

Renal and transplant

Waiting for a kidney

Information for patients, relatives and carers

Introduction

This leaflet will tell you about:

- what happens now that you're registered on the national kidney waiting list
- what you should do while you're waiting for a transplant
- what to do when the transplant team calls you

Please ask your care team if you have any questions or concerns.

What happens now?

We have given you this leaflet because you consented to your name and details being entered onto the national kidney waiting list database held by the NHS Blood and Transplant UK. You can be registered onto the national transplant waiting list either as "active" or "suspended".

Active means that you are actively waiting for a kidney. It means you're ready to go to the hospital at any time day or night, if you are called to receive a kidney transplant.

Suspended means that you are temporarily on hold and will not be offered a kidney transplant during this time. You will be suspended from the waiting list if:

- your kidney function is higher than 15 ml/min and your clinical team thinks that a transplant at this stage would be too early to be beneficial for you (the national guidelines recommend transplantation approximately six months before you will need dialysis)
- you have become unwell and your clinical team concludes that you need to recover before being activated on the national waiting list again
- you need further tests or investigations
- you go on holiday abroad and will not be able to return to hospital in less than three hours if you are called in for a transplant
- you decide you are not ready for a transplant

How are kidneys offered?

Every donated kidney is a precious gift, and it is important that the organ goes to a patient who will benefit from it. Once a potential deceased (dead) donor is identified, blood tests are taken to check the donor's tissue type, blood group, and to check the function of their organs. Other

blood tests are taken to see whether the donor has any infections. This information is then passed to NHS Blood and Transplant and a computer programme checks the national transplant waiting list for suitable patients.

The system does not work as a queue. All transplant teams in the UK must follow the national criteria for selecting patients suitable for a kidney transplant. Patients are prioritised for a kidney transplant from a deceased donor based on:

- the compatibility of their blood group with the donor
- the similarity of their tissue type with the donor
- the similarity of their age with the donor
- how long they have been on the transplant waiting list or on dialysis
- how far apart their transplant hospital is from the donor's hospital
- how difficult it would be for them to get another organ offer

What should I do while I am waiting for a transplant?

In order to prepare for your transplant, it's important to stay as healthy as possible, both mentally and physically. It is important that you:

- keep active, eat well and lose weight if you need to – this will help with increasing your energy levels and managing stress
- stay positive – waiting for a transplant is an emotional time and depression and anxiety are common
- our renal team can offer help by referring you to renal counsellors stop smoking if you are a smoker – smoking affects your lungs, heart and blood vessels and this will have a negative impact on your transplant operation and recovery
- take your medicines as prescribed
- attend your clinic appointments regularly
- do not miss any dialysis session, if you are on dialysis
- have regular dental check-ups, but talk to your renal team before you have any invasive treatment
- have regular blood tests for antibodies (every three months) – we need to keep our information about your antibodies up-to-date to be able to offer you a compatible kidney. Your antibodies will be affected if you have a blood transfusion, are pregnant, have had a previous transplant or a virus
- ensure we have your correct contact details – if we cannot get in touch with you, we will have to offer the kidney to someone else consider family planning – you cannot receive a transplant if you are pregnant. Please speak to your kidney team if you need advice on contraception or fertility when waiting for a kidney transplant

It is also very important that you consider and make plans for the time when you will be called in for a transplant, including:

- how will you get to the hospital (do not drive unless someone can collect your car from the hospital)
- who will look after your dependents or pets
- who should be contacted about what is happening (family members/workplace)

What happens when I am called?

When a suitable kidney is offered to you, your transplant team will call to discuss this with you. This could take place at any time of the day or night. The team may give you some medical information about your donor and discuss potential risks and benefits. If you are happy to proceed with the possible transplant, they will ask you to come to the hospital. Once you are called in, please do not eat or drink anything.

What should I bring with me?

- all the medicines you are taking
- night clothes, dressing gown and slippers
- a wash bag and toiletries
- loose fitting clothing and underwear to wear when you go home
- something to read or music
- a small amount of money

Please do not bring any valuables as we cannot be held responsible for any losses.

Where should I go?

The transplant team will tell you where you need to go when they call you. If you arrive between 09:00 and 17:00, you will be asked to go to the Renal Assessment Unit at Hammersmith Hospital located on the ground floor, F Block. If you arrive after 17:00 you will be directed to Peter's Ward at Hammersmith Hospital located on the 1st floor, F block.

What happens when I get there?

- you will have some initial tests to make sure you do not have COVID or any active infection
- you will have blood tests, including a test called a "cross match" (please read below "What is a cross match test?")
- you may need to have a chest x-ray and an ECG (heart tracing)
- once the initial test results are back and satisfactory, you will be moved to the transplant ward
- you will be asked to have a shower and wear a hospital gown

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- the ward doctor, anaesthetist and surgeon will assess your fitness to undergo surgery
 - the surgeon will discuss with you the type of operation you will undergo, potential risks and will ask you to sign a consent form
 - if you normally are on dialysis, you may need a session before going to the operating theatre
 - we will give you immune-suppressive medication before you go to the operating theatre to prevent the body rejecting the new organ

In rare cases, the team at Hammersmith Hospital cannot do the transplant surgery because there is not enough space. If this happens, we'll need to transfer you to another London hospital where another renal team can do your transplant operation. However, your immediate follow-up appointments after your transplant will be at Hammersmith Hospital.

What is a cross-match test?

This extremely important test determines if you can receive the transplant or not. A cross-match test is where your blood is mixed with a sample of the donor's blood or tissue. This tests for antibodies in your blood that would attack the donor's kidney and reject it. If there is no reaction, known as a **negative cross match**, the kidney is compatible with you and you can have the transplant.

A **positive cross match** means that you have a lot of antibodies in your blood at the time of the transplant. Therefore, it is very likely that your body would reject the kidney within minutes of the transplant. Sadly, a positive crossmatch test means that you cannot have the transplant cannot go ahead and you will have to go back on the waiting list.

Will I be the only one called?

Most of the time, you will be the only patient called in to the hospital to receive the transplant. However, sometimes we need to call more than one patient to find out who is the best match.

What would stop me from receiving the transplant?

Sometimes it is not possible to go ahead with the transplant. This could be because:

- your tests show that you have a new health problem or you are unwell at the time when you are called in
- we find out new health information about the deceased donor (cancer, serious infection)
- a positive cross match, meaning your body will very likely reject the donated kidney
- the donated kidney is not usable – upon arrival the kidney is inspected by the surgeons if it is safe to use. Damage to the kidney during removal, hardening of its arteries or blood clots within the small blood vessels of the kidney are some of the problems that could mean we cannot use the kidney

Where can I get more information?

You can find the information in this leaflet in **other languages** here:

- www.imperial.nhs.uk/kidneyandpancreastransplantation (click 'Patient information')

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- www.kidneycareuk.org/kidney-disease-information/treatments/kidney-transplantation/patient-info-receiving-a-kidney/ (click 'Accessibility and language support' for other languages and text to speech)

Other websites

- www.westlondonkpa.org/
- www.kidneycareuk.org/get-support/free-resources/patient-information-booklets/kidney-transplantation-easy-read/
- www.nhsbt.nhs.uk/organ-transplantation/kidney/receiving-a-kidney/
- www.kidneypatientguide.org.uk/
- www.kidney.org.uk/
- www.sdm.rightcare.nhs.uk/
- www.kidneycareuk.org/
- www.imperial.nhs.uk/patients-and-visitors/patient-information/my-health-records

Useful contact numbers

- Renal Assessment Unit (RAU) 0203 313 6603/6604
- Peter's Ward 0203 313 6661
- Handfield Jones ward - 020 3313 6676 / 020 3313 6674
- Hammersmith Transplant Outpatient Clinic 0203 313 8333
- Renal counsellors 0203 313 6658/6620
- Social support worker 0203 313 6619
- Renal dieticians – Hammersmith Hospital 0203 313 3048
- Patient Advice and Liaison Service (PALS) 0203 313 3322/0088
- Pharmacy Medicines Helpline 0203 313 2627

How do I give feedback about my visit?

We want to hear your **suggestions** or **comments**. Your feedback helps us provide the best service. You can always speak to a member of staff.

You can also contact the **patient advice and liaison service (PALS)** on **020 3312 7777** (10.00 to 16.00, Monday to Friday excluding bank holidays) or email at imperial.pals@nhs.net. The PALS team will listen to your concerns, suggestions or questions and they can help solve problems.

You can make a complaint by ringing **020 3312 1337 / 1349** or emailing tr.Complaints@nhs.net. The address is Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

Other ways to read this leaflet

Please email us at imperial.communications@nhs.net if you need this leaflet in a different format. This could be large print, Easy read, as a sound recording, in Braille or in a different language. You can also click the links on page 5 for this leaflet in other languages.

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