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Deceased donor transplants

This chapter describes the issues surrounding the use of kidneys from deceased donors for transplantation. We look at the different types of deceased donor, the waiting list for a deceased donor transplant and what needs to happen before you go on it. Then we look at your rights and those of the donor's family. We also provide information on preparation for the transplant operation and what to expect afterwards.

Deceased donor transplants use the kidneys that have been removed from someone who has died; approximately 65% of the kidneys transplanted in the UK come from this source. Kidneys may be removed from people who have died and are either 'heartbeating donors', or 'non-heartbeating donors'. The remaining 35% of kidneys transplanted are from living donors (see Chapter 4) (data: UKT). The proportion of transplants using kidneys from living donors is increasing each year. This is partly because fewer and fewer kidneys are available from deceased donors. But the fact that more transplants are coming from living donors is actually a good thing; as these types of transplants are easier to plan and are much more likely to be done before the patient needs to start dialysis.

HEARTBEATING DONORS

A heartbeating donor is someone who has been on a life support machine (ventilator) in an intensive care unit. They may have been killed in a car accident or have died from a stroke. The ventilator is breathing for them. Kidneys are only removed after a person has been diagnosed 'brain dead'. This means the part of the brain called the brainstem, which controls breathing, has stopped working permanently, and the person is legally certified as dead. The doctors then record this in the medical notes.

The concept of 'brain death' was developed in the 1960s when it became possible to keep brain dead patients alive almost indefinitely on ventilator machines, despite there being very little chance that they would recover. Therefore, a series of tests were developed that check the function

of the brain stem and can diagnose brainstem death. These have to be performed twice by senior doctors before death can be certified. If the person who is having the brainstem death tests is considered a potential donor, their family will be approached by the intensive care team and a transplant coordinator so that possible donation of their loved one's organs can be discussed. This is obviously an enormously difficult time for the family, and all the members of the healthcare team make great efforts to support and inform the family through this period.

Research that has looked into the feelings of the families of donors has shown their grief is mostly about the death of their loved one. Organ donation cannot make this worse; in fact often the donor family sees it as a positive factor in an otherwise tragic event.

Brainstem death is irreversible, and the person's ability to breathe for him or herself will never return. A person who is brain dead will never wake up, indeed they are not only 'brain dead', but are dead. A death certificate can be issued.

If the person on the life support machine had no organs suitable for donation, the machine would be switched off at this point. If the person is going to be a donor, however, any organs for donation (such as kidneys, liver or heart) will be removed in the operating theatre. These donors are sometimes called 'heartbeating donors' as the heart is still beating when the operation starts.

As most people have two kidneys, two kidney patients are usually able to benefit from the donation of kidneys from one deceased donor.

NON-HEARTBEATING DONORS

Transplant kidneys can also be removed from people who have been dead for up to 30 minutes. These donors are called non-heartbeating (or asystolic) donors or donors after cardiac death. They may be people who have died very suddenly, usually from a heart attack, severe stroke or head injury, and have no chance of survival. Their hearts have stopped beating, and they are dead. However, they have not necessarily been put on a life support machine.

If you are given a transplant kidney from a non-heartbeating donor, it is likely that the kidney won't work straight away and you will need to have dialysis for a few days or weeks after the operation. Even if the kidney doesn't work straight away, it is just as likely to work in the long term as any other kidney from a deceased donor, and the long-term success of these transplants appears to be the same.

If you are offered a deceased donor transplant, you can ask whether it is from a heartbeating or non-heartbeating donor. You have a right to this information.

Approximately 10% of kidney transplants in the UK are from non-heartbeating donors. Most kidney transplant units in the UK now perform some transplants using kidneys from non-heartbeating donors, and would like to increase the numbers of these transplants. It is harder to organise a non-heart beating transplant than a heartbeating one, as you have to get a surgical team to the donor in less than 30 minutes. We believe that all units should make more effort to carry out such transplants. And, until they do, good kidneys are going to waste.

THE TRANSPLANT LIST

At present, not enough kidneys are donated from deceased donors to meet the demand for kidney transplants. The introduction of seat-belt laws and improvements in medicine mean that fewer people now die as a result of the accidents or illnesses that, in the past, would have made them suitable donors.

People who are waiting for a deceased donor kidney are therefore put on to a list. Their details, including their blood group and tissue type (see Chapter 2), are put onto a national computer at UK Transplant (UKT) in Bristol. When surgeons remove two kidneys from a patient who has died, UKT finds the most suitable patient for each kidney – either locally or in the rest of the country. Kidneys from heartbeating donors are allocated through this national scheme, while kidneys from non-heartbeating donors are allocated by the local transplant centre.

The national organ allocation scheme works on the basis of finding the ‘right’ kidney patient for the ‘right’ donor kidney, when one becomes available. It does not work on a ‘first-come, first-served’ basis. It is not really a waiting list, more of a register. A nationally agreed priority order and ‘scoring system’ decides where the kidneys go. Transplants are allocated to the patient who has the highest priority and points score. Points are allocated according to the best match for the kidney in terms of blood group and tissue type, and the length of time that someone has been waiting. More points are given to younger than older adults, and children have priority for well-matched kidneys. In other words, you are not joining a queue, knowing that your name will come up after a reasonably fixed period of time. However, the longer you wait, the more the points scored, and the greater the chances that you will be offered a

kidney. It is important to stress though that the offer of a kidney is never guaranteed until it actually happens. There are simply not enough kidneys available to offer a transplant to everyone who is suitable.

Even though attempts have always been made to make the kidney allocation system as fair as possible, there has been a tendency for some people to be disadvantaged. This includes people with rare tissue types, who are often of Asian, black or mixed race. This disadvantage is made worse by the high number of Asian people with blood group B, because there are very few blood group B donors. Most donors are white, and their tissue type is generally more likely to be a good match for white patients. Under the kidney allocation system used in the UK in the 1990s, Asian people on the transplant list had only a 50% chance of getting a transplant compared with white people. The kidney allocation system introduced by UK Transplant in 2006 tries to make the allocation system fairer by transferring some blood group O kidneys to blood group B patients, and by making tissue typing match less important in the allocation system. However, it may still be difficult for people with an unusual tissue type to receive a transplant.

KIDNEY ALLOCATION

The way kidneys from deceased donors are allocated to people on the transplant list has changed in the last few years in the UK, but remains a topic of much debate.

The 2006 allocation system gives priority to children and young adults, those who have been waiting for a long time, and to good tissue type matching between the donor and recipient. Allocation also takes some account of the ages of the donor and recipient (so that kidneys go into a recipient of a similar age to the donor), and the distance between the donor and potential recipient (so the transplant operation can be done as soon as possible after removing the kidney from the donor). This is a national system, and a computer allocates kidneys by calculating the number of 'points' for each potential recipient.

Some people feel that this system is very inflexible. They argue especially that not everyone on the transplant waiting list is medically the same. Some people are very stable on dialysis, others have complications from dialysis and argue they will die soon if they do not receive an urgent transplant; for example, they are running out of 'access' into their bloodstream for dialysis.

The previous allocation system allowed far more kidneys to be allocated according to the unit's preference, so that 'clinical urgency' could be taken into account. Using the 2006 allocation system, about one kidney in every seven is still allocated according to centre choice, and the option of allocating kidneys to patients where the situation is clinically urgent still remains.

The current system may also be a problem for people with many antibodies against other people's tissue types, as a kidney to which they have no antibodies may be offered to someone else.

Other people say that only about 1 in 5 people on the transplant list will get a transplant every year, and that it is almost impossible to decide what is fair allocation. Why should people doing 'badly' on dialysis get priority for kidney offers? Aren't the people doing 'well' on dialysis just as deserving? Also, very few people die just because they are having problems with dialysis; they tend to have other life-threatening problems as well.

Some people think that it is up to people from ethnic minority groups to donate more organs, because at the moment more kidneys are donated by white people. However, transplant rates have increased substantially in ethnic minority patients under the new allocation scheme introduced in 2006.

The allocation system does not take account of whether people have young children to look after, or whether they will have a job and can be useful to society after a transplant. This is a concern for some people, but others say that you cannot make judgements of 'social worth' and use them to allocate healthcare treatments.

Many kidneys used to be allocated to the kidney patients who lived in the same region as the donor. This meant that patients living in parts of the country with higher donor rates and lower kidney failure rates could be four times more likely to receive a kidney than someone living in an area where there were fewer donors and more kidney patients. Some people even went so far as to move house so they could be in a 'better' donor area. However, as kidneys have become allocated on a more national basis, allocation is fairer and you should not lose out because there are fewer donors near where you live. But, as we go to press, the system has only just stopped being unfair in the way that is shown in the table on page 28.

Allocation of kidneys for transplantation is a subject that is hotly debated by UK Transplant at regular intervals. The kidney allocation system is subject to regular review, and details of the current policy are on the UK Transplant website. What do you think? The views of kidney patients are given to UK Transplant directly through patient representatives on their decision-making groups, and through local Kidney Patient Associations and the National Kidney Federation. So if you have strong views, you can – and should – make them heard.