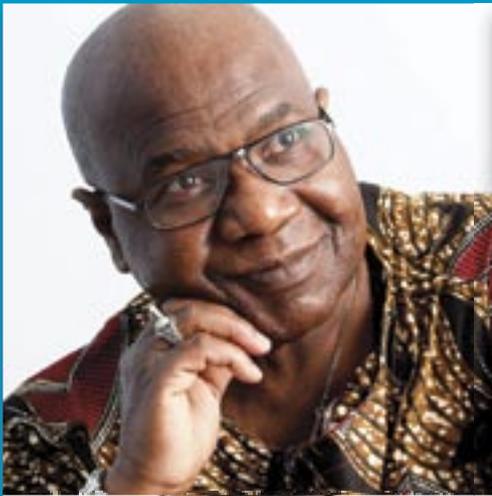


Can I have a kidney transplant?



OVERVIEW

This guide is for patients who have kidney failure and are considering kidney transplantation. We hope it will provide some basic information on assessment for transplantation, the waiting list, living donation, the transplant procedure and some of the risks and benefits of transplantation.

If you have any further questions you want to ask, please ask your consultant or specialist nurse when you see them in the clinic or dialysis unit.

This guide is not intended to tell you about everything that happens after the transplant. If you want more information about what happens after the transplant, you should read the post-transplant guides.

Contact information

ROYAL FREE HOSPITAL PATIENTS

Pre-transplant assessment nurse 0207 794 0500
x 34084

Live donor nurses 0207 317 7604
10 South Ward 0207 830 2189
or x 34131

Royal Free Hospital switchboard 0207 794 0500

LISTER HOSPITAL

**Transplant coordinators/
Live donor nurses** 01438 784708

ROYAL FREE HOSPITAL ADDRESS

**Royal Free Hospital, Pond Street,
London, NW3 2QG**



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THE KIDNEY AND TRANSPLANTATION



Courtesy of i-stock

What is the kidney and what does it do?

The kidney is a bean-shaped organ about the size of a fist. Most people have two kidneys which are situated just above the waist at the back. The main function of the kidney is to clean the blood of harmful waste and balance the amount of salt and water in the body. The kidney also makes Vitamin D (*to keep your bones strong*) and helps to make blood.

What happens when the kidneys fail?

Kidney failure can cause waste to build up in the blood and the body may retain fluid. Patients with kidney failure can feel tired, breathless, have swollen ankles and lose their appetite. When the kidney function is very low, patients will require dialysis or a transplant to take over the function of their failing kidneys.

Does everyone with kidney failure get a transplant?

No. Not all patients will benefit from having a kidney transplant and only half of all patients with kidney failure are suitable to have a transplant. Each kidney patient is assessed individually to see if transplantation is the best option for them and if they

are fit enough to have a transplant. If you are not sure, ask your kidney doctor or specialist nurse to explain this further. You can also call our pre-transplant assessment nurse on **(020) 7794 0500 x 34084** to discuss transplantation and they may make an appointment for you in the pre-transplant assessment clinic.

Do I have to be on dialysis to get a transplant?

No. It is usually better if we can arrange a transplant before you need dialysis. This is called a pre-emptive transplant. If your kidney function is slowly getting worse, please ask your kidney doctor or specialist nurse about pre-emptive transplantation.

What are the benefits of kidney transplantation?

A successful kidney transplant offers the chance to lead a nearly normal life without the need for dialysis. Most patients feel stronger and have more energy after a transplant. In addition, most patients do not need to restrict their fluid intake or the type of food they eat. A good working transplant can help patients with kidney failure live longer when compared to staying on dialysis.

What are the disadvantages of kidney transplantation?

Kidney transplantation requires a major operation and patients have to be fit enough to have a transplant. There are risks involved with receiving a transplant and a number of complications can occur from the operation. Not all kidney transplants work and some transplants can have complications with the blood vessels and draining tube of the kidney. A lot of medication is required after the transplant and patients can suffer from side effects. The medication can weaken the immune system and patients are at increased risk of infection and some cancers. Despite all the tablets, some kidneys will be rejected and may require stronger medication to stop the rejection. We have provided more detail of the risks later in this leaflet.

ASSESSMENT FOR TRANSPLANTATION

How do I know if I can have a kidney transplant?

Only half (50%) of patients with kidney failure are suitable to have a kidney transplant. Each patient will be assessed individually to see if transplantation is the best option for them.

Who will do my assessment?

Your kidney doctor in the clinic or dialysis unit will be able to assess whether you are suitable to have a transplant. The doctor may want you to see a kidney transplant doctor or surgeon at the Royal Free before you can have a transplant. If you are not sure whether you are suitable for a transplant, you can ring the pre-transplant assessment nurse on **(020) 7794 0500 x 34084**

Why might I not be able to have a transplant?

Kidney transplantation requires a major operation and patients have to be fit enough to have an anaesthetic (*which puts you to sleep for the operation*). Patients who have significant heart, circulation or breathing problems may not be fit enough to have a transplant. Patients who have had cancer or serious infections may not be able to have a transplant due to the risk from weakening their immune system after the transplant. Advancing age does not rule patients out from having a transplant but frail patients may not be able to tolerate the operation or medication needed after the transplant. You cannot have a transplant when you are pregnant.

What does the assessment involve?

The doctor will ask you a lot of questions about your health and examine you. You will have blood tests to check for infections, blood count, genetic type and a number of other important tests. You will be asked to have a tracing of your heart (ECG) and a chest X-ray. The doctor may also ask you to book further tests of your heart, blood vessels or other scans (*such as a CT scan, ultrasound or MRI*).

Can I ask questions at my assessment?

Yes. The doctor will tell you some information about transplantation and what is involved but you should also ask any questions you may have about transplantation. It may be an idea to write down any questions you want to ask and bring them with you. You may find it useful to bring along a relative or friend for support and to discuss any issues raised at your consultation. You should also attend one of our transplant information evenings to make sure that you and your relatives are fully prepared for a transplant. If you have any further questions, you can ring the pre-transplant assessment nurse on **(020) 7794 0500 x 34084**.

How do I get on the transplant waiting list?

If the doctors feel you are suitable to have a kidney transplant, they will ask you to sign a consent form and will place your name on the waiting list. If someone is going to give you a kidney, you may want to wait for their kidney without going on to the waiting list.

What if someone wants to give me a kidney?

The best way to receive a kidney transplant is if someone is prepared to give you one of their kidneys. If someone wants to give you a kidney, you should ring the live donor nurses on **(020) 7317 7604** to arrange matching with this person and to see if they would be a suitable donor for you.



THE WAITING LIST



How do I know if I am on the waiting list?

We will ask you to sign a consent form and will send you a letter when you are on the waiting list.

Why do I need to sign a consent form?

UK Transplant organises the allocation of kidneys in the UK. They have to ask your permission to use your personal information for the waiting list. The consent form lets them know that you are happy for UK Transplant to use your personal information and put your name on the waiting list. They do not use this personal information for anything else. We may ask you to sign a consent form to let us know that you are happy to go onto the transplant waiting list and understand some of the risks involved with transplantation.

What should I do while waiting for my transplant?

Carry on as normal but make sure you stay as healthy as you can. Regular exercise will help maintain your fitness and if you smoke, you should stop. Your doctor or specialist nurse will review your fitness for transplant on a regular basis. Let your doctor or specialist nurse know if you are ill or go away on holiday, as you may need to be temporarily suspended from the list. Let your doctor or specialist nurse know when you are

better or return from holiday, so they can reactivate you on the list. If you have dialysis abroad when on holiday, you may need a longer period off the list while we check that you have not caught any infections from the holiday dialysis unit.

What if I move or change my phone number?

It is very important that we have up-to-date contact information for you, particularly phone numbers. A transplant call can come at any time and if we cannot get hold of you, we will have to offer the kidney to someone else. Please let the receptionist or dialysis staff know if you have changed phone number or moved home. Make sure your phone is in working order and always switched on. You never know when you might get that call!

How long will I wait for a kidney?

After you have made the decision to have a kidney transplant there will be a period of waiting until a suitable donor kidney becomes available - unfortunately we cannot predict when this will be. United Kingdom Transplant (UKT) allocates kidneys by blood group and tissue type. This system is in place to ensure the best match between you and the donor kidney. The wait can be anything from a few weeks to many years but on average, patients who are blood group A or AB wait just over two years and patients who are blood group O or B wait just over three years. If your tissue type is rare or you are sensitised to certain tissue types (*from blood transfusions, previous transplants or pregnancy*) you may wait longer than the average.

Can I reduce the wait for a kidney?

Kidneys are allocated by UK Transplant according to blood group and tissue type. Your doctors have no control over the list and we cannot reduce your wait but if someone is prepared to give you a kidney, this may reduce the time to transplantation. If a friend or relative wants to give you a kidney, you should ring the live donor nurses on **(020) 7317 7604** to arrange matching with this person and see if they would be a suitable donor for you.

THE KIDNEY OFFER

When will I be offered a kidney?

The offer of a kidney may come at any time, day or night. Make sure you have your phone switched on and with you at all times. If we cannot get hold of you, we will have to offer the kidney to someone else.

Think about how you will get to the hospital when you are called, remembering that it may be in the middle of the night. If you have pets or young children, think about who will be able to look after them at short notice.

What should I do when I get the offer?

The doctor will ask you to come to the hospital straight away – see the map at the end of this booklet for directions.

Please let the doctor know if you are unwell or have been into hospital recently. We will require you to be in the best possible health for your transplant operation.

DO NOT delay coming to the hospital, as this will increase the time we have to store the kidney and may impact on the transplant.

DO NOT have anything else to eat or drink, as you will need to have an empty stomach for the anaesthetic.

DO switch off all lights and appliances, as you might be in hospital for some time.

DO let a neighbour or relative know that you are going into hospital.

What will happen when I arrive at hospital?

Go straight to the ward and let the ward nurses know that you have come in for a kidney transplant.

The doctor will assess you to make sure you are fit enough to have a transplant. The doctor will take blood in order to make sure you are a match with the kidney and see whether you need dialysis before the operation. You may need a further chest X-ray and ECG (tracing of your heart). An anaesthetist will come to see you to make sure you are fit for anaesthetic for the operation. A surgeon will come to see you and explain more of the risks and benefits about the operation.

The surgeon will ask you to sign the consent form for the operation, if you are happy to have the kidney transplant and understand all the facts about the

operation. You may be asked whether you want to enter a research trial. Enrolling for a trial is entirely optional and your transplant does NOT depend on you entering any trials.

Can I ask about the donor?

Yes. The staff will be able to tell you the age, sex and some relevant medical details about the donor. This will help you decide if you want to have the kidney transplant. Due to the privacy of the donor and their family, we will not be able to tell you any other details about the donor.

If I am called to the hospital, will I definitely receive the transplant?

No. We have to make sure you are fit enough to receive the transplant and nothing has changed since you were last assessed – for example that you have not had heart problems, put on too much weight or have an infection. The kidney has to be matched to your blood to make sure that you do not react to the kidney. If your blood reacts to the kidney (*a positive cross-match*), there would be a high risk of you rejecting the kidney and we would offer the kidney to someone else. This test takes about four hours to complete and may be delayed while we are waiting for the kidney to arrive. If the crossmatch is positive, we will let you go home as soon as we know the result. The surgeon will need to carefully examine the kidney to ensure there is no problem to prevent the transplant going ahead.

If I am called to the hospital, do I have to receive the transplant?

No. It is your choice whether you receive the kidney but kidney offers do not come around often and it may be a long time before you are offered another kidney. The delay involved with assessing you increases the storage time for an organ and may mean that it cannot be offered to another patient. If you do not want to have a transplant, please ask your doctor to remove your name from the waiting list. If you turn down a kidney transplant, we may ask you to come to the Royal Free for a further discussion about transplantation.

TYPES OF DONOR



Yvette Phillips flanked by father and son team, Ossie Fernando (*right*) who performed Yvette's first transplant in 1977 and Bimbi Fernando (*left*) who performed Yvette's second transplant 34 years later in 2011.

Where do donor kidneys come from?

Donor kidneys can come from two sources:

- 1) A living donor (*someone you know who gives you a kidney – friend or family*)
- 2) A deceased donor (*someone who has died and donated their kidneys*)

Are all deceased donors the same?

No. Just like everything in life, donors can vary in age, size, gender, medical problems and how the kidney was retrieved. The doctors should be able to tell you some information about your donor and whether there are any potential issues with the kidney you are being offered.

What are the differences in retrieval?

There are two main types of deceased donors – Donors after Brain Death (*DBD*) and Donors after

Cardiac Death (*DCD*). Up to one third of transplants at the Royal Free are from DCD. DBD are patients who have had a massive injury to their brain (*usually due to a stroke*) and tests have shown that their brain is dead. The patient cannot survive without a machine to help them breathe and they have lost all sensation. The organs are retrieved while the heart is still beating (*which is why they were previously known as heart beating donors*) and the organs are well flushed through with storage solution during the surgery.

DCD are patients who have either had a massive injury to their brain, from which they cannot survive, and their heart stops beating after the machine to help them breathe has been stopped or their heart has stopped and they have died. The organs are retrieved after the heart has stopped beating (*which is why they were previously known and non-heart beating donors*) and the organs are flushed through with storage solution after the heart has stopped.

TYPES OF DONOR

Are there any differences in outcome between DBD and DCD?

In the long term, there is no difference in the function or survival of the kidneys from DBD or DCD but the kidneys from DCD often take longer to start working (*which means you may be in hospital longer*) and there may be a slightly higher complication rate after the transplant. All types of donor may be variable in their suitability to you and the doctors should be able to discuss any issues about the donor. Access to DCD may increase the chances of you having a transplant and your doctor should be able to discuss the potential benefits with you. We may ask you whether you wish to be considered for kidneys from DCD.



Why might I be offered two kidneys?

There is a limited supply of kidneys for transplantation and there are not enough kidneys for everyone on the waiting list. We try to utilise all offers of kidneys, even from donors who may have had medical problems themselves, to maximise the number of patients who can have a transplant. Occasionally, we are offered kidneys from a patient where one kidney would not provide enough kidney function for a patient. In this case, we may offer the kidneys to you as a “dual transplant” and both kidneys would be transplanted to you. This would mean a bigger operation but may

provide you with a transplant that you might not otherwise receive.



Can I get cancer or infection from my donor?

All donors are thoroughly screened for cancer and infection (*particularly hepatitis and HIV*) to reduce any risk to you following transplantation. Although we cannot guarantee the screening 100%, it is very rare for the screening to miss any potential problems. If there are any potential risks to you from the donor, the doctors will discuss this with you and ask whether you want to receive the kidney. Only patients with hepatitis will be offered kidneys from donors with active hepatitis. If you want to know more about donors, why not come to our transplant education sessions or call the pre-transplant nurse.

LIVING DONORS

Receiving a kidney from someone you know (*living donor*) is the best and most reliable way to receive a kidney transplant. There are many potential benefits of a live donor kidney transplant. These include better long-term outcomes and having a kidney transplant at the right time for you. If someone offers to give you a kidney, please contact the live donor nurses on **(020) 7317 7604**. You have to be suitable to receive a kidney.

Who can donate a kidney to me?

Anybody you know can give you a kidney. The donor does not have to be a relative but you have to prove that you know the person giving you a kidney.

Which people cannot be donors?

All donors will have to go through a thorough screening process to make sure that they are fit enough to give a kidney. We would not take a kidney from anyone with diabetes, high blood pressure on more than one tablet or anyone with serious heart or kidney problems. A serious medical condition or previous cancer would usually rule a person out from being a donor.

Can a person manage with only one kidney?

Before a kidney is removed from the donor, we check very carefully that the donor is fit enough to give a kidney and that they have sufficient kidney function to be left with one kidney. We do not allow donors to give a kidney if they do not pass these tests. There are long-term studies of patients who have given kidneys to other people or patients who have had a kidney removed for other reasons. These people manage well with a single kidney and giving a kidney does not increase their risk of having kidney failure themselves.

Are there any long-term problems from giving away one kidney?

Large studies have been performed on people who have given one kidney to someone else. There does not appear to be any significant risk of serious problems from having donated a kidney. There is a slight increased risk of raised blood pressure and protein

in the urine after donation. Therefore there does not seem to be any serious long-term problems from donating a kidney, but we do monitor all donors in the long term to make sure they remain healthy.

What about lost income while my donor is off work?

This depends on the individual's employer. They are not obliged to pay the donor sick pay while they are off work. Most employers are understanding, so it is not usually a problem. If the employer will not pay, we can claim for lost earnings up to £5,000 from the health authority but the donor has to be able to prove that they have lost money while donating. The claim **MUST** be submitted before the transplant operation and the live donor nurses can help direct you to the correct person to make the claim.

Can I pay my donor to give me a kidney?

No. The donor has to give you the kidney without any condition and it is illegal to pay your donor for their kidney or provide any incentive for them to donate.

How do I know whether my donor is a suitable match?

Your donor needs to be matched with you to make sure they are a suitable donor. The live donor nurses will arrange an appointment for you and any potential donors to come to the Royal Free for blood tests for matching.



Royal Free patient Kishor Gohil, (*centre*) received the ultimate gift from his wife Hasmita, who donated a kidney to him in March 2009.

LIVING DONORS

What if my donor does not live in the UK?

We can consider donors from outside the UK (*or far away inside the UK*) by asking them to post their blood to us for matching. Please ask the live donor nurses for details and a posting pack. If the donor is a suitable match to you, we will ask them to provide some basic medical details and have blood tests and an examination by a doctor in the country where they live. If these tests are all satisfactory, we can write to the home office for a visa to allow your donor to come to the UK to donate a kidney. You will have to look after your donor while they are in the UK and provide their travel expenses and accommodation.

What if my donor is not the same blood group?

A donor with the same or compatible blood group is likely to be your best option for a transplant but if you do not have a donor with a compatible blood group, we can consider a blood group incompatible transplant. You will have to have suitably low levels of antibodies to your donor's blood group and be strong enough to manage the extra treatment and immunosuppression involved. Your doctor or the live donor nurses can discuss this option with you.

What if my donor is incompatible with me?

Not all donors are compatible with their potential recipient and not everyone wants to have a blood group incompatible transplant. In this case, you can consider the paired exchange program. This is a national scheme where kidney patients with incompatible donors can be matched with other incompatible donors and recipient pairs. The matching happens four times a year and if you get a match, your donor will be asked to give a kidney to someone else and you will receive a kidney from a suitably matched donor. The operations all take place at the same time and your donor will still donate their kidney at the Royal Free. Please ask the live donor nurses about paired exchange if your donor is not compatible with you.

Should I consider having a kidney transplant in another country?

We would not advise having a kidney transplant abroad. Although some patients have received a kidney transplant from abroad, the overall risk of complications and rejection is higher, and the life span of the kidney is often less. In our experience, the risk of infection after the transplant is higher with half the patients developing a resistant infection and a quarter developing hepatitis from their overseas donor.



Photography courtesy of Uday Lakhani

Uday Lakhani (*left*) with his father, “Mackey” Lakhani. Uday and his father were part of a three-way live donor exchange where Uday received a kidney transplant from another living donor.



Photography courtesy of Andrew Holmes

Andrew Holmes donated his kidney to his wife, Claire. Six weeks after the operation, Andrew ran a marathon!

THE OPERATION

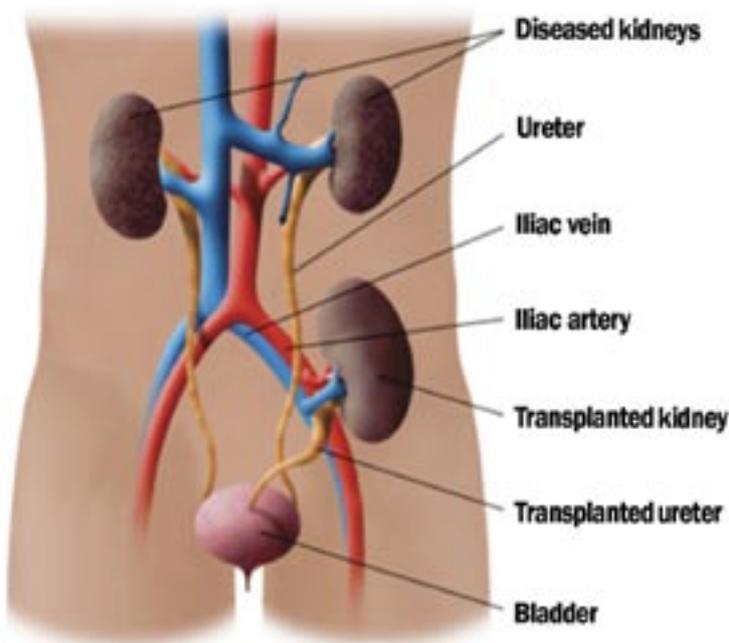
Where do you have your operation?

The transplant operation takes place in the main operating theatre on the third floor of the Royal Free hospital. You will have a general anaesthetic and the operation usually lasts about two to three hours, although you are not likely to be back to the ward for four to five hours.

Where does the kidney go?

The transplanted kidney is placed in the right or left groin just under the skin at the front. It is placed here as it is close to your bladder and main blood vessels of your leg. The operation requires the surgeon to join up your blood vessels to those of the kidney and also join the urine tube (*ureter*) from the kidney to your bladder – see picture below.

Example of a kidney transplant



What happens to your own kidneys?

Your own kidneys are not removed, unless there is a reason to do so. Occasionally, we may need to use the ureter (*draining tube*) from one of your own kidneys to connect up your new kidney.

What tubes will I have after the operation?

- You will have a tube placed into your bladder (*a urinary catheter*) to measure the amount of urine your transplanted kidney is producing. It is usually removed after about a week.
- You may have a tube or two from the operation site (*a drain*) to remove any blood or fluid from the operation site. This is usually removed within a few days, unless it continues to drain.
- You may have a plastic tube (*a stent*) placed inside the urine tube (*ureter*) that connects the kidney to your bladder. You will not be able to see this tube after the operation, as it will be inside your kidney and bladder. This prevents any kinking of the ureter after the operation and is usually removed after four to eight weeks by a day case cystoscopy (*camera to look into the bladder*). If you have a peritoneal dialysis catheter, this will be removed at the same time as your cystoscopy.
- You will have a drip line in your hand and also a central line (*neckline*).
- You will be given control of your analgesia (*painkiller*). This is attached to one of your drip lines and a control button will be placed in your hand. When you press the button, you will get a painkiller that works very quickly to prevent any further pain. This is called PCA - patient controlled analgesia.

Can I eat and drink after my operation?

The operation and anaesthetic may make your stomach stop working for a while. Immediately after your transplant operation you will not be able to eat or drink but after a few hours, you should be able to start drinking sips of water. This will gradually be built up to more fluid and then a light diet. Within a couple of days you should be eating normally.

The doctor will assess how much fluid you should drink every day. Remember it is often necessary to drink much more fluid than you have been used to on dialysis – it may be many litres each day. Some people may pass large amounts of urine after the transplant operation, particularly at night. This is nothing to worry about and will eventually settle down. However, it may require you to have some of your fluids through a drip.

THE OPERATION



Will the kidney work straight away?

Not always. Some kidneys will start working during the operation but some kidneys may take time to start passing urine and clearing the wastes from your body (*delayed function*). Roughly 90% of kidneys from live donors work straight away but about half the kidneys from cadaveric donors take time to start working. The length of time taken for the kidney to work can vary considerably. Most kidneys start working within a week or two of transplantation but occasionally, it may take months to work. During this time, you will need to continue with your dialysis. If you are on peritoneal dialysis, you may need a short period of haemodialysis.

Is it possible that my kidney may never work?

Kidney transplantation is a major operation with complex surgery required to join the blood vessels and draining tube of your new kidney to your body. Occasionally (*roughly 2% of kidney transplants*), the blood vessels can clot or you can bleed and compress the blood supply to the kidney. In this situation the kidney loses its blood supply and has to be removed shortly after it has been transplanted. Some kidney transplants may never work, even with good blood supply and no rejection. This happens in about 2% of

kidney transplants and the kidney is usually removed after a number of months of waiting for it to start working.

Will I need dialysis after the transplant?

In most cases you will not require dialysis. Some patients may need to continue or start dialysis until their kidney works. If you are on peritoneal dialysis, you may need a short period of haemodialysis. Some patients may need a brief episode of dialysis after the operation to rebalance the level of potassium in their blood.

How long will I need to stay in hospital?

Each individual transplant is different and some patients will have to stay longer than others after the transplant. If the kidney works immediately and you recover quickly, you will only have to stay in hospital for six days. If the kidney takes time to work or the doctors feel you need more time in hospital, you may need to stay for a few weeks. Most patients are stable enough to go home after three weeks, whether their kidney has started working or not.

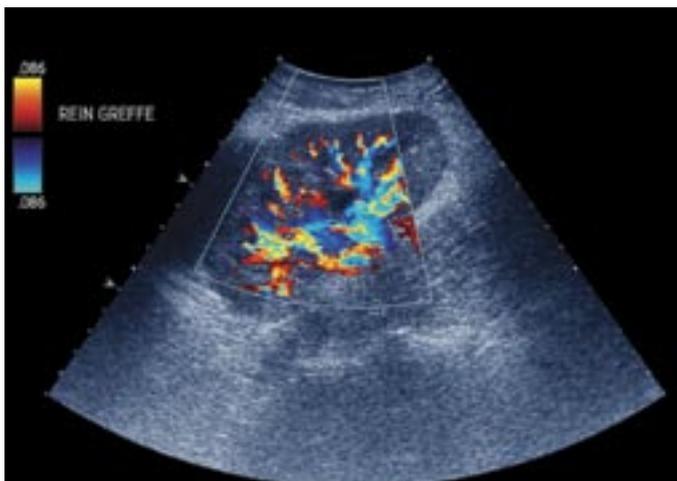
Will I need blood tests after my transplant?

Yes, you will need to have a number of blood tests before the transplant to make sure you are fit enough to have the transplant and to match you to the kidney. After the transplant, we will need to take blood tests at least once a day to monitor the function of the kidney, make sure there is no bleeding, check on the levels of drugs in your blood and a number of other tests. After you are sent home, we will need to do blood tests each time you come to the hospital.

Will I need any scans of my kidney?

Yes. All transplant patients will have an ultrasound scan and nuclear medicine scan of their kidney to make sure that the blood vessels are clear, the kidney is functioning well and the draining tube is not blocked. You may need more scans or X-rays after the operation to make sure the kidney is working well and there are no complications.

REJECTION AND BIOPSIES



Colour doppler ultrasound scan of a transplanted kidney. The red and blue areas indicate blood flow within the kidney.

Will I reject my kidney?

Rejection is a normal response of your body to a foreign kidney. We will give you medication (*immunosuppression*) to stop you rejecting your kidney. Despite this medication, about 20% of patients will reject their kidney within the first year, although this may be higher if you have a blood group or antibody incompatible transplant. The risk of rejection decreases with time and is less likely after the first year. Most cases of rejection are mild and can be treated with steroid injections and an increase in the amount or type of immunosuppression you take. Occasionally, we need to treat rejection with drugs that destroy cells of your immune system.

Stopping your prescribed medication, or not taking it properly, is likely to lead to rejection and the possible loss of your transplant. We ask that you take your medication regularly and on time to avoid rejection or other serious consequences.

Just because you reject your kidney does not necessarily mean that the kidney will fail and most cases of rejection can be stopped with medication. Very rarely (*1% of transplants*), we cannot stop the kidney rejecting and we have to remove the kidney. In this case, you will return to dialysis and may be considered for another transplant in the future. Most episodes of rejection are picked up by a change in your kidney function on the blood tests and it is unusual for you to have symptoms of rejection. If we suspect that you might be rejecting your kidney, we may ask you to have a transplant kidney biopsy.

Will I need a kidney transplant biopsy?

Most patients do not need a biopsy of their kidney while they are in hospital but if your kidney does not work straight away or if we suspect you have rejection, we may need to do a biopsy of your transplanted kidney. If your kidney takes a long time to start working, you may need a biopsy of the transplanted kidney each week until it starts working.

After you leave hospital, you will be asked to have a surveillance (protocol) biopsy at three months and twelve months after your transplant. The surveillance biopsy is to make sure you do not have rejection that has not been picked up by the blood tests or to see if your kidney is being affected by the medication. In addition, your transplant doctor may ask you to have a biopsy at any time to make sure there is no rejection or infection in your kidney.

What does a biopsy involve?

The kidney is scanned with an ultrasound machine and local anaesthetic is given at the site of the biopsy to make the skin on the front of your tummy numb. A special needle device is passed into the kidney from the front of your tummy and is used to obtain a small piece of the kidney, about half the size of a matchstick. You will then be asked to lie on your bed for the next four to six hours while the nurses monitor your blood pressure and pulse. You may have had a biopsy of your own kidney. A transplant biopsy is much more straightforward than this.

What are the risks of having a biopsy?

Most kidney biopsies do not have any complications but there is a small risk (*about 2 - 5%*) of bleeding. Of the patients who bleed, a small proportion require a blood transfusion and a smaller number require a further procedure to stop the bleeding. The risk of damaging your transplant is very small and the benefit of knowing what is going on in the kidney often outweighs the small risk to you of undergoing the biopsy. Your doctor will discuss the risks and benefits of having the biopsy done at the time.

AFTER THE TRANSPLANT

What happens after I go home?

You will be given a supply of your new tablets and will have to come to the transplant clinic at the Royal Free three times a week. This frequency of clinic visits will gradually reduce over the next few months (*three times a week for the first month, twice a week for the second month and weekly during the third month*) and by four months after the transplant, most patients are only coming once every two weeks. After a year, most patients are only coming four or five times a year.

Why do I need to come to clinic so often?

We need to monitor you and your kidney function very carefully after the transplant to make sure you do not have rejection, infection or any other complications after the transplant. You will have blood tests at each visit to monitor your kidney function and the effects of the medication. You will need to have your dressing changed, any stitches removed and the stent in your kidney removed after four to six weeks. We will be monitoring your blood pressure and will be changing your blood pressure tablets and immunosuppression during this time, to get the balance of tablets right.

Will I get transport to bring me to clinic?

You will be able to have transport for the first two weeks after the transplant. After two weeks, you will need to make your own travel arrangements to come to the Royal Free.

When can I drive after my transplant?

You are normally able to drive about six weeks after your operation. We do not suggest driving before this point to reduce the risk of damage to the kidney and wound. You should check with your insurance company and inform the DVLA that you have had a transplant.

When can I go back to work after my transplant?

Our aim is to allow each transplant patient to return to an independent lifestyle with a good quality of life.

Most transplant recipients remain off work for two to three months after the transplant but this depends on the individual patient and their occupation. Please discuss when you can return to work with the doctor caring for you.

What can I eat after my transplant?

There is no special diet after successful transplantation and most of the dialysis dietary restrictions are lifted. We would suggest that you follow a healthy and varied diet after transplantation with a low salt intake and more fruit and vegetables. You are able to drink alcohol after the transplant but only in moderation within the national guidelines of 14 units per week for women and 21 units per week for men. We ask you to avoid grapefruit juice, as this can affect the level of some immunosuppression tablets. If you need further advice, please ask your doctor or specialist nurse to refer you to a dietician.

Will I put on weight after my transplant?

Weight gain is common after successful transplant, particularly within the first year, and is often due to an increase in appetite and steroid immunosuppression. Weight gain will increase blood pressure and your risk of diabetes after the transplant. It is important to maintain a healthy diet and perform regular exercise to keep your weight within the healthy range.



RESULTS AND COMPLICATIONS

How successful is kidney transplantation at the Royal Free?

One year transplant survival

After one year, 94% of kidneys from people who have died are still functioning well. After one year, 95% of kidneys in living donor transplants are still functioning well.

Five year transplant survival

After five years, 81% of kidneys from people who have died are still functioning well. After five years, 87% of kidneys in living donor transplants are still functioning well.

Figures provided by UK Transplant (Data from 2003-2007).

There are both early and late complications from transplantation, as listed below. Despite these risks, most patients are likely to have a longer life with better quality after transplantation.

What are the common early complications?

Delayed function – see above

Rejection - see above

Infection - the anti-rejection treatment that you must take following your transplant will mean that you will be more likely to develop infections. The risk is greater in the early stages after your transplant when the doses of the drugs are higher. The increased risk of infection covers all types of bugs from wound infections, chest infections and urine infections to more unusual, and occasionally life threatening viruses, bacteria and fungus.

Cardiovascular disease – heart and blood vessel disease is more common in patients with kidney failure and we screen all potential transplant patients to reduce the risk of this complication. Despite this thorough screening, a transplant can put extra stress on the body and there is an increased risk of heart attacks and strokes during the operation and for a few months afterwards.

Diabetes (raised blood sugar) - can occur as a side effect of the anti-rejection drugs. It is usually treated with a change in diet and/or tablets. Sometimes there is a need for insulin injections.

Thrombosis - is a rare complication following transplant (2% of transplants) when a clot forms in the vein or the artery of the new kidney. This means that the blood supply to the kidney will stop. If this happens you will have to go back to theatre and in most cases the kidney will have to be removed.

Urine leak - occasionally a leak will occur where the ureter (*urine drainage tube*) from the transplanted kidney joins your bladder. This usually requires a return to theatre and an operation to have the leak repaired.

Bleeding - as with all major surgery there is a risk of internal bleeding. This may require a blood transfusion and a further operation or procedure to stop the bleeding.

Deep Venous Thrombosis (DVT) - following all surgery there is a risk of clots forming in the veins of the leg. Under certain circumstances these clots can be dangerous and move to the lungs. To prevent this happening you will be given special stockings and may have a special pump put on your legs or have injections of heparin for the first few days following the transplant operation.

Lymphocele – the transplant is situated in the groin where small vessels drain excess fluid from the leg. The fluid from the leg can accumulate in small collections in the groin or around the kidney. These do not normally require anything to be done about them but occasionally they will need to be drained with a needle or by an operation.

Damage or infection from the surgery – Wound infection can occur after transplantation and may be deep within the abdomen, requiring a further operation or procedure. Damage to the bowel and other local structures is uncommon (1%) but may require a further procedure or operation.

RESULTS AND COMPLICATIONS

What are the long-term complications of transplantation?

Weight gain is a common problem after successful renal transplantation because of improved appetite and steroid treatment. Increasing weight can increase your risk of diabetes and high blood pressure. It can be minimised by eating a healthy diet and by taking regular exercise.

High blood pressure is very common following kidney transplantation because of the immunosuppressive drugs (*mainly cyclosporin or tacrolimus*), transplant function and pre-existing kidney disease. Many people require blood pressure lowering drugs long-term. Rarely, high blood pressure can be caused by a narrowing of the transplant artery.

Diabetes can develop for the first time following renal transplantation, as outlined above. Diabetes can increase the risk of heart and blood vessel disease as well as lead to some other complications.

Cholesterol levels and other blood fats can increase after a kidney transplant, principally as a side effect of drugs, with various other causes contributing. A healthy diet will help to reduce your cholesterol but cholesterol-lowering treatment may also be required.

Cardiovascular disease such as angina, heart attacks, circulatory problems and strokes are all more common in patients with kidney disease. Receiving a kidney transplant does reduce the risk, when compared to dialysis but it does not remove the risk completely. It is important to stop smoking and follow any advice on blood pressure, cholesterol and diabetes. Keeping your weight down and taking exercise regularly are also sensible measures.

Recurrence of the original disease which damaged your own kidneys is a recognised complication but an unusual cause of transplant failure. Some types of kidney disease are more likely to recur than others and you will be monitored closely for this problem. Occasionally a new form of kidney disease can develop in a transplant kidney.

Cancer is more common in people with kidney transplants (*roughly twice the rate of the general population*) because of the immunosuppressive treatment and types of viral infection. Three of the most common types of tumours to develop are skin cancer, cervical cancer and lymphoma. Careful avoidance of sun exposure and use of powerful sun screens help reduce the risk of skin cancer. Women should also have cervical smears performed annually. Other types of tumours, such as lymphomas are seen more frequently in transplant patients compared with non transplanted patients.

It is clear that many of these side effects can be attributed to the immunosuppressive medication. Unfortunately without these drugs, the kidney transplant will fail. It is important to take your medication regularly without missing doses. Stopping your prescribed medication, or not taking it properly, is likely to lead to rejection and the possible loss of your transplant.

New drugs with fewer unwanted effects are continually under development and your therapy might change in the future. Despite the risk of complications, most patients are more likely to live longer and have a better quality of life with a transplant than having dialysis.



MEDICATIONS

How are my tablets going to change?

Your medication will change after your transplant with some tablets, such as phosphate binders and vitamin supplements, stopping and new tablets starting. We will give you a list of your new medication before you leave the hospital.

The most important new tablets you will be started on are called **IMMUNOSUPPRESSANTS**. These tablets stop your immune system from rejecting the kidney and should be taken regularly every day you have a functioning transplant. Because these medications reduce your own natural immune system, you will also be given medication to prevent you getting some serious infections.

What immunosuppressants will I take?

Initially you are likely to be on a combination of three medicines:

- **Tacrolimus**
- **Mycophenolate Mofetil**
- **Prednisolone**

If you do not take these medications as prescribed, it will result in rejection and the loss of your new kidney.

These drugs need to be finely tuned as too little may lead to rejection and too much may lead to infection. Early after the transplant the need for immunosuppression is high but this need lessens with time, so the drugs will be slowly reduced by your doctors. The level of these drugs have to be monitored in the blood. When you come to clinic, do not take your tablets until **AFTER** you have had your blood taken. After the clinic, you may be telephoned to change the dose of the tablets you are taking or asked to return for further blood tests.

What are the possible side effects?

Immunosuppressants, like most medicines, can have some unwanted side effects. However, just because a medicine has the potential to cause adverse effects, it

does not necessarily mean you will get them. All anti-rejection drugs will increase your risk of infection and some cancers.

The individual immunosuppressives may have their own side effects as follows:

Tacrolimus - shaking of the hands, headaches, impaired vision, 'pins and needles', raised blood sugar levels (*diabetes*), hair loss and kidney damage at high levels of Tacrolimus in the blood.

Ciclosporin - high blood pressure, increased or unusual hair growth, tender or swollen gums, shaking of the hands, raised blood sugar levels (*diabetes*) and kidney damage at high levels of Ciclosporin in the blood.

Prednisolone - irritation of the gut lining, indigestion, increase in appetite, weight gain, rounded face, thinning skin and bones and raised blood sugar levels (*diabetes*).

Azathioprine - side effects are unusual but can cause an upset in liver function and white blood cells in the blood.

Mycophenolate Mofetil - diarrhoea, bloating, heartburn, nausea and vomiting.

Inform the doctors if you experience side effects - they may want to cut down the dose or give you an alternative. Do not stop or alter the dose yourself.

What other medications do I have to take?

You may be asked to take the following :

- **Co-trimoxazole** - an antibiotic to reduce the risk of bacterial infection
- **Omeprazole** - to protect the stomach against ulcers and heartburn
- **Nystatin mouth wash** - to prevent fungal infections of the mouth
- **Heparin** - for the first week after transplant heparin may be given to prevent blood clots.

MEDICATIONS

Can I take any other medicines?

Some of these medicines are affected by, and do themselves, affect other medicines. Please discuss your current medication with the pharmacist if you need to buy 'over the counter' medicines for minor ailments. Your GP may wish to contact the transplant unit/renal ward before giving you any new prescription medicines.

If you have any concerns about any aspect of your medicines, please do not hesitate to ask.

If you are taking either ciclosporin or tacrolimus the following drugs may interact. Your renal/transplant doctor should be informed before these drugs are used.

For example:

- **Erythromycin**
- **St. Johns Wort**
- **Clarithromycin**
- **Herbal medicines**
- **Fluconazole**
- **Grapefruit juice**
- **Ketoconazole**

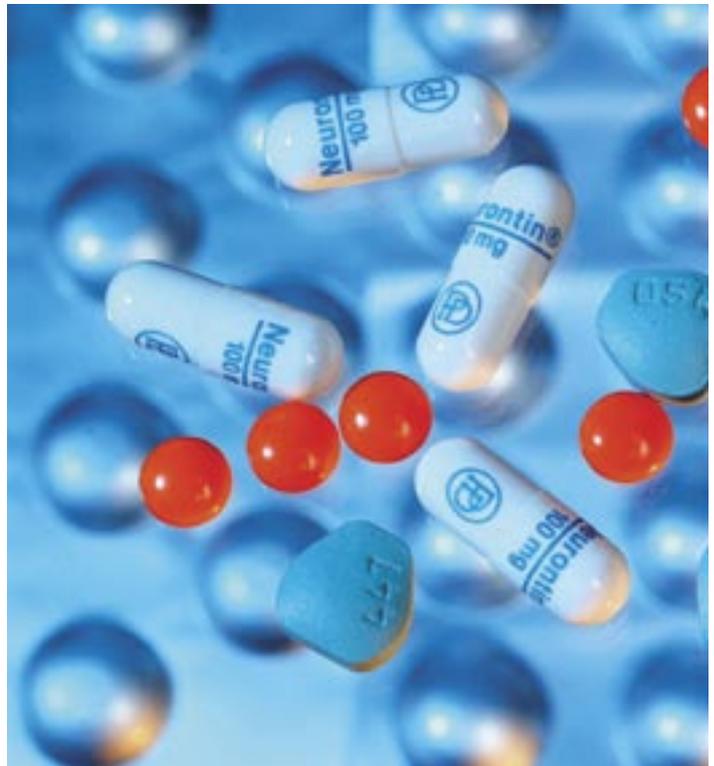
Many other drugs also interact. If you or your doctor are unsure, please discuss with your renal/transplant doctor.

Herbal medicines

It is suggested that you do not take any herbal medicines (*in particular St. Johns Wort should not be used*) without first checking with your renal/transplant doctor.

Grapefruit juice

Grapefruit juice taken with ciclosporin or tacrolimus can alter the levels of these drugs in your blood. It is probably best to avoid grapefruit juice but apple or orange juice is OK. For further advice speak to your renal/transplant doctor.



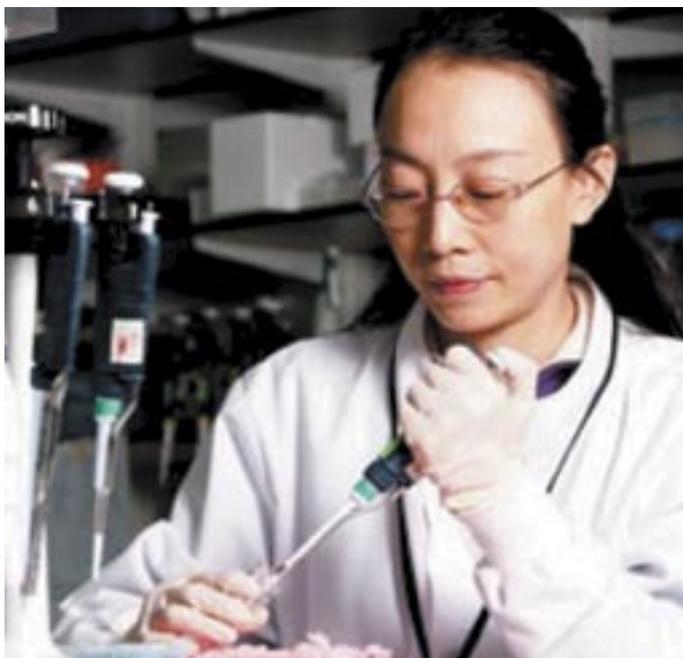
ANY OTHER QUESTIONS

Will I be asked to take part in any clinical research trials?

The field of transplantation is constantly improving and clinical trials are needed to establish the best treatments for patients. You may be asked to take part in clinical research trials but the decision to take part is entirely up to you and there is no obligation for you to take part in a trial. Any trial will be discussed with you in full and you will be given a patient information sheet. If you decide not to take part in any trial, your treatment will not be affected in any way.



Royal Free renal patients who have taken part in clinical trials.



Can I get pregnant after my transplant?



Caroline McGovern with her baby son Ollie. Caroline has had a successful kidney and pancreas transplant.

It is not advisable to consider pregnancy within the first year post transplantation. Transplant patients of child-bearing age should make sure they have adequate contraception following transplantation. Should you wish to take the oral contraceptive pill, discuss this at your out-patient appointment. If you do wish to get pregnant after the first year, you should discuss your wish to have a baby with your consultant, who can refer you on to our local transplant pregnancy service.

Some of the drugs you will be taking after the transplant are harmful to an unborn child and you should not try to become pregnant before your medication has been changed to a less harmful combination. The outcome of the pregnancy and the effect on your kidney depend on the function of your kidney and a number of other factors. You should discuss all aspects of pregnancy with a transplant consultant and a specialist obstetrician before considering pregnancy. They will be able to explain all the risks to you before you become pregnant.

ANY OTHER QUESTIONS



Can I travel after my transplant?

There is no reason to prevent you from travelling within the UK when you feel well enough but you should contact one of the medical staff you see regularly in the transplant follow-up clinic for advice. If you are planning to go overseas - we do not recommend this in the first six months post transplantation.

Can I drink alcohol after my transplant?

It is possible to take alcohol within the limits of the national guidelines:

Men - 21 units per week

Women - 14 units per week

1 small glass of wine = 1 unit

1/2 pint of beer = 1 unit

Living with a transplant - useful links

<http://www.kidneypatientguide.org.uk>

http://www.cks.nhs.uk/patient_information_leaflet/kidney_transplant

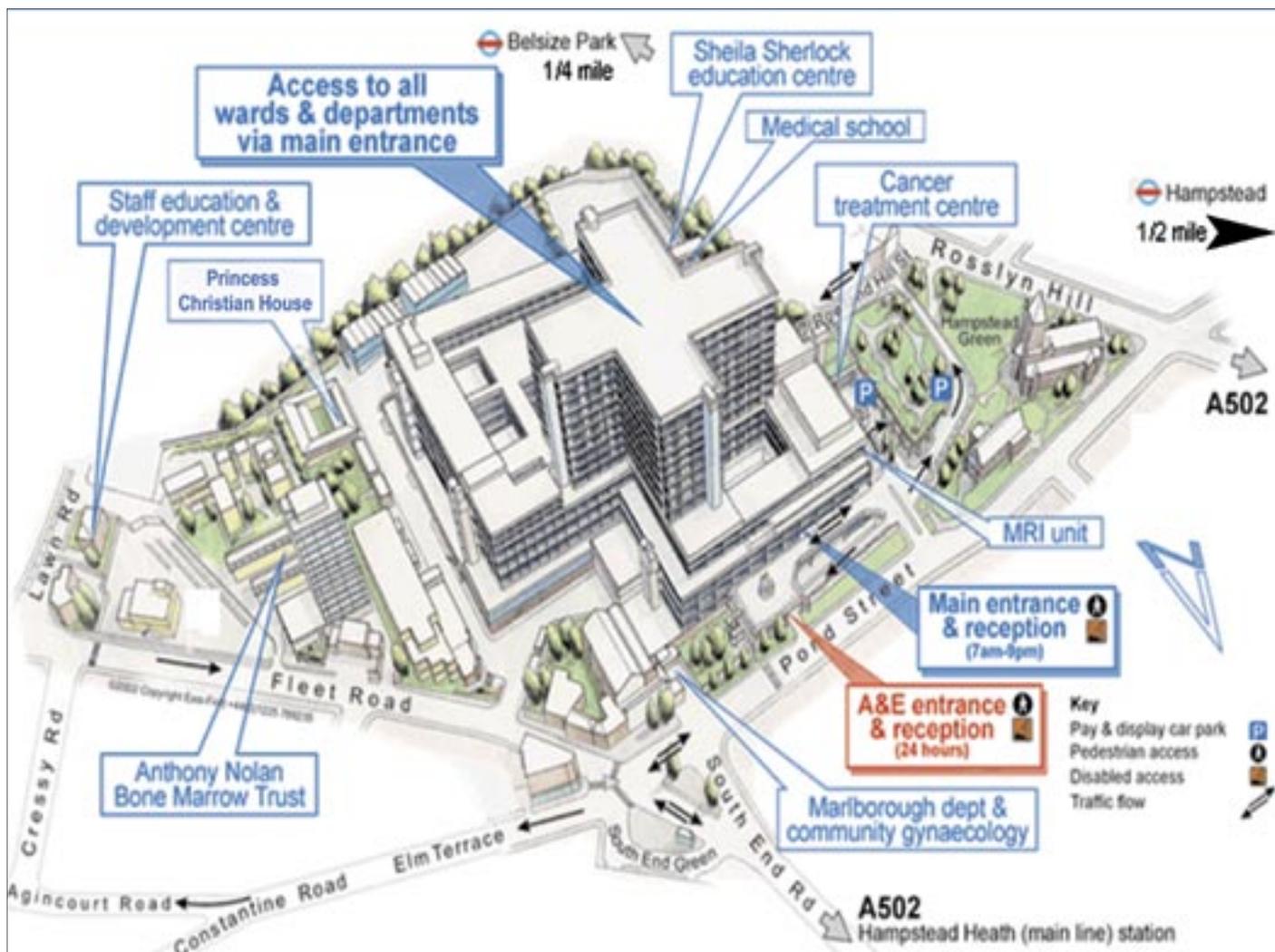
<http://www.kidneycare.nhs.uk>

<http://www.renalpatientview.org>

<http://www.organdonation.nhs.uk>

<http://www.royalfree.nhs.uk>

GETTING TO THE ROYAL FREE



How do I get to the Royal Free?

The Royal Free hospital is situated in Hampstead, London. The main entrance and dropping off point is on Pond Street. Although the hospital is situated well outside the congestion zone and you can drive to the hospital, we would recommend coming to appointments by public transport as traffic is often difficult and parking on site is very limited.

Getting there:

Rail

Hampstead Heath station is near to the hospital and train services are operated by London Overground. The station is accessible to Oyster pay-as-you go users.

Underground

Belsize Park tube station on the Northern Line is slightly uphill for around 150 metres. If you come up Pond Street (from South End Green) you must also walk uphill for around 75 metres.

Bus

Routes: **24, 46, 168, 268** and **C11**.

Parking

Pay and display car parking areas are available near the hospital but these are frequently full. Bicycle parking is available outside the accident and emergency entrance on the lower ground floor.

There is a Corporation of London car park on Hampstead Heath (near the bottom of East Heath Road) which is situated about 15 minutes walk from the hospital. Unfortunately, this car park also fills quickly and can be closed for events on the heath.



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