

# Patient agreement to investigation or treatment

## Kidney Transplantation

**Authors:** Cambridge Transplant Unit

**Brief description:**

- Kidneys can be transplanted into patients who have failed or failing kidneys. The new kidney is removed from either a living donor (usually a relative or spouse) or from someone who has recently died. Following successful transplant the patient should not need dialysis.
- Here, we explain some of the aims, benefits, risks and alternatives to kidney transplantation. We want you to be informed about your options to help you to be fully involved in making any decisions.
- Please ask about anything you do not fully understand or wish to have explained in more detail.
- If you would like this information in another format or language or would like help completing the form, please ask a member of our staff.
- Please sign this consent form and give or send it to your transplant coordinator. This form must be signed before you are put on the kidney transplant waiting list.
- You are asked to read this form carefully, and you and your doctor (or other appropriate healthcare professional) will sign it to document your consent.
- All our consent forms are available on the Addenbrooke’s website:  
<http://www.cuh.org.uk/consent>
- Guidance for health professionals can be found on the Addenbrooke’s intranet site  
<http://nww.addenbrookes.nhs.uk/consent>
- Remember, you can change your mind about having the procedure at any time, even after you have signed the form. However, it is important that you inform your transplant coordinator so you can be suspended from the transplant waiting list.

**For staff use:**

Does the patient have any special requirements? (For example, requires an interpreter or other additional communication method)

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## About Kidney Transplantation

A kidney transplant has been recommended for you because your own kidneys have failed (currently you are having dialysis) or are failing (you will need to start dialysis in the near future).

Your Nephrologist (kidney specialist) will have assessed your condition in a transplant assessment clinic with a Consultant Transplant Surgeon. The transplant team and personnel related to the Transplant Programme have decided that it is appropriate to add your name to the Waiting List in Cambridge for a Kidney Transplant if that is what you would like.

This is a major operation involving a team of transplant surgeons working for approximately two to three hours.

## Before your procedure

- When an appropriately matched kidney is available, you will be contacted by phone at **any time of the day or night**. You will be asked to report to Ward G5 at Addenbrooke's urgently without any delay. This is because the new kidney cannot survive outside the human body for more than a few hours.
- When you arrive, a doctor will see you on ward G5, go through your medical history again, examine you, and take some blood for urgent tests. You may need dialysis before your transplant depending on your blood results. You will then wait for the new kidney to reach Addenbrooke's, before you are prepared and taken to the theatre for the transplant operation. Please be aware that you may have to wait some time for the operation once you have been admitted.
- Sometimes final tests show the kidney is not suitable to be transplanted. If this happens the transplant can not go ahead and you will be able to go home. This will be upsetting for you, and we apologise for the upset involved, but it will be because the doctors believe that having that kidney is not in your interests. Please talk to the transplant team if this happens so you understand the reasons for the decision. You will remain on the transplant list.
- The kidney transplant given to you may require you to have additional medication or tests. This will be discussed with you at the time of the transplant.
- Rarely the transplant team may decide to implant two kidneys into you to increase the chances of the transplant being successful. This option will be discussed with you at the time to gain your consent.

Occasionally a second patient is also called in for the transplant. This happens if there are doubts that the organ will be suitable for a particular patient. If this is necessary this will be discussed with you at the time you are called in for your transplant.

- This procedure involves the use of general anaesthesia. See below for further details about this type of anaesthesia.
- Most people who have this type of procedure will need to stay in hospital for between 7 to 10 days. Sometimes we can predict whether you will need to stay for longer than usual - your doctor will discuss this with you before you decide to have the procedure.

## Who will perform the procedure?

The kidney transplant operation will be carried out by an appropriately experienced and trained surgeon.

## During the procedure

Before your procedure, you will be given the necessary anaesthetic - see below for details.

- We will place several lines (tubes) into some blood vessels in your arms and neck. These enable us to give you fluids and/or blood, and help us take blood for tests and monitor your condition. In addition, a tube might be passed into your stomach through the nose to decompress (deflate) your stomach. We also place a urinary catheter into your bladder during the operation so we can closely monitor your urine production after the operation.
- A team of surgeons will prepare the new kidney before you are anaesthetised. Once you are asleep they will carry out the kidney transplant procedure in you. The surgeon will make a long curved incision (cut) on one side of your lower abdomen (tummy). The new kidney will then be connected up to the blood vessels that take blood to your leg. We also connect the transplant kidney's ureter (tube) to your bladder so that the urine comes out the normal way. **A plastic tube called a "stent" is placed in the ureter to help the join to heal properly. This is normally removed six weeks after your transplant operation.** A drain is also inserted into the abdomen to allow blood and fluid to drain from the transplant site. This is usually removed after two days. Typically the operation takes two to three hours; however in some circumstances the operation might take substantially longer.
- If you are on peritoneal dialysis your dialysis catheter will be removed during the transplant operation.

## After the procedure

- Immediately after your kidney transplant you will be taken to a special area in the theatre suite to recover (the recovery room) where a nurse will check your pulse and blood pressure regularly until you are wide awake. When you are well enough to be moved, you will be taken to G5 where you will be closely monitored.
- After the transplant, most people receive fluid intravenously through lines inserted at the time of the operation. A small, plastic tube (cannula) is inserted in one of the veins of their arm and their neck. These will be attached to a bag of fluid (called a drip), which gives your body fluid until you are well enough to eat and drink by yourself.
- Some people feel sick after an operation, especially after a general anaesthetic, and might vomit. If you feel sick, please tell a nurse and you will be offered medicine to make you more comfortable.
- **Eating and drinking:** Generally you will be allowed to eat and drink on the first or second day after the operation.
- **Getting around and about:** As soon as you are able, you will be encouraged to move around and carry out deep breathing exercises. This both reduces the chance of getting a blood clot in the leg and also helps you to avoid chest infections.
- **When you can leave hospital:** Following a kidney transplant, you are likely to need to stay in hospital for seven days. In some circumstances you might need to stay longer, depending on your clinical condition and your doctor's opinion.
- **When you can resume normal activities including work:** When you leave hospital, you should be able to carry out light daily activities at home. However, it might be a few months before you can return to normal active work.
- **Special measures you need to take after the procedure:** You will be given more detailed information about any special measures you need to take after the procedure. You will also be given information about things to watch out for that might be an early sign of problems (for example, infection).
- **Check-ups and results:** Once you are home after the operation you will be seen in the transplant outpatient clinic twice a week for a month to check your progress and to make sure your new kidney is functioning well. If your condition remains stable the time between clinic visits will increase to once weekly for the next month. Patients referred for kidney transplantation from other hospitals (not Addenbrooke's) will usually return to their hospital after three months or when their condition is stable.

## Intended benefits of the procedure

- Kidney transplantation offers you the possibility of either coming off dialysis or avoiding starting it. Most people who have had a kidney transplant consider they have a better quality of life and avoid many of the complications associated with dialysis. We expect 5 out of 10 of our transplanted kidneys still to be working satisfactorily 10 years after the transplant.

## Alternative procedures that are available

- It is possible to live without a kidney transplant; depending on the condition of your kidneys, you will need to continue with (or start) either haemodialysis or peritoneal dialysis to stay healthy.

## Serious or frequently occurring risks

- Kidney transplantation is a complex procedure and there is a 2 in 100 risk of death in the first year after transplantation. Patients who face higher risks from the transplant operation will be asked to sign a separate consent form. This risk is generally less than the risk of death for an average patient who remains on dialysis for a year.
- There is a 10 in 100 risk of your kidney transplant failing in the first year.
- There is a small risk (2 in 100) that the blood vessels of the new kidney will become blocked (thrombosis) following this procedure. This will lead to failure of the kidney and we will need to remove the new kidney in a further operation.
- There is a small risk of bleeding (5 in 100) following the operation. If this happens we might need to stop the bleeding at a further operation.
- There is a small chance (5 in 100) of a problem with the join between the new kidney and the bladder which will require a further operation to put right.
- After the operation, there is an overall 30 in 100 risk of acute rejection of the new kidney. If this happens, we will need to give you some extra treatment with more powerful medications. This will require an admission into hospital. Rejection like this is usually easy to treat and the kidney usually continues to function well after treatment
- One in three transplants do not work straight away and you will need to continue dialysis until the kidney starts working. If you were on peritoneal dialysis before the transplant you will need to have haemodialysis until the kidney starts working because the peritoneal dialysis catheter is removed at the time of the operation. Most kidneys start working again by a week after the transplant, but very occasionally it might take up to three months.
- Kidney transplants don't last forever and in time the transplant will fail. When this happens you will need to go back onto dialysis. If you are fit enough you would be placed back on the waiting list for another transplant.
- A few kidney diseases can come back in the transplant kidney. If we think there is a significant risk of this, your Nephrologist will discuss this before you are placed on the Transplant List.
- Most people who have had a kidney transplant need to undergo further admissions into hospital in the subsequent months and years. These are necessary to sort out any medical problems that might arise, so we can keep you and your kidney as fit as possible. During these admissions you might have more blood tests, scans, and possibly a biopsy of the kidney.

- As with any other operation, complications can occur after a kidney transplant. Such complications include wound infections, collection of fluid around the kidney transplant, blood clots in the legs and fluid leak from drains and wound sites. These complications can often be managed with medication, rather than any further surgical procedures.
- We take every effort to screen kidney donors for infections and cancer. Nevertheless we cannot guarantee that an infection or tumour will not be transmitted from the donor to you the recipient. The risks are extremely low; for instance the risk of an unknown cancer being transmitted is between 2 and 20 in 10000.
- Sometimes we will use kidneys from donors who we know have special types of cancer which we know rarely spread, such as brain cancer. There have been no cases of spread of such cancers to kidney recipients in the UK and we consider them safe to use. Nevertheless there is a small chance (less than 1 in 100) that such cancers may be transmitted, and treatment in such cases will usually involve removal of the kidney with the expectation that the cancer will be rejected.
- It is important to remember that the kidney you are getting is not “new”, and may not be perfect. Nevertheless your doctors and transplant surgeons will not knowingly transplant any kidney which we do not think will work and get you off dialysis.

## Drugs

- It is common for some drugs, particularly the immunosuppressive drugs, to be used in combinations or for conditions for which they were not originally licensed. This is common practice in transplant units such as ours, and such use has been acknowledged by the National Institute of Health and Clinical Excellence. Any new drugs that we use will have been approved by Addenbrooke's Hospital Drug and Therapeutic Committee, or, in the case of clinical trials, by an appropriate Research Ethics Committee.

## Immunosuppression

- In order to protect the new ‘foreign’ kidney from rejection by your immune system, you will need to take some powerful immunosuppressive medications. While these drugs protect your new kidney, they also reduce your ability to fight infections particularly with viruses. The two most important of these are Cytomegalovirus (CMV) and BK virus (BKV)

CMV can cause anything from a mild fever to a much more serious illness that commonly affects the gut and other organs. Patients at high risk of CMV are given treatment for the first three to six months (when the risk is greatest) to prevent infection. BK virus can affect kidney transplant function. We regularly screen for both of these viruses when you attend your clinic appointments.

- The immunosuppressive medication also result in you having a higher risk of cancer than normal people, particularly skin cancer and a cancer of lymph glands called lymphoma (1 to 2 in 100 patients might get this).
- The potential side effects of these medicines include kidney problems, diabetes, stomach upset and wound problems.
- To reduce any side effects, the medical team will carefully monitor and adjust the dose of medications you take, based on your specific condition. Alternative medication may be available.
- It is very important that you follow our instructions on when and how to take your medication. If you do not follow the dosage schedule strictly (for example: if you miss taking tablets), you run a significant risk of losing your kidney without the prospect of a new one.

Please remember that both your own Nephrologists and the Cambridge Transplant Unit has recommended the kidney transplant procedure to you because the team feels that the benefits will greatly outweigh the risks for you.

## Information and support

If you have any anxieties or questions, please feel free to ask any member of the staff. Further information can be obtained from the Kidney Transplant Co-ordinators who can be reached through the Addenbrooke's Switchboard on 01223 245151 or from the Addenbrooke's website [www.addenbrookes.org.uk](http://www.addenbrookes.org.uk) or [www.cambridgetransplant.org.uk](http://www.cambridgetransplant.org.uk).

## Your anaesthesia

### General Anaesthesia

During general anaesthesia you are put into a state of unconsciousness and you will be unaware of anything during the time of your operation.

### Before your operation

Before your operation your anaesthetist will visit you in the ward. The anaesthetist who looks after you at the time of your operation is the one who is responsible for making the final decisions about your anaesthetic. He or she will need to understand about your general health, any medication that you are taking and any past health problems that you have had. Your anaesthetist 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. They will also 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. Your anaesthetist may examine your heart and lungs and may also prescribe medication

that you will be given shortly before your operation, the pre-medication or 'pre-med'.

**Pre-medication** is the name given to medication (drugs) given to you some hours before your operation. These drugs may be given as tablets, injections or liquids (to children). They relax you and may send you to sleep. They are not always given. Do not worry if you do not have a pre-med, your anaesthetist has to take many factors into account in making this decision and will take account of your views on the topic if possible. Do not be worried about your anaesthetic. When your anaesthetist visits you before your operation, this is the time to ask all the questions that you may have, so that you can forget your fears and worries.

Before your operation you will usually be changed into a gown and wheeled on your bed to the operating suite and into an anaesthetic room. This is an ante-room outside the theatre. The anaesthetist, his or her assistant and nurses are likely to be present. An intravenous line (drip) may be inserted. Monitoring devices may be attached to you, such as a blood pressure cuff or a pulse oximeter. A pulse oximeter is usually a little red light in a small box, which is taped to your finger. It shows how much oxygen you have in your blood and is one of the vital monitors that an anaesthetist uses during your operation to ensure that you remain in the best of health. You may be given some oxygen to breathe.

## During your operation

While you are unconscious and unaware your anaesthetist remains with you at all times. He or she monitors your condition and administers the right amount of anaesthetic drugs to maintain you in the correct level of unconsciousness for the period of the surgery. Your anaesthetist is constantly aware of your condition and trained to respond. Your anaesthetist will be monitoring such factors as heart rate, blood pressure, heart rhythm, body temperature and breathing. He or she will also constantly watch your need for fluid or blood replacement. If you have any other medical conditions, your anaesthetist will know of these from your pre-operative assessment and be able to treat them during surgery.

## After your operation

After your operation your anaesthetist continues to monitor your condition carefully. You will be transferred to a recovery ward where specially trained nurses, under the direction of anaesthetists, will look after you. Your anaesthetist and the recovery nurses will ensure that all the anaesthetic effects are reversed and that you are closely monitored as you return to full consciousness. You may be given some oxygen to breathe in the recovery area, and may find that intravenous drips have been inserted whilst you are unconscious in theatre and that these will be replacing fluids that you might require. You will be given medication for any pain that you might feel, and systems, such as Patient Controlled Anaesthesia (PCA) may be set up to continue pain control on the ward.

You are likely to feel drowsy and sleepy at this stage. Some patients feel sick, others may have a sore throat related to the insertion of the breathing tube during surgery. During this time it is important that you relax as much as you can, breathe deeply, do not be afraid to cough, and do not hesitate to ask the nursing staff for any pain relief, and about any queries you may have. You are likely to have hazy memories of this time and some patients experience vivid dreams. Once you are fully awake you will be returned to the ward.

## **What are the risks of general anaesthesia?**

In modern anaesthesia, serious problems are uncommon. Risks cannot be removed completely, but modern equipment, training and drugs have made it a much safer procedure in recent years. The risk to you as an individual will depend on; whether you have any other illness, personal factors (such as smoking or being overweight) or surgery which is complicated, long or done in an emergency. Please discuss any pre-existing medical condition with your anaesthetist.

- Very common and common side effects (1 in 10 or 1 in 100 people)  
Feeling sick and vomiting after surgery, sore throat, dizziness, blurred vision, headache, itching, aches, pains and backache, pain during injection of drugs, bruising and soreness, confusion or memory loss.
- Uncommon side effects and complications (1 in 1000 people)  
Chest infection, bladder problems, muscle pains, slow breathing (depressed respiration), damage to teeth, lips or tongue, an existing medical condition getting worse, awareness (becoming conscious during your operation).
- Rare or very rare complications (1 in 10,000 or 1 in 100,000)  
Damage to the eyes, serious allergy to drugs, nerve damage, death, equipment failure.



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

### Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

[patient.information@addenbrookes.nhs.uk](mailto:patient.information@addenbrookes.nhs.uk)



### Document history

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Consent form 1

# Patient agreement to investigation or treatment

<b>For staff use only:</b>
<b>Surname:</b>
<b>First names:</b>
<b>Date of birth:</b>
<b>Hospital no:</b>
<b>Male/Female:</b>
<b>(Use hospital identification label)</b>

Responsible health professional/job title

Special requirements .....  
(For example, other language/other communication method)

**Name of proposed procedure or course of treatment**

**Kidney Transplantation** **Side (left/right).....**

**Statement of health professional**

(To be filled in by a health professional with an **appropriate knowledge of the proposed procedure**, as specified in the Hospital's consent policy)

I have explained the procedure to the patient. In particular, I have explained:

- The intended benefits of the procedure the possibility of either coming off dialysis or avoiding starting it. We expect 5 out of 10 of our transplanted kidneys still to be working satisfactorily 10 years after the transplant.
- Any serious or frequently occurring risks from the procedures including those specific to the patient: risk of death in the first year after transplantation, kidney transplant failing in the first year, a small risk that the blood vessels of the new kidney will become blocked risk of bleeding, a problem with the join between the new kidney and the bladder, acute rejection of the new kidney, wound infections, collection of fluid around the kidney transplant, blood clots in the legs and fluid leak from drains and wound sites. Most people who have had a kidney transplant need to undergo further admissions into hospital in the subsequent months and years.
- Any extra procedures that might become necessary during the procedure

Blood transfusion  Other procedure (please specify) .....

I have discussed what the treatment / procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

- The following information leaflet has been provided: Kidney Transplant .....  
..... Version/Date/Ref: 3/August 2010/CF171 .....

This procedure will involve:

General and/or regional anaesthesia  Local anaesthesia  Sedation

Health professional's signature: .....Date: .....

Name (PRINT): ..... Job title: .....

Contact details (if patient wishes to discuss details later)

I have offered the patient information about the procedure but s/he has declined information.

**Statement of the interpreter (if appropriate)**

I have interpreted the information to the best of my ability, and in a way in which I believe s/he can understand:

Interpreter's signature..... Date: .....

Name (PRINT):.....

**Important notes: (tick if applicable)**

- The patient has withdrawn consent (ask patient to sign/date here) .....
- See also advance directive/living will

Copy accepted by patient: yes / no (please circle)

<b>For staff use only:</b>
<b>Surname:</b>
<b>First names:</b>
<b>Date of birth:</b>
<b>Hospital no:</b>
<b>Male/Female:</b>
<b>(Use hospital identification label)</b>

**Statement of patient**

Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy, which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. Do ask if you have any further questions. The staff at Addenbrooke's are here to help you. **You have the right to change your mind at any time before the procedure is undertaken, including after you have signed this form.**

Training doctors and other health professionals is essential to the continuation of the Health Service and improving the quality of care. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a senior doctor. You may, however, decline to be involved in the formal training of medical and other students without this adversely affecting your care and treatment.

**Please read the following:**

**I understand** that I will have the opportunity to discuss the details of anaesthesia with an anaesthetist before the procedure, unless the urgency of my situation prevents this. (This only applies to patients having general or regional anaesthesia.)

**I understand** that you cannot give me a guarantee that a particular person will perform the procedure. The person undertaking the procedure will, however, have appropriate experience.

**I understand** that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

**I have been told** about additional procedures which may become necessary during my treatment. I have listed below any procedures that **I do not wish, without further discussion, to be carried out.**

**I understand** that blood samples for tissue typing will be regularly taken, analysed and stored according to national standards.

**I understand** that any tissue (including blood) removed as part of the procedure or treatment will be anonymised and may be used for teaching or quality control, and stored or disposed of in a manner regulated by appropriate, ethical, legal and professional standards.

**I understand** that all research will be approved by a research ethics committee and undertaken in accordance with appropriate ethical, legal and professional standards.

**I understand** that the research may be conducted within a hospital, university, not for profit organisation or a company laboratory.

**Please tick boxes to indicate you either agree/disagree to the three points below.** **Yes**  **No**

**I agree** that tissue (including blood) not needed for my own diagnosis or treatment can be used for **research which may include genetic research.** **If you wish** to withdraw your consent for the use of your tissue (including blood) for research, please contact the Patient Advice and Liaison Service at Addenbrooke's Hospital.

**I agree** to the use of photography for the purpose of diagnosis and treatment.

**I agree** to anonymised photographs being used for medical teaching.

**I confirm** that the risks, benefits and alternatives of this procedure have been discussed with me and I have read and understood the above and agree to the procedure (or course of treatment) on this form.

**Patient's signature:** ..... **Date:** .....

**Name (PRINT):** .....

If the patient is unable to sign but has indicated his/her consent, a witness should sign below. Young people may also like a parent to sign here (see guidance notes).

**Witness' signature:** ..... **Date:** .....

**Name (PRINT):** .....

**Confirmation of consent** (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)  
On behalf of the team treating the patient, I have confirmed with the patient that s/he has no further questions and wishes the procedure to go ahead.

Signature Date: .....

Name (PRINT): ..... Job Title: .....