

Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone: 0800 183 0204

From a mobile or abroad: 0115 924 9924 ext 65412 or 62301

E-mail: pals@nuh.nhs.uk

Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614, Nottingham NG7 1BR

www.nuh.nhs.uk

Information for potential living kidney donors

Renal Transplant Unit

If you require a full list of references for this leaflet please email patientinformation@nuh.nhs.uk or phone 0115 924 9924 ext. 67184.

The Trust endeavours to ensure that the information given here is accurate and impartial.

This document can be provided in different languages and formats. For more information please contact:

Living Donor Coordinators
Tel: 0115 9691169 ext 59405

Aim of the booklet

This booklet is aimed at people who are thinking of donating a kidney to someone else for the purpose of transplantation, in order to treat kidney failure. It's aim is to explain the process of assessing a potential donor and considerations for the donor and their families

There are currently more than 5200 people in the UK in need of a kidney transplant.

Several hundred patients die each year waiting for a suitable organ.

It is possible for healthy adults to donate a kidney to someone in need of a transplant.

In 1960 the first successful living donor transplant was performed.

Why do people need a donated kidney?

The kidneys perform a number of important functions within the body. Some people have chronic kidney disease which means that their kidneys do not work efficiently. This can happen gradually over many years, or can happen suddenly as a result of another illness. A person can survive with as little as 10% of normal kidney function, but, at this stage, they may begin to feel unwell. They would then need to have some kind of treatment to take over some of the functions of the kidneys. This usually means have a kidney transplant or dialysis.

HTA Approval

The Human Tissue Authority (HTA) is the regulator of living donation in the UK. It exists to establish that donors are not forced to do something against their wishes and to provide a legal framework for the prevention of organ trafficking.

The HTA has a legal responsibility to make sure that a donor has capacity and /or is competent to give consent. The donor must show they understand the risks involved, that they are volunteering of their own free will, and not being coerced into donating the kidney and will not receive any reward for donating the kidney.

The donor and recipient will have an interview with an independent assessor at the end of the testing process to fulfil the requirements of the HTA. They are required to show documentary evidence of their identity and their relationship at this interview.

Long term follow up

The donor will be followed up by the living donor team for the first year post donation. It is highly recommended that the donor has yearly check-ups of their blood pressure, kidney function and urine for the rest of their life. These simple annual checks can be done by the local living donor team or via the GP.

A kidney transplant means that a working kidney is taken from one person and put into another person's body during a surgical operation. The healthy kidney would then take over the function of the diseased kidneys. A kidney transplant can take place before the person reaches the need for dialysis.

On average there are 5200 people waiting for a kidney transplant each year, the number of actual kidney transplants performed (both deceased and living donation) is around 3100 each year, leaving a shortfall of 2100 people needing a kidney transplant per year.

Benefits of living kidney donation.

A kidney from a living donor offers a higher chance of a successful kidney transplant compared with a kidney from a deceased donor.

Although there is no guarantee that any kidney transplant will work, 97% of kidneys donated from living donors are still working after one year, in comparison with 92-94% of kidneys from deceased donors.

At 5 years, 91%, are working, compared with 85% from a deceased donor, and at 10 years, 77% are still working, compared with 72% from deceased donors.

Advantages of living donation

The donor is fully assessed by the living donor medical and surgical teams. The operation is carefully planned to a time suitable for both the donor and recipient and it provides a better opportunity to plan a transplant, especially for recipients who have complex medical conditions.

There is more chance that the kidney will work straight away.

Could I be a living Kidney Donor?

Living kidney donation involves a major surgical operation with risks to the donor. The aim is therefore to reduce the risks to the donor and maximise the benefits to the recipient.

Assessing the suitability of a potential donor involves a process of testing to look at their general health, their individual risk of surgery, and the likelihood of problems in the future.

Some of the test results can be variable, depending on the lifestyle of the donor and therefore made better or worse if lifestyle changes occur. You should therefore consider these if you wish to improve your chances of being a suitable kidney donor.

Weight

Being overweight is known to increase the risks of infection, heart problems and deep vein thrombosis following surgery and can delay the recovery process.

In Nottingham you will not be accepted as a kidney donor if:

Your Body Mass Index (BMI) is above 35, it is preferable for it to be below 30. If it is between 30-35, you will be advised to lose weight before surgery.

If you are intending to lose weight to become a donor it is important to remember that this should be done gradually and become a long-term lifestyle change. Putting the weight back on after donating a kidney could increase the risk of heart problems even more, and put additional strain on your remaining kidney.

Being overweight is also associated with high blood pressure, diabetes, and reduces the chances of suitability.

The Nephrectomy

There are different types of donor kidney removal surgery which can be performed. In Nottingham we remove the kidney using a type of keyhole (or laparoscopic) surgery. You will meet your surgeon at the end of the testing process and he will inform you how he will remove the kidney. There is a small chance that once the surgery has begun, it may not be possible to remove the kidney by keyhole surgery and a bigger incision will have to be made, (open nephrectomy). There will be little difference to yourself, apart from a bigger scar and potentially a little longer recovery time.

Most donor nephrectomies take between 2-3 hours.

What does a potential living donor need to consider?

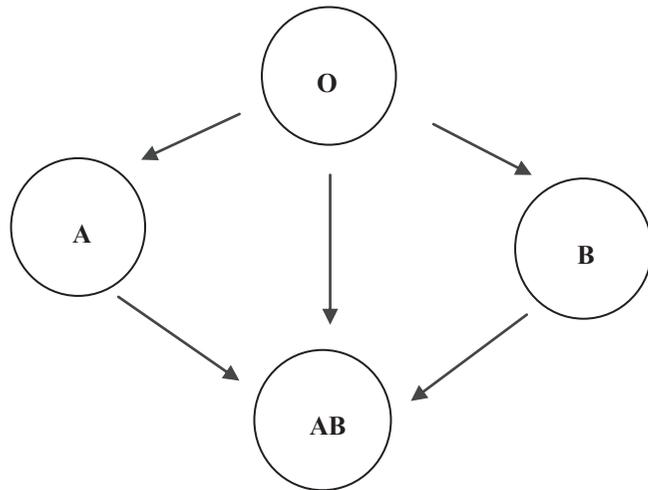
It is worth remembering that the operation to remove a healthy person's kidney is – as far as their own body is concerned — not of any direct benefit. Although all possible precautions are taken, there is always a risk when undergoing surgery and donating a kidney, which is classified as major surgery.

There are also practical considerations, such as the time taken off work for the investigations and recovery after the operation, or domestic responsibilities and arrangements, such as looking after children or the family pet. Coercion from family members may arise and there may be pressure to continue with the donation from within the family.

A number of investigations are performed that may uncover an unknown medical condition, which may lead to more investigations or treatment. The donor also needs to consider the possible impact on their future of having one kidney.

Alternatively, it may be possible to remove the blood group antibodies from the recipient to allow them to accept your kidney.

Who can donate to who?



This form of treatment will depend on how high the recipient's antibody levels are. If too high then it may not be possible to remove the antibody and the only option would be to enter into the paired exchange scheme or stop the testing process.

You will be tested in the early stages of the process, to determine whether you are blood group compatible with your recipient.

Some recipients may have formed antibodies (called HLA antibodies) that are directed against their potential donor cells. This is called a positive cross match. The antibodies would cause the transplanted kidney to be rejected immediately, so it would be unsafe to proceed with the transplant.

If you and your recipient have a positive cross match, the only way forward will be to enter into the National Kidney Sharing Scheme. If you do not wish to enter the scheme then, testing of the donor would stop.

Smoking

People who smoke are known to take longer to recover from surgery than those who don't, and are more likely to develop chest infections and deep vein thrombosis. It is also known that smokers are more likely to suffer from long term health problems. If you smoke and seriously wish to donate your kidney, it is important that you stop smoking to improve your chances of being accepted as a donor and reduce the risks of surgery.

Alcohol

An excessive alcohol intake (more than 14 units per week) can result in liver and kidney damage, as well as contributing to weight gain and high blood pressure. You should aim to keep your alcohol intake to below the limit recommended by NHS England guidelines and avoid "binge drinking".

Exercise

Regular exercise improves the heart health and general levels of fitness and helps maintain a healthy weight. It is therefore helpful for potential kidney donors to ensure they exercise regularly.

Medication

Potential donors on 3 or more blood pressure medications would not be considered for donation, however if you are on 1-2 different types of medication for your blood pressure and it is well controlled, you may be considered as a donor. This would be decided on an individual basis, after looking at other health issues you may have.

There could be some medications that could rule you out as a potential donor. Please inform the coordinators when you meet/ speak to them about any medications you are on and they can advise you.

After donating a kidney it is advisable not to take certain medications, such as Non-steroidal anti inflammatory drugs eg. Ibuprofen, nurofen etc., as these can potentially damage your kidneys. If you take these tablets regularly and cannot do without them, then removing one of your kidneys would not be advisable.

Previous Cancers

If you have had cancer in the past it is likely that you would be unsuitable to donate a kidney due to the risk of future transmission of cancer cells. There are certain types of cancers that would definitely rule you out as a donor, no matter how long ago you had the cancer. These cancers are:

- Breast cancer
- Skin cancers
- Kidney cancer
- Cancer of the womb
- Haematological cancers
- Lung cancer

Previous surgery

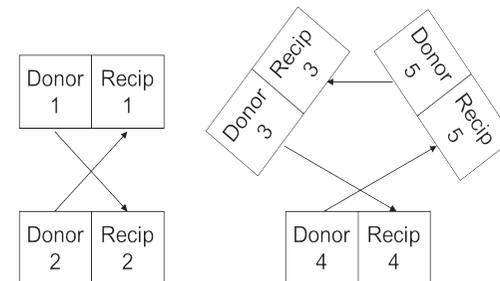
If you have had a lot of abdominal surgery in the past, it may be difficult to remove a kidney due to the scar tissue that forms post surgery, and therefore it may be that although you are fit and healthy, it would not be advisable for you to donate your kidney.

Do I need to be a match and the same blood group as my recipient.

No you do not need to be the same blood group as your recipient. If you are deemed suitable as a donor but you are not the same blood group, you and your recipient can be entered into the UK Living Kidney Sharing Scheme, which allows kidneys to be exchanged between incompatible pairs, resulting in compatible transplants for the recipients. This is shown in the diagram below.

PAIRED EXCHANGE

- 2-way matching runs quarterly since April 2007
- 3-way exchanges also considered since April 2008



2-way exchange
(paired exchange)

3-way exchange
(pooled exchange)

How long will I be in hospital and how long will I be off work?

You will be in hospital for about 3-5 days. Donating a kidney is a major operation and it will take time for you to recover. You will need to take medication for pain for a short time after the operation, but it is anticipated that within one month of the operation you will be feeling almost back to normal. Most donors feel extremely tired after surgery and we would advise you to expect to have between one and three months off work, at which point we would expect you to be back to full health. There is a national scheme that may help with financial assistance if you lose earnings during this process. You would need to discuss your potential loss of earning with your employer first.

Long term risks of living with one kidney.

There is a small chance of a slight rise in blood pressure following kidney donation. The risk of new onset hypertension is approximately 7.5%

The risk of developing renal failure following kidney donation is about 180 per million population. This is less than that expected in the general population, which is around 260 per million population

The risk of developing an asymptomatic leak of protein in the urine is around 12%. Usually this does not have any long term effects.

What is involved in the testing process.

Becoming a living kidney donor is entirely voluntary and you are under no obligation to complete the testing process or go ahead with donation.

The first thing you need to do is phone one of the living donor coordinators on 0115 9691169 Ext 59405 to have a 10 minute chat to discuss your previous medical history. It may be at this stage that you would be told that you are not suitable. If it is deemed that you can continue we would then write to your GP, with your consent, to obtain more information of your medical history. Once we have received that information, we would then invite you to a one to one meeting with one of the living donor coordinators to discuss all aspects of living donation.

After this meeting, if the coordinator and yourself are happy to continue with the process you will undergo a variety of tests, which will include blood and urine tests, scans, and an assessment by a consultant nephrologist and consultant surgeon. All of these tests take approximately 4-6 months to complete and until all tests have been completed, only then will you be deemed suitable to donate. After each test has been done, your results will be reviewed. You may be deemed as unsuitable during the process and therefore it will not be necessary to continue with all the tests.

If you wish to stop, pause or re-commence your testing process, please contact your living donor coordinator.