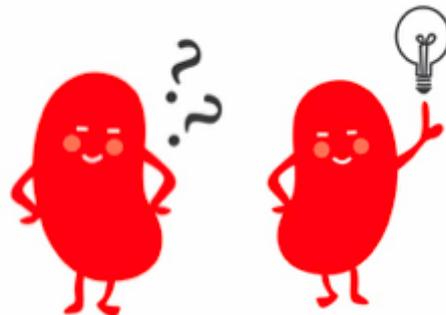


Kidney transplant

Medicine information

Patient name:	
Date of birth:	
Medical record number:	
Kidney transplant date:	



The aim of this booklet is to educate families about medications used for kidney transplant recipients. Please read this booklet carefully and speak to the renal team at PCH if you have any questions or concerns.

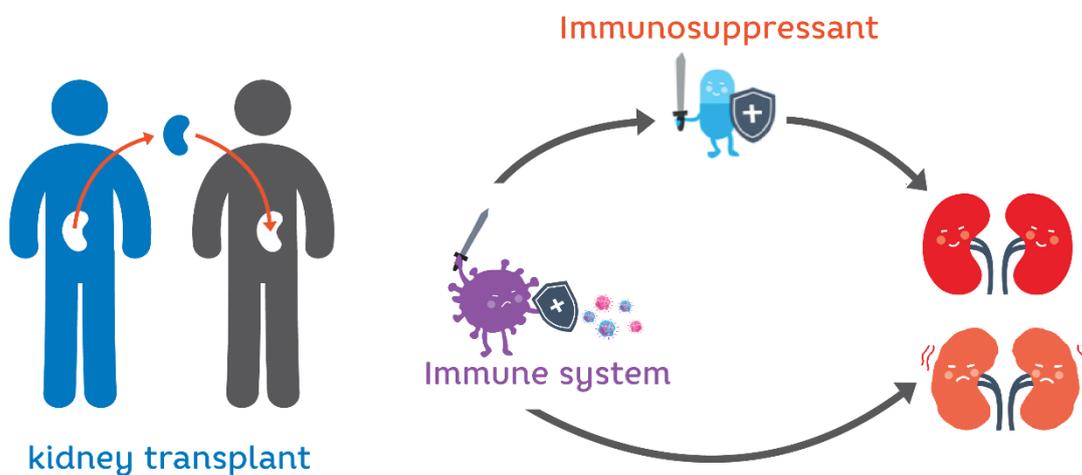


Immunosuppressants

Tacrolimus, Mycophenolate mofetil, Azathioprine, Everolimus

What are immunosuppressants?

Immunosuppressants are medications designed to prevent kidney transplant rejection. As the new kidney is not originally part of your body, the body's immune system will naturally start to attack it resulting in rejection without these medications. While the risk of rejection is greatest early after transplantation, lifetime immunosuppressive medications are required. Long-term outcomes are closely related to people's ability to continue taking their medications.



Kidney transplant

How should I take immunosuppressants?

- Swallow tablets or capsules whole.
- Shake tacrolimus and Mycophenolate suspension well before use.
- Use an oral syringe to measure the prescribed dose of liquid immunosuppressants accurately.
- Take immunosuppressants consistently with respect to food.
- If your child vomits within 30 minutes after taking an immunosuppressant, then repeat the dose.
- If you miss a dose, contact the renal team for advice.

Never take a double dose to make up for the missed dose.

Top tips to help you remember to take your immunosuppressants

- Try and take them at the same time each day to make it part of your daily routine. This will also help maintain stable immunosuppressant levels.
- For capsules and tablets, you can use dose aids such as pill boxes to help you organise your medications for the entire week.
- You can ask your community pharmacy to pack your medications in a blister pack (e.g. Webster pack) for a small fee.
- You can set a reminder for when to take each medication using phone apps such as 'MedicineWise: Manage Medicine' app which is free
- Keep an up-to-date medication list to help you remember how much to take of each medication and when to take it.
- Take a small amount of your medication in your bag when going out, so that you don't miss any dose.

What might I expect when taking immunosuppressants?

You will not see or feel any difference when you are taking immunosuppressants. If you stop taking it, your body will reject the new kidney, which can make you very sick. Like all medications, there are some side effects to be aware of:

- Diarrhoea
- Stomach upset or vomiting
- Headache
- Finding it hard to fall asleep
- Tremor
- Muscle cramps
- Rash
- Hair loss



Some of these side effects go away with time as your body gets used to these medications. If any of these side effects are bothering you, then you should tell your renal doctor.

What are the long-term risks of immunosuppressants?

Taking immunosuppressants results in greatly improved survival and a better quality of life after receiving the new kidney. However, taking these medications also comes with some health risks, including an increased risk of infections and some types of cancer.

Immunosuppressant-associated infections

Taking immunosuppressants can increase your risk of opportunistic infections, from bacteria, fungi, or viruses that are commonly present in our environment that are usually kept in check by the immune system. To reduce the chance of these becoming a problem you will:

- Be prescribed anti-infective medications like co- trimoxazole and valganciclovir
- Get required vaccines before your kidney transplant if possible
- Receive regular bloods tests and physical checks for any signs of active infection in your body
- Have access to the renal team to discuss your care anytime you have a fever over 38.5C (as this can be a sign of infection) or if you come across anyone with an active infection such as chickenpox, shingles or measles.

Immunosuppressant-associated cancers

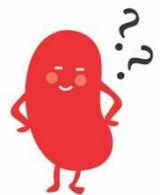
Patients who take immunosuppressant medications are at a higher risk of developing skin or blood cancer. With modern treatment and monitoring protocols these are less common and less of a risk to your health than severe rejection, which occurs when immunosuppressive medication is stopped. **For that reason:**

- Your renal doctor will take blood tests on regular basis to screen for any signs of blood cancer.
- The skin doctor will check your skin before kidney transplant and educate you about skin cancer prevention. You will also receive skin checks at least once a year to check for any early signs of skin cancer.
- It is important to be sun smart while taking immunosuppressants to reduce the risk of skin cancer. This involves wearing protective clothes and putting on sunscreen regularly when you are outdoors.
- You should tell your doctor immediately if you notice any changes to your skin such as the appearance of new moles.

What are the necessary monitoring requirements?

In addition to the regular monitoring already discussed, you will need regular monitoring to ensure you and your new kidney are kept as healthy as possible. These include:

- Blood tests to measure the level of immunosuppressant in your body; this is known as therapeutic drug monitoring
- Blood pressure
- Urine samples
- Taking blood samples to find out about your:
 - kidney function (changes to function can be detected and treated much earlier using regular blood tests)
 - Liver function
 - blood sugar levels
 - blood counts.



What is therapeutic drug monitoring?

It is the measurement of medication level in the blood by taking blood samples. Based on this monitoring, your renal doctor can then adjust your immunosuppressant doses to make sure they are not too high (to minimise side effects) and not too low (to prevent kidney transplant rejection).

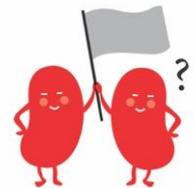
Following kidney transplant, blood tests are required regularly, however they will be much less frequent with time. It is important to have your blood tests done at least two days before seeing your doctor for review. This will be organised by the renal team at PCH.

When should I contact the renal team?

- signs of infection such as fever > 38.5 celcius
- unusual bruising or bleeding
- coca cola or tea coloured urine
- difficulties passing urine
- severe headache or changes in vision
- finding it hard to breath or having chest discomfort
- swelling, such as at ankles or around the eyes
- feeling very tired, dizzy or looking pale
- cramping muscles or tingling around the mouth
- if you or anyone in your house meets someone with chickenpox, measles or shingles.

Can I take immunosuppressants with other medications?

Immunosuppressants interact with many medications, so make sure that you ask the renal team **before** you start taking any new medications. This includes vaccines and medications that you buy from your pharmacy with or without doctor's prescription, herbal and complementary medications.



How should I store immunosuppressants?

Make sure that immunosuppressants are kept in a place that is away from direct heat or sunlight and out of reach of children, for example in a cupboard.

Tacrolimus capsules

- Keep each of the blisters in the aluminum foil and open one foil at a time.

Tacrolimus suspension

- Store in room temperature (below 25°C) but **do not** refrigerate or freeze.

Reconstituted mycophenolate suspension

- Store below 25°C or refrigerate but **do not** freeze.

How should I handle and dispose of immunosuppressants safely?

- Wash your hands after handling immunosuppressant capsules, tablets or liquid.
- It is recommended that your pharmacy adds water to mycophenolate suspension before giving it to you. If you are making it up at home, then make sure that you

- wear gloves.
- Avoid inhalation or direct contact with skin or mucous membranes, such as eyes. If such contact occurs, then wash the skin thoroughly with soap and water.
 - If it comes into contact with your eyes, then rinse eyes well with water.
 - Wear disposable gloves if immunosuppressant capsules break open accidentally or if liquid immunosuppressant is spilt and make sure that you clean it off thoroughly with soap and water.
 - Take any unwanted immunosuppressants to your local pharmacy for appropriate disposal.
 - If your child vomits after taking an immunosuppressant, then it is recommended that you wear gloves when cleaning it to avoid contact with the medication.

How can I fill my child's immunosuppressant prescriptions?

Once you obtain a prescription for immunosuppressants, please take it to PCH Dispensary to prevent switching brands. If you prefer to get your immunosuppressants from your local pharmacy, that is fine. However, ask your pharmacist not to switch brands.

Anti-infective medicines

Valganciclovir, co-trimoxazole

What are anti-infective medications?

Following renal transplant, patients usually take an anti-viral medication called Valganciclovir. This helps preventing infections caused by a virus known as Cytomegalovirus or CMV.

Patients also take co-trimoxazole which consists of two antibiotics called sulfamethoxazole and trimethoprim. Co-trimoxazole prevents the growth of some types of bacteria and fungus such as *P. jirovecii* and *Toxoplasma gondii*.



How should I take Valganciclovir and co-trimoxazole?

Take valganciclovir **once daily** in the morning for six months or per your renal doctor's advice. Take it with or soon after food in the morning.

- **Liquid valganciclovir:** reconstitute as per the instructions on the bottle and keep it in the fridge. Shake well before use and discard any remaining contents 49 days after reconstitution.

Take co-trimoxazole **once daily** at night after food.

- **Liquid co-trimoxazole:** shake well before use.

What should I expect after taking Valganciclovir and co-trimoxazole?

You should not see any difference while taking Valganciclovir and co-trimoxazole regularly. Stopping these medications without your doctor's advice can cause serious infections in people with weak immune system.

You might experience some of the follow side effects

Co-trimoxazole

- An increase in sensitivity to sunlight and susceptibility to sun burn.
 - Reduce exposure to sunlight by applying sunscreen and wearing a hat and covering clothing when outdoors.
- Stomach upset or cramps.
- Nausea or vomiting.
- Poor appetite.
- Diarrhoea.
- Sore, white furry patches on your tongue and mouth cheek (oral thrush).

- For girls, it can cause sore and itchy vagina (vaginal thrush) or vaginal discharge.

Valganciclovir

- Headache
- Nausea
- Looking pale
- Sore, white furry patches on your tongue and mouth cheek (oral thrush)

When should I contact the renal team?

- Signs of an allergic reaction such as skin rash, swelling of the tongue, lips or throat
- Worsening of your eyesight
- Unexplained bruising or bleeding
- Agitation or confusion
- Marked weakness or tiredness
- Yellowing of the skin or eyes

Prednisolone

What is prednisolone?

Prednisolone is another immunosuppressive medication given after transplantation. It belongs to a class of medications called steroids. Depending on your specific immune-related risk of rejection, you may be prescribed steroids after transplantation.

How should I take prednisolone?

- Take prednisolone **once** each day in the morning with or soon after food.
- It is important to continue taking this medication regularly for it to work. Stopping it suddenly can cause unpleasant side effects.
- Prednisolone liquid should be discarded four weeks after opening.

What should I expect after taking prednisolone?

You might not feel any different while taking prednisolone but it is important to keep taking it to prevent kidney transplant rejection.

You might experience some of the following side effects:

- Difficulties falling asleep, taking it in the morning can prevent this from happening.
- Stomach ache, feeling sick (vomiting) or acid reflux (heartburn). Taking prednisolone with food can reduce this.
- Prednisolone can increase appetite, so it is important to have a balanced diet and exercise regularly.
- Prednisolone can reduce cortisol which is a hormone that your body produces naturally. This can be important when there are other stresses on the body such as surgery or infection, and your doctor may prescribe different steroids or temporarily increase the dose at such times.



After taking prednisolone for a long period of time, you might experience some of the following:

- Increased risk of infections such as chicken pox, shingles and measles
- Thinning of the skin and slowing skin healing
- Reduction in growth of young children
- Increase in body hair growth (hirsutism)
- Reduction in the thickness or density of bones making them more likely to fracture (osteoporosis)
- Weakness of the muscles which increases the risk of injuries (myopathy)
- Feeling thirstier than usual or needing to go to the toilet to pass urine more frequently than usual. This can be due to an increase in blood sugar level (diabetes)
- Bruising easily.

These side effects are dose dependent and usually not noticeable at the low doses used for patients with a stable kidney transplant and will be monitored by the renal team to prevent them when possible.

When should I contact the renal team?

- Being exposed to an injury or needing to undergo a surgery
- Severe stomach pain or repeated vomiting
- Unexplained rash, bruising or bleeding
- Unexplained eye pain or a sudden change or worsening in vision
- Feeling thirsty or needing to go to the toilet to pass urine more than usual
- Unexplained mood changes such as feeling very sad or very happy for no particular reason or having sleeping problems
- Unexplained weight gain
- Having irregular periods in girls
- Having an irregular heartbeat.

Useful resources

[Australian Government Therapeutic Goods Administration Consumer Medicine Information](#)

- Search for medications

[Medicine for children](#)

- Leaflets on medicines

[Kidney Health Australia](#)

- Kidney transplants

Contact us

Phone:

Email:

If you can't get in touch with your team, please go to the Emergency Department at Perth Children's Hospital.



Government of **Western Australia**
Child and Adolescent Health Service



Child and Adolescent Health Service
15 Hospital Avenue, Nedlands, WA, 6009.
Telephone: (08) 6456 2222
Produced by: Child Protection Unit
Ref: 1308 © CAHS 2021

This document can be made available in alternative formats on request for a person with a disability.

Disclaimer: This publication is for general education and information purposes. Contact a qualified healthcare professional for any medical advice needed.
© State of Western Australia, Child and Adolescent Health Service.