Life After A Kidney Transplant

a family handbook



This handbook is to provide information and support to families after a kidney transplant. We hope it will help you to manage your child's care and be able to enjoy life, from this point forward, with their new kidney.

Hôpital de Montréal pour enfants

Centre universitaire de santé McGill



Montreal Children's Hospital

McGill University Health Centre

Acknowledgements

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IMPORTANT

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.





Office d'éducation des patients Patient Education Office



This material is also available through the MUHC Patient Education Office website www.muhcpatienteducation.ca

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Dear Parent

A message from your kidney transplant team

Congratulations! Your child has just had a kidney transplant. It's time to go home from the hospital with their new kidney. Sometimes this can be both exciting, and stressful.

Your child's kidney transplant will offer you and your child a more normal lifestyle. Soon, your new day-to-day routine will become part of your normal routine. However, right now, you may be a little nervous about the future, about all of the new medications, about the risk of rejection, and about being different. All this is perfectly normal! You are not alone. Other parents have had the same experience as you and our healthcare team is here to support you.

Using our experience and what parents have told us, we designed this handbook to be useful, practical and easy to read. We hope that it will help as you learn about living with a kidney transplant and how to make this a part of your daily lives. This handbook is meant to help us help you have the most successful outcome possible with your new kidney transplant. You can look up information here during your meetings with the kidney transplant team. You can also review this information later at home.

We hope that this will support you during this exciting time. We trust it will help you and your family adapt as you and your child learn to live life with their new kidney.

Your Kidney Transplant team

(Pediatric Nephrology)



How to use this handbook

Throughout the upcoming months, you will meet a number of healthcare professionals who will provide you with a lot of information. Bring this handbook to each of your appointments. It will help you make sense of and manage all this new information.

Children with kidney transplants can lead happy and fulfilled lives. We encourage you to read this handbook and discuss it with your child, your doctor, your nurses or other members of your treatment team.

Ask us your questions. We are here to help!



Finding the right information for your child

Many people may try to give you and your child health advice without knowing the details of your child's health and recent kidney transplant. You may also find information in books or on the internet which is confusing or misleading.

Be cautious of the information that comes your way: the internet offers a lot of information. However, not all of it is correct. Also, not everything you read will apply to your child's unique situation.

Write down your questions or bring any information you have found to share with your kidney transplant team. We are here to help you make sense of the information you have found and learn how it may apply to your child's unique situation.



Your health care team: who and when to call

You may reach the Montreal Children's Hospital's

Kidney Transplant Program by calling the

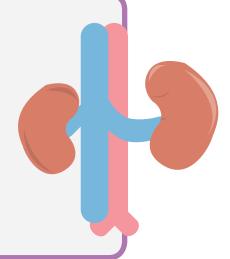
Pediatric Nephrology department.

The Nephrology Department is available on:

Weekdays (Monday to Friday),

From 8 AM to 4 PM.

Phone: 514-412-4461



Call the kidney transplant nurse for questions or concerns about:

- Your medications, side effects, refills.
- Monitoring weight, temperature, blood pressure at home.
- Transplant issues at home, school or daycare.
- Any unusual symptoms.
- How your child is managing.

The nurse is available on:

Weekdays (Monday to Friday),

From 7:30 AM to 3:30 PM.

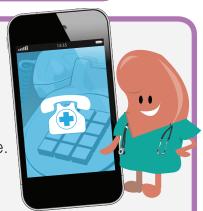
Phone: 514-412-4400 ext. 22523 (Leave a message anytime.)

Fax: 514-412-4359

Email: angela.burns@muhc.mcgill.ca

If the kidney transplant nurse is not available, call 514-412-4400 and ask for the Montreal Children's Hospital nephrologist on-call for any of the following reasons:

- Your child has vomiting, diarrhea, fever.
- Your child is in pain.
- You are having trouble with any medications (missed medications, side effects).



Call the nutritionist for questions or concerns about:

Appetite, food supplements, dietary restrictions, and food records. For information about what kinds of foods you can eat.

The nutritionist is only available on:

Weekdays (Monday, Wednesday and Thursday), From 8 AM to 4 PM.

Phone: 514-412-4400 ext. 22326

Email: lynn.mccauley@muhc.mcgill.ca



Call the social worker for questions or concerns about:

- Schooling, welfare, or insurance
- Making travel arrangements

The social worker is available on:

Weekdays (Monday to Friday), From 8 AM to 4 PM.

Phone: 514-412-4400 ext. 22089

Email: debbie.pealow@muhc.mcgill.ca



Phone: 514-412-4400 ext. 24455



Taking care of your new kidney at home

You can do the following things each day to take care of your kidney transplant. Research has shown these things will help you have the most successful outcome possible with your new kidney:



Drink plenty of fluids

Track your body changes

Take your medications as prescribed

You will be on quite a few medications to prevent rejection of your transplanted kidney. All of them will be absorbed from your stomach into your blood.

To work best, a very specific amount of each of these anti-rejection medications need to always be in your blood. For this reason, it is really important that you take these medications on a schedule (e.g. every 24 hours for medications given once in the morning, every 12 hours for medications given 2 times a day, or every 8 hours for medications given 3 times a day).

Being a few minutes off schedule, every once in a while, is not the end of the world, but taking your medication late on a regular basis will shorten the life span of your transplanted kidney.



See more detailed medication information on pg 26-52.

Drink plenty of fluids

You only have 1 kidney working now. Transplanted kidneys make a lot of urine, even if you haven't had a lot to drink! So, if you get a cold or the flu, or you work or play outdoors when it's very hot, you are much more likely to become dehydrated (compared to someone who has not had a transplant).

The best fluid to drink is water, but anything that becomes liquid at room temperature counts! So if you like ice, popsicles, jell-o or soup, they count as fluid just like juices, milk and water.



Did you know that even a little dehydration is not good for your kidney? Dehydration is the number one cause of injury to your kidney!

For this reason, it is a good idea to get in the habit of drinking plenty of fluids. Drinking plenty of fluids lowers the chances of:

- Kidney damage over the long-run.
- Kidney stones.
- Urinary tract infections.

Your doctor recommends that you drink _____ L of fluids per day.

Track changes in your body

The best way to take care of your kidney transplant is to take care of you!

For this reason, it is important to:



To help us keep track of how you are doing, you will need to be aware of any changes in your body at home. This includes your:



Weight

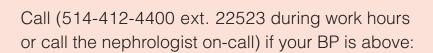
At first, you will be weighed each time you come to clinic. You may notice that you are gaining weight steadily over the first few months. Most likely, this is because you are feeling better and, as a result, eating more! Some medications may also increase your appetite.

It is important to pay attention to how much weight you gain after transplant. If you gain too much, it can affect your blood pressure and also be very difficult to lose. Please discuss this with your dietician to help you make good food choices.



Blood Pressure (BP)

Your kidney doctor may want you to check your blood pressure at home twice a day in the beginning. If your blood pressure stays too high, it can damage your new kidney as well as your heart. If you are on blood pressure medications, make sure to take them on schedule.







Temperature

If everything is running smoothly, your temperature should be around 37 °C (98.6 °F). Take your temperature any time you are feeling unwell or if you have the chills (this could mean your temperature is rising). Fever can be a sign of sickness or even kidney rejection.

Report any fever you've had for more than 1 day. If you suddenly develop a high temperature (above 38.5 °C or 101.5 °F), call us right away. Call 514-412-4400 ext 22523 during work hours or call and ask for the nephrologist on-call.





Illness and Symptoms

Along with your blood pressure and temperature, it is important that you write down any unusual symptoms each day.

For example, please keep a record of any of the following symptoms:





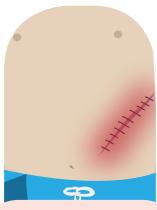






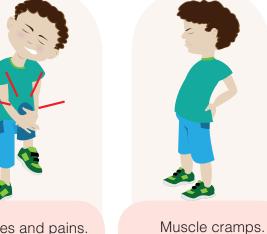


Less urine than usual, or a burning feeling during urination, or a change in urine color or odor.



Swelling, warmth or pain over the transplant scar.







Swelling in your feet, ankles or legs.

If these symptoms last more than a day, or if you have any concerns about your symptoms, please contact us. Call 514-412-4400 ext. 22523 during work hours or call and ask for the nephrologist on-call.



Important health care visits and check-ups



Meetings with your kidney doctor and transplant nurse Blood Tests

Meetings with your pediatrician

Eye care

Dental Care

Vaccinations



Now that you have your new kidney, it is very important that you keep your regular check-up visits as well as routine health care appointments. Keeping all your appointments will help lower the chances of developing serious complications and rejections.

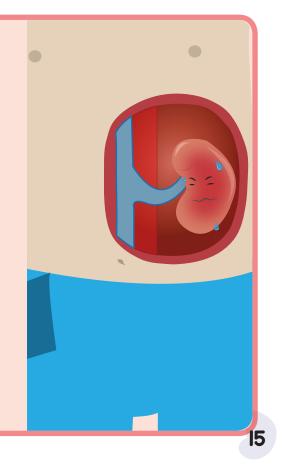
Rejection

Rejection is when your body thinks the kidney transplant doesn't belong there. It begins to try to destroy your new kidney. The chances for rejection are highest right after a transplant. The risk goes down with time.

In early rejection, you may not feel any different, but your blood tests can show changes.

Sometimes you may come for a routine visit and end up in the hospital for a day or 2!

During the 1st year after a kidney transplant, it is not unusual for patients to be hospitalized to diagnose and treat rejection or infections.



Meetings with your kidney doctor and transplant nurse

For the 1st year after your transplant, you will see your transplant team a lot! Plan to see your transplant nurse 2 or 3 times a week and your kidney doctor (pediatric nephrologist) once a week, when you first go home.

Over time, you will visit the clinic less often. For the first 1-2 months (depending on how you are doing), you will come to the transplant clinic every week. After a few months, you will only need to see your kidney doctor every 2 weeks, and less after that. Eventually, you will only meet with us once every 3 months.

To help you plan these visits, your transplant nurse will give you an appointment calendar. This way, you will know exactly when to come to the hospital.



When you come to clinic, please bring the following to review with your transplant team:

Your appointment calendar.

Su M

Your medications list.
 Your list of questions.





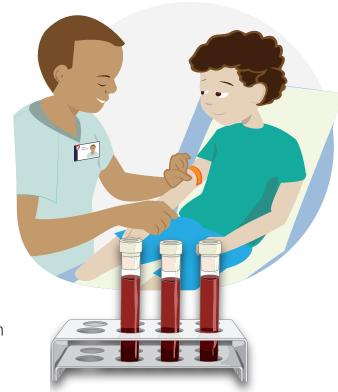
Please also come prepared to discuss any problems or questions you have. At each visit, we will review your medications. We will examine you, check your height and weight, and also take blood and urine samples.

Blood tests

You will need to do blood tests 3 times a week for about 4 weeks. After this, you'll need to do them 2 times a week for 8 weeks, and then, once a week for 6 months. Eventually, you will only need to do your blood tests once a month.

While the chance of rejection goes down over time, it never goes away completely. For this reason, you will always need to do these blood tests at least once a month. (If your blood test results are different to your normal, you may be asked to return on another day as well).

The good news is that, if it's not convenient, you do not need to come to the hospital every month to do your blood tests. We will help you find a place where you can do this near your home.



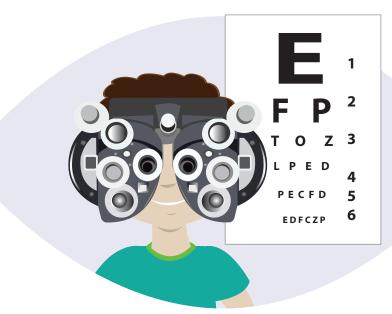
Monthly blood tests are very important because early rejection may have no symptoms. Also, the earlier we are able to treat a rejection episode, the less damage it can cause to your kidneys.

Meetings with your pediatrician

It is very important for you to have a pediatrician or family doctor near your home. Your pediatrician will work together with your kidney doctor to look after you. If your pediatrician prescribes a new medication for you, please double check with your kidney doctor before you take it. This way, we can make sure it doesn't affect your anti-rejection medications. The same goes for vitamins and over-the-counter cold and pain medications.

Please call us before taking any new prescription or non-prescription (including vitamins, herbal, natural, etc.) medications, so that we can help you make sure they do not affect your anti-rejection medications.





Eye care

You should have a routine check-up with your eye doctor (optometrist or ophthalmologist) once a year. After a transplant, you may have a bigger chance of developing eye problems. This may be because your immune system has been reduced or could be a side effect of your medications.

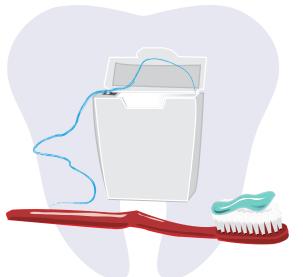
Dental care

From now on you will need to take a dose of antibiotics before all dental procedures (including cleaning). Please call us for a prescription to take before you visit your dentist.





You should see your dentist for a cleaning and checkup every 6 months.



Be sure to brush and floss your teeth daily.

Vaccinations

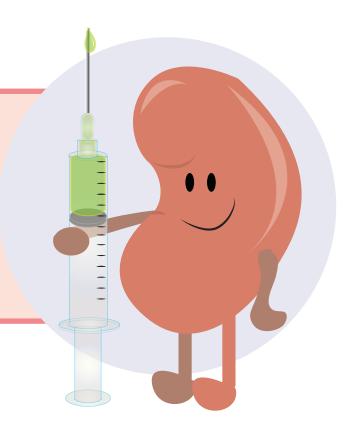
Before your transplant, we gave you many vaccinations to help fight infections that might happen after.

After your transplant, you can **no** longer have any "**live**" vaccinations. This is because you could develop the illness after taking the vaccination. Examples of "live" vaccinations, that you must avoid, are:

- Oral Polio.
- MMR (measles, mumps and rubella).
- Varivax (vaccine for the chicken pox).
- Flumist (the newest nasal spray influenza vaccine for the flu).

However, you will need to keep up with other regular vaccines, just like people who did not have a transplant. Please speak to your pediatrician and transplant team about this.

We recommend that anyone who has had a transplant take the regular influenza injection vaccination (flu shot) every year. Their family members should also get the regular flu vaccine each year, because this helps protect the transplant patient.



Remember that you may call us if you have any questions about vaccinations. Also please be sure to tell us about vaccinations that you might receive at school.



What to do if you get sick

Now that you have a transplant, you might become sicker than usual when you get a cold or a bug (although most mild illnesses are manageable at home). This is because you are taking anti-rejection medications. Even if you come down with a common illness (like chickenpox, a stomach bug, or a urinary tract infection), please call us. You may have to come to the hospital for a check-up. Sometimes you may need to be hospitalized to receive medication or IV fluids.

It is always best to call us before going to the emergency room. We will help you decide where to go to receive the best treatment. Sometimes this may be your pediatrician. Other times, this may be our clinic. Or, it may be the Montreal Children's Hospital Emergency Room.



If you are not well, call us first! You can reach:

Your transplant nurse

514-412-4400 ext. 22523 during the day on Monday - Friday.

The kidney doctor on-call (pediatric nephrologist)

514-412-4400

During the evenings, weekends or holidays.

Ask for the Montreal Children's Hospital nephrologist on-call.



Any other concerns?



Call us if you notice any of the following:

Nausea and vomiting (especially, if you cannot keep your medications down)



A new rash (could be an infectious illness)



Systolic Diastolic

Your blood pressure is above:



Temperature over 38.5°C (101.5°F)



You have less urine than usual



Any pain, tenderness, and/ or swelling around your new kidney



Diarrhea that lasts more than 1 day



The kidney transplant nurse is available on

Weekdays (Monday to Friday), from 7:30 AM to 3:30 PM.

Phone: 514-412-4400 ext. 22523 (Leave a message anytime.)

If the kidney transplant nurse is not available, call 514-412-4400 and ask for the Montreal Children's Hospital nephrologist on-call.

How to measure blood pressure

You may need to check your blood pressure at home: once in the morning and once in the evening.



The following can affect your blood pressure reading:



Follow these steps to take your blood pressure:

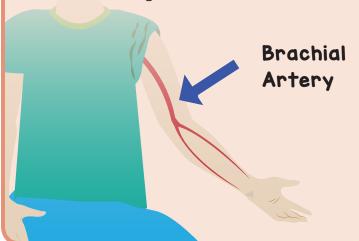
It is best to take your blood pressure after you have rested for 5 minutes.



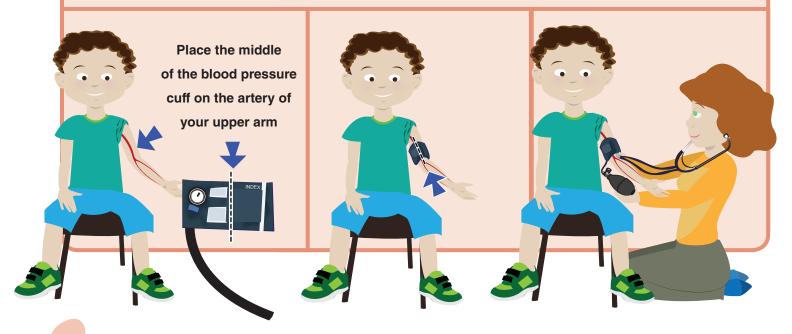
Make sure you are sitting down.
 (It is best to take your blood pressure after you have rested for 5 minutes). It is best to use



2. Use the same arm all the time to check your blood pressure. Usually it is better to measure blood pressure in the right arm. Your arm should be resting on an armrest during the measurement.



3. Cover the artery in your upper arm with the middle of the blood pressure cuff. Your cuff should fit snugly around your arm before you pump it up.



4. If your blood pressure is much higher or much lower than usual, wait 1-3 minutes and try again. (It is okay to take your blood pressure 2 or 3 times to be sure your reading is correct).



	Call us if your locuff reads abo	blood pressure ove:	
	/		
	Systolic	Diastolic	

Medications

After your kidney transplant, you will need to take anti-rejection medications (also called immunosuppressants) for the rest of your life. These medications prevent your body's immune system from seeing your new kidney as not belonging to you. Without them, your own body would attack the transplant and prevent it from working. This is called **rejection**.

Most people go home with 2 or 3 anti-rejection medication. You may also need some other medications. Examples are medications that treat side effects, prevent infection, and help control your blood pressure.

You will be responsible for taking all these medications! It is very important that you understand:

- The name and purpose of each medication.
- How to take each medication.
- When to take each medication.
- The main side effects of each medication.
- How long to continue taking each medication.
- What to do if you forget a dose.
- When and how to order your medication so you don't run out.
- To keep an updated list of your medications with you at all times.
- To organize a schedule with your health care team for your medications and stick with it.





Please call your Transplant team if:

1. You have prolonged vomiting and can't take your medications.



2. You can't get your medications (no way to pick them up, no money, pharmacy says your insurance won't pay, etc.)



3. You have any unusual side effects or symptoms.



4. You have forgotten to take your medications.



5. Any other doctor has prescribed medications for you for other problems. Some medications may interfere with your anti-rejection medications.



6. You want to take an over the counter medication or if you are thinking of taking any type of homeopathic or natural product.

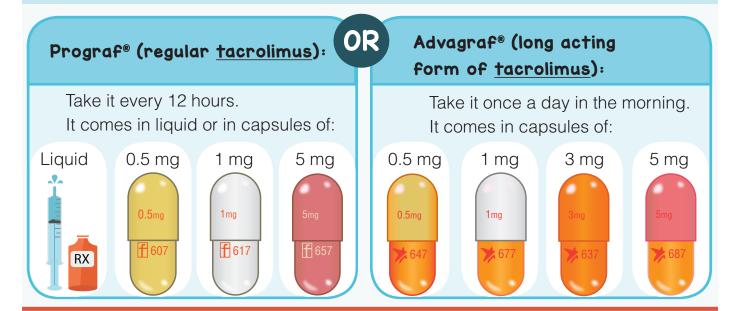


Tacrolimus (brand names: Prograf® / Advagraf®)

Purpose:

<u>Tacrolimus</u> is an anti-rejection medication. It is very important to prevent rejection of your kidney. It is used as long as you have your transplant kidney.

How to take it:



Important:



 Avoid grapefruit/grapefruit juice while taking tacrolimus. Grapefruit can affect the amount of tacrolimus in your blood stream. Please check the ingredient labels on fruit drinks to be sure.



<u>Tacrolimus</u> must be swallowed whole; the capsules must not be opened or crushed.



Tacrolimus (brand names: Prograf® / Advagraf®)

When to take it:

Tacrolimus needs to be taken on a schedule.

For example:

Every 12 hours if you need to take it twice a day



Every 24 hours if you need to take it once a day

It is best to take <u>tacrolimus</u> on an empty stomach because your body absorbs it much better.

This means either

1 hour before you eat



2 hours after you eat

Please discuss the best time for you to take your medications with your transplant nurse.

The amount of <u>tacrolimus</u> that reaches your blood stream is very important. If you don't get enough <u>tacrolimus</u> into your blood stream, it may not prevent rejection. But if you get too much <u>tacrolimus</u> into your blood stream, it may cause kidney damage. This is why we check the level of <u>tacrolimus</u> in your blood just before you take your morning dose. We need to make sure your level is not too low or not too high.

For example:

if you take your <u>tacrolimus</u> at 9 am and 9 pm, you need to have your blood test taken between 8:30 and 9 am **BEFORE** you take your morning <u>tacrolimus</u> dose.

The night before your scheduled blood test, you can take your evening dose of <u>tacrolimus</u> at the regular time.

The morning of the scheduled blood test, bring your <u>morning dose of tacrolimus</u> with you so that you can take it right **after** the blood test. Your doctor will use these blood test results to make changes in your <u>tacrolimus</u> dose, so it is very important to be accurate! **Same time, same way, every day!!!**

Tacrolimus (brand names: Prograf® / Advagraf®)

Main side effects:

Some of the side effects of <u>tacrolimus</u> include an increased risk of infection, an increase in your blood pressure, a slight shaking or tremor in your hands, tingling in your hands or feet, or headache. <u>Tacrolimus</u> can also make your blood sugar go up or increase the levels of creatinine.

Creatinine is a marker of kidney function and goes up when the kidney is not working well.

How long you will need to take it:

<u>Tacrolimus</u> is an anti-rejection medication. You will need to take it as long as you have your kidney transplant.

What to do if you forget a dose:

This medication is **critical** for the life of your kidney transplant, so missing a dose is no joke. **Every dose is important.**

If you forget a dose, take it as soon as you remember, and get back on your schedule. If you don't realize until it's time to take the next dose, don't take two doses at once.

Call your team to help you decide what to do if you have forgotten a dose.



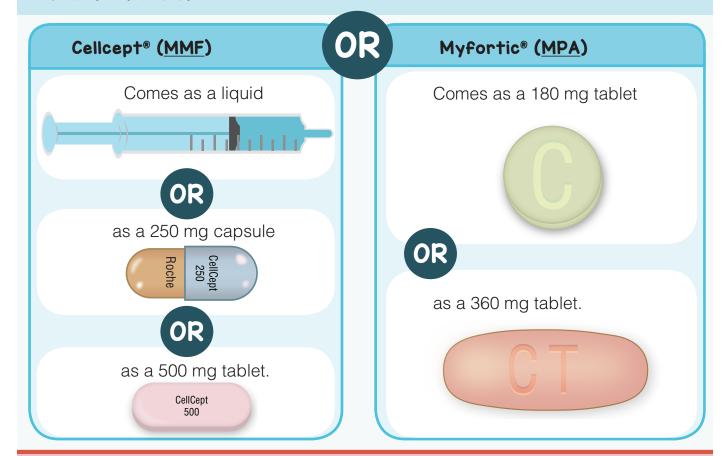


Mycophenolate mofetil - short name: MMF (Cellcept®) or Mycophenolic acid - short name: MPA (Myfortic®)

Purpose:

MMF and MPA are really the same medication. Your body changes MMF into MPA, the active form of this medication. This anti-rejection medicine works with your <u>tacrolimus</u> to help prevent rejection of your kidney.

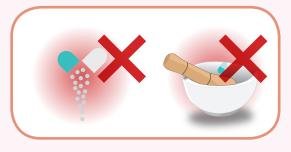
How to take it:



Important:

MMF and MPA must be swallowed whole. The capsules or tablets must not be opened or crushed.





Mycophenolate mofetil-short name: MMF (Cellcept®) or Mycophenolic acid-short name: MPA (Myfortic®)

When to take it:

Most people take their <u>MMF</u> or <u>MPA</u> twice a day. Your transplant doctor will tell you when you should take it. It can be taken at the same time as <u>tacrolimus</u> and your other medications.

Main side effects:

The most common side effects are decreased appetite, nausea, vomiting and diarrhea. There is also an increased risk of infection.

If stomach problems last a long time or are very bad your doctor may need to lower the dose or may suggest to take smaller doses more often.

DO NOT do this on your own!!

If the side effects are very bad, your doctor may need to change you to a different medication.

If you are thinking about getting pregnant, please contact your transplant team. This medication must not be taken during pregnancy. Your doctor will probably replace the <u>MMF</u> or <u>MPA</u> with another medication.



How long you will need to take it:

You will need to take it as long as you have your transplanted kidney.

What to do if you forget a dose:

Take it as soon as you remember and get back on your schedule. If you don't realize until it's time to take the next dose, don't take two doses at once. Call your team if you have forgotten a dose and they will explain how to make up the missed dose.

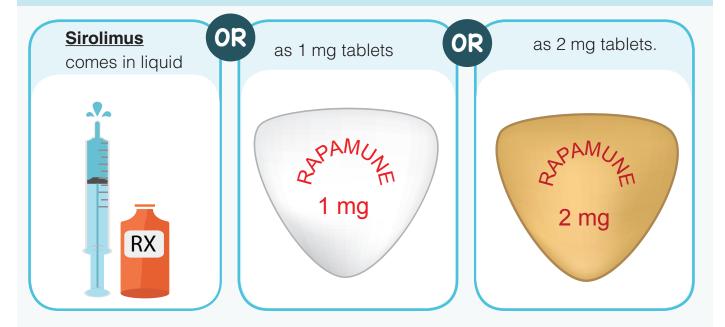


Sirolimus (Rapamune®)

Purpose:

<u>Sirolimus</u> is another anti-rejection medication that may be used to prevent rejection of your kidney. It is used as long as you have your transplanted kidney. It is usually taken instead of <u>tacrolimus</u>.

How to take it:



When to take it:

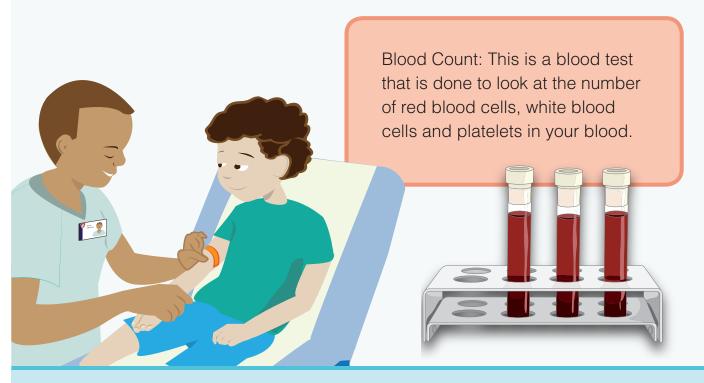
<u>Sirolimus</u> may be prescribed to be taken once a day in the morning or twice a day. You can take it at the same time as your other 'twice a day' medications. <u>Sirolimus</u> is monitored with blood tests just like <u>tacrolimus</u>. The blood test level is done just before the morning dose.

(Continued on the next page).

Sirolimus (Rapamune®)

Main side effects:

The side effects of <u>sirolimus</u> can change and are usually related to the level of the drug in your blood stream. The most common side effects are: an increased risk of infection, nausea, diarrhea, a low red blood cell count (anemia), high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, headache, acne, mouth sores, arthritis, swelling of hands and feet, and muscle cramping. Side effects usually get better as the dose is reduced.



How long you will need to take it:

You will need to take it as long as you have your transplanted kidney.

(Continued on the next page).

Sirolimus (Rapamune®)

What to do if you forget a dose:

This medication is **critical** to the life of your kidney transplant, so <u>missing a dose is no joke</u>.

Every dose is important.

If this happens, take it as soon as you remember, and get back on your schedule. If you don't realize until it's time to take the next dose, don't take two doses at once.

Call your team if you have forgotten a dose.





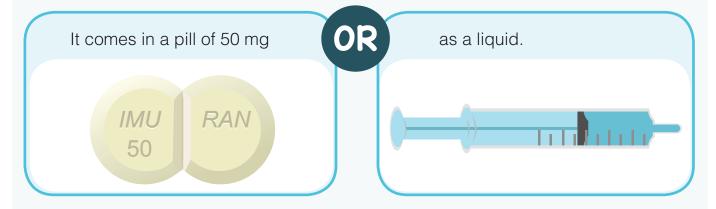
Azathioprine (Imuran®)

Purpose:

<u>Azathioprine</u> is an anti-rejection medication that works with your <u>tacrolimus</u> to help prevent rejection of your kidney. It is a helper immunosuppressant.

How to take it:

Azathioprine comes in liquid or in a pill and is given once a day.



When to take it:

You can take <u>azathioprine</u> in the morning or at night with your other anti-rejection medications.



(Continued on the next page).

Azathioprine (Imuran®)

Main side effects:

Azathioprine lowers your immune system so its main side effect is a higher risk of getting an infection. It can also decrease the number of the blood cells in your blood. Your team will monitor this and will adjust your medication if needed.

<u>Azathioprine</u> sometimes causes nausea or rashes. Call your transplant team if any of these side effects become a problem.



How long you will need to take it:

You will need to take this medication as long as you have your new transplanted kidney.



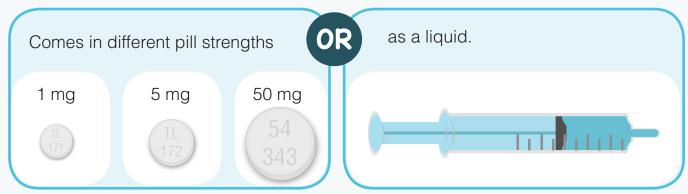
Prednisone

Purpose:

<u>Prednisone</u> works with your other 2 anti-rejection medications to help prevent rejection of your transplanted kidney. Sometimes we use it in very high doses to treat rejection.

How to take it:

Prednisone is available as a liquid and in different pill strengths.



Right after your transplant, while you are still in the hospital, your <u>prednisone</u> dose will be high.

Soon after, your kidney doctor will start decreasing the <u>prednisone</u> dose you are taking.

Your dose will be lowered over the next several months until you are on a very low dose or even none at all.



(Continued on the next page).

Prednisone

When to take it:

Usually your <u>prednisone</u> dose will be once a day, in the morning.

You can take it at the same time as your other medications. When your doctor starts to lower your dose, we may tell you to take your <u>prednisone</u> every second morning, not every day.

	Medicatio Momi				
Type of medication	Medication	Dose	Number	Ir 🛕	
Anti-rejection	Tacrolimus (Prograf)	1.5 mg	1 x 1 mg 1.0.5 mg		▼
Anti-rejection	Prednisone	5 mg	1 x 5 mg		
Anti-rejection	Cellcept (ABAE)	250 mg	2 x 250 mg	[] [] [] [] [] [] [] [] [] []	
Vitamin	Ferrous sulfate	60 mg elemental iron	1 x 60 mg		
Vitamin	Vitamin D	1000 iu	1 pill		
Bladder medication	Ditropan XL	5 mg	1 x 5 mg		
Supplement	Sodium Bicarbonate	12 mEq	2 x 6 meq	0	

Main side effects:

The side effects of <u>prednisone</u> are related to the dose you are taking. That means, the more <u>prednisone</u> you take, the more side effects you may have. Many of these side effects can be treated with medications and diet until your dose of <u>prednisone</u> is lowered.

The common side effects of <u>prednisone</u> include mood swings, stomach upset, fluid retention (swelling), increase in blood sugar levels, acne on the face, neck, and back, increase in blood pressure, increase in appetite, weight gain, and sensitivity to the sun.

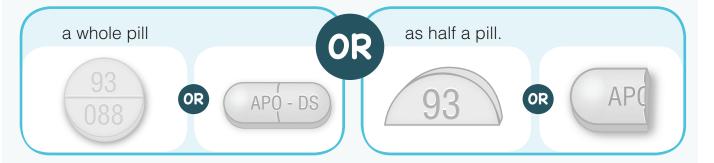
Cotrimoxazole (Septra®*)

Purpose:

<u>Septra</u>® is an antibiotic medication. That means it kills bacteria. When your immune system is lowered to prevent rejection, it may be harder for your body to fight off some infections in your lungs or in your urine. Taking <u>Septra</u>® will help your body to fight off some of these types of infections.

How to take it:

<u>Septra®</u> comes as a pill or a liquid. If you take pills, your pediatric nephrologist may ask you to take a half pill or a whole pill. The pills have a line in them where you can be easily break them in half.



When to take it:

Septra® is only taken once a day. It's ok to take it with your other medications.

Main side effects:

Sometimes <u>Septra</u>[®] causes stomach upset or diarrhea. You may also get an allergic skin rash, especially if you go out in strong sunlight.

If you get a rash, you should not take any more <u>Septra®</u>, and you should call your transplant team.



Cotrimoxazoles (Septra®*)

How long you will need to take it:

You will take <u>Septra</u>[®] every day for about 6 months. After that, you may take it only 3 times a week. Patients may take <u>Septra</u>[®] for the life of their transplant, especially if they have urologic problems.

What to do if you forget a dose:

Take it as soon as you remember and get back on schedule.

*People who are allergic to <u>Septra</u>® (a sulfa drug) will be prescribed a different antibiotic.

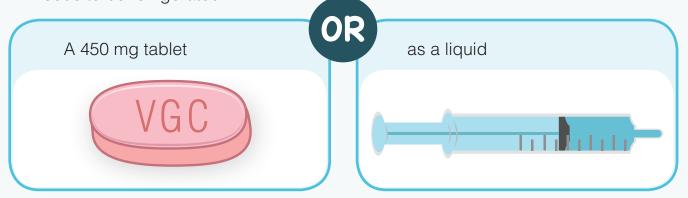
Valganciclovir (Valcyte®*)

Purpose:

We use <u>valganciclovir</u> to **prevent** and **treat** CMV infection. CMV is a very common virus. For most people it doesn't really cause much trouble. But when you have a transplant, your immune system is lowered, and this virus can make you very sick. Your doctor has checked your own blood and your kidney donor's blood to see whether either of you have had CMV before. If you and your donor have never had a CMV infection, you will not need <u>valganciclovir</u>. But if your donor has had a CMV infection, you will need to take <u>valganciclovir</u> for about 3 to 6 months after your transplant. This may not prevent you from getting the CMV virus from the donor kidney, but it can reduce the seriousness of the symptoms from the CMV virus.

How to take it:

<u>Valganciclovir</u> is available in a 450 mg tablet or as a liquid. The liquid form needs to be refrigerated.



Important:

<u>Valganciclovir</u> must be swallowed whole and should not be crushed.





Valganciclovir (Valcyte®*)

When to take it:

It is taken once a day, and it is better to take it with food.

<u>Valganciclovir</u> can be taken with your other morning medications.



Main side effects:

<u>Valganciclovir</u> can affect your blood counts. Your doctor will be monitoring your blood counts when you have your blood tests done.

If you have problems with low counts, your doctor may change your dose or stop the medication.



How long you will need to take it:

You will take valganciclovir for the first 3 to 6 months after your transplant.

What to do if you forget a dose:

Take it as soon as you remember, and get back on your schedule.

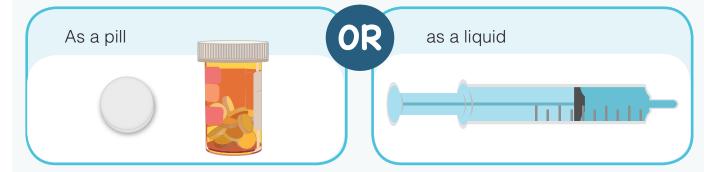
Blood Pressure Medications

Purpose:

You may have high blood pressure after getting your kidney transplant. Some of the medications you are taking can make your blood pressure go up. Changes in the amount of fluid in your body (fluid retention) can make your blood pressure go up too. Sometimes the kidney itself makes your blood pressure go up because of some hormones it is making.

How to take it:

Your pediatric nephrologist will decide which high blood pressure medication (or medications) you need. These medications come as pills or liquids.



When to take it:

Blood pressure medications can usually be taken once or twice a day. It is ok to take your blood pressure medications with your other medications.

How long you will need to take it:

Most of the time, as we lower the dose of <u>prednisone</u> and your body adjusts to your new kidney, your blood pressure will come down on its own. When this happens we can lower and often even stop the blood pressure medications.

What to do if you forget a dose:

Take it as soon as you can and get back on your regular schedule.

(Continued on the page 45).

Side effects for blood pressure medication

Medication:	Possible side effects:			
ACE inhibitors (ACEI) • Enalapril (Vasotec®) • Captopril • Lisinopril • Ramipril • Fosinopril	Dizziness, feeling faint, fatigue, cough, high potassium levels, increased creatinine levels, low red blood cell levels (anemia), funny taste in your mouth, swelling (angioedema) of your face, eyes, lips, tongue or throat (rare but important). Do not take if you are pregnant because it can affect the development of a baby during pregnancy.			
Angiotensin Receptor Blockers (ARB) • Losartan • Valsartan	Dizziness, cough, high potassium levels, increased creatinine levels, swelling (angioedema) of your face, eyes, lips, tongue or throat (rare but important). Do not take if you are pregnant because it can affect the development of a baby during pregnancy.			
Calcium Channel Blockers • Amlodipine (Norvasc®)	Swelling (especially in your legs and feet), redness in your face, a very fast heart rate (palpitations), dizziness, headache, fatigue, skin rash, itching, abdominal (belly) pain, muscle weakness.			
 Beta Blockers Atenolol (Tenormin[®]) Metoprolol (Lopressor[®]) Propranolol 	Low heart rate, fatigue, dizziness, lower sports performance (prefer to avoid in athletes), avoid if you have asthma or heart failure or have diabetes and are on insulin. Don't stop this medication suddenly (risk of extreme increase in BP).			
 Diuretics Furosemide (Lasix®) Hydrochlorothiazide 	Low blood pressure, low potassium levels, weakness, a very fast heart rate (palpitations), rash.			
 Alpha Blockers Prazosin (Minipress®) Terazosin (Hytrin®) Doxazosin 	Possibility of fainting with FIRST dose, dizziness (especially if you stand up quickly), palpitations, swelling, dry mouth, constipation, drowsiness, headache.			

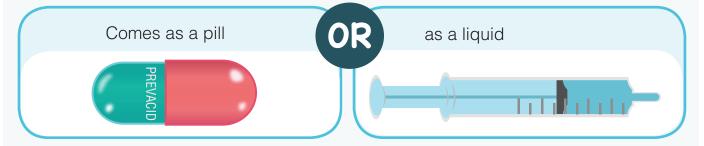
Prevacid® (Lansoprazole) or Losec® (Omeprazole)

Purpose:

These medications prevent or treat stomach upset and heartburn. Some of the medications you are taking for your kidney transplant can cause these symptoms.

How to take it:

These medications are available in pill or liquid form.



When to take it:

These medications are usually given once or twice a day. It's ok to take them with your other medications.

Main side effects:

Rarely, kids on these medications may have headaches, constipation, diarrhea, abdominal (belly) pain, nausea, dry mouth or dizziness.

How long you will need to take it:

This is up to your pediatric nephrologist. If you aren't having problems with stomach upset, you may be able to stop taking this medication during the first 6 months after your kidney transplant.

What to do if you forget a dose:

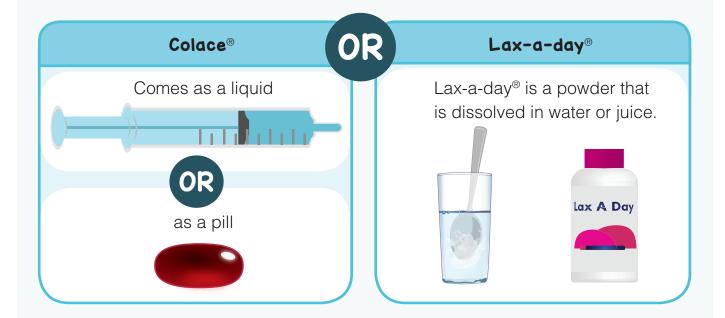
Take it as soon as you can, and then get back on schedule.

Stool Softeners Colace® / Lax-a-day® (polyethylene Glycol 3350)

Purpose:

These medications are stool softeners. Some of the medications you are taking may cause constipation. These will help prevent that.

How to take it:



When to take it:

Colace® is prescribed twice a day and Lax-a-day® is once a day. If you aren't having problems with hard stools or constipation, you can talk to your pediatric nephrologist about taking it less often, or only when you feel like you need it.

Main side effects:

There are no side effects from taking these medications.

How long you will need to take it:

You will need these medications if you have problems with hard stools (constipation).

Medications to treat electrolyte (body salts) imbalances:

Purpose:

Your electrolyte levels (salts) can be too low right after your kidney transplant. This can be because of how the new kidney is working at first. It can also be because of the medications you are taking. You may need to take some supplements to get your levels back to normal. After a while the kidney usually is able to balance your electrolyte level better and the supplements can be stopped.

Magnesium:

Magnesium is used to treat low magnesium levels. It may cause diarrhea, abdominal (belly) cramping, muscle weakness, high magnesium levels, and low blood pressure.

Sodium bicarbonate:

Sodium bicarbonate is used to treat low bicarbonate levels. It may cause edema (swelling), increased gas, diarrhea and abdominal distention (belly swelling).

Phosphorus replacement (KPhos, Joulie's solution):

These medications are used to treat low phosphorus levels. They may cause low blood pressure, high phosphorus levels, nausea, vomiting, and diarrhea.

You will also be able to discuss how to add some of these supplements naturally in the diet with your clinical nutritionist.

Over the counter medications:

Purpose:

After your transplant, you may have some everyday illnesses, just like everyone else. You may want to take medication to help with your headache or cold. Please remember that many medications can change the way your anti-rejection medications work. You must contact you transplant team or pharmacist to see if you can take any of these medications.

Always let your transplant team know if you are unwell and if you wish to take any over the counter medications from the pharmacy.

Here are a few common medications that are often taken and our recommendations:

Recommendations for over the counter medications:

Medication:	How to take it:		
Acetaminophen (Tylenol®)	Acetaminophen can be safely taken when you have a headache, fever or muscle aches. Never take more than what the directions on the bottle say for your age and size. If you are unsure about the dose, please contact your transplant team or pharmacist.		
Ibuprofen (Advil®, Motrin®, Midol®, Naprosyn®)	These medications are not recommended for transplant patients. These medications can affect the kidney and the liver. They may also cause stomach ulcers and bleeding.		
Anti Nausea (Dimenhydrinate / Gravol®)	You can take Gravol® if you have nausea and vomiting, however it is important to call your team to let them know if you are having these symptoms.		

(Continued on the next page)

Over the counter medications:

Recommendations for over the counter medications:

Medication:

How to take it:

Medications for seasonal allergies:

(Claritin[®], Benadryl[®], Allegra[®], Reactin[®])

You can use these medications safely with your transplant. If you have seasonal allergies (hay fever), these medications may make you feel better. Please let you transplant team know if you have allergies.

Herbal and homeopathic medications:



Do not use herbal products, herbal remedies and herbal teas after transplant.

These medications have not been properly tested and are not regulated. They may interfere with your anti-rejection medications by lowering the drug levels, and this may lead to a rejection of your transplant.

Nutritional supplements:



Some patients need to take a multivitamin after transplant, especially if they weren't eating well before transplant.

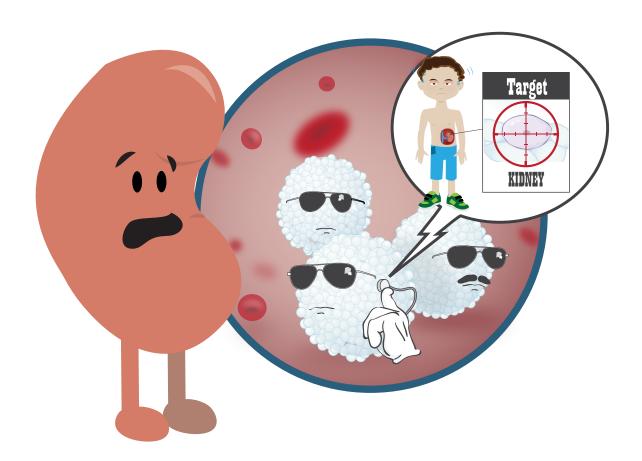
The transplant nutritionist will give you guidelines for healthy eating.

Other nutritional supplements (such as protein supplements and sports supplements) are **not** recommended for transplant patients. If you have any interest in these, please discuss with your transplant team.

Rejection of Your Transplanted Kidney

Rejection is when the body's immune system sees your transplanted kidney as something that doesn't belong to you and tries to destroy it. It can happen at any time, even many years after you've had your transplant.

Acute rejection is a sudden reaction of your body's defense system (immune system) against your kidney transplant. This rejection causes your kidney to stop working properly. If rejection is not treated, the kidney will be destroyed. If your team thinks you have acute rejection, you will have to come to the hospital.



The diagnosis is made by a procedure called a biopsy. A biopsy is when a small sample of the kidney is taken and looked at in the laboratory. The earlier we can diagnose a rejection and treat it, the better the outcome will be.

The treatment for acute rejection is usually strong anti-rejection medications given by intravenous (IV). The results of your transplant kidney biopsy will help your kidney doctor decide which IV medication is best for you. The idea is to stop your body's immune system's attack on the kidney, and to prevent rejection from getting worse.

Signs of Rejection

- 1. Increase in creatinine levels in your blood tests.
- 2. Pain, tenderness, or swelling over the transplanted kidney.
- 3. Increase in blood pressure.
- 4. Increase in temperature.
- 5. Less urine (pee) than usual.
- 6. Sudden increase in weight.



Call your kidney doctor if you notice any of these signs.
Your kidney doctor is available 24 hours a day, 7 days a week.



Remember, the earlier we treat a rejection, the less damage is done to your kidney transplant. A rejection episode that lasts a long time will cause permanent damage to your kidney transplant. Permanent damage may even lead to failure of your kidney transplant and you would need to go on dialysis.

One of the most common causes of acute rejection is **NOT TAKING YOUR MEDICATIONS!**

Chronic rejection is a gradual loss of kidney transplant function. This type of rejection usually happens several months or years after the transplant. The cause of chronic rejection seems to be related to not taking enough immunosuppressive medication over a long period of time. Treatment of chronic rejection is difficult. It eventually leads to failure of your transplanted kidney, and a need for dialysis. After that, you may choose to try for another transplant.

You need to remember that a kidney transplant is a treatment for kidney disease. The kidney may work for a short time, or for a long time, well into your adulthood.

Remember this kidney is "borrowed". Since it did not originally come from your own body, you will always need to take anti-rejection medications. You will need to have monthly lab tests, and regular doctor visits for the rest of your life.

Getting Back to Normal Activities

Avoiding and Minimizing Infection

Anti-rejection medications lower your natural immune system. That's why you need to protect yourself from getting an infection.

You can do this by taking the following steps:

■ Wash your hands often!

You should wash them:







- Keep an alcohol-based hand sanitizing gel with you for times when it's hard to wash your hands in a sink.
- For at least 6 weeks after your transplant surgery (examples of places to avoid during this time: school, shopping malls, movie theaters, places of worship).

You can go outdoors whenever you want.



Try to keep away from people with colds or other infections.

Ask friends to visit only if they are well and have not been around anyone who is sick.

If someone in your family gets sick with a cold or flu:



Ask them to cover their mouth and nose when they cough and sneeze.



Ask them to wash their hands often (or to use a hand sanitizing gel, that is alcohol based).



Avoid place where you could be exposed to mold.

This includes places like:







Speak with your nutritionist about how to prepare food safely to help prevent food poisoning.

If your water supply doesn't come from the city purifying system, please speak with your transplant team about safe water use (e.g. for drinking, brushing your teeth, washing your face).

Pay attention to water advisories in your area, especially in the summer. Water advisories are notices from the city that warn you when the water is not safe to use.

Procedures and surgery:

You may need to have a procedure or surgery for other reasons after your transplant. This could mean that you will need to fast (not eat) for several hours before. It's is important to discuss this with your team, to plan how you will take your anti-rejection

medications and the fluids you need. Usually it's OKAY to take your morning medications with a sip of water, but you may need some adjustments. Please contact your transplant nurse before your procedure or surgery.

If you take <u>prednisone</u> (steroids) regularly, then you may need to take an extra dose before a surgery or procedure. This is called a '**stress coverage**' dose. Sometimes the doctor will give you some steroid medication by intravenous (IV) for stress coverage. Please ask the doctors about this before you have a procedure or surgery.

Diet and Nutrition

It's really important to eat well after your transplant. It will help you get better faster and keep you healthy.

Eat a variety of foods, like fruits, vegetables, low-fat milk, dairy products, lean meats, fish, and poultry.

Milk

Avoid foods that have lots of fat and sugar. Your appetite will be **great** after your transplant but these foods can make you gain a lot of weight.



Some ways to help you eat healthy:





Use low fat dairy products to increase your calcium and phosphorus levels.

Occasional treats are okay! Your nutritionist can help you choose the best foods to eat.

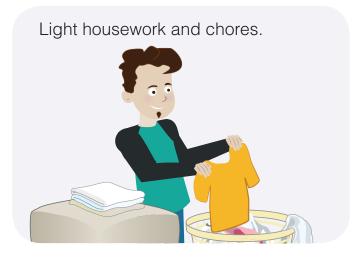
Activity immediately after transplant surgery

In the first month or two after your transplant AVOID the following activities:



Ask your doctor when you can start doing these things again.

It is OKAY to do the following:



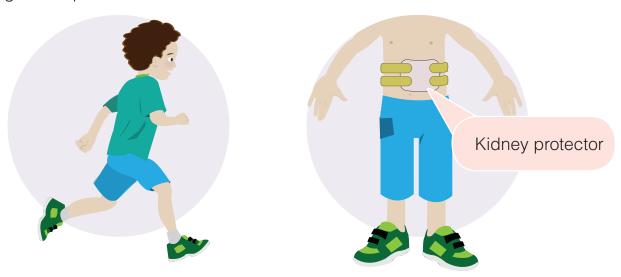




Long term activity / exercise

It is really important for you to do activities and sports outside of school. It will help you feel better overall.

Walking is a great exercise and you can do it every day. Aim for at least 30 minutes of walking a day. Sports are fine too. If you plan on participating in a contact sport, check with your transplant team first. We usually don't recommend full contact sports like football, hockey, boxing or lacrosse. But we'll help you get a "kidney protector" for playing other sports.



Returning to school or work

Most transplant patients can return to their normal routine by 6 weeks post-transplant. Your transplant team can help you transition back to school. Your nurse will provide you with helpful information for your teachers and care givers.



Skin Care

You and the Sun

It is very important to be careful in the sun.

All transplant patients have a higher risk of getting skin cancer or lip cancer. This risk builds up over time.

PLEASE, always protect your skin from sun's ultraviolet (UV) rays because these are what cause skin cancer.

How to protect yourself:

Avoid the midday sun (10 a.m. to 3 p.m.); this is when ultraviolet (UV) rays are the strongest.



Always use sun screen with a sun protection factor (SPF) of at least 15.



Wear a wide brim hat and sunglasses that block UV rays when outside in the sun.



Try to wear clothes with long sleeves and long pants when outside.

Try to stay in the shade.



Acne

<u>Prednisone</u> might cause pimples (**acne**) on your face, chest, shoulders or back. Your kidney doctor can prescribe acne treatment if you need it. Some patients may need to see a skin doctor for this.

Warts

Transplant patients often have problems with **warts**. They may get warts that are bigger and harder to treat. Transplant medications can make it harder to fight off the virus causing warts. If you get warts, have them checked by a dermatologist who has experience with warts in transplant patients.

Once you become a teenager you should see a skin doctor once a year for an annual check-up.

If you see something on your skin that worries you, please tell your transplant nurse or doctor.

Tell your kidney doctor if you discover:



Travel and Vacations

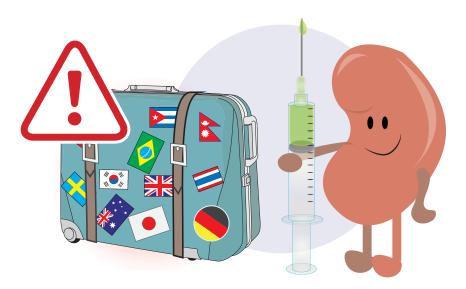
After your transplant, it's usually better to wait at least 6 -12 months before travelling, especially if you will be far from a large health center.

There are some important things to consider if you decide to travel, at any time after your transplant.



Location:

If you plan to travel to countries outside of North America, please visit a travel clinic a few months before you leave. You may need to get some extra vaccinations. You should always discuss this with your transplant team first.



Time zone:

If you travel to a different time zone, then you will need to adjust the timing of your anti-rejection medications. Your transplant nurse can help you make a schedule to gradually change the times.

Medications:

Always carry your medications with you in your carry-on luggage. Make sure you have some extra medications with you in case you are delayed returning home.

It is important to have a copy of your medication prescription with you when you travel, for customs and immigration, or in case you get sick and need to see a doctor.



Hydration:

This is very important to keep your kidney healthy. If you go to a warm, sunny place or do a lot of exercise, you will need to drink extra water. The water supply at your destination might not be as safe as the water at home; you may need to buy bottled water.



Illness:

Try to find out ahead of time where the nearest health facility is at your destination. Your transplant nurse or doctor can help you find the name of a transplant doctor at your destination, in case you get sick. Always carry a list of your medications with you and the contact numbers of your health care team.

It's a good idea to have your blood tests done and have a clinic visit before you leave on your trip, to make sure you are safe for travel.

If possible, arrange for travel health insurance and emergency trip cancellation insurance when you buy your plane ticket. This important for everyone, but especially important if you have a health condition.



Pets:

Pets are an important part of family life for many people. They can bring a lot of happiness to someone who has been ill.

Animals can carry diseases, but few are life threatening.

If you follow the common-sense guidelines below, the risks will be low.





Make sure your pet is healthy and goes for its regular vaccinations and check-ups.



Try to avoid your pet's bodily fluids (pee, poo or vomit). Have someone else in your family clean up messes.



Do not let your pet lick your face.



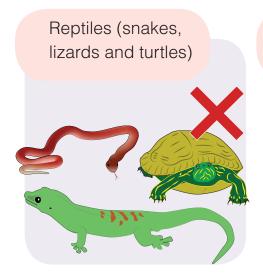
Never clean litter boxes or fish tanks. Someone else in your family can do this.

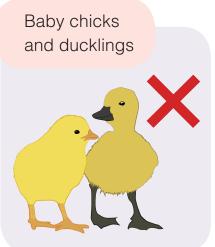


Avoid contact with sick pets, stray animals and exotic animals at all times.

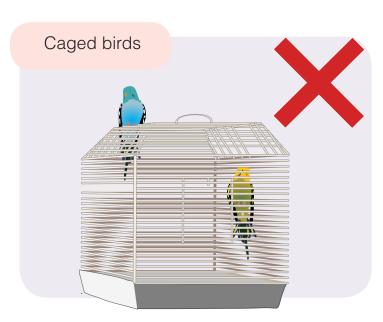


The following pets should be avoided by transplant patients:











Adolescent Issues:

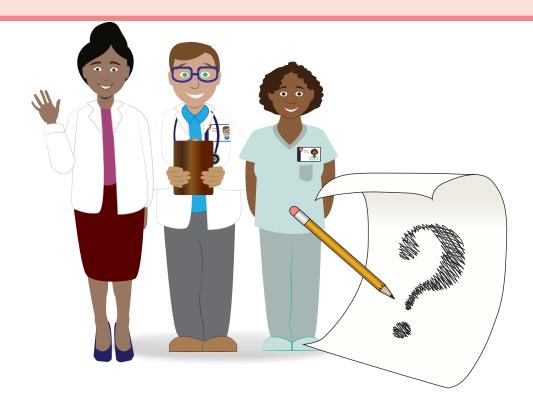
Adolescence is a very important period in your life. During this time, you become more independent and you find out who you are. You develop important relationships and you make important life decisions.

Some adolescents find it very hard to have a chronic illness and to take their medication every day. They may find it annoying to come to the hospital and may try to ignore their health issues.

If you feel like this, we understand and want to help. It's important that we work together as a team to make you as healthy and happy as possible. We, your transplant team, will talk with you about some of the important things in your life during your clinic visits.

We want you to ask questions about anything that concerns you. We will see you alone for part of your clinic visit. You should feel free to discuss anything that bothers you.

Your nurse and doctor are always available to talk when you have concerns.



Alcohol:

Alcohol is processed (metabolized) by the liver. It can affect how your body uses your anti-rejection medications. It is a good idea to avoid alcohol when you have a transplant. If you drink alcohol, you could forget to take important medications. This could lead to a rejection.

Please talk to your transplant nurse or doctor about drinking alcohol and about what to do if your friends are drinking.



Smoking:

Smoking is a risk for everyone. It causes cancer, heart disease and lung disease. It is not a good idea for transplant patients to smoke. Nicotine affects the blood vessels in your body and may lead to problems with the blood vessels in your new kidney.

If you smoke, please ask your nurse or doctor for help in finding a way to quit.



Drugs:

Drugs like cocaine, LSD and Ecstasy can be harmful to your body. Smoking marijuana can put you at risk for a serious illness caused by aspergillus (a fungus/mold found in marijuana). It is not a good idea to use these drugs when you have a transplant.

Please talk with us if you're thinking of using them or if your friends are using them.



Sexual health and fertility

Sexuality is an important part of life. Once you become sexually active, your transplant team might refer you to see a doctor and nurse from the adolescent team to discuss any concerns or questions you have. Important topics are birth control and infection prevention. Girls who are sexually active should see a gynecologist once a year for a routine examination and Pap test.

Safe sex is important for everyone to avoid getting a sexually transmitted infection (STI). Transplant patients have a higher risk if they get an infection because their immune system is reduced. Safe sex is the best way to protect yourself.

Safe sex includes:

- Always using latex condoms with spermicide.
- Limiting the number of your sexual partners.
- Avoiding sexual relations with anyone who has an STI or who has symptoms (open sores, rash or discharge from genitals).
- Asking your potential partner about their sexual history.
- Getting tested (both you and your partner) to know your infection risk before starting to have sex together.



If you think you might have an STI, don't wait! You can go to an STI clinic or community health center or speak to your transplant nurse or doctor.

Examples of STI symptoms:

- Burning or pain when you urinate.
- Strange or weird-smelling discharge from the vagina or penis.
- Itching, burning, or pain around the vagina, penis, or anus (bottom).
- Rashes, sores, blisters, or growths around the vagina, penis, or anus.

Having your own children after a kidney transplant

Having a baby is possible for people with a kidney transplant. Many women with a kidney transplant become pregnant. Many men with a kidney transplant become fathers. However, there are some important things to think about.



Pregnancy for women with a kidney transplant

If you are thinking of having a baby, please talk with your transplant team. This is something that's important to plan. We may need to change some of your medications and you will probably need care with a specialized obstetrician. You may worry whether your original kidney disease could be passed on to your children. Sometimes it may help to see a genetic counselor.

It's usually best to wait *at least* a year after your transplant before getting pregnant. This is to make sure that your kidney function and medication doses are stable.

Unexpected pregnancy

If you find out that you're pregnant, please contact your transplant team as soon as possible. An unplanned pregnancy could be a risk for both you and your baby. We will help you understand all your options and support you in

choosing the best path to follow. Some of your transplant medications could be harmful to your baby but stopping them could lead to a rejection. If you want to continue the pregnancy we will help you make any changes that are needed, in the safest way possible.



Fatherhood for men with a kidney transplant

Many men with kidney transplants can father a baby. A few transplant medications may interfere with sperm quality and number. Please talk to your transplant team about this. It's also important to ask your transplant team if the condition that caused your kidney problem could be passed on to your children. Sometimes they will suggest that you see a genetic counselor.

School / Work

School and work are important parts of our lives. After your transplant you can continue in school or with your job. You will need to be away from school/work for about the first 6 weeks after your transplant and may miss some days because of medical appointments. Your nurse or social worker can help you organize this and get the necessary papers for your school/work.



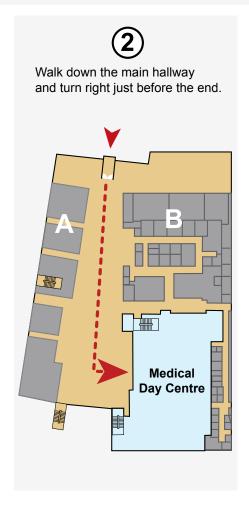
Transition

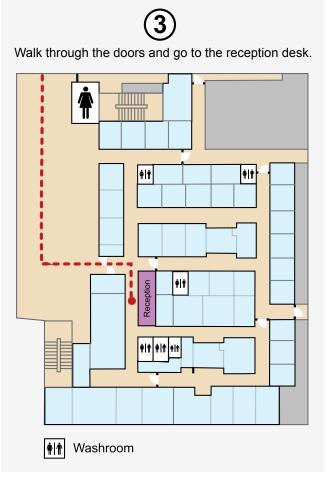
As you grow up to be an adult, your care will transfer from the pediatric to the adult transplant center. Changes can be exciting but are also sometimes scary. Your transplant team will help you get ready for this change a long time before you actually transfer. We will work with you and your parents and also with the adult care team. Gradually you'll take more and more responsibility for your health while still in pediatric care. It is normal for you to continue to need your parents' support and back-up during this time.

When the time comes to move to the adult center, your pediatric team will give your medical history to the adult care team and help you to arrange an appointment. We will also make sure you have a copy of your health summary and all your medications. Your transplant nurse will always be available by phone and will always be able to help you when you do not know what to do or who to call.

B RC Medical Day Centre







A2 South

Montreal Children's Hospital at the MUHC Glen site

1001 Décarie Blvd. Montreal, QC H4A 3J1

To get to A2 South:



Enter through the main entrance of the Montreal Children's Hospital.

