

What is the process if I want to be a living donor?

Once you have decided you want to be a living donor, the person you hope to donate to will contact the living donor co-ordinators at their nearest transplant centre and you will be contacted by one of the team. You will be registered on their system; asked a few basic questions and a DVD and booklet on living donation will be sent to you. An appointment will be made for you to come and see a living donor nurse specialist for some initial tests. These tests are:

Blood Test:

Before you can become a kidney donor you need to have a blood test, this is to check that you and the person you are donating to have compatible blood groups as this reduces the chance of rejection; however transplants take place between people who are not of the same blood group.

Tissue Checking:

Tissue type matching is important for kidney transplants. The tissue type of a person is determined by marker proteins on the surface of white blood cells. The higher the percentage of these proteins that match, the greater the compatibility between you and the person you are donating too. This close tissue match is usually seen when people are closely related. The closer the match the less likely it is for the donor kidney to be rejected.

Urine Sample:

Urine is tested for the presence of bacteria, glucose, protein and blood.

Blood Pressure Monitoring:

High blood pressure can cause kidney damage and may make you unsuitable to be a kidney donor.

These initial tests are important as they make sure you are in good health to be a donor, that your kidneys are functioning normally and that you do not have any underlying medical problems.

At your first appointment you will meet your clinical nurse specialist; their role is to take you through the different stages of the donor process and medical tests. You will be asked for a brief medical history and given the opportunity to ask any questions. Depending on the centre the results of your tests usually come back within a few days.

Stages of The Evaluation Process

There are different stages in the donor assessment process which can take anything from three to seven months to complete. Most hospitals usually let you know in advance your

appointment times for the different stages, including how long they may take. This makes it easier to plan and book time off work.

The five stages of the process may vary depending on the hospital or transplant centre.

1. Initial Discussion
2. Medical Tests
3. Consultant Nephrologist, Review
4. Consultant Transplant Surgeon Review
5. Independent Assessor Appointment

1. Initial Discussion

You will be asked to provide the nurse with a brief medical history i.e. vaccinations, number of children, allergies and any recent medical issues. You will also be asked to sign a consent form allowing the hospital to contact your doctor for other relevant medical information.

2. Medical Tests

These are the medical tests to determine if you are medically suitable to donate a kidney. Having a compatible blood group and tissue match is not enough. These tests are:

1. Glomerular Filtration Rate (GFR), this measures how well the kidneys filter your blood.
2. Electrocardiogram (ECG), this traces the electrical rhythm of your heart.
3. CT Angiogram Renal Scan, this takes pictures of your insides to check the number of kidneys you have, their size, structure and the number of blood vessels attached to each one.
4. X rays of the chest and abdomen.

It is a long day, starting in the morning and finishing late afternoon. A lot of people find it helpful to have someone with them for company.

Consultant Nephrologist, Review

Once your tests are complete the living donor team will discuss your assessment and review your tests. This allows the surgical team to give careful consideration to your suitability. They also consider the person you are donating to. You will be called in for an appointment to review your tests with a nephrologist (a doctor who specializes in kidney disease). During this appointment the consultant nephrologist will review the results of your medical tests. At this stage you will know if you are able to donate, need to go for more tests, or not a suitable donor.

Consultant Surgeon Meeting

At this stage, you will meet the consultant surgeon; they will confirm your final suitability to donate. The consultant will provide you information about other tests, the operation, recovery, medication and follow up once you are discharged from the hospital.

5. Independent Assessor Appointment

At this appointment you will meet someone who is not involved in the assessment or care of potential donors. They have been trained in the legal aspects of organ donation, and no living donor transplant can take place unless they are satisfied that donors are not being coerced or paid to donate.

It is important that potential living donors are aware that regardless of what stage they are in the process, they can withdraw if they change their minds. The living team will always support you in your decision and it will remain confidential. It is also important to know that many family members and friends who wish to donate find that they are not able to do so because of health reasons, this can cause a lot of disappointment and distress, and if this happens the team will offer the right support to help you.

What Are The Risks?

All operations are associated with some risk and although giving away a kidney is a unique type of surgery with potential challenges, serious complications are very rare. There are various people at the hospital you can talk with if you have any concerns.

- Education nurses – these are specialist nurses that are experienced in discussing the physical and emotional impact of what happens when you donate. You can discuss your concerns, anxieties, request for more information and ask questions.
- Peer supporters- They aim to offer support to kidney patients and potential living kidney donors.
- Kidney Patient's Association- offer support to kidney patients and provide information.

Short-term

1. *Short-term* – i.e. around the time of the operation:

Anaesthetic: Complications due to anaesthetic issues are rare, particularly in people who are live donors as they have had a thorough work-up and come into the operation 'well' as opposed to being sick (unlike most people who need an operation). If there are any possible concerns then our experienced anaesthetic consultant will see you well in advance of the surgery.

The Operation:

The kidneys lie beside the major blood vessels and organs such as the colon, pancreas, lungs and spleen and there is the potential for damage during removal of the kidney. There is also a small possibility of bleeding occurring but this can be generally seen at the time and brought under control very quickly by the surgeon. Very rarely but occasionally the donor may need a blood transfusion or to go back to theatre. Spleen – moving the spleen out of the way to reach the kidney can lead to bleeding which ultimately requires removal of

the spleen (splenectomy). Splenectomy weakens the immune system, so in the very unlikely event that this happens you should take lifelong antibiotics. Gut / bowel – moving the bowel out of the way to reach the kidney very rarely causes it damage. Sometimes this is not obvious until a few days after the donor operation, and requires further surgery. In very exceptional circumstances this will involve creation of a temporary colostomy (bag on wall of abdomen for faeces) for a few months to rest the bowel until it can be safely repaired. Lung – the pleura (the space around the lung) may be inadvertently be opened during surgery. If this happens, the lung may collapse. The doctors would then insert a tube into the chest to allow recovery. These complications are mentioned because they are serious but fortunately they are exceptionally rare. Worldwide there are reports of a person donating a kidney having died because of a serious complication and it is estimated that this happens once in every 3000 cases. This is comparable to the risk of dying with having surgery to remove the appendix.

After the operation:

Pain – most people feel sore after an operation but pain will be kept to a minimum using a variety of methods including giving painkillers directly into a vein and by tablets.

Nausea – a surgical procedure or sometimes anaesthetic or pain killing drugs can lead to nausea in some people. This generally settles very quickly and tablets or injections can help if necessary. Infection (chest, wound, urine) – with very careful attention to hygiene and sterility infection is uncommon but an antibiotic will be given if required. The donor will be strongly encouraged to stop smoking in advance of surgery and to breathe deeply to reduce the chances of developing a chest infection. A wound infection can delay the healing process or cause scarring .Blood clot in leg / chest – To minimise the risk of clots, a machine that massages the legs will be put on immediately after the operation. The donor is encouraged to walk around as early as possible after the operation and will also be given injections to keep the blood thinner. Skin numbness – the superficial nerves in the skin are inevitably cut during an incision. Some numbness over the wound is very normal and while it may feel 'funny' it is not harmful and usually resolves (although this can take up to a few months).

Medium-term

2. *Medium-term* – i.e. in the first few months the following can be a problem but remember only a small number of donors have any issues in this period

Pain: rarely some donors have persistent discomfort

Irritable bowel symptoms: it is common for the bowel to take a day or two to work after the operation. Occasionally some people notice that their bowel habit does not return back to

normal with ongoing subtle change toward constipation and/or diarrhoea. While such symptoms can be annoying there is not any serious underlying disease. There may be medications and dietary alterations which will help. It is common for a change in bowel habit in the early days following donating a kidney.

Hernia: a bulging of the tummy may occur where there has been a cut into the abdominal wall muscle. This may complicate any surgery in this area. Again this is irritating rather than sinister, but where it causes distress or discomfort an operation to repair this will often be effective.

Testicular discomfort: very infrequently some men who have donated will experience discomfort in the testicle on the side the kidney has been removed. This can happen as the vein from the testicle joins the vein from the kidney that has been removed. This means a little more blood than usual accumulates in the testicle, and this can be uncomfortable for the first month or two following surgery. Typically this discomfort does settle with time, but it may take some months. There have been cases of persistent pain.

Long-term

3. *Long-term* – i.e. years after donation. Obviously giving a kidney does not exempt you from developing other medical problems that you would have developed in any case.

There are a few that are worth considering in particular:

There is a very strong link between blood pressure and the kidney, so if you have just one kidney it is important to have good or very good, not just average blood pressure. We would prefer to start blood pressure lowering tablets earlier rather than later in someone with only one kidney. If the blood pressure is well controlled then it will not have any detrimental effect on kidney function in the long term.

Kidney function. Your kidney blood tests will not be as good after you have given a kidney as they were before. However provided the results are stable, there is no protein leak in the urine, and your blood pressure is good this is not of concern. Although another doctor may tell you that you have chronic kidney disease, this is based on the assumption that you have two kidneys – and to have this level of function with two kidneys means there must be something wrong with them. However, if you have donated we know that you have a good kidney (or we wouldn't have gone ahead with the operation) and your kidney blood tests are worse not because there is a problem with your kidneys but because you have one rather than two.

After you donate we recommend that you have your blood pressure, urine (to check for protein), and kidney blood tests checked once a year. Usually this will be organised by the team here in the City hospital, but it may be arranged in conjunction with your local GP.

There are two situations when it would be very helpful to still have a second kidney! The first is if your kidney is injured for example in a road traffic accident. The second is if you develop cancer in your one kidney. Fortunately both of these scenarios are uncommon – it is likely that you have heard of someone with breast, or prostate, or bowel, or lung cancer but quite probably you haven't heard of someone with kidney cancer. If it happened that your single kidney was affected by trauma or cancer than you would have priority on the UK transplant list yourself. But we have never had to use this arrangement!

Anything else that will affect one kidney in general will affect both kidneys. Although diseases can occur 'out of the blue' and cause kidney failure, it really will be unexpected given that you will have gone through a thorough assessment process before donating. Nothing is impossible however and in the unlikely event that you did develop a problem with your kidneys there would obviously be a higher chance that you would need dialysis treatment sooner than if you still had both kidneys.

Any potential donor must appreciate that the risks associated with donation, in the short, medium and long-term, are never zero. The assessment process is designed to ensure that the risks for you are acceptably

Psychological risks

Clearly there are huge benefits of live kidney donation. It can be a rewarding and positive experience for someone if they see a close friend or a member of their family regain. Removing their need for fluid and dietary restrictions, giving them more free time and taking away the hassle required to go through dialysis often brings direct benefits to the donor in terms of family and social life.

However, although the vast majority of living donor kidney transplants work very well, as with everything in life, it doesn't always go according to plan. If you give a kidney, but it doesn't work or only functions for a short time, it can be very difficult to cope with this. It is important that anyone who is going to donate a kidney considers this possibility in advance, and feels ready to go ahead. In some cases we know because of the illness of the recipient, that the kidney is unlikely to last a long time, and we will always be honest about this with you in advance.

6. Operation and Recovery

Once the assessments are complete then a date will be scheduled for surgery. This is a joint decision by the transplant team, the doctor looking after the person needing the transplant (the recipient), and of course the donor themselves. Typically, both donor and recipient operations each take 3-4 hours with 2-3 hours in recovery afterward for observation.

Surgical procedure

A kidney can be removed in either of two ways, the laparoscopic (“keyhole” or minimal access) technique or the traditional open surgery. The ‘key hole’ (laparoscopic) technique is widely used in all transplant centres.

Occasionally if the surgeon is not happy with the progress or there is any concern regarding damage to the bowel or blood vessels then a bigger incision will be made. This is called ‘conversion to an open’ operation and happens in approximately 1 or 2 people in every 100 who donate. The purpose is always to maintain the safety of the donor, if you have an open operation you will take longer to recover than after keyhole surgery.

Wounds

Although ‘key-hole’ surgery, clearly there has to be a cut sufficiently long to allow the kidney to come out! This larger incision can be in a similar position to a C-section wound, or may be just below the ribs. Different surgeons sometimes have different techniques, so your own surgeon will discuss in detail where the incisions will be for your particular operation.

Recovery

After the operation, the donor wakes up in the recovery room where they will be for a couple of hours before going to the ward. Once settled, family members are allowed to visit.

Several temporary tubes or lines inserted during the operation. These include a plastic drain tube attached to a wound drainage bag, which collects fluid from the wound and also a urinary catheter, however in some cases these are removed immediately after surgery.

Donors will experience pain after the surgery, paracetamol is provided regularly, initially into the vein via a ‘drip’. Morphine is given as required, sometimes through an intravenous pump.

which gives a dose of morphine on the push of a button (“patient controlled analgesia” or PCA). Morphine may alternatively be given in tablet or liquid form by mouth. Once the tubes are removed donors are encouraged to get out of bed and sit on a chair.

7 Getting Back to Normal

Virtually all living kidney donors do well. In general for most people it is:

- 2-3 days in hospital after the transplant
- 2-3 weeks taking it relatively easy
- 2-3 months to be back to normal activities

Obviously some people are quicker to heal than others, and a small number do have some complication which means it takes a little longer than usual to recover fully.

Early after donation

As soon as you wake up after surgery you will be encouraged to become mobile i.e. moving your legs by flexing and relaxing them, and walking to the bathroom. Although it may seem tough, getting up and moving is a very important part of your recovery to reduce the possibility of a blood clot or chest infection. You will also be encouraged to take deep breathes to fill your lungs.

At Home

After leaving the hospital, the donor will typically feel tenderness, itching and some pain as the incision continues to heal. The wound is closed usually using dissolvable stitches which dissolve gradually by themselves and most donors find that the post-operative discomfort in the wounds has gone by the one month mark.

We would encourage you to push yourself a little bit more every day to build up your stamina. Lifting heavy objects (nothing heavier than a kettle!) should be avoided for at least 4-6 weeks. You should definitely avoid anything particularly heavy that requires you to strain for the first 3 months to reduce the risk of developing a hernia.

You will not need any special medication. All donors are discharged from hospital with pain relief medication and advised how and when to take it. Donors find as the weeks pass they need to take less medication. Ideally you should not take non-steroidal anti-inflammatory

drugs (e.g. ibuprofen, voltarol / Diclofenac) on a regular basis in the long term as very rarely prolonged use can cause kidney disease.

Return to work

The minimum amount of time you should allow yourself to recover is four to six weeks. Since people recover at different rates, with varying degrees of fatigue and pain you may need as long as eight to twelve weeks leave from work for very physical jobs and a shorter time for less strenuous jobs. In most cases it may be beneficial to phase your return to work e.g. mornings only, or three days instead of five. Previous donors suggest tiredness is the most obvious side effect they feel after donation and returning to work full-time directly may be too much.

Driving

It is crucial that you can comfortably wear your seat belt and easily do an emergency stop before you start driving again. This varies depending on speed of recovery and it's important to remember that your energy levels may be reduced at this time. Most people don't drive for the first 3-4 weeks. It is sensible to start with short journeys initially to ensure you are comfortable. We advise donors to check this with their insurance company they are fully covered before driving.

Regular check-ups after donation

Donors are monitored closely after surgery to ensure their recovery is progressing normally. Your coordinator will arrange a check-up two weeks after you leave the hospital and you will have an appointment with your surgeon after around six weeks. Every year, around the anniversary of your donation, we will arrange for your kidney function and blood pressure to be checked. The first year we would like you to come back to the hospital (so we can see you!), but subsequent years we may ask you by letter to attend your GP for a check of your blood pressure, urine and kidney blood tests. When the results are available the coordinators will then contact you by phone to discuss them. If there are any particular concerns of course we will ask you to come back in person for review.

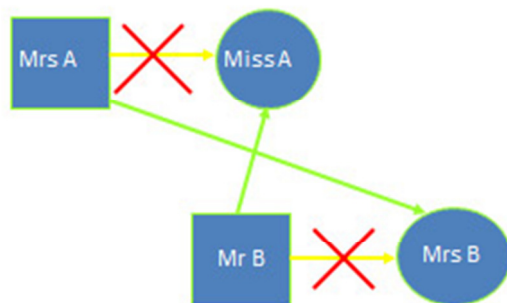
8. “What if I am not a match?” Living donor pool / incompatible transplants

Ideally the donor and recipient should ‘match’ as closely as possible in two areas – the blood group and the tissue type. Until a few years ago if the donor was not the right blood group or the recipient had antibodies to the donor’s tissue type there was no possibility that they could donate. Now however there are options.

Living donor pooled exchange programme

This is a sharing pool scheme for living donor kidneys where they are ‘swapped’. For example, if you (Mrs A) wanted to give a kidney to your sister (Miss A) but you had the wrong blood group, it may be that your kidney will suit Mrs B in another part of the country and that Mr B (who couldn’t donate directly to his wife because of his blood group) has a kidney that would suit your sister, making it possible for two transplants to happen in this pooled exchange programme.

If a donor and recipient pair is entered into the pool then their details are registered with the national centre in England. Four times in the year (January, April, July and October) there is, what is known as, a ‘matching run’ when the computer programme looks at all the people who are registered and works out who would match whom (perhaps the ultimate on-line match!).



The pool exchange system: Mrs A cannot give her kidney to her daughter Miss A because she is the wrong blood group, and Mr B cannot give his kidney to his wife Mrs B because she has antibodies to his tissue type, but Mrs A’s kidney is a good match for Mrs B, and Mr

It is important to note that

- The person giving the kidney, as well as the person getting, stays in at their nearest transplant centre and the kidneys are transported rather than the patients.
- The donor will not be giving a kidney unless there is a kidney coming for their friend / relative on the same day

- All the donors go to theatre at the same time, so there is no opportunity for one donor to change their mind.

The advantage of this scheme is that the patients will receive a good 'straightforward' live donor kidney without any antibody problems. The disadvantage is that there is no guarantee of getting a match.

If a donor and recipient have not been successful in getting matched in the live donor pool after three or four runs, any other options for transplantation will be discussed thoroughly with potential donors and patients by the consultant.