

What to expect when having a Deceased Donor Kidney Transplant Operation



Transplant Manitoba: Pediatric Kidney Program
Section of Nephrology
Children's Hospital of Winnipeg
2021

Welcome,

This booklet is being given to you because you have completed a kidney transplant workup and are ready and safe for a kidney transplant.

This booklet will help you understand what to expect when you are getting ready to come to the hospital for a deceased donor kidney transplant.

Please take some time to read this booklet.

There is space at the end of each section in this booklet for you to write any questions you may have.

If you have any questions about what to expect when you come for a transplant operation, please call us at any time. We will be happy to go over the information in this booklet and answer any questions.

You can call the Pediatric Transplant Coordinator at 204- 787- 4842 or Toll free at 1-877-499-8774 –extension 74842 with questions you may have. The coordinator will meet with you at any time you need to have questions or concerns answered.

The Transplant Manitoba – Pediatric Kidney Program Team

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A quick review of deceased donor transplant

What is a Deceased donor kidney transplant?

- Deceased donor kidneys come from a person who has died, and they and their family has consented to having their kidneys donated for transplant.
- Deceased donor kidneys can come from those who have brain or cardiac (heart) death.
- If you do not have a live donor who can give you a kidney, deceased donor transplants are another good choice for a transplant.



Are deceased donors safe to give kidneys?

- Deceased donors are screened for diseases and infections to make sure they are safe to donate a kidney.
- All deceased donor kidneys are reviewed with the Pediatric kidney transplant doctor and only accepted for transplant if they believe it is a good kidney for you.
- The transplant doctor will discuss anything that is out of the ordinary about the kidney with you.
- The identity and reasons a deceased donor has died are confidential and will not be shared with you.

What is the Transplant Manitoba Deceased Donor wait list?

- The Transplant Manitoba Deceased Donor wait list is a list of all people in Manitoba who need a transplant.
- It is a confidential list and not available to the general public.
- The list is used to help decide who is a priority to get a transplant and to keep track of how many people are waiting and how long they have been waiting for a transplant.

Who is on the Transplant-Manitoba Deceased Donor wait List?

Adults and children who:

- Do not have a live donor
- Have had a completed transplant workup
- Are safe to get a transplant
- Have agreed to get a deceased donor kidney

What does it mean to be “READY” on the Transplant-Manitoba Deceased Donor wait list?

Being “Ready” on the wait list means you:

- Are safe to get a kidney transplant
- Have completed your workup
- Do not have a live donor to give you a transplant
- Have agreed to a deceased donor kidney transplant

What does it mean to be on “HOLD” on the Transplant-Manitoba Deceased Donor wait list?

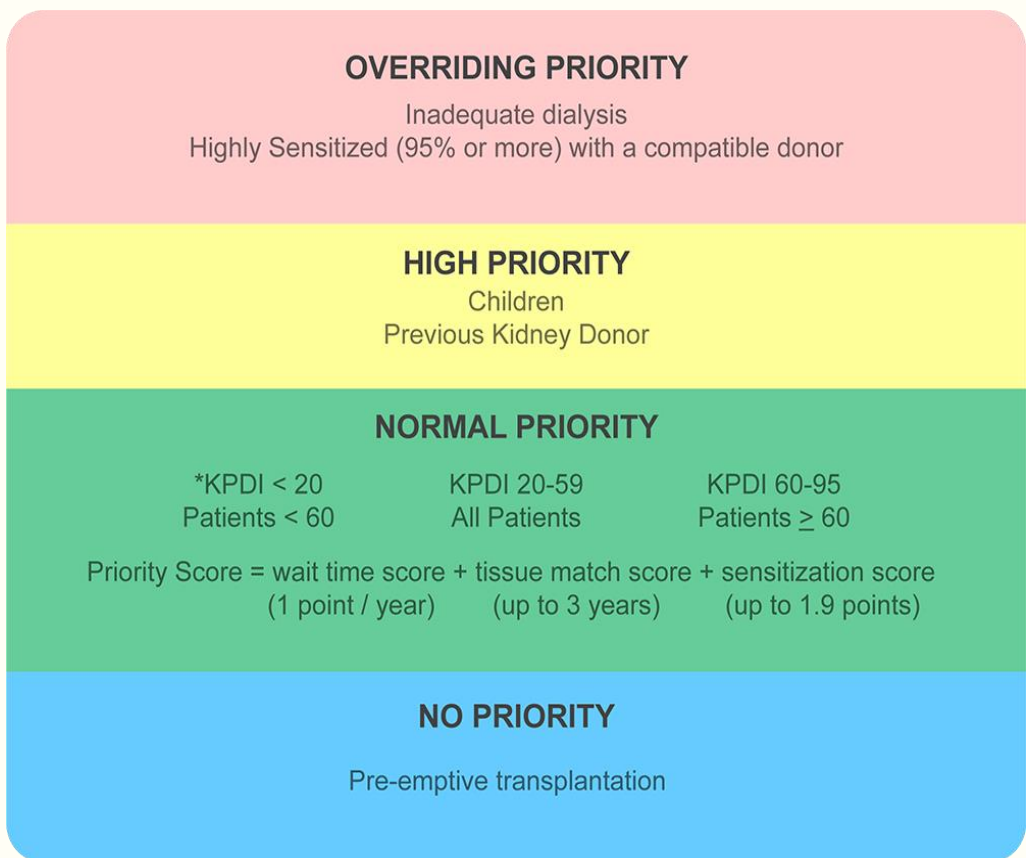
- Being on “hold” on the list means it is not safe for you to get a kidney right now. If you need to go on “hold”, the Pediatric transplant team will talk to you about the reason you are on “hold”.
- Some of the reasons to be on “hold” include:
 - Serious illness
 - Infection
 - Non-adherence, which means you are not able to stick to your health care plan
- Being on “hold” is usually temporary. Once it is safe for you to get a transplant your name will be put “ready” on the list

Can I go on Vacation while on the Transplant-Manitoba Deceased Donor wait list?

- Everyone deserves a vacation, but some vacation spots may be too far for you to get back to the hospital in time for a transplant
- Talk about your plans with your transplant coordinator
- If your vacation is too far away, we can temporarily put your name on “hold” until you come back.
- You will be put “ready” again as soon as you are back
- You do not lose your priority on the list

Do Children get priority on the Transplant Manitoba Deceased Donor Waitlist?

- Children and youth “ready” on the Transplant Manitoba deceased donor list have high priority on the list and keep their priority until they turn 19 years of age.
- The only people with more priority on the Transplant Manitoba deceased donor list are people who are medically unstable and may die if they do not get a kidney quickly.
- This is the priority ranking from Transplant Manitoba – you can find it on the Transplant Manitoba website at: <https://www.transplantmanitoba.ca/transplant-program/kidney-allocation>



KDPI stands for Kidney Donor Profile Index. It is used as a tool to ensure patient safety.

What is a Pre-emptive transplant?

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.

Any Questions?



An illustration of a family of four (a mother, a father, and two children) sitting around a small table, eating a meal. A staff member, a woman wearing a purple vest and a lanyard, stands to the right of the table. Three large question marks are floating in the air above the family, suggesting they have questions or are seeking information.

[illegible]

When will I get a call for a kidney transplant?

- There is no way to predict when you will be called for a transplant, which means it can come at any time of the day or night and any day of the week.
- Wait times depend on many things, including the availability of donors that match you. On average, children wait 12-18 months, but the time can be shorter or longer.
- While you are waiting, it is important to keep your contact information up to date with the transplant coordinator so that, when the call for a transplant comes, we can always reach you.
- If we cannot reach you within a reasonable time frame, the kidney will be offered to someone else.
- Waiting for the call can be hard. We are here to help. Please call anytime if you have questions about the wait for a kidney.

How do the doctors know the kidney is right for me?

- We will always try to find the best kidney for you.
- The Transplant Manitoba- Pediatric Kidney program accepts kidneys that are **blood group compatible**, are of **good quality**, and are at least a **2 HLA antigen match**. The antigens we match are called DR and DQ.

Do you remember what blood group you are and which blood group you can get a kidney from?

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

You can get a kidney from any person that is a blood match or has a compatible blood group.

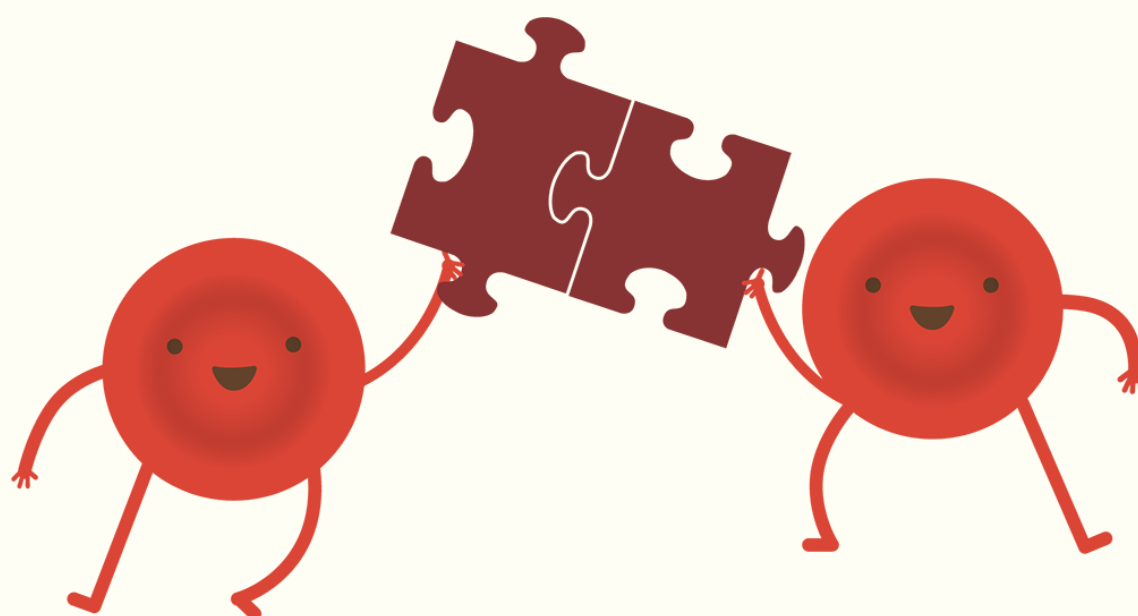
- You may wait longer if you have type B or AB blood group because they are the least common blood groups
- There is no way to say how long you will wait on the list until you are called for a kidney. If you are sensitized, you may wait longer than someone who is not sensitized.

Do you remember what sensitized means?

- It means you have been exposed to something foreign in your body (blood transfusion, pregnancy, or previous transplant) and you have developed an antibody in your blood.
- You may wait longer for a kidney if you have been sensitized because it may be harder to find a match for you.

What are HLA antigens?

- HLA antigens are proteins found on cells. They help the body identify if something is like or not like you.
- We want the transplant kidney to be “like you” as much as possible.
- There are many HLA antigens.
- In our program, we will only transplant a kidney if at least 2 antigens (DR and DQ) match to you.
- You can match more antigens but the minimum match we will accept is a 2-antigen match.
- The better the match, the more likely the body will accept the kidney. You will still need to take medicine to help your body accept the kidney no matter what the match.



What will they ask me when I am called for a transplant?

- The pediatric nephrology doctor will call you to tell you there is a kidney that is a good match and is of good quality that is being offered for transplant.
- The doctor will ask you a few questions to make sure you are safe to accept a kidney. We would not want to transplant a kidney if you are not safe. Some of the questions include questions about recent illnesses, if you are sick right now, and if you are taking any medicines.
- All donors are screened very carefully before being approved for donating. At times, there is something unusual about the donor that may increase the risk to the person getting the kidney. If there is something unusual about the kidney, the doctor will discuss this with you.
- Once you have had all your questions answered and the doctor thinks it is safe for you to get a kidney transplant, you should do the following:
 - Do NOT eat or drink anything
 - Do NOT take any medicines unless directed by the doctor
 - Come directly to the hospital ward CK5. Do NOT go to emergency or admitting unless advised to do so by the doctor. Bring the following:
 - **All your medicines**
 - **If you are on dialysis or tube feeds – bring your machines with you**
 - Any comfort items (pajamas, stuffy, toiletry supplies)
 - Your Manitoba (or other provincial) health card
 - Contact numbers for your support person



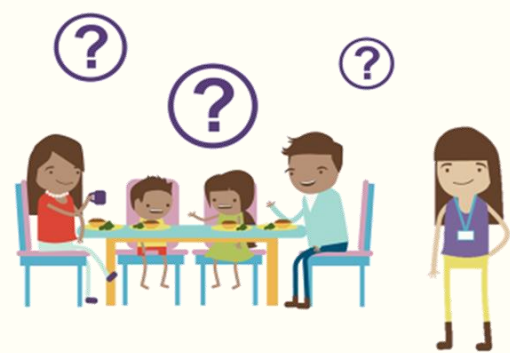
- It is important to go to the hospital as soon as possible. The transplant usually happens within 24 hours of being called.

When I am called for a transplant, will I get the kidney?

- When you are called for a kidney, you can be reassured that our program thinks it is a good kidney for you.
- The doctor will ask you some questions to make sure you are safe to get a transplant.
- If everything is OK, you will be asked to come to the hospital to get ready for the transplant. You will be directed to go directly to the ward CK5. Do not eat or drink or take any medicines unless the doctor tells you to do this.
- Very rarely a person is called for a kidney and does not get the transplant.
- There are many reasons this may happen including: your blood tests are not compatible (they don't match) with the donor or there is something wrong with the kidney when they take it out of the body of the person donating.
- If you are called and do not get a kidney transplant, you will go back on the list to wait for the next kidney that is a match for you.
- You do not lose your priority on the list.



Any Questions?



My questions about being called for transplant:

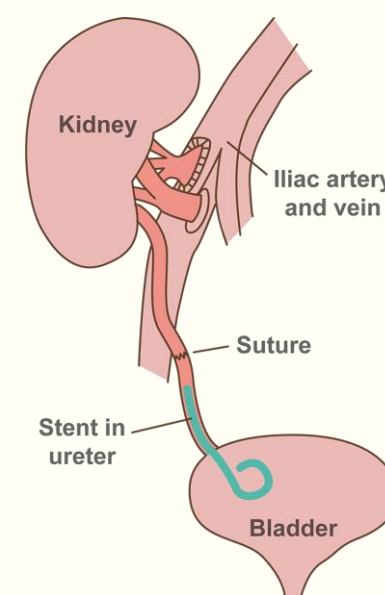
What happens when I get to ward CK5?

- When you arrive on CK5 you will be admitted to the ward and be seen by the nurse, and many medical persons such as medical students, residents, and doctors. You will see the anesthesia doctor, who will talk about the operation. You will also see the transplant surgeon, who will review the risks to getting the transplant and get a surgical consent signed. If you have a peritoneal dialysis (PD) catheter in place, we will remove that at the time of the transplant, so we will get consent for a PD catheter removal at the same time.
- You will have your height and weight checked.
- Your blood pressure, heart rate, breathing rate and oxygen level will be checked – these are called your “vital signs”.
- An Intravenous (IV) will be started for fluids and medicine. Blood will be drawn and sent to make sure you match your donor, and you are safe to get the transplant.
- You will start immune suppressing medicines by IV to prepare your body to accept the kidney.
- You may have dialysis. If you are on peritoneal dialysis, your abdomen will be left empty (no last fill) before going to the operating room. If you are on hemodialysis, you may have a treatment before going to the operating room.
- You cannot eat or drink anything unless advised by the transplant team.
- If you are big enough, you will have special socks called TEDs placed on your legs just before going to the operating room. These are used to help prevent clots in the legs. The TEDs will stay on until you are up and walking around.
- There are many things to do to get you ready for the operation. Many people find this waiting time very emotional. It is normal to feel nervous and afraid. We are here to help. We can answer any questions you may have. Having a friend or family member as a support person is helpful.



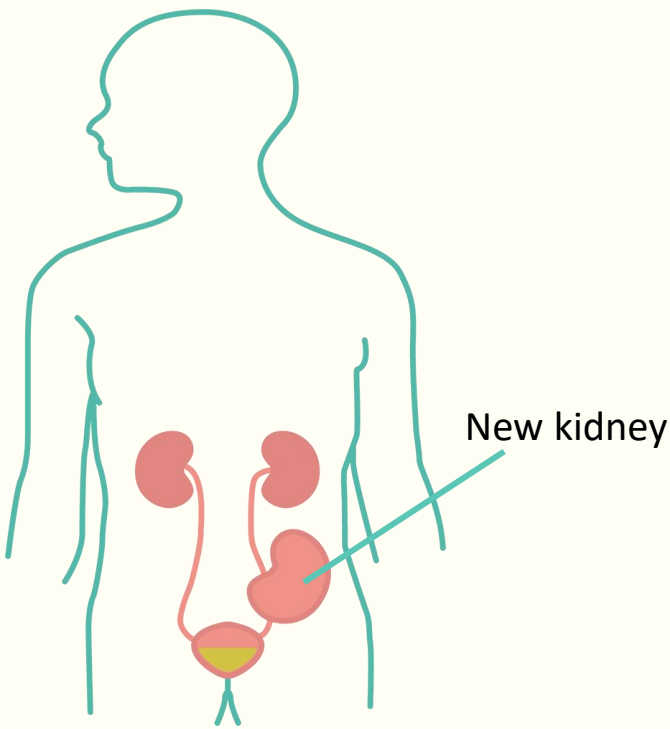
What happens when I go to the operating room?

- Once all the preparations are done and the operating room (OR) is ready, you will be taken to the pediatric OR. Your parent/guardian can come with you to the OR waiting room.
- In the OR you will be given some medicine to help you fall asleep. Once you are asleep, and cannot feel anything, you will have a small tube placed in your mouth and throat which helps your breathing during the operation. Once the operation is over, the tube is usually taken out. Sometimes, a child will go to the pediatric intensive care unit (PICU) with the tube in place. The medical team will decide when it is safe to take out the tube.
- A urine catheter is inserted into your bladder to collect your pee. This will stay in for a minimum of 5-7 days after the transplant.
- A special IV is put into a vein close to your neck. This is used to give lots of fluids. You will have another IV put into your arm to monitor your arterial blood pressure. You may have a 3rd IV in your arm to give medicine or fluids.
- You will not feel any of this because you are in a special sleep and can't feel pain.
- The OR nurse will put a blood pressure (BP) cuff onto your arm to check your BP. Special sticky pads are placed on your chest to monitor your heart rate. You will have a small clip put onto your finger or toe to check your blood oxygen level.
- When all this preparation is done, the operation starts.
- A transplant operation can take 4-6 hours from start to finish. For complicated surgeries, it could take longer. A small tube called a stent is placed in the ureter during the surgery. This helps prevent the ureter from blocking. The tube will be taken out in a separate operation about 6 weeks after the transplant.
- The waiting time during the surgery is very stressful for families. Parents/Guardians should take some time to go to get something to eat and drink. If you have your support person with you, have them come along to wait with you.
- When the surgery is done, you will be sent to the PICU. You will still have all the IV lines and tubes listed above and, now you will have a dressing over the site of your transplant kidney. There will be a tiny catheter (tube) inserted into the stitch line to give pain medicine. This is called a wound catheter. This catheter will come out in a few days.
- The surgeon will usually come to talk to you about the operation.

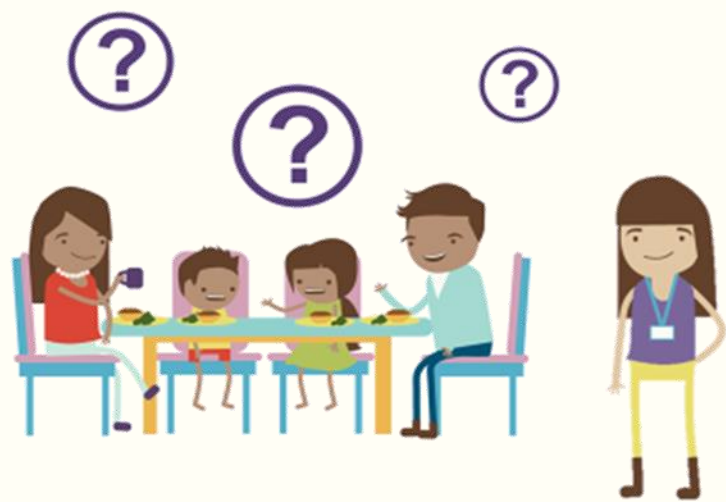


Will the kidney start working right after transplant?

- When the kidney is removed from the donor, it is placed on ice to keep it cool. This can cause cold injury. Deceased donor kidneys have more cold injury because they are placed on ice longer. Sometimes the cold injury can slow the function of the kidney and it does not work right away. If this happens, you may need dialysis for a short time after transplant until the kidney starts to work.



Any Questions?



My questions about going to CK5 and the OR for surgery:

What happens in the Pediatric Intensive Care Unit (PICU)?

- The PICU is a critical care unit. The staff are specialized in looking after transplant patients and those who are very sick.
- You will be admitted to the PICU right after surgery.
- During this time, you are closely monitored to watch for complications, to provide good pain control and you are given lots of fluids to help the kidney.
- A little bit of pain is expected. You will have a wound catheter that gives pain medicines right to the transplant site. You will also get pain medicines regularly in your IV. At times you may need extra pain medicine ---just ask your nurse for medicine if your pain is not well controlled.
- There are many machines and monitors in the room. The staff use these to help with making sure you are doing well after the transplant. The staff are happy to explain what they are for and why they beep!
- You will be able to drink and eat once it is safe for you. The staff will let you know when it is safe.
- You will continue your transplant medicines (also called immunosuppressive medicines) by IV until you can take them by mouth or tube.
- During this time, your blood will be checked often to make sure your kidney is working, and your transplant medicine levels (drug levels) in your blood are not too high or too low.
- During the time in PICU, you are allowed 1 visitor at a time.
- Most children stay in PICU for 24-48 hours. When it is safe, you will be transferred back to the ward CK5.
- Before you go back to CK5, you may have at least one of your IVs removed. The wound catheter may be removed. Your urine catheter will stay in place. The sticky pads on your chest will be removed.
- The TED stockings will be removed once you are up and walking around.



What happens when I get back to ward CK5?

- When you get back to CK5 you will receive the same medical treatment as you did in PICU. The staff on CK5 are experts in transplant care.
- You will start to take your transplant medicines by mouth.
- Your intake (what you drink) and output (what you pee) will be measured to make sure you are getting enough fluids to keep your kidney safe.
- You will have blood taken every morning BEFORE you take your immunosuppressive medicines. Once your blood test is done, you should take your medicines right away. The blood is tested to make sure you have the right amount of medicine in your body and to make sure your kidney is working well.
- As you get better and can drink, eat, and take all your transplant medicines by mouth, your IVs will be removed. Once you are up and walking, your TED stockings can be removed.
- While you are on CK5, you will have intensive teaching by the post-transplant nurse clinician and the transplant pharmacist to get you ready to safely look after your kidney at home. Ask as many questions as you want to make sure you understand how to safely care for the kidney.
- Most children are discharged from the hospital about 7-10 days after a transplant. If there are concerns about the kidney, you may have to stay longer.



When is it safe to go home?

You will be able to go home when you are safe, and you:

- No longer need IV pain medicines.
- Have had your urine catheter removed.
- Are taking all medicines by mouth or in a tube.
- Are drinking all fluids by mouth or in a tube.
- Can get up and move around.
- Have had all the discharge teaching done.
- Your medicine prescription is ready.

What happens after I go home from the hospital?

Follow-up with the post-transplant team is very important to keep you healthy, to monitor for potential complications and, to keep your kidney safe.

- You will be seen in the clinic daily for a week or more. Timing of visits will be discussed with you when you are ready to go home.
- Each day you will have blood and urine testing, a weight, a blood pressure check, a medicine review and, have a checkup with the nurse and transplant doctor. You may also see the pharmacist, dietitian, or social worker.
- After your appointment, the transplant nurse will call you at home to review the results of your blood and urine tests and tell you about any changes to your medicines or other treatments.

How can I keep my kidney healthy?

- There are many things you can do to keep your kidney healthy.
- Research shows that adherence, or sticking to the health care plan, is the most important way to keep your kidney healthy.
- Adherence means taking your medicines on time all the time, drinking your daily fluids, coming to all your appointments and treatments. It also means practicing good self-care such as getting enough rest, exercise and eating well. And it means monitoring for any signs of infection or rejection and letting the transplant team know if you think you have any of these.
- Our goal is to keep you healthy and to keep your kidney healthy and functioning for as long as possible. Most children will need a second kidney transplant in their lives, so a part of your job (and ours) is to work together to keep your first transplant kidney healthy for as long as possible.
- When you are seen in clinic, you will receive ongoing education about how to safely care for your kidney and keep you healthy.



A word about Adherence

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 why 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 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.

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If you have any questions about this information, call the Pediatric Kidney Transplant Coordinator at 204-787-4842 OR Toll free at 1-877-499-8774—extension 74842.



Glossary – what do all those words mean?

ABO - is the short form for blood groups. There are 3 groups: group A, group B and group O.

Adherence (Add-hear-ants) - sticking to something. In transplant this means sticking to the plan of care.

Anesthesia (An-a-th-ee-zee-ah) - is a state of controlled, temporary loss of sensation or awareness that is induced for medical purposes. It may include some or all of analgesia (relief from or prevention of pain), paralysis (muscle relaxation), amnesia (loss of memory), and unconsciousness.

Anonymous (An-on-e-muss) – someone who is not known to others

Antibody (Ant-e-bod-e) - antibodies are proteins (Pro-teens) made by your body when something foreign like an antigen or bacteria or virus comes into your body. Antibodies try to destroy these invaders to protect the body against disease

Antigen (Ant-a-gin) - is something unknown to the body that will trigger the immune system to make antibodies. A transplanted kidney is considered a foreign object.

Arterial line - also called an Art line. This is a small tube placed in an artery at the wrist area. It is used to measure blood pressure

Bladder - is a balloon like object found in the abdomen. It collects the urine (pee) that comes from the kidney.

Blood Pressure - is the pressure of the blood within the arteries. It is made by the contraction (squeezing) of the heart muscle. The first (systolic pressure) is measured after the heart contracts and is highest. The second (diastolic pressure) is measured before the heart contracts and is lowest.

Breathing tube - a small tube placed into the throat to help you breathe when you are under anesthesia.

Catheter (Kath-a-ter) - the name for a tube which is put into the body for dialysis. In hemodialysis the catheter is placed into a blood vessel. In peritoneal dialysis the catheter is placed in abdomen.

Deceased Donor (DD) – a person who has recently died. Either the person or the person's family has offered the kidney for transplantation

Dialysis - the process of cleansing and achieving chemical balance in the blood of patients whose kidneys have failed. Dialysis may refer to hemodialysis or peritoneal dialysis (PD)

Donor - the person who gives an organ to another person.

Graft - an organ or tissue that is transplanted.

Hemodialysis (He- Moe-Di-Al-is-is) - a type of dialysis in which blood is cleaned of wastes by circulating through an apparatus outside the body – you may hear people call it an "artificial kidney"

HLA (human leukocyte antigens) - system is a genetically determined group of markers (antigens) that are present on human blood cells and tissues. They are our genetic make-up and are the way our body identifies itself – they make you who you are.

ICU - short for intensive care unit. A hospital unit that can provide very specialized care

Immunosuppression - medicines that dampen the immune system so it will not attack a transplanted kidney

Immune response - the body's reaction to invasion by any foreign material

Immune system - the system that protects the body from invasion by foreign substances, such as bacteria, viruses, and cancer cells

IV - is short for intravenous. This is a plastic tube that is placed into a vein to give fluids or medicine during transplant

Kidney - one of the two kidney-bean-shaped organs located on both sides of the spine, just above the waist. They rid the body of waste materials and maintain fluid balance by making of urine (pee)

Living Donor (LD) - a person who is alive and who donates an organ for transplant

Match - the compatibility between recipient and donor. In general, the more closely the donor and recipient "match", the greater the chance the transplant will be successful.

Nasal prongs - plastic tubes that are placed under the nose and provide oxygen through holes in the tube.

Nephrologist - A doctor, who studies the kidney, treats kidney disease. A pediatric Nephrologist is a doctor who looks after children and adolescents with kidney disease.

OR - short for operating room.

Peritoneal (Per-it-toe-kneel) dialysis - a way to clean the waste out of the body via the abdomen (tummy).

PICU - short for pediatric intensive care unit. A hospital ward whose staff specializes in caring for the sickest patients.

Recipient (Ree-sip-e-ent) - the person who is getting an organ from another person.

Rejection - an immune response against a kidney, which, if not successfully treated, results in failure of the graft (kidney) to survive.

Sensitized - the development of antibodies by previous exposure to that antigen.

Surgeon - a doctor who performs surgery.

Transplant - an organ (kidney) is taken from the body of one person and put into another person.

TED stockings - special socks that help to prevent blood clots in your legs. These are worn during the transplant operation and until you are up walking around. They are only used if you are big enough. The nurse measures you to see if you are big enough to wear the TEDs.

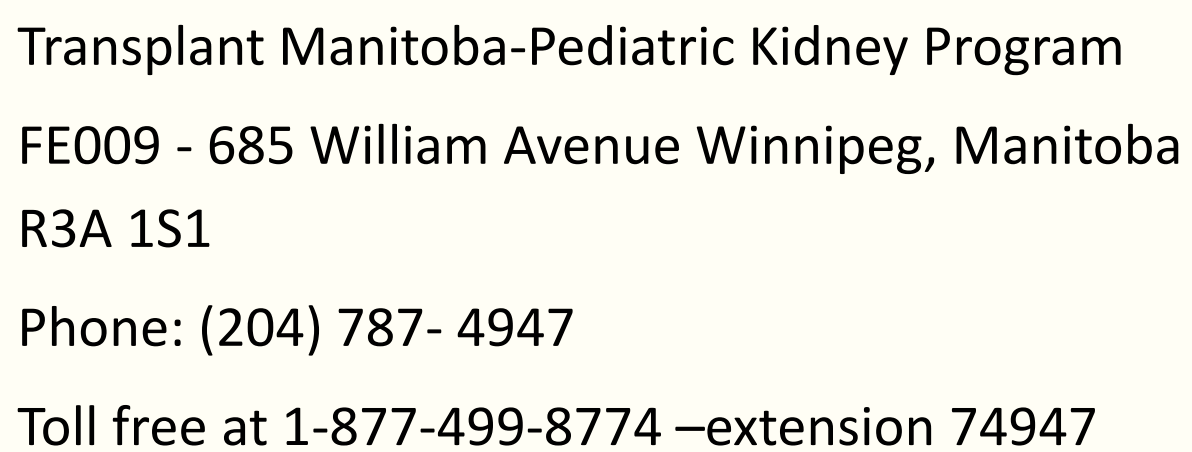
Ureters (Ur-ra-ter) - the tube that connects the kidney to the bladder. It drains the urine from the kidney to the bladder.

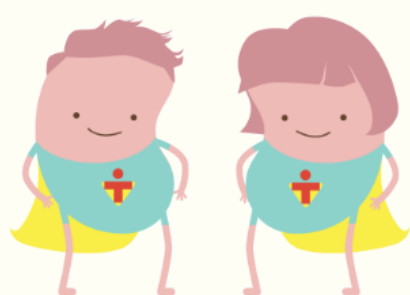
Urethra (Yur- eth-raw) - a tube that drains urine the bladder out of the body.

Urine catheter - a plastic tube placed into urethra and then onto the bladder to help urine drain. The urine catheter is attached to a bag so urine can be collected and measured.

Wound catheter - a small tube placed into the stitch line to give pain medicine.

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Created by Julie Strong BN, Dot Molchan RN, Heather Murison RN, Diane McKenty, RN and Aviva Goldberg MD with Pediatric Nephrology (Children's Hospital Health Sciences Centre).

Special thanks to the Children's Hospital Foundation of Manitoba and the Kidney Foundation of Canada-Manitoba Branch for supporting this project with a grant and funding.

For more information about this resource, please contact Pediatric Nephrology at 204-787-4947 or kidneytwins2@exchange.hsc.mb.ca