

Information for patients on the kidney transplant waiting list

This guide is for patients who have been cleared to go on the kidney transplant waiting list. It will give you details about what you need to do while you are waiting for your transplant and what to expect when you are called. If you have any further questions, please ask your consultant or renal nurse.

Really important

Make sure that all of your contact numbers are current and correct at all times. If you are called for transplant, they will do their best to contact you but they will not leave a message on an answerphone. Make sure you always have your mobile phone with you day and night, turned on, charged, and ensure you can hear the phone when you are in bed. You never know when you might get the call.

Once the Oxford Transplant Centre have confirmed by telephone that you are active on the Transplant Waiting List, a 10ml clotted blood sample will need to be sent to Oxford every month. This will be used if a potentially matching kidney is found. The Oxford team will advise you of the best way to do this; you will need a separate form to your pre-clinic blood test. If you are on haemodialysis, this blood sample will be done automatically by the nurses with your monthly bloods.

What if I move or change my phone number?

It is very important that we have your up-to-date contact details, particularly phone numbers. A transplant call can come at any time and if they cannot get hold of you, they will have to offer the kidney to someone else. **Let the Oxford Transplant Centre Team know straight away if you change your phone number or move home.**

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

- Have a plan about how you will get to Oxford when you get the call – remember it could be day or night. If you do not have someone who can take you, contact a local taxi firm and enquire about costs. Set aside money for a taxi so you know you can always get there.
- Carry on as normal but try to stay as healthy as you can. Regular exercises will help maintain your fitness and if you smoke, **you must stop**.
- Your renal doctor will review your fitness for transplant on a regular basis.
- Let the Oxford Transplant Centre Team know if you are ill or if you go away on holiday so they can suspend you from the waiting list. Let them know when you are better or when you return from holiday then we can re-activate you on the list.

- If you have dialysis abroad while on holiday, you may need a longer period off the transplant waiting list while we check that you have not caught any infections from the holiday dialysis unit.
- Continue with your required dialysis and take all prescribed medication.

How long will I wait for a kidney?

The wait can be anything from a few weeks to many years. NHS Blood and Transplant (NHSBT) allocates kidneys by matching blood group and tissue type. This system is in place to ensure the best match between you and the donor kidney. You do not have to get to the top of a list; it is who the best match is. If your tissue type is rare or you are sensitised to certain tissue types (from blood transfusions, previous transplants or pregnancy) you may have to wait longer than average for a match.

What should I do when I get the call?

- The Oxford Transplant Nurse will call and ask you to come to the Oxford Transplant Centre straight away. Please let the nurse know if you are unwell or have been in hospital recently. You will need to be in the best possible health for your transplant operation.
- Do not delay getting to the hospital, as this will increase the time we have to store the kidney and may impact on the success of the transplant.
- **Do not have anything to eat or drink** following the call, as you will need to have an empty stomach for the operation to proceed.
- You may be called in as a 'back up' recipient. The person who calls you in will tell you if this is the case. This is done to avoid any delay in finding another possible candidate for the kidney if the first person they contacted ('first call') is found not fit enough for transplantation, or has had a positive cross-match to the donated kidney (i.e. an antibody reaction). It is possible that you may be sent home, whether you were 'first call' or 'back up' when you were called in, so please be prepared for this and the disappointment it may cause.

What happens when I get to the Oxford Transplant Centre?

Go straight to the ward where you will be assessed to make sure you are fit enough to have surgery. You will have a blood test to make sure you are a match with the kidney. You will have a chest X-ray and ECG (tracing of your heart). An anaesthetist will come to see you to make sure you are fit for the anaesthetic for the operation. The surgeon will come to see you and explain more of the risks and benefits of the operation after which you will be asked to sign a consent form. You may need a dialysis session before the operation.

Your post-transplant care:

You will be looked after by the Transplant Team in Oxford for the first three months after your transplant. After three months, your care will then return to the Berkshire Renal Unit Team. You will be reviewed in one of our transplant clinics. This could be in Bracknell, Thatcham or Henley. The transplant nurses will be your point of contact and oversee your medication supply, blood results and help with any problems or question you may have.

Useful contacts

www.royalberkshire.nhs.uk

www.ouh.nhs.uk

www.kidney.org.uk

www.nhsbt.nhs.uk

Contacting us

Transplant Nurses: 0118 322 8332

Or telephone 0118 322 5111 and ask to connect to short code 40593, Mon-Fri 9am-5pm

Or email us at: rbft.renaltransplant@nhs.net

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Renal Team, May 2023.

Next review due: May 2025.