

# What I tell my patients about renal transplants in children

People with chronic renal failure will eventually need dialysis or a transplant. This article provides information for children and young people about to undergo renal transplantation.

Knowing what to expect can make the whole process easier to deal with. There will be a number of different people in the transplant team who will be looking after you. Try to meet some of them beforehand, and look around the ward where you will be nursed after the operation.

## Before the operation

### **Are there different types of transplants?**

A new kidney can either come from someone that you know (a living donor) or from someone who has died in hospital (deceased or cadaveric donor). You can discuss with your transplant team which type would be most suitable for you. The two advantages of living donation are that the results are slightly better, and the operation can be planned in advance.

With a deceased donor transplant, you go on a waiting list and when any kidney becomes available in the UK, it goes to the best-matched person. Children are more likely to get a kidney than adults but, because kidneys are allocated according to match, children with an unusual tissue type may wait longer than someone who has a more common tissue type.

The disadvantage of living donation is that the donor has to undergo an operation that does not improve their own health. Therefore, we always make sure that the donor is healthy beforehand. For some people, although a family member may wish to give a kidney, it may not be possible; for example, if they have a different blood group or a medical condition that would prevent donation.

### **Will the kidney be a good match?**

There are certain markers on the cells of your body that only you have (tissue type). We aim to get a kidney that is close to your own tissue type. This means that you are less likely to develop immunity (antibodies) against the kidney (if your body rejects the kidney) and it will then be easier to get a second kidney, if needed.



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### **What happens before the operation?**

Tests will be performed that will give us information about your blood group, your tissue type and some information about your general health, including immunity to some viruses. You will have blood tests, urine tests, a heart scan (also known as an echocardiogram or echo), a heart tracing (electrocardiogram or ECG), ultrasound scans and X-rays to give us information about your kidneys and bladder. You will also have a magnetic resonance angiogram (MRA) to look at the major blood vessels in the abdomen, where the new kidney will go. You may be given vaccinations against chickenpox, hepatitis B and tuberculosis (TB), if required. All of these tests can take a few months to complete.

### **How long will I wait?**

The average time to wait for a deceased donor transplant is about three months; some children will wait for less time and some will wait longer. The time depends on your blood group, your tissue type (how rare or common it is) and how good a match is requested. A good match will mean that it will be easier to get a second or subsequent graft if you need one when you are older. If the kidney is coming from a relative, you will be given a date for the operation. If it is coming from a deceased donor, you will be contacted when a kidney becomes available. When you are on the waiting list, the renal unit needs to be able to contact you

*Having a kidney transplant may seem scary, but the more you know about it, the easier it will be to deal with*

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easily when a kidney becomes available and you need to be able to get into the hospital quickly.

### **What happens before the operation?**

You will be admitted to hospital; blood tests will be taken and, possibly, also some X-rays. You will be examined to make sure you are fit for the operation. If you are on haemodialysis, you may receive an extra session. Your blood will be tested with tissue from the donor to make sure there is no reaction. This is called the cross-match and it takes about four hours to get the result. If there is no reaction (a negative cross-match) the operation will go ahead. With a living donor transplant, this will already have been done. Immunosuppression medicines (to prevent your body rejecting the kidney) will be started and you will go to theatre. Your parents will be able to stay in the theatre with you until you are asleep.

### **What if I am really scared?**

Everyone gets scared before an operation. Knowing exactly what is going to happen can make it easier. Always ask if you have questions and don't be frightened to say if there is a different way you would prefer things done. One of your parents will be able to stay with you, and it may be possible to arrange accommodation for your family near to the hospital, if you come from far away.

### **During the operation**

The operation itself takes about two to three hours. The new kidney will be placed low down in your abdomen (into the pelvis), attached to a big artery and vein, and the tube draining urine from the kidney is sewn into the bladder. For most children your own kidneys will be left in place, unless they are causing infections or very high blood pressure, when they may be removed either before or at the time of the transplant operation.

### **After the operation**

#### **Where will I be looked after?**

The first few hours after the transplant operation are very important. In some units, you will go to the intensive care unit (ICU) or a high dependency unit, or you may go straight back to the ward. Wherever you go, you will be monitored very closely. If the kidney is working well, it often passes large volumes of urine and it is important that your fluid intake keeps pace with this. For this reason, an intravenous line in one of the large veins in your neck will be used to monitor the pressure in your veins, which tells us whether enough fluid has been given.

### **Will I have lots of tubes?**

You will have a tube in your bladder (catheter) and possibly another small tube draining the new kidney (stent). There will also be a tube draining the wound. You may have a tube in your nose that goes down to your stomach (nasogastric tube) and a drip into one of the veins in your neck. There may also be a tiny tube into your spine to make the bottom half of your body numb (epidural).

### **Will it be sore?**

Great care will be taken to make sure that you are not sore after the operation. An epidural anaesthetic will make the lower half of your body numb and you will also get some medicine into one of your veins to prevent pain. If you are old enough, it is possible for you to have control over this drip yourself (also known as patient-controlled analgesia or PCA). Most children's hospitals will have a pain team – a specialist team of doctors and nurses whose job it is to make sure that patients are very comfortable after operations. If you are sore, you must tell the nurse who is looking after you.

### **Will my medicines be different?**

Yes! They are likely to be completely different from the ones you were taking before the operation. Immunosuppressants are the main medicines that you will need to take (see Table 1, opposite for some of the other medicines that you may have to take). Most patients will take three different immunosuppressants. You may also receive injections of a type of medicine called 'monoclonal antibodies' at the time of transplant. All of these medicines work by dampening your immune system, to prevent your immune cells (white cells) harming the new kidney, which they will recognise as being different to your own body.

Medications called steroids and either ciclosporin or tacrolimus are given at high doses early on and later reduced. The blood levels of ciclosporin and tacrolimus need to be checked regularly. In addition, you will receive azathioprine or mycophenolate mofetil at a reasonably steady dose. There are also some newer medicines that your transplant team may feel you would benefit from. As with most medicines, there are side-effects that you should know about (see Table 1, opposite). The list of side-effects seems long but not all patients suffer all of these effects and measures can be taken to reduce them.

### **What are the effects of immunosuppression?**

The main complication is infection. Bacterial infections, such as urinary tract infections (UTIs),

**Table 1. Some medication for transplant recipients, and its side-effects**

Medication	Side-effects
Steroid (prednisolone)	Increased appetite, diet, stretch marks (striae), poor growth, diabetes, acne, high blood pressure and reduced bone strength
Ciclosporin	Reduced kidney function, high blood pressure, increased body hair (hirsutism), thickening of the gums (gum hypertrophy)
Tacrolimus	Reduced kidney function, high blood pressure, diabetes
Azathioprine	Reduced white cell count
Mycophenolate mofetil	Diarrhoea, abdominal pain, reduced white cell and platelet count

are most common in the early stages after your operation. Later on, viral infections like chickenpox can cause a problem. We can test for viruses and give treatment or adjust your medication if you pick one up.

You must know whether you have immunity to chickenpox in your blood. If you do not have antibodies, you must try and avoid coming into contact with other people with chickenpox. If you do come into contact with someone with chickenpox you must let the renal unit know, so that they can arrange for you to be given an injection of antibodies to chickenpox.

#### **Will my diet be different?**

If your new kidney is working well, your diet will no longer be as restricted as before, and you can eat a normal, healthy diet. Steroids may make you very hungry, so you should be careful not to eat too much. Transplanted kidneys may pass lots of urine, so you may have to drink more to keep up with this.

#### **Will there be complications?**

As with any operation, there may be some complications. Sometimes the kidney does not work right away, and you may need to go back on dialysis. You may get an infection in your chest or wound, or a UTI, which will need antibiotic treatment. There may be some bleeding around the new kidney but this is rare. Sometimes the tube draining urine from your kidney to your bladder (ureter) may get blocked or may leak. These complications might require another operation.

You will be on medicines to stop your body rejecting the kidney, which it recognises as being different from your body. You will have regular blood tests; rejection is picked up by an increase in one of these tests called creatinine, which tells us how well your kidney is working. Most episodes of rejection can be treated with extra steroid medication, given intravenously. When rejection

is suspected, a biopsy (an operation to remove a small amount of kidney tissue for testing) will be performed to confirm it.

Occasionally, the disease that damaged your kidneys in the first place may recur and affect the transplanted kidney. This is most likely for people who have focal segmental glomerulosclerosis (FSGS) or atypical haemolytic uraemic syndrome (HUS). High blood pressure (BP) is common after transplantation and your BP will be monitored closely.

#### **How long will I be in hospital for?**

This will depend on whether there have been any complications, but usually children are in hospital for seven to ten days. It is important that blood tests are checked regularly to make sure that the kidney is working properly, so after that time you will still need to go to hospital frequently. The exact number of visits will depend on how well the new kidney is working. It is usually possible to have school work available to do in hospital so that you do not get too far behind. The hospital teachers can speak with your school and make sure that they know the best work to give you.

#### **Follow-up**

##### **When can I go back to school?**

Most children will be off school for about six weeks. You can go back when you feel able. It is best to stay off gym or sports at first. If you are tired initially, you could go back for a half day at first. When you are at school it is better to stay away from people who are obviously ill.

##### **What should I tell my teacher and friends?**

It is important that your teacher knows that you have had a kidney transplant and are on medication to prevent rejection, because this will make you more likely to get some infections. One of the most important infections to avoid is chickenpox.



### **What happens if I become unwell?**

Early on after a transplant, when the levels of immunosuppressants are high, it is important that you contact the renal unit if you are unwell, so that they can advise you what to do. You may need to be examined and given treatment. In the early days after a transplant, it is always better to be cautious.

### **When can my PD catheter come out?**

If you have a peritoneal dialysis (PD) catheter, it can be removed once it is clear that your new kidney is working well. This usually takes place about two to three months after the transplant.

### **Should I avoid any sports?**

It is important to remain active after a transplant, as exercise will keep your weight down and helps keep the blood pressure under control. The only precautions necessary are to avoid rough contact sports, where the kidney could be damaged. The new kidney is placed in the pelvis, where there is less muscle to protect it, so avoid contact sports where you might get a blow to the area. Other sports are good and you should try and do as much sport as you can.

### **How often do I need to come to hospital?**

After six to nine months, most patients attend the hospital once a month. At these visits you will have a blood test, your BP checked and a sample of urine tested. You will usually see the doctor or a nurse, and perhaps the dietitian and pharmacist or other members of the team. Once a year you may have some more detailed tests performed.

In some units it is possible to see the results of your blood tests on the internet. This is through a system called Renal PatientView (see Box 1 or *What I tell my patients about Renal PatientView*, by Neil Turner, in issue 11.1 of the *British Journal of Renal Medicine* for more information). Some people find this really helpful. You will need passwords for this and only you or your family will be able to see the results.

## **Key points**

- **The average time to wait for a deceased donor transplant is about three months.**
- **Your medications are likely to be completely different from the ones you were taking before.**
- **Transplanted kidneys do not last forever but they can last for a long time if they are well looked after.**

## **Box 1. Useful websites**

- **UK Transplant:** [www.uktransplant.org.uk](http://www.uktransplant.org.uk)
- **Renal PatientView:** [www.renalpatientview.org](http://www.renalpatientview.org)
- **National Kidney Foundation:** [www.kidney.org/transplantation](http://www.kidney.org/transplantation)
- **The Renal Association:** [www.renal.org/Patients/patients.html](http://www.renal.org/Patients/patients.html)

### **What happens if I do not take my immunosuppression medicines?**

Patients who stop their medicines usually lose their kidney. You may not notice any difference at first, but eventually the kidney will be rejected. This is a particular problem for teenagers after a transplant and it is worthwhile getting into a routine of taking your medicines regularly. As you get older, you should take more responsibility for your medication, rather than letting mum and dad do it all! Take the medicines at a time when you are most likely to remember them; for example, before or after breakfast and at bedtime. Medicines during the day are more difficult to remember, and if you are struggling with a particular medicine, speak to your doctor or renal unit pharmacist, who may be able to change or adjust the way it is taken. Similarly, if there are side-effects that you find really difficult, speak to someone to see if it is possible to try a different medication.

### **Will I need to take medicines forever?**

Yes. Most patients will need to remain on their immunosuppression medicines, although the doses will become fewer with time.

### **How long will the kidney last?**

Transplanted kidneys do not last forever but they can last for a long time if they are well looked after. About 76% of deceased donor transplants will still be working after five years, and for living related transplants the figure is 86%. More than half of transplants will be working after ten years. Transplants in patients younger than 11 at the time of transplantation do better than those in patients older than 11. We think this is because the older ones are less likely to take all of their medicines. You can find more information on the UK Transplant website (see Box 1, which includes other websites that you might find helpful) ■

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# The Human Tissue Act – what are the implications for the renal community?

The *Human Tissue Act 2004* was fully implemented on 1 September 2006.<sup>1</sup> The Act set a framework for regulating the storage and use of human organs and tissue from the living, and the removal, storage and use of tissue and organs from the deceased, for specified health-related purposes and public display. It covers a wide range of sectors, including pathology, anatomy, museums, tissue banks and transplantation, although this review will focus on the latter. The regulatory body, which has been set up under the *Human Tissue Act*, is the Human Tissue Authority (HTA) and this was established on 1 April 2005. Transplantation is one of the specified health-related purposes under the Act and there are a number of key points that affect organ donation and transplantation from deceased and living donors (Table 1).<sup>1</sup>

## The Human Tissue Act 2004

The high profile issues surrounding organ retention in Liverpool and Bristol made it clear that the legislation surrounding the removal, retention and use of human tissue and organs required change. There were also aspects of the legislation relating to transplantation and anatomy that required clarity and review. *Human Bodies, Human Choices*<sup>2</sup> was prepared to inform the preparation of new legislation and went out for consultation in July 2002. From this the Human Tissue Bill was drafted with the resulting *Human Tissue Act*<sup>1</sup> receiving royal assent in November 2004.

At the heart of the *Human Tissue Act* lies the need to obtain consent for the removal, storage and use of bodies or human tissues for scheduled purposes. These scheduled purposes include transplantation, anatomical examination, determining the cause of death, research and public display.

The *Human Tissue Act* repeals and replaces the existing *Human Tissue Act 1961*, the *Anatomy Act 1984*, the *Human Organ Transplants Act 1989* and the equivalent legislation in Northern Ireland. It will apply to England, Wales and Northern

Ireland. There is a separate *Human Tissue (Scotland) Act 2006*.<sup>3</sup> Both Acts commenced fully from 1 September 2006. In practice this means that both the Unrelated Live Transplant Regulatory Authority (ULTRA) and human organ transplant (HOT) testing will both no longer be required, as all living donor transplantation will be regulated by the HTA, although there will be a transition period.

Offences under the *Human Tissue Act* that relate to transplantation are:

- The removal, storage or use of human tissue for a scheduled purpose without consent
- The storage or use of human tissue donated for one scheduled purpose being used for another one
- Trafficking in human tissues for the purposes of transplantation.

## The Human Tissue Authority

The HTA was set up on 1 April 2005 under the *Human Tissue Act* and is an executive non-departmental public body sponsored and part-funded by the Department of Health. The authority currently consists of 17 members (eight professional and nine lay). The broad remit of the authority is to:

- Inform the public, professions and Secretary of State about those issues for which the authority is responsible
- Issue codes of practice

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**Table 1. Summary of the key parts of the *Human Tissue Act 2004* that relate to organ transplantation<sup>1</sup>**

### Deceased donor transplantation

- Consent – the wishes of the deceased when they were still alive take precedence
- It is lawful to preserve non-heartbeating organs for transplantation while awaiting consent

### Living donor transplantation

- This is regulated by the Human Tissue Authority
- It is an opportunity for paired or pooled donation and non-directed altruistic donation
- Trafficking of human organs is illegal