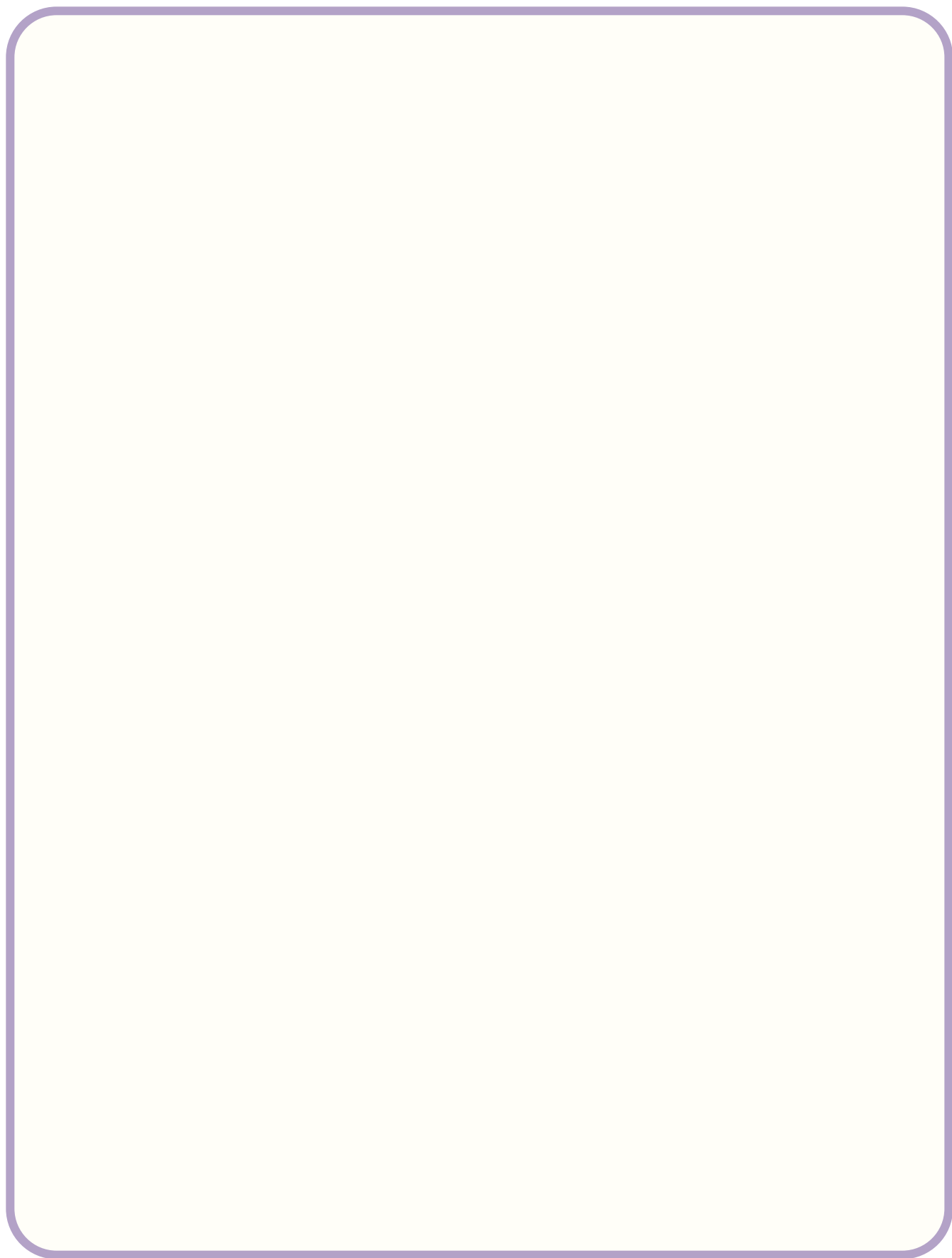


Having a Work up for Kidney Transplant: Tests and Appointments





Transplant Manitoba: Pediatric Kidney Program

Section of Nephrology

Children's Hospital of Winnipeg

Welcome,

You have decided to go ahead with a kidney transplant work-up.

This booklet will help you understand what tests and appointments are done to get you ready for a transplant.

Making sure you are healthy and safe for getting a kidney transplant is the reason you will have all of these tests and doctor visits.

This reading package has been made to help you understand all of the appointments and tests you will have during the workup for kidney transplant.

Please take some time to read this booklet. There is space at the end of each section for you to write any questions you may have to bring to your clinic visits.

If you have any questions about the test or doctor visits, please call us and we will be happy to go over what is in this booklet and answer any questions.

You can call the Pediatric Transplant Coordinator, Julie Strong, at 204-787-4842 or toll free at 1-877-499-8774 and ask for extension 74842 with questions you may have. The coordinator will meet with you at any time to have questions or concerns answered.

The Transplant Manitoba – Pediatric Kidney Program Team



Pediatric Kidney Program



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Having a workup for a kidney transplant is lots of work for you, and for your kidney transplant team.

You have lots to learn, and your transplant team has lots to do to get you ready for your transplant.

Take your time reading this booklet, and if you have any questions or concerns about the appointments or tests, we are happy to talk to you.



Each person is an individual and has their own special needs that make it hard to predict how long it will take to finish all the tests and appointments.

Some assessments take longer and some are faster. How long it takes to finish the tests and appointments depends on if there are issues that come up. If there are issues, it may take longer to finish your assessment.

Some of the things that may delay an assessment include: infections that have to be treated, surgeries that need to be done before a transplant, or social or mental health issues that need to be addressed. As your assessment goes along, we will keep in contact with you to let you know how things are going.

During the transplant assessment, many people get anxious because they want a transplant as soon as possible. Please know that we want you to have a transplant as soon as possible, but we also need to make sure you are healthy and safe enough to have a transplant.

You can call the Pediatric Transplant Coordinator Julie Strong at 204-787-4842 or toll free at 1-877-499-8774 and ask for extension 74842 with questions you may have. The coordinator will meet with you to have questions or concerns answered.



All of the tests done before a transplant are done for **safety reasons**.

Having the tests done helps the transplant team to identify problems and, if possible, fix them before the transplant happens.

Knowing this information helps us to **safely plan for transplant**.

Before you have your transplant, we want to make sure:

- You are in the best possible health to get a kidney transplant.
- We identify any health concerns you might have that could affect the transplant kidney or your health after a transplant, and make a plan to deal with them before the transplant.
- We try to identify and deal with any surgical issues before your kidney transplant.
- We try to identify and deal with any safety issues before your kidney transplant.



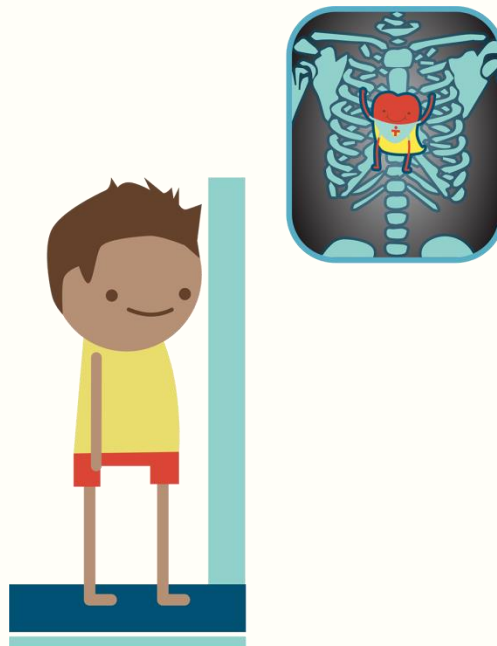
In our transplant program, some tests are **standard**, which means that everyone has these tests.

Other tests depend on your specific kidney disease and medical history.

Standard tests that you will have include the following:

- Blood group
- Human Leukocyte Antigen (HLA) and antigen testing
- Cross Match
- Electrocardiogram (EKG)
- Echocardiogram (Echo)
- Chest X-Ray
- Blood work
- Blood tests to look for previous infections and immune status from vaccinations
- Tuberculosis testing
- Urine tests

We will explain the tests and the reasons for them over the next few pages.



In our transplant program, some specialist appointments are standard, which means that everyone has these appointments.

If you have been seen by any of these specialists in the past, you may or may not need to see them again before transplant.

Other appointments depend on your specific kidney disease and medical history.

You will see the following specialists:

- Dentist
- Dermatologist (skin doctor)
- Hematologist (blood doctor)
- Ophthalmologist (eye doctor)
- Social Worker
- Urologist (kidney and bladder surgeon)
- Vascular surgeon (blood vessel surgeon)



You may also need to see:

- Allergist (allergy doctor)
- Cardiologist (heart doctor)
- Child development doctor
- Endocrinologist (diabetes and hormone doctor)
- Gynecologist (reproductive organ doctor)
- Infectious diseases doctor
- Psychiatrist (mental health doctor)
- Neurologist (brain doctor)
- Orthopedics (bone surgeon)
- Psychologist (behavioral doctor)
- Respiriologist (breathing doctor)
- ENT (ear, nose and throat doctor)
- Pharmacist
- Physiotherapist or Occupational therapist

We will explain the reason for seeing these specialists in the next few pages.

My questions so far:

So let's get started with a quick review of some of the information we shared in the last reading package (**Is Kidney Transplant Right for Me?**) and in the meeting we held with you to talk about kidney transplant.

A kidney transplant is one way to treat kidney failure.

A kidney, taken from another person, is put into the lower front part of your abdomen just in front of your hip bones. The transplant kidney is hooked up to your bladder by the ureter.

A kidney transplant will take over the job of your failing kidneys. It will do the work that your failing kidneys can no longer do, like:

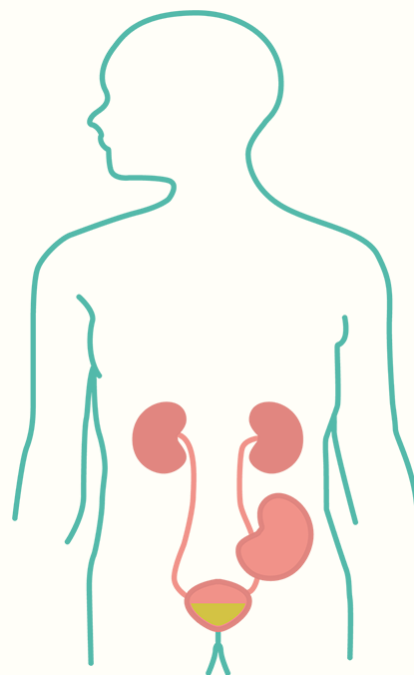
- Making urine and getting rid of extra water from the body
- Cleaning the waste from the body
- Helping to control blood pressure
- Making hormones to help prevent anemia
- Making hormones to help the bones grow properly

A kidney transplant is NOT a cure for kidney disease. Even when you get your transplant kidney you will still need to take medicines and come to the clinic for appointments for as long as you have your kidney transplant.

What types of kidney transplants are there?

There are two types of kidney transplants:

- Living-donor (LD) transplants
- Deceased-donor (DD) transplants



Living-donor (LD) transplantation

A living donor transplant means that someone who is alive gives you one of their kidneys. We can live with one kidney so it is safe for someone else to give a kidney.

This type of kidney usually comes from a close relative like a parent, aunt, uncle, or grandparent.

Living donors must be over the age of 18.

Sometimes it can come from someone unrelated like a friend or an anonymous donor (someone we don't know).



Anyone interested in being a donor must contact the Transplant Manitoba- Gift of Life program. We cannot do this for you.

**Deceased donor (DD) transplantation**

A deceased donor transplant means that someone has died and their family has consented to donate their loved one's organs for transplant.

A deceased donor can be the result of an accident or injury.

We do not know the person.

What is a Pre-emptive transplant?

A pre-emptive transplant means you get a kidney transplant before starting dialysis.

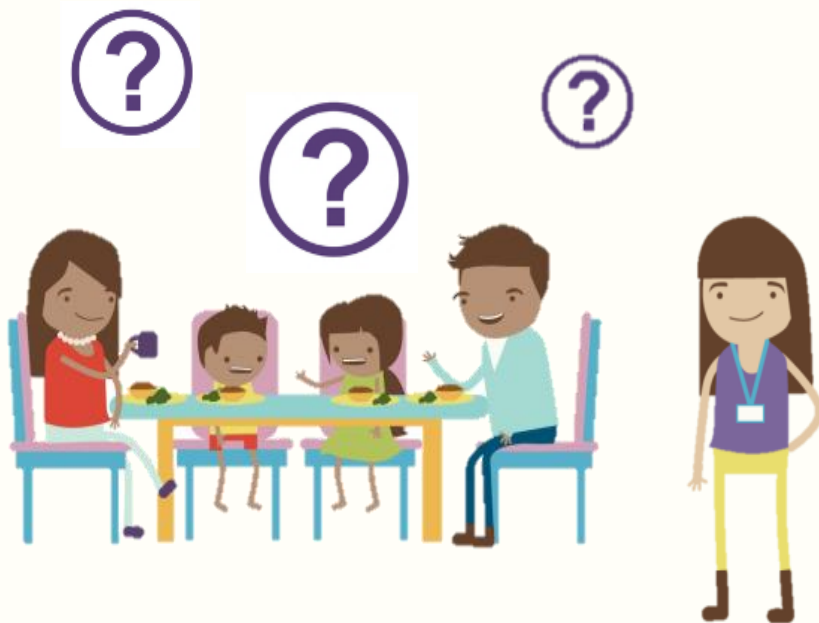
My questions about kidney transplant:

We hope that this review has helped you understand that:

- kidney transplant is not a cure for kidney disease
- there are different types of kidney transplants
- there are risks to the transplant surgery and the transplant medicines
- you will need many tests and appointments done in order to be safe for a kidney transplant
- kidney transplant offers most patients the best possible quality and length of life

Now, let's talk about some of the tests you will have and some of the special doctors you will see during the transplant workup.

Remember, all of these tests and appointments are done to make sure you are healthy and safe for a kidney transplant.



Tests before transplant

You will have many tests before your kidney transplant. As much as possible, the transplant team will try to book tests at the same time as your appointments to see the dialysis or chronic kidney disease team.

Let's start with *blood testing*.

Blood testing

You will have many blood tests during your workup for transplant.

Some of the tests tell the transplant team if your bones, your blood, and body are healthy.

Some of the tests tell the transplant team who is the best kidney match for you.

Here are some of the blood tests you will have:



Blood group

Blood group testing is one of the first tests you will have done.

This test is done to see what blood group you have. There are 4 blood groups: A, B, AB and O.

Remember it is important for us to know your blood group so we know who can safely give you a kidney

My blood group: _____

HLA test

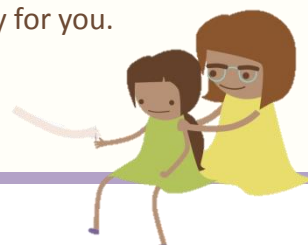
An HLA blood test will be done so we know what type of HLA antigens you have.

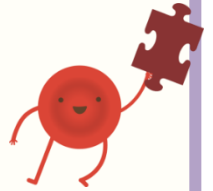
This test will give the transplant team information to help match you with the best donor.

Blood test for antibodies

This test is done at the same time as your HLA test.

This test will tell the transplant team if you have been sensitized and have developed antibodies. This will help the transplant team find the best kidney for you.





Flow Cross match

If you are having a transplant from a live donor you will have a flow cross match.

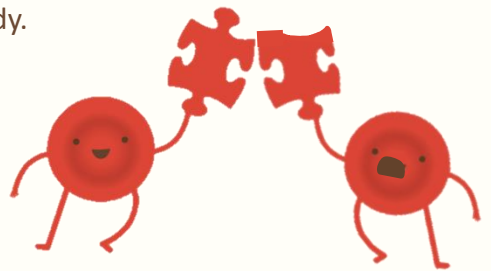
A flow cross match is the name of the test done to make sure your donor's HLA does not react with your HLA.

A negative flow cross match is a good result because it means your blood HLA matches your donor blood HLA.

A positive cross match means the donor and candidate blood HLA are not a good match.

What if you have a positive flow cross match?

We do not transplant people with a positive cross match because it means the transplant kidney **will be rejected** by your body.



How do they do a flow cross match?

You and your potential donor will have blood taken by the lab.

The lab mixes the donor blood with your blood.

If your blood destroys the donor blood, you cannot get a kidney from that person.

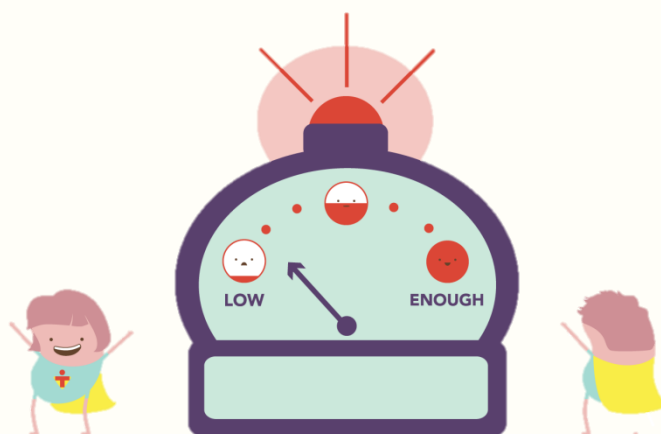
If your blood does not destroy the donor blood, the donor can move forward for workup.

My flow cross match result:

Red blood cell test or hemoglobin test

Every month you will have blood taken at your normal clinic visit to check to make sure your hemoglobin counts are not low.

If the hemoglobin in your body is low it means you are anemic, and you will need to start a medicine to help your body boost the red blood cells.

**Why are my red blood cells important?**

Keeping your red blood cells in the normal range means you will have more energy and helps you recover from surgery faster.

To have a kidney transplant, we try to keep red blood cell count at least 110.

Bone health blood testing

You will also have your blood tested for calcium, phosphate, parathyroid hormone and Vitamin D levels.

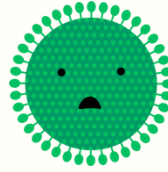


Why are these tests important?

These tests tell the transplant team about your bone health.

Some children with chronic kidney disease who have poor control of their calcium, phosphate, parathyroid hormone and Vitamin D levels can develop something called renal osteodystrophy which causes the bones to grow poorly.

Having healthy bones before and after transplant is important for normal growth.

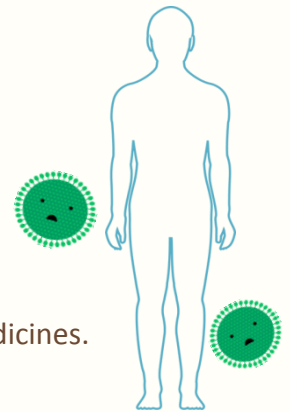


Blood testing for Virus

Every person who is going to have a kidney transplant will have their blood checked to see if they have been exposed to certain viruses.

Some of these viruses can damage the transplant kidney or may reactivate (wake up) when you are on transplant medicines.

Some of the viruses we look for are: cytomegalovirus (CMV), Epstein Barr virus (EBV), herpes virus, and the chicken pox virus (varicella).



Why are these viruses important in transplant?

After a kidney transplant you will be on very high doses of immune medicines.

These medicines work to dampen the immune system.

When the immune system is dampened it means the immune system has a harder time finding and destroying the viruses.

If you have had the virus in the past it can wake up – we call this reactivation (re-ack-ti-va-shun). The reactivation of the virus can make you very sick and may damage the kidney.

What can be done if I have had these viruses?

If you have not had chicken pox, we will ask you to get the chicken pox vaccine before transplant.

If you have had chicken pox or the herpes virus and it reactivates after transplant, we will give you medicine to try to shorten the time of the illness.

We will give you some medicines at the time of transplant to either prevent you from getting CMV or EBV if you have never had these viruses or, to prevent reactivation of the virus if you have already had the virus.



Special blood tests

Some people have kidney disease that is caused by their own immune system.

Many times these diseases have signs that show up in the blood that can tell the doctors if your disease is active or is under control.

If your disease is active, it may not be a good time to have a transplant because the disease might attack and destroy the transplant kidney.

If your kidney disease is caused by one of these diseases, we will test your blood to make sure it is safe for you to have a transplant.

The cause of my kidney disease is: _____



Sometimes you will need other types of blood tests that are unique to you and your kidney disease. The transplant team will discuss any special blood test that you might need.

Now let's talk about some of the other tests you will need.

Urine (Pee) Testing

Some children may no longer pee and some children may still pee even if they are on dialysis.

Urine testing is done for many reasons. Some of the reasons to do urine testing are to:

1. Identify children at risk for infection.
2. Measure how much urine a child still makes before the transplant.
3. Measure any protein in the urine before the transplant. Protein in the pee is not normally present. For some kidney diseases, protein in the urine tells us if their kidney disease has come back after transplant.

If you still pee we may ask you to do 3 urine tests:

1. 24 hour urine collection ---this is sent so we can see how much urine you make in a 24 hour time period. It will also tell us how much protein you have in your urine.
2. Urine for bacteria and fungus – this is very important because we do not want to transplant someone with an infection. If you have a history of infections, you may need to be on antibiotics before and after transplant.
3. Urine sample to test for albumin (a type of protein). This test will tell us how much protein you have in your urine



My questions about blood and urine tests in transplant workup :

Heart Tests

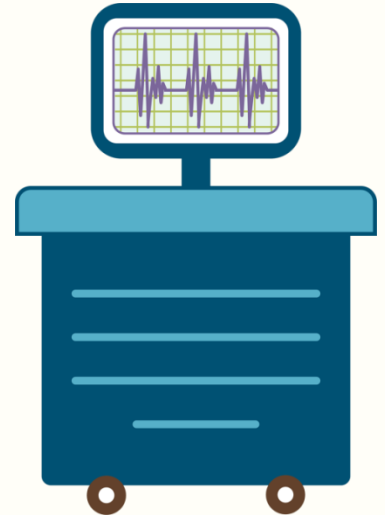
Having a healthy heart is important for everyone. In order to know if your heart is healthy, you will have 2 tests done. Neither of these tests are painful.

One test is called an Electrocardiogram, also called an EKG.

The other test is called an Echocardiogram, also called an Echo.

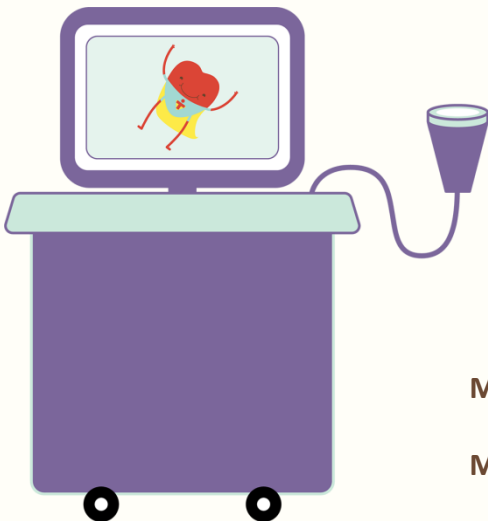
EKG

This test looks at the electrical functioning of your heart. For this test you will have some stickers placed onto your chest. The stickers are attached by wires to an EKG machine. The machine records the electrical pattern of your heart.



Echo

This is an ultrasound test that looks at the structure and the function of your heart. For this test the heart specialist puts some clear jelly-like cream onto a wand. The wand is attached by a cord to the Echo machine. The wand is rubbed over your heart and sends a picture to the machine of what your heart looks like and how well it is working.



What happens if my EKG or Echo is not normal?

The transplant team will send you to a cardiologist (a doctor specializing in heart health and care) to ask what should be done before, during, or after transplant to keep you safe.

Sometimes special heart medicines are required before, during or after a transplant.

My Echo is: _____

My EKG is: _____

X-ray Tests

There are a few x-ray tests that are done before transplant

Chest X-Ray

A chest x-ray is done to look at the lungs and heart to make sure they are normal and to make sure you do not have any active infections that would make a transplant unsafe.

One infection we look for is Tuberculosis, also called TB.

What happens if I have TB?

It is unsafe to transplant someone with TB.

If you have TB you will be sent to see a specialist to get treatment.

Once a person has finished the treatment for TB, they can safely get a transplant.

After transplant a person who has had TB will be monitored closely to make sure the TB doesn't come back.



My Chest X-ray is: _____

Hand X-Ray

This test may be done if you have had trouble keeping your calcium, phosphate and PTH in the normal range.

This X-ray is done to test if you have renal osteodystrophy (bone disease) and shows us if you are still growing or if you have finished growing.

One of the medicines used after transplant can slow growth in high doses.

If you are not growing well, we want to know if it is because you are finished growing or if it is because of the medicines you are taking.

My Hand X-ray and Bone Age are: _____

Other X-rays

Some people may need special kidney X-rays.

If you need a special X-ray of your kidneys before transplant we will talk to you to explain why.



Vaccinations

All children who are being worked up for and are having a kidney transplant should be up to date with their vaccinations. Vaccinations are an important step in preventing infections after transplant.

The transplant team will discuss which vaccines they recommend you should have before transplant.

Some vaccines, such as the chicken pox vaccine and the MMR (measles, mumps rubella), can only be given before transplant because they are “live” vaccines.

If you give a live vaccine to someone who has had a kidney transplant and is on high doses of immune suppressing medicines, the vaccine may cause the disease and make you very sick.

All family members should keep their vaccinations up to date to prevent disease. You and your family should get the flu vaccine each year.

We recommend you get all of your vaccinations before transplant if possible .



Testing for Tuberculosis

A blood test called an IGRA test is needed to make sure you have not been in contact with, or have TB. (Remember the section about chest X-ray and TB?)

If your test is positive, we will send you to see a TB specialist.

It is not safe to transplant someone with TB.

Treatment for TB is available, and most people are safe to transplant after they complete their full treatment for TB.

After transplant, a person who has had TB will be monitored closely to make sure it doesn't come back.

My questions about immunizations and TB tests in transplant workup :

Now let's talk about some of the specialists you will see**Eye Doctor**

The eye doctor will look at your eyes to make sure they are healthy.

One of the medicines you will take after transplant may cause eye problems such as cataracts.

Cataracts are a clouding of the lens in the eye.

Cataracts can cause poor vision.

Some people need surgery to have cataracts removed.

After the transplant, you should see the eye doctor at least once per year.

You should also protect your eyes by wearing sun glasses on sunny days.

**Dentist**

The dentist will check your mouth to make sure your mouth is healthy and it is safe to have a transplant.

The dentist will check for cavities and gum disease.

If you have any problems with your teeth or gums, we will ask that they are fixed before transplant if possible.

Infections in the mouth can cause problems after transplant.

Good mouth care will help prevent infections.

Brush your teeth and floss at least 2 times per day.

Avoid sugary foods that can lead to cavities.

You should see your dentist at least once per year and have your teeth cleaned every 6 months.

If you have braces and they are almost ready to come off, we will ask the orthodontist to take them off before transplant.

If they are not ready to come off, we recommend the braces stay on for at least the first 6 months after transplant.



Hematologist

We will send you to see the hematologist (blood doctor) who will check to see if you are at higher risk for either bleeding or clotting at the time of transplant.

Some people have bleeding or clotting issues and they don't know until they are tested.

It is important we identify those people before transplant so we can plan a safe transplant.

If you are told you have a bleeding or clotting problem, we will make a safety plan with the hematologist for you that we will follow at the time of your transplant.

Many children will wear special socks called TEDS at the time of transplant. These socks help prevent clots in the legs.

The socks stay on until after transplant and you are up and walking.



Dermatologist

Anyone who is going to have a transplant is sent to see the skin doctor called a dermatologist.

Some of the medicines you will take increase your risk of skin cancer after transplant.

You will see the dermatologist before transplant for a review of your skin to check for any unusual moles, rashes and warts. Treatment for warts before transplant is recommended.

We will monitor your skin very closely after transplant.

You can help prevent skin cancer by staying out of the sun during the hottest part of the day, using sunscreen, wearing hats and long sleeved shirts. Even if you have darker skin colour, you still need to protect your skin.

During the workup you should not get any new tattoos or piercings. Talk to the transplant team if you are planning to get a tattoo or piercing.



Social Worker

Kidney failure is a life altering event and can affect families in many different ways.

Although kidney transplant is a good thing, it is not a cure for kidney disease.

You will always need medicines to keep your kidney healthy, and you will always need to come to see the health care team.

Accepting this can be very hard for you and your family.

Social workers see all of the families who have chronic kidney disease, who need dialysis and/or who are planning on a transplant. They will help them cope with these feelings, identify those people who need help, and identify resources. They will also help with some of the practical issues for transplant, like how to pay for the medicines and where to stay after transplant if you live outside of the city.



Urologist

Urologists are doctors who specialize in how the bladder and kidneys work together.

Sometimes, the kidney, bladder or the tubes that connect them do not work properly.

Some people have bladder problems that require surgery to fix the problem or may need to drain urine from the bladder with a tube called a catheter.

You will see the urologist to see if you have a problem that needs surgery.

Depending on what the problem is, the surgery may be done before the transplant, at the time of the transplant, or after the transplant.



Transplant Surgeon

The transplant surgeon could be a vascular surgeon or urologist.

The transplant surgeon is the doctor who actually puts the donor kidney into your body. If you have a peritoneal dialysis catheter in your tummy, the surgeon will also take this out at the time of the transplant.

Everyone who is having a transplant will see the vascular surgeon to decide if there are any special steps that need to be taken during the transplant surgery.

Some people will need to see the vascular surgeon early in their workup; others will see the surgeon just before transplant.

The transplant team will discuss when you will see the surgeon.



My questions about the specialists I will see during transplant workup :

After you have had all the tests and seen the specialist doctors, the Transplant Manitoba – Pediatric Kidney Program (TM-PKP) reviews all of the results to make sure you are safe to have a transplant and to decide on your specific transplant plan

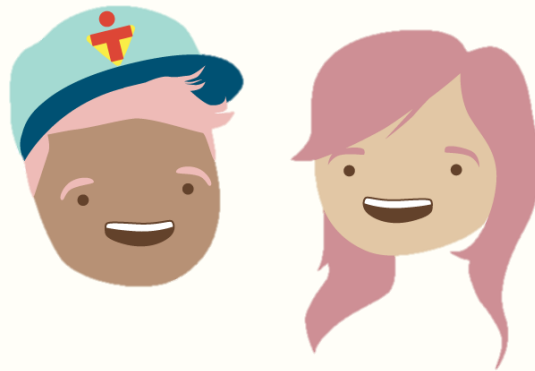
The transplant and chronic kidney/dialysis teams then meet to review all of the results and to ensure there are no new issues that need attention.

If you require more testing or other specialist appointments, we will contact you.

Once both teams agree the workup is complete and you are safe for transplant, we will contact you to discuss the next steps in the process.

If you have a living donor who is ready to donate a kidney, we will talk about booking a date for the operation.

If you do not have a living donor, we will meet to talk about listing you on the Transplant Manitoba deceased donor list.



Is there a possibility that I might not get a transplant after all the tests and specialist appointments?

Most children who complete the workup are deemed safe to move to transplant.

There are some children who are not safe to move to transplant.

For some children this may be temporary and for a very, very small number of children, this decision may be permanent.

Who do I call if I have to rebook any of my tests or appointments during my workup?

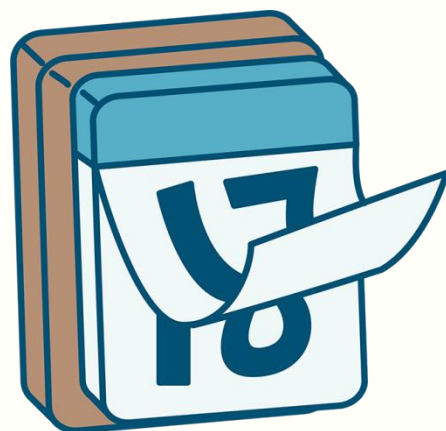
We understand that sometimes things happen that you don't have control over, and you may have to rebook a test or appointment.

Many of these tests and appointments have long waiting times and are difficult to book.

Missing appointments will lead to a delay in completing the transplant work-up.

If you have to rebook any of your tests or appointments, please contact the Unit Assistant at 204-787-8649 or 1-877-499-8774 and ask for extension 78649 as soon as possible.

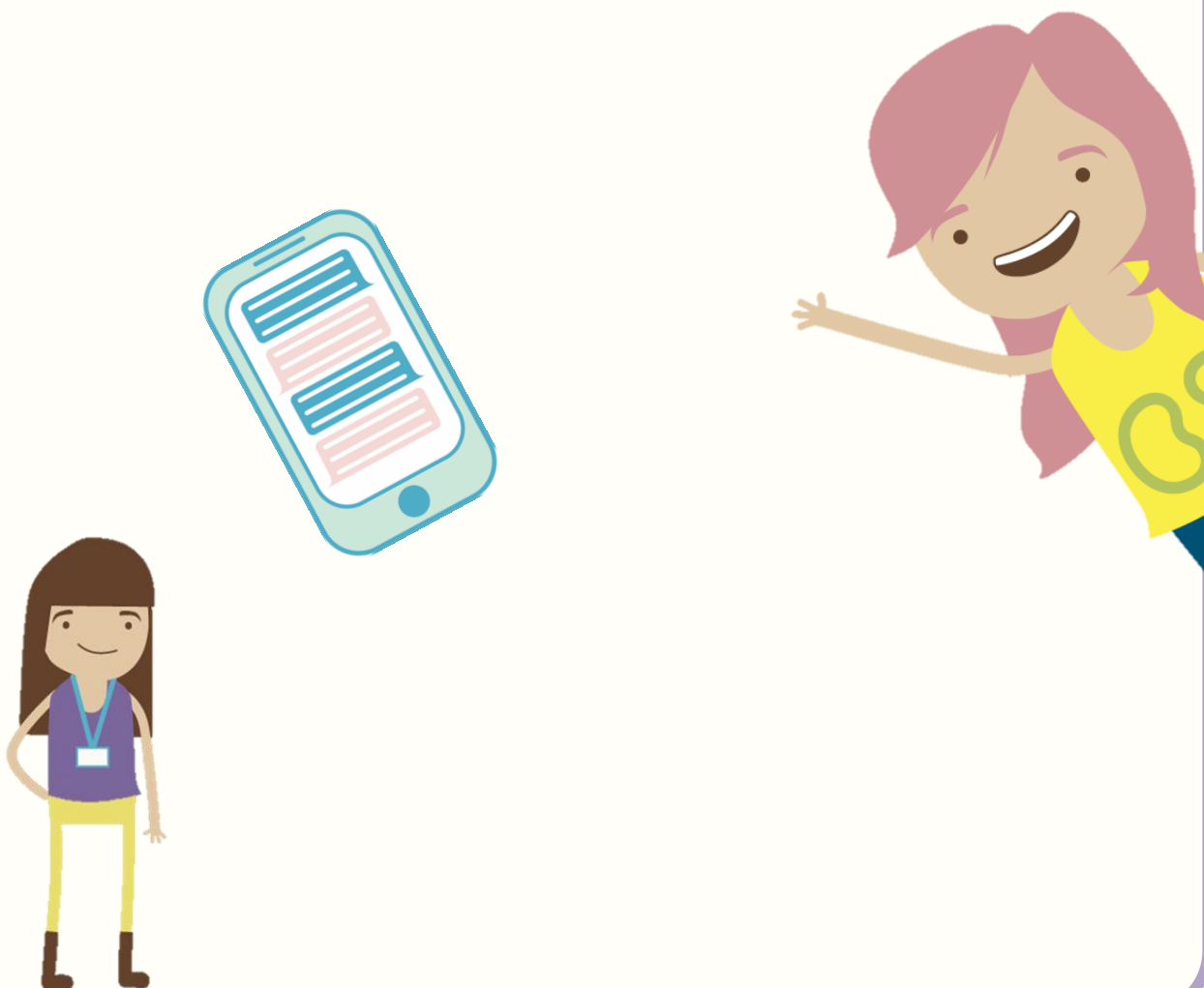
We will do our best to rebook the earliest available appointment.



Who do I call if I have questions or concerns about any of my tests or appointments during my workup?

Contact your Pediatric Transplant Coordinator Julie Strong at 204-787-4842 or toll free at 1-877-499-8774 and ask for extension 74842 with questions you may have about the tests or specialists in your transplant workup.

The coordinator will meet with you if you need to have questions or concerns answered.

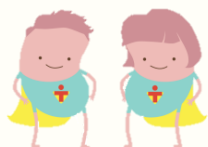


My Final Questions about my transplant workup tests and appointments:





Created by Julie Strong BN, Diane McKenty RN, Aviva Goldberg MD and Kristen Pederson MD with Pediatric Nephrology (Children's Hospital Health Sciences Centre). With thanks to the Children's Hospital Foundation of Manitoba for their generous support.



For more information about this resource, please contact Pediatric Nephrology at 204-787-4947 or kidneytwins2@exchange.hsc.mb.ca or the Children's Hospital Foundation of Manitoba <http://goodbear.mb.ca>