Is Kidney Transplant Right for Me?

Transplant Manitoba: Pediatric Kidney Program
Section of Nephrology
Children's Hospital of Winnipeg

This booklet is being sent to you because your kidney doctor is referring you to be assessed for a possible kidney transplant.

This booklet will give you some of the information that will help you understand what a kidney transplant is, what tests are done to get a person ready for a transplant, and information to help you decide if and what kind of transplant is right for you and your family.

Please take some time to read the booklet. There is a lot of information given here in this booklet, but don't worry. When you come for your first meeting with the Transplant Manitoba—Pediatric Kidney Program team, we will go over it all again, and answer any questions you may have.

There are spaces at the end of each section for you to write down any questions you may have. Feel free to bring your booklet and questions to your appointment with the team.

We look forward to meeting with you soon.

The Transplant Manitoba – Pediatric Kidney Program Team

Pediatric Kidney Program

Children's Hospital
Health Sciences Centre Winnipeg
Hôpital pour enfants
Centre des sciences de la santé Winnipeg

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The Transplant Manitoba – Pediatric Kidney Program team is made up of a group of professionals who are dedicated to the care of children with kidney transplants. Each individual has special skills which, when put together, make up the team.

OUR TEAM:

Dr. Patricia Birk is a pediatric (child) nephrologist (kidney doctor) and the head of the Transplant Manitoba-Pediatric Kidney Program. She is responsible for ensuring the program is current, maintains standards of practice, and meets the needs of the patients and families for whom we care.

Dr. Aviva Goldberg and Dr. Maury Pinsk are pediatric nephrologists. Along with Dr. Birk, they are responsible for the pre-transplant assessment and post-transplant care of children who are having a kidney transplant.

Ashley Giesbrecht is the social worker and is responsible for ensuring children and families have the social, emotional and practical resources needed to prepare for kidney transplant. These needs are based on and tailored to each individual family's needs at the time of assessment.

The department of Child and Adolescent Mental Health is responsible for ensuring children and families are emotionally and mentally prepared for kidney transplantation. They provide ongoing counseling for children and families before and after transplant

Lisa Wilson is the dietitian who is responsible for educating children and families about the special dietary needs of a child with a kidney transplant.

Julie Strong is the pediatric transplant coordinator who is responsible for ensuring the physical, emotional, practical and educational preparation of children and families is complete prior to kidney transplant. She coordinates the tests and procedures the child requires for transplant.

Jody Sawatzky and Camille Boucher are the Transplant Manitoba - Gift of Life Living Donor Program – donor transplant coordinators and are responsible for ensuring the physical, emotional, practical and educational preparation of any potential kidney donor prior to transplant. They coordinate the tests and procedures the potential donor requires for transplant.

Diane McKenty is the pediatric transplant Nurse Clinician responsible for the post transplant care and education of children and families with a kidney transplant. Diane is responsible for the day to day contact for families after transplant.

Dot Molchan is the transplant clinic nurse; she works closely with Diane in caring for children with kidney transplant.

Kristin L'Heureux is a social worker from the Transplant Manitoba – Adult kidney program. She is involved in the transition process and, along with the pediatric team, assists in helping adolescents transition from the pediatric to the adult transplant world.

Julie Palansky RN- Nurse Clinician, Amber O'Neill RN, Dr. Kristen Pederson and, Dr. Allison Dart, and the pediatric hemodialysis nurses are all members of the Manitoba Pediatric and Adolescent Dialysis and Chronic Kidney Disease team (MPACKT). They are responsible for caring for children and families until kidney transplant. They work closely with the transplant team by helping to prepare the children physically and emotionally for kidney transplant.

Nancy Dodd is a process engineer who works with our team to ensure we are meeting transplant safety and standards in order to maintain our accreditation as a transplant program. She also helps us with work flow, process and quality initiatives.

Our commitment to you and your family

You and your child have been referred to the Transplant Manitoba –Pediatric Kidney Program for evaluation for a kidney transplant.

Our team is committed to excellence in kidney transplant care.

We believe in family centered care. This approach to care requires involving those persons identified as family members in all aspects of care and decision making.

We believe in a team approach to caring for children and families. This involves the building and mutual respect of relationships within the team.

We believe every child and family has the right to honest and accurate information at all times throughout the process.

Our goal is to ensure that you and your child are fully informed and educated about why a kidney transplant is suggested, the process of evaluation for kidney transplant, the risks and benefits of a kidney transplant for you and your child, the potential long term complications of kidney transplant and the importance of the transition process for adolescents with a kidney transplant to the adult care program.

We work closely with the Transplant Manitoba- Gift of Life Living Donor program. We believe in the confidentiality of the transplant process for both the candidate (the person getting a kidney transplant) and the donor (the person giving the kidney).
We understand that children will grow, mature and eventually move to an adult transplant service and that, as transplant care givers, we have a role in helping children successfully transition to the adult service.

We believe that successful transition of children to adolescence and adulthood requires a defined process, ongoing education and, a supportive environment for both the child and the family.

Mission Statement

Vision
Leadership in pediatric kidney transplantation

Mission
To provide state of the art, comprehensive, family-centered care to children and families requiring a kidney transplant at Children's Hospital, Health Sciences Centre Winnipeg.

Purpose
We are a group of transplant professionals dedicated to leading, advancing, and advocating for patient care, research, and education to improve kidney transplantation for children.

Values

Excellence
In all aspects of care delivery from pre-transplant assessment to transplant, post transplant care and transition to the Adult Transplant Service. We promote excellence in patient outcomes for transplant in the Pediatric Kidney Program

Innovation
In program development, research and care provision in pediatric kidney transplantation

Accountability
To children and their families, the Pediatric Kidney Program, and the global transplant community for the care we promote and deliver

Respect
For individual choice, family decisions, cultural values, and team involvement in all communications, interactions and processes

Quality
In transplant assessment processes, care provided during and after transplant, educational materials and communications

Communication
With children, families and other professionals in a timely and respectful manner to ensure accuracy, involvement and understanding

Integrity
Acting on the highest standards of ethical practice in all aspects of individual and organizational functioning

Collaboration
With children, families and other professionals in a timely and respectful manner to ensure quality care

Research
In basic science, clinical and social science research to improve the understanding of outcomes related to pediatric kidney transplantation and the care provided to children and families requiring kidney transplant.

So now that you know who we are, what we believe, and what our commitment to you and your family is, let's get started learning about kidney transplant.

This booklet has information about kidney transplant that you can read before coming to meet with the Transplant Manitoba-Pediatric Kidney team. When you meet with us we will review this information and answer any questions you might have.

There are spaces after each section for you to write any questions down. Bring your booklet and questions to your meeting.

The process for kidney transplant

When a child's kidney function reaches the point where they will need dialysis or, if a child is already on dialysis, the Manitoba Pediatric and Adolescent Dialysis and Chronic Kidney Disease team (MPACKT team) will talk to the child and family about a referral to the Transplant Manitoba—Pediatric Kidney Program (TM-PKP) for an assessment for a possible kidney transplant.

The MPACKT team has sent a letter to the TM-PKP asking them to meet with your child and your family to discuss the kidney transplant process.

The transplant coordinator will review your child's medical records to understand more about their medical history.

The Transplant Manitoba—Pediatric Kidney Program will make an appointment for your child and family to be seen by a transplant doctor.

The transplant doctor and transplant coordinator will talk to you about transplant. They will review the types of transplant, the risks and benefits of transplant, complications and how long transplanted kidneys last. They will discuss if a transplant is right for your child.

If a transplant is right for you and your child, a workup will be organized. The transplant coordinator will review what tests and appointments are needed before transplant, will organize these, collect the results and prepare you and your child for transplant.

Once your child has finished their work-up and you and your child are ready to have a kidney transplant, and, if there is a live donor who is ready to give a kidney, the transplant operation will be booked in the operating room. If your child does not have a live donor, they can be put on the Transplant Manitoba- Kidney Transplant List to wait for a deceased donor kidney transplant, or we will talk to you about the Living Donor Paired Exchange Program. Very rarely, a child may complete a work-up and not be able to receive a kidney transplant.

My questions about the process for kidney transplant:

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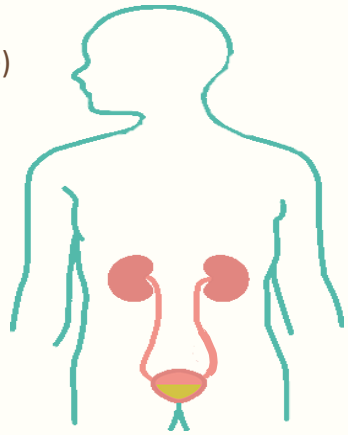
What do the kidneys do?

Before we talk about kidney transplant, it is important to know what your kidneys do for you. Here is a quick review of what the kidneys do.

The kidneys do five things to help your body:

- Make urine (pee) to keep your body fluids in balance
- Control your blood pressure
- Clean out wastes like creatinine (Cree-at-tin-in) , from your body
- Make a hormone that helps keep your bones strong by balancing phosphate, calcium and Vitamin D
- Make a hormone that helps your body make red blood cells and prevent anemia

Most people have two kidneys located in the lower back behind the ribs. Some people are born with only one kidney. The kidneys are attached to the bladder by a tube called a **ureter** (Ur-a-ter). **Urine** (pee) is made in the kidney and travels down the ureter into the bladder and is then passed out of the **urethra** (Yur-eth-raw).



My questions about the kidneys:

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How does the kidney clean the blood?

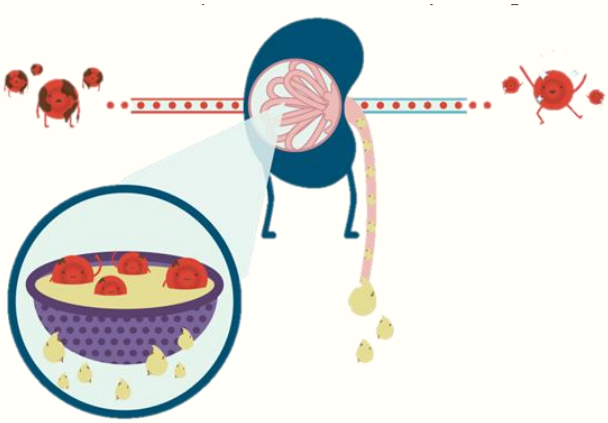
Each kidney is filled with thousands of nephrons (neff-rons). These are made of little filters (glomeruli) and tubes that drain pee out of the kidney.

Filters (glomeruli) found in the kidney work like a coffee filter.

Blood from the body carrying waste and water go through the filters in the kidney.

Waste and extra water are filtered out of the blood and go down the tubules into the ureters. The kidneys hold onto things the body needs like proteins and blood.

The waste and water that comes from the ureters enter the bladder and then are peed out of the body through the urethra.



My questions about how the kidney filters and cleans the blood:

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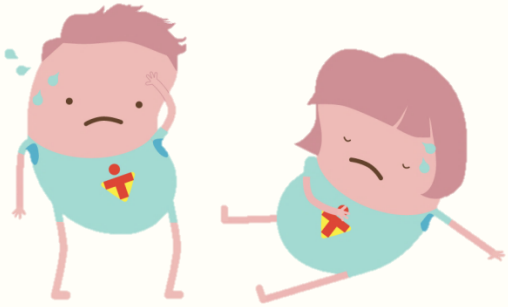
What happens when the kidneys stop working ?



When your kidneys stop working:

1. You may no longer be able to pee and your body gets puffy.
2. Your blood pressure goes up and you may have headaches or damage to your eyes, blood vessels or heart.
3. You can't clear the wastes such as creatinine (cree-at-tin-in) from your body so you feel sick and tired.
4. You may not grow normally and your bones may not grow straight.
5. You become anemic (a-knee-mik), which means your blood is low in red blood cells and iron, and you don't have energy to concentrate at school or play.

My questions about what happens when the kidneys stop working:

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What happens when the kidneys stop working ?

How does the team know when the kidneys stop working?

- Kidney function is calculated by a formula using your height and creatinine. This is called as estimated Glomerular (Glum-air-u-lur) Filtration Rate or eGFR.

- An eGFR estimates how well the kidneys filter waste like Creatinine. We talk about this as an approximate percent of normal kidney function.

- When kidneys are working properly an eGFR is about 90-120.

- As your kidneys fail, the eGFR gets worse and the numbers go down.

- The doctors have stages which tell them how well your kidneys are filtering waste. The higher the stage, the lower the eGFR and the worse your kidneys are functioning.

- For example if the doctor tells you your eGFR is 25, this means you have about 25% or a ¼ of normal kidney function.

- When your eGFR is about 20 (Stage 4), the doctor will ask the TM-PKP team to meet with you and your family to talk about transplant.

- Your child may need to start dialysis or have a kidney transplant when the eGFR is less than 10.

eGFR = estimated Glomerular Filtration Rate = How well the kidney filter wastes.	
Stage 2 – 3	eGFR is more than 30
Stage 4	eGFR is between 15- 29
Stage 5	eGFR is less than 15 *may need dialysis or kidney transplant when eGFR less than 10*

My questions about a GFR:

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What types of treatment are there when your kidneys stop working?

There are two types of treatments that are used when your kidneys stop working:

1. Dialysis (Di-AL-is-is)
2. Kidney Transplant

Dialysis

Dialysis is a way to clean your blood and get rid of the extra water in your body. Dialysis gives you a eGFR of about 30 to 40.

There are two types of dialysis:
1. Hemodialysis (Hem-O-Di-Al-is-is)
2. Peritoneal (Per-it-toe-neel) Dialysis

Hemodialysis (Hem-O-Di-Al-is-is)

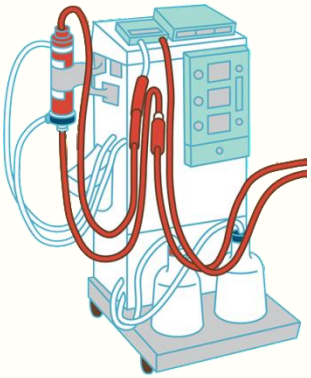
Hemodialysis is a type of dialysis that is done through the blood.

You need to have access to the blood for this. This is either using a catheter (Kath-a-ter), or a fistula (Fist-Chew-la) . A catheter is a special tube placed into a blood vessel in the neck. A fistula is a connection made between two blood vessels in your arm.

This type of dialysis is done in the hospital 3-4 times per week, but sometimes more often.

You are hooked up to a machine by tubing attached to the fistula or the catheter. Your blood is taken out of your body, a bit at a time, is cleaned in the dialysis machine filter and is then returned back to your body.

It takes about 3-4 hours for each session.



Peritoneal dialysis

Dialysis can also be done through the tummy – this is called Peritoneal (Per-it-toe-neel) dialysis.

This type of dialysis is done at home at night while you sleep.

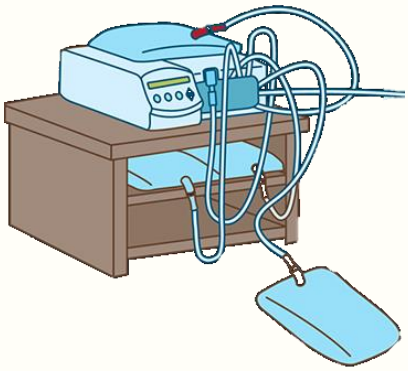
You need to have a special catheter put into your abdomen (Ab-doe-men). This catheter is outside of your stomach and bowels.

You are hooked up to a machine by the catheter. The machine pumps special fluid into the space around your tummy called the peritoneal cavity.

The fluid sits in the peritoneal cavity and draws the extra water and waste into the fluid like a sponge.

Then, the machine sucks the dirty waste and water away and sends it out of the tube into a waste bag. This fluid is flushed down the toilet or sink or bathtub in the morning.

This happens many times over night while you sleep. In the morning you unhook from the machine and go to school or play.



My questions about the types of dialysis:

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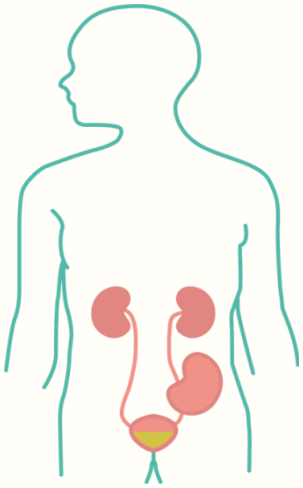
Kidney transplant

Kidney transplant is another treatment option for kidney failure.

A kidney taken from another person is put into the lower front part of your abdomen.

The transplanted kidney is hooked up to your blood vessels and your bladder.

It works like your own kidney to clean waste and water from your body.



My questions about transplant:

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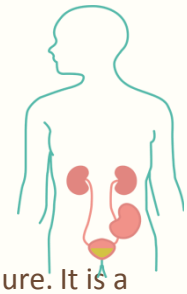
What is the best treatment for you?

Your doctor will talk to you about dialysis and transplant. Together, you and your doctor will decide which is the best treatment for you.

When you come to your transplant assessment meeting, the Transplant Manitoba – Pediatric Kidney Program will talk to you in more detail about kidney transplant.

So let's talk about kidney transplant in more detail.



What is a kidney transplant?

Kidney transplant is another option for kidney failure.

It is important to understand that a kidney transplant is not a cure for kidney failure. It is a chronic condition. You will still need to take medicines and see the doctor for the rest of your life.

A kidney, taken from another person, is put into the lower front part of your abdomen (belly), just in front of your hip bones and under your skins and muscles. It is hooked up to your blood vessels and your bladder.

Your own kidneys usually stay where they are. If your kidneys need to be taken out before transplant we will discuss this with you.

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

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

Our goal is to have a kidney last 20 years or more. Most children will require a second transplant during their life.

My questions about transplant:

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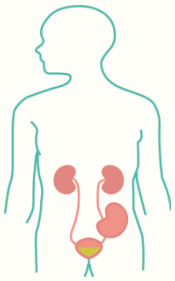
What types of kidney transplants are there?



There are two types of kidney transplants:

1. Living-donor (LD) transplants
2. Deceased-donor (DD) transplants

Living-donor (LD) transplantation

A living donor transplant means that someone who is alive gives you one of their kidneys. A person 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, older sibling, aunt, uncle or grandparent. It can also come from a close friend and sometimes from an anonymous (An-on-i-mus) donor. Living donors must be over the age of 18 and be healthy enough to donate one of their kidneys.

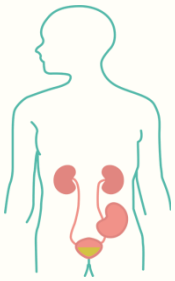
Deceased donor (DD) transplantation

A deceased donor transplant means that someone has died and they or their family has agreed to donate their organs as a gift of life to those who need them. We do not know the name of the person who has died or other details about them. We do know details that relate to how healthy their kidneys are and how safe they are for transplant.

You may hear the word Pre-emptive transplant

Pre-emptive transplantation

A pre-emptive transplant just means the person gets the kidney transplant before they start on dialysis. This is the goal for our program. A pre-emptive transplant is not always possible.



Living donor paired exchange

There is a Canada wide program called the Kidney paired donation program (KPD)

If you are not blood compatible the adult donor program will discuss if the KPD is a possible option for you

Briefly – the donor and candidate are entered into the national program.

They find the best match for the donor and a match for the candidate and you then get a kidney from a living donor who is not related.

The donor program will discuss this with any donor who comes forward but is not compatible.

Transplant Manitoba
Gift of Life

My questions about the types of kidney transplant:

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What are the benefits and drawbacks of a LD and a DD transplant?

Live Donor Kidney Transplant

The **benefits** of LD kidney transplants are:

- You usually don't have to wait as long to get a transplant because once you and your donor are ready we will book the next available operating date.
- Usually the new kidney lasts longer than a DD kidney.
- The donor is a healthy adult who has gone through a full set of tests to make sure they are healthy, and that it is safe for them to give up one of their kidneys.
- Usually the new kidney is only out of the donor's body for a short time before it is put into your body. This means that there is less injury to the kidney from being without blood flow (more about this soon).
- There may be a better HLA match between the donor and the person getting a kidney (more about HLA soon).

The **drawback** is that not everyone has someone who can donate a kidney.

Deceased Donor Kidney Transplant

The **benefit** of DD transplant is that you can still have a transplant even if you don't have an LD.

Children have priority on the waitlist for a DD kidney.

The **drawbacks** of a DD are:

- There is usually a longer wait time to get a transplant.
- The length of time the kidney lasts is not quite as good as a LD transplant for many reasons. Some reasons include injury to the kidneys that happened as the donor was dying (e.g. a car accident) and the time the kidney spends without blood flow between the donor and the recipient [also called cold ischemic (is-kee-mik) time.]

My questions about the benefits and drawbacks for the different transplants:

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How well do kidney transplants do?

A kidney transplant is not a cure for kidney failure. But, a kidney transplant can last a very long time if you look after it well. Most children will need a second transplant during their lifetime.

Kidney transplants last for different lengths of time. How long a kidney will last after a transplant depends on many things including:

- The type of transplant – Live Donor or Deceased Donor.
- Complications at the time of the transplant and after the transplant.
- Rejection episodes and the development of chronic scarring.
- Adherence (Add-hear-ants) -sticking to the medical care plan.

On average well over 80% of transplants are still working 5 years after transplant. Live donor transplants tend to last a bit longer but this is not always true.

Live donor transplants usually last longer for several reasons:

- The donated kidney usually comes from a parent or other family member and may be a better tissue match (more about this later).
- The donor is healthy.
- The surgery is planned so the time the kidney is out of the body is short – this means there is less damage to the kidney.

My questions about how kidney transplants do:

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What are the risks and benefits to kidney transplant?

The benefits of having a kidney transplant are:

- Improve your quality of life.
  You should be able to go to school, go to your activities and be with friends and family.

- Physically feel better.
  You will have more energy to do the things you want and you will not feel sick all the time.

- No need for dialysis.
  Having a successful kidney transplant means you will no longer need dialysis. You still need treatment like medicines and appointments, but these should be easier than dialysis over time.

- Grow and develop.
  Your bones will be healthier and you may grow better.

My questions about the benefits of transplant:

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The risks of having a kidney transplant can be separated into:

1. Surgical risks
2. Medical risks

Not everyone will develop surgical or medical risks but it is important that you know about them before you have a transplant.

Even though the risks listed in this booklet are the most common risks, there may be some risks unique to you.

When the transplant team meets with you, we will talk to you about any other risks.

We will take a few minutes now to explain the risks and how we can either prevent or treat them.

Surgical risks:

Surgical risks may happen at the time of transplant.

Surgical risks will be talked about in more detail with the transplant surgeon when it is time for you/your child to have the kidney transplant.

The most common risks are:

1. **Clots**
2. **Bleeding**
3. **Obstruction**
4. **Fluid collection**

1. **Clot** – sometimes a clot of blood can form somewhere in the transplanted kidney, usually the new artery or vein, which stops the blood from getting into or out of the kidney. A big clot can damage a kidney so much the kidney has to be removed. Clots can also develop in the lungs and legs – this is prevented by getting a person up and moving early after transplant. As part of the transplant workup we send children to a specialist to check if they have clotting problems. If you are at increased risk for clots we will develop a specific transplant plan to prevent clots.

2. **Bleeding** – usually a person only loses a small amount of blood during a kidney transplant operation. Sometimes an artery or vein can be accidently cut and bleeding occurs. It can usually be repaired quickly with more surgery. As part of the transplant workup we also send children to a specialist to check if they have bleeding problems. If you are at increased risk for bleeding we will develop a specific transplant plan to prevent bleeding.

3. **Obstruction** (Ob-struck-shun) – an obstruction is a blockage or kink usually to the ureter. It can happen when the new ureter is hooked up to the bladder. To prevent an obstruction, a little plastic tube called a “stent” is put into the ureter. The stent gives the ureter a chance to heal. The stent is taken out about 6 weeks after transplant in a separate operation.

4. **Fluid collection –** some people will develop a collection of fluid around the kidney called a lymphocoele (limf-o-seal). The fluid is usually reabsorbed by the body over time.

My questions about the surgical risks of kidney transplant:

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Medical Risks:

Medical risks can happen right after transplant or months or even years after the kidney transplant.

The highest chance for medical risks is in the first 6 months after the transplant.
This is because during the first 6 months after transplant you are on the highest amount of immunosuppression (transplant medicine).

The most common risks are:

1. **Rejection**
2. **Chronic scarring of the transplant kidney and AMR, DSA**
3. **Infection**
4. **Disease recurrence**
5. **Cancer**
6. **Death**

1. **Rejection** – rejection means that your body's immune system knows the transplanted kidney is not yours and is trying to get rid of it. Rejection can happen at any time during a transplant.

Acute rejection happens within the first few weeks to months after a transplant. It is most often caused if a person stops taking their medicines or misses doses of their medicines.

Transplant medicines work like a blanket that cover and hide the transplant kidney from the immune system. When a person stops taking the transplant medicines it is like taking the blanket off of the transplant kidney. Once the blanket is off, the immune system can see the transplant kidney. The immune system will attack and try to get rid of the transplant kidney.

Another way to think about this is to imagine standing on a frozen pond. If you make one or two holes in the ice, you may be safe. If you make many holes in the ice, the ice will break and you will fall through. Missing your medicines is like making a hole in the ice.

The best way to avoid acute rejection is to make sure you take your medicines on time, in the same way , every day.

The good news is most rejection can be avoided by taking medicines and in most cases treated with medicines.

The bad news is the more rejection you have the more damage you have to the kidney. This can lead to chronic damage of the kidney.

2. **Chronic damage/scarring** – usually happens because the person has had many episodes of rejection. Chronic scarring of the kidney can lead to kidney loss and the person will have to go back onto dialysis. The best way to avoid chronic scarring is to take your medicines on time, in the same way, every day and follow your health care plan.

   a. **Antibody mediated rejection (AMR)** –- can happen anytime. This is caused when the person getting the transplant develops antibodies to the transplant kidney. Antibodies attack the kidney and destroy it. Antibodies come from being sensitized with blood transfusions, pregnancy and previous transplants. We screen your blood before transplant to find out if you have been sensitized so we know if you have antibodies already. AMR can also occur when a person does not take their anti-rejection medicines on time, in the same way , every day. This type of rejection is very hard to treat and sometimes results in loss of a kidney. Taking the anti-rejection medicines on time, in the same way, every day is one way to avoid AMR.

   b. **Donor Specific Antibodies (DSA)** – This is what your body makes as part of antibody mediated rejection. The most common reason DSA forms is from not taking your medicines on time, in the same way, every day. DSA is very difficult to treat. This may lead to damage and loss of the transplant kidney

My questions about rejection and chronic scarring:

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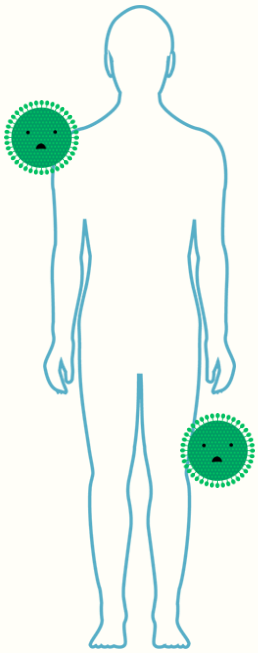
3. Infection

When your immune system is working normally, you can fight off most infections.

After a transplant you are more at risk for infections because the medicines you need to take make it harder for the immune system to fight infections.

You are at the most risk for getting infections in the first 6 months after a transplant because this is when you are taking the highest amount of the transplant medicines.

Why do the medicines for my transplant make me more at risk for infections?



The immune system is the body's natural defense against things like infections, abnormal cells, and foreign things that do not belong in our bodies – like a transplant kidney.

The immune system works like an army. When the body is invaded by something that doesn't belong, or is abnormal, the immune system finds it and tries to destroy it.

Transplant medicines work by suppressing the body's immune system. This means it makes it harder for the body to find other invaders like infections.

Why do I have to take medicines if they make it hard for my immune system to fight infections?

Medicines work like a blanket that cover and protect the kidney from the immune system. The medicines work to protect the kidney from being found and destroyed by the immune system. The job of the transplant team is to find the balance between keeping you healthy and giving you the right amount of medicine to protect the transplant kidney.

There are 2 types of infections that are common after transplant. They are **bacterial** and **viral** infections.

a. Bacterial infections

Bacteria are found everywhere inside and outside our body. Not all bacteria in the body are bad.

People taking transplant medicines are at more risk for getting bacteria that cause infections because the transplant medicines make it harder for the immune system to find and fight infections.

Bacterial infections can usually be treated with antibiotics.

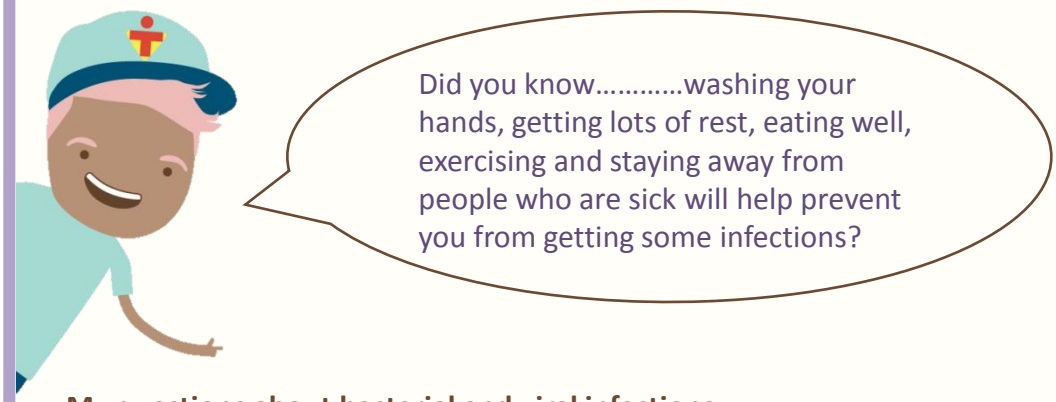
b. Viral infections

Viruses are the cause of many infections such as the flu, diarrhea and colds. All of us have had viruses in our lives.

Sometimes a virus can stay hidden in our body for years and when the time and circumstances are right, come back and make us sick again.

When a virus comes back and makes us sick again, this is called re-activation.

People with transplants who are taking transplant medicines are at a greater risk for getting a new virus and for having a virus they have had before re-activate.



My questions about bacterial and viral infections:

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Some of the common viruses important in transplant include:

Chicken Pox also called Varicella (Var–i-sell-a)

Chicken pox is a member of the Herpes Virus family.

People who are going to have a transplant have their blood checked to see if they have had chicken pox or the chicken pox vaccine.

Some people will need a vaccination for chicken pox before a transplant if they have not had the disease or enough chicken pox vaccination.

If a person gets chicken pox after transplant, there are medicines that can be given to make it go away faster.

If you have had chicken pox, the virus can stay dormant (hidden) in your immune system.

Sometimes chicken pox can re-activate and this disease is called shingles.

Shingles can be treated with anti-viral medicines. This medicine doesn't make the virus go away forever, but will make the infection last for a shorter time.

Cytomegalovirus (CMV) (Sigh-to-meg-a-low-virus)

CMV is a common virus that infects most people at some time during their lives. Most healthy people who have had CMV don't know they have had this infection.

Almost all people have been exposed to CMV by the time they are adults.

It is very common in transplant patients.

CMV is a member of the herpes virus family.

Like other herpes viruses, CMV infection can become dormant (hidden) for a while and may reactivate at a later time.

Before a transplant, blood is tested to see if you/your child has had CMV. We can prevent CMV by giving a medicine at the time of transplant and in the early months after transplant.

After transplant blood tests are done and the doctors examine the child to look for signs of CMV. If you have CMV you will be treated with medicine.

Some of the common viruses important in transplant include:

Epstein - Barr virus (EBV)

EBV is a member of the herpes family of viruses and most people will become infected with EBV sometime during their life time.

Before a transplant, blood is tested to see if you/your child has had EBV. We can prevent EBV by giving a medicine at the time of transplant and in the early months after transplant.

After transplant, blood tests are done and the doctors examine the child to look for signs of EBV. If EBV is found, medicine doses are lowered.

In transplant patients, EBV can be linked to a type of cancer.

BK virus

BK virus is another virus that is very important in transplant.

Another name for BK virus is Polyoma (Paul-ee-oh-ma) virus.

BKV is a virus that is found in the kidney and bladder.

A kidney with BKV that is transplanted into a person who has never had BKV can cause damage to the transplant kidney.

About 90% of adults have been exposed to BKV but many children have not.

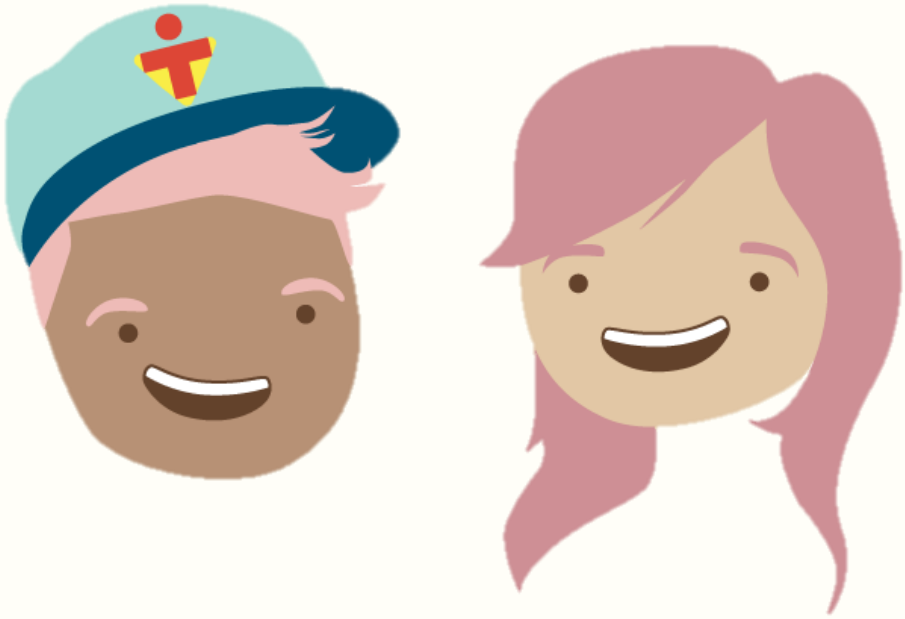
There are no medicines to prevent BK virus.

After transplant we test pee and blood to see if there is BK virus in the body.

BK virus can also be seen on a kidney biopsy.

Kidney transplant patients infected with this virus can be treated by using antiviral drugs and by lowering medicine doses. In some cases we cannot stop the virus from causing permanent damage to the kidney

Transplant candidates will have their blood checked for viruses and will have all their vaccinations updated before transplant. Some live vaccines, like the Chicken Pox vaccine, are not given after a transplant.



My questions about common viral infections:

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4. Disease recurrence

Some diseases may come back after transplant.

The most common diseases that may come back after transplant are diseases which are caused by problems in the immune system.

At the time of your transplant talk, the doctor will discuss if there is a risk that your disease will come back after transplant, and what the risk is.

In many cases it is possible to treat a disease when it comes back and prolong the life of the kidney.

My questions about disease recurrence:

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5. Cancer

Did you know our bodies are always making cancer cells? Cancer cells are cells that cannot stop growing.

Our immune system is always searching for and killing any abnormal cells in our body – cancer cells are abnormal cells.

When you have had a transplant, the transplant medicines which suppress the immune system make it a harder to find these abnormal cells and stop them from growing.

The **most common cancers** seen after transplant are:

a. **Skin cancer** - Skin cancer risk can be reduced by wearing sun screen all year long and by wearing sun glasses and a hat while in the sun. Before you have a transplant you will see a dermatology (skin) doctor who will check your skin for signs of cancer. After transplant the doctors are always monitoring for any signs of cancer.

b. **PTLD (post-transplant lymphoproliferative disease)** – pronounced Lim-Fo-Pro-Liff-Er-A-Tiv. PTLD is a type of white blood cell cancer. This type of cancer is related to the EBV virus and is treated by lowering the amount of transplant medicines and sometimes chemotherapy.

c. **Other cancers such as lung cancer or cervical cancer** - You can help prevent lung cancer by not smoking. HPV is a sexually transmitted virus that can cause cervical cancer and genital warts and cancer. Boys and girls who are sexually active should use condoms. Girls who are sexually active should have regular PAP tests. Transplant patients should be up to date on their Gardasil (HPV) vaccination.

Transplant candidates will see a dermatologist to have a skin check and have other tests to check for cancer before transplant.

My questions about cancer:

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6. Death:

This is the scariest possible risk for all transplant candidates and their families.

With any procedure there is an increased risk of death.

The risk of dying after a transplant is **extremely** rare.

Overall the risk of death from staying on dialysis is greater than the risk of death from transplant.

One of the reasons we do such an extensive workup is to identify as many risks as we can, and put a plan in place to try to prevent those risks from happening.

The greatest risk to death is right at the time of the transplant operation and during the first 6 months when you are on the most amount of immune medicines.

The doctor will talk more about the risk at the time of your talk.

My questions about the risks of transplant:

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What about risks and benefits to the kidney donor?

Anyone who is interested in being a kidney donor will be given the contact information for the Transplant Manitoba -Gift of Life donor program coordinator at the meeting held to talk about your child's transplant.

Anyone who is interested in finding out more or about being a kidney donor must contact the Transplant Manitoba –Gift of Life program themselves to notify the program of their wish to donate.

Those who are interested in being a donor will have an initial screening phone call by the Transplant Manitoba -Gift of Life donor program coordinator to see if they can go ahead for a formal assessment.

The doctors in the Transplant Manitoba -Gift of Life donor program will discuss general risks and benefits and anything specific to that person when they meet.

You can get information about being a donor on the Transplant Manitoba Website at: http://www.transplantmanitoba.ca/decide/living-kidney-donor

My questions about risks and benefits to the kidney donor:

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A word about Adherence (Add-hear-ants)

Adherence means sticking to the health care plan. Some examples of the health care plan are taking transplant medicine on time, in the same way, every day, drinking the water you need to keep a kidney healthy, and coming to clinic.

Non-adherence means not sticking to the plan of care.

Non-adherence is one of the major reasons children, and especially teenagers, have rejection and lose their kidneys.

If the kidney is too damaged from rejection it will no longer work.

When the kidney no longer works, the person will have to return to dialysis.

Why is medical adherence important in kidney transplant?

Adherence is important

a. in keeping your/your child's kidney in good shape and to **prevent rejection** so the kidney will last as long as possible.
b. to keep you/your child in **the best possible physical, emotional, and social condition** so they can participate fully with family and friends in normal activities of life such as school, family activities and outside interests.
c. to minimize any risks to you/your child's health.

What does medical adherence include after transplant?

Sticking to the plan of care includes:

a. Taking all medicines on time, in the same way, every day.
b. Making sure you drink the amount of water that the transplant doctors have prescribed. This is usually at least 2-3 liters of water per day (more when sick or active).
c. Coming to all of your appointments.
d. Keeping yourself healthy by washing your hands, getting lots of rest, exercising to avoid gaining lots of weight, and avoiding people who are sick.
e. Getting your annual flu shot.
f. Contacting the doctors or nurses when you don't feel well or are worried about your kidney.

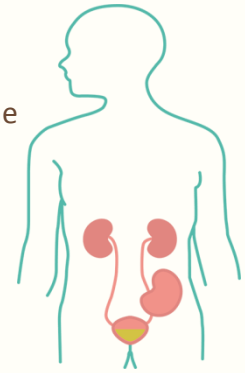
What are the steps in kidney transplant?

The first step in a kidney transplant is coming to meet with the Transplant Manitoba –Pediatric Kidney Program (TM-PKP) team to talk about the transplant process and the workup, and making a decision about going ahead with the planning for a kidney transplant.

A transplant is not for everyone. The TM-PKP team will explain the risks and benefits of a kidney transplant and give their best recommendation based on the meeting.

Some families decide they are ready and want to go ahead with the work up for transplant. Other families need more time to decide. The TM-PKP team will support the decision a family makes.

In *extremely rare circumstances*, a child is not a candidate for transplant. When this happens, the TM-PKP team will discuss the reason why and the options for care.



Going ahead with kidney transplant workup

If you decide to go ahead with the transplant workup, the first step is to have some blood taken for several tests including blood group, HLA tissue typing and antibody (ant-e-body) testing.

Finding out what blood group you are is important in the transplant process.

Why is blood group important?

In kidney transplants, the donor (the person giving a kidney to someone else) must be blood compatible with the candidate (the person getting the kidney). If they are not compatible, the child will reject the kidney and the body will try to get rid of the transplant kidney.

What are the blood groups?
There are 4 blood groups: O, A, B and AB.
A child with type A blood can get a kidney from a person with type A or O blood.
A child with type B blood can get a kidney from a person with type B or O blood.
A child with type AB blood can get kidney from any blood group – A, B, AB or O blood.
A child with type O blood can only get a kidney from a person with type O blood.

A transplant **donor** with blood group O is called the "universal donor" and can give a kidney to anyone no matter what their blood group.

A transplant recipient with blood group AB is called a "universal recipient" and can get a kidney from any blood group.

Your Blood Group	Compatible Blood Groups
A	A & 0
B	B & O
AB	A, B, AB, & O
O	O

You may have heard someone say I'm "Rh negative" or "Rh positive". In kidney transplant the donor and recipient RH does not matter. An Rh positive person can give a kidney to an Rh negative person and visa-versa, as long as they are a blood group match.

My questions about blood group matching:

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What is HLA and why are they important in kidney transplants?

HLA stands for Human Leukocyte (Lew-ko-site) Antigens. The doctors and nurses call them HLA. You will also hear them called HLA antigens.

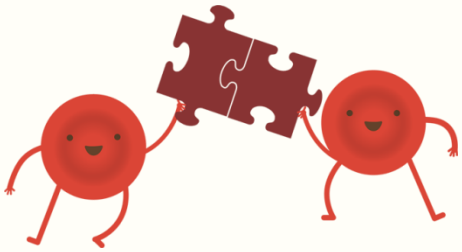
HLA are markers found on our cells in our bodies.

HLA antigens are our genetic make up and are the way our body identifies itself – they make us who we are.

A person inherits a set of HLA from each parent. So if we look at your HLA, half will be the same as your father and half will be the same as your mother.

When matching a donor to a candidate, we look at all the HLA antigens from the candidate and the donor to find the best possible match.

In our transplant program we try to find the best match for you.



When matching a donor and candidate we want to try and get the best match possible.

A better HLA match means there may be less of a chance that the kidney will be **rejected** by the child's body.

My questions about HLA:

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What is an antibody and why are they important in kidney transplants?

Antibodies (ant-ee-bod-ees) are proteins (pro-teens) made by your body. Antibodies are made when something foreign comes into the body.

When a foreign antigen (like an infection, a vaccine or blood) comes into your body, the immune system makes a copy of the antigen. This copy is called an antibody.

The immune system does this so the next time that foreign antigen comes into the body, the immune system will remember it, and try to get rid of it. This is a normal thing for the immune system to do, and helps keep us healthy.

Antibodies made to HLA antigens are called HLA antibodies.

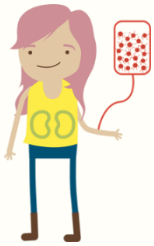
We call the making of these HLA antibodies "sensitization (sen-sa-tie-zay-shun)".

You will hear the doctors and nurses asking if you are sensitized.

How does our body get sensitized with antigens and then make HLA antibodies?

Our body can make HLA antibodies and we may become sensitized when we have had:

- Blood transfusions
- Previous kidney transplants
- A previous pregnancy



Is sensitization important in transplantation?

YES, if a child (candidate) is transplanted with a donor's kidney and the child has antibodies to that kidney or they are "sensitized" to that kidney, there is more risk that the kidney will be rejected by the child's body.

Rejection means the body's cells start to attack the transplanted kidney and try to get rid of it.

My questions about sensitization:

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In review:
The 3 important things we need to know when starting a transplant workup are:

- **Blood Group**

- **HLA Antigens**

- **If you are "sensitized" with HLA Antibodies**

My questions about the three important things I need to know when starting a kidney transplant workup:

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What else happens during a transplant work-up?

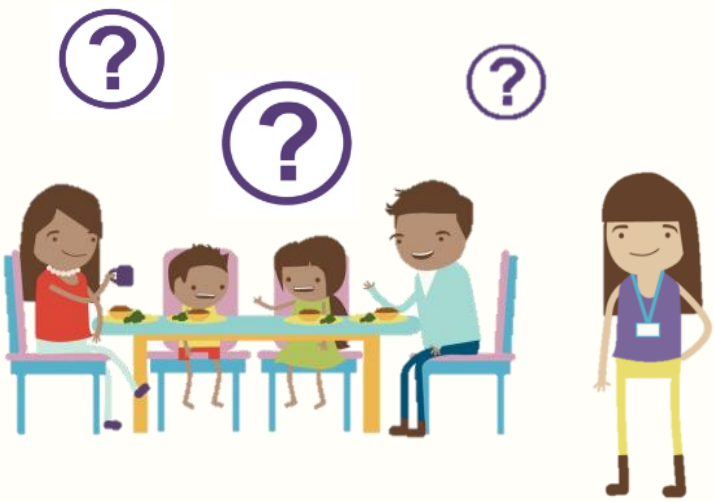
Once we know your blood group and HLA and antibody testing, then the rest of the workup will start. This will include many tests and appointments.

You will be given a reading package on all of these tests and about the doctors you will see during the workup.

The pediatric transplant coordinator organizes the tests and appointments to make sure your child is safe and ready for transplant.

Once ready, our team will meet with you again to review the results of all the tests and appointments, talk about the details of the surgery if you have a donor or, if you do not have a donor, talk about listing you on the Transplant Manitoba deceased donor list.

We will also talk about the expectations and post-transplant care.



You will have an appointment to meet with the transplant coordinator and one of the transplant doctors.

The coordinator and the doctor will discuss the risks and benefits of kidney transplant.

They will also talk with you about any specific risks to your child.

At the end of the meeting, they will discuss with you whether or not you are ready to proceed with a kidney transplant work-up.

If you are ready to proceed, blood group, HLA antigen and antibody testing will be arranged.

And then you will start the work-up with many tests and appointments.

Once this is all completed, you will meet again with the transplant coordinator and transplant doctor to review these results and decide if you are ready for transplant.

The date and time of my meeting to discuss a potential transplant is: _____.

If at anytime after the initial meeting, you as a parent (or another family member) decide that you are interested in being a kidney donor, you will be seen by the Transplant Manitoba – Gift of Life Living Donor Program.

This is a separate, confidential program.

You will be given the phone number to the Transplant Manitoba-Gift of Life coordinator to call. ***You will need to contact the living donor program yourself. We cannot make this phone call for you.***

The process for your assessment to be a donor includes screening questionnaires, a donor information session, tests and appointments. You will be seen by a doctor from the Transplant Manitoba-Gift of Life program who will decide if you are safe to donate a kidney.

The transplant candidate who has a living donor will be booked for the transplant as soon as all the work-up for the transplant candidate and the donor is finished and a transplant operating room slot is ready.

Sometimes a child may not have a living donor.

A child who does not have a donor will have the same workup as a child who does have a living donor.

The only difference is, at the end of the workup, the child without a living donor will go on the deceased donor transplant waiting list.

My final questions:

Please feel free to bring your booklet along to your meeting.

At the meeting we will be more than happy to answer any questions or concerns you have about kidney transplant.

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