Patient information and consent to kidney transplantation

Key messages for patients

- When you are called to come in for a transplant follow the instructions given by the transplant coordinator; they will usually ask you not to eat or drink anything following the call.

- Please read this information carefully, you and your health professional will sign it to document your consent.

- Please bring with you all of your medications and their packaging (including inhalers, injections, creams, eye drops, patches, insulin, herbal remedies and CPAP machines), a current repeat prescription from your GP, any cards about your treatment and any information that you have been given relevant to your care in hospital, such as x rays or test results. If you are on peritoneal dialysis please bring a bag of PD fluid with you so you can do this on the ward just in case you have to wait before the transplant.

- Simple painkillers such as paracetamol and ibuprofen may be required after surgery. Simple bowel medication such as senna and lactulose may be required after surgery. It is suggested that you discuss with your pharmacist and have a seven day supply of these medications at home to take as you need according to the instructions.

- When a suitable kidney is available, you will be contacted by phone. This may be at any time of the day or night: please keep your mobile phones charged and with you. You will be asked to report to Ward G5 without delay. This is because the new kidney cannot survive outside the human body for more than a few hours.

- Transplantation is not without risk. Some of these risks are outlined in this document. By putting you on the transplant waiting list your doctors have decided that the risks to your life from having a transplant are less than the risks of long-term dialysis. Nevertheless, if there are some risks that you would rather avoid you can indicate them when you sign the consent form.

- Please call the kidney transplant co-ordinators via the hospital switchboard on 01223 245151 if you have any questions or concerns.

Please read this information carefully. You and your health professional will sign it to document your consent. After signing this consent form please give or send it to your kidney transplant coordinator. This form must be signed before you are put on the kidney transplant waiting list. After the procedure we will file the consent form in your medical notes and you may take this information leaflet home with you.
Important things you need to know
Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent up to the time the operation begins. If you do change your mind and no longer wish to have a transplant, it is important that you inform your transplant co-ordinator immediately, so that you can be removed from the transplant waiting list.

A kidney transplant operation requires a general anaesthetic. You will have the opportunity to discuss this with the anaesthetist.

We will only carry out the procedure on your consent form unless, in the opinion of the health professional responsible for your care, a further procedure is needed in order to save your life or prevent serious harm to you. However, there may be procedures you do not wish us to carry out and these can be recorded on the consent form. We are unable to guarantee that a particular person will perform the procedure, but the person undertaking the procedure will have the relevant experience.

All information we hold about you is stored according to the Data Protection Act 1998. We will also share information about you with NHS Blood and Transplant who are responsible for the administration of transplantation in the UK.

About kidney transplantation
A kidney transplant operation has been recommended for you because either your own kidneys have already failed and you are on dialysis already, or your kidneys are failing and you will need to start dialysis soon. The donor kidney is removed from either a living donor (usually a relative or spouse or friend) or from someone who has recently died.

Kidney transplantation is a major operation involving a surgical team working for around three hours. If successful, it will restore your kidney function and you will not need dialysis.

Kidney transplantation is the start of a different way of life. You will need regular follow up by the kidney specialists, and you will need to take immunosuppression medicines for as long as the transplant lasts. These are explained in more detail in this document.

Intended benefits
Kidney transplantation offers you the possibility of either coming off dialysis or to avoid starting it. Most people who have had a kidney transplant consider they have a better quality of life and gain relief from (or avoid) several of the complications associated with dialysis.

We expect 96 out of 100 of our kidney transplants to be working at least one year after the transplant operation; we expect 60 to 70 out of 100 to be still working after 10 years.
Who will perform my procedure?

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

Before your procedure

Your nephrologist (kidney specialist) and transplant surgeon will have discussed your condition with you and with other surgeons and personnel related to the National Transplant Programme. They will have decided to add your name to the Cambridge Transplant Waiting List for a kidney transplant. When an appropriately matched kidney is available, you will be contacted by phone.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring all your medications and any packaging (if available) with you.

When you arrive on ward G5, a doctor will see you and go through your medical history, examine you, and take some blood for urgent tests. **Please let us know if you have any concerns about your current health, new medical problems, or if you have recently received a blood transfusion.** You will then wait for the donor kidney to reach Addenbrooke’s Hospital, before you are prepared and taken to the theatre for the transplant operation. You may need to have dialysis before your operation, even if you have never had it before. 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 cannot go ahead and you will be able to go home. This will be upsetting for you, and we apologise for any distress caused, but it will be because the doctors believe that having that particular kidney is not in your best interest. Please talk to the transplant team if this happens so you understand the reasons for the decision. You will remain on the transplant list.

We usually call one person in for a kidney transplant, but very occasionally a second patient is also called in. This happens if there are doubts that the kidney will be suitable for the intended recipient for immunological reasons (i.e. reasons related to the risks of rejection). If this is necessary it will be discussed with you at the time you are called in for your transplant.

**Hair removal before an operation**

If you have hair on your abdomen this will be removed before your operation by the healthcare team in the theatre suite using an electric hair clipper with a single-use disposable head. Please do not shave the hair yourself or use a razor to remove hair, as this can increase the risk of infection. Your healthcare team will be happy to discuss this with you.
It is usually necessary to shave other areas of your body during the procedure to allow equipment/machines, for example diathermy machines (used to seal blood vessels), to make a connection to your skin to achieve the best and safest performance.

**During the procedure**

We will place several fine tubes (cannulas/lines) into some blood vessels in your arms and neck. These give you fluids and/or blood, and help us take blood for tests and monitor your condition. In addition, a tube may be passed through your nose into your stomach to decompress (deflate) it. We also place a urinary catheter into your bladder during the operation to drain the urine, and this will stay in place for about five days.

A team of surgeons will first prepare the donor kidney and then carry out the transplant procedure on you. The surgeon will make a long, curved incision (cut) on one side of your lower abdomen. The donor kidney will then be connected up to the blood vessels that take blood to and from the leg on that side. We also connect the tube (the ureter) that takes urine from your kidney to your bladder so you can pass urine as normal. Typically, the operation takes three hours; if we encounter any difficulties or if you have had previous abdominal surgery or a previous kidney transplant, the operation might take substantially longer.

During surgery, you may lose blood. If you lose a considerable amount of blood your doctor may want to replace the loss with a blood transfusion as significant blood loss can cause you harm. The blood transfusion can involve giving you other blood components such as plasma and platelets which are necessary for blood clotting. Your doctor will only give you a transfusion of blood or blood components during surgery, or recommend for you to have a transfusion after surgery, if you need it.

Compared to other everyday risks the likelihood of getting a serious side effect from a transfusion of blood or blood component is very low. Your doctor can explain to you the benefits and risks from a blood transfusion. Your doctor can also give you information about whether there are suitable alternatives to blood transfusion for your treatment. There is a patient information leaflet for blood transfusion available for you to read.

If you are on peritoneal dialysis your dialysis catheter will be removed during the 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.

**We leave a small plastic tube called a stent across the join** between the urine tube from the kidney (the ureter) and the bladder. This will be removed a few weeks after the transplant at an operation called a cystoscopy that requires a local anaesthetic.
After the procedure

Once your surgery is completed you will usually be transferred to the recovery ward where you will be looked after by specially trained nurses, under the direction of your anaesthetist. The nurses will monitor you closely until the effects of the general anaesthetic have adequately worn off and you are conscious. They will monitor your heart rate, blood pressure and oxygen levels. You may be given oxygen via a facemask, fluids into your drip and appropriate pain relief until you are comfortable enough to return to the transplant ward.

Patients with certain pre-existing health problems may be transferred to the intensive care unit (ICU/ITU) on level 3 or 4, or the transplant high dependency unit (HDU) on ward F5. These are areas where you will be monitored much more closely. If your surgeon or anaesthetist believes you should go to one of these areas after your operation, they will tell you and explain to you what you should expect.

Eating and drinking. Generally, you will be allowed to eat and drink on the first or second day after the operation.

Getting about immediately after the procedure. We will encourage you to move around and carry out deep breathing exercises as soon as you are able to do so, usually the day after your transplant. This both reduces the chance of getting a blood clot in the leg and also helps you to avoid chest infections. If you have any mobility problems, we can arrange nursing or physiotherapy help.

Leaving hospital. Following a kidney transplant, you are likely to need to stay in hospital for 7 to 10 days. In some circumstances you might need to stay longer, depending on your clinical condition and your doctor’s opinion.

Resuming 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. You should not drive for the first four weeks after the transplant.

Special measures after the procedure: Sometimes people feel sick after the operation and might vomit. If you feel sick, please tell a nurse and you will be offered medicines to make you more comfortable.

We will give you more detailed information about any special measures you need to take after the procedure. We will also give you information about things to watch out for that might be early signs of problems (for example, infection).
**Check-ups and results:** In the period after the operation, you will be seen in the transplant outpatient clinic at Addenbrooke’s very regularly (twice a week for the first four weeks) to check your progress and to make sure your 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 hospitals other than Addenbrooke’s will usually return to their hospital after three months or when their condition is stable.

**Significant, unavoidable or frequently occurring risks of this procedure**

At the end of the first year after a kidney transplant around 96 out of 100 (96%) kidney transplants will still be working. To help you understand what these mean visually we have printed below a drawing showing 100 people. 4 of the 100 are left white, representing the four kidneys that will be lost in the first year.

A kidney transplant is a complex procedure. **There is a small risk (3 in 100) of death in the first year;** this proportion is illustrated by three black figures in the cartoon above. 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 2 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. Patients who face higher risks from the transplant operation will be asked to sign a separate consent form. The remaining 93 figures in the cartoon above represent the 93% of patients alive with a
functioning kidney at the end of the first year after the transplant. To put it another way, your chance of losing your kidney or dying in the first year is the same as your chance of drawing an ace from a deck of cards.

**Thrombosis.** There is a small risk (3 or 4 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.

**Reoperations.** There is a small chance (5 in 100) that you will need a second operation soon after the transplant to stop bleeding or remove blood clots or to correct leaking from the join with the bladder.

**Acute rejection.** After the operation, the overall risk of acute rejection of the kidney transplant is 25 in 100. If this happens, we will need to give you some more powerful treatment which will usually reverse the situation, although rarely (1 or 2 in 100 cases) the kidney transplant may be lost from acute rejection.

**Continued dialysis after transplantation.** Between 30 and 50 out of 100 kidney transplants (30-50%) from dead donors 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 transplant operation. Most kidneys start working again by a week after the transplant, but very occasionally it might take up to three months.

**Admissions.** Many people who have had a kidney transplant need to undergo further admissions into hospital in the subsequent months and years. These are necessary so that we can check the health both of yourself and your kidney transplant by using blood tests, scans, and biopsies.

**Lymphocoele.** Around 15 in 100 patients develop a collection of fluid around the kidney in the first three months. This can press on the kidney and block the flow of urine to the bladder. If this occurs you will need the fluid removing and may need a second operation to permanently drain the fluid.

**Other complications.** As with any other operation, complications can occur, such as wound infections, blood clots in the legs or on the lungs, fluid leakage from drains and wound sites. These complications can often be managed with medication, rather than any further surgical procedures. There is also a small risk of a heart attack (myocardial infarction) as a consequence of the operation; to reduce the chances of this you will have had several tests on the heart to check it is sound enough to get through the operation.

Occasionally the transplant surgery may result in some numbness on the outer aspect of the thigh – this is the result of a nerve passing near to where the kidney is transplanted.
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.

Recurrent disease. Some diseases can recur 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. The following is a list of some of the diseases which can come back in the transplanted kidney along with the percentage of transplants likely to fail from recurrent disease within 10 years after transplantation:

- mesangiocapillary glomerulonephritis type I (“MCGN”) 14%
- focal segmental glomerulosclerosis (“FSGS”) 13%
- membranous nephropathy 13%
- IgA nephropathy (“IgA”) 10%

The Donor Organs

It is important that you appreciate that transplantation involves taking a risk, but you should remember that your doctors have recommended that you join the transplant waiting list because they believe that the risks of a transplant are less than the risks of remaining on dialysis. The following section is about the donor kidney and highlights some of the risks of transplantation.

If you do not wish to take these risks let your doctor know and indicate your wishes on the consent form so that you will not be called in for a transplant from such a donor.

Although the kidney you get is new to you, you will not be getting a new kidney. The organs have come from someone who has died and wanted to donate them to help someone like you after his/her death, or from someone who is alive and wanted to donate a kidney. It is uncommon for a young patient to be a dead 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 2016 it was 54 years old, with some donors aged up to 80 years old.

Kidneys from older donors generally work less well than kidneys from younger donors. In 2016/17 over one third (36 in 100) of dead organ donors were over 60. Even though the transplant kidney may not be perfect (most are not), nevertheless your doctors and transplant surgeons will not knowingly transplant any kidney that they do not think will work well enough to get you off dialysis and give you a better quality of life.

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, for example when the donor is over 70 years. This option will be discussed with
you at the time to gain your consent. Typically these will be two kidneys from an older donor.

**En bloc transplants.** Occasionally the transplant team are offered kidneys from a very young donor (under 5). In this case it is usually 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 an increase in the chance that the blood vessels to the kidney may clot (thrombose) around the time of the transplant. If the team feel you would be suitable for *en bloc* kidneys this option will also be discussed with you at the time you are put on the waiting list.

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 check carefully 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 (for example cytomegalovirus, which we can usually treat effectively after the transplant). The risks of you catching a life-threatening infection are small (less than 1 in 100).

Some donors are known to take intravenous drugs or have 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 (say 1 or 2 in 100), that an infection in a high-risk donor such as these may be missed, usually because they have caught the infection in the few weeks before death and the tests cannot detect this; in such cases the infection may be transmitted to the recipient. If such an infection was transmitted to you, you would need to take anti-viral drugs, possibly for the rest of your life, in addition to immunosuppression.

Some donors will have evidence of a past Hepatitis B infection. We often find that these organs would be safe to transplant as transmission of hepatitis B from such donors is rare following kidney transplantation (around 1 in 100). Most kidney patients have been immunised against Hepatitis B. If you were to receive a kidney from a donor with evidence of a previous hepatitis B infection you may need to take preventative antiviral medication for up to a year following your transplant.

Approximately 1 in 2000 donors has a cancer that we do not know about, and which can be passed on with the kidney transplant. This may result in the recipient of the kidney dying, although in some cases the cancer may be treated by removing the transplant and stopping immunosuppression. Unfortunately, we cannot predict which donors may have a hidden cancer or when this might occur.

Around 2 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 2 in 100) that, if your kidney donor had such a cancer, it might be passed on to you. There is a 98 in 100 chance that this will not happen.

Some donors may have had a cancer treated in the past and are believed to have
been cured of it. We make every effort to get all the details of these cancers and their treatment before deciding that the organs are safe to use.

**Brain death and circulatory death donors.** Some organ donors are confirmed to be dead by testing the brain function while they are on a ventilator, and while their heart is still beating; these are brain death donors. Others have irreversible damage to their brain but are not brain dead; nevertheless the brain damage is such that they will not recover so they have their treatment, including ventilation, stopped and as a result their heart stops; these are called circulatory death donors. Almost half of all dead donors in the UK (42% in 2016) were circulatory death donors.

After a transplant, some kidneys do not work straight away, but take a few days or weeks to recover function. This is more common with circulatory death donors (50 in 100) than brain death donors (30 in 100). The long-term results of circulatory death and brain death donor kidneys are similar. If you do not wish to have a kidney from a donor following circulatory death let your doctor know and indicate your wish on the consent form so that you will not be called in. However because such donors account for almost half of our kidney transplants you will have to wait longer for a transplant.

**The risks of waiting.** In choosing not to have a particular sort of donor you should be aware that there are complications associated with waiting on the list for a long time. For example, of all the patients placed on the national waiting list for a kidney transplant in the UK between 2013 and 2014, 27 in 100 (27%) had received a transplant within a year, while 1% (1 in 100) had died on the waiting list and 1% had been removed from the waiting list because they were no longer fit enough to have a transplant. After three years 58% (58 in 100) had received a transplant, 7% had died while waiting and 5% had been removed from the waiting list. The longer you wait for a transplant the greater the chance that you have complications or even that you might die while on the waiting list.

We will only use a donor kidney that we think will work and will give long, life-supporting function, and which we think has an acceptable risk.

**Drugs**

You will need to take a number of medications on a long-term basis to prevent rejection of the kidney transplant. This is called immunosuppression. If you stop the immunosuppression medicines you will probably lose the transplant.

In order to protect the kidney transplant from attack (rejection) by your immune system, you need to take immunosuppressant medications. Some of these drugs are used in combinations or for conditions for which they were not originally licensed. This is common practice in transplant units such as ours, and the National Institute of Health and Care Excellence have acknowledged such use. Any new drugs that we use will have been approved by Addenbrooke's Hospital Drug and Therapeutics Committee, or, in the case of clinical trials, by a Research Ethics Committee.
Problems with immunosuppression

The powerful immunosuppressive medications which you need to take to protect your transplant organs can also reduce your immunity and make you more susceptible to some infections, particularly viral infections. In the first 3-6 months we will give you some antiviral drugs to minimise the risks of harmful viral infections. After six months the amount of immunosuppression you need is less, so the risk of infection is less.

The potential side effects of the immunosuppressive medicines include infections, kidney problems, diabetes, stomach upset and wound problems.

It is sensible for all patients on the waiting list to be immunised against hepatitis B and, if you have never had chicken pox, to be immunised against this also. All women should have regular cervical smears.

The immunosuppressive medication increases your chances of developing cancer. Some cancers are much more common in transplant patients. Around 2 in 100 patients may develop a cancer of the lymph glands (lymphoma), which would require treatment and which can be fatal. Skin cancer is also very common, particularly if you have spent your life working outdoors. To reduce your chance of skin cancer you will be advised to wear a sun block cream (Factor 50) whenever you are out in the sun, and cover up where possible.

To reduce any side effects of immunosuppression and other drugs, the medical team will regularly monitor the medications you take and adjust them when required, based on your specific condition.

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 (i.e. if you miss taking tablets), you run a significant risk of losing your kidney. If we think you lost your kidney because you did not take the drugs as advised, it is unlikely that you would be offered a further transplant.

Please remember that the Transplant Unit and your own kidney specialist have recommended the kidney transplant procedure to you because the doctors believe that the benefits will greatly outweigh the risks for you.

Research

The transplant unit in Cambridge has been at the forefront of research in transplantation since the programme began in 1965. We have pioneered the use of new immunosuppressive drugs and new techniques for storing kidneys. It is possible that you will be asked to participate in some research studies at the time of your transplant. Please consider these carefully. You do not need to take part, but the results of the research may help you or people like you in the future.
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 perform some of the functions of healthy kidneys.

Information and support

If you have any anxieties or questions, please feel free to ask any member of staff. Further information can be obtained from the transplant co-ordinators who can be reached directly on 01223 274637 or 01223 348031 or through the Addenbrooke’s contact centre on 01223 245151; Information can also be obtained from the Addenbrooke’s website www.cuh.org.uk

Anaesthesia

Anaesthesia means ‘loss of sensation’. There are three types of anaesthesia: general, regional and local. For a kidney transplant you will have a general anaesthetic (see below).

Before your operation

Before your operation you will meet an anaesthetist who will discuss with you the most appropriate type of anaesthetic for your operation, and pain relief after your surgery. To inform this decision, he/she will need to know about:

- your general health, including previous and current health problems
- whether you or anyone in your family has had problems with anaesthetics
- any medicines or drugs you use
- whether you smoke
- whether you have had any abnormal reactions to any drugs or have any other allergies
- your teeth, whether you wear dentures, or have caps or crowns.

Your anaesthetist may need to listen to your heart and lungs, ask you to open your mouth and move your neck and will review your test results.

Pre-medication

You may be prescribed a ‘premed’ prior to your operation. This is a drug or combination of drugs which may be used to make you sleepy and relaxed before surgery, provide pain relief, reduce the risk of you being sick, or have effects specific for the procedure that you are going to have or for any medical conditions that you may have. Not all patients will be given a premed or will require one and the anaesthetist will often use drugs in the operating theatre to produce the same effects.
Moving to the operating room or theatre
Before starting your anaesthesia the medical team will perform a check of your name, personal details and confirm the operation you are expecting.

You will change into a gown before your operation and we will take you to the operating suite. When you arrive in the theatre or anaesthetic room, monitoring devices may be attached to you, such as a blood pressure cuff, heart monitor (ECG) and a monitor to check your oxygen levels (a pulse oximeter). An intravenous line (drip) may be inserted and you may be asked to breathe oxygen through a face mask.

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. Your anaesthetist achieves this by giving you a combination of drugs.

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 at the correct level of unconsciousness for the period of the surgery. 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.

What will I feel like afterwards?
How you will feel will depend on the type of anaesthetic you have had, how much pain relieving medicine you need and your general health.

Most people will feel fine after their operation. Some people may feel dizzy, sick or have general aches and pains. Others may experience some blurred vision, drowsiness, a sore throat, headache or breathing difficulties.

What are the risks of 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 performed in an emergency.

Very common (1 in 10 people) and common (1 in 100 people) side effects
Feeling sick and vomiting after surgery
Sore throat
Dizziness, blurred vision
Chest infection
Headache
Bladder problems
Damage to lips or tongue (usually minor)
Itching
Aches, pains and backache
Pain during injection of drugs
Bruising and soreness
Confusion or memory loss

Uncommon (1 in 1000 people) side effects and complications
Muscle pains
Slow breathing (depressed respiration)
Damage to teeth
An existing medical condition getting worse
Awareness (becoming conscious during your operation)
Heart attack or stroke

Rare (1 in 10,000 people) and very rare (1 in 100,000 people) complications
Damage to the eyes
Serious allergy to drugs
Nerve damage
Death
Equipment failure

Deaths caused by anaesthesia are very rare. There are probably about five deaths for
every million anaesthetics in the UK.

For more information about anaesthesia, please visit the Royal College of Anaesthetists’
website: [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
Information about important questions on the consent form

1 Creutzfeldt Jakob Disease (“CJD”)

We must take special measures with hospital instruments if there is a possibility you have been at risk of CJD or “variant” CJD. We therefore ask all patients undergoing any surgical procedure if they have been told that they are at increased risk of either of these forms of CJD. This helps prevent the spread of CJD to the wider public. A positive answer will not stop your procedure taking place, but enables us to plan your operation to minimise any risk of transmission to other patients.

2 Photography, Audio or Visual Recordings

As a leading teaching hospital, we take great pride in our research and staff training. We ask for your permission to use images and recordings for your diagnosis and treatment; they will form part of your medical record. We also ask for your permission to use these images for audit and in training medical and other healthcare staff and UK medical students; you do not have to agree and if you prefer not to, this will not affect the care and treatment we provide. We will ask for your separate written permission to use any images or recordings in publications or research.

3 Students in training

Training doctors and other health professionals is essential to the NHS. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a registered professional. You may, however, prefer not to take part in the formal training of medical and other students without this affecting your care and treatment.

4 Use of Tissue

As a leading biomedical research centre and teaching hospital, we may be able to use tissue not needed for your treatment or diagnosis to carry out research, for quality control or to train medical staff for the future. Any such research, or storage or disposal of tissue, will be carried out in accordance with ethical, legal and professional standards. In order to carry out such research we need your consent. Any research will only be carried out if it has received ethical approval from a Research Ethics Committee. You do not have to agree and if you prefer not to, this will not in any way affect the care and treatment we provide. The leaflet ‘Donating tissue or cells for research’ gives more detailed information. Please ask for a copy.

If you wish to withdraw your consent on the use of tissue (including blood) for research, please contact our Patient Advice and Liaison Service (PALS), on 01223 216756.
Privacy & dignity

We are committed to treating all patients with privacy and dignity in a safe, clean and comfortable environment. This means, with a few exceptions, we will care for you in same sex bays in wards with separate sanitary facilities for men and women.

In some areas, due to the nature of the equipment or specialist care involved, we may not be able to care for you in same sex bays. In these cases staff will always do their best to respect your privacy and dignity, e.g. with the use of curtains or, where possible, moving you next to a patient of the same sex. If you have any concerns, please speak to the ward sister or charge nurse.

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.

If you smoke you will reduce the life of your kidney transplant and increase your chances of life threatening heart and lung disease.

Other formats:
If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 348043, or email: interpreting@addenbrookes.nhs.uk For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk.
Kidney transplantation

A Patient's side left / right or N/A

Consultant or other health professional responsible for your care

Name and job title:

Any special needs of the patient (e.g. help with communication)?

Please use 'Procedure completed' stamp here on completion:

B Statement of health professional (details of treatment, risks and benefits)

1 I confirm I am 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:

a) the intended benefits of the procedure (please state)
   - To replace the function of your diseased kidney with normal function from a transplant kidney.
   - We expect nine out of ten of our kidney transplants to work at least one year after the transplant operation; we expect six out of ten to be still working after 10 years.

b) the possible risks involved. Addenbrooke’s always ensures any risks are minimised. However all procedures carry some risk and I have set out below any significant, unavoidable or frequently occurring risks including those specific to the patient:
   - 3 in 100 chance of dying in the first year following the transplant operation.
   - 3-4 in 100 risk that the blood vessels of the new kidney will become blocked following transplantation leading to failure of the kidney which will then need to be removed.
   - 5 in 100 chance that you will require at least one further operation following the transplant.
   - After the operation, there is a 20-25 in 100 risk of acute rejection of the kidney transplant requiring admission for treatment.
   - Some diseases may recur in the transplant and cause it to fail sooner than it would have otherwise done.
   - Wound infections, blood clot in the legs or on the lungs, heart attacks, strokes, fluid leaks from drains and wound sites, and numbness in the thigh occur occasionally.
   - We take every effort to screen kidney donors for infections and cancers, but we cannot guarantee that an infection or cancer will not be transmitted from the donor to you the recipient. The chances of this happening are small.
   - Most patients will require further admissions to hospital in months or years after transplantation.

c) what the treatment or 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 alternative to transplantation is to continue on dialysis.
Consent Form

Kidney transplantation

d) any extra procedures that might become necessary during the procedure such as:

☑ Blood transfusion ☐ Other procedure (please state)

The following information leaflet has been provided:

Kidney transplantation

Version, reference and date: CF171 version 6 August 2018

or ☐ I have offered the patient information about the procedure but this has been declined.

This procedure will involve:

☑ General and/or regional anaesthesia ☐ Local anaesthesia ☐ Sedation ☐ None

Signed (Health professional): Date: D.D./M.M./Y.Y.Y.Y.

Name (PRINT): Time (24hr): H.H.:M.M.

Designation: Contact/bleep no:

C Consent of patient / person with parental responsibility

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and that my questions have been answered to my satisfaction and understanding.

Important: please read the patient information about this procedure and then put a tick in the relevant boxes for the following questions:

1 Creutzfeldt Jakob disease (CJD)
Have you ever been notified that you are at risk of CJD or variant CJD for public health purposes? If yes, please inform your health professional.

☐ Yes ☐ No

2 Photography, Audio or Visual Recording

a) I agree to the use of any of the above type of recordings for the purpose of diagnosis and treatment.

☐ Yes ☐ No

b) I agree to unidentified versions of any of the above recordings being used for audit and medical teaching in a healthcare setting.

☐ Yes ☐ No

3 Students in training

I agree to the involvement of medical and other students as part of their formal training.

☐ Yes ☐ No

Patient safety – at the heart of all we do

Addenbrooke’s Hospital | Rosie Hospital

CF171 Kidney transplantation v6 August 2018
We assume that you are willing to accept a kidney from any donor that we consider appropriate for you considering your health at the time unless you indicate donor types below that you do not wish to consider. A full explanation is given in the information sheet. If you indicate you do not wish a particular type of donor you should remember that you reduce your chance of receiving a kidney.

In deciding what to accept you need to be mindful that dialysis isn’t perfect, and that for most patients it has a higher risk of death than a transplant.

- **a). I do not wish to receive organs from a donor after circulatory death** and understand that nearly half of all donors are circulatory death donors. Kidneys from such donors have equal long term outcomes, but are slower to start to work immediately after transplantation. By deciding not to have a kidney from this type of donor I realise I may spend longer on the waiting list.

- **b). I do not wish to receive a kidney from a donor who has died from a brain cancer**, although I realise that there is only a small (less than 2 in 100) chance of the cancer being transmitted to me. 2 in 100 kidney donors have died from a brain cancer.

- **c). I do not wish to receive organs from a donor who has a history of cancer**, although I realise that there is only a small (less than 1 in 100) chance of that cancer being transmitted to me.

- **d). I do not wish to receive organs from a donor known to use intravenous drugs or whose behaviour puts them at risk of viral infections** even though their viral tests suggests I would have less than 2 in 100 chance of becoming infected and needing to take antiviral drugs as a result. Around 2 in 100 donors exhibited such high risk behaviour.

- **e). I do not wish to receive a kidney from a donor over 60**, because the function of the kidney is often poorer. I realise that 36 in 100 kidneys are from donors over 60 and I will therefore have to wait longer for a transplant.

- **f). I do not wish to receive a pair of kidneys as a “dual” kidney transplant.** I understand that this is done because the transplant team believe one kidney alone will not be enough, but two would be sufficient for me. Between 5 and 10 in 100 transplants in Cambridge are dual transplants.
By agreeing to have a kidney transplant I am aware that I am also agreeing that:

a) I understand the need to take medication for the life of my transplanted kidney.
b) I understand the need for long term follow up.
c) I understand that I may need to arrange my own transport to clinic appointments.
d) I understand there will be a stent removal procedure at six weeks under local anaesthetic.

Please indicate which one of the following statements applies to you:

☐ I have read and understood the Patient Information about this procedure and the above additional information.

☐ I have chosen not to read or receive the Patient Information about this procedure.

I agree to the procedure or treatment.

Signed (Patient): ................................................................. Date: …./…./……

Name of patient (PRINT): .................................................................
Consent Form

Kidney transplantation

**E Interpreter's statement (if appropriate)**

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

**Signed** (Interpreter): .......................................................... **Date:** ____________ / __________ / __________

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

Or, please note the language line reference ID number: ................................................................

**F Withdrawal of patient consent**

- The patient has withdrawn consent (ask patient to sign and date here)

**Signed** (Patient): .......................................................... **Date:** ____________ / __________ / __________

**Signed** (Health professional): .......................................................... **Date:** ____________ / __________ / __________

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