

Confirmatory typing

Blood sample confirmation
for possible donor/patient
stem cell match

WBM - 300 02/11



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Confirmatory typing

In the past you gave us a blood sample to join the Welsh Bone Marrow Donor Registry and you have been on our list of volunteer stem cell donors ever since. A hospital has asked for you to give another blood sample because you are a possible match for a patient who needs a transplant of stem cells (see 'general questions' for more details about stem cells). You may be one of several people who are a likely match at this stage.

The next step is to give a blood sample for confirmatory typing. If you want to do this, we will arrange to take the samples from you.

What is confirmatory typing?

The confirmatory typing sample is used to decide which person is the closest match for the patient. It can take up to eight weeks or even longer for the doctor to decide which person would be best. This may be because they have asked for samples from a large number of people, or because the doctor is assessing whether the patient is still suitable for a transplant. As soon as we hear from the hospital, we will let you know whether you have been chosen. While you are waiting for the results of this confirmatory test, please do not give blood because this may mean the patient has to wait longer for you to donate your stem cells if you are chosen.

What happens if I am chosen?

If the confirmatory typing shows that you are the best match for the patient, you will be chosen to donate your stem cells. If you want to go ahead, a registry nurse will meet you to explain everything about donating 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 are willing to go ahead with the donation, we will ask you to sign a consent form to confirm this. We will then arrange for an independent doctor to assess you to make sure you are fit enough to undergo the procedure. This assessment will include a full physical check-up as well as blood and urine tests, a chest X-ray and an electrocardiogram (ECG) to check your heart.

The doctor will also assess whether your veins are suitable for the peripheral blood stem procedure. If your veins are not suitable, donating peripheral blood stem cells would not be an option for you.

There are two ways of donating stem cells for a transplant – having them taken straight from the bone marrow (donating bone marrow) or having them taken from the blood (donating peripheral blood stem cells).

This information booklet will answer some of the questions you may have about these two methods. If you have any more questions or want more information, please contact one of our registry nurses on **0800 0187377 or 0800 815902 (this call is free).**

Donating bone marrow

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Donating bone marrow is a way of donating stem cells. We collect the stem cells direct from the bone marrow. A sterile needle is inserted in your pelvis and the marrow is sucked out using a syringe attached to the needle.

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To donate bone marrow, you will usually need a general anaesthetic. However, another option is to have a spinal anaesthetic. The operation will usually take place in a private hospital (normally Cardiff or Newport).

Are there any risks or side effects?

As with any procedure involving a general anaesthetic, there is a small risk. The doctors will check that you are fit enough to have the surgery.

Some people develop mild anaemia after donating bone marrow because we could collect the equivalent of up to three pints of blood. Developing anaemia may cause dizziness, fainting, weakness or tiredness. You may also experience palpitations (a fast heartbeat). This should get better soon because bone marrow quickly replaces itself.

Will it hurt?

After the operation, you may feel sore, uncomfortable or have an ache in your back. These symptoms normally take one week to disappear. Paracetamol or other mild painkillers usually get rid of the pain or discomfort.

What happens when I go into hospital?

You will go into hospital the day before your operation. This is so that the doctor and anaesthetist can check again that you are fit enough to donate. The staff in charge of your care will explain all the procedures. If you do not understand anything or have any questions, please ask the doctor or nurse. They will ask you to sign a consent form agreeing to donate your bone marrow.

Usually you will have to stop eating six hours before your operation, but you may be allowed small amounts of clear non-alcoholic fluid, such as water, up to three hours before your surgery. (The nurses caring for you will give you specific advice). This lessens the risk of you being sick while you are unconscious from the anaesthetic. On the morning

of your operation, the nurses will ask you to have a shower or bath and will give you a gown to wear.

You will also need to wear some special tight 'stockings' that help reduce the risk of blood clots forming in the deep veins of your legs. You may then be given a 'pre-medication' tablet or injection to help you relax and make you feel sleepy. After this, you will need to stay in bed and use the 'nurse call' system if you need anything.

The operation usually starts between 8am and 9am, but sometimes can be later in the day. Shortly before your scheduled operation time, a nurse or porter will take you to the anaesthetic room where the anaesthetist will give you the general or spinal anaesthetic. Once the anaesthetic is working, you will be placed face-down on the operating table. This operation is carried out either by two doctors or one doctor and a specially trained nurse.

What happens when the operation is over?

After the operation you will spend a short time in the recovery room before being taken back to your ward. You may feel slightly cold, have some pain or may feel or be sick. Please let the nurses know if you are in pain or feel sick, because they can give you some medication to lessen the symptoms. You will probably feel quite sleepy at this stage. You may also have a sore throat. This is because the anaesthetist puts a tube into your windpipe to allow you to breathe while you were under the anaesthetic. Nurses on the ward will regularly check your pulse, blood pressure, temperature and your dressings.

You can start drinking as soon as you feel well enough and the nurses looking after you tell you it is OK. Until you are drinking, you will have a 'drip' to stop you getting dehydrated. Once you are drinking enough without being sick, you will be offered a light meal. You should be able to eat normally after three to six hours.

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Usually you will be able to go home the day after the operation and, in certain circumstances, the doctor may be happy for you to go home the same day. You should not drive home. If necessary, we will provide transport for you to return home.

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Donating peripheral blood stem cells

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, you will need to have a course of injections before you donate your blood 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 stem cells, which then spill over into the bloodstream so we can collect them.

Are there any risks or side effects of G-CSF?

G-CSF injections often cause side effects. Most people experience some mild to moderate bone pain in the breastbone (sternum), lower back, arms and legs. Taking paracetamol usually reduces the pain. It is normal to get flu-like symptoms such as weakness, aching muscles, tiredness, headaches and a mild fever. Most side effects will disappear within 24 hours of stopping the injections.

Based on information available about healthy people who have received granulocyte, no long-term risks have been found so far. If you agree, we will take blood samples from you for up to two years. A 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, you may feel light-headed or experience chills, numbness around your lips, face or fingers, or you may have cramps in your hands.

Where do I need to go to have the G-CSF injections?

You can have the first three injections of G-CSF in your home or at work. The fourth injection will take place either at 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 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 clinic 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 ask you to donate again at a later date.

General questions

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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 they 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

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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 accomodation?

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 nurse 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, peripheral blood stem cells, 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.

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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

