NHS
Greater Glasgow
and Clyde

Kidney Transplant

Your questions answered

Renal Transplant Unit
Queen Elizabeth University Hospital
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Contents

Introduction

Welcome to the Renal Transplant Unit at the Queen Elizabeth University Hospital.

The information in this booklet is designed as a guide only and aims to answer questions about having a kidney transplant.

You will also have opportunities to ask questions and to discuss any of your concerns abo ut transplantation with doctors, nurses and other healthcare professionals.

Useful contact numbers

Hospital switchboard	☎ 0141 201 1100
Renal transplant ward (4C)	☎ 0141 452 2401
Transplant Coordinator secretary	☎ 0141 451 6200

Kidney Transplantation

What are the benefits of transplantation?

Having a transplant can make a big change to your quality of life. There are many advantages to having a transplant including:

- You will not have to rely on dialysis.
- You will no longer have to restrict how much fluid you have or follow a special diet. However, you should continue to eat healthily.
- You should feel more energetic and be better able to cope with your everyday life, your job or your studies. Many patients can return to full-time employment.
- For most people sexual function improves, fertility in young women also improves meaning the chances of future successful pregnancy are better.
- Having a transplant will mean fewer restrictions on your life, for example greater freedom to travel.
- Life expectancy is generally better with a transplant than with dialysis.

What are the potential disadvantages of kidney transplantation (see section on complications for further details)?

- Risk of failure
- Infection
- Cancer
- Diabetes
- Side effects of medication

Kidney Transplant Assessment

Each patient is assessed individually to determine whether transplantation is the best option. Not everyone is suitable to have a transplant. For those people who are, a transplant will, in most cases, allow a better quality of life than dialysis. The kidney team will discuss transplantation during your clinic visits.

Your kidney doctor will refer you to the transplant assessment clinic when they feel it is appropriate. Clinics are held at Stobhill Hospital and the New Victoria Hospital; your appointment location will depend on where you stay. If you are unable to make your appointment please tell the Transplant Coordinator Secretary on ☎ **0141 451 6200**.

When you attend for your transplant assessment appointment you will see a Transplant Surgeon. They will assess your health and fitness and make sure that you do not need any further investigations before your transplant operation. The Transplant Surgeon will also take this opportunity to tell you about the operation, risks and benefits, potential complications and the medication you will need after your transplant. You will also see one of the Transplant Coordinators.

The clinic visit also allows you to ask any questions you may have about kidney transplants, it may be an idea to write them down in advance of your appointment and bring them with you on the day.

If we consider you suitable for a transplant we will tell you in writing when your name is activated on the waiting list.

It will be necessary to have additional investigations as part of the assessment process. These are important as the results help your kidney doctors and transplant surgeons know whether you are well enough and what the risks are to you. We may discuss your case further at our multi-disciplinary team meeting. If we think the risk to you is too high we will advise you that you are unsuitable. We may re-consider the decision if your health improves and the risks are thought to be acceptable.

Where do kidneys come from?

There are two sources of kidneys for transplant:

1. From a living donor
2. From a person who has died (deceased donor)

Living Kidney Donation

A successful kidney transplant offers the best treatment for kidney failure and a living donor transplant can offer the best outcomes.

Who can donate to you?

You do not need to be related to a person in order to receive a kidney transplant from them. The donor can be a partner, unrelated family member or a friend. It can be very hard to ask someone to donate their kidney, as it is a huge question to ask. However talking about transplant with your friends and family is the first step to take.

What is involved for the donor?

Anyone can be assessed as a potential kidney donor as long as they are over 18, there is no upper age limit and everyone is assessed on an individual basis. This assessment process can take between 3 and 9 months, but this will vary for every donor. All donors go through an in-depth assessment; this includes blood and urine tests, imaging of the kidneys, blood pressure monitoring and clinic appointments with specialist doctors and surgeons. The Living Donor Transplant Coordinators will support the donors throughout the assessment and will guide them through the process.

How to start the process?

Anyone wishing to be considered as a living kidney donor should contact the Transplant Coordinators who will send out a registration form and health questionnaire. If you, your family or friends have any questions, or wish further information on living kidney donation, please do not hesitate to contact the team.

Non – Directed Altruistic donation

This is where a person volunteers to donate a kidney to an unknown recipient. Altruistic donors must be over 21 years of age. The benefit of this type of donation is that a person on the transplant waiting list receives a living donor kidney and the number of patients waiting for transplant is reduced.

Transplant Coordinator Team ☎ 0141 451 6200

Further information can be found online

🌐 **https://www.organdonationscotland.org**

Deceased Donation

This can be either from a person who has suffered brain death, usually as a result of an injury or brain haemorrhage (known as DBD which means Donation after Brain Death) or from a person who has been declared dead following absence of breathing or heartbeat (known as DCD which means Donation after Circulatory Death). Kidneys from a DCD donor may be slower to work initially but the long term results are just as good.

Are there risks from the organ donor?

We assess all organ donors to find out if they have potential to pass on any infection or illness to transplant recipients. Nevertheless there still remains a risk of transmission of serious infection and cancer with the donor kidney.

We take care to assess the function of the donor organ before transplant. Due to the shortage of organ donors, we now consider some people to be potential donors who we would not have accepted as donors a few years ago. This means you could receive an organ from an older donor or that the organ to be transplanted is not functioning perfectly. However outcomes of transplants from such donors are still very acceptable. If there are any special risk factors associated with a donor over and above those described, we would discuss these with you before any transplant procedure.

The Transplant Waiting List

How does the national kidney transplant waiting list work for deceased donation?

Kidneys from deceased donors are allocated by a national matching scheme. This tries to achieve a balance between obtaining best outcomes from transplants and fair access to a transplant. The scheme is based on a number of factors with emphasis on how long people have waited.

Details of the matching scheme can be found at: 🌐 **www.odt.nhs.uk**

Suspension from the waiting list

This can happen if you are unwell or it is thought at any time that a transplant would be too risky. When suspended, you are no longer open to kidney offers but still accrue waiting time points. You will also be suspended when:

- if you go on holiday outside the UK
- and for 2-3 months after your return if you have dialysis in a country where there is thought to be a risk of transmission of certain viruses.

What should I do while waiting for my transplant?

- Try to maintain a healthy lifestyle
- Continue to follow dietary advice
- If you have been advised to lose weight, try to do so
- Keep to your fluid restriction
- Take the medication prescribed by your doctors
- Exercise
- Stop smoking
- Continue to attend your dentist regularly
- Make sure you are up to date with any vaccinations which your renal unit recommends

All the above will help to keep you in good health for when you are called in for your transplant operation.

Please make sure you

- Tell us of any change of address or telephone number
- Tell us if you are going on holiday so we know how to contact you

Getting a call for transplant

What do I need to consider when called in for a transplant?

- How are you going to get to hospital?
- Who is going to look after your children?
- Who is going to look after your pets?
- Things you need in hospital - nightclothes, toiletries and a little money for newspapers etc. Many people find it useful to have a bag packed in advance. Thinking about what you need when you get that "Call" can be difficult.
- Lock up the house remembering to turn off all appliances.
- Tell someone where you are, pop a note through your neighbour's letterbox.
- When we call you, tell us if you are unwell: if you have developed new medical problems, we may advise you not to have the transplant. Bring all of your usual medications with you.

Is it definite that the transplant operation will go ahead?

No, sometimes patients waiting for a transplant from a deceased donor are called in but the transplant does not go ahead. If this happens a member of staff will discuss this with you at the time. This can be due to:

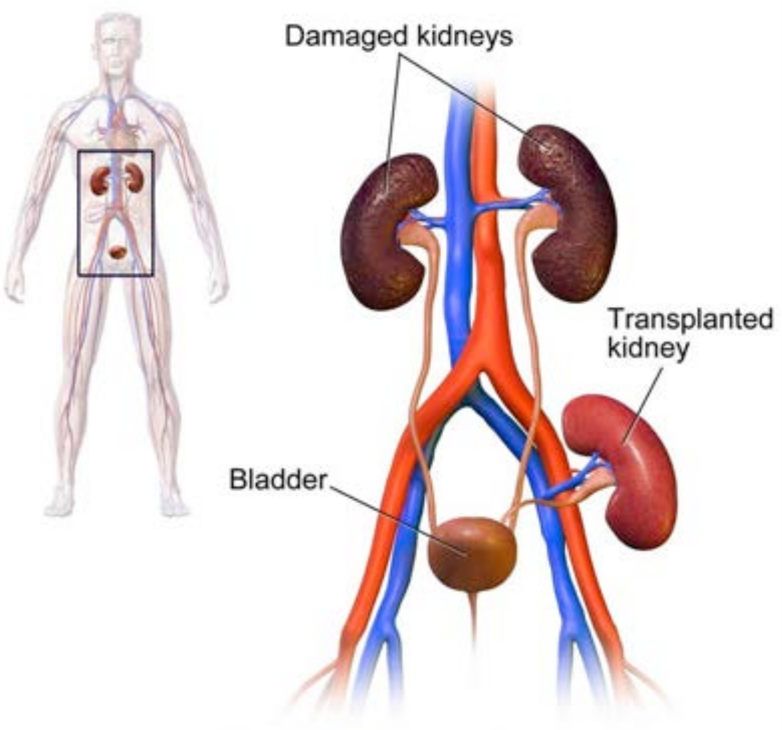
- Organ donation not proceeding.
- If you are unwell at the time of being called.
- The kidney may be considered unsuitable either due to a problem with the kidney or because tests indicate that you have antibodies which would react with the donor kidney.

Where does the operation take place?

The kidney transplant operation takes place at the Queen Elizabeth University Hospital and we will admit you into Ward 4C.

What happens during the kidney transplant operation?

A kidney transplant generally takes two to four hours. The surgeon will put the new kidney into the left or right lower abdomen. We do not remove your own kidneys during the operation.



Kidney Transplant

The blood vessels of the donor kidney are attached to your blood vessels and the ureter is joined to your bladder. A small tube called a stent is placed inside the ureter to make sure you are able to pass urine. Six to eight weeks after your transplant we remove the stent under local anaesthetic as a day case procedure using a cystoscope (passing a camera into your bladder). It's just like having a catheter inserted.

What tubes will I have after the operation?

A wound drain is usually left in near to the transplant kidney to drain out any blood or other fluid from the operation site; we remove this after a few days.

A catheter in your bladder drains the urine into a bag for monitoring.

You will have a drip line in your hand or arm and also a central line (neck line).

You will also have an infusion called a PCA (Patient Controlled Analgesia) attached to one of your drip lines to deliver a dose of painkiller when you need it.

These are short term and we usually remove them after a few days.

Complications

Early complications

- The kidney may not work straight away. If this happens, you may need dialysis until it begins to work. This may be days, or sometimes weeks after the transplant. Kidneys from living donors almost always work immediately but it is not unusual for kidneys from deceased donors to have delayed function. If the kidney does not work immediately, you will have scans and sometimes biopsies to make sure that other problems such as rejection have not occurred.

- Sometimes the kidney transplant never works although this is rare.
- Occasionally patients need further surgery after their transplant. This may be because of bleeding or problems with the connections between the kidney and your blood vessels and bladder.
- Rejection is one of the most important risks and this occurs because your immune system recognises the transplanted organ as foreign. To prevent this happening you must **always** take your prescribed anti-rejection medications as directed by your transplant team. These anti-rejection medications are also known as immune-suppressants. We can usually treat rejection by changing your medicines and kidneys are rarely lost for this reason alone.
- You will have a higher risk of infection following transplantation. This is because the anti-rejection medications lower your immune system. Your transplant team will monitor you closely to reduce your risk of infection. It is important to continue taking all of your anti-rejection medications despite this risk. The most common infection after a transplant is a urine infection.
- Viruses are among the most common types of infection after transplantation. Infections such as the common cold or flu may last longer than normal. You should be aware of signs of infection such as fever, lethargy, unusual tiredness, cloudy or smelly urine. If you think you have an infection or there is something else wrong you should get medical advice sooner rather than later.

Later complications

- Long term use of steroids (prednisolone) increase the risk of osteoporosis causing bone fragility and sometimes fractures.
- A condition called New Onset Diabetes after Transplantation (NODAT) occurs in almost 10% of people in the first year after kidney transplantation. This is a result of the anti-rejection medications and we treat it in the same way as diabetes in the general population by changing your diet and usually medicines (that might include insulin).
- You will have a higher risk of skin cancer following your transplant because of the medications you need to take. You can reduce this by taking the following precautions before and after your transplant –
    - Check your skin frequently to be aware of any changes, such as new moles or changes to existing moles (e.g. they become red or itchy). Your transplant clinic or GP will refer you to your local skin clinic for a skin check once a year. It is very important that you attend this clinic.
    - Avoid direct sunlight on the skin. Always wear sun cream with a high sun protection factor (SPF) – ideally more than 50 SPF - when outside between March and October and when travelling in hot countries.
- There is a slightly increased risk of other types of cancer including lymphoma and cervical cancer. It is very important that you attend all of your routine population screening test appointments. If you are over 50 you should participate in the national bowel screening programme every two years. Women should have cervical smear tests and breast screening in line with the national programmes.

Transplant Medication

Post Transplant medication

After transplant it is essential that you take anti-rejection medication known as immunosuppressant drugs. Without these drugs almost all transplant kidneys will fail because of rejection but this medication reduces your immunity to infection. In the early months we will give you additional medication to reduce your vulnerability to infection. Please ask any friends and family not to visit you at the time of your transplant if they are unwell, or are in close contact with someone who is unwell.

You may find that some of the medicines initially cause some unpleasant side-effects, this often settles down, but tell the staff at your clinic visits if it is a problem.

We will reduce the dose of your immunosuppressant medicines with time but you will need to take these drugs for life or as long as the kidney is functioning. If you were to stop taking the immunosuppressive medication there is a high likelihood of transplant failure.

The usual anti rejection medicines used are:

- Tacrolimus
- Prednisolone
- Mycophenolate mofetil or Azathioprine

At the time of your transplant operation we will give you a booklet called PHIL (Personal Health Information Log) in which details of the following are recorded

- Medication and doses
- Clinic appointments
- Skin Cancer Awareness
- Electronic Renal Patient View (a website where you can view your own laboratory test results)
- Other important information

Please make use of the book after your transplant and bring it to clinic appointments.

Going Home

How long you stay in hospital will depend on how quickly you recover, the usual length of stay is 5 – 14 days. It is important that you become mobile as soon as possible after the transplant in order to reduce the risk of blood clots in the veins in your legs. The nursing staff will usually get you out of bed the day after the transplant, even if it is just to sit in a chair. Day by day you will start to feel stronger and become more comfortable moving around. As you start to feel better we will encourage you to start taking care of yourself and to learn about your medication in preparation for going home.

Once you have gone home we will continue to monitor you very closely in the Transplant clinic, initially at the Queen Elizabeth University Hospital. The frequency of your visits will reduce with time but will also depend on how well you continue to recover. Most patients will need to attend twice a week after discharge, but this will reduce to monthly by about a year. After a year, most patients will transfer to a clinic closer to home.

Additional Information

Diet

One of the benefits of a successful transplant is that you can start to enjoy a normal diet again. You will also be free from any fluid restrictions. In the longer term a healthy diet is important and we encourage you to eat foods high in fibre and low in saturated fats, salt and sugar.

Going back to work

How long you take off will depend on the type of job you do and how quickly you recover. If you have a desk job you should be able to return to work within about 6 - 8 weeks, if you have a physical job you may need 3 months off.

Exercise

You should avoid strenuous exercise for 3 months after the transplant. In general it is important for you to keep fit and healthy and we would encourage you to have an active lifestyle. This could merely be walking rather than fitness activities.

You should avoid contact sports such as rugby or martial arts as there is a risk of injury to the transplanted kidney.

Pregnancy

Women of childbearing age may have their fertility restored by a transplant if it works. Similarly, men may also have an increase in fertility. We would advise the use of contraception after transplantation. We do not advise that women become pregnant in the first year after a transplant but many women do have successful pregnancies after that. If you wish to become pregnant it is best to discuss this with your Transplant Doctor sooner rather than later.

Women should not become pregnant while taking a drug called mycophenolate mofetil, which is used to prevent rejection, but there are other alternatives available.

We would advise men not to father a child while taking this drug without discussing it first with their doctor.

British Transplant Games

The British Transplant Games takes place annually in a different UK venue over 4 days in the summer. The aim of the event is to encourage transplant recipients to regain fitness and to promote friendship, whilst also increasing awareness of organ donation. Participants can choose to compete in a variety of events including athletics, swimming, cycling, golf, badminton, tennis, bowling, snooker and darts. Some people compete to win medals, others go along to participate at their own level, enjoy the fun and meet others. For further information please ask the Transplant Coordinator or visit the following websites:

🌐 **http://www.britishtransplantgames.co.uk**

🌐 **http://www.transplantsport.org.uk**

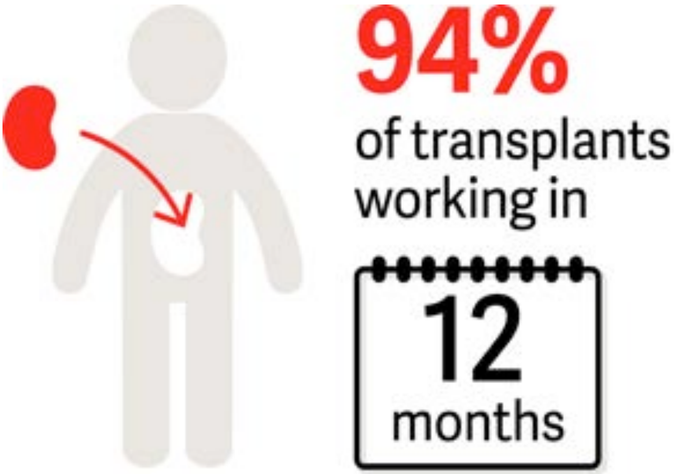
Writing to your Donor Family

Deciding whether to write to your donor's family is a personal choice. It may help to know that usually donor family members express appreciation for the letters or cards they receive from transplant recipients. Nevertheless, some recipients will choose to write to their donor family and others will not. You may not want to write at this time, but you may decide to later. Whatever your decision, there is no time limit for sending a letter or a card. If you do decide to write a letter the Transplant Coordinator can provide you with guidance on the content. Some donor family members may send a letter or card to you in response to your letter. Others may choose not to write to you at this time, this is their personal choice.

Renal Recipient Transplant Coordinator
Office/Administration Block
Floor 1, Zone 3
Queen Elizabeth University Hospital
Glasgow, G51 4TF

Outcomes

How successful is a kidney transplant?



Outcomes after transplantation are monitored closely and a report is published every year. Our outcomes are compared with all of the other transplant centres in the UK to make sure standards are kept high.

- At present around 94 out of every 100 people who have a kidney transplant for the first time will be alive and still not needing dialysis 1 year after the transplant.
- Around 85 of every 100 people who have a kidney transplant for the first time will be alive and still not needing dialysis 5 years after the transplant.
- Approximately 92 of every 100 people who have a kidney transplant for the first time will still be alive 5 years after the transplant.

Useful websites

- http://www.kidney.org.uk
- http://www.nhs.uk/conditions/Kidney-transplant
- http://www.odt.nhs.uk
- http://www.kidneypatientguide.org.uk
- http://www.patientview.org

Notes