

Patient Information Leaflet

Assessment for transplantation and your time on the waiting list

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The Transplant Assessment Clinics are usually run in the afternoon of the second and fourth Wednesday of each month, at Derriford. There is also a clinic at the Royal Devon and Exeter Hospital on the last Thursday afternoon of each month. Patients are seen by a transplant surgeon and, in some cases, also separately by a nephrologist from Derriford Hospital. A Seminar is held on the same day prior to the Transplant Assessment Clinic. The Seminars are run by the Transplant Nurses, and in Plymouth they take place on Mayflower Ward, Level 3 (kidney ward). Patients attending the Transplant Assessment Clinic are encouraged to attend the seminar beforehand. It is an opportunity to find out more about the advantages and disadvantages of transplantation and ask any questions.

The Transplant Assessment Clinic follows on from the Transplant Patient Seminar and patients are seen throughout the afternoon. During the consultation the doctors will review the patient's medical history. They will usually wish to examine their abdomen, assess their pulses to check their blood flow through to their legs, and listen to the heart and lungs.

The doctors will also review the results of any relevant medical investigations. These tests often include cardiac (heart) tests such as ECGs (electrocardiograms), echocardiograms (an ultrasound scan of the heart), cardiac MRIs or myocardial perfusion scans (stress test). This is to try to ensure that patients are fit enough for the transplantation surgery. For a similar reason, patients may be asked to do a Cardiopulmonary Exercise Test (CPET) at some point before, or sometimes after, the Transplant Assessment Clinic. This is a fitness assessment on an exercise bike.

Some patients will also need a doppler ultrasound test to see how good the blood flow through the arteries and veins supplying their legs is. This is usually required if the patient is diabetic or if their pulses are hard to feel.

The doctors in the Transplant Assessment Clinic will discuss the patient's suitability for transplantation with them directly. They will also consider any particular concerns that may apply to the individual (for example, the likelihood of surgical problems or recurrence of the original kidney problem). The doctors will also discuss the possibility of living kidney donation with the patient and consider the different types of deceased donor kidney transplantation. If you have a potential living kidney donor then you are more than welcome to discuss this with the living donor coordinators so that they are able to get in touch with them.

Sometimes the doctors in the Transplant Assessment Clinic may consider that further tests are required to assess the patient's suitability for transplantation. They may ask the patient's local kidney team to organise these.

Blood tests are also taken during the clinic appointment. The blood tests required usually include "tissue typing tests" (tests to ensure that organs can be correctly matched to patient in the future). Tests to screen for infections (including HIV, hepatitis, EBV and CMV) are also usually performed in view of the need to dampen down a patient's immune systems to prevent transplant rejection.

It is not always possible for the doctor in the Transplant Assessment Clinic to say for certain, during your consultation, whether you are definitely suitable for transplantation. This is because they will want to see the results of blood tests and of any additional tests they recommend. You may also want to talk to your own kidney doctor. For this reason the patient's case is then discussed at the weekly Transplant Multidisciplinary Meeting where the final decision is made. This usually happens the week after the Transplant Assessment Clinic appointment but can take longer. The outcome of the decision is communicated to the patient by the Transplant Nursing Team.

If the patient is accepted for transplantation then they will either go on to have a kidney transplant from a living donor or they will be activated onto the deceased donor Transplant Waiting List.

The Transplant Waiting List

Patients active on the Transplant Waiting List are those who have been assessed in the Transplant Assessment Clinic and who have been considered to be fit enough to receive a transplant. Patients can be on the deceased donor transplant waiting list whilst any potential live donors undergo testing.

Allocation of kidneys to patients on the Transplant Waiting List

Unfortunately the number of organs available for transplantation is lower than the number of people on the Transplant Waiting List. This is a national problem.

The organs that do become available are all very different. This is because all donors are different, the donors may be young or old, may have different medical problems, and will of course have different blood groups and genetics. The patients on the Transplant Waiting List are all also, of course, very different and their individual needs vary too. Therefore not every kidney that becomes available is suitable for every patient on the list. For example, for the more elderly patients and for those that are experiencing problems on dialysis, the focus is often on getting an early transplant, whereas for younger patients who are managing okay on dialysis the focus is usually on getting a transplant that will work well for a long time and it may be appropriate to wait longer for this.

The allocation of kidneys offered for donation is coordinated by a national organisation called NHS Blood and Transplant (NHSBT). This organisation keeps a secure database of all the patients in the UK who are waiting for organ transplants. This information includes their names, addresses and, most importantly, their tissue types. When a kidney becomes available an algorithm is used to identify potential patients who could benefit from it. The algorithm takes into account the blood group of the donor and the age and genetic match with possible recipient. NHSBT will then allocate the kidney to the identified patient.

This information is given to the Transplant Centre, and the on call kidney doctor and surgeon at Derriford Hospital, to decide if this kidney is likely to be suitable for the patient to whom it has been allocated. The team will also call the patient's local kidney team if they need further information to help make this decision.

Once the kidney has been retrieved from the donor the patient to whom it has been allocated will be phoned by the Transplant Co-ordinators and asked to come to Derriford Hospital. More information about this is provided below but it is at this stage that the information about the kidney offer is shared with the patient (who may choose to proceed to have the transplant or not).

The average amount of time that a patient waits on the deceased donor Transplant Waiting List varies between the different UK transplant centres. Over recent years Plymouth has had one of the shortest average waiting times. For some patients the wait, for various reasons, might be much longer than the average.

Patients on the Transplant Waiting List are required to have a blood test every six weeks to check the antibodies in their blood. This is to ensure that NHSBT have up-to-date information when making their decisions about allocating donor organs.

Advice for patients on the Transplant Waiting List

Kidneys from deceased donors are allocated by a central organisation NHS Blood and Transplantation (NHS-BT). The offer can come through at any time of the day or night. Patients on the Transplant Waiting List must therefore be contactable at all times and must keep the transplant centre updated with changes in their contact details.

Patients on the Transplant Waiting List are encouraged to keep a bag packed ready for a hospital stay. It is sensible they bring any medications that they are taking, any dialysis fluids they may need for peritoneal dialysis, and pyjamas, a wash bag, slippers and a small amount of money.

They are also advised to discuss the likelihood of being called in at short notice with their relatives and carers and to have arrangements in place for dependents and pets. Similarly, it is sensible for patients on the Transplant Waiting List to discuss their situation with their employers as they will be called up with minimal notice and will be off work for a few weeks (at least). It is also important for them to think about how they will get to Derriford Hospital (bearing in mind it may be the middle of the night).

Consenting to transplantation

Transplantation offers the opportunity to avoid dialysis and live a longer life. However there are some risks involved. These are mainly due to the surgery and the drugs that are required to prevent rejection. The risks may vary from patient to patient. It is important that patients understand these risks.

Information is provided to patients in the clinics (at both the transplant centre and their local kidney clinics), in the Transplant Assessment Clinic, and at the Patient Seminars. Written information is also provided.

The surgeon will run through the risks and benefits again on the day of the transplant surgery and ask the patient to complete a consent form.

When the day arrives

- Patients will get a telephone call from the transplant coordinator based at University Hospitals to say that they have a potential kidney. If the allocated kidney is for a patient in either Exeter or Cornwall the transplant coordinator will also talk to the nephrologist on call at that specific centre to make sure they are also happy with the offer.
- The transplant coordinator will ask the patient to make their way to Mayflower Ward as soon as possible. The coordinator on call will guide the patient through the process and answer any questions they might have. Once they arrive on Mayflower ward they will be introduced to the nurse who will be looking after the potential recipient.
- A laboratory test (cross-match) is needed to check that the donor kidney is compatible with the patient's antibodies. It takes roughly three to four hours for a complete report. However, as mentioned earlier, if enough information is already available then the patient can undergo a virtual

cross match, eliminating the waiting time prior to the operation. If the cross match shows that the organ is not suitable, it may be necessary to cancel the operation. Usually the patient would still be eligible for the next kidney offer.

- A transplant surgeon will go through the procedure of the operation and explain once more about what to expect and the risks of complications. When the patient fully understands, they will sign a consent form for the operation. Patients are encouraged to ask any questions they might have at this point.
- The patient will be seen by an anaesthetist who will examine them and tell them about having a general anaesthetic.
- When the theatres are ready for the patient, the porters will come and collect them and take them to theatre. A nurse will come with the patient as well. Patients often feel nervous, that's normal.
- In the theatre department, the patient will go first to the reception ward where a nurse will go through the reception procedure and ask a few questions.
- The patient will then go to the anaesthetic room, where the anaesthetist and his/her assistants will explain what they are going to do. They will put a small needle into the back of the patients hand and the anaesthetist will inject a drug that sends them to sleep.

How will I get the best kidney for me?

Finding the right kidney is rather like finding the right partner in life; the more people you have to choose from, the more likely you are to find someone with the right match. This is where NHSBT comes in. They act like a matching agency and keep a secure database of all people in the UK who are waiting for organ transplants. This includes names, addresses and, most importantly, their tissue types. Whenever a kidney donor becomes available anywhere in the country, they are informed and their staff, who works around the clock, search the database for the person whose tissue type has the closest match to the donor. As soon as you have decided to go for a kidney transplant, your name and details will be added to this database.

Then begins the wait. It could be weeks; it could be years; but always remember, the system is designed to find you the best kidney. The average waiting time in the UK is around three years at the moment. In Plymouth our average waiting time is 18 months.

While you are on the waiting list, you will also have to attend for regular blood tests to check your antibodies, (LCA) as they can change after an infection or blood transfusion. It is important that your file in the database is kept up to date to offer you the right kidney.

Your notes:



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Contact: Administrator
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