



OrganDonation

Teaching Resource Pack



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The British Transplantation Society

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	Page
Introduction	1
Guidance for Teachers	3
Transplantation Milestones	5
Transplant Laws in the UK	7
The Need for Transplants	12
Statistics	20
Transplantation Process	22
Donor/Recipient Stories	29
Ethical Dilemmas	39
Religious Views	42
The Future	44
Some Common Questions and Answers	47
Activity Sheets	55
Personal Reflections	62
Glossary of Terms	65

Introduction

These resources have been written as a response to a recommendation made by the Scottish Transplant Group. This Group began meeting in February 2001. Its remit is to give advice and make recommendations to the Scottish Executive on matters relating to organ donation and transplantation, this being an area in which Health Ministers both then and now have shown particular interest. It soon became very clear to the Group that raising awareness about organ donation and transplantation was crucial and that education has a vital role in this process of awareness, particularly in the context of young people. The concept of the teaching resource pack was endorsed by the then Education Minister.

The need for donor organs is expected to increase as transplant surgery becomes increasingly common and more successful. However, transplantation is strictly limited by the number of available organs, and this is influenced by several factors:

- improved management of patients with brain haemorrhage or head injury;
- more people involved in car accidents are surviving;
- dramatic decrease in road traffic accidents.

This is all good news, but the consequences are that not enough organs are available for transplantation, and the waiting lists are increasing.

The content of the pack is in keeping with the National Priorities. The Scottish Executive has identified five National Priorities which all Education Authorities must address in its Improvement Plan. The fourth National Priority is in the context of Values and Citizenship, and states that the Education Authority wants:

“To work with parents to teach pupils respect for self and one another and their interdependence with other members of their neighbourhood and society and to teach them the duties and responsibilities of citizenship in a democratic society.”

The materials within this resource pack address this National Priority by raising awareness of the issues within transplantation and organ donation for our society today.

The general public has mostly positive views about organ donation, but often these do not translate into communication of their wishes to their loved ones, joining the NHS Organ Donor Register, or carrying a donor card. There is also a perceived general lack of knowledge amongst the general public about key concepts in organ donation and transplantation.

Apart from its intrinsic value as a teaching resource for both Personal and Social Education (PSE) and Religious, Moral and Philosophical Studies (RMPS), the development of this pack has the potential, in time, to create a generation who can make informed choices about organ donation. These materials therefore are written to create awareness, to impart information, and to encourage discussion on the ethical issues around organ donation and transplantation. It is then for young adults to make informed choices.

Knowledge and information should also reduce any possible fears and confusions which may persist around these issues.

These materials have been written with the collaboration of:

- Scottish Executive Health Department;
- NHS UK Transplant;
- British Transplantation Society;
- transplant co-ordinators;
- surgeons and physicians;
- Scottish Executive Education Department;
- Scottish Health Promoting Schools Unit.

Aims

- To create awareness in senior school pupils of matters related to organ donation and transplantation.
- To discuss ethical issues surrounding organ donation and transplantation.
- To be aware of work currently being done in transplantation and of future developments.
- To empower young people to be able to make informed choices about organ donation and transplantation, from a knowledgeable context.

Guidance for Teachers

The aim of the materials in this pack is to educate young people on the issues surrounding organ donation and transplantation, not to promote the subject or pressurise them into consent or participation. Young people and adults, throughout their lives, are faced with choices about a whole range of issues. These materials are designed to enable informed, educated choices in this very important area for our society.

The materials can be used with senior pupils as part of their core RME or PSD programmes. They can also be used with certificate classes who are studying the following SQA Courses or Units in the RMPS:

- Intermediate 1 Medical Ethics
- Intermediate 2 Medical Ethics
- Advanced Higher Prolongation of Life

Teachers should ensure they are working from the most recent SQA RMPS arrangements and that they follow the correct assessment procedures as required by the SQA.

The materials are also designed for use in the Senior School Personal, Social Education Programmes (PSE). The resources aim to be as contemporary as possible, but inevitably by their very nature these issues are changing as medicine and science progress. It would therefore be important for teachers to 'keep up to date' by referring to the appropriate websites mentioned in the resources. It would also be important to check for the most recent statistics and data.

The resources are designed to bring out the issues which lie behind organ donation and transplantation. Teachers would not necessarily use all the units, but rather exercise their professional discretion to select appropriately according to the educational need and timescale allowed.

Methodologically, the aim is to stimulate discussion and informed debate. The units are designed to encourage:

thinking

enquiry

analysis/evaluation

reflection

expression

The pupils should be encouraged to form their own opinions through a process of personal search, while at the same time appreciating other opinions which come from an equally well-informed position.

The importance of these resources and the implicit methodology cannot be overstated. As citizens, young people, like all of us, are required to make decisions. Sometimes these are decisions which make the difference between life and death. Clearly this is the essence of organ donation and transplantation. However, it is virtually impossible to develop the ability to express ideas and engage in the critical thinking that leads to decision making without first establishing a firm basis in relevant knowledge and understanding. Students need to be encouraged therefore not only to acquire and retain knowledge but to appreciate the importance of knowledge and evidence as the basis for expressing and justifying their opinions. It is hoped that these resources will go some way to help in this process of informed decision making in this highly important and sensitive area.

The video prepared as part of the pack provides real life stories concerning organ donation and transplantation, and is intended to be used as a general introduction.

A glossary has been included covering the medical terms used in this pack.

Anyone wishing to contact the local transplant co-ordinator or wanting further information should contact the Communications Directorate, NHS UK Transplant tel: (0117 975 7575).

Transplantation Milestones

4/5



History of Transplantation

Aim

To create awareness of the history of transplantation and its development to the present day.

About Transplantation

Organ donation and transplantation is the process of removing an organ from one person and implanting it in another. The organ being removed must be donated ('gifted'). Following a transplant about 2,700 people take on a new lease of life in the UK every year.

Kidney transplants are the most commonly performed. Transplants are regularly carried out on the heart, liver, lungs and pancreas.

Tissue such as corneas, heart valves, skin, bone and tendons can also be donated and transplanted.

Today more than 5,500 people in the UK are waiting for an organ transplant that could save their life or dramatically improve their quality of life.

Transplants are one of the most miraculous achievements of modern medicine. However, they depend on the generosity of donors and their families.

The increasing effectiveness of transplantation means that many more patients can be considered for treatment. More people also need a transplant, but there is a serious shortage of donor organs. For some people this means waiting, sometimes for years, and undergoing difficult and stressful treatment. For all too many it means they will die before a suitable organ becomes available.

Transplantation Milestones

- 1902 Alexis Carrel demonstrates method of joining blood vessels to make organ transplant feasible.
- 1905 First reported cornea transplant takes place Olmutz, Moravia (now Czech Republic).
- 1918 Blood transfusion becomes established.
- 1948 Foundation of the National Health Service.
- 1954 First kidney transplant operation performed in USA.
- 1960 First successful living donor kidney transplant performed in UK.
- 1963 First liver transplant.
- 1965 First kidney transplant in UK using organ from a person who has died.
- 1967 First heart transplant operation performed by Dr Christian Barnard in South Africa.
- 1968 First heart transplant in UK.
- 1968 First liver transplant in UK.
- 1968 National Tissue Typing and Reference Laboratory (NTTRL) established at Southmead Hospital, Bristol.
- 1971 Kidney donor card introduced in UK.
- 1972 National Organ Matching and Distribution Service (NOMDS) founded in Bristol.

- 1979 NTTRL and NOMDS merge to become UK Transplant Service.
- 1980s First transplant co-ordinators appointed.
- 1981 UK kidney donor card changed to multi-organ card including kidneys, corneas, heart, liver and pancreas.
- 1983 Launch of the UK Cornea Transplant Service (CTS).
- 1983 First combined heart and lung transplant in UK.
- 1985 Lungs added to the UK donor card.
- 1986 First lung-only transplant in UK.
- 1986 Establishment of the Bristol Eye Bank.
- 1987 First 'domino' UK heart transplant, where the patient receiving a heart and lung transplant donated their healthy heart to another.
- 1989 Establishment of the Manchester Eye Bank.
- 1991 UK Transplant Service becomes special health authority and is re-named United Kingdom Transplant Support Service Authority (UKTSSA).
- 1994 NHS Organ Donor Register established.
- 1994 First living donor liver transplant in UK.
- 1995 First living donor lung lobe transplant in UK.
- 2000 NHS UK Transplant takes over from UKTSSA with new, extended remit.

Transplant Laws in the UK



Aims

- To make pupils aware of the present legislation governing organ donation and transplantation.
- To consider potential changes in the law to fit in with a European context.
- To raise discussion on some moral issues within each position.

Legislation

Two key laws govern organ donation and transplantation:

- The Human Tissue Act 1961;
- The Human Organ Transplants Act 1989.

The Human Tissue Act

The Human Tissue Act 1961 defines how an organ and tissue donor is identified.

The Act states that if a person has expressed a wish in writing, or orally in the presence of two or more witnesses during his or her last illness, that their body or any specified part may be used after death for therapeutic purposes or for medical education or research, the person lawfully in possession of their body may, unless there is reason to believe the request was subsequently withdrawn, authorise removal from the body of any part, in accordance with the request.

At present, a person must express their wish to be a donor in writing or verbally to two or more witnesses. This system is commonly known as 'opt-in'. A person who wishes to 'opt-in' puts his/her name on the NHS Organ Donor Register, maintained by NHS UK Transplant. This is a national, confidential list of people who are willing to become donors after their death. It can be quickly accessed by transplant co-ordinators to see whether an individual has expressed willingness to be an organ donor.

If there is no evidence of such a wish, the person lawfully in possession of the body may still authorise the removal of any part from the body

provided that, after making reasonable enquiries, he/she has no reason to believe that the deceased had expressed an objection or that the surviving spouse or any surviving relative objects.

The Human Organ Transplants Act

The Human Organ Transplants Act 1989 makes any commercial dealings in human organs for transplant a criminal offence.

It is also an offence to advertise the buying or selling of organs or to withhold information required by law about transplant operations. The Act also makes it illegal to transplant an organ removed from a living person unless the donor and recipient are genetically related.

The legislation was accompanied by The Human Organ Transplants (Unrelated Persons) Regulations 1989 which, subject to certain conditions, allow donation between donors and recipients who are not genetically related. This might include, amongst others, partners, husbands and wives.

The Unrelated Live Transplant Regulatory Authority (ULTRA) was established by the 1989 Regulations and its role is to be satisfied that certain conditions have been met before transplants between persons who are not genetically related will be allowed. It is concerned to ensure that no payment or inducement has been made or offered, and that no pressure has been put on the donor. The Authority will also want to be certain that an independent doctor (that is one not involved in the transplant) is satisfied that:

- no payment is involved;
- the case is being referred by the doctor with clinical responsibility for the donor;
- the donor is aware of the nature of the operation and the risks involved;
- the donor's consent was not obtained by coercion or the offer of an inducement;
- the donor understands that he or she can withdraw at any time before the operation.

Further information on the legislation is available from:

www.uktransplant.org.uk

Millions of people carry donor cards which indicate a willingness to donate organs in the event of death. Carrying a donor card has no legal validity and does not allow organs to be retrieved automatically.

When a donor card or register enrolment form is signed it is also very important that close relatives or those closest are informed of this decision. Even if a name is on the register or a card is carried, relatives are still consulted; so it is important that they can provide information about the donor's

wishes. If the person who has died did not carry a donor card, or had not added their name to the NHS Organ Donor Register, their family will be asked what they think the person's wishes would have been.

No conditions can be made by the donor or their family about who they want to receive any organs donated. The organs are allocated to whoever is the best match throughout the country.

Discussion point

Should people be able to attach conditions to organ donation?



I request that after my death

A. any part of my body be used for the treatment of others , or

B. my kidneys corneas heart lungs
liver pancreas be used for transplantation.

Signature _____ Date _____

Full name _____
(BLOCK CAPITALS)

In the event of my death, if possible contact:

Name _____ Tel. _____

Remember to tell someone close to you that you want to be an organ donor. We'll need their agreement if the time ever comes.

Figure 1 – The Stages in Becoming a Donor



It cannot be overstated that an individual must communicate to their loved ones their willingness to donate organs in the event of their death.

There are many who believe that it is time to change the law from the 'opt-in' position.

Consider the various possibilities for discussion.

Compulsory Donation

Some would say that as the organs are of no use to an individual once dead, it should be mandatory that they are retrieved and used to save the lives of others.

Discussion point

Is it right that healthy organs are buried in the ground or cremated with the body if they could be transplanted?

'Opt-Out' (Presumed Consent)

Another argument put forward is that instead of 'opting-in' an individual would 'opt-out', that is someone's organs would be retrieved automatically unless he/she had indicated an unwillingness to donate organs after death.

There are two different forms of 'opt-out':

- a. organs are retrieved regardless of the wishes of the family, unless the person had registered an objection (hard opt-out);
- b. in the absence of any declaration from the deceased, the issue of donation would be discussed with the family (soft opt-out).

This is a very emotive subject, and bad publicity from families in such situations might affect the overall attitude of the public to organ donation and transplantation.

International Comparison

Currently there are 14 European nations operating under a system of 'presumed consent'.

- Austria
- Belgium
- Czech Republic
- Finland
- France
- Greece
- Hungary
- Italy
- Luxembourg
- Poland
- Portugal
- Slovak Republic
- Spain
- Sweden

Argentina, Brazil and Chile have transferred to this system as well. All of these nations have adopted the system of 'presumed consent' in the last 30 years.

Some, like France and Belgium, operate a soft 'opt-out' system, which requires that a reasonable effort be made to determine the wishes of the deceased (if not obvious) by conferring with family, friends or checking the register.

Required Request

This refers to a requirement for staff in intensive care environments *always* to ask the family for permission for organ donation when medical treatment has stopped and death has been confirmed by brain stem tests.

At present it is at the discretion of the medical staff whether to approach the family with a request for organ donation. There may have been occasions when organ donation was not considered, and families were not approached, therefore denying them the right to make a decision about organ donation.

In the USA it is the law that a request for organ donation must be made, if appropriate, after death.

All of these issues relate to 'cadaveric donation', the retrieval of organs from someone who has died. There is clearly the potential for tension between fulfilling the wishes of the person who has died, and respecting the feelings of the family, who have just lost a loved one.

Some organs can be donated by people who are still alive, and living donation is discussed in the section on kidney transplantation (page 16).

Tasks and Discussion points

- In your own words, state what the following terms mean: Opt-In; Opt-Out (Presumed Consent); Soft Opt-Out; Hard Opt-Out; Compulsory Donation; and Required Request.
- Discuss with your group possible problems associated with each of these positions eg, some believe that if they carry an organ donor card when admitted to intensive care, doctors will not treat them as well as they might in order to gain organs.
- Another problem to discuss is what rights do you have as a 'dead person'. Some believe that as you cease to exist, you have no rights. Others believe that you have the same rights as when alive. What do you think?

The Need for Transplants

12/13



People need transplants for many reasons. The most common of these are:

- disease;
- genetic disorder;
- accident;
- alcohol/drug abuse.

So what can be done? What can be transplanted?

ORGANS – kidneys, heart, lungs, liver, pancreas, small bowel

TISSUE – corneas, heart valves, bone, skin, connective tissue

- Heart and lungs need to be transplanted within 4-5 hours of removal from the donor.
- Ideally livers should be transplanted within 9-10 hours of removal from the donor and kidneys within 24 hours of retrieval.
- Tissue can be stored in special banks for various times.

How is transplantation organised?

When death has been confirmed in a patient who could be considered as a potential organ donor, the local transplant co-ordinator is contacted. The transplant co-ordinator checks the history of the donor to confirm that there are no medical or social barriers to donation. The co-ordinator also discusses the possibility of donation with the next of kin.

All patients who are waiting for transplants are registered on the National Transplant Database at NHS UK Transplant and a computer search is made to find the most suitable patients for the organs that have become available, a process known as 'matching'. Once the patients and their locations are identified, the doctors at those transplant units are alerted and asked to confirm acceptance of the organ. As they do so, the preparation of their patient for the transplant operation begins.

A team of specialists is called to the donor's hospital to carry out the surgery to remove and preserve the organs for transport to the transplant unit. If necessary, special transport arrangements, such as an ambulance with a police escort or a chartered aeroplane, will be made to ensure no time is lost.

It can happen that when a donor's organs are examined, they are found to be affected by disease or damaged in some way which makes them unsuitable for use. This will mean that a waiting patient's hopes are dashed, and that their wait for a transplant must continue.

More information on the way transplantation is organised is given in the section 'Transplantation Process' on page 22.

HEART TRANSPLANTATION

The Scottish Heart Transplant Unit was opened in December 1991 to provide heart transplantation services for the people of Scotland. Those who need a combined heart and lung transplant must go to Newcastle for their operation.

The heart pumps blood around the body to feed the cells with oxygen and nutrients.

Mr Andrew Murday, Transplant Consultant, Glasgow Royal Infirmary says:

“Each year in Scotland many thousands of people die from heart disease. A few of these can be saved by heart transplantation. Although most of the deaths from heart disease occur in older people, it can affect all ages. Some babies are born with abnormal hearts, a few children and teenagers develop heart muscle weakness, and as people get older they can have heart attacks and sometimes abnormalities of the heart valves.

For the majority, these conditions are treated with pills or conventional operations. When these treatments are no longer an option, then heart transplantation is sometimes all that is left.

Each year in the United Kingdom only about 200 heart transplants are carried out. The number of donor hearts that become available limits this number. The results are good. About 10 years after heart transplantation, more than half will still be alive, which is much better than the outcome if the same severity of heart failure is managed with other forms of treatment. We also know that the procedure dramatically improves people’s quality of life.

Some time in the future we may be able to use artificial hearts, or perhaps even hearts developed by biological engineering. Until then, heart transplantation will remain the only treatment option for a small but very sick group of people.”

LIVER TRANSPLANTATION

The Scottish Liver Transplant Unit (SLTU) was opened in November 1992 to provide liver transplantation services to the people of Scotland.

The liver is the largest organ in the body. It has many functions, the most important of which is making new proteins and processing waste products.

Liver transplantation is done for two major reasons:

- To treat the symptoms of chronic liver disease such as primary biliary cirrhosis.
- To increase the life span of a patient dying from either acute or chronic liver failure.

In many people's minds, liver disease is associated with alcohol-related problems. Scotland does have a reputation for 'hard drinking', but for many years this was not the major cause of liver disease – primary biliary cirrhosis was the most prevalent. However, recent analysis indicates that Hepatitis C (hepatitis caused by a virus) is becoming the more common reason for transplantation.

Drug abuse, too, can be a cause for liver failure, particularly an overdose of paracetamol.

There are many sensitivities and prejudices amongst the public on these cases - they present what we call 'ethical dilemmas'. There will be an opportunity to discuss these issues further on.

Dr Ken Simpson is a liver transplant physician at Edinburgh Royal Infirmary. This is how he describes his work:

"In general, physicians, as distinct from surgeons, treat patients with medicines rather than surgical operations. So we play no role in the technical aspects of the liver transplant operation. Our contribution to the assessment of a patient is to check what has caused the patient's liver disease and how bad the disease is, if there is anything else short of transplantation that can be done for them, do they have any other diseases or conditions that may make liver transplantation difficult or even dangerous? Following the operation we monitor for complications such as rejection and infection and treat them, if they occur, for the lifetime of the patient. Another important role is in the education of the patient and their relatives about liver disease and transplantation so they are able to make an informed choice about whether they would like the operation or not. Sometimes it can be very difficult telling a patient or their relatives that a transplant is inappropriate, as there is no alternative treatment, such as dialysis in the case of patients with renal disease."

KIDNEY TRANSPLANTATION

We have two kidneys situated just above the waist towards the back, one on each side of the spine.

The kidneys are vital organs in our bodies and when they fail (renal failure) people suffer tiredness, swelling, breathlessness, anaemia, anxiety and nausea. This in turn forces a complete change of lifestyle for the individual sufferers and their families. Many have to have dialysis. This artificially carries out the duties of a kidney in cleansing the blood. This can be done either at home or hospital – usually three times a week for 3-6 hour sessions.

Kidney Donors

There are two sources of kidneys for transplant:

- from a person who has died usually having suffered brain death as a result of an injury or brain haemorrhage;
- living kidney donation – usually from a family member/partner.

Mr John Forsythe, a consultant transplant surgeon, has this to say:

"I think those of us who work in the field of transplantation are very lucky. I am a surgeon, and can say that the operations involved in transplantation are very different to any other forms of surgery. Most of the time, surgeons remove organs or parts of organs from the body because they are diseased. In transplant surgery, we remove an organ from somebody who has donated it to a friend or relative, or from somebody who has died. We then transplant the organ into another individual who is in desperate need. The transformation is astounding. Quite often, I pass patients in the corridor two months after their transplant surgery. It is only when they stop me that I recognise them, because they look so different when they are healthy compared to when they were sick.

Unfortunately, I also see people becoming very ill and dying while waiting for a transplant. I know that a donated organ could save their lives.

Therefore I think it is very important that everyone who is involved in the field of transplantation makes an effort to let the general public know of the benefits of transplantation. I also know that the gift of donation at the time of tragedy can provide some comfort for a family who are trying to come to terms with losing someone they love.

It is also important to me that, if people have strong views against organ donation or transplantation, these are known to their family. I would never want to remove an organ from someone who did not want this to happen. We should provide information so that people can decide for themselves."

Mr Murat Akyol, a transplant surgeon for 22 years, who currently works in the Transplant Unit at Edinburgh Royal Infirmary, said this of his work:

"Performing a transplant is a gratifying experience, more so than any other surgical procedure, since it makes so much difference to a patient's quality of life or is indeed life saving.

It is also a uniquely humbling experience knowing that it relies on the courageous and generous gift of organs from a donor family."

Living Donor Kidney Transplant

In Britain about 1,500 kidney transplants are performed annually. The majority of these are from those who have been confirmed dead by brain stem tests (see page 24). This occurs most often in hospital intensive care units and often as a result of spontaneous brain haemorrhage or after a road traffic accident. These donors are called cadaveric donors. However, for many of the reasons studied already, there are too few kidneys available to help all those waiting on the list. In the future there will be more emphasis on increasing the number of living donor kidney donations to overcome this shortage.

In the 1990s living kidney donation in the UK accounted for only 10% of kidney transplants. It now accounts for more than 20%. In living donation, kidneys for transplantation come from living relatives or close friends. Since the make-up of the body within families can be similar, or, more rarely as in the case of identical twins, the same, there is a greater chance of a successful kidney transplant if the kidney donated is from a living relative. One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will hamper them in later life. A healthy person can live a completely normal life with only one kidney, lifestyle should not be affected and normal work can continue.

Children/Young People and Kidney Transplants

Children and young people who have kidney failure receive priority for transplantation.

Like adults, children sometimes have to go through other treatments while they wait for a transplant. This is called DIALYSIS.

Dialysis is a way of removing wastes and excess water from the body by using a filter.

There are two types of dialysis:

1 HAEMODIALYSIS

- Normally done in hospitals.
- Three times a week and lasts about 2-4 hours.

The patient's blood flows through the artificial filter by means of a machine. Needles (inserted into a specially enlarged blood vessel called a fistula, usually in the arm) take the blood to the machine and return it to the body.

2 PERITONEAL DIALYSIS

- Can be done at home, at work or if necessary at school and on holidays.
- Done during the day or by a small machine at night during sleep.

The peritoneal membrane is the lining of the abdomen surrounding and protecting many of the body's internal organs. It has a very rich blood supply, making it an ideal area in which to carry out dialysis.

Discussion point

Children/young people who are on dialysis, particularly haemodialysis, frequently miss school.

- What sort of problems do you think their high absence rate causes to these children?

Once transplanted, children can come off dialysis, but they will have to stay on a certain amount of drugs for the remainder of their lives. Sometimes there are initial side effects from the drugs such as weight gain or acne. If they stop taking the drugs their bodies will reject the new organ.

Discussion points

- Why do you think young people might stop taking their medication?
- How might the side effects of drugs make a young person feel?
- Is there anything the school community could do to help minimise the problems faced by these young people?

Ethnic Minorities

In the United Kingdom, the Asian, black African and black Caribbean populations have a high rate of diabetes and hypertension, diseases which can lead to organ failure. This means that Asian and black African/Caribbean people are three times more likely to need a transplant. At present nearly 400 black patients are waiting for a transplant; some of them are children.

When someone needs a kidney transplant, the doctors have to try and match, as far as is possible, the tissue of the patient with the tissue of the donor. The better the match, the better the likelihood of a successful transplant and the better the chance of the patient getting a new lease of life.

The reality is that it is more likely that a better match will be found among donors from the same population groups or ethnic groups. This makes it essential that there are people from all ethnic groups registered as potential donors, and in particular from the Asian, black African/Caribbean communities.

TISSUE DONATION

What is tissue donation?

Blood is a type of tissue that can be donated over and over again to save many lives. However, blood is not the only body tissue that can be donated.

Other tissue includes:

- skeletal bone;
- tendons;
- heart valves;
- bone marrow;
- skin;
- corneas.

The main differences between organ and tissue donations are:

- Tissue can be obtained from people up to 24 hours after their death.
- Tissue can be stored for much longer than organs. In fact tissue can be stored for up to 10 years in some cases.

Tissue donation is probably the least well known type of donation, as Elizabeth Melville, the tissue transplant co-ordinator in Edinburgh, describes:

“A lot of people don’t know about tissue transplant. It doesn’t grab the headlines like organ donation. But it’s not just organs that can be donated after death to help others live better lives. For example, if heart transplant is not possible, the valves inside the heart can be used to treat youngsters born with heart defects so that they can run around and breath properly. Tendons from the legs can be used to treat people with serious knee injuries so that they can walk again. Skin can be used to save the lives of people who have sustained severe burns and the corneas can be used to treat conditions or injuries that cause blindness. Some people are uneasy about all of this – they think it’s a bit morbid. But we have to look at the people whose lives are saved or substantially improved by these transplants.”

It’s very important that people discuss their wishes about donation with those close to them because it is the family who carry the responsibility for revealing the wishes of their loved one after death. It’s such a special gift, such a deep tenderness towards others at such a difficult time. It has been my privilege to witness this and the gratitude and joy of those, and their loved ones, whose lives are restored by it.”



In the UK during 2002:

- organs from 765 people who died were used to save or dramatically improve many people's lives through 2,334 transplants;
- a further 2,214 people had their sight restored;
- living donor kidney transplants increased by 4% (358 in 2001, 371 in 2002);
- the number of live kidney transplants doubled since 1997.

Updated figures can be obtained from www.uktransplant.org.uk

Discussion point

- How would you feel if you or someone you loved received a life saving organ?

More Facts

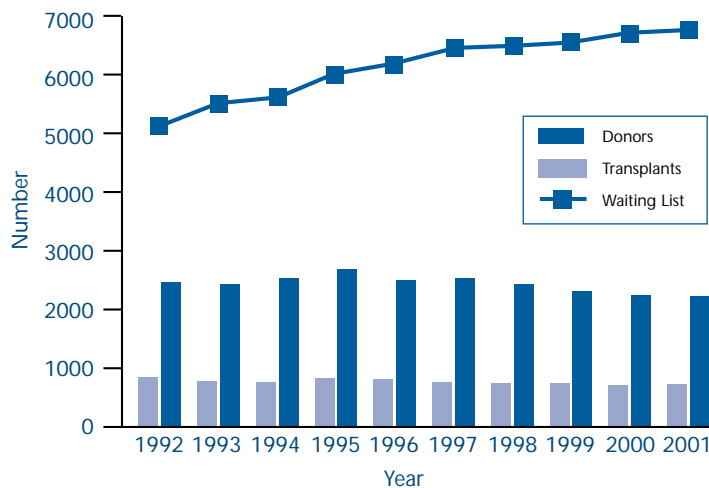
- 5,662 people are still actively waiting for transplants.
- In the UK, 235 young people under the age of 18 received a transplant in 2002.

Transplantation Process

22/23



Waiting Time to Transplant



Number of cadaveric donors and transplants in the UK 1992-2001 and patients on the waiting list at 31 December

We are dealing with a national shortage of organs. Patients must wait for an organ. Some will die waiting.

Does transplantation work?

Transplantation has been described as 'one of the great success stories of the latter half of the 20th century'.

Transplants are now so successful that a year after surgery:

- 95% of kidneys in living donor transplants are functioning well;
- 86% of kidneys from people who have died are still functioning well;
- 80% of the organs in liver and heart transplants are still functioning well.

When can organs be retrieved?

Although half a million people die every year, the majority of these are conventional deaths: there is no heartbeat, breathing stops and soon all other organs die, including the brain.

Confirmation of death by brain stem tests is a well established criterion throughout the world. Organs can be retrieved following confirmation of death by brain stem tests.

What is the brain stem?

The brain stem is located at the base of the brain and controls your breathing, blood pressure and other vital functions. Severe damage to the brain can cause the brain stem to die. This may be caused by an accident resulting in serious head injuries or by a brain haemorrhage or stroke. Brain stem death is diagnosed after satisfying strict medical pre-conditions. Two senior and experienced doctors, not involved in transplantation, perform five simple tests. The tests are performed twice.

(see diagrams on next page)

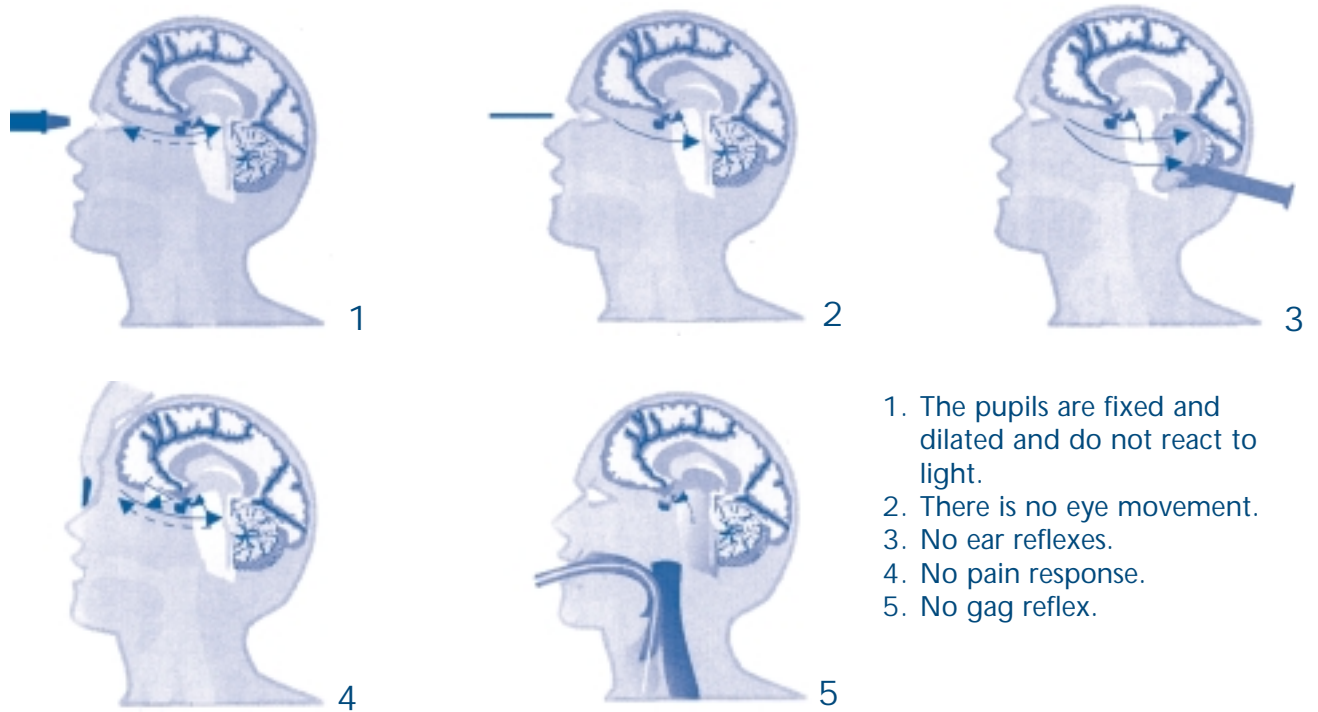
Once death has been confirmed by brain stem tests and organ donation has been agreed, a communication network is triggered, sometimes leading to consent for donation, but not always.

Average Waiting Times to Transplant – in Days

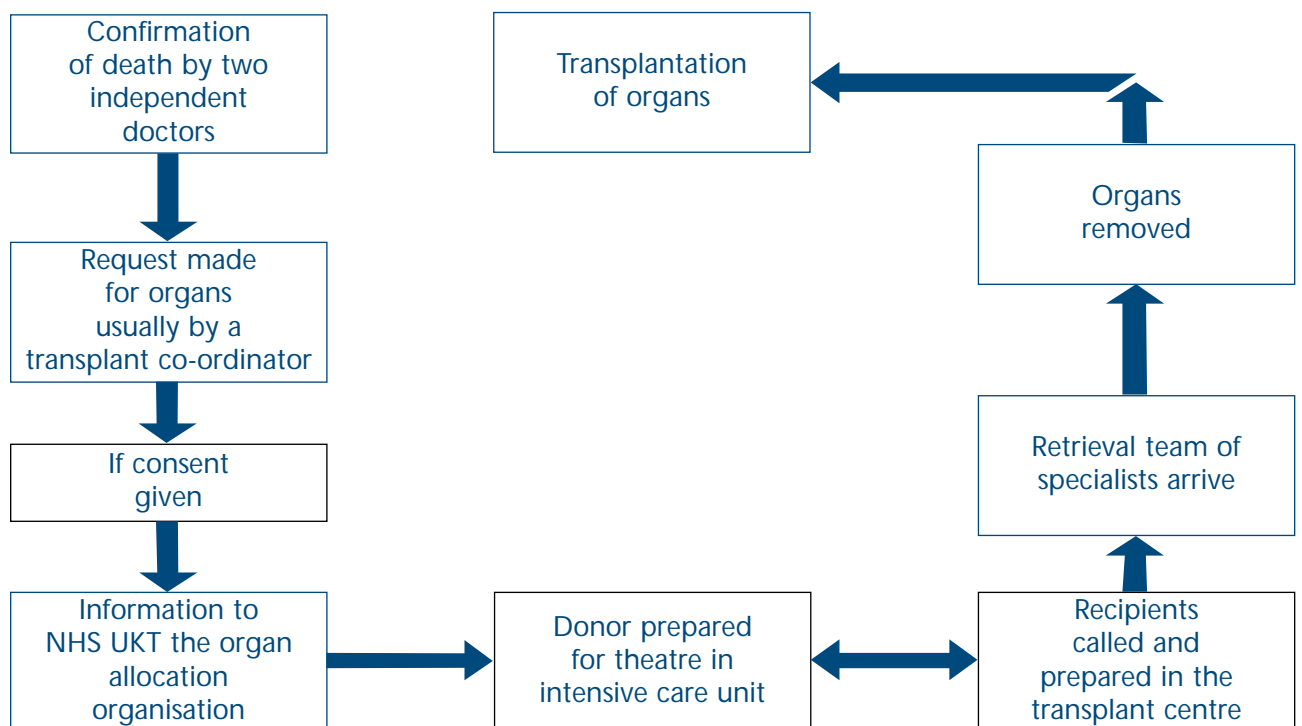
Organ	Adults	Children
Kidney	506	203
Heart	164	73
Lung	374	1,292
Heart/Lung	491	546
Liver	60	69

Remember, these are average times. It could be shorter or longer. The waiting time can be very stressful, as families and friends watch their loved ones deteriorate and suffer.

Brain Stem Tests



Process To Transplantation



So How are the Organs Allocated?

'I've heard people jump the queue if they are private patients.'

'I've also heard people jump the queue if they know or are related to the consultants.'

There are many stories, rumours and confused ideas about the allocation of organs. This is what actually happens.

Organ Allocation

The number of people needing organ transplants in the UK is greater than the number available. So there has to be a system to ensure that all patients are treated equally and that donated organs are allocated in a fair and unbiased way.

All patients who are waiting for a transplant are registered on the NHS UK Transplant National Transplant Database. A computer programme is used to identify across the UK the best match and the transplant unit to which the organ is to be offered.

The system of allocation differs according to the type of organ, whether it's a heart, lung, kidney, liver or cornea, but there are some guiding principles.

Patients waiting for a heart or liver who are classified as super urgent are given priority. This is because their life expectancy without a transplant can be measured in days or even hours. If there are no super urgent patients on the waiting list, the organ is offered to patients on the transplant list who are nearest in age and blood group to the donor. The location of donor and recipient is also considered to minimise the delay between retrieving and transplanting organs.

Children are given priority for kidneys because they tend not to thrive on dialysis and may suffer growth impairment. Organs donated from children generally go to child patients to ensure the best match in size but, when there are no suitable child recipients, organs from young people are given to adults.

When an organ becomes available anywhere in the country, the duty office at NHS UK Transplant is notified immediately. Staff search the national database to find out whether there are any super urgent cases, with blood group or age compatibility, in any of the transplant centres.

Sometimes there are no suitable patients anywhere in the UK but a reciprocal arrangement with the European Union enables donor organs to be offered to other EU countries.

Role of NHS UK Transplant

The ethical dilemmas on page 39 demonstrate clearly how organ donation and transplantation present challenging moral dilemmas. The allocation of organs is the responsibility of NHS UK Transplant, which was originally established in 1991 and is directly accountable to all UK Health Ministers.

The key role of NHS UKT is to ensure that donated organs are matched and allocated in a fair and unbiased way. Matching, particularly in the case of kidneys, is so important that donation and allocation need to be organised nationally. The larger the pool of organs, the better the likelihood of a good match.

NHS UKT is in a unique position in that it does not have a direct relationship with patients and does not provide 'hands on' care.

Discussion point

- Why is this an advantage when allocating organs to recipients?

What Does NHS UK Transplant Do?

NHS UK Transplant's specific responsibilities include:

- managing the NHS Transplant Database which includes details of all potential donors and patients who are waiting for, or who have received, a transplant;
- providing a 24-hour service for the matching and allocation of donor organs and making the transport arrangements to get the organs to patients;
- maintaining the NHS Organ Donor Register;
- improving organ donation rates by funding initiatives in the wider NHS;
- contributing to the development of performance indicators, standards and protocols which guide the work of organ donation and transplantation;
- acting as a central point for information on transplant matters;
- providing central support to all transplant units in the UK and Republic of Ireland;
- auditing and analysing the results of all organ transplants in the UK and Republic of Ireland to improve patient care;
- raising public awareness of the importance of organ donation.

NHS Organ Donor Register

Besides telling family, relatives and friends of the decision to donate organs, there is also the National Organ Donor Register, held by NHS UK Transplant in Bristol. If someone wishes to donate organs after their death they can add their name to the Register. This enables doctors, nurses and transplant co-ordinators to confirm an individual's wishes to the family, close relatives and close friends.

It is interesting to note here that around 50-60% of families agree to organ donation when asked. It is very rare for families to refuse consent if they knew that their loved one wanted to donate.

Scottish Context

Here in Scotland when organs become available, if there is no suitable match on the NHS UKT super urgent list, then the following process is followed:

- the heart is offered to the Scottish cardiac transplant co-ordinator based in Glasgow;
- the lungs are offered to the Newcastle transplant co-ordinator where Scottish patients are transplanted;
- the liver is offered to the Scottish Liver Transplant Unit based in Edinburgh;
- the kidneys are allocated by the best tissue match in the country. If there is an equal match, factors such as age etc are taken into account.

A Day in the Life of a Transplant Co-ordinator

The role of the transplant co-ordinator is important in the process of donation and transplantation. Here is a fairly typical account from Jen Lumsdaine a transplant co-ordinator working in Edinburgh.

"Transplant co-ordinators organise the transplant process. There are two different types – *donor transplant co-ordinators* are responsible for the care of a patient who has died, speaking to the family and organising the organ donation process. *Recipient transplant co-ordinators* are involved in assessing patients for the transplant waiting list, organising the transplant operation and follow-up. Most transplant co-ordinators are registered nurses.

In Scotland, there are recipient transplant co-ordinators for liver and heart transplants. In some units, the donor transplant co-ordinator has a dual role – also working as a kidney recipient transplant co-ordinator. I work in a team of four, and this is a description of some of our work.

08.30 hrs: Kidney Transplant Unit ward round. This involves the multi-disciplinary team that includes surgeons, physicians, nurses, dieticians, pharmacists and transplant co-ordinators. Each patient on the ward is reviewed and their progress, including blood results and anti-rejection medication are discussed with the patient. Today we have admitted a mother and son, in preparation for a live kidney donor transplant tomorrow. The mother has undergone six months of testing to prove she is very healthy, with two well-functioning kidneys. Final tests today will give the go ahead for tomorrow. The other patient being reviewed is a 35-year-old man who had been waiting for a transplant for six years, and finally received a call two weeks ago. The transplant was successful and he is waiting to go home. During the ward round he asks if he can write a letter to the family of the donor to thank them for this gift.

09.30 hrs: Following the ward round, I attend to some of the paperwork involved from the transplant yesterday. It is important that all the legal documents are completed and sent to NHS UK Transplant.

11.00 hrs: Education is a significant part of the transplant co-ordinator's role. Today I am speaking to a group of medical students about brain stem death and organ donation. All health professionals are involved in transplantation, and for new doctors and nurses it is important they are taught how to approach bereaved families and discuss organ and tissue donation.

12.00 hrs: The hospital media department has contacted the transplant co-ordinators asking for information and volunteer patients to talk to the press about transplantation. Most of the transplant recipients are willing to do this – without organ donors they would not have received a transplant, and it is important to highlight this to the public. We set up an interview with one lady who is entering the Transplant Games this year – an Olympic-type event for organ recipients.

13.30 hrs: Transplant Assessment Clinic: Patients who are reaching end-stage organ failure attend this clinic to review their suitability for a transplant. This involves an in-depth discussion and examination by the transplant surgeon, and information from the transplant co-ordinator concerning life on the transplant list, the operation and the care following a transplant.

15.00 hrs: Whilst in clinic I am called by an anaesthetist from one of our local intensive care units. They have just performed the first set of brain stem death tests on a 28-year-old man who had been in an accident. As the first set of tests had shown the man to be brain stem dead, they asked if I would attend the unit to discuss organ donation with the family following the second set of tests. Already the family had mentioned that the man had carried an organ donor card and had discussed his wishes with them.

I leave the hospital immediately, to drive 50 miles to the hospital. On arrival, the anaesthetist tells me the second set of tests have been completed, confirming brain stem death. The family are willing to speak to me.

16.30 hrs: Along with the nurse who has been caring for the patient, I discuss with his family the offer to donate his organs. This is perhaps the most important part of my role and I assure the family that the operation is performed with dignity and respect by the transplant team who will attend the hospital. We have a detailed discussion concerning which organs will be donated, his past medical history and the follow-up we provide.

17.30 hrs: The next two hours are spent gathering information about the potential organ donor, taking blood for tissue-typing and virus checking, and supporting the family. When all the information is complete, I contact NHS UK Transplant, a special health authority based in Bristol. The duty office will take details and inform which transplant centres in the UK to contact for organ allocation. NHS UK Transplant holds the names of everyone in the UK who is waiting for a transplant. The system in place can immediately work out which centre or patient should be offered an organ. As there are no super-urgent patients (those patients who are so ill they need a transplant within 72 hours), I can call the liver

team in Edinburgh and the heart team in Glasgow to offer a life-saving transplant to someone in Scotland.

19.30 hrs: Having spoken to the recipient transplant co-ordinators for the liver and heart teams, they are organising for their transplant teams to come to the hospital to remove the liver, kidneys and pancreas, heart and lungs. The family also kindly agreed to corneal (eyes) and tendon donation, so I contact the tissue co-ordinator who will arrange for an ophthalmologist (eye surgeon) and orthopaedic surgeon to come to the operating theatre.

21.00 hrs: The family are saying goodbye to the patient, and we have arranged to meet the next morning when the operation will be completed and they can visit him in the Chapel of Rest in the mortuary. This is a very difficult time, and as a transplant co-ordinator I am always aware that it is due to the kindness of families at a time of acute grief that transplantation can proceed.

21.30 hrs: The donor is still on a ventilator, which provides oxygen to the organs. The anaesthetist and operating theatre assistant arrive in the intensive care unit to transfer him to theatre. The operation can take from 6-8 hours, and is performed under sterile conditions like any other operation. The organs are perfused with a special preservation fluid, as they will not have a blood supply until transplanted. The heart and lungs are quickly transferred, as the recipients are already in another hospital waiting and they must be transplanted within 4 hours. The liver and pancreas are transplanted within 12 hours. The kidneys are allocated by the best tissue match, and are usually transplanted within 24 hours.

03.30 hrs: The surgeons have finished the operation, and along with the theatre staff we perform 'last offices'. This involves washing and dressing the donor, in preparation for transfer to the mortuary.

04.30 hrs: One of the kidneys has been allocated to a local patient, and I telephone the surgeon, kidney doctor and transplant unit. At 05:00 hrs I phone the recipient, who has been waiting for 3 years for a transplant and ask him to come into hospital. It has been an emotional day.

10.00 hrs: I meet with the family of the gentleman who died, and take them to the mortuary to view the body. We talk briefly about which organs have been donated, but this is a time for their grief. I will write or visit soon, giving them information about all the people who received a transplant today."

There are many different people involved in the transplant process, and all work with the awareness that a grieving family has given their permission at a very difficult time. In one day, some of the people involved included:

Consultant Anaesthetist	NHS UK Transplant
Intensive Care Nurses	Anaesthetist
Physiotherapists	Theatre Staff
Procurator Fiscal	Transplant Surgeons
Laboratory Staff	Perfusionists/Nurses
Tissue Typist	Tissue Co-ordinators
Recipient Transplant	Ophthalmologist
Co-ordinators	Orthopaedic Surgeon

Discussion points

- What do you notice about Jen's typical day?
- What does Jen regard as the most important part of her role? What are her reasons?
- Jen knows there is a potential organ donor. Describe the process she follows from consent to transplantation.
- What do you think would have been the most emotional or moving times in her day?

Donor/Recipient Stories



Story 1

Peggy Murray is the wife of a liver transplant patient. She has written this story, recording her thoughts, fears and joy. Read the story.

Call at midnight: Our experience of transplant – Peggy Murray

"I remember that Sunday in January as an awful day. I stood at the bedroom window looking at the trees blowing and creaking, a dirty long streak of loose polythene entwined itself round the telegraph wires in a mad dance. The sky was almost black. It all just seemed to sum up misery. He was silent in bed in the room behind me and far from well. All he ever said was 'I'm fine'. He had had another fall and there was a purple bruise down the side of his face. It had been a struggle to lift him back up and we managed only with a chair placed against the table and a series of slow hauls and pushes. Later, as the heavens opened and rain poured down on the dispiriting scene outside, I remember thinking this is just the end. Pathetic fallacy it is called, in plays like 'King Lear' and it seemed very apposite to me. I did not think he would survive until the operation.

He had by now been on the waiting list for a liver transplant for only 4 days. First, there had been months of tests and assessments, in and out of hospital. On the last Wednesday he had at last been put on the waiting list officially and given a bleeper so that he could be alerted at any time of the possibility of an operation. At his interview as I sat beside him, the lady co-ordinator laid out very clearly the pros and cons and conditions. I knew he had no real option – it was the operation or nothing. Nothing meant just the continuation of the slow and awful decline of the past months. At the interview he was in such a state of confusion and toxicity that I fear very little of what was said stayed with him. Only someone who knew him well might be aware of that. His responses as usual were highly socially appropriate, though shorter than they would have been once. That day we left with instructions to have the bleeper with us at all times. He was to avoid infection and report any that occurred, to drink lots of water and exercise daily.

And now it was Sunday and his yellow face looked up blankly from the bed as he responded once again that he was fine and feeling better. He had kept (or been kept) rigidly to his regime of pills but they were clearly not going to be enough. As well as falling and being increasingly unsteady, his memory had got so much worse. This made life one of continual vigilance. Determined as ever to help, he would go to the freezer to get some item out for tea time and later I would find many other melting packets left on the adjoining shelf or on the floor. His ability to write deteriorated and I would find him trying to practise his signature, although he no longer wrote anything. Phone calls had to be monitored in case important messages were forgotten. Cooker and water taps had to be checked, and when he was fit to walk, he had to be kept within sight if we were out, because if he turned a corner he might get lost.

The awful Sunday passed and Monday dawned - another blustery day. He got up late and wanted to read his papers and have his breakfast, but he soon was tired and went back to bed. A friend called to see him, but he was then sound asleep and there seemed little point in waking him to tax him with trying to chat. The friend left with a very grave face.

He got up later briefly, but nearly fell over again, and it was a relief when he wanted to go back to bed to rest. 'Fine, but a little tired' he said. No complaints, very little speech.

It was 10 minutes to midnight and I was completing the nightly rituals of letting the dog out and locking up when the phone rang. Strangely I answered it with no thought other than that it was one of the many relatives who kindly kept in touch and rang at all hours to enquire. A warm and calm voice, but an unfamiliar one, told me that there was a possibility that they had a liver match for him, and could I get him in to hospital to be ready for an operation in the morning? He was to have nothing more to eat or drink in the meantime.

I wakened him and got him in to his dressing gown, still full of sleep, but pleased enough to do as he was asked. Soon the ambulance was there, although I had been warned that as a 'non-urgent' case we might have two hours to wait. The run-up

through the sleeping streets of Edinburgh and the park was another chance to appreciate the care and professionalism of the ambulance attendants, one driving while the other kept patient and passenger relaxed and comfortable. They wheeled him through the darkened hospital corridors and up in the lift to the Unit, leaving us only when a waiting nurse and doctor there took over. Over the next 2 hours the nurse and doctor went through all the preliminaries with great thoroughness as I sat by him and replied for him in some measure, occasionally having to correct his recollections or information, although in some strange way the occasion appeared to have jolted a rather better level of functioning than he had recently shown. Heart, blood pressure, blood tests were all systematically taken as the clock moved on through the witching hours and the rest of the Unit – and the city – slept.

About 3 o'clock all was in readiness and he was wheeled away to a bed in the ward. I was free to leave or take the kind offer of a bed for the night in the relatives' room. Mindful of my canine housemate, and feeling that it was probably easier to face the next day at home, I made my way through the dark and silent corridors once more, out of the A & E exit and to the taxi rank across the road.

Next morning I learned that the operation was indeed to go ahead and from 10.30am he would be in the theatre. Phone calls to alert the rest of the family and close friends took up part of the day, and it passed, as even the slowest of days do, until at 6.30pm there was a call from the surgeon in charge to say it had all gone well. He had been 'healthy' all through and he was now in Intensive Care.

When his offspring and I saw him next day in Intensive Care the first thing we noticed was the change to a pinkish tinge in his skin colour. A lovely Canadian nurse – Maggie – was looking after him and he had, she said, been singing a Hebridean song to her. He had no recollection of an operation and thought it might still be to come. The change in his looks was dramatic and already he was taking a bit of interest in the world around.

The next few weeks were a bit rocky, with complications from infection and a rather embarrassing couple of days of confusion and agitation. In public he would have committed a breach of the peace. In his delirium he was back at work and laying down the law – in every sense – to the ward staff and patients. They must have found it, in every sense, a sore trial! But that passed and slowly but surely physical recovery began. The work of the physiotherapists and occupational therapists helped this along and even when the added diagnosis of diabetes had to be faced things never looked so bleak again.

The grey and faltering figure who was helped home after 7 weeks was, however, only beginning on the long road to fitness. My sister came from half-way around the world to help in the first crucial weeks and the hospital back-up with advice and equipment made it feel that we were not facing this alone. The continuing daily care and counsel of the district nurses helped incalculably.

Six months along the line, with clinic check-ups becoming encouragingly fewer and levels of medication lessening, progress has become steadier and faster. Walking has improved and his self-help skills are completely restored. All the aids so thoughtfully supplied are no longer needed and he took great delight in storing them personally in the garage for collection as soon as that was possible. Most cheering progress is exemplified by the return of his writing ability. He will now write a perfectly legible note – with spelling intact and grammar correct. He added a few notes to this account which I have included. He remembers almost everything. He can cook and mow the lawn – and he knows what we have to put on the grocery list. He tells the most awful jokes once again. While these may seem trivial, they are not to us – or anyone who has had to deal with the enveloping fog caused by this type of liver disease. He has been able to enjoy two brief breaks away from home among familiar and delighted relatives.

He has, truly, a new lease of life. He is restored to being the cheery fellow we used to know, able to enjoy the pleasures of home and neighbourhood and especially the delights of the growing grandchildren of whom he was scarcely aware last year. And if he has a life back, that makes two of us.

We have much to thank everyone for – the surgical, medical and nursing staffs and all relatives and friends, our church members, and all of the many faiths who remembered him in prayer groups and individually, our National Health Service, within which we indeed got signal advice.

There is – there was – someone who has to be thanked and that person is one I have not yet mentioned throughout this account of a marathon sojourn. I do not know this person's name or even if he is male or she is female,

although I suppose the former. I only know the person's blood group and that his liver was of a suitable size. I also know that without his donation, without his thought for another, I would not be writing this story of a life leased back. So, thank you from all of us Mr Unknown Donor, and thanks to your family who at the saddest of times thought of others and ensured a second chance for a stranger.'

Discussion points

- How did you feel when you read Peggy's story?
- Liver transplantation is life-saving. Peggy also said 'after 10 years of illness I got my husband back'. What do you think Peggy would say about organ donation?

Story 2 – Euan Abel (8 years old)

Euan was 8 years old when he died after suffering severe head injuries in an accident. Read over his story.

An 8-year-old Scottish boy has died after falling down a lift shaft in a hotel in a French ski resort.

The screams of Euan Abel, were heard by his sister Heather, 14. Dr Graeme Abel, the boy's father, spoke of his family's grief and said he hoped his son's organs would help save other children. The family was with a party of 26 friends, including 14 children, all from Scotland, for a skiing holiday in a popular resort.

Dr Abel said: "The one positive thing that has come from this is that because Euan was able to get to hospital, he was able to donate his heart, both kidneys, his pancreas and both lobes of his liver for others. That will probably have helped six children who might otherwise have died". His son's organs were donated through the European transplant network. "We have lots of anger yet to come, but hopefully his heart is still beating somewhere in some other child who has been severely ill. Euan was always a very generous boy. This was something else he was able to give."

Dr Abel said: "Euan and his sister Heather had got up early to see off some friends who were going home on an earlier flight. They took the lift up to the next floor, and when they got out into the lobby it was in darkness because the lights were on saver-switches. Heather went across to push the time-switch and Euan turned right into what he thought was a corridor. It was another lift shaft. The lift had got stuck between floors in the night, and the fire brigade had rescued the occupants. For some reason the lift doors had been left open. Euan just went straight down."

Heather ran to get her parents. Graeme Abel ran to the ground floor and, with the help of a friend, was able to force the lift doors and climb into the shaft. He said: "I carried Euan out. He was unconscious and dying. He had emergency surgery for a ruptured spleen, but we knew he had very severe head injuries, and over the next 48 hours it became obvious he wasn't going to survive them."

Discussion points

- Why do you think Euan's parents donated his organs? Do you think it would be an easy decision?
- Do you feel the donation of Euan's organs would help the family in any way?
- It is likely that at least six children's lives were saved as a result of Euan's death. How do you think the parents of those children would feel?
- What do you think of Euan's parents?

Story 3 – ‘Heart Operation Athlete’s Tribute to Family of Saviour’

Reg Chisholm had a heart transplant in 1999. Read his story which was printed in a Scottish newspaper.

“A top athlete who had a heart transplant has dedicated his medal haul to the man who saved his life. Reg Chisholm returned from the European Heart and Lung Transplant Games as Scotland’s number one. And he has given thanks to the family of the man who allowed him to live again.

He said ‘I know nothing about him, but I will forever be grateful they allowed me to have his heart.’ Looking at the 2 golds, silver and a bronze he brought back from the Games in Austria, he admitted the donor was in his thoughts.

He said ‘He was always in the back of my mind, whoever he was. These medals are my tribute to him.’ Reg, 48, had a massive heart attack when he was 45. He was told he needed a transplant or he would die, and days later a donor was found. In December 1999 the dad of three was under the knife at Glasgow Royal Infirmary. It was the start of a new life for the Dunbar-based ScottishPower worker.

He said ‘I thought, this man didn’t have the chance to live on, so I should try to keep his heart in top condition’. The former Dunbar Rugby Club forward won the 21km veterans’ cycle race, then gold in the biathlon, silver in the 1,500 metres and bronze helping the Spanish team in the 4 x 100 metres relay.

He added ‘It’s a dream come true. I can hardly believe it. I wanted to do it for myself, my wife Norma, and my sons and grandkids. But above all I wanted to do it for that man who didn’t have the chance. I also wanted to thank his family.’

Discussion points

Reg said of the donor:

“I know nothing about him, but I will be forever grateful they allowed me to have his heart.”

- Discuss in your group whether you think the recipient should know anything about the donor. Should the donor’s family know who the recipients are? Can you see any difficulties in these situations?
- Discuss how Reg’s heart transplant would also be good news for his family.

Story 4 – Donor Family

Rebecca Nix, 21, died in a car crash in America. Yet as her mother Jane explains in this emotional letter, her only daughter’s childhood pledge has given dozens of other people renewed hope.

“Dear Rebecca,

You were a gentle, caring child, always putting others first. So it came as no surprise when you announced you wanted to be an organ donor. You were only 7, and I can remember how serious you looked pushing the consent form into my hand. There’d been a talk at school, and your mind was made up. I talked it through with your dad, both of us touched by your determination. It was such a strange request for a child, but so like you. We signed the form.

As you grew up your donor card stayed in your purse getting tattier as the years passed. You even had to update it. I never gave it another thought, to be honest. Not until that fateful November night in 1996. You’d been working as an au pair in America for 8 months, looking after 3 small boys. I was wrapping presents when the phone rang. I answered it, imagining your chirpy voice. But it was your friend Donna. She sounded tearful, struggled to get the words out. ‘There’s been a car crash,’ she said ‘Becky’s dead’. I dropped the phone, screaming. After 10 minutes of sobbing, I rang your dad on his mobile. ‘Rebecca’s dead,’ I blurted. ‘Please drive home safely.’

Sitting alone, my mind played back our last conversation. You told me all about the new grey sweatshirt you’d bought. Before you rang off you said, ‘I love you mum.’ Now I’d never hear those words again. I hugged your dad when he arrived home, ashen-faced and speechless. We were too choked to speak.

The night wore on. A call from a doctor at the Hartford Hospital in Connecticut filled in the gaps about the accident. You were driving to meet the school bus and crashed head-on into another car. You’d died instantly, he said. You hadn’t suffered. That was a comfort.

We couldn't sleep, lost in grief. Then a strange thing happened. An image of your red-and-black donor card sprang into my mind. I jumped up, my thoughts racing. Did she have it on her? Do the doctors know about it? It was like you were propelling me forwards. Your dad dialled the hospital. He didn't mince his words. 'Take whatever you can from Rebecca,' he said. We were told your heart, lungs and liver couldn't be used because they'd been starved of oxygen. But there was hope other parts could be transplanted. The nurse thanked us and promised she'd be in touch. A wave of relief flooded over me. The next day we learnt surgeons had removed your eyes, heart valves, sections of your skin and bones. At least you were coming home to us.

Three days later I went to see you in the chapel of rest near our Birmingham home. You were wearing the American sweatshirt you'd told me about, you looked as if you were sleeping. I slipped your favourite brown lipstick in beside you, together with your Winnie The Pooh gloves. 'You're still my little girl,' I whispered. 'You always will be.'

A month after your death the first letter came. Your corneas had restored the sight of a 24-year-old man and a 41-year-old woman. We cried. Your skin had been grafted onto children suffering severe burns. Your heart valves were given to two men, while your bones were used to replace diseased tissue in dozens of patients.

A total of 74 people were helped by you. So even in death you reached out to others. Our grief is still raw, and it would be too painful to contact any of them, but the hospital has told us every single one wanted to pass on their thanks for your special gift. I think every bereaved parent has an overwhelming fear their child will be forgotten. But we know that will never happen to you, Rebecca. It's such a comfort to know you've given so many people a better life. I'm so proud of you in death as I was during your all-too-short lifetime.

Your mum, Jane Nix"

Story 5 – A Decision not to Proceed

The Transplant Co-ordinator was called to the Intensive Care Unit (ITU) to speak to the parents of a 17-year-old male who had been declared dead following brain stem tests as a result of a road traffic accident. He had just passed his driving test and his parents had helped him buy the car. He was brought into the Accident and Emergency and later was transferred to the ITU where he was in a coma, attached to a life support machine in a critical condition with little hope of survival. When it became apparent that nothing further could be done for this patient the family were informed and the doctors explained that they were going to perform brain stem death tests. The doctors went on to test the patient's brain stem function and along with the scan of his brain found that he had suffered irreversible damage to his brain stem. When two sets of brain stem tests were completed and confirmed that the patient was dead this was then explained to the parents and then they were asked if they would like to discuss the option of organ donation as their son had carried an organ donor card. When the transplant co-ordinator spoke to the parents they were aware that their son had carried a donor card but felt unable to agree.

Discussion points

- Why do you think the parents decided not to proceed?
- Should the health care professionals have asked why the parents felt unable to agree?
- What about the rights of the patient?
- Is the donor card legal and binding?
- Can anyone give consent for someone who has died?
- If organ donation proceeded how might this affect the transplant programme?
- Do the laws in other parts of Europe work more effectively or are they ineffective?

Living Donation



Story 6 – The Story by Joyce

“In June 1999 I had a kidney removed due to polycystic kidneys and began haemodialysis. Both sisters offered me a kidney and a meeting was arranged with the transplant surgeon and the co-ordinator. Information about the procedure was given honestly, making it clear that the donor underwent a more painful operation than the recipient and all the risks involved. Having discussed the benefits for me within the whole family, it was decided to go ahead to see if Elizabeth was compatible.

Life on dialysis was limiting but I was lucky and kept well, managing to hold down a part-time job as a teacher. My family were very supportive and took on many new roles than they had previously, as I attended haemodialysis three times weekly.

When Elizabeth came up for the 2 days of pre-transplant tests, I was swaying from being very positive and keen, to being worried and upset. Elizabeth was planning to undergo major surgery for me with no benefit to herself, other than hopefully seeing me enjoy a normal life again. This was brought out in the open and she reassured me that she did not feel pressurised or obliged to go ahead. When the results came through we were given a date for July and planning began in earnest. Children and pets had to be taken care of and it was important that arrangements were flexible.

I was admitted 2 days before the operation and underwent routine checks. Elizabeth was admitted the next day. I had my final dialysis that evening and returned to the unit to find both families and our dad there. It was a tense evening and after the visitors went away, Elizabeth and I did a jigsaw in the day room until 12.30am, putting off the moment of going to bed and being left with our thoughts.

On the morning of the operation we were both up early, showered and Elizabeth went to the operating theatre about half an hour before me. The next thing I knew was waking up and my husband being by my bed and it was all over. Elizabeth was opposite me in the High Dependency Unit and once we were both awake and had reassured each other we felt ‘great’, there was amazing relief and hilarity that the operation was behind us.

The next day I got up with the help of the physio and really felt great, but was concerned that Elizabeth was obviously in discomfort and sleeping a lot. The staff were fabulous and assured me that this was the normal pattern, the donor initially taking longer to recover. It took another 3 days for Elizabeth to return to her usual self and after that there was no stopping her.

I was also discharged after a week and initially attended hospital every few days for blood tests.

Life is so different for me!!

I have a new found energy, can eat a much larger variety of foods, can drink lots of fluids, have much more time to myself – and really am a new person. All thanks go to my sister Elizabeth and the team of people in the Transplant Unit.”

Story 7 – The Story by Elizabeth

“When my sister Joyce was told she had kidney failure, I cannot remember actually making the decision about asking to be considered as a donor, I just knew it was what I wanted to do. My husband and children were completely supportive. I think that this is vital to the whole process, because it inevitably involves you all.

My younger sister was also keen to be considered. So we told Joyce, and a meeting was arranged with the transplant surgeon and transplant co-ordinator.

One of my main impressions of this time was that much of the information given seemed to be pointing towards the more negative aspects of what might happen, despite the superb success rates. This was to ensure that the donor was as clear as possible about what was involved and that the offer was made with no pressure from any quarter. When it became clear that I was compatible and my general health was good, a 2-day admission to hospital was arranged for a series of more specific tests. This was my first visit to hospital, excluding the birth of our children, but any apprehension was soon dispelled by the supportive attitude of all staff. The tests consisted of blood tests, blood pressure, a chest X-ray, an ultrasound scan and a renal angiogram. I actually quite enjoyed the experience!

This was also a very important point in the whole process. It was during this time that I realised how complex Joyce’s feelings were about what was happening to us all. It was a very emotional time for her. As far as she was concerned, it was because of her that I was in hospital – despite the fact that the tests themselves were straightforward and far from dreadful. It highlights the fact that this is something the recipient cannot repay and how difficult it can be to accept this. Personally, I think it is probably easier to be a donor. The good part of this was that it provided an opportunity to reaffirm our feelings and remain very positive about continuing.

Much to our delight, the results showed that my general health was good and I had 2 well functioning kidneys. Reality strikes! Dates were put into place and arrangements made. As a teacher, I am fortunate to have a long break in the summer and it was arranged that this was when the operations would take place. This was at our request, and another example of how well we were looked after.

The day before the transplant was scheduled, I was admitted into the Transplant Unit. ‘Unit’ is an excellent description of the place. Every person, without exception, works as part of the team to provide a service second to none. The atmosphere is so positive and caring that it helps to dispel the inevitable apprehensions. The night before the transplant was most peculiar. It is very comforting to be in hospital with someone you know so well and this helped me in many ways. Our families visited and it was a time of mixed emotions. Everyone is affected by what is happening. It is not just the donor and recipient. When Joyce and I did eventually go to bed, it was with hope and expectation.

Early the next morning I was prepared to go to theatre first, and Joyce soon after. The operations take place in a specially designed twin theatre. The faces I saw on the ward, on the way to theatre and in the anaesthetic room were familiar. All had introduced themselves previously, which is so helpful when the surroundings are unfamiliar. The operations are carefully planned with consultant transplant surgeons leading the two teams. After the kidney is removed, it is transferred to the adjoining theatre to be transplanted.

When I woke up on the High Dependency Ward Joyce was opposite and we seemed to come round about the same time. We both reassured each other that all was well. What a wonderful feeling! Everyone on the ward helped to make sure that everything was done to make us as comfortable as possible. When our families visited later in the day there was so much joy and laughter. Now we had to hope that the kidney would do its job and make Joyce feel better than she had been in a long time.

The next few days were filled with a variety of checks such as blood tests, urine counts and fluid intake. The physiotherapist was on hand to make sure mobility returned as quickly as possible. My recovery was made so much easier by the signs that the kidney was doing its job. Joyce was feeling good! I will never forget her euphoria on the morning of the second day when she noticed that the whites of her eyes were no longer yellow, but clear white – a very positive sign.

Things continued to go well and after a week in the Unit I was allowed home. A follow-up, 6 weeks after the operation, ensures that blood and urine tests have returned to normal. It is also made very clear that if anything crops up at home which causes concern, there is always someone available at the Transplant Unit to answer questions and provide support.

Being a kidney donor is a unique experience that not everyone who wishes to has the opportunity to take. I was fortunate to be able to do this and would encourage others to do so as well. Personally I feel richer as a result of the whole experience and through meeting so many special people.”

Discussion points

- What fears do you think Elizabeth and Joyce would have about living donation?
- Imagine you are in the position of being able to donate your kidney. How would you feel about it?
- Do you think daughters/sons should be allowed to donate their kidneys to a parent? Can you see any obstacles?

Ethical Dilemmas



Ethical Dilemmas

Organ transplantation is not just a part of medical history. Today it has become a moral and major ethical challenge: to whom shall we give these organs when there are so few available?

Patients are waiting longer than ever to receive organ transplants in Scotland because of a lack of donors. A decade ago a large proportion of donated organs came from car crash victims. However, this source of organs has lowered considerably for the following good reasons:

- better road safety programmes;
- effective drink-driving campaigns;
- traffic calming measures eg, speed bumps;
- compulsory use of seat belts;
- advances in medical treatment and care.

As a result, the number of organs had been falling by about 3% every year. Though this trend has now been halted, the number of people in need of a transplant is increasing by the same level. This discrepancy in supply and demand gives rise to many ethical dilemmas about recipients.

Here are some of the issues people discuss and that the medical world faces.

Discuss in class these situations:

1. Robert has died and he carries a donor card and has signed the NHS Organ Donor Register. The transplant co-ordinator approaches Robert's wife, and she says 'no'.

What is the right thing to do?
Do you follow Robert's wishes or his wife's?

2. Michael is suffering from chronic liver disease, caused by alcohol-related problems. Without a transplant he will die. Michael is known to be a very heavy drinker.

Should Michael be given a liver transplant?
Should he be given another chance?
Would there be any conditions?

3. Kate is 17 years old. Her mum has a serious kidney disease and has been on dialysis for over 2 years. Kate, distressed by her mum's suffering, offers to donate her kidney to her mum. They approach the transplant co-ordinator and surgeons to discuss this possibility.

What do you think the professionals' response to this offer would/should be?

4. What if in Scotland there was an 'opt-out' system rather than 'opt-in'.

Should a person who has 'opted-out', and clearly indicated his refusal to donate organs, be entitled to receive an organ in order to save his or her life?

5. What about smokers?

Should they have as equal a chance as others to receive a life-saving organ?

6. A convicted killer imprisoned in Scotland requires a heart transplant and after several months on the list, he receives a heart transplant.

How do you feel about this? How do you think the donor would have felt?

7. America is moving closer to allowing payment for organ donation. Presently this is illegal, both in America and here in the UK.

However, in the face of such a shortage of organs, do you think financial rewards and incentives should be offered?

What concerns might be raised about financial reward for organs?

8. Luisa lives in a shanty town in Brazil. She has 7 children, and struggles every day to provide food for them. She decides to sell one of her kidneys to a wealthy family in Brazil whose 11-year-old son is seriously ill awaiting a kidney.

What are Luisa's motives in offering her kidney? Do you think this arrangement should proceed? Think of the obvious advantages and less obvious disadvantages.

9. 'NEED A KIDNEY TRANSPLANT? I CAN DONATE A KIDNEY TO YOU FOR FREE.'

This advert appeared in newspapers from Patricia. She believes that to offer her kidney to save another's life is a good thing to do.

At present it is illegal for a stranger to donate to a stranger.

Do you think Patricia should be allowed to carry out her wishes in giving one of her kidneys to a stranger?

10. Jim sends off his form to the NHS Organ Donor Register but writes on it 'I do not want my organs to go to anyone who is not Scottish'.

Will his wishes be respected?



Many people in our society base their decision making on the religious values and principles they hold. This is no different when families are asked to consider organ donation: they often wish to consult with religious authorities. It would then be of help to know a little about the attitude of various religions to organ transplantation.

In general, with the exception of a few religious groups such as Shintoists, Jehovah Witnesses and Rastafarians, all major world religions either actively or passively support organ donation or are neutral. Romany Gypsies do not accept transplant of organs.

Here is a summary of the main religious views.

The Christian churches: None of the Christian religions has ethical objections to organ donation. Christian churches encourage organ and tissue donation, stating that we were created for God's glory and for sharing God's love. They encourage members to register as organ donors and prayerfully support those who have received an organ transplant.

Buddhism: Buddhists believe that organ and tissue donation is a matter of individual conscience and place high value on acts of compassion. A Buddhist leader describes their position as:

"We honour those people who donate their organs to saving lives."

Hindu and Sikh: The Hindu and Sikh religions have no objections to organ donation. Indeed, Hindu mythology has stories in which the parts of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion indicating that parts of humans, dead or alive, cannot be used to alleviate the suffering of other humans.

Judaism: All branches of Judaism support and encourage donation. According to one Rabbi:

"If one is in the position to donate an organ and save someone's life, it's obligatory to do so, even if the donor never knows who the beneficiary will be. The basic principle of Jewish ethics is 'the infinite worth of the human being'."

Islam: Under Islamic law it is practice for bodies to be buried as quickly as possible after death. Therefore, sometimes requests for organ donation are refused. However, in 1995 the Muslim law (Shariah) Council UK issued a directive supporting organ donation and transplantation. The religion of Islam believes in the principle of saving lives and supports organ transplantation with that context.

Shinto: In Shinto the dead body is considered to be impure and dangerous, and thus quite powerful. 'In folk belief, injuring a dead body is a serious crime' according to E. Namihira in his article, *Shinto Concept Concerning the Dead Human Body*. To this day it is difficult to obtain consent from bereaved families for organ or tissue donation, the Japanese regard them all in the sense of injuring the body. Families are often concerned that they do not injure the 'itai', the relationship between the dead person and the bereaved people.

Discussion points

- Why do almost all the main world religions support organ donation and transplantation? What are the general shared principles they hold regarding human life?
- Consider the views held by the Shinto religion regarding the dead human body. What do you think about their ideas?

See also the following leaflets prepared by NHS UK Transplant:

- Christianity and Organ Donation;
- Judaism and Organ Donation;
- Buddhism and Organ Donation;
- Hindu Dharma and Organ Donation;
- Sikhism and Organ Donation;
- Islam and Organ Donation

Copies available from www.uktransplant.org.uk





Non-heartbeating Donation

Today most of the organs that are donated come from those who have died. The patient is on a ventilator, the heart is still beating and death has been confirmed by brain stem testing.

The ventilator provides oxygen which keeps the heart beating and blood circulating after death. These donors are called heartbeating donors. Organs such as hearts and lungs, which deteriorate very quickly without a blood supply, are usually only donated by heartbeating donors. Very few people die in these circumstances.

Patients who die in hospital but are not on a ventilator can, in some circumstances, donate their kidneys, and in certain other circumstances, other organs. They are called non-heartbeating donors. Both heartbeating and non-heartbeating donors can donate their corneas and other tissue such as skin, bone and heart valves.

Because of the shortage of donated organs, interest in non-heartbeating donation is growing.

In a small number of hospitals, patients who are certified dead on arrival or die in the accident and emergency department can donate organs, in particular kidneys as they are able to tolerate longer periods without oxygen than other organs. For this to happen, however, steps have to be taken to preserve the kidneys until the next of kin

are contacted and the possibility of organ donation discussed with them. This is a special technique in which the kidneys are flushed with a cold preservation fluid. To do this a small tube is inserted into a blood vessel in the groin. This must be done within minutes of death to ensure the kidneys remain suitable for transplantation.

If the family object then the procedure goes no further and the small tube is removed. If the family agree to donation then the kidneys are removed and transplantation is carried out in the usual way.

Discussion point

- How do you think the public would react to non-heartbeating donation?

Elective Ventilation

Elective ventilation is the use in intensive care of artificial ventilation in a selected group of deeply comatose patients close to death in order to preserve the patient's organs for transplantation after death.

Elective ventilation first took place in the late 1980s and increased donation. However, in 1994 elective ventilation was stopped because there is a common law requirement that medical treatment should be intended for the 'patient's own benefit'.

Some people think that this decision should be changed. They argue that patients who are deeply comatose from brain injury or bleeding into the brain should be allowed ventilation for the sake of organ donation, when this is the stated will of the patient or the will of his or her next of kin.

Mr Jetmund Engeset, a consultant transplant surgeon, believes that there should be a change in the law. He says:

"I believe this is for the good of everyone. For the person who receives the organ, they are given a new chance of life. Society benefits because there are fewer people on dialysis and the donor's family benefits because they can feel some good has come out of their sadness. I have seen the uplift which is generated among donors' families by organ donation."

Intensive care exists to offer support to organ systems and thus allow patients to get over a life threatening illness and get back to life. Many intensive care doctors in Scotland are therefore not in favour of elective ventilation as it may involve doing things to a patient from which they cannot benefit. Some may see elective ventilation as an unwarranted interference in the process of a patient dying.

However, if intensive care is inappropriately applied it can also prolong death and thus give rise to increased distress to both patient and their relatives.

Discussion points

- Do you think the law should be changed?
- What do you think about the intensive care point of view?

Xenotransplantation

The future might lie in retrieving organs from other sources. Xenotransplantation involves transplanting from one animal species to another, with pigs the most likely source.

This requires genetic modification of the animal, to reduce the chance of the human body rejecting the organ. At present, xenotransplantation is against the law in the UK, because of concerns about the transmission of disease from one animal species to another.

Mr Chris Rudge, Medical Director of NHS UK Transplant, said:

"This would appear to be an exciting development. It will be for the Department of Health to decide if or when preliminary medical trials can begin. There is still a lot of research to be done. There are very real concerns over the possible transfer of infections."

However, there are other issues.

Dr Penny Hawkins of the RSPCA said:

"We have every sympathy for people who need organ transplants, but it does not mean it's right to do anything to animals to solve the problem. This technique involves animal suffering."

Similarly, a spokesperson from Compassion in World Farming said:

"CIWF is not alone in recognising the real risk to the human population of the spread of animal viruses."

Some also say that 'scientists are playing God by challenging the natural order'.

Some feel repulsion at the idea of placing animal parts inside humans.

However, is it wrong to deny long-suffering patients on waiting lists the hope and chance of a better life?

Discussion points

- The Minister for Health and Community Care has received an angry letter from an Animal Rights group expressing concern at the growth and retrieval of pigs' organs for human transplants.
- In your group discuss an answer the Minister would give and write it in the form of a letter.
- How do you feel about using animal organs?
- Are scientists playing God? If so, why or why not? What do you think?

A monochromatic blue photograph of five young people in school uniforms. They are gathered around a table, looking at papers and talking. The scene is lit with a cool blue light, creating a serious and focused atmosphere. The young man at the top left is looking down at the papers. The young woman next to him is also looking down. The young woman in the middle is looking towards the young man on the right. The young man on the right is looking towards the young woman in the middle. The young woman at the bottom right is looking towards the young man on the left. The papers on the table are slightly out of focus, but they appear to be documents or books.

Some Common Questions and Answers

(Provided by NHS UK Transplant)

What is organ donation?

Organ donation is the gift of an organ to help someone who needs a transplant. The generosity of donors and their families enables about 2,700 people in the UK every year to take on a new lease of life. Thousands of people have their sight restored by donated corneas.

When was the first transplant?

A cornea was first transplanted in 1905. Blood transfusion became established in 1918 and the first successful kidney transplant was in 1954. The first heart transplants took place in 1967.

What can be transplanted?

Kidneys, heart, liver, lungs, pancreas, small bowel, corneas, heart valves and bone can all be transplanted. Skin can be used to treat patients with severe burns. Techniques are improving all the time and it may soon be practical to transplant other parts of the body.

What organs or tissue can I donate?

The organs that can be donated include heart, lungs, kidneys, pancreas, liver and small bowel.

Tissue that can be donated includes corneas, skin, bone, heart valves and other tissue. Corneas can be transplanted to restore the sight of a person who has a severe eye disease or injury. Bone and tendons are used for reconstruction after an injury or during joint replacement surgery. A bone transplant can prevent limb amputation in patients suffering from bone cancer.

Heart valves are used to help children born with heart defects and adults with diseased or damaged valves. Skin grafts are used as protective dressings to help save the lives of people with severe burns.

Most people can donate tissue. Unlike organs, tissue can be donated up to 24 hours after a person has died and can be stored for longer periods.

Reproductive organs and tissue are not taken from dead donors.

Why are even more donors needed?

Every year hundreds of people die while waiting for a transplant and many others lose their lives before they even get on to the waiting list. There is a serious shortage of organs and the gap between the number of organs donated and the number of people waiting for a transplant is increasing.

Transplants are very successful and the number of people needing a transplant is expected to rise steeply due to an ageing population, an increase in kidney failure and scientific advances which mean that more people are now able to benefit from a transplant.

The number of available organs has fallen for several reasons. Only a very small number of people die in circumstances where they are able to donate their organs. Because organs have to be transplanted very soon after someone has died they can only be donated by someone who has died in hospital. Usually organs come from people who are certified dead while on a ventilator in a hospital intensive care unit, generally as a result of a major accident like a car crash, a brain haemorrhage or stroke.

The numbers of people, particularly younger people, dying in these circumstances is falling mainly because of welcome improvements in road safety, medical advances in the treatment of patients and the prevention of strokes in younger people. While only a very few people die in circumstances which would enable their organs to be donated, virtually everyone can donate their corneas to help others to see or give bone, skin or other tissue after their death.

Another major reason is that many people have not thought about donation or discussed it with their families. Too few people have joined the NHS Organ Donor Register or made sure that their families know their wishes. Relatives who do not know a person's wishes may refuse permission for organs to be used.

How do they know you are really dead?

Organs are only removed for transplantation after a person has died. Death is certified by a doctor or doctors who are entirely independent of the transplant team. Death is certified in the same way for people who donate organs as for those who do not.

Most organ donors are patients who die as a result of a head injury, brain haemorrhage or stroke who are on a ventilator in a hospital intensive care unit. In these circumstances, death is confirmed by brain stem tests. The ventilator provides oxygen which keeps the heart beating and blood circulating after death. These donors are called heart beating donors. Organs such as hearts and lungs, which deteriorate very quickly without an oxygen supply, are usually only donated by a heart beating donor.

Patients who die in hospital but are not on a ventilator can, in some circumstances, donate their kidneys and, in a very small number of cases, their liver. They are called non-heartbeating donors. Both heart beating and non-heartbeating donors can donate their corneas and other tissue such as skin, bone and heart valves.

Can they keep you alive with machines?

No, the patient is dead. A ventilator keeps the body supplied with oxygen and this means the heart will continue to beat and circulate blood. This preserves the organs so they can be donated for transplant. When the ventilator is turned off the heart will stop beating within a few minutes.

Will they just let you die if they know you want to be a donor?

No, the doctors looking after a patient have to make every possible effort to save the patient's life. That is their first duty. If, despite their efforts, the patient dies, only then can organ donation be considered and a completely different team of doctors would be called in.

Can I donate if I die in the accident and emergency department?

Yes, in a small number of hospitals, patients who are certified dead on arrival or die in the accident and emergency department can donate organs, in particular kidneys which are able to tolerate longer periods without oxygen than other organs. For this to happen however, steps have to be taken to preserve the kidneys until the next of kin are contacted and can let their wishes be known. This includes a special technique in which the kidneys are flushed with a cold preservative fluid. This is done through a small tube which is inserted into a blood vessel in the groin.

This must be done within minutes of death to ensure the kidneys remain suitable for transplantation and the deceased is not deprived of the opportunity to donate. If the wishes of the deceased are known (for example they are on the NHS Organ Donor Register), this procedure will be performed. However, organ donation itself will never take place without full discussion with the relatives.

Can you donate an organ while you are still alive?

Yes, in some cases. The shortage of organs has led to an increasing number of organ donations by living people.

The most common organ donated by a living person is a kidney, as a healthy person can lead a completely normal life with only one functioning kidney. Kidneys transplanted from living donors have a better chance of long-term survival than those transplanted from people who have died. There are a number of reasons for this, the main one being that the donor is alive and healthy. About 1 in 5 of all kidney transplants are from a living donor.

Most living donor kidney transplants are between close family members because they usually provide the best match. The donor might be a brother, sister, mother, father, aunt, uncle, grandparent or child. The majority are between parent and child but living donor kidney transplants between people who are not blood relatives – such as husband and wife or between partners or close friends – are becoming increasingly common.

Before a living donor transplant can go ahead there are strict regulations to meet and a thorough process of assessment and discussion.

Part of a liver can be transplanted, and it is also possible to donate a segment of a lung and, in a very small number of cases, part of the small bowel.

Hearts are also donated by living people. This is because for some patients with diseased lungs who need a transplant, it is more effective to give them a combined heart and lung transplant, even though their heart is perfectly healthy. In these cases, the patient's healthy heart is then transplanted into a patient needing a heart transplant. This is known as a 'domino' transplant.

Why do we need to agree to become organ donors?

In the UK organs from a potential donor can only be used if the legal requirements of the Human Tissue Act 1961 and Human Organ Transplants Act 1989 have been met. Under these Acts it is essential to try and find out whether the dead person objected to donation and to seek the views of close relatives.

Putting your name on the NHS Organ Donor Register and carrying a card makes it easy for your relatives to know your wishes. We know that if a person has expressed a wish to be an organ donor then the relatives rarely object. That is why it is so important that you make sure your family is aware of your views on organ donation.

What is the NHS Organ Donor Register?

The NHS Organ Donor Register is, quite literally, a life-saver.

It is a confidential, computerised database which holds the wishes of more than 10 million people who have decided that, after their death, they want to leave a legacy of life for others. The register is used after a person has died to help establish whether they wanted to donate and, if so, which organs.

Do I need to register if I have a donor card?

Yes, cards can and do get lost or damaged and you may not be carrying one when you are taken to hospital. Adding your name to the register is a more permanent way of expressing your wishes. You can still carry a card if you wish to. Do not forget to tell your relatives what your wishes are.

Will my name and address be given to other organisations?

No, this information will only be used by NHS UK Transplant to register your wishes on the NHS Organ Donor Register. Your personal details would not be passed to any individual or organisation without seeking your explicit consent.

I am not sure if I have already registered, what should I do?

Either write in and ask (the confidential nature of the register means that NHS UK Transplant cannot tell you over the phone) or apply to join and their system will identify if you are already on the register and update any relevant details.

Who would get my organs if I became a donor?

Many things need to match, or be very close, to ensure a successful transplant. Blood group, age and weight are all taken into account. For kidneys the most important factor is tissue type which is much more complex than blood grouping. The more accurate the match, the better the chances of success.

There is a national, computerised list of patients waiting for an organ transplant. The computer will identify the best matched patient for an organ, or the transplant unit to which the organ is to be offered.

The waiting list and donor organ allocation system is operated by NHS UK Transplant. It works round the clock, every day of the year and covers the whole of the UK and Republic of Ireland.

Are donors screened to identify if they have a transmittable disease?

Yes, blood is taken from all potential donors and tested to rule out transmittable diseases and viruses such as HIV and hepatitis. The family of the potential donor is made aware that this procedure is required.

Can I be a donor if I have an existing medical condition?

Yes, having a medical condition does not necessarily prevent a person from becoming an organ or tissue donor. The decision about whether some or all organs or tissue are suitable for transplant is made by a doctor, taking account of the medical history. Usually, but not always, it is possible for some organs or tissue to be donated.

Can a donor be under 16?

Yes, if he or she has expressed such a wish, and the parents agree to donation.

Can older people be donors?

In the case of corneas and bone donations, age does not matter. For other organs, it is the person's physical condition, not age, which is the deciding factor. Doctors decide in each case whether it is possible to use them. Organs from people in their 70s and 80s are transplanted successfully.

Does the colour of my skin make a difference?

Yes and no. Organs are matched by blood group and tissue type. The better the match, the greater the chance of a successful outcome. Transplants are more likely to be successful where the donor and the patient are from the same ethnic group, because they are likely to be a better match.

A few people with rare tissue types will only be able to accept an organ from someone of the same ethnic origin, so it is important that we have donors from all ethnic groups.

Successful transplants are carried out between people from different ethnic groups, wherever the matching criteria are met.

Are there religious objections to transplants?

Most major religious groups approve and support organ transplantation, as it is consistent with life-preserving traditions. However, if you have any doubts, you should discuss them with your own spiritual or religious leader.

If someone needs an organ desperately is there any point in making a special appeal?

Yes and no. Any special appeal usually results in more people agreeing to become donors and can increase the number of organs available in the future.

However, family appeals through the newspapers and television will not result in an organ immediately becoming available for the person on whose behalf the appeal was made. The patient will still be on the waiting list, just like everyone else, and the rules that govern the matching and allocation of donor organs to recipients still apply.

Can I agree to donate some organs or tissue and not others?

Yes, you can specify which organs you would wish to donate. Simply tick the appropriate boxes on the NHS Organ Donor Register form or on the donor card, and let those close to you know what you have decided.

Can I agree to donate to some people and not to others?

No, organs and tissue cannot be accepted unless they are freely donated without any conditions attached in terms of potential recipients. The only restriction allowed is on the organs or tissue to be donated.

Could my donated organ go to a private patient?

Possibly, but this is unlikely. Patients entitled to treatment on the NHS are always given priority. These include UK citizens, members of Her Majesty's forces serving abroad and patients covered by a reciprocal health agreement with the UK.

Other patients would only be offered an organ if there were no suitable patients entitled to treatment under the NHS. Every effort is made to ensure that a donated organ does not go to waste if there is someone who can benefit.

Would any of my organs be given to someone in another country?

Yes, there is an agreement that any organs that cannot be matched to UK patients are offered to patients in other European countries. Likewise, UK patients benefit from organs offered by other European countries. This co-operation increases the chance of a suitable recipient being found, ensuring that precious organs do not go to waste.

Does donation leave the body disfigured?

No, organs are always removed with the greatest of care and respect for the person by properly trained surgeons. This takes place in a normal operating theatre under the usual conditions. Afterwards the wound is carefully stitched up and a dressing is placed over it. Only those organs and tissue specified by the donor or their family will be removed.

The donor's external appearance is also fully restored where tissue has been donated.

The funeral will not be delayed and relatives may see the body after the operation if they wish. The transplant co-ordinator will stay with the family during the whole process if the family wishes.

Does being a donor cause delays to funeral arrangements?

No, once relatives have agreed, everything has to be done very quickly to improve the chances of successful transplants, usually within 12 hours.

Does a donor's family have to pay the cost of donation?

No, there is no question of any payment at all. The NHS meets the costs related to the donation of organs.

Will the NHS pay the cost of the funeral?

No, funeral costs are met either by the family or from the person's estate and not by the NHS or any Government authority.

My relative wants to be a donor. What do I need to do when they die?

If they are certified dead in a hospital, simply tell any of the doctors or nurses involved in their care that they wanted to donate. The earlier you are able to tell staff, the more likely it is that organs can be transplanted successfully.

If your loved one dies elsewhere, for instance at home or in a hospice, they can still donate tissue. Let the doctor who certifies death know their wishes.

Will organs that are removed for transplant be used for research purposes?

Organs that cannot be used for transplant will only be used for medical or scientific research purposes if specific permission has been obtained from the donor's family.

How is organ donation different from organ retention?

The problems of organ retention arose because proper consent was not obtained from parents or relatives for organs and tissue removed at post-mortem to be retained for research or other purposes. Organs are only removed for transplantation with the consent of relatives.

Can I leave my body for medical education or research after I have donated my organs?

No, bodies cannot be accepted for teaching purposes if organs have been donated or if there has been a post-mortem examination. Corneas can however be donated.

Arrangements for whole body donation for research purposes or for anatomical examination can be made through HM Inspector of Anatomy.

Would a donor's family ever know who the recipient was?

Confidentiality is always maintained, except in the case of living donors, who are usually within the same family. If the family wishes, they will be given some brief details such as the age, sex and area of the country of the person or persons who have benefited from the donation. The patients who receive the organs can obtain similar details about the donors.

The families may want to exchange anonymous letters of thanks or good wishes through the transplant co-ordinators and in some instances donor families and recipients have arranged to meet.

Why should I discuss my wishes with my relatives?

So that there can be no doubts about what you would want to happen. Families are always consulted when there is a possibility of organ donation. Facing up to the death of a loved one is hard. Having to make a decision about organ donation when you are unsure what that person would have wanted can be difficult.

A key reason why relatives do not agree to donation is that they do not know what their loved one would have wished. However, objection is almost unknown if the family is aware that their relative wished to donate.

Why can my family overrule my wishes?

Few, if any, transplant surgeons would go against the wishes of a family. Whilst there are unlikely to be any repercussions against a surgeon who removed organs in the face of family objections from a person who wished to be a donor, there are few surgeons who would add to the stress of a grieving family by acting contrary to their wishes. Negative publicity from such an act would also have a detrimental effect on organ donation.

Even if you think your family will object, you should join the NHS Organ Donor Register and tell them of your decision to be a donor when you die. If there is written evidence of your wish to be a donor, most people will accept that, after death, your wishes should be respected.

What if I have no family or other relatives?

You can join the NHS Organ Donor Register and tell a friend or close colleague about your decision.

Should I put my wishes in my will?

By the time your will is read, it would be far too late for you to become a donor.

Can I change my mind?

Yes, you can simply go to the Sign Me Up section of the web site www.uktransplant.org.uk and fill in the form asking for your name to be removed. If you prefer, you can write to the NHS Organ Donor Register, UK Transplant, FREEPOST (SWB1474), Patchway, Bristol BS34 8ZZ. If you have an organ donor card, tear it up. Let your family know that you have changed your mind.

Can people buy or sell organs?

No, the Human Organ Transplants Act 1989 absolutely prohibits the sale of human organs.

I am interested in giving blood, what do I do?

Blood is needed constantly, for all kinds of things, such as cancer treatments, operations and in childbirth. There are thousands of places all over the country that hold blood donor sessions and new blood donors are always welcome. Almost anyone aged 17 to 60 years and in general good health can give blood.

I am interested in donating bone marrow, what do I do?

Without bone marrow, blood cannot be produced. When things go wrong and the bone marrow becomes damaged, for example as a result of treatment for leukaemia or a related cancer of the blood, the patient must receive a transplant to survive.

The British Bone Marrow Registry (BBMR) is run by the National Blood Service working in co-operation with the other UK bone marrow/blood donor registries.

Activity Sheets



ACTIVITY 1 – IDENTIFYING ORGANS AND TISSUES

DESCRIPTION SHEET 1

Ask members of your group to match the following descriptions with the correct organ or tissue. Only give them the first clue to start with, then the second, and so on.

Then, with your group, try to think of one or two additional facts about this organ or tissue, to report back on later in the lesson.

Clues

1. This organ was first successfully transplanted in 1967, and now 85-90% of transplant recipients are still well one year later.
2. It is a powerful pump and it is situated in the chest.
3. This organ is made of muscle but can become very diseased.
4. Every year on 14 February (St Valentine's Day) this organ is pictured on thousands of greetings cards.

DESCRIPTION SHEET 2

Ask the members of your group to match this description with the correct organ or tissue. Only give them the first clue to start with, then the second, and so on.

Then, with your group, try to think of one or two additional facts about this organ or tissue, to report back on later in the lesson.

Clues

1. About 60% of these organs are still functioning one year after transplantation.
2. They are sometimes transplanted together with another organ.
3. They can be very badly damaged by smoking.
4. They enable the body to take in oxygen for respiration and get rid of carbon dioxide.
5. They are situated in the chest.

DESCRIPTION SHEET 3

Ask the members of your group to match this description with the correct organ or tissue. Only give them the first clue to start with, then the second, and so on.

Then, with your group, try to think of one or two additional facts about this organ or tissue, to report back on later in the lesson.

Clues

1. Hepatitis C Virus can cause this organ to fail.
2. If this organ is not working properly, it can make you look a yellow colour.
3. This is the largest organ in the body.
4. It is the body's food processor, store house distributor and detoxifying factory.
5. It is situated in the abdomen.

DESCRIPTION SHEET 4

Ask the members of your group to match this description with the correct organ or tissue. Only give them the first clue to start with, then the second, and so on.

Then, with your group, try to think of one or two additional facts about this organ or tissue, to report back on later in the lesson.

Clues

1. This organ was the first to be transplanted.
2. When you drink a lot of water, these organs work hard.
3. As most people have two of these in their body, this is an organ that can be transplanted from 'living donors'.
4. These organs process all the blood in the body to filter out waste products.
5. Due to its distinctive shape and colour, a common bean is named after this organ.

DESCRIPTION SHEET 5

Ask the members of your group to match this description with the correct organ or tissue. Only give them the first clue to start with, then the second, and so on.

Then, with your group, try to think of one or two additional facts about this organ or tissue, to report back on later in the lesson.

Clues

1. Almost all of these tissues are still functioning one year after grafting, and the long-term success rate is excellent.
2. Recipients have a tissue graft, rather than an organ transplant, since it is not a whole organ that relies directly on a blood supply.
3. When these tissues are diseased, it may not be possible to drive, watch television, read and write.
4. They enable light rays to pass into the body so that we can see clearly.

ACTIVITY 2: TRANSPLANT QUIZ

1. A person who gives an organ or tissue to another is called a ____ (5).
2. The organ that pumps blood around the body (5).
3. Name for a heart, lung, liver, etc. (5).
4. The transparent "window" at the front of the eye (6).
5. This organ filters waste products out of the blood (6).
6. In the video, Billy was undergoing kidney _____ before he was offered a transplant (8).
7. Heart, lungs and liver are all organs that can be _____ from one person to another (12).
8. The transplant _____ talks to the relatives of a potential organ donor (11).
9. Even if you asked for your organs to be donated after your death, your _____ are always asked (9).
10. One person's ____ can give another the gift of life (5).
11. These are used to take in oxygen (5).
12. A person who receives an organ or tissue from another is called a _____ (9).
13. The largest organ in the body (5).
14. Sometimes transplanted organs can be _____ by the body (8).
15. It has to completely stop functioning before a person's organs can be donated (5, 4).

ACTIVITY 3: TRANSPLANT QUIZ

1. Put a ring round the parts of the body that can be transplanted.

Brain Bone Cornea Kidney Heart Lungs Liver Pancreas Bone Marrow

2. A donor is someone who gives an organ. TRUE/FALSE
3. Transplant patients take drugs to prevent their new organs being rejected. TRUE/FALSE
4. Once kidneys or a liver have been surgically removed from a donor, they can be used months later. TRUE/FALSE
5. Carrying a donor card shows that you would like to be a donor after your death. TRUE/FALSE
6. A recipient is a person who receives a transplanted organ. TRUE/FALSE
7. Anyone can successfully donate a kidney to anyone else. TRUE/FALSE
8. There are more than enough organs and tissues available for transplants. TRUE/FALSE
9. Tests for brain stem death are carried out by two doctors not connected at all with the transplant teams. TRUE/FALSE

SOLUTIONS TO ACTIVITIES

ACTIVITY 1: IDENTIFYING ORGANS AND TISSUE

Solution

1. Heart
2. Lungs
3. Liver
4. Kidney
5. Cornea

ACTIVITY 2: TRANSPLANT QUIZ

Solution

1. Donor.
2. Heart.
3. Organ.
4. Cornea.
5. Kidney.
6. Dialysis.
7. Transplanted.
8. Co-ordinator.
9. Relatives.
10. Death.
11. Lungs.
12. Recipient.
13. Liver.
14. Rejected.
15. Brain Stem.

ACTIVITY 3: TRANSPLANT QUIZ QUESTIONS

Solution

1. Bone: Cornea: Kidney: Heart: Lungs: Liver: Pancreas: Bone Marrow.
2. True.
3. True.
4. False.
5. True.
6. True.
7. False.
8. False.
9. True.

Personal Reflections

62/63



PERSONAL REFLECTIONS

From Darkness

It is a light, so crisp, so sharp,
That has invoked a pain deep inside,
My views are of that never seen,
Yet no words....I hide.

I shadow with a vengeance,
A fear of something not known,
I feel that I am surrounded,
And yet, still so alone.

I uncover with some courage,
Some faith and great trust,
I want to share all the beauty,
It's not a choice, it's that I must.

My life has been that of darkness,
For which I've lived throughout each day,
Never a glimpse of friendly faces,
No smiles were seen my way.

But, today I live rejoicing,
For I know that God has might,
After many years of blindness,
I've been given the gift of sight!

(by Angela Maskin – wife of cornea transplant
surgeon, Steven L Maskin)

Published by the National Library of Poetry

Poem to my Donor's Family

Two families,
Each unknown to the other,
Yet bound together
Forever and irrevocably
By a golden chain
Whose links are
Love, unmatched generosity,
And indescribable gratitude.
Today is forever burned
Into the memories of both families.
One will remember with sadness
The tragedy which took their loved one.
The other will remember with joy
The gift which gave their loved one back to them.

Ah! That wonderful gift!
The gift of life!
Praise be to God
For families who can, despite their grief,
Give to others so they might live.

You are my donor family.
I am the recipient of your loved one's heart.
How can I ever say "Thank You"?
I pray for you every day
And thank God for you every day.
Because of your gift...your wonderful gift...
I walked down the aisle at my son's wedding.
I saw my other son graduate from college.
And I have faith I will see my grandchildren.

May God bless you and keep you;
May he comfort you and strengthen you.
This is my prayer for you.
My wonderful donor family.
I will always carry you in my heart.

*Mildred Calvert – received a heart transplant
28 May 1998*

Sarah (aged 12) wrote this about her family's decision to donate her brother's organs after he sustained fatal head injuries on Millennium night.

"When my family was told that we could give his organs, I knew my mum and dad would say 'yes' and there was no doubt about that. It made me feel there was a bit more happiness for me and my family and other families around the world.

I think people should give organs because you feel like a good person and you are helping others."

Catherine now aged 19 describes how she felt when involved in the decision to donate her brother's organs. He was 15.

"Nothing in this world can prepare you for the death of someone you love. There are no remedies awaiting to ease the throbbing pain. The reality just becomes a ticket to a different way of life, a life of coping and hopefully growing. I remember when we were asked about donation. I remember thinking it was all very quick, I still hadn't accepted my brother was dead let alone whether or not I was comfortable donating his organs. However my family, Mum, Dad my sisters and myself all sat down together and discussed what we thought. Looking back I suppose the overriding feeling was that we just couldn't say 'no'..."

Jane, a close friend of a donor describes how she felt:

*"Time begins to alter, expanding, contracting, spiralling
There is no rhythm to this time
Our boy gives life to five families
Their families explode with anticipatory joy, ours
burn pain into the fabric of our lives."*

Glossary of Terms



GLOSSARY OF TERMS

Anaemia	A shortage of red blood cells in the body, causing tiredness, shortness of breath and pale skin.
Blood group	An inherited characteristic of red blood cells. The common classification is based on whether or not the person has certain antigens (called A and B) on their cells. People belong to one of four groups, called A, B, AB and O.
Brain haemorrhage	Bleeding into the brain substance.
Cadaveric organ donor	A person who has donated organs after death.
Cornea	The curved transparent structure forming part of the outer coat of the eye.
Diabetes	A disorder characterised by high levels of glucose (sugar) in the blood stream due to insulin insufficiency.
Graft	A transplanted organ or tissue.
Haemodialysis	A treatment for kidney failure in which blood is purified by passing it across an artificial membrane to remove waste products.
Heart valves	A fold of membrane that permits the flow of blood in one direction. The four major heart valves are the mitral, tricuspid, aortic and pulmonary valves.
Hepatitis	Inflammation of the liver.
HIV	Human immunodeficiency virus, the virus that causes Acquired Immunodeficiency Syndrome (AIDS).
Hypertension	High blood pressure.
Mortality rate	The ratio of the total number of deaths to the total population.
Peritoneal dialysis	A treatment for kidney failure where fluid is inserted into the peritoneal cavity via a catheter. The toxins and excess fluid are then drawn across the peritoneal membrane back into the fluid.
Persistent vegetative state	A state where a person has suffered a severe brain injury resulting in a coma with sleep and awake cycles but no evidence of awareness.
Primary biliary cirrhosis	A slow, chronic liver disease that can gradually destroy the bile ducts within the liver.
Rejection	The process by which the immune system recognises a transplanted organ as not its 'own' and then tries to destroy it. Rejection can be acute or chronic.
Renal angiogram	A type of X-ray that looks at the kidney's blood vessels.
Tissue typing	A set of proteins on the surface of the cells which can be numbered to provide a 'tissue type'. The three main sorts of tissue type characteristics (called A, B, and DR) are used for matching in kidney transplantation.
Transplant	The replacement of an organ or tissue in the body.
Xenotransplantation	The transplanting of tissue or organs from one type of animal into a human or other type of animal.

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