

Having a kidney transplant from a deceased donor

Kidneys can be donated from live donors, or from those who have died (a deceased donor). This leaflet explains more about having a kidney transplant from a deceased donor, including the benefits, risks, alternatives, and what you can expect at the time of the transplant. (The figures we quote in this leaflet relate to the Guy's and St Thomas' NHS Foundation Trust kidney transplant programme).

If you have any further questions, please speak to a doctor or nurse caring for you.

What is a kidney transplant?

A kidney transplant is a treatment for patients with kidney failure. A kidney is removed from one person (the donor) and given to another person (the recipient). There are alternative treatments, but a kidney transplant is usually the best treatment for kidney failure patients who are fit enough for the operation. A kidney transplant is not a 'cure', and has risks as well as benefits.

Why should I have a kidney transplant?

For most patients, having a kidney transplant leads to a better quality, and longer, life. This is because you no longer have to rely on dialysis; you have more freedom to travel and work, and can eat and drink more freely. Most people say they have more energy and feel more able to cope with everyday activities.

Your sex life and fertility are likely to improve. If you are a woman of childbearing age you will usually be able to conceive after a transplant, although we suggest you wait one year before trying for a baby.

What are the risks?

As with any medical procedure there are risks associated with kidney transplantation and it is important to understand these. Most deceased donors will have had long-term health problems before their death. Where relevant we will discuss these with you before your transplant.

Some of this information may be worrying, but we believe it is better for you to understand the potential risks as well as the potential benefits of having a deceased donor kidney transplant. Everyone's situation is different and we will talk to you about your individual risks and benefits before a decision is made about adding your name to the national transplant pool.

Primary non-function

Sometimes the new kidney transplant never works (we call this 'primary non-function'). This happens in between three to five out of every 100 kidney transplants. The failed transplant may then need to be removed by the surgeon.

Delayed kidney function

About half of kidney transplants from deceased donors start to work within a few hours of surgery. If this doesn't happen, (called 'delayed graft function' and sometimes referred to as 'sleepy kidney'), you will need dialysis until the new kidney starts working. This may be a few days or sometimes a few weeks. You will need regular ultrasound scans of the kidney and a once weekly kidney biopsy (where a tiny piece of tissue is removed from your kidney with a needle and examined under a microscope) to make sure that there are no other problems..

Infection

In the first few weeks after a kidney transplant you may get an infection in your chest, surgical wound, or urine. This happens in approximately 10 to 20 out of every 100 patients. These infections can usually be treated with antibiotics, but sometimes another operation is needed.

Bleeding

Between 20 and 40 out of every 100 kidney transplant patients need a blood transfusion after surgery. Of these, five to ten might need a further operation to stop the bleeding. If you are taking blood-thinning medications such as warfarin, you are more likely to need a blood transfusion and to need another operation.

More surgery

A further operation may be needed for bleeding, infection, or to rule out any problems with the first operation. Between five and ten out of every 100 patients may develop a hernia or 'rupture' in the transplant scar and may need an operation to repair this.

All patients who have a kidney transplant will need to have the plastic tube (stent) that has been placed between the new kidney and the bladder removed. This is done four to six weeks after your transplant in the operating theatre as a day procedure. Occasionally more surgery is needed months or years later if complications occur.

Rejection

Sometimes your body may recognise the new kidney as foreign and start to attack it. This process is called rejection. Between 10 and 20 out of every 100 patients who have had a kidney transplant will have an episode of rejection during the first year. Rejection is diagnosed by taking a kidney biopsy. Most episodes of rejection can be treated by increased doses of immunosuppressant medication.

Risks of immunosuppressant medications

You will need to take medication to suppress the immune system during the whole time that the kidney transplant lasts. This medication has side effects including an increased risk of infection and, in the longer term, cancer (particularly skin cancer). Other side effects include a higher risk of high blood pressure, high cholesterol (a fatty substance found in the body that can cause narrowing of the blood vessels), and diabetes (a condition in which there is too much sugar in the blood).

While you are in hospital, the kidney pharmacist will talk to you about these possible side effects and how to monitor and manage them. For example, using sun protection creams to reduce the risk of skin cancers. At your transplant follow-up clinics we will check your blood pressure, cholesterol and blood sugar.

Diseases passed on from the donor

In rare cases, the transplanted kidney may unknowingly carry diseases such as cancer or infection. All deceased donors are tested for viral infections such as HIV (which attacks the immune system), hepatitis B or C (viruses that can cause liver damage). All organs are inspected carefully for signs of cancer. Overall, less than one in every 1000 transplanted organs will unknowingly carry a cancer or a serious viral infection like HIV, hepatitis B or C.

If we know that the donor had a history of cancer or had a higher than average risk of HIV or hepatitis B or C, your doctors will discuss this with you before the transplant. If you think that the risks are too high you can decide not to go ahead with the transplant. This will not affect the rest of your treatment and you will not lose your place in the kidney transplant pool.

Other infections, for example with cytomegalovirus (CMV), are very common in the community and are commonly caught from transplanted organs, but cause little or no long-term harm. You may need to take medication to reduce the risk of these milder infections, and we will discuss this with you at the time of your operation.

Other risks

Between one and two patients out of every 100 may develop a blood clot in the legs or lungs after kidney transplantation. Heart attacks or strokes are uncommon, affecting between two and three of every 100 patients after transplantation. These problems are more common in older patients and those with previous heart or blood vessel problems. Aspirin is given to reduce the risks of these problems.

Survival

Sadly between four to six out of 100 patients will not survive the first year after kidney transplant surgery. This is due to complications from the surgery, complications from the immunosuppressant medications or other health issues.

Are there any alternatives?

If you have kidney failure you must have specialist treatment to keep you alive. Your kidney care team at your local renal centre will have discussed the different types of treatment with you and will have given you information to read. You may also wish to visit our website www.mykidney.org.uk for further information. Apart from deceased donor kidney transplantation, the other treatment options are:

- **Live donor kidney transplant** – a kidney transplant from a live donor is a very good option, as they tend to work straight away, and usually work for longer than a kidney from a deceased donor. However for many kidney patients finding a suitable live donor can be difficult. Please ask us for more information about other types of kidney transplants if you require it.
- **Dialysis** – an artificial process by which the toxic waste products of food and excess water are removed from your body. Although dialysis will keep you alive, long-term dialysis can result in problems such as hardening of the arteries and thickening of the heart muscle. Dialysis can be either haemodialysis (HD) or peritoneal dialysis (PD). You can ask the team caring for you for more information on the different dialysis options.

The main complications of HD are associated with getting access to your blood. This is done via a fistula (where an artery and vein are joined in a small operation), graft (a small piece of plastic connecting your artery and vein) or dialysis line (a small plastic tube in your neck) and this may become more difficult with time.

The main complication associated with PD is infection in the abdomen (tummy). Rarely, PD patients can develop thickening and scarring of the lining of the abdomen; this is thought to be related to staying on PD for many years.

- **Conservative management** – managing the symptoms of kidney failure without the use of dialysis or choosing not to have dialysis or a kidney transplant, but receiving support from the healthcare team. This option is for those with a limited life expectancy due to other serious health conditions. If you have been referred to a surgeon for possible kidney transplantation, this is not likely to be a good option for you.

What happens while I'm waiting for a kidney transplant?

If, after discussion with the kidney doctors, you decide that a kidney transplant from a deceased donor is a good option, your name will be placed in the national deceased donor kidney transplant waiting pool. Most people wait for between two and four years before they receive a deceased donor kidney transplant. Some patients have shorter or longer waiting times depending on their tissue type, blood group, age, and whether they have antibodies (specific proteins) in their blood against other tissue types. If you become unwell while you are waiting, you may need to be temporarily removed (suspended) until you're well enough to be put back into the pool. For more information, please refer to our leaflet **Understanding the Kidney Transplant Pool**.

If you dialyse abroad in a country where blood-borne infections are common you will be suspended from the transplant list for two months. This is because the transplant medications can be dangerous for people with recently acquired infections.

You will need to stay as fit as possible to prepare for your kidney transplant by dialysing regularly (if you have already started dialysis) and taking all your medications. Make sure you attend all of your booked clinic appointments so that we can monitor your health. Keep to a healthy diet, take regular exercise, and don't smoke. Stay out of the sun and use a high protection sun block to reduce your risk of developing skin cancers.

You must make sure that we have your contact details up to date so that we can call you if a kidney becomes available. If you have a mobile phone keep it on, and with you at all times, if not give us additional phone numbers where we may be able to get in touch with you (parents, friends etc).

If you are being prepared for a living kidney donor transplant you will be removed from the deceased donor waiting pool once a date for the transplant surgery has been confirmed.

What happens when I am called in for a kidney transplant?

Most people are called in for the kidney transplant late at night. You will be asked to come to Richard Bright ward, on level 6, Borough Wing, Guy's Hospital, where you will have blood tests and be checked by the transplant team and anaesthetists. Sometimes the transplant does not go ahead if there are problems with your blood tests, or the kidney. Do not eat or drink anything; the transplant staff will tell you if you can eat or drink anything after you come in.

You can be told the approximate age of the donor, their sex, and the cause of death (as long as this does not harm the donor's confidentiality). You may also be given some information about the donor's medical history (e.g. history of cancer, or whether they have an increased risk of an infectious disease), if this is relevant. We will talk to you about your individual risks and benefits, especially in relation to the deceased donor.

Giving my consent (permission)

We want to involve you in decisions about your care and treatment. If you decide to go ahead with the transplant, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

What happens during a kidney transplant?

The operation is carried out under general anaesthetic. Whilst you are asleep, a cut is made in the right or left groin. The blood vessels of the donated kidney are sewn into your blood vessels. The tube carrying urine from the kidney (ureter) is sewn into your bladder. A small soft piece of plastic tubing (stent) is placed inside the ureter to help it heal. The operation usually takes between two to four hours. Your own kidneys are left in place (if they are still there).

Sometimes the surgeon may want to give you both kidneys from the same donor if one kidney may not provide enough function for you. This is known as a double or dual kidney transplant. This operation takes longer (between four and six hours). If the surgeon thinks this is the best treatment for you they will discuss this with you before the transplant.

For more information about having a general anaesthetic, please refer to our leaflet **Having an anaesthetic**.

Will I feel any pain?

You will feel some pain after the operation, but this will be controlled with strong painkillers given into your vein. You will control the amount of painkiller you receive by pushing a button (patient-controlled analgesia – PCA). Most patients feel comfortable within hours of the operation.

What happens after a kidney transplant?

Most people are in hospital for between five to ten days after the transplant. If you need more surgery, or there is a problem with the kidney transplant, you may need to be in hospital for longer.

The nurses and doctors will check you regularly whilst you are in hospital. You will have a catheter (a hollow, flexible tube) to drain urine from your bladder. The catheter will be removed five days after the operation. You will have an ultrasound scan to check the blood flow to the kidney. Most patients can eat and drink within hours of the operation, and you should be able to sit out in a chair the day after the transplant.

What do I need to do after I go home?

Before you go home the pharmacist will go through all of your medications and tell you what they are for and how to take them. You will also be given information about how long to rest,

removal of dressings, and pain relief. To start with, you will be seen three times a week in the transplant clinic to make sure that the kidney transplant is working well, and that you are getting better as expected.

How long will my kidney transplant last?

Between 90 and 93 out of every 100 kidneys from deceased donors are still working one year after transplantation. On average, kidney transplants from deceased donors last for between 10 and 15 years. For some patients the kidney lasts much longer and for others it may only last a short time. The length of time that the kidney lasts depends on the age of the donor, other medical problems that the donor may have as well as many other factors. Sometimes the disease that damaged your own kidneys can come back and damage the kidney transplant.

Can I have another kidney transplant if it fails?

Most people can have further transplants if this happens. If your transplant fails you might need to have an operation to remove the failed kidney. The success rate for second or third transplants is generally as good as for the first, however you will likely have to wait longer. You will also need to go through the same tests again to make sure you are healthy enough to have another kidney.

Useful sources of information

Internet:

www.mykidney.org

Guy's and St Thomas' and King's College Hospital Trusts' kidney information website - describes the different stages of kidney disease and explains the treatment options and support available.

www.organdonation.nhs.uk

NHS Blood and Transplant website – describes the national policies on kidney transplantation, transplant statistics, and how recipients are chosen for deceased donor kidneys.

www.guysandstthomas.nhs.uk/our-services/transplant/overview.aspx

Guy's and St Thomas' website, transplant section - includes information on live donor kidney transplantation, pancreas transplantation, and surgery to form access for haemodialysis.

www.guysandstthomas.nhs.uk/our-services/kidney/overview.aspx

Guy's and St Thomas' website, kidney section - all of our kidney and transplant information leaflets are listed here and can be read on-line or downloaded.

Booklet:

Your Guide to Kidney Transplantation – an in-depth guide on kidney transplantation from Guy's and St Thomas' and King's College Hospital Trusts, includes detailed information on all aspects of kidney transplantation including transplant medications and their side effects. If you do not already have a copy please ask us for one.

Other:

Renal Clinical Psychologists Tel: 020 7188 5969

Renal Social workers Tel: 020 7188 5684 / 4023

National Kidney Patient Helpline Tel: 0845 601 02 09

Contact us

For further information, please contact the transplant pool recipient co-ordinator on 020 7188 9391 .

Or call the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask for bleep 1521 and wait for a response. This will connect you to the transplant pool recipient co-ordinator directly.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership