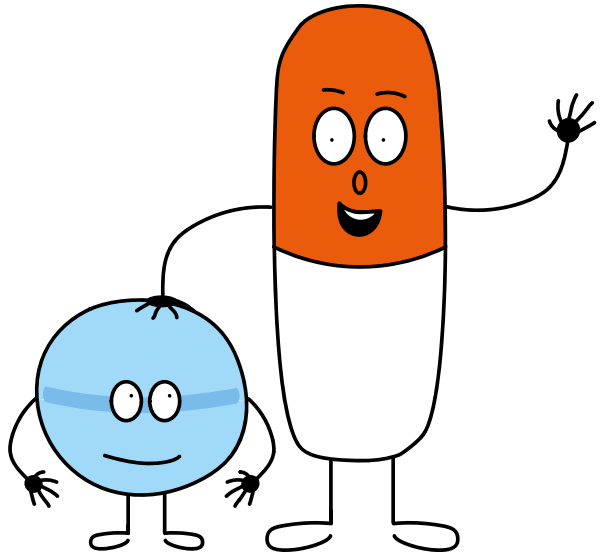


Medicines after a kidney transplant

Information for patients



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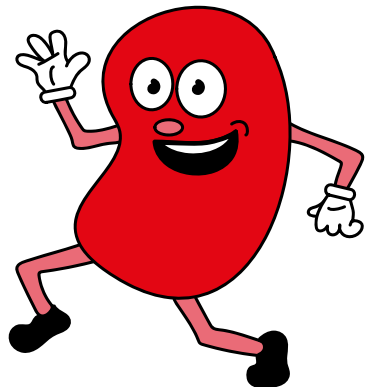
After your child's transplant, medicines will play an essential role in keeping your child's new kidney working properly and maintaining general good health.

Your child will have to take some medicines for the rest of their life. Other medicines will be necessary only for a limited time after the operation.

From time to time, the dose of a medicine may change, or your child may be switched from one medicine to another. Learning to manage your child's medicines may take some effort but the entire children's nephrology team is here to help you. This leaflet will aim to give you some guidance on what your child's medicines are for and why they need to take them.

Will my child continue to take the medicines they were taking before their transplant?

Some of the medicines your child is taking for their kidney problems prior to a kidney transplant will normally stop afterwards e.g. phosphate binders, renal vitamin supplements and Epoetin (Aranesp). This will be discussed with you and your child prior to discharge after a kidney transplant and the list of medicines that have stopped will be shown on your discharge document.



What type of medicines will my child take after their renal transplant?

After your child's transplant they will take a few different medicines for different reasons. Your child will be started on several different types of medicines at first, but the number usually reduces over the first few months. Each of the different types of medicines will be discussed over the next few pages.

The exact regime of medications used will be guided by your child's underlying condition and history. The medication choices are individualized and will be discussed in more detail by one of the children's nephrology consultants.

Anti-rejection medicines / Immunosuppressants

Your body's normal response to anything that it sees as a foreign object is to attack it. This helps us stay healthy and fight infection. After a transplant, your child's new kidney will be seen by their body as foreign and their immune system will automatically try to attack it. This is called rejection. To prevent this from happening your child will need to take antirejection medicines (also called immunosuppressants) for the rest of the life of their transplanted kidney. Without these it is very likely that your child's body will reject the kidney. **It is essential that your child does not miss or stop any immunosuppressant medication unless directed to by the children's nephrology team.** Immunosuppressants will reduce your child's immune system and reduce their body's ability to fight infection.

There are also other risks associated with immunosuppressants like skin cancer and the children's nephrology team will discuss all of these with you in detail.

Tacrolimus (Tac-ro-lie-mus)

(e.g. Modigraf (Mod-e-graf), Adoport (Ad-o-port))

Tacrolimus works by blocking the production of cells that attack the new kidney and cause rejection.

There are different brands of Tacrolimus and it is very important that you remain on the same brand that the children's nephrology team start you on. You must not switch between brands unless your consultant tells you to.

Tacrolimus is usually a twice daily medication taken 12 hours apart and on an empty stomach (your child should not eat for at least 1 hour before and 1 hour after tacrolimus).

Adoport capsules should be swallowed whole with a glass of water. The children's nephrology team will advise you on the number of capsules that you need to give to your child. If you are uncertain about what to do, contact the children's nephrology team for advice.

If your child is unable to swallow tablets they will be prescribed Modigraf granules. The children's nephrology team will advise you on how many sachets are required and how to administer these safely. When preparing Modigraf please make sure you are wearing gloves and wash your hands thoroughly afterwards. Open the required sachets of Modigraf with scissors and tip the contents into a glass of water, stirring until dissolved. Your child should drink all of

this straight away. The glass should then be rinsed with the same amount of water and your child should drink this as well. Read the patient information leaflet provided and if you have any uncertainty contact the children's nephrology team for guidance.

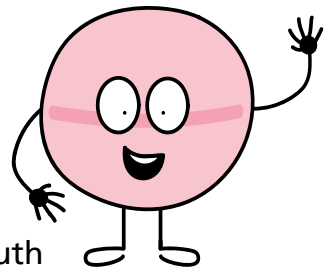
If your child has a feeding tube (e.g. nasogastric tube or gastrostomy) this should only be used for giving Tacrolimus if this is approved by the children's nephrology team. Do not change between giving Tacrolimus by mouth or via a feeding tube as this will affect the blood level of Tacrolimus and may increase the chance of rejection or side effects.

Regular blood tests will be required initially after your child's transplant in order to check the Tacrolimus level in their blood. This is to ensure an optimum dose with minimum side effects. When attending clinic, **DO NOT** give your child's morning dose of Tacrolimus and bring the dose with you to hospital so it can be given after your child's blood test.

Your child's dose of Tacrolimus may be altered according to the blood results. If this is necessary you will be contacted by telephone.

Side effects

- Tremor (shaking) of the hands
- Headache
- Vivid dreams
- Upset stomach
- Hair loss on the head
- Numb, hot or tingly hands, feet or mouth



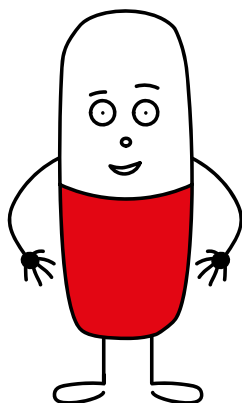
- Diabetes
- High blood pressure
- Altered kidney function – this will be constantly monitored in transplant clinic.
- Skin cancer - very rare

Your child may experience some of these side effects. Tell the children's nephrology team if they do, there is often a solution. Your child's blood pressure, blood sugars and kidney function will be checked in clinic and changes can be made if necessary.

Your child should wear high factor sun cream (SPF 30 or above) when in sunlight whilst on Tacrolimus because of the risk of developing skin cancer. See 'azathioprine' for further information.

Taking other medicines with Tacrolimus

Some medicines can increase or decrease your child's tacrolimus level in the blood. This may increase their chance of side effects or rejection. Always check with the children's nephrology team before giving your child any prescribed medicines or any new over the counter medicines or herbal remedies.



Medicines your child should avoid while taking Tacrolimus

- Some antibiotics called erythromycin and clarithromycin
- Non-steroidal anti-inflammatory drugs such as ibuprofen or diclofenac (can affect your child's kidney)
- Some antifungals e.g. fluconazole
- St Johns Wort

Your child should avoid eating grapefruit or drinking grapefruit juice as it contains a chemical that affects the level of tacrolimus in their blood. Other citrus fruits are safe to eat or drink.

What to do if you forget to give your child a dose of Tacrolimus

A missed dose of tacrolimus should be given to your child at least 6 hours before the next dose is due. If there is less than 6 hours **DO NOT** give that missed dose and carry on with the next dose at the normal time. **NEVER** give your child a double dose to make up for missed doses.

What do I do if my child vomits after I give a dose of Tacrolimus?

If your child vomits within 30 minutes of receiving a dose of tacrolimus, repeat the same dose again. If your child vomits after 30 minutes do not repeat the dose and wait until the next normal dose is due.

If your child continues to vomit or you are concerned they are unwell please contact the children's nephrology team.

Azathioprine (A-za-thigh-o-prin)

Azathioprine is an immunosuppressant used alongside tacrolimus to prevent rejection of the transplant kidney. It works by blocking the production of white cells that are involved with causing rejection.

Azathioprine comes in 25 mg and 50 mg tablets and should be given to your child once a day in the morning or evening after food. Your child should swallow the tablets whole (without chewing) with a glass of water.

If your child is unable to swallow tablets, the tablets can be given crushed and mixed with a small amount of soft food. The tablets can also be dissolved in a small amount of water and given to your child by mouth or via their feeding tube. Make sure you wear gloves when making and handling this solution and wash your hands thoroughly afterwards. The children's nephrology team will support you with giving Azathioprine and all the other medication prior to discharge following the kidney transplant operation.

Side effects

- Inflammation of the pancreas - which can cause severe back and stomach pain
- Abnormal liver function - this will be regularly monitored when your child is seen in clinic
- Reduced white cell count (increasing risk of infection)
- Unexplained bruising (due to low platelet levels in the blood)

It is important to inform the children's nephrology team if your child develops signs of infection (e.g. fever, lethargy, vomiting, generally unwell), is bruising easily, has stomach pains or their skin or the whites of their eyes look yellow (jaundice) whilst taking azathioprine.

Taking azathioprine for a long time can increase your chance of getting certain types of cancer, including skin cancer. Though this is very rare, we would advise avoiding strong sunlight, using sunscreen (SPF 30 or more) and that your child wears clothes that cover their arms and legs when out in sunlight, even on cloudy days.

Taking other medicines with Azathioprine

Azathioprine is generally well tolerated but can interact with other prescribed medication. Always check with the children's nephrology team before giving your child any new medication, including herbal medication.

What to do if you forget to give your child a dose of Azathioprine?

A missed dose of azathioprine should be given at least twelve hours before the next dose is due. If there is less than twelve hours before your child's next dose then do not give the missed dose and carry on with the next dose at the normal time. Never give your child a double dose to make up for missed doses.



What do I do if my child vomits after I give a dose of Azathioprine?

If your child vomits within 30 minutes of receiving a dose of azathioprine, repeat the same dose again. If your child vomits after 30 minutes do not repeat the dose and wait until the next normal dose is due.

If your child continues to vomit or you are concerned they are unwell please contact the children's nephrology team.

Do I need to be concerned if my child is taking Azathioprine and sexually active?

Azathioprine can be harmful to an unborn baby. It is therefore important that boys or girls taking azathioprine use adequate contraception to prevent an unplanned pregnancy. Both boys and girls should continue effective contraception for at least 6 months after stopping Azathioprine.

Mycophenolate Mofetil (MMF) (My-co-fen-o-late Mo-fa-till)

Another type of immunosuppressant your child may take after a kidney transplant. It acts to reduce the number of white cells in the blood which play an important role in rejection.

General Information

Mycophenolate Mofetil does not need to be prescribed brand specific. Mycophenolate mofetil is available as 250mg capsules, 500mg tablets and a liquid (1 gram in 5 ml).

Mycophenolate mofetil should be taken twice a day, every morning and evening, 12 hours apart. Your child should swallow the tablets/capsules whole (without chewing) with a glass of water. If your child is unable to swallow tablets, they will be provided with the liquid medication and you will receive instructions on how much liquid to give.

Side-effects

- The most common side-effects are:
- Stomach upset (diarrhoea and vomiting) - taking the medicine with or just after food can help.
- Reduced white cell count (increasing risk of infection)
- Unexplained bruising

It is important to inform the children's nephrology team if your child develops signs of infection (e.g. fever, lethargy, vomiting, generally unwell) whilst taking mycophenolate.

Taking other medicines with mycophenolate

Some other medicines can reduce the amount of mycophenolate that is absorbed into the body. We recommend not taking iron supplements or antacids containing magnesium or calcium (e.g. Maalox®) within two hours of taking mycophenolate. Always check with the children's nephrology team that any new medicine is safe for your child to take.

What to do if you forget to give your child a dose of Mycophenolate

A missed dose of mycophenolate should be given within four hours of when the dose was due. If more than four hours has passed since the dose was due then do not give that missed dose and carry on with the next dose at the normal time. Never give your child a double dose to make up for missed doses.

What do I do if my child vomits after I give a dose of Mycophenolate?

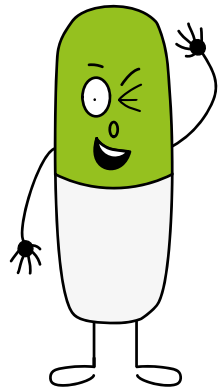
If your child vomits within 30 minutes of receiving a dose of mycophenolate, repeat the same dose again. If your child vomits after 30 minutes of receiving the dose do not repeat the dose and wait until the next normal dose is due.

If your child continues to vomit or you are concerned they are unwell please contact the children's nephrology team.

Do I need to be concerned if my child is taking Mycophenolate and sexually active?

Mycophenolate can be extremely harmful to an unborn baby. It is therefore important that your child uses adequate contraception to prevent an unplanned pregnancy.

For a female taking mycophenolate we recommend the use of at least one form of contraception (but preferably two forms of contraception) before starting treatment and whilst on treatment with mycophenolate.



Contraception should be continued for six weeks after stopping mycophenolate treatment.

For a male taking mycophenolate we recommend the use of one form of contraception (either themselves or their partner). This should be continued for at least 90 days after stopping treatment.

When your child reaches the point of wanting to start a family please discuss with the medical team as medications can be adjusted to support trying to have children. This can be discussed in more detail at the time.

Prednisolone (Pred-ni-sa-lone)

Prednisolone is an immunosuppressant and a steroid. It is a corticosteroid produced normally by your body which is not the same as an anabolic steroid misused by some body builders.

General Information

Prednisolone is often used in children after a kidney transplant. It is gradually reduced over a period of weeks. After taking prednisolone for more than a few weeks, your child's body will reduce the amount of natural steroid it produces and so it is important that you reduce your child's dose as instructed and do not stop it suddenly. You will always be given a blue steroid card to carry around with you. If your child is having prednisolone you need to inform your doctor or dentist before any surgical procedures or dental treatment.

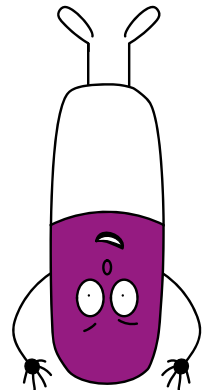
Prednisolone should be given once a day in the morning. Giving prednisolone to your child with food may reduce the

chance of indigestion. Prednisolone is available as 5mg tablets that your child should swallow whole with water. If your child does not swallow tablets they will receive treatment with 5mg soluble tablets that can be dissolved in water and then taken orally or given via a feeding tube. There is also a Prednisolone liquid but this is high in sugar so we do not use this. You will be asked to make up the required dose using the 5mg tablets. For example, a dose of 20mg would require giving four 5 mg tablets. The children's nephrology team will provide instructions on what to do before your child is discharged home.

Side-effects of Prednisolone

Prednisolone has a number of possible side effects. Most of the side effects happen slowly over a period of time. The children's nephrology team will reduce your child's dose to the smallest amount to prevent rejection.

- Stomach upset and indigestion (take with/after food to reduce this)
- Night disturbances
- Swollen ankles
- Weight gain due to increased appetite
- Rounded face
- Diabetes (increased sugar in blood)
- Thinning of the bones
- Poor growth



You may notice your child has some of these side-effects. Tell the children's nephrology team if they do as there is often a solution.

What to do if you forget to give your child a dose of Prednisolone

If you forget to give your child's prednisolone but remember before 8pm, give it and then give their next dose at the normal time the following morning. If you remember after 8pm, do not give the missed dose and give their normal dose in the morning. The later in the day you give the dose the more chance your child will experience night time side effects.

What do I do if my child vomits after I give a dose of Prednisolone?

If your child vomits within 30 minutes of receiving a dose of prednisolone, repeat the same dose again. If your child vomits after 30 minutes of receiving the dose do not repeat the dose and wait until the next normal dose is due.

If your child continues to vomit or you are concerned they are unwell please contact the children's nephrology team.

Medication that protect against infection

All anti-rejection medicines act on the body's immune system. They reduce the body's ability to either detect foreign substances or fight off attacks. This is good for preventing rejection of your child's new kidney, but it also means your child cannot easily fight off infections caused by viruses, bacteria or fungi. All transplant patients have a higher risk of infection compared to people not taking immunosuppression medicines. This is especially true during the first few months following the transplant, when doses or amounts of anti-rejection medicines are at their highest. Infection can be just as life threatening as rejection and should be taken very seriously.

Antibacterial medicines

To prevent bacterial infections, particularly lung and urinary tract infections, your child will be prescribed an antibiotic called **Cotrimoxazole (co-try-mox-a-zol OR septrin)** which contains two medicines called trimethoprim and sulfamethoxazole. Cotrimoxazole comes as 480 mg tablets or in two liquid forms, 480 mg in 5 ml and 240 mg in 5 ml. It should be given by mouth or via your child's feeding tube in the evening. If your child is allergic to either of these medicines, you must make the children's nephrology team aware and an alternative can be prescribed. The children's nephrology team will let you know when your child can stop this medication, usually six months after the transplant.

Antifungal Medicines

Nystatin (Ni-sta-tin) is given to prevent fungal infections; this is usually just for the first 3 weeks after the kidney transplant operation. Nystatin comes as a liquid that should be dropped into the mouth four times a day. It should be kept in contact with the mouth for as long as possible. In some instances, your child may be prescribed Fluconazole (Flu-con-a-zol) for a longer period instead. If this is necessary the children's nephrology team will talk to you and your child in more detail at the time.

Antiviral Medicines

Valganciclovir (Val-gan-cy-clo-veer) is given to some patients to prevent a viral infection known as cytomegalovirus (CMV).

The most common cause of viral infections in transplant patients are CMV (which stands for cytomegalovirus) and herpes viruses.

Herpes simplex viruses can cause cold sores and genital sores (although it is usually not transmitted sexually). Herpes zoster infection can cause chickenpox and shingles. If you think your child has a cold sore or has been exposed to chickenpox/shingles you should speak to the children's nephrology team as your child may need stronger medication than you can buy in your local pharmacy.

If your child is particularly at risk of developing CMV infection after their transplant your child will be started on Valganciclovir. Valganciclovir is available as a 450mg tablet or a 50mg/ml liquid. The dose of valganciclovir required may change depending on transplant kidney function so always make sure you are aware after clinic what dose your child should have. If your child needs treatment with valganciclovir this is usually continued for 3 months after the transplant operation. However length of treatment can vary based on circumstances for individual patients and you will be given specific instructions about valganciclovir by the children's nephrology team.

Other Medications

Initially after the kidney transplant your child will receive **Enoxaparin (E-nox-e-par-rin)** to reduce the risk of blood clots. This is administered to your child as an injection, usually into the leg, twice daily for the first week. We can insert an insuflon (a small cannula that sits just under the skin) into the leg to make the injections more comfortable for your child.

Once your child is mobile and eating and drinking, they will be changed from enoxaparin to aspirin. **Aspirin (Asp-rin)** is used to prevent the formation of blood clots and your child

should continue this for a minimum of 3 months after the kidney transplant operation. Aspirin can irritate the stomach so should be given with or after food.

Some of the medication used after a kidney transplant can cause stomach (gastric) irritation, therefore initially your child will be started on **Lansoprazole (Lans-o-pra-zol)** to reduce the amount of acid produced by the stomach. This is usually stopped 1 month after the kidney transplant operation.

Discharge from hospital

Once your child has been discharged home we will make contact with your GP to make sure they have all the information they need, including important information about your child's medications.

The hospital will supply you with the first 3 months of medication after your child's transplant, after this period the medication should be ordered and supplied from your child's GP.

It is very important that you do not run out of medication. Ensure you order your child's medicines from their GP when you have 2 weeks remaining supply of the medication.

Occasionally it may be necessary to change some of the doses of your child's medication. This often needs to be done over the telephone after your appointment, once the children's nephrology team have seen your child's blood results. It is essential that the children's nephrology team has an accurate record of your child's medication at each appointment so you will be asked to bring all your child's medicines to each appointment or bring digital photographs of all their medications that clearly show the strength and dose that your child is taking.

This booklet is a guide through some of the important information regarding your child's medication after a kidney transplant. A member of the children's nephrology team will talk through the information in this booklet before you are discharged home.

As a team we are here to support you and your child through their transplant and beyond, so ask questions, talk things through if you need to.

More information about kidney transplantation can be found at www.infokid.org.uk and information about transplant medication can be found at www.medicinesforchildren.org.uk

Useful contact details

Renal clinic nurse specialists:

Office - 0113 3925241

Mobile - 07733 001247 or 07810 836456

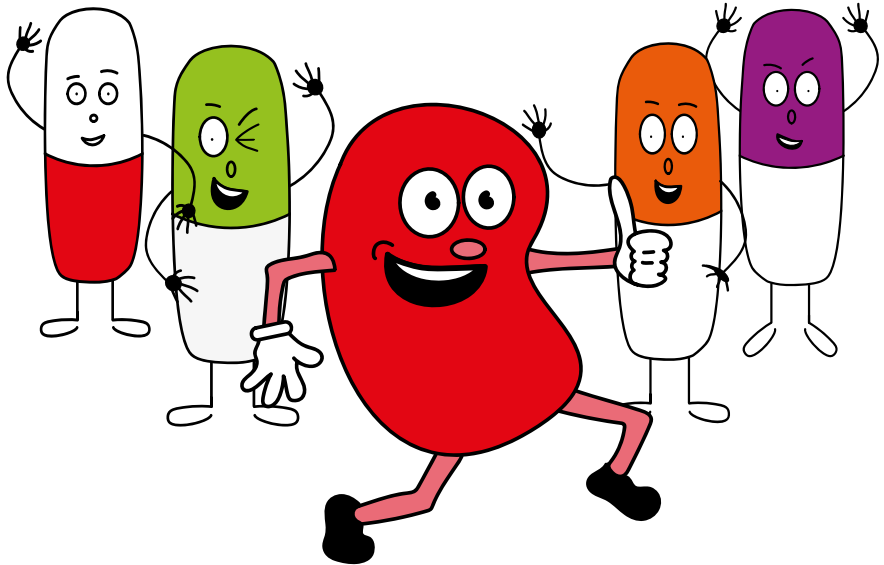
Email - leedsth-tr.paediatricrenalservice@nhs.net

Children's nephrology administrative team:

0113 3925583 or 0113 3925640

Children's nephrology ward:

0113 3927450 or 0113 3927550



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Produced by: Medical Illustration Services • MID code: 20240926_003/DG

LN005449

Publication date

11 / 2024

Review date

11 / 2027