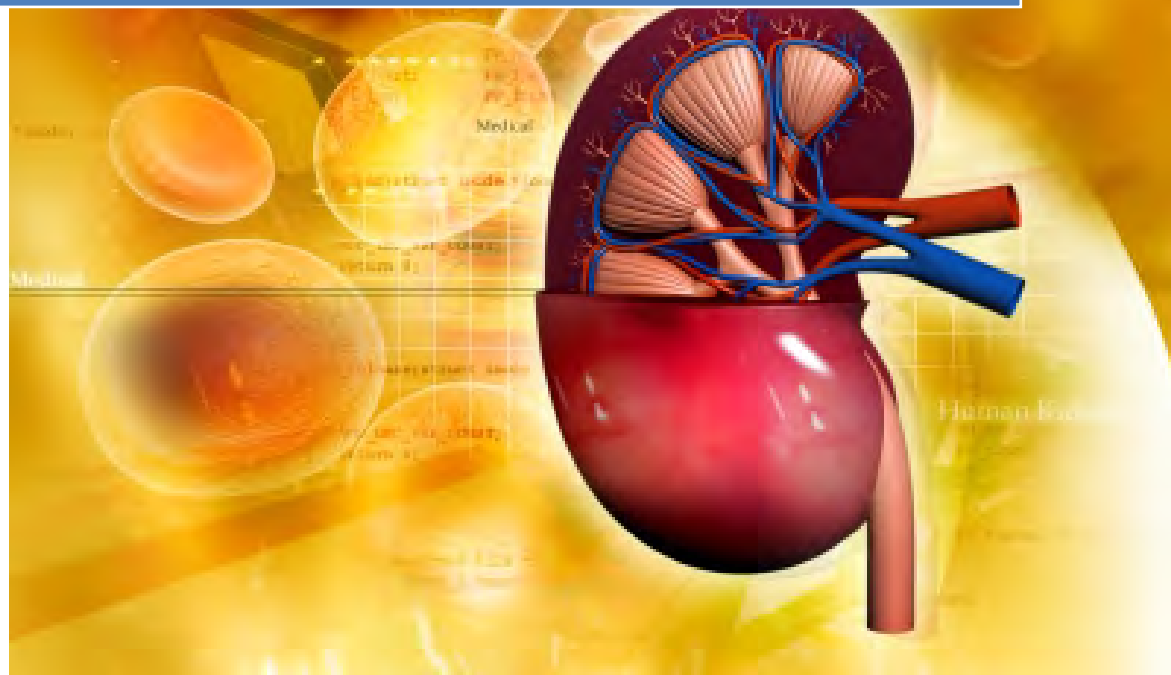


Kidney Transplant Patient Information Package



Transplant Manitoba
Gift of Life

Transplant Manitoba Adult Kidney Program

Table of Contents

Introduction	1
Transplant Manitoba program	1
Abbreviations	1
Telephone Numbers	2
Pre-transplant	3
Referral	3
The Transplant decision.....	3
<i>If you are undecided about receiving a transplant</i>	<i>3</i>
<i>If you have decided that transplant is not for you</i>	<i>4</i>
Pre-transplant evaluation.....	4
<i>The Ready list</i>	<i>5</i>
Types of kidney donors.....	5
<i>Deceased donor</i>	<i>6</i>
<i>Living donor.....</i>	<i>6</i>
Matching deceased donor kidneys for transplant.....	7
Average wait times	9
<i>Keeping your contact information up to date</i>	<i>9</i>
The phone call	9
Fasting before transplant surgery	10
Transportation	10
Accommodation	10
What to bring to the hospital	11
Other responsibilities	11
Preparing for transplant day.....	13
Pre-admission appointments for transplant from a living donor.....	13
Admission to hospital	14
Transplant from a deceased donor.....	14
Transplant from a living donor	14
Visitors	14
Precautions.....	14
The operation	15

PACU (post-anesthesia care unit)/Recovery Room	15
On the ward.....	16
Blood clot prevention	16
Blood tests	17
Immunosuppressive (anti-rejection) medications.....	18
Tacrolimus	18
<i>Common side effects of tacrolimus</i>	19
Prednisone.....	19
<i>Common side effects of prednisone</i>	20
Mycophenolate Mofetil (Cellcept® or generic)	20
<i>Common side effects of mycophenolate mofetil (CellCept® or generic)</i>	21
Other medications	21
Pharmacy	21
What should be done if a dose of medicine is forgotten?	22
Prescription refills.....	22
What should you know about your medicines?	23
Possible complications of kidney transplantation.....	24
<i>Skin cancer</i>	26
<i>Bowel cancer</i>	27
<i>Other cancer</i>	27
<i>Diabetes</i>	27
<i>Medication related complications</i>	29
Diet	30
Employment & Income Assistance (EIA) dietary allowance (if applicable)	31
Going home after your transplant	32
Outpatient transplant clinic visits.....	32
Adult appointments/follow-Up	33
Outpatient tests.....	34
<i>Urine sample</i>	34
<i>Blood testing</i>	35
<i>Kidney biopsy</i>	35
Ureteric stent removal	35
<i>On-going care</i>	35

Research Studies	35
Part of your care plan: social work and psychiatry.....	36
Social Work.....	36
What to consider	36
<i>Medication costs</i>	37
<i>Transportation to clinic</i>	38
<i>Short or long term disability:</i>	39
<i>Living organ donor reimbursement program</i>	39
<i>The Kidney Foundation of Canada</i>	39
<i>Transplant Manitoba</i>	40
Psychiatry	40
Resources and other post-transplant related information	41
Medic-Alert bracelet.....	41
Writing to your donor family.....	41
For more information.....	42
Recommended websites.....	43

Introduction

This booklet is your introduction to kidney transplant and what you can expect before, during and in follow up. It is important that you read it carefully and follow all the directions given. In addition to this, ***it is also highly important that you keep your contact information up-to-date at all times.*** This includes your phone number(s) and mailing addresses so we can contact you to schedule appointments and your transplant surgery.

Transplant Manitoba program

The Transplant Manitoba Program at the Health Sciences Centre, Winnipeg is committed to providing transplant services in Manitoba. The first kidney transplant in Manitoba was done in 1969. Since then, over 1,400 kidney transplants have been done.



Provides	Supports	Coordinates	Educates
<ul style="list-style-type: none">•pre-transplant patient evaluations•follow-up care to transplant patients	<ul style="list-style-type: none">•Research for transplantation	<ul style="list-style-type: none">•Organ donation process from both living and deceased donors	<ul style="list-style-type: none">•Patients•Health professionals•The public

For more information on the Program go to: www.transplantmanitoba.ca

Abbreviations

ATN.....acute tubular necrosis	FNIHB..... First Nations Inuit Health Branch
BUN.....blood urea nitrogen	I + O intake and output
Crcreatinine	IV intravenous
EDS.....exception drug status	SPF sun protection factor
EIA.....employment and income assistance	WBC..... white blood cell
FK506 tacrolimus	

Telephone Numbers

Drug Coverage:

Manitoba Pharmacare (204) 786-7141
Trillium Drug Plan (Ontario Drug Benefits) 1-800-575-5356

Financial Assistance:

Human Resources Development CPP,
Income Security Programs
1-800-277-9914
Employment and Income Assistance
(Winnipeg), Central Intake Services
(204) 984-4000
Revenue Canada 1-800-959-8281
Veterans Affairs Canada 1-866-522-2122

Transportation:

Handi-Transit (Winnipeg) (204) 986-5722

Information about kidney disease:

The Kidney Foundation of Canada,
Manitoba Branch
Winnipeg (204) 989-0800
Westman Office, Brandon (204) 726-0031
Gift of Life Program (204) 787-3481
Adult Kidney Program (204) 787-7001

Important Health Sciences Centre Winnipeg numbers:

Paging (204) 787-2071
Pre-Transplant Clinic (204) 787-1076
Renal Transplant Clinic (204) 787-3138
Renal Social Worker (204) 787-8589
Renal Transplant Clinic Pharmacist
(204) 787-3744
GD4 (204) 787-3747
GG123 Specimen Collection Station
(LAB) (204) 787-3822
GB3 (204) 787-3734 (weekend clinic visits)
GE327 (204) 787-3701 Ultrasound
Lennox Bell Lodge (204) 744-6511

Other Important Numbers:

Medic Alert 1-800-668-1507
Manitoba Blue Cross (204) 775-0151
First Nations & Inuit Health Branch
(204) 983-0911

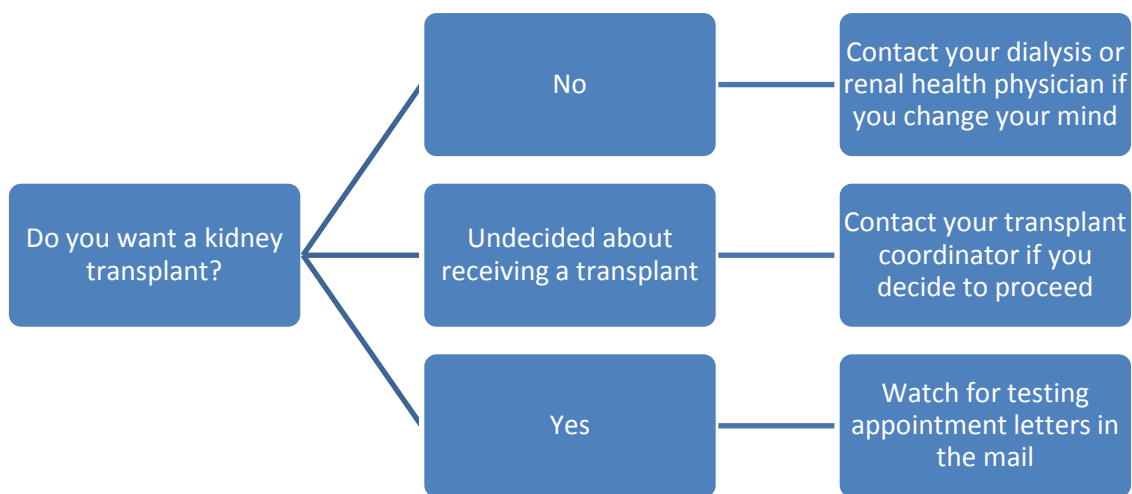
Pre-transplant

Referral

The first step in getting a kidney transplant is a referral to the Transplant Manitoba Adult Kidney Program from your nephrologist. Your nephrologist would have arranged several tests for you to complete to prepare you for this appointment. Once you have completed these initial tests the referral will be sent to the transplant program. An appointment will then be arranged for you to meet with the transplant nephrologist who specializes in transplant. This doctor will discuss with you what is involved with receiving a kidney transplant. Following this appointment you will meet with the social worker.

After your meeting with your transplant nephrologist you will be asked about your decision on receiving a kidney transplant.

The Transplant decision



If you are undecided about receiving a transplant

It is your responsibility to contact your transplant coordinator if you eventually chose to begin work up. You will be given your transplant coordinator's business card with the information provided to you at the time of your transplant assessment. You can remain undecided for up to one year. If after a year you decide you would like to have a transplant, you will need your renal health physician to refer you to the transplant program again.

If you have decided that transplant is not for you

There is nothing more for you to do. However, if you change your mind in the future you must let your dialysis or renal health physician know so that you can be referred back to the transplant program.

Pre-transplant evaluation

Once you have decided at the end of your appointment with the transplant nephrologist that you wish to have a transplant, several appointments will be made for you. These tests include:

Blood tests

- to determine your blood group, HLA typing and serology (these are described on the following pages)

Abdominal ultrasound

- to identify any abnormalities that may interfere with a transplant

Psychiatry consult

- to make sure that you have a full understanding of the transplant process. This doctor will also review with you how you will cope with a kidney transplant

Cardiovascular assessment

- if you are diabetic, 50 years or older, have a cardiac history , been on dialysis for five years or more or have received a transplant previously, you will have tests done to check the circulation to your heart, neck and legs (stress test, echocardiogram, carotid Doppler, ankle pressures). If necessary, you may be referred to a Cardiologist to determine if you need a coronary angiogram.

Please Note

Women who are sexually active will require regular PAP smears. Women over 50 years of age need a routine mammogram.

All testing appointments will be mailed to you in a letter. A copy of these appointments will be mailed to your renal health clinic or dialysis unit for their records. It is very important for you to check your mail frequently. If you are unable to make an appointment it is your responsibility to call and change the appointment. If you miss more than three appointments in a row you will not be rescheduled and your transplant workup will be

placed on hold. If you are on dialysis, we do our best to book your appointments around your dialysis schedule. **It is important for you to notify your transplant coordinator of any change in your address in order for your appointment letters to reach you.**

The approximate time for a transplant work up is six to nine months. It may be longer if further testing is required based on your initial testing.

Please Note

Compliance with medications and appointments is mandatory to be in good standing on the transplant list. If you are unable to make an appointment you must call and have that appointment rebooked to fit your schedule.

The Ready list

When all testing is complete, reviewed and found to be acceptable by your transplant nephrologist you will be placed as **Ready** on the transplant waiting list. . Ongoing updates will be necessary. You will receive a call from your transplant coordinator who will review your information and obtain contact numbers from you so we can reach you when you are called for a transplant. You will also receive a letter stating that you are now ready for transplant. A copy of this letter will

be sent to your dialysis or renal health clinic.

Your wait time on the **Ready** list begins with the first day you started dialysis – either hemodialysis or peritoneal dialysis.

Once you are on the **Ready** list for transplant, ongoing updates are necessary to ensure that your health has not changed and that you remain healthy enough to receive a kidney transplant. These updates will be made by the transplant program and a letter will be sent to you detailing these upcoming appointments.

While on the ready list and closer in wait time to receiving a deceased donor kidney transplant, you will need to attend a pre-transplant clinic.

It is important for you to notify your transplant coordinator of any changes regarding your health/medical status such as an infection. You may be placed on **HOLD** for transplant if there are any changes. However, once you are cleared, you will return to the list at the same place as when you left.

Not all patients are suitable to receive a kidney transplant, and sometimes patients who are listed for transplantation become unsuitable for various medical reasons and do not return to the **Ready** list.

Your transplant coordinator is your contact person to the transplant program. If you have any questions regarding your transplant status you can contact your coordinator.

Types of kidney donors

There are two ways that a kidney becomes available for transplant:

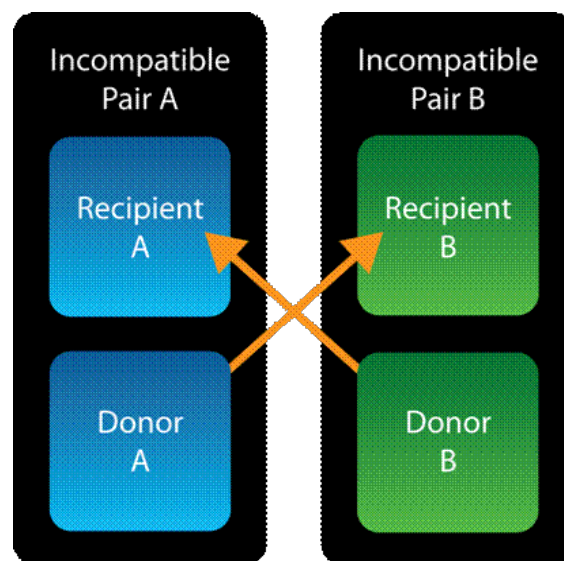
Deceased donor

A deceased donor is a person who dies as a result of a severe brain injury, causing “brain death”. Both kidneys from a deceased donor can be used – one for each of two recipients. You may be put on a wait list for this kind of transplant if you do not have a possible living donor.

Living donor

The second way to receive a kidney is from a living person, either from a relative or someone you are very close to.

If you have a living donor but they are not a match to you because of blood group or tissue incompatibility, the Living Donor Paired Exchange (LDPE) Program is an option. With Paired Exchange your incompatible donor will be matched to a compatible recipient and you will receive a kidney from someone who you are compatible with. Matched pairs remain anonymous before and after the transplants. This is a national program and additional information will be given to you if you decide to participate. A living donor is preferred since the time to transplant is much shorter and the average living kidney donor transplant lasts longer than a deceased donor transplant (20 years versus 12 to 15 years).



If someone wishes to be a possible living kidney donor for you, they should call the **Living Kidney Donor Coordinator** at **(204) 787-2400**.

Matching deceased donor kidneys for transplant

A kidney is matched to patients who are waiting using several blood tests:

Blood Group

- A, B, AB or O

HLA Typing

- This test determines the genetic tissue match between you and the donor.

HLA Crossmatch

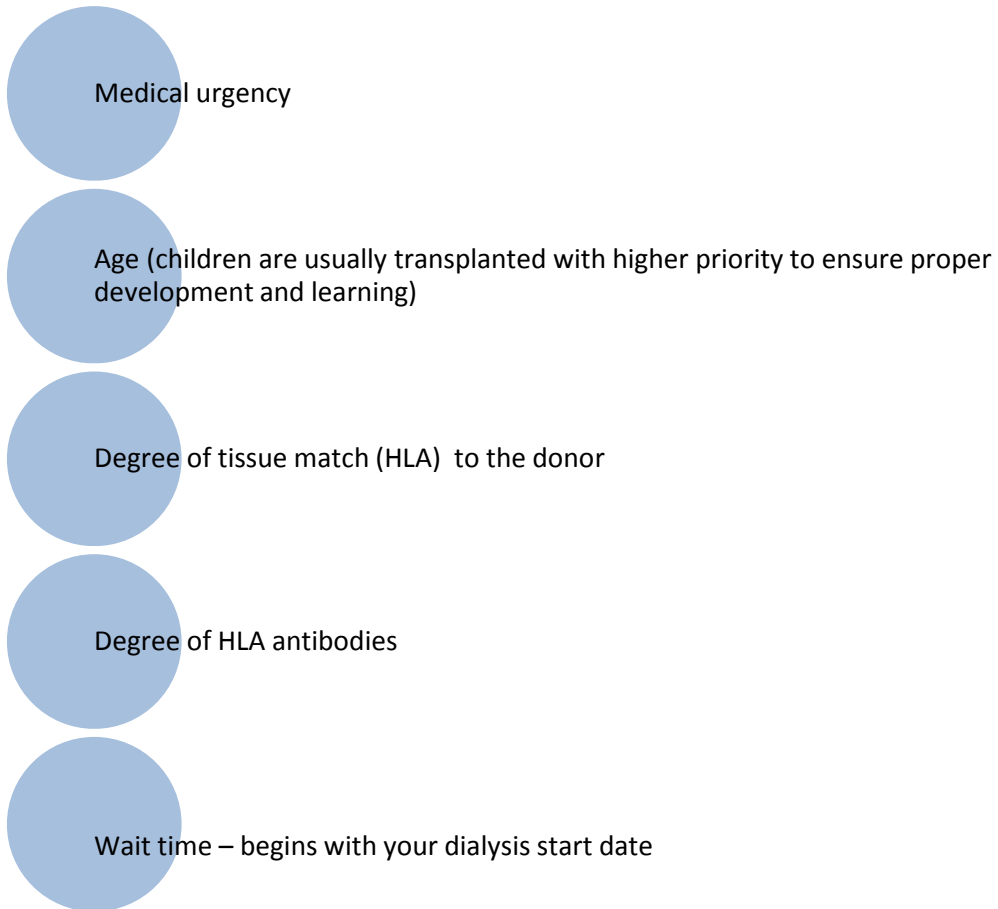
- This test will tell us whether you are fully compatible with the donor – a positive test means you are a high risk to reject the kidney. A negative result means you are less likely to reject the new kidney.

HLA Antibody Screening

- This tests to see if you have any HLA antibodies in your blood that could make you reject the donor kidney. Once you are placed **READY** on the transplant wait list, these antibody samples are drawn **monthly** and **14 to 18 days after any blood transfusions**. If you are on hemodialysis, this sample is drawn by the dialysis unit. Peritoneal Dialysis patients and patients followed by Renal Health clinics must get this drawn on their clinic day or at an outside lab. Without up-to-date samples, we cannot tell if you are a good match to the kidney donor.

To ensure the donor organs are safe for transplanting, blood tests (also referred to as *serology*) are done to detect infections such as HIV, hepatitis and other infections.

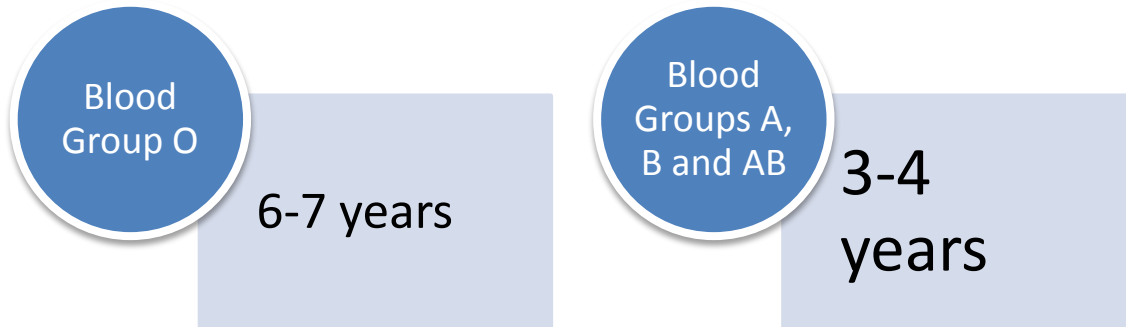
To find the person who will make the best recipient we consider five main factors



For a complete description of the Kidney Allocation formula, please refer to the Transplant Manitoba website: www.transplantmanitoba.ca

Average wait times

Wait times vary depending on blood type:



Tissue matching (HLA matching) and level of sensitization (HLA Antibodies) can also affect wait times, making them shorter or longer than average. For example, someone who is highly sensitized with many HLA antibodies could wait longer and someone with a very good HLA match could wait less.

Keeping your contact information up to date

This is very important to note: you are responsible for notifying the transplant program of any changes in your address or phone number. We are not responsible if we are not able to locate you.

You should also provide us with two or three other contact numbers in case you are not at home. If you are planning to be out of town and away from your regular contact number you should provide us a phone number for the place you will be staying and let us know when you are home again.

Call the transplant program office at (204) 787-7001 with any changes.



The phone call

If you are one of the potential recipients matched for a deceased donor kidney, a technologist from the Transplant Immunology Lab will call you. **This phone call could happen at any time of the day or even during the night.** They will ask you a few questions about your state of health such as if you have a cold, the flu, any infections and if you have received any blood transfusions. It is important to be healthy at the time of your transplant.

They may ask you to come in **right away** to give a fresh blood sample for the **HLA Crossmatch test**. They may even ask you to be admitted to the transplant ward (GD4, Purple Bear Zone) at the Health Sciences Centre while you wait for the Crossmatch result.

The result of the Crossmatch is usually available within 12 to 24 hours. At this point you will find out if you are the one to receive the donor kidney or not.

The lab calls three to four possible recipients for every pair of deceased donor kidneys. You may receive a "false alarm" before you successfully receive a kidney transplant.

Fasting before transplant surgery

Fasting is an important step in preparing for surgery. The decision of when to begin fasting and for how long will depend on timelines when you get your call from the Transplant Lab. You should have **nothing to eat or drink** (except a sip of water for taking any medicine) until you hear from the Transplant Immunology Laboratory if you will be receiving a transplant that day. If you are diabetic, you should check with the transplant doctor to give you directions for your insulin.

Transportation

If you have any questions about your travel arrangements they should be discussed ahead of time with your coordinator or social worker so you have a travel plan in place before receiving your call for a transplant.

In most cases, you are responsible for your own transportation to the hospital when you are called. If you are to drive a long distance it is recommended that someone drive with you. If you live in a remote northern community, the Transplant Lab technologist will coordinate travel arrangements for you either by air (Air Ambulance, or, if possible, the next available commercial flight) or by ground, depending on how quickly you are required to come in.

Accommodation

Following the transplant, you can expect to be in Winnipeg for several weeks or months.

For more information on transportation and accommodation please refer to the Social Work section.

What to bring to the hospital

You should bring your own personal items with you to hospital such as:

- ☐ Tooth brush
- ☐ Lip and skin moisturizer (fragrance-free)
- ☐ Hair brush or comb
- ☐ Housecoat (opens all the way down the front)
- ☐ Slippers
- ☐ Loose, comfortable clothing (such as a track suit) is also appropriate
- ☐ Medications that you are taking (complete list of the names, doses and times)
- ☐ Do not bring valuables



Other responsibilities

Your suitability to receive a kidney transplant will depend partly on your health at the time of the phone call to come to the hospital. There are several things that you can do to help:



Sometimes, problems may come up even though you are taking care of yourself. Your doctors may order special tests or ask you to see a specialist. **It is important that you keep your scheduled appointments.** The Transplant Program needs the results of the tests and the opinions of the specialists to help us know if it is okay for you to get a transplant.

Please Note

The Transplant Program may temporarily remove your name from the waiting list if you cannot follow your plan of care. Your name will be put back on the waiting list after you are able to follow your plan of care for several months.

Preparing for transplant day

Pre-admission appointments for transplant from a living donor

When you are scheduled for a living donor kidney transplant, the following appointments will be made for you to attend **one week before the surgery date**:

Final HLA Crossmatch – This blood test will be done on both you and your donor. This test will be familiar to you as it has been done previously. This test now needs to be repeated 1 week before the transplant to make sure there is no change in the result of this test which will affect the kidney transplant. You will also have blood drawn for chemistry, hematology and repeat serology at this time.

Pre Admission Clinic visit – This appointment will involve you meeting with the anesthetist who will put you to sleep for the surgery. Post-operative pain control will also be discussed.

Surgical Assessment – You will meet with the surgeon who is going to perform your kidney transplant. The surgeon will meet with you to describe the surgery, review the risks of surgery, and have you sign the consent for surgery.

Social Worker – You will meet with the social worker again to address any outstanding issues that you may have and to assist you in your final preparations for surgery.

History and Physical – you will meet with a transplant nephrologist in the transplant clinic to have a history and physical done in preparation for your admission for surgery. This physical is done to make sure there are not any new medical issues that have come up that would affect the transplant surgery. At this time you will also be asked to do two urine samples if you have urine output (to check for urinary tract infection), chest X-ray and EKG.

Transplant Coordinator Meeting – You will meet with the transplant coordinator who will review with you the admission process and answer any questions that you may have regarding your upcoming transplant. He/she will also take you on a tour of the transplant ward and provide you with any requisitions for additional testing needed including blood work for antirejection medication levels, if indicated.

Transplant Pharmacist – You will meet with the pharmacist to discuss anti-rejection medications with you. He or she will arrange for a prescription for your anti-rejection medications. You will be started on one of your anti-rejection medications on the evening of this visit. You may be approached to participate in a research study in which an alternate medication or alternate start time for the medication will occur.

The above appointments will be outlined in a letter that will be sent out to you.

Admission to hospital

You will be admitted to a semi-private room. This means you will be in a room with one other person. The staff will make sure that your roommate is appropriate. Your roommate may be male or female in order to accommodate this.

If you are receiving a transplant from a deceased donor

The deceased donor kidney transplant operation is usually done within four to 24 hours of your admission to hospital. You will be seen by the kidney doctor, nurse, anesthetist and the surgeon as part of your preparation for surgery. You may also need dialysis to get you ready for surgery.

If you are receiving a transplant from a living donor

The ward will make every effort to put you and your donor in the same room following surgery. After your living donor goes home, you will have a new roommate.

If you are on Peritoneal dialysis you will be asked to bring enough supplies for the evening of admission and some extra in case contamination occurs. If you are on a night cyclor you will be required to bring it in. You will be responsible for performing your own PD treatment.

If you are on hemodialysis you may need to have a treatment in the Central Dialysis Unit on the evening of admission. This will be determined by blood results.

Visitors

You will be asked on admission to name **two visitors**. These two people are the designated visitors for the first 48 hours of your stay in hospital. Exceptions to this rule may be made by the staff under special circumstances. Children should not visit during this time. Visitors will be instructed in infection control measures. **Good hand washing** when entering and leaving the room is the most important step in preventing infection. Visitors with obvious infections (colds, flu) will not be allowed to visit.



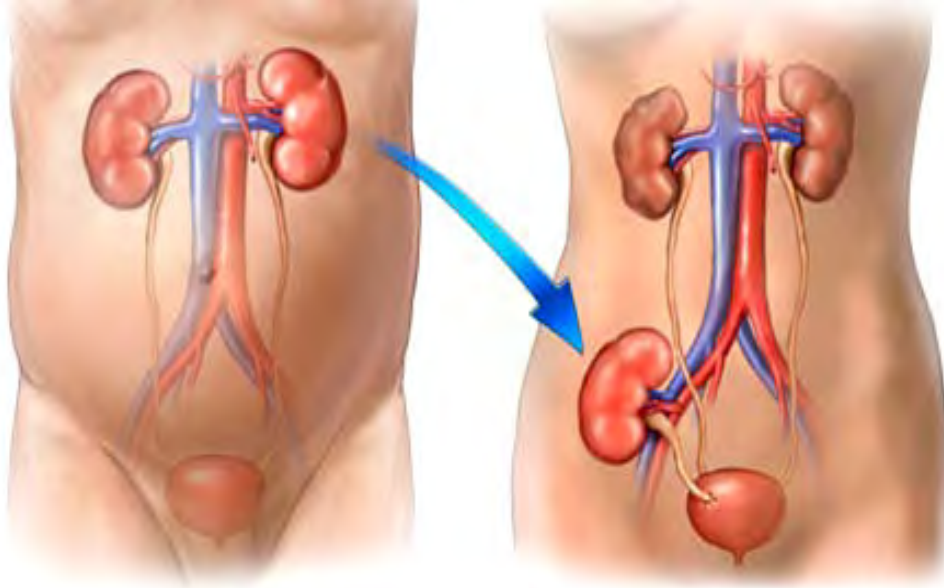
When a loved one is in hospital friends and family often bring gifts. Flowers are a popular choice, however, potted plants are not permitted in your room as the dirt may contain bacteria or mold. Fruit baskets, another common gift, will not be allowed as you may still be on a dietary restriction in the early days after your transplant.

Precautions

While in hospital, you will be in protective isolation since you will be on large doses of anti-rejection medications. These medications make it easier for you to pick up an infection. You will be asked to wear a mask when out of the room. It is preferable that you not go and visit in the patient lounge.

The operation

The operation takes three to four hours. The kidney is placed down in the pelvic area, either on the left or right side.



During surgery, a special tube (stent) may be placed in the ureter between the transplanted kidney and the bladder. It helps to keep the ureter open during the first few weeks after surgery. It is removed six to eight weeks later.

If you have a peritoneal dialysis (PD) catheter in place, the Transplant surgeon will decide whether or not to remove it at the time of transplant surgery. This will be discussed with you at the time you sign the consent form for kidney transplant surgery. If the PD catheter is left in, arrangements for removal will be made once you are discharged from hospital.

PACU (post-anesthesia care unit)/Recovery Room

In PACU (the Recovery Room), nurses will watch your blood pressure, breathing, and urine output. They will also help with any pain you may have. A few hours later, you will go back to your hospital room.

After surgery, you will have:

- oxygen from a mask or a tube by your nose for a short time;
- an intravenous line (IV) giving you water, sugar, and salt;
- a catheter in your bladder (to allow easy and accurate measurement of the urine from your new kidney and to allow for healing); and
- a bandage covering the incision on the lower part of the abdomen.

It is not uncommon to have blood in your urine at this point.

On the ward

You will be given medication to help control pain in your incision area, but it is important that you tell the nurse if you are having pain. Several hours after the surgery, the nurse will have you sitting up on the side of the bed. The nurse will also help you do **deep breathing and coughing exercises** to help prevent pneumonia.

Blood clot prevention

Because you have had surgery you are at risk for blood clots forming in your legs. Blood clots can become loose and travel to your lungs. To prevent blood clots, the nurse will have you dangle your legs over the side of the bed on the evening of your surgery and have you walk the day after your surgery. You will also get a blood thinner injected daily under your skin.

Important symptoms to report to the nurse are:

- calf pain, redness, warmth and/or swelling
- sudden shortness of breath or difficulty breathing
- chest pain

If you experience these symptoms after you are discharged, this is a medical emergency and you should go to an Emergency Room immediately for treatment.

The **staples** (stitches) are removed from the incision about 10 days after the transplant if dissolving stitches are not used.

As your new kidney begins to work better, the Foley catheter and IV will be removed.

It can take a few days for your **stomach** to start working. You will only be given ice chips until your bowels start to work. The nurse will listen to your stomach for any rumbling sounds before you will be started on food.

You may have **nausea** after surgery. It is important to tell the nurse so that we can help.

It is important to keep track of your **fluid balance** (the amount you drink and the amount of urine you pass). The nursing staff will teach you how to keep track of your fluid balance. It is important to write your fluid levels on the sheet by your bed. You will be weighed every day.

You will have many tests to check how well your new kidney is working. **Blood tests** will be taken every four hours for the first few days, then less often. The nurses and doctors will watch for signs of rejection of your kidney. **Urine samples** will also be taken.

You may have a renal scan. This test looks at the blood flow to the new kidney and takes about one hour.

An important part of your recovery is learning how to take care of yourself and your new kidney. You will get **a new list of medications**. The nurse and pharmacist will show you how best to take them. You will also be taught how to look for signs of infection and rejection. The nurse will review this information with you and/or your family several times. Please ask many questions.

You will be in the hospital for about **five to seven** days if there are no complications. Some people have to be in the hospital for a longer stay. Before you leave the hospital, the clinic nurse, social worker, transplant pharmacist and dietitian will come to see you.

Blood tests

Urea and creatinine (waste products), sodium, potassium, calcium and sugar will be measured by blood tests. These tests will tell how well your new kidney is working.

Hemoglobin (Hgb):

Normal value 120 – 160 g/L

- Hemoglobin carries oxygen from your lungs through the body. Hemoglobin is partly responsible for how energetic you feel. With a new working kidney, your hemoglobin should return to normal. It can even overshoot the normal value and we may have to remove the extra blood (a phlebotomy).

White Blood Count (WBC)

Normal value 4.5 -11

- White blood cells (WBC) are the weapons your body uses to fight infection. It is important to watch your white blood cell count. A high number might show that you have an infection somewhere. With your immune system lowered by medication, you may not have the normal symptoms of an infection. By watching the WBC, we also get an idea of how well your body's defense system is working.

Creatinine and Urea

- The kidney helps to get rid of some wastes your body makes. Creatinine and urea are two important wastes. The normal levels are:
 - Creatinine (Cr) 44-106 umol/L
 - Urea (U) 2.8-7.1 mmol/L

Sodium, Potassium, Calcium

- These are minerals in your body that you get mostly through eating and drinking. The kidney is responsible for keeping a balance between these minerals. The normal levels are:
 - Sodium (Na) 135 - 147 mmol/L
 - Potassium (K) 3.5 - 5 mmol/L
 - Calcium (Ca) 2.1 - 2.6 mmol/L

Tacrolimus

- A transplant medication you might take is called tacrolimus (either Prograf® or Advagraf®). We measure the amount of tacrolimus in your blood to be sure you are on the right dose. Each person's body responds differently to this medication. The blood level should be measured just before your next dose.

Immunosuppressive (anti-rejection) medications

You will take anti-rejection medications after the transplant. These medications will help your body accept your new kidney.

Please Note

You will need to take anti-rejection medications for as long as your new kidney is working. If you do not take these medications, you will hurt your kidney and you may lose it.

The anti-rejection medications used most often are:

Tacrolimus

- ***Prograf® (tacrolimus IMMEDIATE release) or***
- ***Advagraf® (tacrolimus EXTENDED release)***

Prednisone

Mycophenolate mofetil

- ***CellCept® or generic***

Tacrolimus

[tak-row-lim-us]

Tacrolimus is a medication used to lower your body's immune (defense) system. It is used to prevent your kidney from being rejected.

Tacrolimus comes as two versions:

- tacrolimus IMMEDIATE release (Prograf®), and
- tacrolimus EXTENDED release (Advagraf®).

Make sure you know which version you should take. Only your transplant doctor should change the version.

Prograf® (tacrolimus IMMEDIATE release), is available in capsules with different strengths. The capsules are the same colour on the top and bottom:

- 0.5mg – yellow capsule
- 1mg – white capsule
- 5mg – pink capsule

Prograf® is taken twice a day – every 12 hours. It is important to take it at the same time every day. It can be taken with or without food – but do it the same way every day.

Advagraf® (tacrolimus EXTENDED release) also comes in capsules with different strengths. The capsules are one colour on the top and orange on the bottom.

- 0.5mg capsule – yellow top and orange on bottom
- 1mg capsule – white top and orange on bottom
- 3mg capsule – orange top and orange on bottom
- 5mg capsule – pink top and orange on bottom

Advagraf® (tacrolimus EXTENDED release) is taken once a day in the morning. It is important to take it at the same time every day. It can be taken with or without food – but do it the same way every day.

The dose of tacrolimus (either version), depends on its blood level. Blood work *must* be done *before* you take your morning dose.

After you leave the hospital, the Transplant Clinic will tell you your tacrolimus dose.

Common side effects of tacrolimus

- | | |
|---|--------------------------------|
| • Upset stomach and occasional diarrhea | • Tremor |
| • High blood pressure | • Increased risk of infections |
| • Headache | • Increased blood sugar |

Prednisone

Prednisone is a steroid that helps to lower your immune system. It is not like the steroids that athletes use illegally. Most patients take prednisone for as long as they have a transplanted kidney.

Prednisone is available in 1 mg, 5 mg, and 50 mg tablets. The amount you will take will change. In hospital the nurse will tell you the daily dose. After you leave the hospital, the Transplant Clinic will tell you the dose.

Prednisone is usually taken once a day, in the morning, with food.

NEVER stop your Prednisone suddenly. This can be life threatening.

Common side effects of prednisone

- Increased appetite (weight gain)
- Delayed healing of cuts and sores
- Round face, chubby cheeks
- Salt and water retention
- Acne
- Mood swings (on high doses)
- Stomach ulcers
- Increased blood sugar (diabetes)
- Feeling shaky
- Night sweats (on high doses)
- Thinning of bones, especially hips
- Changes in vision (cataracts)
- Increased risk of infections

Mycophenolate Mofetil (Cellcept® or generic)

[my-ko-fen-o-late]

Mycophenolate is a medication used to lower your body's immune system. It is taken twice a day and should be taken on an empty stomach. Some people may need to take mycophenolate with food. It should always be taken the same way.

Take mycophenolate at the same time as tacrolimus. Do not take mycophenolate until *after* your blood work is done.

Mycophenolate is available in 250mg capsules and 500mg tablets. The pills should be left in the original pharmacy container until taken. The pills should be swallowed whole and not crushed or chewed.

Common side effects of mycophenolate mofetil (CellCept® or generic)

- Diarrhea
- Nausea and vomiting
- Stomach cramping
- Headache
- Difficulty sleeping
- Increased risk of infections
- Should not be taken while pregnant

Other medications

Many prescription and non-prescription medicines can interact with your anti-rejection medications. Herbal and natural supplements, teas and cleanses can be harmful to the kidney or interact with your anti-rejection medications so check with the transplant pharmacist before you start any new products.

It is important to tell any doctor or dentist you visit about the medications you are taking. If there are any questions about new medications or changes to the ones you take, please check with the Transplant Clinic.

Please Note

Some prescribed medicines that may interfere with your immunosuppressive medications.

- Antibiotics: erythromycin (ERYC®), clarithromycin (Biaxin®)
- Anti-inflammatory medicine: indomethacin, naproxen (Aleve®), ibuprofen (Advil®)
- Anti-seizure medicines: (phenobarbital, phenytoin, carbamazepine)

Also avoid grapefruit and grapefruit juice.

If these or other medicines are prescribed to you by another doctor, the transplant clinic must be told right away.

IT IS IMPORTANT TO REMEMBER THAT THE DOSAGES OF TACROLIMUS, MYCOPHENOLATE, AND PREDNISONE CAN CHANGE FROM DAY TO DAY.

TO PREVENT REJECTION, NEVER FORGET TO TAKE THESE PILLS.

Pharmacy

There is a pharmacist in the transplant clinic who works with your doctors and nurses. This pharmacist will teach you how to take your medicines safely, effectively and correctly to maintain your health.

An up-to-date medication record is kept on all your current and past medications as well as any allergies or medical conditions. This record allows your pharmacist to monitor your treatment and it prevents taking medications that interact with each other. For each prescription, your pharmacist will make sure the medication and dosages are correct for your health condition and check for any interactions with other medications you are taking.

Your pharmacist will help you understand how to take your medicine correctly, provide you with information on what side effects may occur and what

you should look for to report to your doctor. Feel free to talk with the pharmacist in the clinic or at the drugstore anytime about concerns you have about your medications.

Your drugstore pharmacist can help you if you have special problems such as sore hands from arthritis, poor eyesight, or have difficulty opening your containers. If you need help in organizing what time of day to take your medications, your pharmacist can assist you with ways to organize your medications so you are less likely to forget to take them.

Types of services are different between drugstores, so make sure you find one that has the services you need.

What should be done if a dose of medicine is forgotten?

Take the missed dose as soon as you remember, then continue with your regular schedule. If it is almost the time for the next dose when you remember, do NOT take two doses. Call the Transplant Clinic or your pharmacist if you have questions.

Remember to “**COMMUNICATE BEFORE YOU MEDICATE**”. Keep asking questions until you are satisfied. The more you know, the better you will feel.

Prescription refills

Call your drugstore **several days before you run out of medicine**. If needed, your drugstore will send reorder requests for your prescriptions to the Transplant Clinic by fax ((204) 787-3406). Requests made on a Friday will not be filled until Monday (or Tuesday of a holiday weekend).

Do not call the transplant clinic for most refills. Only call if the transplant doctor has prescribed narcotic medications. These cannot be faxed but must be picked up in person from the transplant clinic. Please contact the clinic at least **one day before** you will come in.

When traveling, take your medicine with you. Store your medicines in your carry-on luggage when traveling by plane. Bring extra doses with you in case you are delayed in returning home.

Please Note

Keep all medicines out of the reach of children.

Non-prescription medicines are powerful and can interact with your prescription medications or badly affect your health condition. Check with your pharmacist or physician before taking any non-prescription medicines.

What should you know about your medicines?

You should be able to answer the following questions for each medicine that you take. If you do not know the answers, ask your doctor, pharmacist or nurse to help you.

1. *What do I take this medicine for?*

- ☐ What is the name of the medication?
- ☐ What problem or symptom will it help?

2. *How am I to take this medicine?*

- ☐ How much do I take (the dose)?
- ☐ How often do I take it each day?
- ☐ What time of day should I take the medications?
- ☐ Can I take it with food or alcohol?
- ☐ Are there any foods I should avoid?
- ☐ Are there other medicines I should not take?
- ☐ How long will I take this medicine?
- ☐ What do I do if I miss a dose?

3. *What should I expect from this medicine?*

- ☐ How will I know if the medicine is working?
- ☐ What side effects may occur?
- ☐ What am I to do if a side effect occurs?

4. *How should I store my medicine?*

- ☐ Does it need special storage?

Possible complications of kidney transplantation

The three main complications of kidney transplantation are:



Slow-starting kidney

Sometimes a transplanted kidney is slow to start working. The most common reason for a "sleepy" kidney after the surgery is Acute Tubular Necrosis (ATN). You may feel let down that your kidney is not putting out much urine, but ATN gets better on its own. Your new kidney usually gets back to full function. While you have ATN, you might need dialysis until the doctor decides your kidney function is better.

Rejection

Rejection occurs when the body sees that the transplanted kidney is not its own and tells your immune system to fight against it.

Rejection is often "silent"; you may not feel any different.

Early rejection can show up on blood tests or a **kidney biopsy**. Kidney biopsies are the best way to know what is going in your kidney. A kidney biopsy is often done after six months.

Rejection is uncommon, usually has no signs and symptoms and can only be suspected by changes in the bloodwork.

If you have rejection, it can be treated with a very high dose of a steroid (prednisone by mouth, or methylprednisilone [Solumedrol®] by IV) or other drugs might be used. The steroid is used to try to stop the rejection. Your dose of prednisone will be high for a few days then lowered slowly.

Infection

Your body's defense system will be weakened by the anti-rejection medications. You are more likely to get colds, the flu and other infections.

Signs and symptoms of infection

Fever with or without chills

Swelling, redness, tenderness, heat or pus from around any local area, such as a wound or incision

White, patchy sores in the mouth and throat (thrush)

Cold sores

Cough with sputum or phlegm, or increased or colored phlegm.

Burning or discomfort when passing urine. This may be a urinary tract infection. You may have other symptoms like:

- Frequency: feeling that you have to void much more often than normal although when you do void, it is only for small amounts of urine.
- Nocturia: a need to get up in the night to void when you do not normally do this. Many transplant patients normally have to void during the night.
- Hematuria: blood in the urine may present as a darker, or tea-coloured urine.

Please Note

If you experience any signs or symptoms of infection contact the nurses in the transplant clinic at (204) 787-3138 between 8 am and 4 pm.

If your problem is urgent, go to the emergency department at the Health Sciences Centre or the hospital nearest your home if you live outside Winnipeg.

Other possible complications post-transplant

Increased risk of cancer

Transplant recipients have an increased risk of developing cancer because of how the anti-rejection drugs change their immune systems. Cancer may occur at any time after transplant.

The types of cancer that are more common in kidney transplant patients are:

- lymphoma
- skin cancer
- bowel cancer
- cervix and breast cancer (for women)
- prostate cancer (for men)

Early detection of cancer greatly increases the chances of successful treatment. You should take steps to help ensure any abnormalities get proper attention.

Women should:



- ☐ Do a breast self-exam each month and report any changes immediately.
- ☐ After age 50, have regular mammograms. Some women may need one earlier.
- ☐ Go for a Pap smear each year. A Pap smear checks for changes in the cells on the cervix. Cancer of the cervix begins as abnormal cells. Early detection usually makes this type of cancer curable.

Men should:



- ☐ Do a monthly check for any abnormal testicular lumps, and report them.
- ☐ After age 50, have prostate checks regularly with your family doctor.

Skin cancer

It is important to lower your sun contact.

- Wear a hat, long sleeves and long pants.
- Use a sunscreen approved by the Dermatology Association of Canada.
- Avoid the sun between the hours of 11 a.m. and 3 p.m.

Check your skin regularly and tell the transplant team about any new or unusual moles, lesions, or lumps on your skin. The type of cancer that may develop after excessive sun exposure is easily treated if found early.

Bowel cancer

Bowel cancer is more difficult to detect. You should report a change in bowel habits such as alternating diarrhea and constipation, or if you have blood in the stool. Telling the transplant clinic about these symptoms may result in earlier treatment for this type of cancer.

After age 50, screening for colon cancer should be done. Screening can be done by colonoscopy, sigmoidoscopy or having the lab test stool samples for very small amounts of blood.

Other cancer

Transplant patients may get other cancers at the same rate as other people. The treatment for any cancer is more complicated because of the need to use anti-rejection drugs to protect the transplant. Most often, the earlier the cancer is detected, the easier it is to treat. Everyone is encouraged to be very aware of changes in their bodies that could indicate a problem.

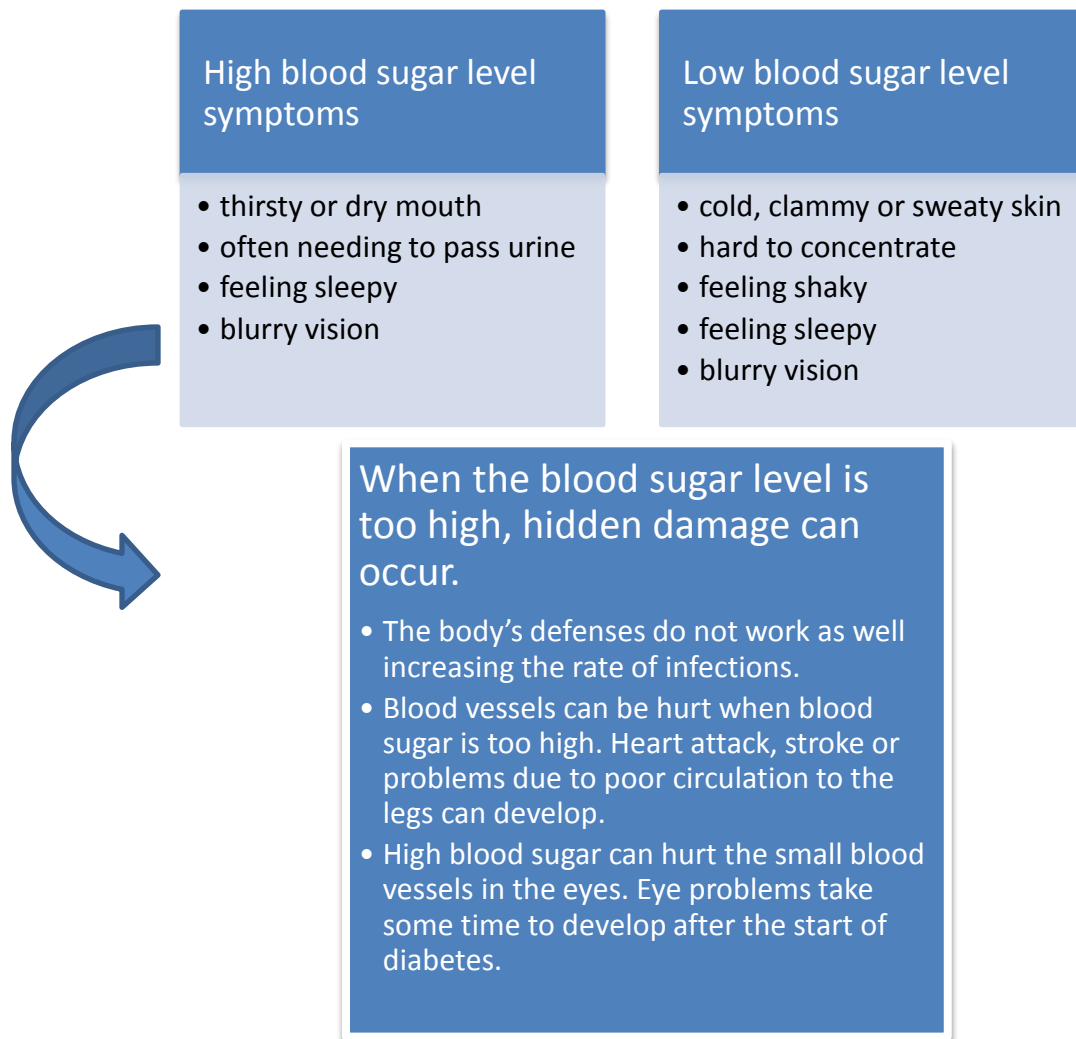
Diabetes

A kidney transplant does not stop the effects of diabetes on the body.

If you have diabetes, you may need to use insulin injections instead of diabetes pills or a higher dose of insulin.

If you do not have diabetes but are overweight, older or have a family history of diabetes, you may get diabetes after the transplant. Up to 1 in 3 people will get high blood sugar levels after their transplant.

There are two main problems with diabetes: abnormal blood sugar levels and infection and circulation issues.



The aim of treatment of diabetes is to keep the sugar levels in the blood as close to normal all the time. The most important step is to regulate the amount of food entering the body each day – in other words, keep to a careful diet!

Being overweight makes diabetes much worse. it is important to lose weight if you are overweight, and avoid putting on weight if you are not. Losing weight can be difficult, but in some cases it is all that is needed to make the diabetes go away completely.

A careful diet is all that some people with diabetes need for their treatment, but in some cases drugs are also needed. These may be tablets or injections of insulin. Insulin is the body's natural substance for regulating the amount of sugar in the blood, and boosting

the level of insulin after meals with an injection may be needed to keep the sugar levels stable.

Medication related complications

Other problems you may have because of the anti-rejection medications may include:

Cataracts

Thinning of
the bones
(osteoporosis)

Stomach
ulcers

High blood
pressure

High
cholesterol

Inflammation
of the
pancreas



Diet

The dietitian from the transplant clinic will come to visit you before you are discharged from the hospital to review general nutrition guidelines. In some cases, your diet will be the same as before the transplant. In other cases, it may be quite different. Following your diet after your transplant is important as good nutrition may help to protect your kidney.

The transplant dietitian is available during your clinic visits to answer any of your nutrition questions or concerns.

Special considerations for you now include

Protein: include a good quality protein choice at each meal.

Sodium (salt): a moderate restriction of dietary sodium can help blood pressure or reduce swelling.

Fluid: keeping well hydrated is important. Drink at least 2-3 litres per day.

Potassium: a potassium restriction is generally not needed for most people if your new kidney is working well. Some transplant medications can cause high potassium levels and a potassium restriction may be needed.

Phosphorous: high phosphorous levels tend to drop after a new transplant. Foods high in phosphate are encouraged to help normalize levels.

Calcium: to maintain and promote bone health, it is important to eat or drink calcium containing foods such as dairy products

Weight gain: you may find that your appetite has increased after transplant. This does not always reflect your body's needs. Undesirable weight gain and large waist circumference (apple shape) can lead to serious problems including high blood pressure, increased risk of developing diabetes, elevated cholesterol and can cause your kidney not to work well. Eating a healthy diet with appropriate portions and limiting excess high fats and sweets can help to limit unwanted weight gain. Regular exercise when advised by your doctor can help to control your weight.

Cholesterol: Some transplant medications may increase the risk of high blood cholesterol levels. Limit total fat intake, especially saturated and trans fats. Medication may be needed in addition to diet changes if cholesterol level is too high.

Vitamins/herbs: check with your transplant dietitian, pharmacist or doctor before starting any vitamins or herbal products, as they are generally not needed.

Food safety: people on anti-rejection medications are at increased risk of infection. Proper food handling and hand washing helps to prevent food-borne illness. Buffets and salad bars are not recommended as it can increase the risk of food contamination and food-borne illness. Meat, poultry, fish and eggs should be fully cooked.

Grapefruit and grapefruit juice: are not recommended as they can cause blood levels of antirejection medications to get too high.

These are general nutrition guidelines following a kidney transplant. Your individual diet may change depending on your blood work. Your transplant team will advise you if you need to make changes to your diet.

Employment & Income Assistance (EIA) dietary allowance (if applicable)

For patients that qualify for EIA diet allowances, renewals can be requested from the transplant dietitian at a scheduled appointment. Please be aware that dietary requirements often change post-transplant, which may result in a change to your diet allowance.

Going home after your transplant

Outpatient transplant clinic visits

After leaving the hospital, you will be seen in the Transplant Clinic. The following is an example of how often you will be seen in the Clinic. You will be seen more often if there are changes in your medications or if you have a problem.

Adult Transplant Clinic

Green Owl Zone, Room GE412

Phone: (204) 787-3138

Adult Appointment Schedule:

<i>Week 1</i>	<i>Daily, no weekends</i>
<i>Week 2</i>	Monday, Wednesday, Friday
<i>Week 3-8</i>	Twice per week
<i>Month 3</i>	Once a week
<i>Month 4-5</i>	Every 2 weeks
<i>Month 6-7</i>	Every 3 weeks
<i>Month 8-12</i>	Every 4 weeks
<i>After 1 year</i>	Every 8 weeks

Adult Transplant Clinic Appointments will be booked between the hours of:

<i>Day</i>	<i>Time</i>
<i>Monday</i>	08:00 – 11:30 a.m.
<i>Tuesday</i>	08:00 – 11:30 a.m.
<i>Wednesday</i>	09:00 – 11:30 a.m.
<i>Thursday</i>	08:00 – 11:30 a.m.
<i>Friday</i>	08:00 – 11:30 a.m.

The clinic will be closed on the 4th Wednesday of every month.

Saturdays, Sundays and Holidays: you will be given instructions to be seen on the ward GB3 (Green Owl Zone) if required.

Adult appointments/follow-Up

At each clinic visit you will follow this process.

1. Go to GE412 (Green Owl Zone) to pick up the paper work needed for the lab.

2. Go to lab at GG123 (Green Owl Zone) where blood work will be drawn. Wait times may vary.

4. Each clinic visit you will be seen by the nurse. The nurse will check your weight, blood pressure and ask you questions about the your general health. The nurse can answer your health questions at this time.

6. Your visit in the clinic may also include seeing the doctor, pharmacist, social worker or dietician. Tell your nurse if you need to see them

3. **You will be informed if you are required to fast** (nothing to eat or drink after midnight) by the transplant clinic

5. Each visit the nurse will also review your complete medication list with you. It is important that you bring an updated list of all your medications with you to each visit.

7. In the first 3 months of your transplant clinic visits the nurse will call you in the afternoon to give you blood work results, any medication changes and to make follow-up appointments. After 3 months the nurse will call you in the afternoon **only** if there are changes or concerns with your bloodwork.

Please Note

IF YOU ARE NOT AT HOME, IT IS YOUR RESPONSIBILITY TO CALL THE CLINIC BY 3 P.M. AT (204) 787-3138.

IT IS ALSO HELPFUL TO HAVE A PHONE WITH AN ANSWERING SYSTEM

If you live outside Winnipeg it may be possible to have some of the tests done in your local area once your kidney function is stable.

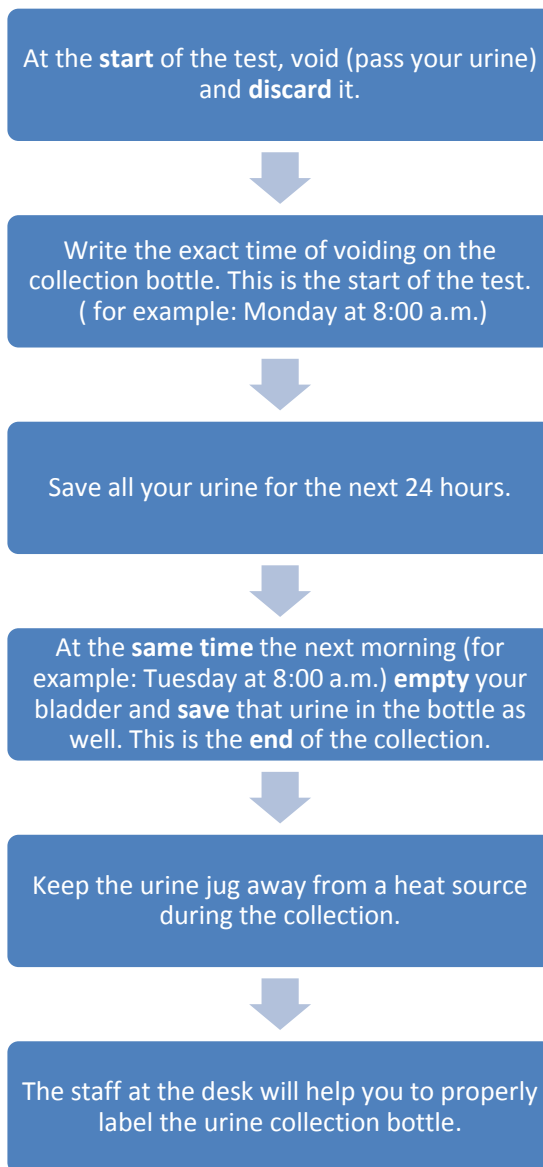
Outpatient tests

Urine sample

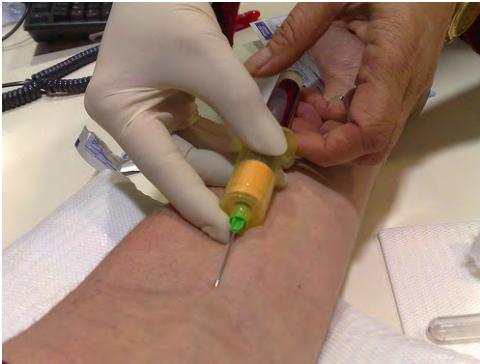
You may be asked to provide a urine sample at some of your clinic visits. This happens more in the beginning of your transplant.

You will also be asked to bring in a 24-hour urine collection a few times each year. You will get a collection jug at clinic. These are important measures of how your kidney is functioning.

How to collect a 24-hour urine



Blood testing



Every clinic visit you will need to have your blood tested. This is very important to see how well your kidney is working. Blood tests need to be done by 9:30 a.m. for the tacrolimus level result to come back that day.

Remember DO NOT take your cyclosporine, tacrolimus (Prograf® or Advagraf®), or mycophenolate (Cellcept® or generic) until **AFTER** you have had your blood tests drawn.

After your blood tests, take your anti-rejection drugs as you were last told. Wait for the clinic to call in the afternoon with your new dose before taking the evening dose of anti-rejection drugs.

Kidney biopsy

Kidney biopsies are the best way to know what is going on in your kidney. Kidney biopsies may be done if there are concerns about how your kidney is working (high creatinine level or protein in the urine, for example). Biopsies are also recommended routinely at six months. This will be discussed with you prior to the biopsy and arranged by the Transplant clinic staff. Information about where to go will be given to you at the time of booking.

Ureteric stent removal

This will be booked for you with Urology at six weeks post-transplant.



you.

On-going care

Each year the clinic will send you to get a chest x-ray and EKG. Yearly dental, eye and gynecologic care are your responsibility. If you do not know how to make these appointments you can ask your nurse. Other tests that are done as needed are extra blood work, renal scans and bone scans. These will be set up for

If you are unable to keep an appointment, please re-book it yourself. These tests are very important to give you the best care possible. Please do the tests as ordered. If you have any difficulty with re-booking, the Transplant Clinic will help you.

Research Studies

Patients in the Transplant Clinic may be asked to participate in research studies done by the doctors. You will be asked for your consent after you have received a full explanation of the study.

Part of your care plan: social work and psychiatry

Social Work

Social workers are members of your health care team who are there to provide you with support, counseling, education, advocacy and information about community resources. These things can help you and your family adapt to the changes a transplant brings. Social workers can also discuss your return to work.

Your kidney disease may have been treated with diet, medications, and dialysis. Transplant is another way to treat it. Having a kidney transplant is a change in your life and your family members' lives and brings new things to learn so that you stay healthy. It is a time when it is normal to be hopeful and anxious at the same time. You may notice changes in your lifestyle that can be a source of stress for you and your family. Some people experience disappointment, increased worry, frustration and sadness.



What to consider

It is important to prepare for transplant both emotionally as well as from a financial point of view. Many patients do not prepare as they do not expect to get a “call” due to the long wait list times. Being prepared can limit last minute panic and lower the anxiety that may occur. As a family’s situation changes, it may be useful for you to adjust your “transplant plan.” You may want to review it every year.

The costs associated with having a kidney transplant include:

- medications
- travel
- parking associated with clinic appointments
- accommodations in Winnipeg for about two months (depending on the distance that you have to travel to attend the post-transplant clinic).

Medication costs

Medication costs after a transplant are very expensive and need to be taken exactly as written to make sure that your new kidney continues to work well.

It is your responsibility to know how you will have your medication paid for.

For some of your medications your transplant doctor will have to apply to Manitoba Health for Exception Drug Status (EDS) approval so that these medications are covered by Pharmacare, Employment and Income Assistance (EIA) Disability, First Nations Inuit Health Branch (FNIHB).

You should apply for provincial drug coverage even if you have private medication coverage.

Employment and Income Assistance (EIA) Disability: Your medications will be covered. It is important to ensure that you have your EIA medical card with you when your prescriptions are filled.

FNIHB: Your medications will have to be approved by Ottawa. You will need to bring your Status Card with your medical coverage number on it when coming for a transplant.

Manitoba Pharmacare: All Manitoba residents are eligible for Pharmacare, if not covered by EIA or FNIHB. Each family is assessed a deductible according to family income. You are required to pay your deductible before Pharmacare will pay for the eligible medication costs. To be eligible for this deductible, you are required to be up to date with filing your income taxes.

If your monthly medication costs are high compared to your monthly income you may be eligible to apply to pay your deductible by installments. The government of Manitoba website can provide further information. Visit www.gov.mb.ca/health/pharmacare. You can also contact the renal transplant social worker who can assist with the processing of your application.

Some medications, including cyclosporine (Neoral®) Eprex® and Aranesp®, are not covered by Pharmacare but can be obtained at no cost through the Health Sciences Outpatient Pharmacy located in the Psych Health building.

If you are a resident of another province, the renal transplant social worker can help you in find out what your coverage options are.

Medication coverage through work benefits

It is important to know the percentage of your coverage and if there is a maximum amount in any year. You have to pay the cost of medications that is higher than your employment benefit coverage until your Pharmacare deductible is reached. Your plan may require a copy of the EDS approval letter from Manitoba Pharmacare.

Transportation to clinic

Some practical things you should know include getting to and from your daily clinic appointments when you are discharged from hospital following your transplant.

Remember, you run a great risk of getting an illness by associating with groups of people, so you should not plan to take the regular bus for these appointments immediately after transplant.

You could arrange for someone to drive you, drive yourself, or ask to be registered with Handi-Transit.

Parking

Parking can also be expensive at HSC. Parking passes at a reduced rate, are available at:

- HSC Cashier's Desk, 820 Sherbrook St. entrance, Orange Bison zone, (204) 787-3179
- Parking Operations Office, BA104, 791 Notre Dame Avenue; Monday-Friday, 8:30 a.m. – 4:15 p.m., or
- Lennox Bell Lodge, 4th floor, 60 Pearl Street

A \$25.00 deposit for parking transponder is required.

Weekly parking passes are available for \$30.00 and \$50.00 per week, depending on the parkade. Please note:

- The fourth consecutive week is billed at flat rate of \$10.00.
- Rates are subject to change.
- For more information go to www.hsc.mb.ca/parking/weekly

Accommodation Costs

People who normally live outside Winnipeg will need to relocate for several weeks or months to the city. Accommodation costs are your responsibility, unless you have coverage through FNIHB or EIA. You should check on what resources you have available to you through employment or private insurance such as Blue Cross, or other personal resources.

Some people pay to stay at Lennox Bell Lodge, a hostel attached to the hospital. Information about rates or room availability can be obtained by calling the Lodge directly at (204) 787-4271 or visiting www.hsc.mb.ca/lennox.

Patients who are covered by EIA benefits should speak directly with their financial worker. The transplant social worker will be able to assist you with this.

The renal transplant social worker can provide information about accommodation in Winnipeg by calling (204) 787-8589. Some patients are responsible for paying their own accommodation costs in Winnipeg after a transplant. They may choose, with help from family and friends, to have a social to raise funds to offset transplant costs.

Tax implications

Some accommodation, transportation costs, and Pharmacare deductible costs can be used as part of your medical expenses when filing your income tax return. Go to www.cra-arc.gc.ca and search for “travel expenses for medical treatment” for more information.

Short or long term disability:

If you are employed, it is important to know what coverage you will have through short or long term disability, sick time, or Employment Insurance Sickness Benefits. Your employer or human resource department should be able to provide you with information. If you are self-employed it is important to have a plan to cover wage loss following a transplant.

If you are on disability before the transplant, you may not be eligible after the transplant. Disability coverage depends on medical reviews after the transplant.

Living organ donor reimbursement program

If you have a living donor, your donor may be eligible for reimbursement of some of the expenses associated with being a donor. This fund is managed by the Kidney Foundation, Manitoba Branch (Manager of Kidney Care Programs (204) 989-0806 or toll-free 1-800-729-7176), and the application process is through the renal transplant social worker prior to transplant.

The Kidney Foundation of Canada

Mission Statement

The Kidney Foundation of Canada is a national, volunteer organization dedicated to improving the health and quality of life of people living with kidney disease. The Foundation:

- Funds research and related clinical education,
- Provides services for the special needs of individuals living with kidney disease,
- Advocates for access to high quality health care, and
- Actively promotes awareness of and commitment to organ donation.

Patient Service programs include:

- **Information and referral services**
- **Patient manual "Living with Kidney Disease"**
- **Education brochures**
- **Patient assistance program (Financial):** Any patient with kidney disease or their family is eligible for this program. The program is based on financial need. It is a program of "last resort" when no other resources are available.

All applications for the program are made through your transplant social worker.

- **Peer support programs and Self Help Groups:** Transplant support groups, and one-on-one support.
- **Patient Symposia and Education Days**
- **Income tax preparation:** Volunteer services are available to assist with income tax claims to ensure that patients are aware of existing tax credits. This is available to families with a combined annual income under \$30,000.

For more information contact: The Kidney Foundation of Canada, Manitoba Branch (204) 989-0800 or the Westman Chapter (Brandon) at (204) 726-0031.

Transplant Manitoba

Transplant Manitoba needs your help to promote organ donation and transplantation in Manitoba! Public displays, speaking engagements to community groups and schools, media events, our Garden of Life at Assiniboine Park - these are just a few of the volunteer opportunities that you can get involved in!

Call (204) 787-1897 for more information or visit our website www.transplantmanitoba.ca.

Psychiatry

Like physical complications, emotional problems can also occur after transplant.

Being seen by a psychiatrist does not mean that the staff thinks you have a mental illness. All patients are assessed by psychiatry prior to their transplant as a preventative measure. There may also be concerns that a person has developed a mental illness that requires treatment. These include clinical depression (this does not mean the occasional sad mood), anxiety disorders and many others.

Medications may also cause side effects that change your emotional state. A change in the medications you take or other new medications to offset these side effects may be needed. Untreated, emotional problems can have a negative impact on your physical health and your recovery.

Chronic illness can place a severe stress on you and your family. Don't be surprised if you or a family member has trouble coping with all the changes that are happening in your life. Often it helps to have someone who will listen to you, answer your questions and offer you advice. Never be afraid to ask – this is why the Transplant team is there.

Resources and other post-transplant related information

Medic-Alert bracelet

You will be given an application form for a "Medic-Alert" bracelet.

Medical problems listed should include:

- renal transplant
- diabetes (if appropriate)
- the anti-rejection medications you take
- allergies or drug reaction

Include this emergency number on the form:

- Nephrologist on-call – Phone (204) 787-2071



Writing to your donor family

Deciding to write to the kidney donor's family is a personal choice. You may send a letter or you may feel more comfortable sending a simple card. Family or friends may also write saying how your transplant has changed their lives.

It may help to know that many donor families find cards or letters from recipients offers them comfort, consolation and often closure. Despite their loss, many families look forward to a letter or card from a recipient.

All correspondence is anonymous. The identity of the recipient, the donor and both their families is kept confidential. For this reason, information that could lead to your identity is not allowed. Even without a name, your message remains one of the most powerful and meaningful acknowledgements a donor's family receives.

Guidelines for correspondence may be viewed on the Transplant Manitoba website at: www.transplantmanitoba.ca or you may call Transplant Manitoba at 204 787-7001 and ask to speak to a Gift of Life Coordinator.

When completed, place your card or letter in an unsealed envelope. On a separate piece of paper, write your full name, the date of your transplant and your telephone number. Place both in a second sealed envelope and give it to the nurses in the Transplant clinic or to the staff in the Transplant Manitoba – Gift of Life Program office in room GF428 at the Health Sciences Centre. You may also mail the correspondence to:

Transplant Manitoba- Gift of Life Program

Donor and Recipient Correspondence

GF428 – 820 Sherbrook Street

Winnipeg, Manitoba R3A 1R9

For more information

This booklet is an introduction to your life with a kidney transplant. It may not answer all your questions. If you have any questions about what you have read in this book, please feel free to discuss them with your doctor, the Transplant Coordinators or the nurses in the Transplant Clinic.

We hope to make your transplant experience as easy as possible. The Transplant Program team is here to help you.

Along with this booklet, you may wish to enhance your knowledge by accessing the Internet. While there is lots information on the Internet, be aware of incorrect medical or “cyber quackery.” A good website will list:

- the owner or sponsor,
- their credentials and qualifications,
- information on how to contact them, and
- the date information was last updated.

Recommended websites

Transplant Manitoba

- www.transplantmanitoba.ca
- Contact information, events and news from the world of organ donation and transplantation in Manitoba

Transplant Adherence: Taking Charge of Your Post-Transplant Health

- www.transplantadherence.ca
- Information and newsletters for people who have a transplant

Transplant Medication Information Teaching Tool (TMITT)

- www.tmitt.ca
- Videos about anti-rejection drugs you take.

BC HealthLink

- www.healthlinkbc.ca
- General Canadian health information

Medline Plus

- www.nlm.nih.gov/medlineplus
- General health information (American site)

Check with the Transplant Program team if you have any questions.