

Patient Information Booklet
Kidney Transplantation
Cardiff Transplant Unit



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WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Introduction

You have been given this information booklet because your kidney specialist thinks you may benefit from a kidney transplant. The booklet gives you information about kidney transplants in general which will help you when you meet with your transplant surgeon to discuss whether this is the right treatment for you. Don't worry if you don't understand everything immediately as you will have the chance to discuss any concerns with the transplant team.

Who can have a kidney transplant?

A kidney can be transplanted into patients who have failed or failing kidneys. Patients whose kidneys have failed need either regular dialysis (haemodialysis or peritoneal dialysis) or a kidney transplant to keep them healthy. Both dialysis and transplantation are effective ways of treating kidney failure but each has its advantages and disadvantages. When considering whether or not to proceed with a transplant it is therefore helpful to know how this compares with the alternative of continuing with dialysis. Only approximately 4 out of every 10 patients with kidney failure are suitable for a kidney transplant, and it is usually a patient's general health that will determine whether they are fit enough for the procedure.

The potential benefits of kidney transplantation

Kidney transplantation offers the possibility of either coming off dialysis or avoiding starting it. Most people who have a kidney transplant consider they have a better quality of life and many will also live longer than if they were to stay on dialysis. A successful transplant allows freedom from dietary and fluid restrictions and may also provide more freedom for work or travel. Transplant recipients often say they experience an improvement in their energy levels and fertility can also improve. We would expect 9 out of 10 kidney transplants to be working a year after the transplant and 5 out of 10 to be working 10 years after a transplant.

The risks of kidney transplantation

Transplanted organs are not new organs and therefore come with some risks which must be weighed against their potential benefits. Your transplant team will advise you and help making this decision.

General risks

- As with any surgical procedure there is a small risk of serious complications. The risk of death during the first year after the procedure is approximately 2 in 100 overall, although this does vary depending on the recipient's general fitness. This should be compared to the risk of death for a dialysis patient during a year which is approximately 5 in 100 overall (again this figure may vary considerably depending on several factors including age and other health problems).

- Not all kidney transplants work immediately and it may be necessary to continue on dialysis for a short period after the surgery until the kidney begins to function. Overall about 1 in 3 kidneys do not function immediately and, although most have started to work by the end of 2 weeks it may take up to 3 months for the transplant to 'wake up'.
- A very small number of kidney transplants (less than 1 in 100) do not function at all. If this occurs the recipient will have to continue on dialysis but can usually go back on to the transplant waiting list in the same position as they were prior to the unsuccessful transplant.
- There is a small risk (2 in 100) that the blood vessels to the new kidney will become blocked (thrombosed) in the first few days following a transplant. If this occurs the kidney will fail and a second operation will be required to remove it.
- There is a small risk (5 in 100) of bleeding following the surgery and a second operation may be required to stop this.
- There is a small risk (5 in 100) of a problem with the join between the transplant kidney and the bladder. This can occur at any time but is most common between 3 months and 2 years after a transplant. A further procedure may be required to put this right if it occurs.
- Other complications related to the surgical procedure can occur in the first few days or weeks after a transplant. These include wound infections, collections of fluid around the kidney, blood clots in the legs and fluid leak from the drains or wound sites. These complications can often be managed without the need for further surgical procedures.

Risk of transmission of cancer from the donor

Every effort is made to screen kidney donors for cancer and therefore it is extremely rare (less than 2 in 1000) for an unknown cancer to be transmitted from donor to recipient. Sometimes we accept kidneys from donors who have special types of cancer (for example brain cancer or treated kidney cancer) as we consider them to be safe. The risk of transmitting a cancer to the recipient in such situations is very low (less than 1 in 100) but we would always discuss these individual cases with you before proceeding.

Risk of transmission of infection from the donor

All kidney donors are tested for infections that may cause problems for transplant recipients. Some infections are commonly transmitted to the recipient with a transplanted kidney and in these cases it may be necessary for the recipient to take medication after their transplant to prevent the infection from causing any problems. One infection that can be transmitted to kidney transplant recipients is called Cytomegalovirus (CMV).

This is a common virus which many people in the general population have had, and causes only a mild illness for most people. After a transplant it can cause a more serious infection and therefore we often give medication to prevent this infection from becoming active.

More serious infections such as hepatitis or HIV are much less likely as the donor will have had blood tests performed showing that they do not have these infections. Although the blood tests are very accurate it is not possible to completely guarantee that a serious infection will not be transmitted with the transplanted kidney.

For most donors the risk of this occurring is very small (for example less than 1 in 50000 for HIV) and in any situation where the transplant team feel the risk is higher than normal it will be specifically discussed with you before proceeding.

Risk of rejection

Overall approximately 2 in 10 kidney transplant recipients will develop 'acute rejection' of the new kidney. This is where the body tries to fight against the kidney and is most common in the first 6 months after a transplant. It is diagnosed by taking a small sample of the kidney (a biopsy) and in most cases is reversible as long as it is treated without delay. The treatment usually involves admission to hospital for a few days to receive more powerful anti-rejection drugs. Most kidneys continue to function well after treatment for rejection.

Risks associated with the drugs used after transplantation

Kidney transplantation is only possible with the use of 'anti-rejection' drugs called immunosuppressants. Without these drugs the body would see the transplanted kidney as 'foreign' and try to eliminate it as if it were an infection. The drugs prevent this from happening but may cause some side effects and also increase the risk of certain complications.

The risk of side-effects will depend on the exact combination of drugs used, but might include stomach upset, kidney problems, diabetes, weight gain and wound problems. To reduce any side effects the transplant team will monitor and adjust the dose of medications, and alternative drugs may be available if necessary.

It is very important to follow our instructions on when and how to take these drugs, and if the dosage schedule is not followed strictly (for example if doses are missed) there is a significant risk of losing the kidney. Complications caused by the anti-rejection drugs are less common but may be more serious. People taking these medications have a higher than average risk of infections and also of developing certain cancer (especially skin cancers and a cancer of the glands called lymphoma). Skin cancer is quite common and up to 1 in 5 kidney transplant recipients will develop one at some point, although it is usually treatable if identified early. Protecting the skin from the sun will help to reduce this risk. Lymphoma after kidney transplantation occurs in approximately 1 in 100 patients and this can be more difficult to treat. Many transplant recipients who develop lymphoma will lose their transplant and some will die due to the disease.

The majority of transplant recipients get on well with their immunosuppression tablets, but if problems develop it may be possible to switch to a different combination.

The categories and types of donors

The kidney used for a transplant can come either from a live donor or from a deceased (cadaveric) donor.

Live donors

Relatives or close friends of patients with renal failure may donate one of their kidneys for transplantation and this has many advantages. In general terms kidneys from live donors are of higher quality than those from cadaveric donors and we therefore encourage anyone in need of a kidney transplant to consider this as their best option.

The donor will have been carefully assessed and deemed fit enough to donate their kidney and the procedure is performed on a planned basis at a convenient time. There is no need to wait on the national waiting list and therefore it is often possible to perform the transplant quickly, even before the recipient has started dialysis. Transplants from live donors tend to work quicker, better and last longer than those from cadaveric donors.

Cadaveric donors

Kidneys from cadaveric donors are allocated on a national basis (across the whole of the United Kingdom) and to receive such a kidney you would have to be added to the kidney transplant waiting list. The donor may be from any part of the UK and usually will have died on an intensive care unit. There are many causes of death that may allow organ donation to occur, for example a stroke or a head injury and the exact cause of death may influence the results following transplantation. There are many other factors that may also influence how a transplant will function including donor age and whether they had other health problems, and it can therefore be difficult to predict how well an individual kidney transplant will work. We take great care to consider the information about each kidney donor before accepting the kidney for transplantation and we would not transplant a kidney we did not think would work. It may still be reasonable to accept a kidney that is not likely to work as well as the average transplant but this will depend on many factors, and we would discuss this with you before proceeding.

Many donors of kidneys we use for transplantation in the United Kingdom will have been 'Non-Heart Beating' or 'Donors after Circulatory Death'. The kidneys from this subset of cadaveric donors tend to take longer to start working but overall function just as well as kidneys from other cadaveric donors.

Information about the donor that may be shared with you

The transplant team are able to share some but not all information about the donor with you. The details that may be discussed are age range (by decade), gender and cause of death. If the donor was at higher than normal risk of transmitting an infection or cancer this can also be discussed in order to help make a decision as to whether to accept an individual offer or not. The donor's family may also receive some basic information about you; age range (by decade), gender and the outcome from the transplant.

The Transplant Waiting list

Details of all patients in need of a kidney transplant in the United Kingdom are held on a single list by an organisation called NHS Blood and Transplant (NHSBT). Whenever a new kidney from a cadaveric donor becomes available NHSBT allocate it to an individual recipient based on a number of factors, including how closely the donor and recipient's tissue type match, how long the recipient has been waiting, and the difference in age between donor and recipient. Because of the need to match kidneys carefully (to minimise the risk of rejection and improve the chances of a successful transplant) not everyone on the list will wait the same length of time. The average waiting time is increasing due to a shortage of organ donors but at present it is approximately 3 years. For certain patients the average wait is longer than this, for example those from ethnic minorities (due to the difficulty in finding a matched donor) and those who have had previous transplants (as they tend to form 'antibodies' which will exclude some donors).

Getting on the transplant list

To become 'active' on the transplant waiting list you must be assessed by a transplant surgeon and passed fit enough to receive a kidney transplant. To help make this decision it will be necessary to perform a number of tests including blood tests, X-rays and a heart scan which may take some time to organise and interpret. The surgeon will explain the surgery, risks and benefits to you again and you will have the opportunity to discuss any specific questions you may have.

Before you can receive a kidney transplant we need to know about your blood group and tissue type to allow us to match you with a kidney. We get this information by taking blood samples from you and analysing them in the Welsh Transplantation and Immunogenetics laboratory (WTAI), where a sample is also stored in case any additional tests are required for your benefit in the future. Excess samples are sometimes used anonymously for quality control purposes, ethics committee approved research, service development or education.

You will also need to have blood tests to check whether you have ever been exposed to various viruses as this can be important after a kidney transplant. You may be aware of some of the viruses we check for (for example HIV and hepatitis) but there are others that you probably won't have heard of (such as Cytomegalovirus and Epstein Barr Virus). Some of these viruses are very common and none of them will necessarily stop you from having a transplant, but we may give you a different combination of drugs afterwards to reduce your risk of complications.

The virology and tissue typing blood tests are repeated regularly whilst you are on the waiting list, and *should continue even if you are temporarily suspended from the list* (see page 11).

It usually takes some time to get the results of all your tests together after your consultation with the transplant surgeon and you will not therefore be activated on the list immediately. You will receive both a telephone call and a letter from us telling you that you are 'active' on the transplant list. *If you have not received these, you are not on the list!*

Being 'active' on the transplant list

You may receive an offer of a kidney for a transplant at any time of day or night and it is therefore important that we know how to get hold of you at all times. As you may be on the waiting list for some time it is essential that you keep the transplant coordinators informed of any changes to your telephone numbers or address (do not rely on your dialysis unit to inform the coordinators).

During your waiting time you should try to keep yourself as healthy as possible and following the advice given to you by your kidney specialist will help to achieve this. Maintaining a healthy weight and not smoking are especially important as these factors can affect the results from transplantation.

You will still be able to go on holiday but must inform the transplant coordinators when and where you are going (it may be necessary to temporarily suspend you from the waiting list until you return).

When you are allocated a kidney you will be contacted by phone at any time of the day or the night and you will be asked to make your way to the Cardiff Transplant Unit without delay. When you arrive you will be seen by a doctor who will go through your medical history again and examine you to make sure you are well enough to go ahead with the surgery. You will have blood tests and an X-Ray of your chest and it may be necessary for you to undergo dialysis (depending on your test results). You will then need to wait for the kidney to arrive in the hospital, which may take several hours. Occasionally final tests show that the allocated kidney is not suitable for you, in which case the reasons for this will be explained and you will be allowed to go home. If this happens you will remain on the transplant waiting list.

Suspension from the transplant list

It is very important that your general health is as good as possible when you receive a kidney transplant and it is not safe to undergo the procedure if you have certain active health problems, for example a recent heart attack or current infection. If your health deteriorates whilst you are on the transplant waiting list it may be necessary to suspend you from the list whilst you are undergoing investigations or treatment. We will inform you if this is required and if your health improves following treatment you would usually be re-activated on the transplant list.

Other contact whilst on the waiting list

The Cardiff Transplant Unit has an active research program, aiming to continually improve outcomes for our current and future transplant recipients. You may be contacted whilst on the waiting list to inform you of any current research projects to help you to make an informed decision about taking part.

About the surgery

The surgery is a major operation involving a team of transplant surgeons working for approximately 2 to 3 hours. The surgery is performed under general anaesthetic (i.e. you will be completely asleep in a state of unconsciousness). The risks of a general anaesthetic have reduced considerably over recent years due to modern equipment, training and drugs and the individual risk to you will depend on a number of factors including your general health, whether or not you smoke or are overweight and the duration and complexity of the surgery.

The risks and possible side effects of a general anaesthetic are:-

Very common and common side effects (1 in 10 to 1 in 100 people)

Nausea or vomiting after surgery, sore throat, dizziness, blurred vision, headache, itching, aches and pains (including backache), pain during injection of the drugs, confusion and brief memory loss.

Uncommon (1 in 1000 people)

Chest infections, bladder problems, muscle pains, slow breathing, damage to teeth, lips or tongue, awareness (becoming conscious during your operation).

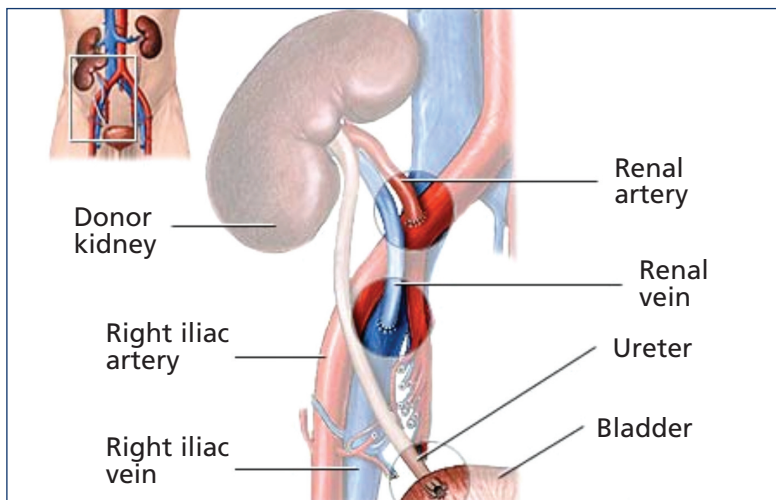
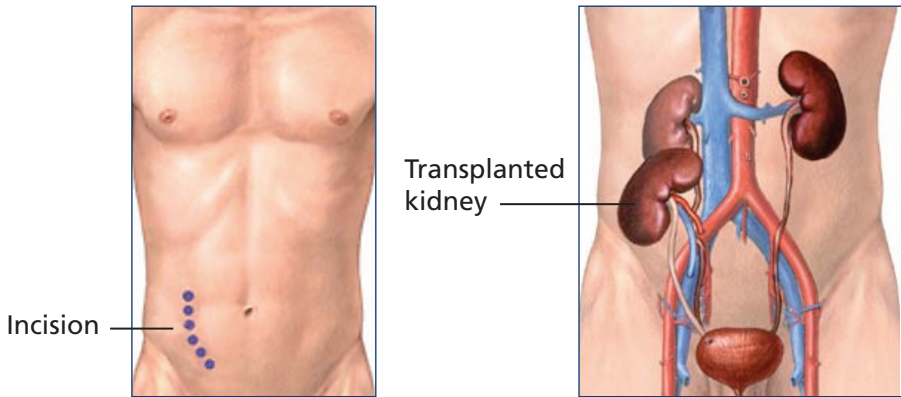
Rare or very rare (1 in 10,000 to 1 in 100,000 people)

Damage to the eyes, serious allergy to drugs, nerve damage, death, equipment failure.

Once you are under anaesthetic you will be connected to various tubes and lines to monitor you during and after your transplant. It will be necessary to insert a plastic tube (called a central line) into one of the veins in your neck to help guide us on how much fluids you require and also to give you certain drugs. A urinary catheter will also be inserted into your bladder to closely monitor how much urine your new transplant kidney produces.

The surgery itself will be performed by an appropriately trained and experienced surgeon and will involve a cut on your abdomen (tummy) on either the left or the right side just above the groin. We may need to shave some hair from your abdomen as this reduces the risk of wound infections, but please note this needs to be done immediately prior to surgery so should not be done until you are in theatre.

The kidney will be connected to the blood vessels that take blood to your leg. We will also connect the transplanted kidney's ureter (water pipe) to your bladder so that after the transplant you will pass urine in the normal way. A plastic tube (called a stent) will be left in the ureter and this is usually removed about six weeks after your surgery. **Your own kidneys will not be removed during the transplant.** We often insert a surgical drain (a small plastic tube) close to your new transplant which is usually removed after a few days.



About the recovery from surgery

Immediately after the transplant you will be taken to an area in the theatre suite to recover (the recovery room) until you are wide awake. You will then be taken back to the Cardiff Transplant Unit and monitored closely. You will be allowed to eat and drink quite soon after the operation but for the first few days we will probably give you extra fluid through a drip. You will need regular blood tests whilst in hospital and may also need to have an ultrasound scan of your new kidney to ensure it is functioning normally.

You will be encouraged to mobilise (initially with help from the nursing staff) as soon as possible as this helps with your recovery, and reduces the risk of developing chest infections or blood clots.

Most people are discharged home after 7-10 days but sometimes it is necessary to stay in hospital for longer than this. When you leave hospital you should be able to perform light daily activities but it may be a few months before you can return to normal active work. You will be taught about your new drugs before discharge home and also given advice on things to watch out for that might be an early sign of problems (such as infections).

Importance of long-term follow-up

For the first few weeks after discharge you will be seen 2-3 times a week in the transplant clinic to ensure the kidney is functioning well and that no problems have developed. If the kidney function remains stable and you remain well the time between clinic visits will gradually increase, and most long term transplant recipients need to attend clinic only once every 3 months. If you are from West Wales, after 6 months your follow-up will continue in Morriston Hospital.

It is very important that you attend all of your clinic appointments and take all of the medications prescribed to you. Problems can develop at any point after a kidney transplant and many of them will not necessarily make you feel unwell - the only way to be sure is to be assessed regularly.

Consequences of non-transplantation

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

Further information and support

If you have any anxieties or questions, please feel free to ask any member of staff. A transplant surgeon will assess you and discuss the contents of the booklet with you at the time of your transplant assessment. If you wish to discuss any of the information from this booklet before you see your surgeon please contact the Cardiff Transplant Recipient Coordinators (if you are usually treated in Cardiff, Newport, Abergavenny, Merthyr Tydfil or Llantrisant) or the Morriston Recipient Coordinators (if you are usually treated in Swansea, Carmarthen, Bridgend, Haverfordwest, Aberystwyth, Neath or Llanelli).

Contact details:-

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Mae'r wybodaeth hon ar gael yn Gymraeg - gofynnwch am fwy o fanylion

