

Going home after your kidney transplant

Information for parents/carers



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

The Children’s nephrology team will talk through this booklet before your child is discharged home. It will be a useful source of information for the future to help and support you and your child make the most of a 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 feel free to 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 3926793

Outpatient Monitoring

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

Follow up after discharge is done in the Children's outpatient clinic (C floor, Martin Wing). When you attend appointments clinic staff will check your child's height, weight, 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 to go.

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

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

Once your child has had these tests and measurements you and your child will see the doctors and, when relevant, other members of the Children's nephrology team.

Blood test results are discussed in the results meeting, which happens on a Tuesday morning. You will be contacted by one of the clinical nurse specialists (CNS) if there are any changes that need to be made. If there are any more urgent issues you will be contacted on the day of your appointment.

Initially after discharge we will need to monitor your child's kidney function through regular blood tests. An example of the schedule we use is outlined below

Day 1-28 - attend clinic 3 times a week

Month 2 - attend clinic 2 times a week

Month 3 - attend clinic 1 times a week

After this initial period of monitoring, if things are stable, we will start to space out appointments, initially fortnightly then to monthly, and eventually to every 6-8 weeks.

At Home

Medication

When you first go home the hospital will provide you with a three month supply of all transplant medication. After this period the medication should be provided by your GP. Please ask your GP practice to add the medication to your repeat prescription soon after discharge. This is so that if there are any problems they can be resolved before you run out of medication. If you have any issues with supply of medication for your child please discuss this with the Children's nephrology team.

Fluid

On discharge the doctors will discuss a fluid target. This is an amount that has to be reached in order to keep your child's transplant kidney working well. This is just as important as the medications your child has to take.

Ideally water or dilute juice is best for hydration. Caffeine containing drinks (e.g. tea, coffee, cola) can make your child pass more urine, so avoid where possible, or limit to one or two small cups a day.

Bottled water should be avoided unless it has been carbonated (fizzy water). Tap water in the UK is fine to drink.

Isolation

For three months after the transplant it is important to keep your child isolated to reduce the risk of exposure to infection. The reason we recommend isolation for the first three months after the transplant is because your child's immunosuppressant medications will be at a higher level to reduce the chance of a rejection episode and this will put your child at greater risk of infection.

Your child should avoid contact with large groups of people e.g. schools, supermarkets or swimming pools. Essentially anywhere your child may come into contact with lots of people.

We think it is important that you and your child are still able to socialise, so to reduce the risk of being exposed to an infection we recommend a maximum of four additional visitors from outside your household at any one time providing the visitors are well. Unfortunately large gatherings for birthday parties or celebrations are not recommended within the first three months.

**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 your child develops a temperature over 38 degrees centigrade, with no obvious cause or if you are worried about them you must ring the Children's nephrology team for advice.

The most likely cause of a temperature is usually a common cold or another virus. However urine infections that can affect the transplant kidney, transplant kidney rejection and septicaemia (blood stream infection) can also cause a fever so medical assessment is necessary.

Diarrhoea or Vomiting

It is important to let us know if your child experiences any vomiting, as it may affect the amount of immunosuppressant medication being absorbed from the stomach into the blood. The level of immunosuppressant medication in the blood may fall too low if your child vomits soon after taking the medication and this could lead to rejection.

Persistent diarrhoea can also affect the level of immunosuppressant drugs and may cause changes to the tacrolimus level, as absorption will be affected.

If your child has persistent diarrhoea and/or vomiting lasting for 24 hours or more, please call the Children's nephrology team for advice

Headaches/Dizziness

Headaches can be a common side effect of some of the medication your child is taking. Please talk to us if you notice your child has headaches or dizziness or if you are worried they have other side effects from their treatment.

Do not stop any of your child's medication without speaking with the Children's nephrology team.

Infection Prevention and Treatment

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

Chicken Pox/Measles

These can be more serious for a child who has had a transplant. Following your child's kidney transplant it is important that your child's nursery or school notifies you if there is someone with symptoms of chicken pox who has had close contact with your child. Close contact is classified as being in the same room for longer than 15 minutes. If this is the situation please contact the renal nurse specialists.

The same advice applies if your child comes into contact with someone with measles.

Cold Sores and Thrush

These can be more serious in children after a transplant and need prompt attention to avoid complications. It is important that you notify the Children's nephrology team, but you can get treatment for both these infections from your GP. Please discuss with us first.

Pets

Children on immunosuppressant medication are at increased risk of infection from pets, and should avoid contact with animal faeces (poo). Good hand washing is important to ensure your child's safety at all times.

Dental Care

It is important that you keep up with dental appointments for your child. If your child needs dental work antibiotics may need to be considered but they are not usually necessary.

Other important information

Exercise

It is important for your child to mobilise early after a kidney transplant. Light exercise for short periods is important and we encourage normal play. As the kidney transplant lies close to the front of the abdomen we recommend that your child avoids hard contact with that area so contact sports such as rugby, judo and gymnastics involving bar exercises should be avoided. Swimming and PE at school are usually fine.

Vaccinations

If your child requires vaccinations after their kidney transplant, it is important to check it is safe for them to be administered first.

There are two types of vaccine:

- Live
- Inactivated or 'killed'.

Live vaccines have a tiny amount of live bugs in them and have the potential to make someone taking immunosuppressant medication unwell.

It is very important that your child does not receive any live vaccinations following their kidney transplant.

Inactivated or killed vaccines are safe for your child to have after their kidney transplant. It is important that these vaccines are given in line with government guidance.

However your child must not have any vaccinations for at least six months after their 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 it is the killed vaccine that is administered. Ideally your child should have their Flu vaccine at least two weeks before they are exposed to anyone else who has had the live vaccine. If the school is carrying out live vaccinations in school, it is important that your child is not in the same room when the vaccinations are taking place.

Travel

We recommend you do not travel outside the UK for the first year after your child's kidney transplant. Please discuss any travel plans with us in advance. We would always recommend your family are reviewed in a travel clinic before you go as there may be extra vaccinations or medication which are required, for example, anti-malarial medication. Some anti-malarials can affect immunosuppressant medication, so please speak to us before giving your child any additional medications.

When travelling we recommend that you work out how much medication your child will need for the time that you are away and take double this amount with you. The renal nurse specialists can help 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 medication for your holiday. Always ensure you have enough medication for your child in case of unexpected delays - we want you to have a stress free holiday!

With each supply of your medication please also take the most recent clinic letter and a cover letter with your child's medication to explain the importance of the medication. These can be obtained from the renal nurse specialists.

Make sure you have adequate travel insurance before travelling.

It is extremely important that your child takes care in the sun, as their immunosuppression increases the risk of sensitivity to the sun and a small increased risk of skin cancer. Your child should avoid sun exposure when the sun is at it's strongest: between 11am and 3pm. It is recommended that all children wear sunscreen with an SPF of at least 30 ideally 50, with a UVA rating of 4 or 5 stars. Inadequate protection can lead to an increased risk of skin cancer. Please apply sun cream frequently to all exposed areas of your child's skin and make sure they wear sunglasses, protective clothing and a hat whenever possible.

Top Tips to keeping safe on holiday

Ensure your accommodation has high standards of cleanliness. If sanitation is of concern then your child should only drink fizzy bottled water or bottled water with a tamper-proof seal, or cooled boiled water. If unsafe to drink tap water then also avoid ice cubes in bars and restaurants, ice cubes from cooled boiled water will be fine.

Your child should avoid swimming in stagnant water, to avoid bacteria or parasites that might make them very sick. Ensure you and your child wear proper footwear in wet areas as some parasites can enter the body through the skin on your feet. Use insect repellent to avoid mosquito bites.

If you are travelling to a different time zone, speak with the specialist nurses about how to adjust your child's medication schedule.

Letter of Thanks

It is possible to find out some information about the person who donated their kidney to your child. Due to patient confidentiality this information is limited to the age and sex of the donor. Likewise if the family of the donor asked for information about the recipient they would only be told the age and sex of the organ recipient.

We can help if you would like to send a letter of thanks to the 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.

