

Going home after your kidney transplant

Information for young people



This booklet is to guide you through some of the important things you need to know now that you have had a kidney transplant.

The Children’s nephrology team will talk you through this booklet before you are discharged home. It will be a useful source of information for the future to help and support you make the most of your new lease of life.

We have tried to answer many of the common questions that patients and their families ask after having a kidney transplant. However please ask us any questions you may have. There is no such thing as a silly question, so please ask.

Below is a list of useful contact numbers for the team

Children’s nephrology ward (L50)	0113 392 7450 0113 392 7550
Renal clinical nurse specialists (CNS)	0113 392 5241 07733 001247 07810 836456
Children’s nephrology specialist dietitians	0113 392 0624
Children’s nephrology administrative team	0113 392 5583 0113 392 5640
Clinic appointments	0113 392 6793

Outpatient Monitoring

Discharge from hospital after your kidney transplant may be a scary and overwhelming time but as a team we are here to support you.

After you are discharged from the hospital we will see you regularly in the Children's outpatient clinic (C floor, Martin Wing). When you come for appointments clinic staff will check your height, weight, manual blood pressure and urine dipstick.

Bloods will be taken in the phlebotomy department which is located on B floor of Martin wing - a member of the team will show you where this is on your first visit.

It is important **NOT** to take the morning dose of tacrolimus on the day of your clinic appointment.

This is because one of the blood tests is to check the level of tacrolimus in your blood. Please bring the dose with you and it can be taken after the blood test has been done.

Once you have had these tests and measurements you will see the doctors and if needed other members of the Children's nephrology team.

We will discuss your blood test results in our results meeting, which happens on a Tuesday morning. You will be contacted by one of the renal clinical nurse specialists (CNS) if there are any changes that need to be made. If there are any more urgent issues you or your parent/carer will be contacted on the day of your appointment.

When you leave hospital, we will need to monitor how well your transplant kidney is working with very regular blood tests.

For the first month you will need to come to hospital to have blood tests at least three times a week (usually Mondays, Wednesdays and Fridays).

If things are going well we will then ask you to attend twice a week in the second month (usually Mondays and Thursdays).

For the third month we will see you and do blood tests once a week in the transplant clinic on a Monday.

After this time we will gradually see you less often. Initially it will be every two weeks, gradually once a month, and then later we will ask you to come to the kidney transplant clinic every 6 to 8 weeks.

At Home

Medication

The hospital will provide you with a three month supply of all your transplant medication. Ask your parents or contact the GP yourself, to arrange for these medications to be added to your repeat prescriptions as soon as possible. You can then order more medication from your GP when needed. This avoids you running out of any medicines.

Any problems or worries you can ask the CNS team.

Fluid

On discharge the doctors will discuss a fluid target with you. This is an amount that has to be reached in order to keep your transplant kidney working well. It is just as important as the medications you have to take. The best thing to drink is water or diluted juice. You can drink drinks that contain caffeine, but they do make you pass more urine so avoid or limit to a small cup a day.

Do not drink bottled water unless it has been carbonated (fizzy water), other bottled juices or pop are fine to drink.

Isolation

For three months after you get your kidney it is important to keep yourself isolated to stop you catching infections. This is because your immunosuppressant medications will be at a higher level to start with and so you are more at risk of catching infections.

While isolating, you should not go to places where there are lots of people e.g. schools, supermarkets and swimming pools. Essentially do not go anywhere you may come into contact with lots of people.

We think it is important that you are still able to see people, but to try and keep you safe you should have no more than four visitors (people that don't live with you) in one go. Visitors should only come to see you if they are well and do not have any infections themselves e.g. cough or cold. We know it is rubbish, but you cannot have big gatherings for birthday parties or celebrations for at least the first three months after the kidney transplant.

Isolation can be a challenging time but it is an essential part of post-transplant care.

Monitoring to follow once you are at home

Temperature

If you get a fever with a temperature over 38 degrees centigrade, it is important to call the specialist nurses. Sometimes we will be able to give you advice and let you stay at home, other times you might need to be admitted so we can check you over, do some blood and urine tests and organise whatever treatment you need.

Diarrhoea or Vomiting

It is important to let us know if you have been sick or had diarrhoea for 24 hours or more. This is because you might become very dehydrated and diarrhoea and vomiting can affect how well your body absorbs all the medication.

Both of these things can damage your transplant kidney so letting us know early means we can put steps in place to try and keep you well and protect the transplant kidney as much as possible.

Headaches/Dizziness

Headaches can be a common side effect of some of your medication. Please talk to us if you have headaches or dizziness or if you are worried about some other side effects of your treatment.

Please do not stop taking any of your medication without speaking with us.

Infection Prevention and Treatment

Contact with other people with infections can be harmful to you. There are a few things which you need to be aware of:

Chicken Pox/Measles

These can be more serious for you after your transplant. Following your kidney transplant it is important that your school tells you and your parent/carer if there is someone with symptoms of chicken pox who has had close contact with you. Close contact is if you have been in the same room as someone with possible chicken pox for longer than 15 minutes. If this happens please contact the renal nurse specialists for advice.

The same advice applies if you come into contact with someone with measles.

Cold Sores and Thrush

These can be more serious for you after your transplant. They should be treated quickly to avoid the infections becoming more complicated. It is important that you or your parent/carer notify us if you get these infections but you can get treatment for both these infections from your GP. Please talk to us first.

Pets

Children and young people on immunosuppressant medication are at increased risk of infection from pets, and you should avoid contact with animal poo. Good hand washing after contact with your pet or animals is really important to make sure you stay safe and well.

Dental Care

It is important that you keep up with any dental appointments. If you need any dental treatment you might need antibiotics but usually these are not needed.

Other important information

Exercise

It is important for you to get moving early after your kidney transplant operation. Light exercise for short periods is important and we encourage you to get moving. As the kidney transplant lies close to the front of your tummy we recommend that you avoid any hard contact with your tummy. We also suggest not doing any contact sports like rugby, judo and gymnastics that involve bar exercises.

Swimming and PE at school are usually fine.

Vaccinations

If you require any vaccinations after your kidney transplant it is important to check it is safe to have these.

There are two types of vaccine:

- Live
- Inactivated or 'killed'.

Live vaccines have a tiny amount of live bugs in them and these vaccines can make you unwell.

It is very important that you do not have any live vaccinations following their kidney transplant.

Inactivated or killed vaccines are safe for you to have after your kidney transplant. It is important that you get all the inactivated or killed vaccines that are recommended as you get older.

You should not have any vaccinations for at least six months after your kidney transplant.

The Flu vaccine is important to have annually. Each year there is a live (nasal spray) and a killed (injection) vaccine available. Please ensure that you get the killed vaccine (injection) each year. Ideally you should have the Flu vaccine at least two weeks before seeing anyone that has had the live vaccine. If the school is carrying out live vaccinations in school, it is important that you are not in the same room when the vaccinations are occurring.

Travel

We recommend you do not travel outside of the UK for the first year after your kidney transplant. Please discuss any travel plans with us in advance.

When travelling we recommend that you and your parents work out how much medication you need and then take double this amount with you. The nurse specialists can help you with this if you are unsure. If travelling abroad we suggest that you take half of the medication in your hand luggage and half in the checked-in luggage. That way if one bag is lost or stolen you still have enough for your holiday. Always make sure you have enough medication with you in case there are any delays - we want you to have a stress free holiday!

With each supply of your medication you should take the most recent clinic letter and a cover letter to explain the importance of your medication. You can get these letters from the renal nurse specialists.

Make sure you or your parent/carer organise adequate travel insurance before travelling.

It is really important that you take care in the sun. You should avoid sun exposure when the sun is at it's strongest: between 11am and 3pm.

You should wear sunscreen with an SPF of at least 30 ideally 50, with a UVA rating of 4 or 5 stars. Make sure you apply sun cream to all exposed areas of your skin, wear sunglasses, protective clothing and a hat whenever possible.

Not protecting your skin properly can put you at increased risk of skin cancer so it is really important that you follow the advice in this booklet.

Top Tips to keeping safe on holiday

You should only stay in accommodation that is really clean. Where possible avoid tap water and ice cubes, unless you are sure the tap water is safe. Instead of tap water you can drink fizzy bottled water, bottled juices or bottled water with a tamper free lid.

You should avoid swimming in still water (swimming pools are fine), to stop you getting infections from bacteria or parasites (bugs and germs) that might make you very sick. Make sure you wear proper footwear in wet areas as some parasites (germs) can get into your body through the skin of your feet.

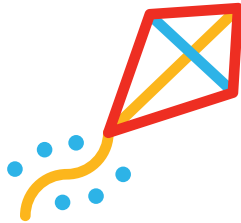
Use insect repellent to avoid getting mosquito bites.

If you are travelling to a country with a different time to the UK, then talk to one of the renal nurse specialists about how to change your medication timings.

Letter of Thanks

It is possible to find out some information about the person who donated their kidney to you. To protect the privacy of the donor you will only be told their age and sex. Similarly if the family of the donor ask for information about you they would only be told your age and sex to protect your privacy.

We can help if you would like to send a letter of thanks to your donor family.



We understand you may have lots of questions, so please don't hesitate to get in touch with us on one of the numbers on the first page of this booklet.

There is some space on the back page for you to make a note of things you may want to ask the team.

