

Having a kidney transplant: Is it right for me?

i **Information for patients**
Sheffield Kidney Institute (Renal Unit)



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Introduction

If you are thinking about having a kidney transplant, you will probably have questions about the operation and how it may affect you.

It is important that before you decide to go on the list for a kidney transplant you and your close family fully understand what is involved.

We will explain the operation to you in more detail when you come to the transplant clinic - there will be a lot to take in during your appointment with the transplant team. Hopefully we will have answered any questions you might have. If you would like more information at this stage we have another leaflet "Having a kidney transplant: Giving my consent" that tells you about the operation. We explain how to get this leaflet at the end of this booklet.

What do the kidneys do?

Your kidneys do many things. The main ones are:

- Making urine
- Clearing wastes out of the body
- Helping to control your blood pressure
- Making a hormone (erythropoietin) that produces red blood cells
- Helping to keep your bones strong by balancing the amount of calcium in your body

When you have kidney failure you need treatment to help your body to continue to do these things. This treatment may include some or all of:

- Different types of tablets and medicines
- Changes to what you eat
- Limits on the amount of fluid you drink in a day
- Dialysis
- Kidney transplant

Sometimes a kidney transplant happens before a person needs to start dialysis. Some patients may need to have dialysis for a time before a kidney becomes available.

What is a kidney transplant?

A kidney transplant is the name of the operation where a person is given a kidney from someone else.

- The person having the kidney is called the **recipient**.
- The person giving the kidney is called the **donor**.

Is everybody able to have a kidney transplant?

No, not everybody is able to have a kidney transplant. When your kidney specialist refers you to the transplant surgeon, you will be assessed to see if a transplant is the best option for you.

Having a transplant is a major operation and you must be in a fit condition to have a general anaesthetic. This means that you will be asleep when the operation is carried out and this may take up to 4 hours.

The reasons why a kidney transplant may not be the best option for some people include having:

- Heart disease
- Lung disease
- Severe hardening of the arteries

Also, patients who have a history of cancer may need to wait until we are certain the cancer is cured before a transplant operation is done.

Some people prefer not to have the operation. Whether you decide to go ahead with the transplant or not, the choice is yours. You can always change your mind in the future and ask to be considered for a transplant again.

Can I have any kidney?

No, because everybody has a different **tissue type** which we inherit from our parents. (Only identical twins have the same tissue type).

Your body's immune system recognises that the transplanted kidney is foreign to you, and reacts against it as if it was an infection and tries to destroy it. This process is called **rejection** when it refers to a transplant.

Before you go on the transplant list, we will need to check your tissue type. Tissue types are identified by letters of the alphabet and numbers. There is a group of tissue types which are important for kidney transplantation.

Though it is impossible to get a complete tissue match, we try to get as close a tissue match as possible within a reasonable time. A close tissue match reduces the chances of the kidney rejecting and increases the chances of the kidney working.

Where do the kidneys come from?

Having a transplant means that you will have a kidney from another person (the donor). There are two types of donor:

Living donor

In this case, the kidney is donated by a living person. The donor could be a partner, family member, friend or even a stranger who has offered to give one of their kidneys.

- The potential donor will need to have a number of tests and investigations. This is to make sure they are healthy and fit enough to have the operation to donate a kidney, and to live the rest of their lives with one kidney.
- Both you and the potential donor will need to have blood tests to see if a direct donation is possible. If you and the potential donor

are not compatible, they can enter the National Living Donor Kidney Sharing Scheme.

- If you know someone that would like to be considered as a possible living kidney donor, it is important that they contact the Living Donor Coordinator themselves. We explain how to do this at the end of this leaflet.

We have more detailed information in a leaflet called “Information for donors and their families about living kidney donation”. We explain how to get this leaflet at the end of this booklet.

Deceased donor

In this case, the kidney is donated by people who have died and their family agreed to donate their organs for transplantation.

- Most kidneys for transplantation are from people who have died following serious brain damage. These donors are called **‘heart-beating’** donors because the heart beats for a while after they have died until the kidneys are donated.
- Some kidneys come from donors following stopping of treatment because they will not get better with treatment. They are called **‘non heart-beating’** donors because the heart stops beating before the kidneys are donated. Kidneys can be donated up to 40 minutes after the heart stops beating.
- An **expanded criteria** donor is one where the deceased donor is older than 60 years and / or has high blood pressure, diabetes or a stroke.

If you are offered a kidney from an expanded criteria donor, your surgeon will discuss the situation with you. You will be asked to decide if you want to accept a kidney from an expanded criteria donor.

We sometimes accept kidneys from donors with brain tumours as the tumour very rarely spread to the rest of the body including the kidney. Again, the surgeon will discuss this with you and you will be able to decide if you want to accept the kidney.

How is the operation done?

A kidney transplant is done using a general anaesthetic. This means you will be asleep during the operation. The anaesthetist will usually put an injection in your back (an epidural) before you go to sleep so that you will have good pain relief when you wake up and recover from the operation.

The kidney is placed in the lower abdomen on either the right or left hand side just above your groin.

To do this, the surgeon makes a curved cut about 10 inches (25 cm) long in the lower part of your abdomen just above the groin.

- The kidney is joined to your blood vessels in the pelvis.
- The tube that carries urine from your new kidney (the **ureter**) is joined to your bladder.
- The ureter comes with the donor kidney and is joined to your bladder during the transplant operation.
- A small plastic tube called a stent is placed inside the ureter to stop it from becoming blocked while the join with your bladder is healing.

Will my own kidneys have to be removed before my transplant?

Only about 5 patients out of every 100 (5%) going on the transplant list need their own kidneys removing. In most cases of kidney failure, although the kidneys are not working, they do not cause any problems, so your own kidneys are not normally removed.

Some reasons why your own kidneys may need to be removed first are:

- **Infection**, because this could make you very ill when you are given drugs to suppress your immune system after the operation.

- **Polycystic kidneys** can be very large and their size means there may not be room to put in a transplant kidney.

If you do need to have your kidneys removed this would be done well before the kidney transplant to give you time to recover.

Do I need to take any medicines after the transplant?

Yes. You need to take drugs that suppress your immune system to stop rejection happening. These drugs are called **immunosuppressants**. Because your body can reject the kidney at any time after the transplant, the drugs **must** be taken every day. Without these drugs, your immune system would destroy the transplanted kidney in the same way as a germ that could cause an infection.

For the first three months after your transplant, you will need immunosuppressant drugs at a higher dose. After this, your doctors will usually be able to reduce the dose a little, but they will never be stopped.

We explain about the side effects of these medicines later in the leaflet.

Will I need to come to clinic after the transplant operation?

After your kidney transplant, you will need to come to the Sorby Renal Outpatients Department at the Northern General Hospital regularly. At first, this will be three times a week, usually on a Monday, Wednesday and Friday. We cannot always give you a choice of an appointment time.

When you come to the outpatient clinic you will:

- Have your blood tested
- Have your urine tested
- Have the tablets and other medicines you take reviewed
- Be examined by a doctor

You **must** wait for the results of your blood tests or to see a doctor. This can take 2 - 4 hours.

As time goes by, you may be able to come to the clinic less often. The follow up will become twice a week, then once a week, then once a fortnight and so on. This will depend on:

- How well your kidney is working
- What changes are needed to the tablets and medicines you take.

Transport can be provided for your clinic appointments for up to 6 weeks after your operation. **You will need to use your own transport for any further clinic appointments after 6 weeks** (unless you have been assessed as allowed hospital transport).

What are the benefits of a kidney transplant?

A successful transplant means that you will:

- No longer need dialysis
- No longer have a restricted diet or fluid intake
- Have an increased feeling of well-being
- Have increased energy levels so that you do not get tired so easily
- Be able to lead a normal life, for example it will be easier to travel, eat out or take up hobbies

After having the transplant, you may also find that you are able to get back to work, if you are not already working.

You are much more likely to be well and live longer if you have a transplant than if you stay on dialysis

Are there risks in having a kidney transplant?

As with all operations, there are risks and complications that you should know about. These will be explained in more detail when you come to clinic and you will be able to ask questions. Some risks can happen soon after the operation and some later on. If you would like more information about the risks at this point, we have another leaflet "Having a kidney transplant: Giving my consent" that tells you about the operation. We explain how to get this leaflet at the end of this booklet.

Remember - you will be closely monitored after the operation and this will help us to detect any problems early on and give you any further treatment you may need.

1. Risks from the anaesthetic:

You will be given another leaflet with this one called "Your anaesthetic at Sheffield Teaching Hospitals" when you have been to the transplant clinic. The leaflet will explain the risks of having an anaesthetic, and these will be explained to you again by the anaesthetist when they examine you before the operation. You will also be able to ask any questions you have at this time.

If you would like to read a copy before you come for your appointment at the transplant clinic, we explain how to get this leaflet at the end of this booklet.:

2. Risks from the operation:

- **Bleeding.** You may need a blood transfusion or sometimes another operation is needed to find the cause of and stop the bleeding.
- **Infection.** This could be in your wound, chest or kidney transplant. You will be given antibiotics to treat any infection.
- **Wound breakdown.**

- **Blood clots in the legs.** This blocks the flow of blood around your body.
- **Blood clots in the lung (pulmonary embolism).** In rare cases, a piece of blood clot breaks off and travels to the lungs and causes chest pain and severe breathing problems.
- **Death.** The risk of dying after an operation is 1 in 100 (1%) in people less than 65 years old and 5 in 100 (5%) in people over 65 years old.

3. Risks and complications from the kidney transplant:

- **Rejection.** This is when the body's immune system tries to destroy something it sees as foreign, in this case the kidney transplant. Rejection can be:
 - **Acute.** This can happen in the first 3 months after the operation. About 10-15 in 100 (10-15%) have acute rejection but in most cases these can be treated. About 1 in 100 (1%) lose a kidney due to acute rejection.
 - **Hyperacute.** This happens in the first 24 hours after the operation. It is extremely severe and destroys the kidney. The risk of this happening is less than 1 in 100 (1%) but if it does happen it will not respond to treatment and you will need to have the kidney removed.
 - **Slow, on-going chronic.** This happens over a longer time.
- **Problems with the blood supply to the kidney.** You would need more treatment or an operation to deal with this problem.
- **Problems with the ureter.** The ureter is the tube from the kidney to the bladder. This can either cause a leak of urine into the tissues or a blockage meaning urine may not be able to flow out from the kidney. You would need more treatment and possibility another operation. This happens in less than 2 in 100 (2%) of cases.
- **Lymphocele.** In less than 5 in 100 (5%) of cases, fluid may collect around your kidney. This is usually treated by inserting a drain

under local anaesthetic. In some rare cases you may need an operation to drain the fluid.

- **Thrombosis (clot) of the kidney.** This happens in about 2 in 100 (2%) of cases. You would need an operation to remove the transplant kidney.

4. Risks from the immunosuppressant drugs:

Immunosuppressants are a group of drugs you need to take after having a kidney transplant, to help stop your body rejecting the kidney.

You will need regular blood tests to check that the number of white blood cells is not too low and make the risks of developing an infection too great.

- **Infections.** Patients taking immunosuppressant drugs are more likely to get infections, because the tablets that help to stop rejection reduce the number of white blood cells that fight infections. Patients with a transplant are most likely to develop illness such as:
 - Flu and flu-like illnesses
 - Urine infections
 - Shingles
- **Cancer.** Patients taking immunosuppressant drugs have an increased risk of developing cancer several years after having the transplant. The most common cancers **in patients with a transplant** are skin cancer and cancer of the lymph glands (lymphoma). **If you develop cancer, your immunosuppressant drugs may need stopping, changing or the dose reducing. This may increase the risk of your kidney transplant being rejected and the kidney may need to be taken out.**
- **Diabetes.** Patients taking immunosuppressants have an increased risk of developing diabetes. This would mean that you would

need to take tablets or inject insulin to control your diabetes and make changes to your diet.

5. Risks from the kidney and organ donor

- **Infection.** Very rarely, patients having a kidney transplant can catch an **infection from the transplanted kidney**. Some of these infections can be very serious such as hepatitis (inflammation of the liver) and Human Immunodeficiency Virus (HIV).
- **Cancer.** Although patients that are known to have cancer cannot donate a kidney, it is impossible to completely exclude the risk of having a kidney with a small, previously unknown cancer in it. The risk of this happening is extremely small.

Another important risk for you to consider is the risk of your original kidney problem affecting your transplant kidney. Your kidney doctor will explain if this is the case with you.

- If you have any concerns please discuss them with a surgeon at the time. **It is important that you understand what the surgery involves and how it may affect you and your life.**
- You should be aware that if you currently receive certain state benefits, these may be reviewed after your transplant operation.

Please bear in mind that the complications explained above are uncommon and the majority of patients do not suffer any complications at all.

Will my transplant kidney work straight away?

Not all kidneys work straight away. If this is the case with you, you may need to carry on having dialysis. This may be for a few days or up to 2-3 weeks, until the kidney starts to work.

There is a greater chance of your kidney not working straight away if your kidney is from a **non-heart beating donor**, than if it came from a **heart-beating donor**.

What is the success rate of kidney transplants?

The success rate of kidney transplants is shown in the chart below.

It explains, **out of every 100 transplant operations**, how many kidneys are likely to be working over 1, 5 and 10 years.

Type of donor	1 Year	5 Years	10 Years
Deceased donor	94	85	70
Living donor	97	94	79
Expanded criteria donor	83	55	

A kidney from a non-heart beating donor has the same chance of working as one from a heart beating donor.

In some cases, kidney transplants do fail. There is a 2 in 100 (2%) risk of the kidney not working at all.

It may be possible for you to have another kidney transplant in the future. This would depend on why the first kidney failed and if you were fit enough for the operation for example. You would need to be referred to the kidney transplant assessment clinic again.

Are there any other procedures I need after having a kidney transplant?

4-6 weeks following the transplant you will need the stent removed from your bladder. If you have a peritoneal dialysis catheter, this will be removed at the same time.

More information about this procedure is explained in the booklet that you will be given while you are in hospital after having a kidney transplant called "Going home after having a kidney transplant".

How do I get on the transplant waiting list?

Your kidney consultant will refer you to the kidney transplant surgeons when they feel you are medically fit for a transplant.

If you feel that you are ready for a transplant, but your kidney consultant hasn't discussed this with you, talk to them about this at your next visit to the clinic.

If you have a potential living donor, you may be referred earlier to the transplant team. This is so that your donor can have the tests and investigations they need to make sure they are able to donate a kidney.

Once your consultant (kidney doctor) has referred you, you will be sent an appointment for the transplant clinic through the post.

When you come to this appointment, please bring your next of kin, partner or a very close friend with you to your appointment. You will be given a lot of information while you are in clinic, and it can be helpful if there is someone else who knows what has been discussed.

At your clinic appointment, you will:

- be asked some questions about your health
- have an examination.

If the surgeon thinks you are fit enough to go on the transplant waiting list, they will explain:

- the risks of having a transplant
- the benefits of having a transplant
- what happens during and after the operation

You will then have a chance to ask any questions that you might have.

You will probably want to go home and think about what you have been told before you make a decision about going on the transplant list. It can be helpful to discuss what you have been told with the person who came with you to the appointment. Or, you may feel ready to make a decision straight away.

If you decide you do want to go on the transplant list, a medical examination will be carried out. You will also have some blood tests done to check your blood group and tissue type.

We need this information so that you get a kidney that matches your tissue type as closely as possible. It takes about 3 weeks for the results of these blood tests to come back.

You may also need some other tests doing to make sure you are fit enough to go on the transplant waiting list. These may include:

- X-rays
- Scans

Once we have the results, and everything is satisfactory, your name will be placed on the National Transplant Waiting List. The list is kept on a computer at the NHS Blood and Transplant (NHSBT) offices in Bristol.

Next, you will get a letter telling you that you have been placed on the transplant list with the number of the transplant unit on it.

As well as a home telephone number, we also need your mobile telephone number. This is because if a kidney does become available

you must get to the hospital quickly as there is only a short time that the donor kidney can be kept.

You will also be sent another leaflet about being on the kidney transplant waiting list. It will help you remember what you have been told about the operation and the risks and benefits for example.

How long will I have to wait for a kidney transplant?

The NHS Blood and Transplant (NHSBT) computer that holds the national transplant waiting list will match a donor kidney to the best possible recipient using:

- Blood group, and
- Tissue typing

This means that it is difficult to predict how long anyone will have to wait for a kidney transplant. It depends on a number of factors including:

- Your blood group
- How common or rare your tissue type is.

Some patients are fortunate enough to get a kidney within a few days or weeks of going on the list. Others have to wait many years. The average waiting time is about 3 years.

Where can I find further information?

If you would like a copy of any of the leaflets mentioned earlier in this booklet, you can either:

- Download the leaflet via the Sheffield Teaching Hospitals website at:
www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet
- Contact the Transplant Manager on: **0114 271 5138**

If you would like more information on having a kidney transplant, you can contact either:

- The Transplant Manager on: **0114 271 5138**
- Or NHS Blood and Transplant: www.nhsbt.nhs.uk/
- Or you could look on the NHS Choices website:
<https://www.nhs.uk/conditions/kidney-transplant/>

There is also a video clip of a kidney transplant patient talking about his experiences of the operation.

If you would like more information about Living Donation, please contact:

- Living Donor Coordinators on: **0114 271 5983**

Use this space below to note down any questions you may want to ask at your appointment:



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