Donating bone marrow

Answering some of the questions you may have about donating bone marrow to the Welsh Blood Service
Donating bone marrow

You recently gave us 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 bone marrow. We have also included another booklet on donating peripheral blood stem cells. This is to help you decide whether you would rather donate peripheral blood stem cells or bone marrow.

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).

What happens before I donate?
We will arrange for a registry nurse to meet you to explain everything about donating bone marrow and answer any other 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 an independent doctor to assess whether 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.

What is an anaesthetic?
We use anaesthetic to temporarily reduce or take away feeling so that we can carry out procedures or surgery that...
would otherwise be painful. It makes you temporarily unconscious (in the case of a general anaesthetic) and the dose you are given is carefully controlled by the anaesthetist. During your general or spinal anaesthetic, your anaesthetist will give you many different sorts of drugs. Some take away pain, some block certain reflexes, some make you sleepy and some stop you feeling sick.

**Why does the anaesthetist need to ask so many questions?**
Everyone is different and your anaesthetist will choose the anaesthetic to suit you. Each anaesthetic is carefully tailored to your health and the surgery you are having. The anaesthetist needs to know a great deal about your previous health, any medicines you take, whether you drink alcohol or smoke, whether you are allergic to any medicines and how any anaesthetic you have had before affected you. If you do smoke, you should stop smoking for at least two days before you go into hospital. You cannot smoke in hospital.

**Are there any risks or side effects?**
Some people develop mild anaemia (not having enough red blood cells) after donating bone marrow because we could collect up to the equivalent of 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 uncomfortable or have an ache in your back. These symptoms normally disappear over the next week or so. Paracetamol or other mild painkillers usually lessens the pain or discomfort. Long-term back problems are unusual.
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
• Bathroom towels and toiletries

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 if you 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.

**How do you take my bone marrow?**

Once the anaesthetic is working, you will be placed face-down on the operating table. Two doctors (or a doctor and a specially trained nurse) will take the bone marrow from both sides of the back of your pelvis at the same time. A special sterile needle is pushed through the skin, through the bone and into the marrow cavity. The bone marrow is then taken using a syringe attached to the needle. It is collected in a bag similar to that used when you normally give blood.

The operation will last between one and 1½ hours and we will take up to 1½ litres (about three pints) of bone marrow. Although this sounds a lot, your body has enough reserves of bone marrow and should replace it quickly. If you had to give a unit of blood, the doctors will give it back to you during the operation or when you are in the recovery room.

**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, while you were under the anaesthetic, the anaesthetist puts a tube into your windpipe to allow you to breathe. Most people find this soreness goes away within one or two days. 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...
dehydration. 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.

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.

**What happens when I go home?**

When you leave hospital, you will be prescribed painkillers and sometimes iron tablets. Iron tablets can cause constipation, or you may need to go to the toilet more often. They can also make you feel sick. Taking the tablets with food or after a meal may help reduce these effects. Please read the information leaflet that comes with the tablets. Please tell us if you feel dizzy or short of breath, or if you have any concerns or questions.

It is also important to consider your diet and include foods rich in iron such as: red meat; liver; kidney; black pudding; corned beef; oily fish; eggs; Oxo cubes and Bovril; cereals with added iron; wholemeal bread; baked beans; lentils; kidney beans; nuts – especially almonds, cashews, brazils and walnuts; dried fruit – especially apricots, figs and dates; green vegetables including watercress and spinach; curry powder; cocoa; and chocolate.

You should also eat foods rich in vitamin C to help your body absorb the iron, such as vegetables, salad, fruit and orange juice.

On the day after your operation, you can remove the dressings covering the sites where the needles were put in, if the dressings are dry. You should tell us if you have any concerns.

How long it takes to recover from an anaesthetic is different for everyone. You may find that you get tired.
more easily for the first week or two. You can expect to have up to a week off work, although sometimes you may need longer to recover. You should avoid lifting heavy objects, strenuous gardening or exercise for up to a week after the operation. You may need longer to recover.

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 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 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 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.
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 nurse 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