

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

(The figures we quote in this leaflet relate to the Guy's and St Thomas' NHS Foundation Trust kidney transplant programme.)

Contents

- 3** What is a kidney transplant?
- 3** Why should I have a kidney transplant?
- 3** What are the risks?
- 5** Survival
- 6** Are there any alternatives?
- 7** What happens while I'm waiting for a kidney transplant?
- 8** What happens when I'm called for a kidney transplant?
- 9** Consent – asking for your consent
- 9** What happens during a kidney transplant?
- 9** What happens after a kidney transplant?
- 10** What do I need to do after I go home?
- 10** How long will my transplant last?
- 10** Can I have another kidney transplant if it fails?
- 11** Useful sources of information
- 12** Contact details

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 other 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 will also probably improve.

What are the risks?

As with any medical procedure, there are risks associated with kidney transplantation and it is important to understand these. The risks are summarised below and described in detail in our booklet **Your guide to kidney transplantation**, if you have not yet received a copy, or would like another copy of this booklet, please ask for one.

- The kidney may not work straight away. Kidneys from living donors almost always work immediately. About half of kidneys from deceased donors work straight away.

- Out of a hundred kidney transplants, 2-5 never work.
- Sometimes, patients need further surgery after their transplant.
- Rejection can happen because your immune system recognises the transplanted organ as 'foreign'. To stop this happening you must always take your prescribed anti-rejection medications.
- You will have a higher risk of infection after transplantation. This is because the anti-rejection medications lower your immune system.
- You will need to take medication to suppress the immune system for the rest of the life of the transplant. These can have side effects, which are described in detail in our booklet **Your guide to kidney transplantation**.

Most deceased donors will have had long-term health problems before their death. Where relevant we will discuss these with you before your transplant.

In rare cases, the transplanted kidney may carry hidden diseases such as cancer or infection. All deceased donors are tested for viral infections including HIV (which attacks the immune system) and 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 1,000 transplanted organs will have an unknown cancer or a serious viral infection.

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 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.

Some of this information may be worrying, but we believe it is better for you to understand the possible risks, as well as the possible 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.

Survival

Sadly 2-4 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, [w: www.mykidney.org.uk](http://www.mykidney.org.uk) for more 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. 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.

Supportive care

This covers 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 into the national waiting pool for deceased donor kidney transplantation. Most people wait for 2-4 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 from the pool (suspended) until you're well enough to be put back in. For more information, please refer to our leaflet, **Understanding the kidney transplant pool.**

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 up-to-date contact details 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 you don't, make sure you 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?

The details are included in **Your guide to kidney transplantation**.

Sometimes the transplant does not go ahead if there are problems with your blood tests, or with the kidney. You may then be sent home.

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 their 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 (for example, history of cancer) if this is relevant. We will talk to you about your individual risks and benefits, especially in relation to the deceased donor.

Consent – asking for your consent

We want to involve you in decisions about your care and treatment. You will have an appointment in the Transplant Education Clinic to discuss your personal benefits and risks of having a transplant, and to agree on the types of donor offer you might be suitable for and would like to accept. 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 and is described in **Your guide to kidney transplantation**.

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

What happens after a kidney transplant?

Most people are in hospital for 4-7 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 while you are in hospital. You will have a catheter (a hollow, flexible tube) to drain urine from your bladder. The catheter is usually removed 4-5 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 of bed, in a chair, the day after the transplant.

What do I need to do after I go home?

Details of the medications, and what to do when you go home, are included in **Your guide to kidney transplantation**.

How long will my kidney transplant last?

Out of every 100 kidneys from deceased donors, 92-96 are still working one year after transplantation. On average, kidney transplants from deceased donors last 10-15 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 many factors, including the age of the donor, and other medical problems that the donor may have had. 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 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

w: www.mykidney.org

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

w: 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.

w: www.guysandstthomas.nhs.uk/transplant

The transplant pages of the Guy's and St Thomas' website include information on kidney and pancreas transplantation.

w: www.guysandstthomas.nhs.uk/kidneyservices

The kidney pages of the Guy's and St Thomas' website, include all of our kidney care leaflets which can be read on-line or downloaded.

Booklets and leaflets

You should have been given copies of the following leaflets. If you haven't, or if you would like another copy, please ask us:

- **Your guide to kidney transplantation**
- **Understanding the kidney transplant pool**
- **Having an anaesthetic**

Contact us

For further information, please contact the transplant pool recipient co-ordinators, **t:** 020 7188 9391.

For more information leaflets on conditions, treatments and services offered at our hospitals, please visit **w:** 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, Monday to Friday, 9am-5pm

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 and accessible 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

Leaflet number: 4168/VER4

Date published: January 2020

Review date: January 2023

© 2020 Guy's and St Thomas' NHS Foundation Trust

A list of sources is available on request