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# Aftercare following your kidney transplant

Renal and Transplant Services

Information for Patients

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# 1. Introduction

This booklet is a general guide for people with a kidney transplant. Sometimes you may be given different advice by your transplant doctor. If so, **always follow your doctor's advice.**

# 2. Useful numbers and contacts

## Glenfield Hospital and Leicester General Hospital

| | |
|---|---|
| Ward 37 (Transplant ward 24hrs) ……. | (0116) 258 4126 |
| Ward 37 Ward clerk ……. | (0116 258 4197 |
| Ward 27 Nephrology ……... | (0116) 258 8082 / 8083 |
| Ward 30 Nephrology ……. | (0116) 258 4129 |
| Transplant clinic co-ordinator ……. | (0116) 258 8024 |
| Live donor & transplant Office ……..... | (0116) 258 4736 |
| Outpatients 2 (Leicester General Hospital)…….. | (0116) 258 4411 |
| Kidney Pharmacy Team …….. | (0116) 258 8177 |
| (Kidney) Renal dieticians ……. | (0116) 258 2652 |
| Transplant surgeons' secretary …….. | (0116) 258 4658 |

## 3. Medicines after kidney transplantation

After your kidney transplant your medicines will change. You will take some new medicines. You may also be taking some of the medicines from before.

The transplant pharmacist will help you understand your new medicines. Before you go home we will give you:

- A booklet called ‘Medicines after kidney transplantation’ with important information about your new medicines.
- This is also available in a short video format. Use your smart phone to scan this QR code to watch the videos or visit: https://www.youtube.com/watch?v=obMwErHr8kw&list=PLoaqlhejgAzPbI6DEqYc7oKRl7YFjI2xa&index=2
- A list of all your medicines that tells you how and when to take them. You will use this list to practise taking your medicines in hospital before going home.
- A supply of all your medicines. This should be for at least 14 days. We will tell you how to get more supplies. **Please make sure that you never run out of medicines.** If you have any problems getting them, speak to the transplant pharmacist right away.
- A copy of your discharge letter. This also has a list of all your medicines.

**After discharge from hospital please contact your GP surgery. This is so your doctor can update your list of medicines and make sure your records are up to date.**

## 4. Outpatient clinics

After your kidney transplant operation you will be seen in the transplant clinic 2 to 3 times a week at **Leicester General Hospital.**

Your appointments will be on **Monday and Friday mornings** and **Wednesday afternoons**. The clinic co-ordinator will give you a time for your appointment. After a few weeks your appointments will be less often. You must get to your transplant clinic appointment on time. If you are running late or you cannot come to your appointment, call the transplant clinic right away.

It is up to you to make transport arrangements to come to all your appointments. There is a NHS transport service. Call the **transport booking centre** to check if you are allowed to use this service. Ask a member of staff on Ward 37 if you need the telephone number for your area. A card should be in your transplant discharge pack.

When you come to clinic you will be asked:

- to give a pee (urine) sample,
- have blood tests,

This is to check how your kidney transplant is working and to check your medication levels. We will also measure your blood pressure.

Sometimes your medicines will change in the clinic. You need to bring your medicines card with you and update your medicine list in clinic. This way it is easier to remember the changes. If you need a new updated medicines list, please contact the kidney pharmacy team.

Sometimes you might get admitted to hospital from the clinic. This is more common in the early days after the operation. If you live far from Leicester you should bring your medicines and an overnight bag when you come to the clinic.

Your transplant doctors (surgeons) will look after you for the first 6 months after your transplant operation. Then you will see a kidney doctor (nephrologist) in the clinic. At this point some people are referred back to the kidney doctor in their local kidney unit instead of coming to Leicester.

## 5. Fluid management

After your kidney transplant, it is important to know how much fluid you drink and how much fluid comes out. For example, the amount of pee or fluid coming from a drain. This is called fluid balance. You need to write the amount of fluid that ‘goes in’ and ‘comes out’ every day on a form called a fluid chart.

Your nurse will help you to fill in your fluid chart when you are in the hospital. At home you need to measure all of the cups, mugs and glasses that you use so you know how much you drink. You also need a container with measurements for your pee. You need to clean this with soap and water after each use and disinfect regularly.

You need to bring your completed fluid charts to each clinic visit. The transplant doctors will use your fluid charts to work out how much fluid you need to drink.

**Once your kidney is working well you are not expected to continue checking your fluids.**

If you have diarrhoea or have been sick (vomiting) you may need to drink extra fluid until it settles down. Always check with your transplant doctor first.

## 6. Nutritional advice and weight management

### Food hygiene and safety

The medicines that prevent your body from fighting the new kidney are called anti-rejection medicines. They reduce your body’s ability to fight infections. For that reason it is important not to eat foods with a high risk of carrying infection and to practice good food hygiene. The sheet gives you information to help you do this.

### Eating well after your transplant

Your anti-rejection medicines can increase blood sugars, fat levels and make you hungrier. This can make people put on weight. Being overweight increases the risk of heart problems, stroke and diabetes. To stay healthy and have less chance of these health problems you need to keep a healthy weight by eating well and exercising regularly. This booklet gives more information on following a healthy, well balanced diet.

Sometimes people's kidney transplant does not work right away. Because of this, potassium and phosphate levels can be high. If this happens, you should follow a low potassium and/or phosphate diet.

Some people have low phosphate levels after their kidney transplant. They need to take tablets to bring their phosphate levels up to normal. The 'Eating well after your transplant' booklet has information on foods high in phosphate to help increase phosphate levels.

To see **a Renal Dietician for monitoring, support or advice, please ask your transplant doctor, nurse or pharmacist to refer you to the Renal Dietetic Service.**

You can also visit the Leicestershire Nutrition and Dietetic Service website for more dietary information: www.lnds.nhs.uk

## 7. Exercise

Regular physical exercise after having a kidney transplant is really important. Eating well and exercising will help you to avoid putting on weight.

Regular exercise has lots of other benefits:

- it helps to keep your heart in good shape,
- control blood pressure and blood sugar levels,
- build strong bones and muscles,

It will help you to get fitter so you can lead a full and active life without feeling tired all the time.

After a kidney transplant most people have more energy. It is important to increase the amount of exercise you do without trying to achieve too much too soon:

- Start gently and build up bit by bit as you begin to feel fitter and more confident. The main thing with exercise is to do it regularly. For example, workout every other day.
- Push yourself just a little bit so you are slightly warm and out of breath, but you should still be able to speak.
- Aim to keep up this level of effort for about 30 minutes. It will take a while to get to this level.
- Start by doing 10 or 15 minutes, 2 times a day. Do activities that you enjoy and get your friends or relatives to join in to keep you going. It is good for them too.
- If you go to the gym do not do any heavy lifting/weights for at least 12 weeks.

## 8. Social

- **Employment and financial information**

After your kidney transplant operation you can go back to work as soon as you feel better and your transplant doctor is happy with your recovery. Most people can return to their jobs a few weeks after their kidney transplant. Depending on the job you do, you may be advised to start with fewer hours and build up from there. You can also talk about this with your employer. Talk to your transplant doctor if you work with people that get infections time and again or if you do heavy lifting in your job.

- **Fit (sick) note**

Before you go home from hospital, you will be given a ‘fit note’. Please ask your nurse or doctor for one. This is a sickness certificate to cover the time that you are in hospital and for the first few weeks after your kidney transplant operation. You need to contact your GP for more ‘fit notes’ for as long as you are unfit to work.

- **Benefits**

If you **had** any type of benefits before your kidney transplant (like disability living allowance) you must let your benefits centre know as soon as you go home after your operation. This is important because the benefits you can claim for may now be different.

Some people qualify for free prescription medicines. For example, having a medical exemption or receiving some benefits. Other people need to pay for their prescription medicines and it is normally cheaper to buy a pre-payment certificate. You can check with your pharmacist if this is the best thing for you.

To get a pre-payment certificate you can call the NHS business service authority on **0845 610 1171** or visit the website www.nhsbsa.nhs.uk

## Driving

We recommend that you **do not drive** for a few weeks after your kidney transplant. When you feel fit to drive, ask the transplant doctor in clinic for advice before you start driving again.

You must tell your car insurance company that you have had a kidney transplant before driving. You only need to tell the (Driver and Vehicle Licensing Agency ) DVLA that you have a kidney transplant if you have other illnesses (like diabetes). You can ask the DVLA for the full list of medical conditions that they need to know about.

## Travelling abroad

You must avoid travelling abroad for the first few months after your kidney transplant operation. You may need to have vaccines and malaria medicines before you travel. You must always check with your transplant doctor before you book your holiday.

Your transplant doctor will give you a holiday letter before you travel.

This letter will have:

- a summary of your medical history,
- your medicines,
- your recent blood test results.

You must pack enough medicines (and a little extra) to take while you are on holiday. Always carry your medicines and your holiday letter in your hand luggage.

You should also have medical insurance in case you become ill during your holiday. Ask for cover suitable for people with a kidney transplant and all other medical conditions you have.

# 9. Infections

Anti-rejection medicines lower your body's defences (or immune system) to stop you rejecting your kidney transplant. Anti-rejection medicines weaken your body's defences which makes you more likely to get infections. Sometimes the infections are caused by unusual micro-organisms (like a virus called cytomegalovirus or CMV) and they are called 'opportunistic infections'.

If your body's defences are low it is also harder to fight infections. You need to tell your doctor if you think you have an infection. Symptoms of an infection are: feeling sick, tired, having a temperature, a sore throat, dark, smelly pee or having pain when peeing.

You must not be in contact with people who have chickenpox or shingles. Tell your doctor right away if you have been in contact with people who have these infections.

### Vaccines

Some vaccines are not good for you because of your anti-rejection medicines. They are called **live vaccines.** There are also vaccines recommended after your kidney transplant. You can get them at your GP surgery. For example, we recommend the flu vaccine every year and the pneumonia vaccine every 5 years.

**You must wait for at least a month after your transplant before you have any vaccines.** You may also need special vaccines when you travel abroad. You can speak to your doctor, pharmacist or nurse for advice about vaccines.

### Pets

Always wash your hands after touching any type of animal or their waste. Avoid allowing your pet such as, dog to lick your face. If possible, get someone else to clean the pet's waste for the first few weeks after your kidney transplant.

# 10. Health after transplantation

**Skin care and sun protection**: People taking anti-rejection medicines have a higher risk of developing some types of cancer (especially skin cancer). Tell your doctor if you have new moles or a mole changes shape or bleeds. Your skin will be checked at least once a year by a specialist skin doctor (dermatologist).

You can take some simple precautions to protect your skin by following these tips for sun protection measures:

- Apply a high sun protection factor (SPF) sunscreen with both UVB and UVA protection. Choose a SPF sunscreen of 50 with 4 or 5 UVA stars.
- Use sunscreen **every day** to all exposed areas of skin especially your head and neck, central chest, backs of hands and forearms. Apply sunscreen and also protect your skin with clothing and shade.

Apply plenty of sunscreen before going out in the sun and apply again every 2 hours when outdoors, also apply straight after swimming and towel-drying.

- Wear protective, tightly woven clothing, such as long-sleeved shirts and trousers, sunglasses and a broad-brimmed hat that shades your face, neck and ears.
- Avoid going out in the sun between 11am and 3pm when the sun rays are strongest. Step into the shade before your skin gets red or burns.
- Remember that winter sun can contain just as much of the damaging ultra-violet light as summer sun.

**Testicular and breast examinations**: Because of the increased risk of cancer, you must do regular breast or testicular examinations. You will find information on how to do this in the information pack that you get after your transplant.

**Smear test**: Female transplant patients must have regular smear tests. This is done at your GP surgery. If you have had a hysterectomy this may not apply to you. Check with your doctor if you are not sure.

**Mouth care**: It is important to look after your teeth and have good mouth hygiene. You should see your dentist at least 2 times a year. Transplant patients do not normally need to have antibiotics before having dental work. Tell your transplant doctor if you get mouth ulcers so you can have treatment.

**Diabetes**: Some anti-rejection medicines can increase blood sugar levels and can cause diabetes. Sometimes the blood sugars go back to normal without treatment. Some people need to take medicines or have insulin injections to control the blood sugars.

**Hair loss**: Some anti-rejection medicines can sometimes cause hair loss, especially **tacrolimus**. You should avoid harsh treatments that can weaken your hair for the first few months after starting your anti-rejection medicines. This includes perms, bleaching or damaging hair dyes. Tell your transplant doctor if you have hair loss and may need to see a specialist skin doctor (dermatologist).

## 11. Fertility and sexual health

Kidney transplant patients must wait to get pregnant for at **least 1 year after the transplant**. This allows the body to get used to the new kidney.

Some anti-rejection and other transplant medicines must be avoided during pregnancy because they can harm the unborn baby. Women of childbearing age must use effective birth control while they are taking transplant medicines. If you were taking the oral birth control pill before your transplant ask your transplant doctor when you can start taking it again. You must also ask your doctor about taking hormonal replacement therapy (HRT).

You will need to go to a special clinic called the pre-conception clinic for a detailed talks about your circumstances. This will help you decide if you want to become pregnant. Your medicines may be changed before you start trying for a baby.

Speak to your kidney doctor if you are thinking about having a baby. Men taking transplant medicines may want to speak to their doctor before fathering a baby.

# 12. Access to healthcare

## When to call the transplant ward

After you go home you can call the transplant ward for advice and support. For example, call for advice if you are not feeling well or for information about your medicines.

You can also call to ask for your blood test results. Nurses giving out this information will have to do a full identity check for confidentiality reasons. Please call the ward yourself for blood test results rather than someone else. Sometimes the ward may be very busy and staff may ask you to call back for your blood tests results.

It is best to call the ward **between 10am and 5pm, Monday to Friday**. This is because there are more staff (doctors and pharmacists) available during these hours to help you than in the evenings and weekends.

## Visiting your GP or Emergency Department at a local hospital

**Please do not come to the transplant ward unless a doctor has asked for you to be admitted.**

If you call the transplant ward or speak to your GP, you will be told where to get medical help. You should always follow this advice and go where it is best for you.

Sometimes you will be asked to come to the transplant ward or to be admitted to hospital. Other times you will be told to visit your GP, walk-in centre or to go to your local Emergency Department. It all depends on what the issue is. Sometimes it is best to be treated by other doctors if the reason that you are unwell is not related to your kidney transplant.

If you go to another hospital you always need to tell your doctors and nurses that you have a kidney transplant. Please ask them to tell your transplant doctors on ward 37 that you are in hospital (up to 6 months post transplant).

# 13. Issues and tests after kidney transplant

### Delayed kidney function

Sometimes the kidney transplant may not work right away. This is called “delayed kidney transplant function”.  There are a lot of reasons why this can happen and most kidney transplants start working after a while. Some people need to have haemodialysis or peritoneal dialysis for a short time until the kidney transplant starts to work.

### Rejection

Your body has natural defences (your immune system) to protect you. These defences will attack anything that does not belong to your body (like germs). When you have a kidney transplant your defences will know that your new kidney is not part of your body and they can attack it. This can damage your new kidney transplant and stop it from working. This is called rejection.

Rejection can happen at any time and it is more common during the first few months after the transplant. Your doctor will check for rejection when you attend clinic appointments. Rejection can be treated with more powerful immunosuppression medicines and these are injections.

### Kidney transplant biopsy

A kidney transplant biopsy means removing a very small sample of the kidney transplant (about half the size of a matchstick). The sample is taken through the skin using a special needle.

A biopsy of the kidney transplant is done when blood and pee tests have shown that the transplant is not working normally. The biopsy is the best test to look for rejection and other problems in the transplant kidney.

## 14. Contacting the donor's family

If you have a kidney transplant from a deceased donor you may want to contact the donor's family. Even if you do not know who they are you can write a letter to them. Give the letter to the transplant coordinator who will pass it on to the family.

You can find more information about contacting the donor's family in the information pack that you get after your transplant.

## 15. Useful websites and organisations

**(Patient knows best) PKB:** https://patientsknowbest.com/renal/

Patient knows best is an internet website where you can see information about your kidney transplant on your phone. For example, your contact details, blood test results and your letters from the transplant doctors. All this information is safe and you need a password to see it. You will find all the information on registration from the (PKB) website.

**Transplant Support Network:** www.transplantsupportnetwork.org.uk

This is a nationwide network of volunteer transplant patients and their carers who offer support in one area for others coping with transplantation.

**Organ donation and transplantation (previously UK transplant):** www.organdonation.nhs.uk/

This website has information about many aspects of transplantation like news, statistics and campaigns. It also has information on how to become a donor.

**Leicestershire Kidney Patients' Association:** www.lkpa.org.uk

The LKPA (Charity No. 505795) is a charity which promotes and supports the health and welfare of kidney patients (and families), Leicester General Hospital and its satellite kidney units to;

- offer education or information about kidney disease to the general public.
- support its members by the means of telephone, website and newsletters.

- give out small grants for basic needs, helping to organize educational sessions, social events and outings.
- also gives funds to help staff of the kidney (renal) unit of Leicester General Hospital to further their research and education into kidney problems.

**Kidney Patients UK** www.kidney.org.uk/kpa

The (National Kidney Federation) NKF is a federation of about 70 separate Kidney Patient Associations (KPAs) geographically spread across the UK. These pages contain details of the local contact and activities of each KPA.

**Transplant Sport UK:**This group organises sports and social events for transplant patients. www.transplantsport.org.uk

**NHS 111:** can help if you have an urgent medical problem and you are not sure what to do. www.111.nhs.uk or phone **111**.

**Diabetes UK:** For support and information to help people manage their diabetes. www.diabetes.org.uk or phone **0845 120 2960**

**Lab Tests Online UK:** This website has information to help patients understand tests better. www.labtestsonline.org.uk

**Food Standards Agency:** This website has information about healthy eating and understanding food labels. www.food.gov.uk

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice
Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
إذا كنت ترغب في الحصول على هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો.

If you would like this information in another language or format such as EasyRead
or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net

**We are a research hospital and you may be asked to take part in research**



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