Kidney Transplant Guide

Information for patients
before a kidney transplant
Introduction

This booklet has been written for patients with kidney disease who are considering receiving a kidney transplant at Addenbrooke’s Hospital.

A kidney transplant brings many benefits, but the main ones are:
• freedom from dialysis
• freedom from diet and fluid restrictions.

A successful transplant is a very good treatment for kidney failure and can significantly improve your quality of life and your life expectancy. However, kidney transplantation is not a perfect treatment. In agreeing to have a kidney transplant you must be willing to accept the risks involved with having such a large operation and understand that the transplanted kidney will not last forever. It is also important to remember that transplantation is only one of the treatment options for patients with kidney disease, and that not everyone is suitable for a kidney transplant.

Below is a list of useful contact numbers for the Cambridge Transplant Centre. Please feel free to contact them for any further information you may require.

Renal Transplant Coordinator 01223 348 031 or 01223 274 637
Pancreas Transplant Coordinator 01223 216 536
Live Kidney Donor Coordinator 01223 596 177
Or via email: renaltransplantcoordinators@addenbrookes.nhs.uk

www.cuh.org.uk/transplant

Your named transplant coordinator is:

Affix sticker here
Assessment for a transplant

In order to be registered or ‘activated’ onto the kidney transplant list you must first be properly assessed to find out whether transplantation is the right treatment option for you.

If you are keen to consider having a kidney transplant, your kidney doctor will refer you to the transplant team at Addenbrooke’s Hospital. You will then be invited to an assessment clinic, where you will meet one of our transplant doctors and a transplant coordinator. Transplant assessment clinics take place in Addenbrooke’s Hospital and at the dialysis units around the East Anglia region.

Your transplant assessment clinic appointment

What / who to bring with you:
- a list of your current tablets and medicines
- a list of current and past medical conditions you may have including any operations you have had (please include dates)
- a relative or close friend to support you and ensure that you don’t miss anything.

You will meet a transplant doctor who will:
- review your medical history and recent investigations, including an ECG (tracing of your heart) and a chest X-ray
- examine your abdomen
- assess the blood flow to your legs
- listen to your heart and lungs
- discuss with you the risks involved in having a kidney transplant and the different types of donors available.

You will also meet a transplant coordinator who will go through your consent forms and tell you more about:
- waiting for a kidney transplant
- what happens when we have found a suitable kidney for you
- the transplant operation
- what happens after transplantation.
After your appointment we may need to perform some more tests to ensure that you are well enough to undergo the transplant operation safely, these may include:

- an exercise treadmill test
- an echocardiogram (detailed scan of your heart)
- blood tests to check your blood group and tissue type.

In order to minimise the risk of complications during and after your operation it is important that you **try to maintain a healthy lifestyle**. This may include making lifestyle changes, such as stopping smoking, reducing how much alcohol you drink, losing weight and / or improving your level of fitness. Your doctor will advise you of any changes you may need to make before being considered for a kidney transplant at Addenbrooke’s Hospital.

After all the necessary investigations have been completed, the transplant team will advise you if you are fit enough for a kidney transplant and whether it would be the right treatment for you.

### Different types of kidney donors

Before consenting to kidney transplantation it is important that you understand the different ways that kidneys are donated in the UK.

**Deceased donor kidney transplants**

Most of the kidney transplants performed in the UK come from people who have died and wanted their kidneys to be used by someone after their death.

There are two types of deceased donors:

**Brain-death donors**

This type of donor will have been assessed as having an irreversible and total loss of brain function. The donor’s heart continues to beat as long as the donor remains on a ventilator (breathing machine). The kidneys receive a blood supply until they are removed from the donor.

**Circulatory death donors**

Some patients sustain catastrophic brain injury from which they will not recover, but are not brain-dead. Nevertheless, further treatment is not considered to be in their best interests so, after discussion with the donor’s family, treatment is discontinued by stopping ventilation and
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stopping any drugs that they are on. Following this, their heart stops beating and they are confirmed to be dead. Once this has occurred, the donor can be transferred to an operating theatre and the kidneys removed. In circulatory death donors the kidneys have no blood supply for several minutes before the surgeons cool the kidneys and remove them. This may mean that after transplantation a kidney from a circulatory death donor may take longer to start working again than a kidney from a brain-death donor. In the long term, circulatory death donor kidneys work as well as kidneys from brain-death donors.

If you are on the deceased donor kidney transplant list then you may be offered a kidney from either brain-death or circulatory death donors. The kidney’s suitability will be assessed by the transplant surgeon and a nephrologist prior to being offered to you.

Dual transplants
Sometimes the transplant team may decide to implant two kidneys into you to increase the chances of the transplant being successful. We do this whenever we think a single kidney will not work well enough for you, but both kidneys from the donor should. This option will be discussed with you at the time to gain your consent.

Occasionally the transplant team are offered kidneys from a very young donor (under five). In this case it is better to transplant both kidneys into a smaller recipient. In the long term these kidneys work very well, and grow in the recipient, but their size means that there is a small increase in the chance that the blood vessels to the kidney may clot (thrombose) around the time of the transplant. This option will also be discussed with you at the time.

Living donors
A living donor kidney transplant is when you receive a kidney from a healthy individual who wishes to give you one of their own kidneys. This is usually a family member, relative or friend. About a third of all kidney transplants in the UK are from live donors. The benefits of this are that an ideal donor can be chosen and you can prepare for the transplant beforehand. The transplant itself takes place in the daytime on a day to suit you. Having a living donor often allows you to have a kidney transplant before you need to start long-term dialysis.
Altruistic donors

This is a form of living donation where an individual volunteers to donate one of his / her kidneys to an unknown recipient. To ensure anonymity of the donor, the recipient is chosen from the deceased donor kidney transplant list in the same way in which deceased donor kidneys are allocated.

You can find out more information on live donation and altruistic donors by speaking to one of our living donor coordinators on 01223 596 177.

At your transplant assessment clinic appointment your doctor will discuss the differences between living and deceased kidney donation and which options would be best for you.

Consenting to transplantation

Before you are registered or ‘activated’ on the deceased donor kidney transplant list you must have read the information we give you and sign a consent form to show that you understand what a transplant involves and that you agree to have one. The information below should help you to understand the general risk involved in choosing to have a kidney transplant. You can find more information about the specific complications associated with the transplant later in this book.

At the end of the first year after a kidney transplant around 92 out of 100 (92%) kidney transplants will still be working. To put it another way, your chance of losing your kidney in the first year is the same as your chance of drawing an ace from a deck of cards.

A kidney transplant is a complex procedure. There is a small risk (two in 100) of death in the first year; this proportion is illustrated by the two white figures in the cartoon opposite. To put this in perspective, there is also a significant risk of dying whilst on dialysis. The risk of dying on dialysis is higher in patients with diabetes and in older patients. For example, there is a two in 100 chance of dying each year on dialysis in patients aged 18 to 34, increasing to 15 in 100 in patients aged 65 to 74.

Your transplant coordinator will discuss the consent form with you and will answer any questions you may have.
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By signing our consent form you are also agreeing to have your information held on the national transplant database.

High-risk consent

Following assessment, some patients will be deemed to be at higher risk of serious complications; for example, you may be older (above 70 years of age) or have a previous history of heart or lung problems. If your doctors think you are at greater risk of complications or dying as a consequence of having a transplant you will be asked to sign a high-risk consent form. If you are asked to sign this form, it is very important that you read it carefully and have a clear idea of the risks involved for you. This includes the possibility that your initial hospital stay may be longer than the average six to ten days, you may develop complications that require further admissions to hospital, and you may end up worse than if you stayed on dialysis. Because the risks differ for each patient, the transplant doctors and coordinator will explain why you are higher risk and what that means for you.

Having weighed up the potential risks and benefits, some patients feel that life on dialysis is so restrictive that they want to go ahead with the transplant, whilst others feel happier to continue with dialysis.
For some patients, the transplant doctors may think that the risks of a transplant are too high and will not place you on the waiting list. If you think this is unfair you can ask to be referred to another transplant unit for a second opinion.

It is for you to decide whether or not you wish to consent to kidney transplantation. We will always respect your final decision.

The donor organs

It is important you understand that although the organ you get will be new to you, you will **not** be getting a **new** kidney. Brain-death and circulatory death donor organs have come from someone who has died and wanted to donate them to help someone like you after his / her death. It is uncommon for a young patient to be an organ donor, or for the donor to die of an accident; most organ donors have died of a medical condition, such as a stroke or heart attack. The average age of an organ donor in the UK is increasing, and in 2012 was 54 years old, with some donors aged up to 80 years old. Half of all organ donors are smokers.

It may be that you want to opt out of having a kidney from the types of donor listed below. At the time of consent you will be given the opportunity to talk through the risks involved with different donors and the options available to you.

**Some donors have medical problems which we do not know about** at the time of death and which might be transmitted to you. We make every effort to carefully check all organ donors for the presence of life-threatening infections, but some donors may have viral infections that we either do not know about or which we believe represent a low risk to you as a recipient. The risk of you catching a life-threatening infection is small (less than one in 100).

**Some donors are known to have taken intravenous drugs or had other behaviour that increases their chance of having a hepatitis virus or HIV / AIDS.** We check all our donors for these viruses but there is a small chance (one or two in 100), that an infection in a high-risk donor such as these may not be identified and therefore transmitted to you. If one were transmitted inadvertently, you would need to take anti-viral drugs for the rest of your life in addition to your immunosuppression.
Approximately one in 2000 donors has a cancer that we do not know about, and which can be passed on with the kidney transplant. This is often a fatal complication. Unfortunately we cannot predict which donors may have a hidden cancer.

Around two in 100 donors have died from a cancer in the brain. Such cancers only rarely spread outside the brain, so it is common for transplant doctors to transplant organs from such donors. Nevertheless, there is a small chance (around two in 100) that, if your kidney donor had such a cancer, it might be passed on to you.

Some donors may have had a cancer treated in the past and are thought to be cured of it. We make every effort to get all the details of these cancers and the treatment before deciding that the organs are safe to use. No cancers have been transmitted from such donors in the UK, but there is a small risk that this might happen.

What to expect whilst you are on the transplant list

Once you have made the decision to receive a kidney transplant from a deceased donor and you have signed the consent form you will be discussed by the transplant team at Addenbrooke’s Hospital and, if they are happy, you will be ‘activated’ on the list. Because of the shortage of organ donors, patients wait an average of two to three years for a transplant. Some patients are fortunate enough to get a kidney transplant quickly, within the first year, while others will have to wait four or five years, or sometimes longer. Your transplant doctors will tell you if they think you are likely to have to wait longer than average.

Whilst you are waiting for a transplant it is vital that you continue to lead as healthy a lifestyle as possible. The transplant team will see you regularly (every six or 12 months) in the assessment clinic to make sure that you continue to be fit enough to have the transplant operation. You must attend these appointments in order to remain active on the transplant list.
Receiving a kidney transplant from a deceased donor could happen at any time, day or night; this means you should ensure that you are always contactable via phone whilst you are active on the list. Keep your mobile phone charged.

Once you have been placed on the list, you will remain active unless otherwise informed. It is extremely important that you let your transplant coordinator know as soon as possible if you become unwell, are admitted to hospital or feel you may have a problem which might affect the transplant operation. They will be happy to discuss and advise you on any issues that arise.

Your transplant coordinator also needs to know the following information whilst you wait for a kidney transplant:

- change of contact details
- holiday dates and location (including travel within the UK)
- if you receive a blood transfusion
- if you have had a live vaccine.

In certain circumstances, such as if you are admitted to hospital or become pregnant, we may suspend you from the list to ensure that you are not called in for a transplant when you are not available or perhaps temporarily not well enough to receive one. Once you believe you are ready to become active again, please ensure that you let us know.

Whilst you are on the transplant waiting list, it is important to regularly check your blood for antibodies to help with the selection of a compatible donor kidney for you. National guidelines recommend that antibodies are checked at least every three months and the Tissue Typing Laboratory will remind your transplant coordinator when this check is due.

Who decides who gets a kidney?

When a kidney is donated by a deceased donor, the blood group and tissue type of the donor are checked. These are then matched with all the patients on the national list, which also gives some priority to patients who have been waiting the longest. Before you are contacted about the kidney, the transplant doctors will review the details of the kidney you are being offered, to check it is suitable, and this will also be discussed with doctors at your own hospital.

More information on organ allocation can be found at the following website: www.organdonation.nhs.uk/
What happens when a kidney becomes available for you?

When we have found a suitable kidney for you, you will receive a phone call from one of the transplant coordinators at Addenbrooke’s Hospital. They will ask you to confirm your details and ask if you are well. When you get the call it is important that you:

**Keep calm** as the coordinator will need to ask you a few questions and give you clear instructions about what you need to do.

**Listen** to what the transplant coordinator tells you. He / she will advise you when you need to stop eating and drinking in preparation for the surgery. If you are a diabetic you will be advised how to manage your sugar control during this time. He / she will also tell you which ward you need to report to when you arrive for your transplant.

**Be prepared** and think about what you want to bring into hospital with you beforehand. Once you have received the call, it’s important that you don’t spend too long at home packing.

The following is a checklist of essential things you should bring into hospital for your transplant:

- any medications that you are taking
- a wash bag
- some money to buy things at the shop
- some comfortable slippers
- if you are on peritoneal dialysis, remember to bring your next bag exchange and equipment.

Please refrain from bringing in too much personal property, as space is limited on the ward. **Do not bring any valuables in with you.**

**Think ahead** and make sure you have a plan about how you will get to Addenbrooke’s Hospital. If you think this could be a problem, please discuss this with your transplant coordinator beforehand.

**Plan** your route to Addenbrooke’s Hospital. You may find it useful to visit us so that you can practice your travel route beforehand. We would be more than happy to show you around the transplant unit.
Arrive safely ensuring you get to Addenbrooke’s Hospital as soon as you can. Please remember not to drive dangerously or break the speed limit.

Getting ready for your transplant

Once you have arrived at Addenbrooke’s Hospital and have made your way to the ward you will be seen by the following people:

The transplant doctor will take some blood tests, insert a cannula (small tube) into a vein in your hand, examine you and confirm your medical history and current medications. He / she will see whether you need some haemodialysis before the transplant and prescribe your new medications.

The nursing staff will measure your blood pressure, temperature, heart rate and weight. They will ask you some questions that will help them care for you whilst you are in hospital. They will also perform an ECG (heart tracing) and take routine swabs. They will then ask you to have a shower, help you get changed for theatre and give you some new medications prior to your operation.

The transplant surgeon will check that you are well enough to have the operation and will go through the consent form with you again. He / she will discuss any issues with you about the donor at this point.

Your anaesthetist will need to understand about your general health, any medication that you are taking and any past health problems that you have had, in particular any problems with previous anaesthetics. He / she will want to know whether or not you are a smoker, whether you have had any abnormal reactions to any of the drugs or if you have any allergies. He / she will want to know about your teeth, whether you wear dentures, have caps or a plate. Your anaesthetist needs to know all these things so that he or she can assess how to look after you in this vital period.
Waiting for the operation

Once you have seen all of the above staff, you will be advised on how long it will be before you are taken to theatre for your transplant. You may have to wait for a few hours until we know definitely if the kidney is suitable to use. You will be kept updated during this time. Sometimes when we look at the kidney, or examine a small piece of it under the microscope, we decide that it is not suitable to be transplanted and the operation will then be cancelled. If this happens we will discuss the reasons why before you are sent home. Please do not be disheartened at this point as the transplant team wants to ensure that you receive the best possible kidney and being called in for what turns out to be a ‘false alarm’ will not affect your status on the list.

The kidney transplant operation

The transplant operation takes place in the operating theatre where you will have a general anaesthetic (be put to sleep). A team of transplant surgeons and nurses will prepare the new kidney and carry out the kidney transplant procedure. The operation takes two to three hours, although in total you may be away from the ward for five to six hours. Occasionally it may take longer in the event of unexpected findings.

The transplanted kidney is usually placed in either the right or left groin area, as illustrated. It is placed here as it is close to your bladder. Normally your own kidneys are not removed unless there is a reason to do so. As a result, you will end up with three kidneys (your own ‘native’ kidneys and the transplanted one).

The operation requires the surgeon to join up your blood vessels to those of the transplanted kidney. The urine tube (ureter) that will drain the urine from the transplanted kidney will be connected to your bladder. We usually leave a plastic tube (a stent) across the join with the bladder.

The skin wound may be closed up with small metal staples, dissolvable (invisible) stitches or glue.

If you have a peritoneal dialysis catheter, it will be removed at the time of the transplant operation.
After the operation

After the kidney transplant has been carried out you will usually return to the transplant ward. Sometimes it may be necessary for you to be looked after in the intensive care or high dependency unit for a day or two, depending on your recovery from the operation. The nursing staff will make sure that you are comfortable and will monitor the transplanted kidney to make sure it is working well.

When you wake up you will notice that you will have a number of different plastic tubes in your body, the most common ones will be:

A **tube in your neck** to help us measure your fluid volumes and give you temporary dialysis if required.

A **small tube in your hand or arm** to give you medications and pain relief.

A **plastic drain tube in your abdomen** to help drain away any blood and fluid from the operation.

A **urinary catheter**, a tube which passes up your urethra into the bladder, to help us monitor your urine output and allow the internal stitching to heal.
Most of these lines should be removed after two to three days. The urinary catheter will remain for five days to allow the sutures to heal.

During the transplant you will also have a small plastic tube (ureteric stent) placed between your new kidney and your bladder to help maintain the flow of urine. The stent will be removed after six weeks as a day case procedure using a local anaesthetic.

Recovering from the operation

Eating and drinking is usually encouraged as little as six hours after the operation. Whilst you are in hospital, the transplant nurses will encourage you to record everything you drink and measure the urine you pass, even after the urinary catheter has been removed. This will help us to check how well the kidney transplant is working.

On the first day after your operation your nurses will help you out to your chair for a few hours, where you will be taught how to carry out deep-breathing exercises. You will be encouraged to be mobile around the ward as soon as possible as this will help speed up your recovery and reduce your chances of getting a blood clot in the leg or a chest infection.

You are likely to be in hospital for six to ten days following a kidney transplant. However, this could be longer depending on your condition and your doctor’s opinion.

Although you will be able to carry out daily activities when you get home, we advise you to rest for about six weeks and to allow a few months until you really get back to normal active work. Following your discharge from hospital, the transplant team will ask you to attend regular transplant clinics twice a week to monitor you for possible complications such as rejection or infection.

If you were referred from another dialysis unit, your initial clinic visits will be at the Addenbrooke’s Hospital outpatients department. However, once your doctors are happy with your progress they may refer you back to your local hospital; this is usually about three months after your transplant. In due course appointments will become less frequent.
If possible, you should arrange your own transport to and from the outpatients department.

It is important for you to recognise that caring for your kidney transplant is the best way of ensuring its success and keeping you free from dialysis.

You can contact the transplant clinic on 01223 274 593 or 01223 217 452.

Complications associated with kidney transplantation

Although kidney transplantation is a very successful treatment for kidney failure, complications can occur. Your transplant team will do its best to reduce your chance of having any complications and to treat any arising problems straight away. You can minimise the risk of complications by following instructions carefully and keeping your transplant team informed of any problems that occur.

Possible complications after having a kidney transplant may include:

About five in 100 patients experience a urine leak where the donor ureter joins your bladder. This usually requires a return to theatre for an operation to have the leak repaired.

About five in 100 patients experience internal bleeding, which may require a blood transfusion and possibly a further operation to stop the bleeding or remove any clots that have collected.

About four in 100 patients have a blood clot form in the vein or the artery of the new kidney. This means the blood supply to the kidney will stop. If this happens you will have to go back to theatre and, unfortunately, it usually results in the kidney having to be removed.

There is a 15 in 100 chance that you could develop a lymphocoele (a collection of lymph (tissue) fluid). The fluid usually collects in a small pocket next to the transplanted kidney and can block the flow of blood to the kidney or the flow of urine from the kidney. If this happens it will need draining.
Following all surgery there is a risk of deep vein thrombosis (DVT), which are clots forming in the veins of the leg. To prevent this happening you will be given injections of a blood thinning drug whilst you are in hospital. You will also wear surgical stockings to encourage the blood flow in your legs whilst you are less mobile.

Problems associated with the medication taken after transplantation:
There is a small chance that you could develop diabetes (raised blood sugar) as a side effect of your anti-rejection (immunosuppression) drugs. It is usually treated with a change in diet and/or tablets. Sometimes there is a need for insulin injections.

High blood pressure is very common following a kidney transplant, particularly during the early months. Many people require blood pressure lowering drugs after a kidney transplant. It is vital to control high blood pressure as, if left untreated, you could be at risk of heart disease or a stroke and it can damage the transplanted kidney.

The anti-rejection drugs will make you more likely to develop infections. The risk is greater in the early stages after your transplant because the doses of anti-rejection drugs are higher. It is important to inform your transplant team if you think you have an infection. If you know family or friends who have a serious infection, it is a good idea if you avoid visiting them while they are unwell.

You are twice as likely to develop cancer if you are on anti-rejection drugs compared with the general population who aren’t taking anti-rejection drugs. In particular you will be more prone to developing skin cancers. For this reason we encourage you protect yourself from the sun by using powerful sun screens and avoiding direct exposure to the sun.

Problems associated with organ transplantation:
About half of all transplanted kidneys will experience delayed graft function. It may take several days for your new kidney to start working and you may need haemodialysis during this time. If your kidney takes more than a few days to start working properly or temporarily stops, your doctors may take a biopsy (tissue sample) of the new kidney to see if you have rejection.
Roughly 30 in 100 patients will experience acute rejection within the first six months of their transplant. Your body will recognise that your kidney is ‘foreign’ and the natural response is to attack and reject it. You will be given anti-rejection medication to reduce the chance of this happening; these medications will need to be taken for the life of your kidney transplant. Rejection is treated by changing the dose of anti-rejection drugs and / or by prescribing a new drug in addition. As rejection can be detected following one of your regular blood tests, it is critical that you attend your clinic appointments regularly.

Some patients will experience anxiety and mood swings. The transplant operation can put a lot of stress on you and your family. It is very common for patients or relatives to have anxieties. There are counselling services to help you adjust to life at home. Please ask your transplant team for more information about these services.

About this book

‘Information for patients before a kidney transplant’ is written with contributions and advice from many members of your renal transplant team and from patients and their families.

This document is designed to be continuously updated to include the most up-to-date advice.

Whatever your role in kidney transplantation, if you are reading this text, your comments and suggestions for improvements to this document are very welcome.
Privacy and dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk

Please note: we do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.