

Waiting for a kidney

Information for patients, relatives and carers

Introduction

This leaflet provides answers to some questions you or those who care for you may have. It is not intended to replace the consultation between you and your healthcare team but aims to help you understand more about what you have already discussed together, now that you are registered on the national kidney waiting list.

What happens now?

You have been given 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 and ready to attend 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)

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- 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 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 allocation system does not operate 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. Your 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 seek advice from the renal team before any invasive treatment
- have regular blood tests for antibodies (every three months) – we need to keep our information about your antibodies up-to-date in order 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/work place)

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, you will be asked 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 are discharged home
- reading materials 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 attend 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 exclude the presence of 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
- 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 being taken to the operating theatre
- you will be given immune-suppressive medication before you go to the operating theatre to prevent the body rejecting the new organ
- in rare cases where the team at Hammersmith Hospital cannot perform the transplant surgery due to lack of capacity in the operating theatres, you may be transferred to another London hospital where another renal team can perform your transplant

operation. However, your immediate follow up appointments after your transplant will take place 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 the transplant can go ahead.

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 the transplant cannot go ahead at this time 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, on some occasions, it is necessary 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
- new health information is discovered 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 make a kidney not usable

Where can I get more information?

Websites:

- <https://www.imperial.nhs.uk/our-services/kidney-and-transplant/kidney-and-pancreas-transplantation>
- <https://www.westlondonkpa.org/>
- <https://www.nhsbt.nhs.uk/organ-transplantation/kidney/receiving-a-kidney/>
- <https://www.nhsbt.nhs.uk/organ-transplantation/kidney/receiving-a-kidney/deceased-donor-kidney-transplant/>
- <https://www.nhsbt.nhs.uk/organ-transplantation/kidney/benefits-and-risks-of-a-kidney-transplant/>
- <https://www.kidneypatientguide.org.uk/>
- <https://www.kidney.org.uk/>
- <http://sdm.rightcare.nhs.uk/>

Useful contact numbers:

- Renal Assessment Unit (RAU) 0203 313 6603/6604
- Peter's Ward 0203 313 6661
- De Wardener Ward 0203 313 6690/6693
- 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 make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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