



Human Tissue Authority

Information about donating bone marrow
and peripheral blood stem cells

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If you, or a member of your family, are considering donating bone marrow or peripheral blood stem cells (PBSC), this leaflet will give you information about the role of the Human Tissue Authority (HTA) in the assessment process. Peripheral blood stem cells are cells found in the bloodstream which are able to develop into all of the different cell types in blood.

This leaflet provides details about:

- the law relating to donating bone marrow and PBSC;
- the role of the HTA, which regulates these donations;
- who can become a donor; and
- the HTA assessment process that the donor and the person who needs the transplant (the recipient) need to go through before the donation can go ahead.

It is important that you read this leaflet, together with the other information you receive from the transplant unit. That way, you will know exactly what is involved for the donor (or the person acting on their behalf), and the person who will be receiving the transplant.

The Human Tissue Act and the role of the Human Tissue Authority

In England, Northern Ireland and Wales, donating bone marrow and PBSC is regulated by the Human Tissue Act 2004 (HT Act). In Scotland, bone marrow donated by children is regulated by the Human Tissue (Scotland) Act 2006. Both these laws reflect improvements in good practice, particularly in relation to getting people's consent (or permission) before donation.

We, the HTA, provide advice and guidance about the HT Act and make sure that people follow it. Our aim is to create a framework for donation that is clear and that patients, families and professionals have confidence in. We are made up of both lay members (members without a professional interest) and professional members.

We are responsible for approving all donations of bone marrow or PBSC from children and adults who do not have the ability to make an informed decision. These children or adults are not able, for whatever reason, to agree to the donation.

Donations of bone marrow and PBSC by children and adults who are able to give their consent are approved locally by the hospital and not by us.

Why donate bone marrow or PBSC?

People with serious illnesses such as cancer or leukaemia usually receive chemotherapy or radiotherapy as part of their treatment. As well as destroying the cancer cells, this treatment may damage their bone-marrow stem cells. Transplants of normal stem cells from bone marrow or peripheral blood allow doctors to give much bigger doses of drugs and radiation to these people. The donated stem cells 'rescue' the patient. Also, the transplant may produce immune cells which help to keep the patient in remission (this is when the patient does not currently have cancer).

Who can donate bone marrow or PBSC?

Bone marrow and PBSC can only be taken from living donors. The most suitable donor is usually a close relative, such as a brother or sister. There is a one-in-four chance of a brother or sister being a good match.

If a brother or sister is not a suitable match, it is sometimes possible to get a match from a donor who is not a relative. However, to help reduce complications from the transplant, a donor who has a similar genetic make-up to the recipient is preferred.

It is important that you fully understand the procedures and risks associated with donating bone marrow or PBSC before the transplant goes ahead. Your local transplant centre will be able to give you more information about this so that you know exactly what is involved.

Consent

We must make sure that the donor has given their consent for the donation to take place.

If a child is not able to give their consent, someone will need to act on their behalf to agree to the donation. This is likely to be the child's parent or parents. If there is any dispute as to the child's best interests, the matter should be referred to a court for approval.

In the rare case of an adult not being able to give their consent, the law says that a court must say whether the donation can go ahead.

Assessment process

Before a transplant can take place, the donor and recipient must be thoroughly assessed to make sure that this is a suitable treatment for the recipient, and that there is not unnecessary risk for the donor. This includes medical testing, checks to make sure that they are compatible, and discussions about the risks and benefits of the procedure.

In the case of child donors, it is important that they understand the information to a level that is consistent with their age. For younger children, this process may involve a session with a play therapist. If the child is too young to understand information about the donation, the person acting on their behalf (usually their parent) must fully understand the procedure and risks.

Both the donor and the recipient are free to withdraw from the procedure at any time during the assessment period, and up until the time that treatment begins.

Any possible donor who is not able to give their consent must be interviewed by a local Accredited Assessor (AA) who can recommend whether or not we should give approval for the donation to go ahead. The AA acts as our representative and should not be one of the doctors or nurses who are responsible for the donor and recipient. The AA will interview the donor, or the person acting on behalf of the donor, to make sure that they understand what is involved in the donation.

The AA must make sure that:

- a registered medical practitioner has explained to the donor (or the person acting on behalf of the donor) the nature of the medical procedure, the risks involved and the effects on the family;
- the donor (or the person acting on behalf of the donor) understands the information provided by the registered medical practitioner, and agrees to their bone marrow or PBSC being removed;
- the donor (or the person acting on behalf of the donor) gave their permission freely; and
- the donor (or the person acting on behalf of the donor) understands that they are entitled to withdraw their permission at any time, and understands what this will mean for the recipient.

Reward

The AA will give us a report to review. We must be satisfied that the donor (or person acting on behalf of the donor) is not under any pressure to donate and they have given their consent freely. In other words, we need to be satisfied that there is no evidence of inappropriate reward affecting the donor's (or the person acting on behalf of the donor's) decision to agree to the procedure.

If you are acting on behalf of a donor, it is important to understand that while it may be normal to offer a child a reward to make up for an unpleasant experience – like going into hospital or undergoing a painful procedure – a reward must not be used to persuade the child to agree to the procedure.

It is difficult to define what might be an appropriate reward for a child, as this is likely to vary considerably between different families and different cultures. Some rewards may influence the decision of the donor and so persuade them to donate. We will not approve a donation where there is evidence to suggest the donor has not given their consent freely. If you are not sure, you should discuss this with the transplant coordinator at the hospital you are going to, or with the Accredited Assessor.

Note

It is a criminal offence to carry out a transplant operation between two living people if the conditions of the HT Act are not met. This includes consent being given by the donor and recipient. It is also an offence to be involved in buying or selling human tissue to be used in a transplant, or in advertising the buying or selling of human tissue. The penalty for these offences is a prison sentence of up to three years, or a fine, or both.

More information

This leaflet is a guide only. For more information about us or the HT Act, visit www.hta.gov.uk or contact:

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This leaflet is available on our website in Welsh, Urdu, Gujarati, Punjabi, Hindi and Bengali.

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