side effects can be serious.
G-CSF injections can sometimes make the spleen (an organ in your abdomen) grow larger. Very rarely this can result in the spleen bursting and causing internal bleeding. You may need to have an operation and the G-CSF would be stopped. If you have abdominal pain (usually under the left ribcage), dizziness and palpitations, or shoulder pain, you should tell us immediately.

Very rarely, people have had severe allergic reactions to G-CSF. You must go to hospital immediately (or dial 999) if you get a rash over your body, itching, swelling (of your body or your lips), feel very dizzy or find it difficult to breathe.

Healthcare at Home provide a 24-hour on-call service while you are having the G-CSF injections. They will give you the numbers to contact in an emergency.

Based on the information available about healthy people who have received G-CSF, no long-term risks have been found so far. If you agree, we will take blood samples from you for up to two years. The registry nurse can discuss this more fully with you.

Important information about pregnancy
We do not know if G-CSF can harm an unborn baby. To prevent pregnancy use a reliable method of birth control, such as condoms used with a spermicide, or the contraceptive pill, from the time you first meet the registry nurse to six weeks after your donation. You can discuss this in more detail with the nurse. You may need to have a pregnancy test before you start the G-CSF injections.
Will it hurt?
The G-CSF injections may sting slightly.

When you donate peripheral blood stem cells, you may feel uncomfortable when the needles are put in your arms. This should not feel any worse than when donating your usual pint of blood.

During the apheresis procedure (see ‘What happens on the day I donate?’ on page 5), you may feel light-headed or experience chills, numbness around your lips, face or fingers, or you may have cramps in your hands.

Please let the person who is looking after you know if you have any of these symptoms.

Where do I need to go to have the injections?
You can have the first three injections of G-CSF in your home or at work. The fourth injection, will take place at either the collection centre or at the Welsh Blood Service in Llantrisant. This is because we need to take a blood sample to check how well your bone marrow is responding to the G-CSF before we give you the fourth injection.

Where do I need to go to have the procedure?
The procedure will usually take place in a private hospital (normally Newport). It is usual to be admitted to hospital the day before the procedure.

What should I take into hospital?
You should bring the following things.

• A dressing gown
• Slippers
• A hairbrush
• Toothbrush and toothpaste
• Magazines or books
• Any medicine you are taking
• A letter from our registry about going into hospital
You should wear comfortable clothing such as a sleeveless top, a top with short sleeves or sleeves that roll up very easily. This is because you will be having needles in both arms during the procedure and wearing a top that has long or tight sleeves could be uncomfortable or make it difficult to put the needles in your arms.

**What happens on the day I donate my blood stem cells?**

On the day you donate, a doctor or nurse will explain the procedure in more detail. If you have any questions, please ask the staff, who will be pleased to answer your questions. They will then ask you to sign a consent form agreeing to have the procedure.

We collect stem cells from your blood by a procedure called apheresis. First, the nurse places a sterile needle into a vein in each arm. Blood is then removed from a vein in one arm and passes through plastic tubes into the cell-separating machine. The machine separates the stem cells from the rest of your blood. Your stem cells are collected into a bag, and the rest of your blood is given back to you using the vein in your other arm.

It can take between four to six hours to collect the cells. Sometimes you may need to stay until the next day for another collection. However, if a second collection is not necessary, and as you do not need a general anaesthetic, you do not need to stay at the hospital overnight. In some cases, we can arrange hotel accommodation if you need it. **It is best not to drive home after the procedure because you may feel rather tired.** If necessary, we will provide transport for you to return home.

Occasionally, we may not be able to collect enough stem cells from you even after a second collection. In these circumstances, we may need to ask you to donate again at a later date.
What happens when I go home?
How long it takes to recover after the procedure is different for everyone. You may feel tired and have side effects from the G-CSF, so it may be best not to do much for about 12 hours after the procedure. Avoid lifting heavy objects or doing strenuous exercise during this time. It is best to leave the bandages on for a couple of hours to reduce the risk of bruising. Many people go back to work the next day, but you may find you need extra time off work.

One of our registry nurses will regularly contact you to check on your progress. If you have any problems, contact your GP or ask your registry nurse to refer you to one of our medical officers.

General questions

What are blood stem cells?
Blood stem cells are immature blood cells that are formed in the bone marrow (this is a spongy material found inside the bones, especially the pelvis). Stem cells develop to form three main types of blood cells – red blood cells that carry oxygen, white blood cells that fight infection, and platelets which help to stop bleeding. Your stem cells are constantly being renewed.

Why do I need to be a donor?
If a person’s bone marrow stops working properly, he or she can suffer from anaemia and infections and are likely to bleed more easily. The person may become very ill or even die. Sometimes the only way to cure the problem is to transplant healthy blood stem cells from a well-matched donor. If the transplant works, the patient’s bone marrow starts to produce new, healthy blood cells.
Can I change my mind about donating?  
Yes, you can change your mind. However, the person receiving your stem cells starts their treatment about 10 to 14 days before the transplant date. This treatment involves high doses of chemotherapy which is sometimes combined with radiotherapy. This helps to kill any cancer cells before the transplant, but also makes it easier for the transplant to work. The patient’s bone marrow can be permanently damaged by this treatment so it is important to have normal donor stem cells to give back once the treatment has started. If you change your mind before the patient starts this treatment, we can search for another donor. If the patient has already started treatment and you do not go ahead with your donation, the patient is put at considerable risk of dying as he or she needs a well-matched stem-cell transplant to survive.

Will I know who the patient is?  
No. We have a strict anonymity policy designed to protect you and the patient from potential problems. This means you will receive very little information about the patient. However, you can ask for a progress report on the patient’s condition if you want. Please bear in mind that he or she might not survive the transplant. Also, many transplant centres do not provide any progress reports and those that do often take many months to send us any information.

Am I covered if something goes wrong?  
We arrange insurance for all donors. It is not likely that anything will go wrong but, if anything does, please contact our registry office first so we can process your claim.

What happens if I have a problem before or after my stem cells are collected?  
We will contact you quite frequently. We will phone you about two weeks before the procedure to see if you have
any worries or problems, and we will contact you again seven days before the procedure. After you return home we will contact you regularly until you have made a full recovery. After this, we will contact you once a year for at least five years.

**Do I have to pay for any travelling or accommodation?**

We will give you an expenses form to claim back money spent on:

- travelling to and from our centre and to hospital;
- meals; and
- any hotel accommodation.

Also, if your employer does not make up the difference between any ‘sick pay’ and normal pay, you can claim for loss of earnings. Please ask the registry nurses for further details.

**Will I be asked to donate more than once?**

Our policy is that you can only donate to one patient. This means that once you have donated your stem cells we will remove you from our register. On some rare occasions, we may ask you to give a second donation. This second donation may be bone marrow, blood or special white cells called T-cells. T-cells are sometimes used to treat patients who become ill again after having had a transplant. To allow for the possibility of a second donation, we will ask you to wait one year before giving your next normal blood donation. You do not have to donate more than once to the same patient if you do not want to.

You could still donate to a family member if you wanted to.
3 Other information

Sometimes we may need to change the date of the donation several times, usually because of changes in the patient’s condition. This means that other arrangements, such as your medical examination, may also need to be changed. We appreciate that this may not be convenient, so please tell us if you have any problems.

You can start giving blood again about a year after your operation.

This booklet is a guide to what will happen when donating stem cells, but sometimes things may happen slightly differently. If you need any more information or have any questions, please contact one of our registry nurses on 0800 0187377 or 0800 815902 (this call is free).

Useful websites
Welsh Blood Service
www.welshblood.org.uk
Welsh Transplantation and Immunogenetics Laboratory
www.wbmdr.org.uk
Anthony Nolan Trust
www.anthonynolan.org.uk
British Bone Marrow Registry
www.blood.co.uk/pages/marrow_info.html