

Living kidney donation

This information sheet is aimed at providing you with an overview of living kidney donation. The information given here will be discussed in greater detail when you have made a decision to commence your 'workup'.

The Lister Hospital is not a kidney transplant centre but has a dedicated team of transplant co-ordinators. Your work up will take place over two sites, the initial phase of testing will be carried out at the Lister Hospital in Stevenage, and the second phase will be carried out at the designated transplant centre.

The renal transplant clinical nurse specialists

The renal transplant co-ordinators are a team of specialist nurses who are responsible for 'working up' potential live donors (and their recipients) for transplantation, they are not the transplant team. The transplant team is the group of doctors, surgeons and nurses that you will be referred to for the final part of your workup at the centre where the operation will take place.

Please be aware that we are bound by confidentiality and must not at any time disclose any information regarding you or the potential recipient. We will not discuss appointment dates or test results with your potential recipient. If you would like them to know any information, then it is up to you to tell them.

Due to the nature of the choice you are making in donating a kidney, **we cannot be seen to pressurise you and therefore, it is up to you to keep in contact with us.** Our contact details are on the last page of this information sheet. If we are unavailable, please leave a message and we will contact you as soon as possible.

The process of living donation

You will be assessed by the renal transplant co-ordinators. It is essential you give full details of any current or past medical conditions or illnesses. In order to decide whether you are a suitable kidney donor it will be necessary to carry out a number of tests, this process is known as the 'workup'.

You, as the donor, are screened very carefully to see that you are perfectly healthy and have two functioning kidneys. We must be completely satisfied that you are in good health, that you really want to give a kidney and are not reacting to pressures, wherever they may come from.

We will need to contact your General Practitioner (GP) to obtain a copy of your medical history. To allow us to do this we will require your written consent, this forms part of the initial Donor Health Questionnaire. We may need to share this information with other healthcare professionals for the purpose of living donation.

Detailed information regarding the risks, benefits and likely outcomes of donation for both donor and recipient will be discussed with you in clinic. You will be asked to undertake a series of tests which are explained in more detail later in this information sheet.

When we have received your test results, you will need to see a nephrologist (kidney doctor) who will assess your suitability for donation. If the nephrologist is satisfied that you can proceed as a living kidney donor, they will refer you to the relevant transplant centre for the final part of your workup. Please be aware that there is only one live donor clinic each month and we will do our best to ensure you are seen promptly.

It is important to be aware that if any of the results from your tests are difficult to interpret, we will repeat them. We may also request other investigations or refer you to another specialist for further testing.

Workup tests at the Lister Hospital

Radiology tests:

- Chest X-ray
- Ultrasound scan of your kidneys, ureter and bladder

Urine tests:

- Midstream sample for urinalysis and culture
- Albumin/creatinine ratio (ACR)

Heart tests:

- Electrocardiogram (ECG) - electrodes measure the rate and rhythm of your heart
- Echocardiogram - an ultrasound scan of your heart.
- Other heart tests may also be required.

Blood tests:

You will be required to have blood tests to ensure that you are fit enough to donate a kidney. We will screen you for the presence of certain viruses, these are:

- Human immunodeficiency virus (HIV)
- Hepatitis B
- Hepatitis C
- Cytomegalo virus (CMV) which has symptoms similar to a bad cold
- Epstein Barr virus (EBV) also known as glandular fever
- Varicella zoster virus (VZV) which is chicken pox
- Toxoplasmosis which is a parasite usually picked up from cats
- Syphilis (a sexually transmitted infection)

These blood tests will be discussed further with you in clinic by the renal transplant co-ordinators and you will be required to sign a separate consent form to allow us to test you for these viruses.

Blood tests to match you with your recipient

Blood group

There are four main blood groups: O; A; B and AB. You do not have to be the same blood group but the recipient will need to be tested to make sure they will not react to your blood.

Tissue type

This test determines your individual make up of cells. Before transplantation, the tissue type of the donor and recipient is matched to minimise the chance of rejection. This information is held by the

tissue typing department at the transplant centre. In some cases, it can take up to 6 weeks to receive the results of this test

Crossmatch

Your blood is mixed with the recipient's blood to see if there is any reaction. If the test is negative, the transplant can safely proceed. A positive crossmatch usually means that you are unable to donate directly to your recipient. However, you may be eligible for the paired and pooled programme which is explained later in this information sheet.

This test is also repeated in the 2 weeks prior to the operation date. This is done to ensure that the recipient has not developed any new antibodies.

If you wish to know the results of your tests prior to your appointment with the nephrologist, then please contact the renal transplant co-ordinators. **We do not normally contact you with the results.**

Other assessments

It is essential for you to be assessed by a **renal counsellor**. This is to ensure that you are psychologically aware of the issues and implications surrounding living donation.

There may be medical reasons that indicate that kidney donation is not possible. This does not imply any failing on your part and this will be discussed with you fully.

Transfer to centre

Following your consultation with the nephrologist, you will then be referred to the relevant transplant centre. The transplant centre will then undertake the final part of your workup. This involves:

- Final tests include GFR (glomerular filtration rate), MRA (magnetic resonance angiogram) or CT (computed tomography). These tests look at your kidneys and their function in greater detail and will be explained to you by the renal transplant co-ordinators.
- The Human Tissue Authority (HTA) carefully monitors living donor transplants. The Human Tissue Act 2004 requires the HTA to approve all transplants from living donors, whether they are relatives or not. The HTA works closely with the Organ Donation Directorate of NHS Blood and Transplant to do this. You may be asked to provide proof of relationship.
- You will need to see a surgeon for assessment and an operation date is then planned with you. Although we try to accommodate individual circumstances, it is important to realise that no guarantees can be made about the length of time the assessment process will take, or to guarantee a particular date for the operation.

At any stage, right up to the time of operation, you can withdraw from the process for any reason, and your reasons for withdrawal will always remain confidential.

The operation

The term used for the removal of a kidney is **nephrectomy**. The transplant centres linked with the Lister Hospital use either a laparoscopic (keyhole) nephrectomy or a mini open nephrectomy. These will be explained in more detail by the renal transplant co-ordinators.

As a donor you are in excellent health, however, any surgery has some risk and the surgical risks associated with this operation are:

- Pain will be experienced, and this will be managed by painkilling medication after surgery.
- Bleeding following the surgery.
- Complications are rare, however you may need to go back into surgery. Re-operation occurs in less than 2% of donations.
- Death is extremely rare. The rate of mortality is estimated to be between 1 in 1600 and 1 in 2400.

After the operation

- It is expected that you will remain in hospital for 3-5 days.
- It is recommended that you do not return to work for at least four weeks post-donation, although this will be dependent on the type of job you have.
- There is no guarantee that the recipient's transplant will be successful.

Follow-up

You will be followed up post-operatively by the transplant centre. Following discharge, you will be asked to attend a follow-up appointment 1 year after donation at the transplant centre. After this, you will be required to attend either the Lister Hospital or your GP for follow-ups at years 2, 5, 10 and then every 5 years thereafter. **You are strongly advised to attend these appointments.**

Reimbursement

You may be entitled to a reimbursement of loss of earnings and other costs incurred as a result of living donation once the operation has gone ahead. Please ensure you advise the transplant centre at the initial meeting that you are considering this claim as they will need to organise the necessary documentation before the operation goes ahead.

Driving

Your doctor will decide when you are medically able to drive post-donation (usually anything from 2 weeks after surgery). You do not need to notify the DVLA of your operation unless you drive a bus or lorry. Further information can be obtained from the renal transplant co-ordinators.

Incompatibility

Sometimes a live donor and recipient will not be compatible, either through blood group or tissue typing, and therefore direct donation may not be possible. In some cases it is possible to remove the antibodies which are causing the incompatibility in the recipient. However, there is also the option of the National Living Donor Kidney Sharing Scheme.

National Living Donor Kidney Sharing Scheme (NLDKSS)

Paired Programme

When a donor agrees to give one of their healthy kidneys to a known recipient, the donor and recipient will be assessed to find out if they are suitable for an exchange. In some cases, the donor and recipient blood groups or tissue types are mismatched or incompatible. If so, as a pair, they can be put forward for 'paired donation' where they are matched up with another donor and recipient in the same situation.

Pooled Programme

- Sometimes more than two donors and two recipients will be involved in a swap. This is called 'pooled donation'. Each recipient gains from a transplant that they would not otherwise have had. The donors might not have given their kidney to the person they know, but that person will have received a kidney from one of the other pooled donors.
- With pooled and paired donation, all the donor and recipient operations are planned to happen on the same day so the organs can be exchanged at the same time.
- Complete confidentiality is preserved, so none of the recipients will know whose kidney they have, and none of the donors know who has received their healthy kidney.
- All transplant centres use national guidelines to workup potential donors, so please do not be concerned regarding the quality of the donor kidney.
- More than one donor can enter the pool for a recipient at any one time.
- The length of time it takes to find a match depends on the number of donor and recipient pairs on the national register. It is important to understand that it is not possible to say how long you will wait before a suitable match is found.

If you require further information about the paired or pooled programme, please speak with the renal transplant co-ordinators.

Further information

- **NHS Blood and Transplant** - www.nhsbt.nhs.uk
- **NHS Organ Donation - Living Kidney Donation** - www.organdonation.nhs.uk
- **National Kidney Federation** - www.kidney.org.uk
- **Human Tissue Authority (HTA)** - www.hta.gov.uk
- **Kidney Research UK** - www.kidneyresearchuk.org
- **International Association of Living Organ Donors Inc** - www.livingdonorsonline.org

Booklets:

- Gift of Life: living kidney donation - Novartis, Astellas and NHSBT
- Could I be a Living Donor? – NHS Blood and Transplant

A member of staff will give you more information about obtaining these booklets.

Acknowledgement

This information leaflet has been written with the help and advice from the transplant team at Addenbrookes Hospital, as well as members of the Lister Hospital Renal Team, living donors, renal patients and their families.

Useful contact details

East and North Hertfordshire NHS Trust:

- Website www.enherts-tr.nhs.uk
- Telephone 01438 314333

Lister Renal Transplant Co-ordinators:

- Telephone 01438 285466 or 286363
- Email - Livedonorcoordinator.enh-tr@nhs.net

Renal Transplant Administrator:

- Telephone 01438 286367

Renal Social Worker and Psychologists:

- Telephone 01438 284957
- Email - rsw.enh-tr@nhs.net and rps.enh-tr@nhs.net

Ward 6B, Nephrology (Renal) Ward, Lister Hospital:

- Telephone 01438 285063

Leaflet information

You can request this information in a different format or another language; please speak to your doctor or nurse.

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