Multi-Organ Transplant Program

Kidney Transplant Program

London Health Sciences Centre

Patient Handbook

Multi-Organ Transplant Program

Kidney Transplant Program

This handbook provides you with information about the Kidney Transplant Program at London Health Sciences Centre.

We encourage you and your family to become familiar with the contents of this booklet.

We recommend that you review this information and write down any questions that you may have.

London Health Sciences Centre
Multi-Organ Transplant Program

London Health Sciences Centre, University Hospital
339 Windermere Road, London, Ontario, N6A 5A5
Phone 519-685-8500 · Fax 519-663-3141
www.lhsc.on.ca/transplant

*Cover photo: Hiram, a transplant and dialysis patient,
has helped promote greater awareness about the need for organ donation.
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Revised 2017, London Health Sciences Centre

Contact information

London Health Sciences Centre	519-685-8500
Outpatient Pharmacy (UH)	519-663-3231
Nephrology Outpatient Clinic	519-685-8500 ext. 33346
Surgical Outpatient Clinic	519-685-8500 ext. 33188
Multi-Organ Transplant Unit	519-663-3015
Renal Transplant Coordinator *(Sault Ste. Marie, Windsor, PD London, South Street, CKD Clinic at University Hospital*)	519-665-8500 ext. 33851
Renal Transplant Coordinator *(Sudbury, London satellites, Adam Linton Dialysis Unit, CKD Clinic at Victoria Hospital)*	519-685-8500 ext. 32331
Social Worker	519-685-8500 ext. 32411
Living Donor Program	519-685-8500 ext. 33552
Multi-Organ Transplant Program	website: www.lhsc.on.ca/transplant email: motslhsc@lhsc.on.ca

For more information, please visit these web sites:

Canadian Organ Replacement Register
http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_corr_e

Kidney Foundation of Canada
www.kidney.ca

MedicAlert
www.medicalert.ca

Trillium Gift of Life Network
www.giftoflife.on.ca

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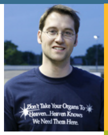


Transplant assessment

Transplantation is the ideal choice of therapy for most patients with chronic renal failure. Successful transplantation offers patients a better quality of life without the need for dialysis. As well as feeling better, most recipients enjoy greater freedom, including work and travel.

The transplant process, however, can be a difficult time for both the patient and the patient's family. Every person considering transplantation approaches the issue as an individual with his or her own fears, hopes and expectations. We are here to help you decide if transplantation is the right choice for you. We hope that this booklet will help you feel more comfortable and knowledgeable about transplant as an option for kidney disease.

Everyone undergoing a transplant assessment must first complete certain medical tests. Because you have already completed this series of tests to determine your suitability for a kidney transplant, the next step is assessment. Your assessment is done on an outpatient basis over the course of two days. You will meet the following team members during your visit:

- Nephrologist (a doctor who specializes in kidney disease)
- Transplant Surgeon (a doctor who performs the transplant surgery)
- Transplant Recipient Coordinator (a nurse who explains the transplant process to you, and is also your contact person during the assessment and waiting period)
- Social Worker (the social worker provides you and your family members with emotional and practical support throughout the transplant process)
- Anaesthetist (a physician who will administer your anaesthetic during surgery)

Dialysis and accommodations

Your assessment will be done over a two-day period, as it is not possible to schedule all of your appointments in one day. If you need a dialysis treatment during this time, arrangements will be made. Unfortunately, we are not always able to provide your dialysis treatment at your normally scheduled time. If you use peritoneal dialysis, please bring enough supplies with you for your visit to London.

There is a full range of accommodations available in London. Please refer to the separate information sheet in your assessment package.

The transplant assessment can be stressful. We recommend that, if possible, a family member or close friend attends these appointments with you. You will receive a lot of new information about transplantation during your assessment appointments. It is also a good practice to write down any questions you have so they can be answered.

Results of assessment

Once you have completed your transplant assessment, you will return home. If any further tests are required, they can usually be done at your own centre of care. The transplant recipient coordinator will request any necessary tests with your local physician or dialysis/ clinic nurse. In London, the physicians (nephrologist and surgeon) will review all of your test results. There will be a waiting period between the time of your assessment and your acceptance to the list. It may take several months to determine your suitability for a transplant. **Once you have been accepted**, you will receive a letter from the transplant coordinator, stating you are on the list. Arrangements will be made at that time to provide you with a pager.

You can write down any questions or concerns to discuss with the transplant team:

Will my transplant be from a living donor or a deceased donor?

Patients can receive a new kidney from either a living donor or by placing their name on the waiting list for a deceased donor. We recommend that patients receive a kidney transplant from a living donor, if possible, for the following reasons:

- shorter waiting time for transplant
- dialysis can sometimes be avoided altogether
- better patient and transplant survival
- shorter hospital stay
- less likelihood of needing short-term dialysis after the transplant

Family members, spouses, and close friends can be considered for living kidney donation. Potential donors must be healthy and their blood type must be compatible with the recipient. If your potential living donor is not compatible, the two of you may want to consider participating in the Living Donor Paired Exchange Registry, which is designed to match unsuitable recipient-donor pairs with other pairs who do not match.

There are numerous medical tests that the potential donor needs to complete in order to be assessed and approved for living donation. We recommend that anyone interested in finding out more about living kidney donation contact our living donor coordinator at 519-685-8500 ext. 33552 or visit www.lhsc.on.ca/livingkidneydonation. Please remember that a family member or friend's decision to donate is voluntary and must be free from any pressure. Also, it is illegal to pay for organs in Canada.

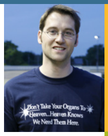
If you do not have a living donor, your name can be placed on the waiting list for a deceased donor transplant. Over the past decade, waiting times have become longer for patients on the transplant list. The average waiting time for a deceased donor transplant is 2 to 3 years. Some patients wait much longer as a result of several factors, including their blood type.

Another factor that affects the waiting time is that there are not enough donated organs for everyone on the waiting list. Most deceased donors are **brain-dead donors**. All brain function has stopped and these patients will not recover. Brain death has been the basis for most organ donation over the past 30 years.

More recently, **donation after circulatory death (DCD)** is used. This involves patients in the ICU who have no possibility of recovery. Following discussion with the family, life support is discontinued and declaration of death occurs after the heart stops.

Along with brain-dead donors and DCD donors, we also use **expanded criteria donors (ECD)**. These are donors who may have high blood pressure, mild diabetes or a slight reduction in kidney function. We evaluate the donated kidney to ensure it has the best possibility of working well. Occasionally both kidneys from an ECD donor are transplanted into a patient to make sure there is enough kidney function.

The types of donors will be discussed in more detail when you come for your transplant assessment. Some kidneys may be identified as "exceptional distribution". If this is the case, this will be explained to you in detail, and you will need to give your consent to accept that organ.



Acceptance on the waiting list

Monthly blood sample

Once accepted on the waiting list, it is very important that the transplant lab receives a monthly blood sample. If you are on hemodialysis, arrangements can be made to draw this blood sample along with your monthly blood work. Patients who are on peritoneal dialysis or not on dialysis at the time of assessment will need to make arrangements to have this blood sample drawn monthly. Please check with your clinic or dialysis unit to ensure this happens. Without this monthly blood sample, the transplant team will not be able to test your blood with potential donors ("crossmatch test"). Failure to provide this monthly sample will prolong your wait for a kidney transplant. You may need to be placed "on hold" on the waiting list until there are recent blood samples in the lab.

Drug coverage

To be on the transplant waiting list, you must have proof of adequate drug coverage. You will need to take anti-rejection medication for as long as you have your transplant kidney, and these drugs are expensive. You may have drug coverage through a private drug plan or you may be eligible for some assistance through the provincial Trillium Program.

If you are a senior citizen or receive General Welfare Assistance, Family Benefits Assistance, Mother's Allowance and have a drug card, you need not apply to the Trillium Program.

The Trillium Program helps Ontario residents who must spend a large part of their income on medication. This program is also available to those with insurance plans that do not provide 100% coverage of drug costs. Owing to the high cost of anti-rejection drugs, we require that all patients have Trillium approval or full drug coverage through an insurance policy before being placed on the active transplant list.

If you presently have an insurance policy covering the costs of drugs, please check with your insurance company regarding the following drugs (or generic equivalent):

Advagraf (tacrolimus)
0.5mg cap DIN# 02296462
1mg cap DIN# 02296470
3mg cap DIN# 02331667
5mg cap DIN# 02296489

Myfortic (mycophenolate sodium)
180mg tab DIN# 02264560
300mg tab DIN# 02264579

Rapamune (sirolimus)
1mg tab DIN# 02247111

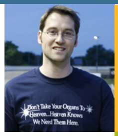
Valcyte (valganciclovir)
450mg tab DIN# 02245777

If you do not have drug coverage, apply to the Trillium Program immediately. This has benefits for both you and your family. Please remember that you cannot be on the transplant list without proof of adequate drug coverage. If you need assistance with the application process, please contact your dialysis social worker or call the telephone helpline that is provided on the application form.

Trillium application forms can be obtained from your pharmacy. The application asks for information about your family, your drug costs and your previous year's income. There is no fee to apply. Please complete this form and mail as soon as possible. We recommend you keep a copy for your own records. **This application form must be renewed every year.**

Once you have received confirmation from your drug company or the Trillium Program that you have coverage for these drugs, please send a copy of your acceptance letter either to your program *or* to:

Renal Transplant Recipient Coordinator
London Health Sciences Centre, University Hospital
339 Windermere Road
London, ON N6A 5A5



The waiting period

If you are fortunate to have a potential living donor, you can choose not to be placed on the waiting list. Once the transplant team accepts you, your donor will be assessed. If suitable, a transplant date will be arranged. If you have a living donor, then your waiting time for the transplant will likely be less than 6 months.

If you do not have a potential living donor, your name will be placed on the transplant waiting list. The waiting period varies from months to years, depending on several factors such as your general health, blood type, immune system, and the availability of donated organs. When a kidney becomes available, a decision is made to select the most suitable recipient. Some factors in determining suitability include blood type, negative crossmatch, and gene match.

Remember, it is very important that the transplant lab receives a blood sample every month. If you are on hemodialysis, arrangements can be made to draw this blood sample along with your monthly blood work. Patients who are on peritoneal dialysis or not on dialysis at the time of assessment will need to make arrangements to have this blood sample drawn monthly. Please check with your clinic or dialysis unit to ensure this happens. Without this **monthly blood sample**, the transplant team will not be able to test your blood with potential donors (“crossmatch test”). Failure to provide this monthly sample will prolong your wait for a kidney transplant. You may need to be placed “on hold” on the waiting list until there are recent blood samples in the lab.

Once accepted on the transplant list, it is also very important that we are able to locate you at all times should a kidney become available. However, you do not need to sit at home by the phone waiting for our call. You will be provided with a pager. Some people have cell phones. We must have your current home telephone number, work number, and an alternative contact, such as a spouse’s work number. If you plan to go on vacation or away for the weekend, it is your responsibility to contact the transplant coordinator in advance to provide contact numbers while you are away.

REMEMBER:

We must always have your correct address and phone number on file in the event of a transplant.

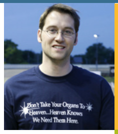
It is your responsibility to inform your dialysis unit and transplant team of any changes.

Staying healthy

While waiting for your transplant, you should try to remain as healthy as possible. All patients are asked to stop smoking and to maintain a healthy lifestyle in preparation for the transplant. Attend all your routine health care visits, eat a balanced diet appropriate for kidney patients, and continue to engage in physical activity. Healthy individuals recover faster and have fewer complications after surgery. Although your dialysis unit/renal clinic is responsible for keeping the transplant team updated on your condition, we welcome your enquiries or health status updates.

Ongoing health assessment

While on the active transplant list, it is important to keep your yearly medical check-ups with your family physician. Women need pap smears every two years, and women aged 40 or older also require a routine mammogram as directed by their physician. Men over age 40 need yearly PSA (prostate) levels. You will need investigations such as a stress test/echocardiogram done every two years while waiting for your transplant. The transplant recipient coordinator will contact your dialysis unit or renal clinic if any further investigations are needed.



Getting 'the call' and coming for surgery

In preparation for your trip to London for your transplant, you should make a list of items that you need to bring, such as:

- provincial health card
- medications
    - please bring all your medications in their original containers
    - keep them here at the hospital for the pharmacist to review on admission and before discharge
    - if you use an insulin pen, bring it along with the cartridge of insulin that is in it (it is not necessary to bring all your insulin)
    - please bring your medication coverage information or drug card
- glucometer/test strips/lancets if you have **diabetes**
- supplies for 2-3 exchanges if you are on **peritoneal dialysis** (it is not necessary to bring your cycler to the hospital); also bring a sampling bag
- pyjamas, house coat, slippers
- toiletries (toothbrush/toothpaste, shampoo/conditioner, brush/comb, deodorant)
- dentures/denture paste/cup, if needed
- eyeglasses, hearing aid, cane/walker, if needed
- shaving kit - cordless electric shaver preferred or bring your usual shaving kit
- casual, loose fitting clothing if you are staying in the London area following discharge (Northern patients)
- list of contact numbers for family members, friends etc.
- money for incidentals (i.e., phone/TV rental). To prevent blood clots, your surgeon will prescribe Thromboembolic (TED) stockings that cost $35. Your surgeon may also prescribe an abdominal binder to support your incision. The cost is approximately $45-$70 depending on size. These costs may be covered by your insurance plan. If payment is a concern, please review with your social worker. Payment can be made at the Business Office on discharge or via billing at a later date.

The call

Despite the uncertainty of the waiting period, we encourage you to lead as normal a life as possible. When we find a kidney for you, either a physician or the transplant coordinator will call you at home. If there is no answer at your home, we will page you. Your pager will beep and provide you with a number to call. You will be given instructions as to what you should do. If you have had any recent infections or health setbacks, you must inform the individual who calls and she/he may determine that it is safer not to proceed at this time. You will be asked to report to the Admitting Department, main floor upon your arrival at University Hospital. Depending on when you were last dialyzed, you may need a dialysis treatment before transplant surgery. This will be arranged once you arrive at the hospital. Remember not to eat or drink anything from the time you are called.

Transportation to the hospital

People who live in Ontario are responsible for the cost of transportation to London at the time of their transplant. Depending on your location and if time permits, you may be able to drive to London. If you live in Northern Ontario, air ambulance (ORNGE) will assist getting you to London. You will need to bring money for your taxi fare (approximately $40) from the airport to University Hospital. Northern patients who come by air ambulance will have to make transportation arrangements for their return home at their own expense. Northern patients are also expected to stay in the London area for a minimum of 3 weeks following discharge from hospital.

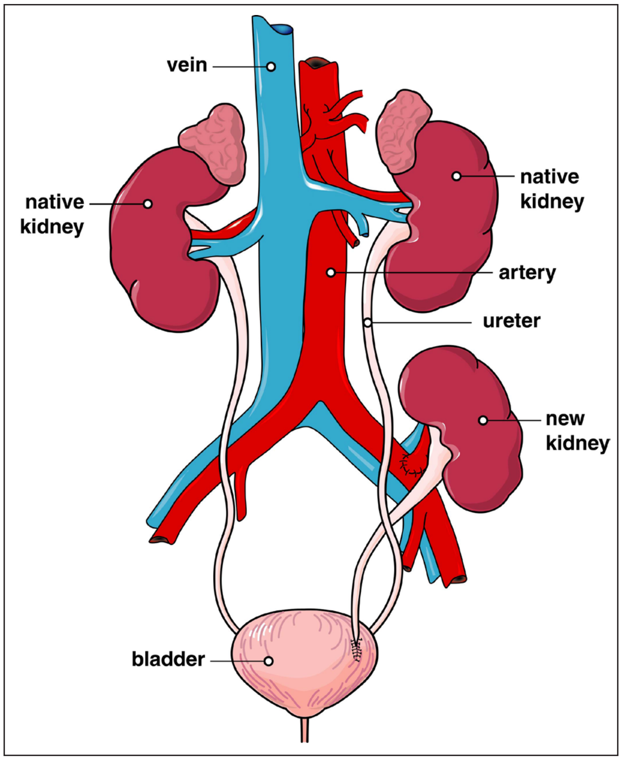
While you are on the waiting list, the transplant team recommends that you try saving money for these expenses, fund raising in your community, or approaching local service clubs for assistance. Service clubs usually request confirmation of need and estimate of costs. Our social worker will be happy to provide this information to assist you, at your request.

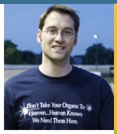
Surgery

Once your admitting paperwork is complete, you will be taken to your hospital room to be prepared for surgery. This involves some blood work, chest x-ray, an ECG and a physical exam. You will have an intravenous (IV) started. If dialysis is needed, it will be done at this time. If you are on peritoneal dialysis, you will need to drain your abdomen of solution before going to the operating room (OR). It would be helpful if you bring the necessary supplies to do two manual exchanges when you come to the hospital. You should also bring supplies to cap your PD tube. You will also meet with the surgical team who will review the risks and benefits of the transplant procedure and answer any questions you have.

All patients will receive an intravenous dose of either basiliximab (Simulect) or Thymoglobulin (anti-rejection drugs) along with methylprednisolone (intravenous prednisone) and an antibiotic before going to the OR.

Once you are ready and the operating room and surgeon are ready, you will be taken to the OR. The transplant surgery usually takes 3-4 hours. The surgery will be done by the on-call surgeon. Once you are out of surgery, you will be taken to the recovery room where you will remain for approximately 2 hours. You will then be transferred to the Multi-Organ Transplant Unit, located on the 4th Floor. This is a 12-bed unit where kidney, kidney-pancreas, pancreas, heart and liver transplant recipients recuperate. The average hospital stay is 5-10 days.





Postoperative care

After being transferred to the transplant unit, you will have several lines and tubes attached to you. These play a significant role in your recovery:

Central Venous Pressure (CVP) Line

This line is inserted by the anaesthetist into a neck vein while you are asleep in the operating room. It provides us with an intravenous line for fluids and medications, and allows us to monitor your fluid status. The CVP line is usually in for about 2-3 days. Sometimes, it can be in for longer periods of time.

Intravenous (IV) Line

You will have an IV in either your right or left arm. This provides an extra line for giving IV fluids until you can eat and drink. Medications can also be given through this line.

Foley Catheter

This is a small rubber tube that is inserted through your urethra (where you pee) into your bladder during surgery. It prevents your bladder from filling up with urine, and allows the new ureter (inserted into your bladder) time to heal. The Foley catheter is usually removed 5 days after your operation. The urine produced by your new kidney will contain blood for several days after your surgery.

Ureteral Stent

Patients usually have a stent inserted during surgery. This is a flexible tube that is placed in the ureter between the new kidney and the bladder. It will need to be removed about 4-6 weeks after your transplant surgery. This procedure is done by your surgeon in the Outpatient Clinic and takes approximately 30 minutes. You will be given an appointment for the procedure before your discharge from hospital.

Hemovac Drain

This is a small plastic tube (catheter) that may be inserted into your abdomen near your incision line. This tube drains away fluid into a small plastic container to prevent fluid from collecting around the kidney. Usually this drain is removed within the first week after transplant. Not all patients need to have a drain after surgery.

Oxygen

You may require oxygen through a mask or nasal prongs during the first 24-48 hours after your surgery. The oxygen amount will be adjusted depending on the oxygen saturation level, which will be measured through a probe on your finger.

Heart Monitor

You will be attached to a heart monitor for the first 24-48 hours after your surgery to monitor your heart's rate and rhythm.

TED Stockings

You will need to wear thigh-high, tight stockings made from special elasticized material that helps bring the blood back up to your heart. This is necessary because you will not be as mobile or walking as much during the first 24-48 hours after your surgery and we want to prevent blood clots in your legs.

Insulin Pump

For patients who have diabetes and require insulin, insulin will be given intravenously for the first few days after surgery. Once you can eat and drink adequately, the physicians will switch you back to injections. Please note that your insulin requirements may change quite frequently for the first few weeks after surgery.

Blood Work

You will have blood work every 4-8 hours for the first 24 hours and then daily until you are discharged. Occasionally, you will need it more frequently, depending upon your condition.

Kidney Ultrasound

Within the first 24 hours, you will have an ultrasound of your kidney. This will likely be done in your hospital room. This test helps the physician determine how well your kidney is draining and to make sure there are no leaks of urine or lymph fluid around your kidney. This procedure takes about 30 minutes.

Kidney Biopsy

A biopsy is the most informative test to diagnose rejection. Not all patients require a biopsy when they are being treated for a rejection episode. The physician performing the biopsy will thoroughly explain the procedure beforehand, and you will be asked to sign a consent form. If you do not already have an IV in place, you will have an IV saline lock inserted on the morning of the biopsy. The biopsy is done in the clinic or ultrasound department, and you are awake for the procedure.

What happens when the kidney doesn't work right away?

Sometimes, after a kidney transplant, the kidney does not work immediately. The most common reasons include rejection, too much medication, or delayed graft function (DGF) often called "sleepy kidney". You may need to continue dialysis after you go home.

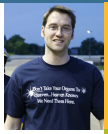
If you have rejection, you will be given strong drugs to reverse the rejection. If you are absorbing too much medicine and the high drug level is interfering with the kidney working, then your dose will be lowered. "Sleepy kidney" (DGF) sometimes happens because the kidney is "in shock" after being removed from the donor. This is a problem that usually gets better by itself over time as the kidney "wakes up" and begins to function. There is no treatment for DGF except to wait for the kidney to start to work on its own. We will continue to check you and your blood tests closely until the kidney starts to work, but you may need dialysis. DGF can last several days to several weeks. This can be a very difficult time for you while you wait for the kidney to begin working.

Anti-rejection medication

After your transplant, you will be prescribed anti-rejection medications. Usually patients take a combination of a few different drugs. It is important that you take these medications exactly how you are told to take them. If you do not, then your body could start attacking the kidney and cause damage (rejection). Taking your medications regularly and in the same way each day will help ensure the same amount is in your blood every day. This is important because if you have too little in your blood, you are at increased risk for rejection; if you have too much in your blood, you are at increased risk of side effects.

Before being discharged, you will be given specific information about each drug you will be taking at home. For general information about the different drugs, see the section about anti-rejection drugs beginning on page 17 or visit www.lhsc.on.ca/Patients_Families_Visitors/MOTP/Pharmacy/index.htm.

The use of alternative therapies, such as herbal remedies, is not recommended. These products can affect how well your anti-rejection medications work.



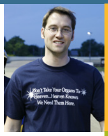
Pain control and activity

The first few days after your surgery are usually the most uncomfortable. You will experience pain following surgery, but this tends to be mostly in the incision area. You will be given medication for pain relief. Initially, this medication will be given to you intravenously by a pain pump. When you can eat and drink, your medications will be changed to tablets.

Another type of pain that you may experience is bladder spasms, which usually occur within the first 2 weeks after surgery. Bladder spasms feel like a sharp urgent need to pass urine around the Foley catheter. These spasms do not last for a long time, but if you experience them, tell your physician or nurse. Sometimes, by simply flushing your catheter, this problem can be solved. If not, you will receive medication to help relieve the discomfort.

Following any major surgery, it is important that your lungs are fully inflated and clear of secretions in order to prevent pneumonia. Within the first 24 hours after surgery, you will be encouraged to practice deep breathing and coughing exercises. A pillow can be used to support your incision site. Along with these exercises, you will be encouraged to sit at the side of the bed within the first 24 hours after surgery. Following this, you are expected to get up and walk about, at first in your room then later in the corridor. At the beginning, this will be uncomfortable for you, but after several days it will become easier and you will feel better for it. Plan to do your exercises and activities about 30-45 minutes after you have received your pain medications so you can move about more easily, with less discomfort.

It is recommended that you not lift anything heavier than 10 pounds for the first 3 months after your surgery. Gradually increase your daily activity. Your tolerance for activity will depend on how active you were before your surgery. There are many benefits to participating in an exercise program both before and after your transplant.



Daily routines

Within a few days after your transplant, a fairly predictable daily pattern will begin to emerge. This daily routine will continue until you are ready to be discharged. Every morning your nurse will take blood, which enables us to monitor your kidney function and general well-being. After your blood work is drawn, you will need to get up and weigh yourself. After your temperature, blood pressure and pulse are taken, it will be time for breakfast. After breakfast, the team members will visit you on rounds and answer any questions you have.

Often, patients forget their questions or concerns when visited by the team members. It might be helpful if you write down your questions so you will have them ready when your doctors visit. It is very important that all your questions or concerns be discussed.

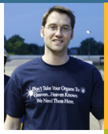
After 5 or 6 days you will begin to feel more like “your old self”. You will slowly regain your energy and become more active. You will notice that most of the lines and tubes will be taken out during the first 48-72 hours. This will allow you to get around more easily.

Once you are feeling better, members of the transplant team will begin teaching you about your medications, activities, and your everyday routine in preparation for your discharge home. You and your family are encouraged to watch the medication videos and ask any questions you have. Average hospital stay is 5-10 days depending on how you are doing.

Depending upon where you live, you may be required to spend several weeks in the London area once you are discharged from hospital, before returning home.

A Guide to Daily Events

Day of Surgery **"Before"**	· No further eating or drinking, once called for surgery. · Come to the hospital as soon as arrangements can be made. · If you are on PD, please bring supplies for three exchanges. · After your arrival from the admission area to your room, it will become very busy as we prepare you for surgery (i.e. physical exam, tests, blood work, etc.). · Please be aware of all your medications and dosages, and bring your medications in their original containers.
Day of Surgery **"After"**	· The surgeon will contact your family after the surgery. The waiting room is across from the main elevators on 2nd floor. · You will go to the recovery room for approximately 1-2 hours. · Family may visit once settled back in your room. · Your vital signs will be checked frequently. · The nurse will give you medication regularly to relieve your pain. · An intravenous line will be coming from the right or left side of your neck. · A tube called a "catheter" will be in your bladder to drain urine. · You will need to wear oxygen prongs in your nose. · There will be a gauze bandage over your incision.
Every Morning	· Every morning at approximately 5:00 am, blood will be taken. · You will be weighed before breakfast (expect a large weight gain after surgery).
Day 1 **After Surgery**	· Your bandage will be removed. · An ultrasound will be done to check the new kidney. · You may drink only liquids as tolerated. · You will be out of bed to a chair, and encouraged to deep breathe and cough.
Day 2	· Increase diet from fluids to solids as tolerated. · Up in the chair for meals and walk three times in corridor. · Your incision is left without a bandage if there is no drainage. · Your vital signs are checked every 4 hours and the heart monitor stopped.
Day 3 until Discharge	· These days focus on returning to your regular diet, increasing your activity, and making discharge plans. · The bladder tube will be removed about 5 days after your surgery. · You will receive visits from the dietitian and social worker to discuss any concerns before discharge. · Written material is provided for you to read (i.e. "Going Home with your New Kidney"; MedicAlert form). · Your nurse will instruct you on the Self-Medication Program and the pharmacist will visit to review your medications. You will watch the medication videos. · Signs and symptoms of infection and rejection are reviewed. · A return appointment is made (staples will be removed at this appointment). · The pharmacist reviews prescriptions for medications to take home with you. · Your nurse makes sure that you are able to take your medications correctly. · You understand the information taught and feel comfortable going home. · Upon discharge, a clinic appointment is made for you.
2-3 months	· Intensive monitoring in the nephrology clinic.



Discharge planning

Once you are feeling better, preparation for discharge will begin. Your transplant nurse will start the self-medication program with you. This program will help you become familiar with all of your new medications, their names, what they look like, what they do, and when to take them.

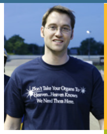
On the day of your discharge, the doctors will write your prescriptions for the medications you will take at home. We recommend that you have these first prescriptions filled at our hospital pharmacy, which is located in the main lobby. The Prescription Centre Pharmacy is open Monday to Friday, 9:00 am to 5:00 pm. If your discharge is during a weekend, plans will be made for you to pick up your prescription medications on Friday before the pharmacy closes.

At LHSC, our focus is not only your care and treatment while in hospital, but also your discharge from hospital. A discharge policy is in place ensuring that patients who no longer need acute care services are discharged in order to accommodate other patients who require admission. The involvement and cooperation of patients and families in discharge planning not only helps to meet their needs, but also balances the use of precious health care resources. **Discharge time is 11:00 in the morning**.

Before leaving the hospital, you will be given an appointment time for your first follow-up clinic visit. The transplant clinic is held on Monday, Tuesday and Thursday mornings in the nephrology outpatient clinic. If you are staying at a hotel, a friend's home or with family for the first few days after discharge, it is important to give the transplant team a phone number where you can be reached, especially if we need to make any adjustments to your medication.

During the first month, post-transplant care involves twice-weekly visits for a clinic visit and blood work. In the next 2-3 months, you will be seen weekly, followed by visits every 2 weeks for another month. After 3 months, patients are usually seen monthly in clinic. Eventually, you will only need to attend clinic every 3 or 4 months depending on your kidney function. These clinic visits usually take the better part of the morning. Please be prepared to spend this time in clinic. It is during these visits that we may identify complications such as rejection or infection. If, for any reason, you are unable to attend a scheduled appointment, please call the clinic to reschedule.

Once the transplant team is confident that your kidney function is stable, they will allow you to return home. A nephrologist in your own community will provide follow-up care for you. If you live in London or the surrounding area (Sarnia, Chatham, Owen Sound, Hanover or Goderich), the transplant team at University Hospital will provide follow-up care. If you are a patient from Windsor, Sudbury or Sault Ste. Marie, physicians in your city will care for you once your condition is stable and you have returned home.



Anti-rejection drugs

Brand Name:	**Advagraf®**
Common Name:	**tacrolimus extended release (ER)** (also known as FK-506)

What is it?

Advagraf® (tacrolimus ER) is a very potent immunosuppressive drug which helps prevent you from rejecting your transplanted organ(s). You will probably have to take it for the rest of your life. You may be taking other medications along with Advagraf® (tacrolimus ER) to prevent rejection, such as prednisone, mycophenolate and sirolimus.

How should it be taken?

Advagraf® brand of tacrolimus is an extended release capsule specially designed to be taken only **once** a day. It works best if taken in the morning, and at the same time every day. You may take it either with or without food, as long as you take it the same way every day. In the hospital, you will take Advagraf® (tacrolimus ER) at 8AM. When you go home, you may take it at whatever time is most convenient for you as long as it is at the same time **every morning**. Do not open, cut, crush, or chew the capsule.

Advagraf®, the extended release tacrolimus, should not be confused with Prograf®, the regular release tacrolimus. They cannot be interchanged. If your medication looks different than what you have been taking, talk to your pharmacist or transplant doctor.

DO NOT take Advagraf® with grapefruit or grapefruit juice. This may cause the amount of Advagraf® in your blood to increase. Orange juice has no effect and is safe to drink.

Dose changes

For the first few months after your transplant, your dose of Advagraf® will change often. Dose changes are based on the amount of Advagraf® in your blood. The dose will vary among different people. Your transplant doctor will tell you what dose you should take. Take this medication exactly the way your transplant team tells you to.

When you leave the hospital, you will continue to have your Advagraf® blood level checked periodically. When you come to the clinic for blood tests, **DO NOT** take your Advagraf® dose that morning. Bring it with you and **take it after** your blood is drawn. Your doctor will tell you if you need to change your dose (for the next day) after seeing the results of your blood test.

If you miss a dose

Take it as soon as you remember, as long as it is within 14 hours of your usual time. For example, if you take Advagraf® at 8AM and you forget, you need to take it by 10PM. If you remember more than 14 hours later, skip the missed dose and carry on the next day as usual. NEVER double the dose. It is important to remember to take this medication regularly and on time to that is can work most effectively for you. Missing too many doses can lead to rejection.

If you are sick

If you vomit within ½ hour of taking Advagraf®, you should take it again. If you vomit more than ½ hour after taking your dose, it is not necessary to take another dose. If you have diarrhea for several days or continue to vomit, you should contact your transplant team. They may want to check your Advagraf® blood level.

How should Advagraf® be stored?

Keep your medications away from extremes of temperature (very hot or very cold). Keep them at room temperature, away from children. Do not keep medication in your vehicle. When you travel, take your medication in a carry-on bag and keep it with you at all times.

What are the side effects?

Advagraf® can cause nausea, stomach discomfort, diarrhea, constipation, headache, tremors, difficulty sleeping, flushing, or tingling in your hands and feet. Some people may also develop high blood pressure or slowing of kidney function. All anti-rejection medications can increase your risk for infections and certain types of cancers, especially skin cancer. You should report anything unusual to your transplant team.

Many of these side effects can also occur when your blood levels of Advagraf® are too high, which is why it is important for your transplant team to continue to monitor your blood levels.

Some people may also develop high blood sugar or diabetes and require medications or insulin to treat this.

Other information

Advagraf® is a very specialized medication and may not be readily available at your pharmacy. Be sure you always have enough on hand so you never run out.

Drug interactions

Many prescription and non-prescription medications can interact (not mix well) with Advagraf® and affect the way it works in your body. It is important to check with your doctor or pharmacist before you take any new medications, even products you buy off the shelf, to make sure it will not affect the amount Advagraf® in your blood or cause added side effects.

It is also recommended that you avoid herbal or homeopathic medications, as these may also affect how Advagraf® works in your body.

Drugs used to treat high cholesterol or triglycerides may become more potent when taken with Advagraf®. You should always check with your transplant team before taking these types of medications (e.g., atorvastatin, simvastatin, pravastatin, lovastatin, rosuvastatin, fenofibrate, etc.).

You should also check with your transplant team before having any vaccinations.

Some examples of medications that do not mix well with Advagraf® are listed below. This is not a complete list, so you should always check with your transplant team or pharmacist before taking any new medications not prescribed by your transplant team.

Medicines which may increase Advagraf® (tacrolimus ER) blood levels:

- diltiazem
- verapamil
- fluconazole/ketoconazole/itraconazole/voriconazole
- erythromycin/clarithromyzin (azithromycin is safe)
- estrogen
- birth control pills
- magnesium-containing medications (e.g. Milk of Magnesia, Maalox)
- grapefruit/grapefruit juice

Medicines which may decrease Advagraf® (tacrolimus ER) blood levels:

- phenytoin
- phenobarbital
- carbamazepine
- rifampin
- St. John’s Wort

Drugs that may cause additive harm to kidneys:

- Aspirin (unless prescribed by your doctor)
- Ibuprofen (Advil), Naproxen (Aleve) and other anti-inflammatory medications

Brand Name:	**Myfortic®**
Common Name:	**mycophenolate sodium**

What is it?

Mycophenolate sodium is an immunosuppressive drug used to prevent rejection in patients who have had an organ transplant. You will need to take other anti-rejection medications, such as prednisone and tacrolimus, along with mycophenolate.

How should it be taken?

Mycophenolate is taken twice daily, every 12 hours. It works best when taken on an empty stomach. Do not crush the enteric coated tablets. Keep the tablets in the blister pack foil until you are ready to take them. Mycophenolate should be stored at room temperature. Keep this medication away from children.

If you miss a dose

Take the missed dose as soon as you remember. If it is almost time for your next dose, skip the missed dose. Do not double up the next dose.

What side effects can this medicine cause? What can I do about them?

You may experience nausea or vomiting, diarrhea or constipation, heartburn, acne, tremors, or headache. Heartburn and stomach upset is quite common. If this happens to you, you can try taking this medication with food. Notify your doctor immediately if you have any unusual stomach pain or blood in the stool, or if you have had any serious stomach problems in the past.

As with all immunosuppressive drugs, you will be more prone to getting infections. Mycophenolate sodium may cause some types of blood cells to decrease (specifically, white blood cells), so it is important to keep all your blood work appointments.

Cautions/Other advice:

If you are pregnant or plan to become pregnant, you must inform your physician. Mycophenolate may be harmful to the unborn baby. Breastfeeding is not advised as mycophenolate may pass into the breast milk and harm your baby.

Do not take any antacids that contain magnesium or aluminum hydroxide (e.g. Mylanta, Maalox, Amphojel, Gaviscon) with this medication. Antacids can make mycophenolate less effective. Antacids that contain calcium (e.g. Tums) have no effect on mycophenolate, and they are safe to use.

Do not take azathioprine (Imuran®) if you are taking mycophenolate. Inform your physician if you are taking acyclovir, gancyclovir, or cholestyramine as these medications may interact with mycophenolate.

Common Name: **Prednisone**

What is it?

Prednisone is a corticosteroid hormone. Your body produces a form of prednisone called cortisol, which helps your body respond to stress, such as infection. When you take prednisone tablets to prevent rejection, your body produces less cortisol and relies on you to take prednisone tablets regularly. If you stop taking prednisone suddenly, your body cannot produce cortisol quickly enough and you may become ill. Your transplant team will decrease your prednisone dose gradually (taper) to allow your body to adjust. Although prednisone is used to prevent rejection in transplant recipients, it also has many other uses such as treating arthritis, asthma, allergies, and inflammation.

How should it be taken?

Prednisone is taken once daily, usually in the morning. It should be taken with food or milk to prevent stomach irritation. Your doctor will tell you when to reduce your dose.
DO NOT STOP TAKING PREDNISONE SUDDENLY. If you forget a dose, take it as soon as you remember. If it is time for your next dose, skip the missed dose and carry on as usual.
Do not double your dose.

In some people, prednisone may be tapered down to every second day. You may wish to keep a calendar to remind you what days to take your prednisone.

What side effects may occur? What can I do about them?

Prednisone has many side effects, particularly with long-term use. Your transplant team is aware of these side effects and will try to decrease your does as much as possible without causing rejection.

If you experience nausea, vomiting, stomach irritation, or heartburn, take this medication with food or milk. If these effects persist or your stools become black and tarry, contact your doctor.

Mood swings may occur at high doses. Acne, round face, thin skin, easy bruising, slow wound healing, headache, insomnia, weight gain, swollen feet, muscle weakness, blurred vision, cataracts, weak bones, increase appetite and thirst may also occur.

If you are diabetic, prednisone may make it more difficult to control your blood sugar and require you to use more insulin. If you are not diabetic, prednisone may require you to temporarily or permanently take insulin or pills to control your blood sugar levels.

Are there any other special precautions to take?

Be sure to tell any doctor, dentist, surgeon, nurse, or pharmacist who is involved with your health care that you are taking prednisone.

Brand Name: **Rapamune®**

Common Name: **Sirolimus, Rapamycin**

What is it?

Sirolimus is an immunosuppressive medication that is used to prevent rejection of transplanted organs. You may be taking other anti-rejection medications along with sirolimus.

How should it be taken?

Sirolimus is usually taken once a day. You should take it at the same time every day, for example in the morning. You may take it either with or without food; however, you should be consistent (for example, always take it with food or always on an empty stomach).

DO NOT take sirolimus with grapefruit or grapefruit juice as this may cause your blood levels of sirolimus to increase. Other juices, including orange juice, have no effect on sirolimus blood levels.

Sirolimus is available as a tablet or a liquid. If you are using the liquid form, your pharmacist will show you how to take it.

Dose changes

Your dose of sirolimus may change often after your transplant. Dose changes are based on the amount of sirolimus in your blood or if you are experiencing any side effects from the medication. The dose will vary among different people. Your doctor will tell you what dose you should take.

When you leave the hospital, you will continue to have your sirolimus blood level measured when you come to clinic. On clinic days, DO NOT take sirolimus until AFTER you have had your blood work taken. You should bring it with you to the clinic and take it after having your blood drawn.

If you miss a dose

If you miss a dose, take it as soon as you remember. If it is almost time for the next dose, skip the missed dose and carry on with your usual dose. Do not double the dose to catch up.

If you are sick

If you vomit within ½ hour of taking sirolimus, you should take it again. If you vomit more than ½ hour after taking sirolimus, it is not necessary to take another dose. If you have diarrhea for several days or continue to vomit, you should contact your transplant team.

Side effects

Sirolimus may cause nausea. diarrhea, tremors, dizziness, high blood pressure, high cholesterol and triglycerides, unusual heartbeat, infections, acne, excess hair growth, anemia, unusual bleeding or bruising, certain types of cancers (e.g., skin cancer) or mouth sores. You should rinse your mouth with water several times after taking sirolimus as this may help prevent mouth sores.

Report any signs of infection such as fevers, chills, sore throat, white patches in your mouth or other mouth sores, or changes in vaginal discharge to your transplant team. Also, if you have any unusual lumps or swollen glands, unusual swelling, sweating at night, or unexpected weight loss, reports these symptoms.

Women taking sirolimus should talk to their transplant team before becoming pregnant as sirolimus may be harmful to the unborn baby.

Drug interactions

Several medications do not mix well with sirolimus and may affect the level of sirolimus in your blood. You should avoid these medications unless your transplant team tells you it is okay.

Medications that increase your sirolimus blood level

- diltiazem
- verapamil
- fluconazole
- itraconazole
- ketoconazole
- erythromycin
- clarithromycin
- cimetidine
- grapefruit, grapefruit juice

Medications that decrease your sirolimus blood level

- phenytoin
- phenobartibal
- carbamazepine
- rifampin

Drugs that are used to treat high cholesterol and triglycerides may become more potent when taken with sirolimus. You should always check with your transplant team before taking these types of medications (e.g., atorvastatin, simvastatin, pravastatin, lovastatin, rosuvastatin, fenofibrate, etc).

You should also check with your transplant team before having any vaccinations. Do not use herbal medications while taking any anti-rejections medications. You should also avoid using non-prescription (“over-the-counter”) medications.

Other information

Store your medication at room temperature, away from excessive heat and humidity. Sirolimus is a very specialized drug and may not be readily available at every pharmacy. Be sure you always have enough on hand so you never run out.

Brand Name: **Thymoglobulin®**

Common Name: **Antithymocyte Globulin**

What is it?

Thymoglobulin® is a very powerful anti-rejection drug. It is often used with patients who have previously rejected a kidney transplant and are receiving their second transplant, or with patients whose new kidney is slow to start working. It can also be used to treat an acute rejection episode.

How to take it?

This medication is given only intravenously, once a day. The physician will prescribe a dose based on several factors: your weight, kidney function, and white blood cell count. If you are taking other transplant medications, your physician may discontinue or reduce the dosage of some drugs while you are taking Thymoglobulin®. To reduce some of the side effects, your physician may order Tylenol® and Benadryl® to be given to you before your dose of Thymoglobulin®. This is usually only necessary for the first few doses.

Side effects

You may experience some of the following side effects:

- difficulty breathing
- fever
- chills
- nausea
- rash
- vomiting
- diarrhea
- muscle aches
- infection or pain during infusion

If you do, report them to your nurse as soon as possible. Your platelet and blood cell levels may also decrease. These levels will be monitored every day while you are taking this drug.

Brand Name: **Simulect®**
Common Name: **Basiliximab**

What is it?

Basiliximab helps the body accept the transplanted organ.

How to take it?

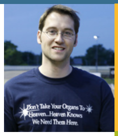
This drug is used in combination with other medications to prevent rejection after transplantation. It is given intravenously on the day of transplant surgery and again four days after the transplant while you are in the hospital.

Are there any precautions?

- Tell your doctor all drugs that you are taking. This drug may not mix well with some other medications.
- Talk with your doctor before getting any vaccines. This drug may either increase the chance of an infection or make the vaccine not work as well.
- Discuss with your doctor if you are pregnant or may be pregnant, or if you are breastfeeding.

What are possible side effects?

- flu-like symptoms including headache, weakness, fever, shakes, aches, pains and sweating (mild pain drugs may help)
- anemia
- hard or loose stools (constipation or diarrhea)
- upset stomach or vomiting
- change in appearance of teeth or gums
- high blood pressure
- swelling in the arms or legs
- belly pain



Possible complications after transplant

Complications are possible after your transplant. Your transplant team will do their best to reduce your chance of having complications.

Delayed graft function ("sleepy kidney")

It is important to remember that not all transplanted kidneys function immediately. Some kidneys are slow to start. In this case, you may need several dialysis treatments until your kidney "wakes up". Sleepy kidneys sometimes last several weeks or more.

Rejection

Rejection is an attempt by your immune system to attack your transplanted kidney and to destroy it. Rejection can occur any time, but the risk is greatest during the first 6 months after your transplant. It is not uncommon for transplant patients to experience a rejection episode. Most rejection episodes are successfully treated. It is important to treat the rejection episode as soon as possible. The longer treatment is withheld, the more likely permanent damage will be done.

Rejection episodes can be treated with either a large dose of steroids (methylprednisone) for 3 days or, in more severe cases, treatment with Thymoglobulin®. In some cases, you may require intravenous immune globulin (IVIg) and/or Plasmaphoresis (PLEX). Most times, it is necessary to perform a kidney biopsy to identify rejection. You may or may not have any signs or symptoms to suggest that you are rejecting your new kidney. Sometimes, the only clue is abnormal kidney function tests. This is why it is very important to attend all scheduled clinic visits.

Kidney transplant patients should be aware of some of the signs and symptoms that may indicate rejection. If you experience any of these, do not wait until your next clinic appointment. Call your transplant team promptly if you experience any of the following:

- pain or tenderness over the kidney
- fever or chills (temperature >38˚)
- sudden weight gain
- decreased urine output
- swelling in ankles, feet or hands, puffy eyelids
- general feeling of ill health

Infection

Anti-rejection medication interferes with your natural immunity making you more prone to infections after your transplant. There are different types of infections:

- **Viral** (CMV, EBV, Herpes simplex (cold sores), Herpes zoster (shingles) or chickenpox)
- **BK Polyoma Virus:** this is becoming an important cause of kidney transplant failure and, at present, there are few treatment options
- **Fungal** (candida)
- **Bacterial** (signs of bacterial infection include fever, cough, sore throat, burning sensation when voiding, redness, swelling or drainage around an incision)
- **Pneumocyctis Carinii Pneumonia (PCP)**: A type of pneumonia that immune-suppressed patients are more prone to get. You will be given medication to prevent this.

If any type of infection is suspected, you should call your doctor.

Cancer

There is a slightly increased risk of cancer associated with the use of any immunosuppressive drug. It is very important to have yearly health check-ups with your family doctor. It is recommended that women have a pap smear and mammogram every 2 years, and a stool sample for occult blood testing should be done for women older than 40 years. Men over 40 years old should have yearly prostate check-ups and stool for occult blood. Skin cancer is the more common type of cancer seen in transplant patients. Report any new moles or any skin changes to your physician. Always wear sunscreen when you are out in the sun. Another type of cancer is a blood cancer called PTLD, Post-Transplant Lymphoproliferative Disorder. Report any unusual lumps or bumps, unexplained weight loss or night sweats to your doctor.

Diabetes

Glucose, a simple sugar, is the main source of energy in the body's cells. Diabetes occurs if sugar accumulates in your body because either your body is not using it properly or your body is not producing enough insulin. Some of your prescribed drugs (prednisone, Advagraf) can cause diabetes or make diabetes worse. Early signs and symptoms include tiredness, unusual thirst, weight loss, excessive production of urine, blurred vision and confusion. Monitoring blood sugar after your transplant is done to detect high levels. If you were taking insulin, after the transplant you may require higher doses. If you were taking pills or watching your diet to control your blood sugar before transplant, you may need to take insulin after transplant. If your blood sugar goes high immediately after your transplant, it may return to normal as your dose of medication is decreased. If your blood sugar remains high when you are ready to go home, you will be taught how to check your blood sugar, how to give yourself insulin, and how to change your diet to help control your blood sugar.

Cataracts and glaucoma

There is an increased risk of cataract formation and glaucoma in patients who are on prednisone for long periods of time. Once you are transplanted, it is a good idea to have your eyes checked yearly.

Bone disease

Transplant patients have an increased risk of bone disease (osteoporosis), which can increase the risk of bone fracture. To lower your risk, make sure you are getting enough calcium and vitamin D in your diet (unless your doctor says not to). Consult your dietitian for good dietary sources of calcium.

Resuming your lifestyle

Peritoneal Dialysis Catheter & PermCath Removal

The peritoneal dialysis catheter or PermCath is usually removed 1-2 months after your transplant, once we know that the new kidney is functioning well.

Exercise

Exercise promotes physical and mental well-being and helps keep your bones strong. After your surgery, you should gradually increase your level of activity and exercise. Before starting any exercise program, remember to check with your transplant team.

Work and Activity

Returning to work or school should be discussed with your transplant team. The time frame depends on many factors, including your recovery and the type of work you do. Most people are ready to return to work after 3 months.

Sexual Activity

You may resume sexual activity as soon as you feel well enough. For women, a normal menstrual cycle will usually return. Time is variable and women should assume that they could become pregnant and take necessary precautions. Women of childbearing years can successfully conceive a child but should not plan to become pregnant for at least 1 year after transplant. It is very important to discuss the issue of getting pregnant before doing so with your transplant doctor, as many of the medications may be harmful to the developing baby and need to be changed **before** conception.

Smoking

Smoking has been proven to be harmful to your health. If you are a smoker, it is expected that you will stop smoking before your transplant. Smoking will shorten the life span of your kidney. If you need help quitting, ask your physician or pharmacist for advice on what is best for you.

Travelling

You are able to travel as often as you like after your transplant, although it is recommended that you check with your transplant team if you are considering an extended trip within 6 months of your transplant. If your trip requires you to be vaccinated, check with the transplant team before doing so. Do not take vaccines that come from live vaccines. Always ensure you take more than enough medications with you and always store medications in your carry-on luggage. Medications should always be in their original containers.

Should you have a pet after your transplant?

Transplant recipients are more prone to infections because of their weakened immune systems. Although animal contact may increase the risk of any type of infection, it doesn't mean that recipients can't enjoy the companionship that pets bring into people's lives. However, it's important to follow a few simple rules, which will help you reduce the risk.

- Wash your hands: Washing hands thoroughly with soap and water after any contact with an animal is a must. Avoid direct contact with animal feces.
- Caring for your pet: If your pet is sick, always make sure you see a veterinarian as soon as possible. Cats and dogs that have diarrhea should be seen by a veterinarian for specific infections.
- Animal cleanliness: When cleaning your pet's cage or litter always make sure to wear gloves and wash your hands thoroughly afterwards. Do not keep litter in places where food is prepared or eaten. If you have a cat, it is preferable to keep it indoors.
- Feeding your pet: Make sure you pay attention to your pet's diet. By protecting your pet from any diet diseases, you can protect your own health as well. Pets should be fed only high-quality commercial pet foods. If eggs, poultry or meat products are given to your pet as supplements, they should be well-cooked. Any dairy products given to your pets should be pasteurized. Additionally, pets should be prevented form drinking toilet bowl water and from having access to garbage.

If you are considering adopting a pet, it is preferable to adopt an animal that is at least 6 months or older and in good health. Unfortunately, some animals such as reptiles, chicks or ducklings are not recommended for transplant recipients. If you come in contact with these animals, always make sure you wash your hands thoroughly with soap and water.

MedicAlert Jewellery

All transplant patients should wear a medical alert bracelet or necklace. The information contained on a bracelet or necklace provides valuable information at the time of an accident. If you already wear one, make sure it is updated after your transplant. Application forms are available at the hospital and in most drug stores, or you can get more information from their website (www.medicalert.ca). Information should include 'renal transplant/ immunosuppressed'. If you need any help in completing the form, please ask.

Family Physician

The transplant team is unable to provide total care to all of our patients. We ask that all health problems unrelated to your transplant be directed to your family physician. If your doctor thinks that our help is required, we would be happy to assist him or her. If you have not seen your family physician in the past year or so, or if your doctor requires an updated summary of your care, please let the team know.

Appendix 1

Transplant Clinical Research

Even with our best efforts using today's medications, some recipients will experience organ rejection and many will experience undesirable short and/or long-term side effects. Therefore, research (clinical trials) is currently underway to find the safest and most effective immune-suppressing drugs that will allow transplanted organs to work better and last longer with fewer or milder side effects.

- A clinical trial is a research study designed to learn more about the safety and effectiveness of new medications. Clinical trials are a necessary part of developing new treatments for diseases.
- Treatments being studied may be new drugs or new ways of using approved drugs.
- You can only participate in a clinical trial by agreeing to do so.
- If you agree to participate in a trial study, your doctor and/or research nurse will help determine if you are a suitable candidate for that particular study.
- You may ask as many questions about the study as you like. It is important that you understand and are comfortable with all aspects of the study.
- You may withdraw from the study at any time, for any reason, without any risk of affecting your medical care.

Your responsibilities will be to:

- Respond truthfully to the study questions.
- Make every effort to follow the instructions of the study.
- Take the study medication as prescribed.

The privacy laws require that study staff working with you receive your written permission before sharing any of your health information for study purposes. Some of the individuals who could have access to your information include your study doctor, his or her research staff, the research staff of the drug manufacturer who is sponsoring the study, the research ethics board and the regulatory agencies.

Your personal records relating to the study will be kept confidential. A research number will be assigned to you and this number will be used to identify all your research data. Any reports that result from a research study will not identify you or any other participants by name.

Appendix 2

London Health Sciences Centre
Multi-Organ Transplant Program

Multi-Organ Transplant Program
339 Windermere Road, PO Box 5339
London, Ontario, Canada N6A 5A5

www.lhsc.on.ca

March 2014

FAQ: Measles and Transplant Patients

You likely have heard or read about recent outbreaks of measles in several communities. This letter is intended to provide general information about measles for transplant patients who take anti-rejection drugs.

1. What is measles?

Measles is an infectious disease caused by the measles virus. This virus is very contagious and is usually transmitted through the air (i.e. coughing). Direct person-to-person contact (i.e. touching) is not necessarily needed for virus transmission. It is important to remember that spreading of the virus from the infected person starts about 5 days before a rash appears to about 4 days after the rash.

2. Who is at risk of measles?

Patients who have not had measles or the MMR vaccine may be at risk of catching measles. Most people born before 1970 likely have had measles, but this is **not** 100%. Transplant patients are at risk if they *never* received 2 shots of vaccine or only one shot of vaccine prior to their transplant. A few patients may not have had a good response to the vaccine and would need to be tested for immunity to be certain.

3. What are the symptoms of measles?

Measles usually starts with fever, 'flu-like' symptoms, sore throat, and lack of appetite. Some patients also develop red eyes, sneezing, coughing and then a typical rash. Red rashes usually start on the face and then spread to form red patches on the body. Patients start to improve even 1-2 days after the rash starts, but they may still have a cough for many days. Although there is little data, it is possible that transplant patients may be at higher risk of measles complications of the lungs, ears or brain.

4. What should I do to protect myself?

Generally transplant patients need to stay away from people who are ill and use common sense. *Washing your hands after touching surfaces, avoiding people with fever, cough or rashes are reasonable precautions, even if you have had vaccinations.*

5. What should I do if I develop symptoms?

If you develop rash or fever, please call your doctor, the transplant team or the transplant infectious diseases team (Dr. Hosseini at 519.663.3840). Please **do not go** to the doctor's office without calling first as you may transmit measles to other patients. You can take Tylenol® if you develop rash or fever. Rest and drinking fluids are always helpful. Please do not take aspirin if you are younger than 18. This medication may cause a severe side effect called Reye's syndrome.

6. Is a test available for the diagnosis of measles?

Yes. Your doctor may arrange for some laboratory tests and blood work. For some patients it may not be needed to do the test.

7. Can I receive the measles vaccine?

There is a vaccine called MMR which provides protection against measles, mumps, and rubella. **Since it is a live virus vaccine, MMR vaccine must be avoided by all TRANSPLANTED PATIENTS ON ANTI-REJECTION DRUGS. It is important for all family members and close contacts to have been immunized so that they do not get measles.**

Dr. Patrick Luke & Dr. Anthony Jevnikar	Dr. Seyed Hosseini
Co-directors, Multi-Organ Transplant Program	Director of Transplant Infectious Diseases

University Hospital • Victoria Hospital and Children's Hospital

Appendix 3

London Health Sciences Centre
Multi-Organ Transplant Program

Important: Your consent for participation in the Canadian Transplant Registry

Dear Patient,

In spring 2014, Canadian Blood Services (CBS) launched the Highly Sensitized Patient (HSP) listing through the Canadian Transplant Registry (CTR) with Ontario. The CTR is an online registry managed by Canadian Blood Services in Ottawa, and it also includes the National Organ Waitlist and Living Donation Paired Exchange Registry. The HSP Registry enables programs to access a larger number of potential donors from which to find kidney transplant opportunities for highly sensitized patients. It is anticipated that 20-30% of wait-listed kidney patients in Ontario meet criteria for HSP. As a renal patient with London Health Sciences Centre, you may be eligible for listing if you meet the criteria.

Obtaining your consent

In compliance with Ontario privacy law, CBS requests your consent for its collection, use and disclosure of your personal health information for purposes of the Registry as described in the *Public Notice for Participants of the Canadian Transplant Registry*.

Please read the Public Notice document from Canadian Blood Services. This Public Notice provides information with regard to Canadian Blood Services' collection, use and disclosure of your personal health information, for purposes of operating the Registry. Your personal health information will only be shared with CBS when you meet the eligibility requirements for HSP listing.

IF YOU AGREE TO PARTICIPATE IN THE REGISTRY, NO FURTHER ACTION IS REQUIRED BY YOU. Your personal health information will be entered into the CTR and maintained by Canadian Blood Services as described in the Public Notice.

You may choose not to participate in the CTR. If you wish to withhold or withdraw your consent to participate in the Registry, you must discuss your decision with your transplant coordinator, either Jessica McDougall or Diane Smith, at LHSC to obtain a Withdraw/Withhold Consent Form. If you have any questions regarding how the HSP Registry will impact you, please speak to your transplant physician.

Please note that if you do not contact us, you will be automatically registered in the Registry if you meet the criteria. If you wish to withdraw from the Registry, please call your transplant coordinator.

How to contact Canadian Blood Services

If you want general information about the CTR, please contact Canadian Blood Services by email at transplantregistry@blood.ca. If you have any questions about the Public Notice, please contact Canadian Blood Services' Privacy and Access Office by email privacy@blood.ca or by phone at 1.877.262.9191. Information about CBS priv acy practices also can be found on its website at www.blood.ca.

Notes

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