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

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Cover photo: Hiram, a transplant and dialysis patient, has helped promote greater awareness about the need for organ donation.
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Transplant assessment

Transplantation is the ideal choice of therapy for most patients with chronic renal failure. Successful transplantation offers the patient a life without the need for dialysis. 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 realize that this can be a stressful time for you and your family. 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 your upcoming transplant.

Everyone undergoing a transplant assessment must first complete certain medical investigations. 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 Coordinator (a nurse who explains the transplant process to you, and is also your contact person during the assessment and waiting phases)
- Social Worker (the Social Worker provides you and your family members with emotional and practical support throughout the transplant process)
- Anaesthetist (a doctor 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, or you can visit www.londontourism.ca for more information.

The transplant assessment can be stressful. We recommend that, if possible, a family member or close friend attend these appointments with you. You will receive a lot of new information about your transplant during your assessment appointments. It is also a good practice to write down any questions you have so they can be answered at the time of your assessment.
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 arrange 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 jot down any questions or concerns that you have so you can discuss with the transplant team.
Patients can get a new kidney from either a living donor or by placing their name on a waiting list for a deceased donor. 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. We recommend that patients receive a kidney transplant from a living donor if possible, for the following reasons:

- reduces waiting time
- dialysis can sometimes be avoided (called ‘pre-emptive transplant’)
- improves patient and transplant survival
- reduces hospitalization
- increases organ supply
- reduces likelihood of requiring dialysis for a time after the transplant

With living donation, family members, spouses, and close friends can be considered for kidney donation. Potential donors must be healthy and their blood type must be compatible with the recipient. 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 living donation call our living donor coordinator at 519-685-8500 ext. 32331 for further information regarding the donor assessment process. Please remember that a family member or friend's decision to donate is voluntary and must be free from any pressure.

In the event that you do not have a living donor, your name will be placed on the waiting list for a deceased donor transplant. A deceased donor is a person who recently died of causes unrelated to kidney disease, and he or she has been declared “brain dead” – all brain function has stopped and the patient will not recover. Brain death has been the basis for obtaining organs from most donors over the past 30 years of transplantation. However, some patients with devastating injury or illness have low levels of brain activity, which prevents declaration of death despite these patients being completely dependent on life support in intensive care units. Unfortunately, without declaration of brain death, families have been unable to donate organs from these patients.
Recently, some families have been given the opportunity to donate their loved ones’ organs after life support is discontinued and heart activity stops. This is known as donation after cardiac death (DCD). In a situation when the patient’s condition is terminal and the family requests organ donation after death, life support is discontinued and declaration of death occurs after heart activity stops. As a result of the short delay required to obtain the organs from these donors, organs are deprived of oxygen for a brief period of time so there can be some damage which can affect the function of the organs after transplantation. For this reason, we consider only younger donors (under 50 years of age) with no known medical conditions that might affect kidney function. We know from the results of other centres that these organs are likely to function as well as organs from brain-dead donors. If your kidney is from a DCD donor, the transplant team will inform you of this when they call you in for a transplant.

Despite all of the advances in transplantation, there are not enough organs for everyone in need. Patients can wait years for a kidney transplant; for this reason, we have started a Donation after Cardiac Death (DCD) program, as described above. As well in recent years, due to the shortage of organs, we have also been using organs from donors in which kidney function may have been affected. These donor kidneys may have reduced but adequate function after transplantation. These donors are called Expanded Criteria Donors (ECD) because they do not meet the strict criteria of our “standard” donors and include donors who may have high blood pressure, mild diabetes or a slight reduction in measured kidney function. Selecting these donors is made on an individual basis and with a careful analysis of the donor kidneys for their suitability. In many cases, the kidneys we select from these donors perform as well or better than kidneys from “standard” donors when transplanted into suitable recipients. In some cases, both kidneys from a single donor are transplanted into a single patient to ensure adequate kidney function. If the kidney you are offered is from an Expanded Criteria Donor, you will be told of this when the transplant team calls you in for a transplant. However, specific details of the donor cannot be provided to ensure that the donor cannot be identified.

The selection of deceased donors is obviously complex and includes considering pre-existing medical conditions, their age, and cause of death. Recipients also have individual characteristics and considerations that are used in the selection process, in addition to the length of waiting time. In the end, we want the best possible outcome for your new kidney given the available donors. More specific questions on the above can be answered on a case-by-case basis with your physicians and transplant coordinators.
If you are fortunate to have a potential living donor, your name will not be placed on a transplant waiting list. Once the transplant team accepts you, your donor will be assessed. If the donor is 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, cytotoxic antibody levels, 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 tissue match.

Once accepted on the transplant list, it is 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. We must have your current home telephone number, work number, spouse's work number and cell phone number, if you have one. 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.

While awaiting your transplant, it is very important that the transplant team receives a monthly blood sample (red top tube) from you. If you are on hemodialysis, arrangements can be made to obtain this blood sample along with your monthly blood work. Patients who are on peritoneal dialysis or not on dialysis at the time of the 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 match you with potential donors. Failure to provide this monthly sample will prolong your wait for a kidney transplant.

It is also very important to have a “game plan” for when you receive “the call” that we have a kidney for you. You should know who is going to drive you to the hospital. For patients coming from the Sault or Sudbury regions, arrangements will be made for you to come by Air Ambulance, however, you are responsible for getting yourself to the local airport and paying for the taxi from the London airport to University Hospital. Some people have found it helpful to have a bag packed, ready for the call.
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 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 set backs, you must inform the individual who calls and they may determine that it is not safe to proceed at this time. You will be asked to report to the Admitting Department, main floor upon your arrival to the 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. If you are on peritoneal dialysis, it would be helpful if you bring the necessary supplies to do several manual exchanges when you come to the hospital.

Surgery

Once your admitting paperwork is complete, you will be taken to your hospital room to be prepared for surgery. This usually involves some blood work, chest x-ray, and an ECG. 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).

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 surgeon on-call. Once you are out of surgery, you will be taken to the Post-Anaesthetic Care Unit (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, heart and liver transplant recipients recuperate. The average hospital stay is 7-10 days.
After being transferred to the transplant unit, you will have several lines and tubes attached to you. They play a significant role in your recovery. These include:

**Central Venous Pressure (CVP) catheter**
A catheter is inserted by the anaesthetist into a vein in your neck while you are asleep in the operating room. This catheter 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.

**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.

**Foley catheter**
This is a small rubber tube that is inserted through your urethra into your bladder, in order to drain the urine. 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 5-7 days after your operation. The urine produced by your new kidney may contain blood for several days after your surgery.

**Ureteral stent**
Patients will 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 approximately 6-8 weeks after your transplant. 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 prior to your discharge.
**Oxygen**
You will be given 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.

**Insulin pump**
For individuals who are diabetic 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 subcutaneous 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 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.

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

**Renal biopsy**
A renal biopsy is the most informative test performed 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 before you have the biopsy 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 first few days after your surgery are usually the most uncomfortable. You will experience pain following surgery and this tends to be localized in the incision area. You will be given medication for pain relief. Initially, this medication will be given to you intravenously. 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.

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. Following any major surgery, there is always a concern that your lungs are fully inflated and clear of secretions in order to prevent pneumonia. 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, initially in your room then out in the corridor. At the beginning, this may 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 medication 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 as tolerated. 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.
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 home. 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 is recommended that you write down any questions that you have so you will have them ready when your doctors visit. It is very important that all your questions or concerns are addressed.

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 week. This will enable 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. Education classes are held on a regular basis, and a schedule will be given to you. You and your family are encouraged to attend these classes and watch the medication videos. Your hospital stay may be as short as 6 or 7 days.
Once you are feeling better, preparation for discharge will begin. Your transplant nurse will start the self-medication program (SMP). 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, 9:00am to 5:00pm.

If your discharge is during a weekend, plans will be made for you to pick up your prescription medications on the Friday before the pharmacy closes.

Before leaving the hospital, you will be given an appointment time for your first clinic visit following your discharge. The transplant clinic is held on Monday and Thursday mornings in the nephrology outpatient clinic located on the main floor. If you are staying at a hotel, a family or friend’s home for the first few days after discharge, it will be important for you to give the transplant team a phone number where you can be reached. This is very important since we may have to make an adjustment to one of your medication doses.

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. (See Letter to all LHSC Patients, page 32)

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. Patients from the Sudbury and Sault regions usually stay in London for several weeks following discharge. 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 (Windsor, Sarnia, Chatham, Owen Sound, Hanover or Goderich), the transplant team at University Hospital will provide follow-up care. If you are from the Windsor area, you can be cared for by the physicians in Windsor once your condition is stable.

During the first month, this involves twice-weekly visits for blood work and a clinic visit, then weekly visits for the next month, 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.
Your immune system protects you from infection (bacteria and viruses) by recognizing and attacking foreign substances. Your new kidney is seen as something “foreign” so your immune system will try to attack it. To stop this natural tendency, you will need to take anti-rejection medication. These medications suppress and reduce the effectiveness of your immune system. You will need to take these medications for as long as you have your kidney. Stopping or missing doses will result in a rejection episode.

The following information is a general guide to some of the medications available for use after your transplant. This information does not cover everything there is to know about each medication, nor does it replace your doctor or pharmacist’s advice. It is very important that you are familiar with your medications before you leave the hospital. We recommend that you review this section several times so you are sure you understand the purpose and dose of each medication. The following drugs are the most common ones used after transplantation. You may, at one time or another, be taking any combination of the following medications.

**Brand Name:** Neoral®

**Common Name:** Cyclosporine

**What is it?**

Cyclosporine is a very potent immunosuppressant that helps you to prevent 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 cyclosporine, such as prednisone, mycophenolate mofetil, or sirolimus, to prevent rejection.

**How should it be taken?**

Cyclosporine should be taken every 12 hours. During your hospital stay, you will take it at 8AM and 8PM (or 6AM and 6PM). When you go home, you can take it at whatever time is convenient for you, as long as it is **every 12 hours** (eg. 9AM and 9PM or 7AM and 7PM). It may be taken with food or on an empty stomach, but you should try to be consistent (eg: always with food or always on an empty stomach).

**DO NOT** take cyclosporine with grapefruit or grapefruit juice as this may cause your blood levels of cyclosporine to increase. Orange juice has no effect on cyclosporine blood levels.
Cyclosporine is available as a capsule or as a liquid. If you are using the liquid form, your pharmacist will show you how to measure your dose.

**Dose changes**
For the first few months after your transplant, your dose of cyclosporine will change frequently. Dose changes are based on the amount of cyclosporine in your blood. The dose will vary among different people and different types of transplants. Your doctor will tell you what dose you should take.

When you leave the hospital, you will continue to have your cyclosporine blood level checked periodically. You may be asked to take your morning dose of cyclosporine and report to the lab exactly 2 hours AFTER swallowing your dose OR you may be asked to have your blood checked BEFORE you take your morning dose. You will be told what to do before you go home.

**If you miss a dose**
Take it as soon as you remember if it’s within 6 hours of when you should have taken it. If you remember after 6 hours, skip the dose completely and continue with your regular schedule. **NEVER** double the dose. It is very important to remember to take this medication regularly.

**If you are sick**
If you vomit within 1/2 hour of taking cyclosporine, you should take it again. If you vomit more than 1/2 hour after taking cyclosporine, 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 cyclosporine blood level.

**How should cyclosporine be stored?**
Keep cyclosporine away from extremes of temperature (very hot or very cold). Keep it at room temperature, away from children.

If you use capsules, keep them in the foil wrapper until you are ready to swallow them. If they have been out of the foil wrapper and exposed to air for more than 2 hours they may have lost some of their potency and should be thrown away.

If you use the liquid, you should only open one bottle at a time and use it up within 2 months of opening it.
Where can you get cyclosporine? How much does it cost?
Cyclosporine is a very expensive drug; however, in Canada the provincial governments will pay for it. For this reason, cyclosporine can only be obtained from transplant hospitals (if you live in Ontario). Before you go home, be sure you know where you will be getting your cyclosporine. Be sure you always have enough cyclosporine on hand so you never run out.

Side effects
Cyclosporine can cause some stomach upset. It can also cause a tremor, particularly in the hands, which usually improves or goes away with time.

Some people, particularly women, may notice an increase in hair growth on the face, forearms, and upper body.

Good dental health is important as cyclosporine may cause the gums to become red and swollen, bleed or grow over the teeth. See your dentist regularly and be sure they know you are taking cyclosporine.

Cyclosporine may also cause headaches. If these are bothersome or occur more than usual, be sure to report them to your transplant team. Some people also notice a change in vision.

Cyclosporine can cause high blood pressure, or problems with high potassium levels in the blood. Your doctor may prescribe medications to lower your blood pressure or ask you to reduce the amount of potassium in your diet. Cyclosporine may also cause high cholesterol or gout, or it may slow kidney function in some people. It is important to take this medication exactly as directed, avoid medications that don’t mix well, and keep all your clinic appointments so your transplant team can monitor your kidney function.

Be aware of the signs of infection. While you are taking anti-rejection medications you will be more prone to infections. Avoid or limit exposure to other people who have infections. Cyclosporine may slightly increase your risk of certain types of cancers, such as skin cancer. Be sure to protect yourself from the sun.

Drug interactions
Many medications can interact with cyclosporine. It is important to check with your doctor or pharmacist before you take any new medications, even medications you can buy without a prescription, to ensure they will not affect the amount of cyclosporine in your blood. A list on page 15 outlines some common drug interactions with cyclosporine. It is also recommended that you avoid herbal medicines, as these may also affect cyclosporine blood levels.
### Drugs that increase cyclosporine blood levels
- ketoconazole  
- fluconazole  
- itraconazole  
- macrolide antibiotics (mainly erythromycin and clarithromycin)  
- corticosteroids  
- oral contraceptives  
- norethisterone or danazol  
- calcium channel blockers  
  - diltiazem  
  - verapamil  
  - nicardipine  
- metoclopramide  
- imipenem  
- methylprednisolone  
- allopurinol  
- amiodarone  
- cholic acid and derivatives  
- protease inhibitors

### Drugs that decrease cyclosporine blood levels
- phenytoin or phenobarbitone  
- rifampin i.v.  
- sulfadimine i.v.  
- trimethoprim i.v.  
- nafcillin  
- carbamazepine  
- octreotide  
- barbiturates  
- metamizole  
- probucol  
- orlistat  
- St. John’s wort  
- troglitazone  
- ticlopidine

### Drugs that cause harm to kidneys
- non-steroidal anti-inflammatory drugs:  
  - ASA  
  - ibuprofen  
  - Advil®  
  - Motrin®

### Drugs suspected to increase cyclosporine blood levels
- H2-antagonists  
- cephalosporins  
- thiazide diuretics  
- furosemide  
- androgenic steroids  
- acyclovir  
- warfarin

### Drugs suspected to decrease cyclosporine blood levels
- sulfinpyrazone  
- anticonvulsants
Brand Name: Prograf®

Common Name: Tacrolimus (also known as FK-506)

What is it?
Tacrolimus is a very potent immunosuppressive drug, which helps prevent you from rejecting your transplant organ(s). You will probably have to take it for the rest of your life. You may be taking other medications along with tacrolimus to prevent rejection, such as prednisone, mycophenolate, or sirolimus. Tacrolimus may also be used to treat rejection.

How should it be taken?
Tacrolimus is usually taken twice a day, every 12 hours. While in the hospital you will take it at 8AM and 8PM. When you go home, you can take it at whatever time is most convenient for you, as long as it is every 12 hours (eg. 9AM and 9PM or 7AM and 7PM, etc.) It may be taken with food or on an empty stomach, but you should try to be consistent (eg. always with food or always on an empty stomach).

DO NOT take tacrolimus with grapefruit or grapefruit juice as this may cause your blood levels of tacrolimus to increase. Orange juice has no effect on tacrolimus blood levels.

Dose changes
For the first few months after your transplant, your dose of tacrolimus will change often. Dose changes are based on the amount of tacrolimus in your blood. The dose will vary among different people and different types of transplants. Your doctor will tell you what dose you should take.

When you leave the hospital you will continue to have your tacrolimus blood level checked periodically. When you come to the clinic for blood tests, DO NOT take your tacrolimus 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 after he or she has seen the results of your blood tests.

If you miss a dose
Take it as soon as you remember, if this is within 6 hours of when you should have taken it. If you remember longer than 6 hours, skip the dose completely and continue with your regular schedule. NEVER double the dose. It is very important to remember to take this medication regularly so that it can work the best for you. Missing too many doses can lead to rejection.

If you are sick
If you vomit within 1/2 hour of taking tacrolimus, you should take it again. If you vomit more than 1/2 hour after taking your dose of tacrolimus, 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 tacrolimus blood level.

How should tacrolimus be stored?
Keep your medications away from extreme temperatures (very hot or very cold). Keep tacrolimus at room temperature, away from children.
What are the side effects?

Tacrolimus can cause nausea, stomach discomfort, diarrhea, tremors, headaches, difficulty sleeping, flushing, numbness or tingling (especially around the mouth) and increased sensitivity to touch. Some people may also develop high blood pressure, high potassium in the blood, or slowing of kidney function. Hair loss has been associated with tacrolimus and seems to be dose related. Some people may also develop diabetes and require medication or insulin to treat this. Many of these side effects can also occur when your blood levels are too high, which is why it is important for your transplant team to continue to monitor your blood levels of tacrolimus.

Other information

Tacrolimus 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.

Drug interactions

Many prescription and non-prescription medications can interact with tacrolimus and affect the way it works in your body. It is important to check with your doctor or pharmacist before you take any new medication to make sure it will not affect the amount of tacrolimus in your blood. A list of some common medications that don’t mix well with tacrolimus is included below. It is also recommended that you avoid herbal medicines, as these may also affect tacrolimus blood levels.

Drugs used to treat high cholesterol and triglycerides may become more potent when taken with tacrolimus. You should always check with your transplant team before taking these types of medications (eg. atorvastatin, simvastatin, pravastatin, lovastatin, rosuvastatin, fenofibrate, etc.). You should also check with your transplant team before having any vaccinations.

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<th>Drugs that decrease tacrolimus blood levels</th>
<th>Drugs that cause harm to kidneys</th>
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<tr>
<td>diltiazem</td>
<td>phenytoin</td>
<td>ibuprofen and other anti-inflammatory drugs</td>
</tr>
<tr>
<td>verapamil</td>
<td>phenobarbital</td>
<td>Aspirin®</td>
</tr>
<tr>
<td>fluconazole</td>
<td>carbamazepine</td>
<td></td>
</tr>
<tr>
<td>itraconazole</td>
<td>primidone</td>
<td></td>
</tr>
<tr>
<td>ketoconazole</td>
<td>rifampin</td>
<td></td>
</tr>
<tr>
<td>erythromycin</td>
<td>herbal preparations</td>
<td></td>
</tr>
<tr>
<td>clarithromycin</td>
<td>St. John's wort</td>
<td></td>
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<tr>
<td>cimetidine</td>
<td></td>
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<tr>
<td>estrogen</td>
<td></td>
<td></td>
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<tr>
<td>birth control pills</td>
<td></td>
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<tr>
<td>grapefruit or its juice</td>
<td></td>
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<tr>
<td>nicardipine</td>
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<tr>
<td>clotrimazole</td>
<td></td>
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<tr>
<td>metoclopramide</td>
<td></td>
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<td>cisapride</td>
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<tr>
<td>chloramphenicol</td>
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<tr>
<td>danazol</td>
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<td></td>
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<tr>
<td>bromocriptine</td>
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</tbody>
</table>
Brand Name: CellCept®
Common Name: Mycophenolate Mofetil (MMF)

What is it?
Mycophenolate mofetil, or MMF, 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 cyclosporine or tacrolimus (FK-506), along with mycophenolate.

How should it be taken?
Mycophenolate is taken twice daily, every 12 hours. It may be taken at the same time as all your other pills. Do not open or crush the capsules. Keep the capsules 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 medication 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 are quite common. If this happens to you, you should take 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. MMF 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 (eg. Mylanta, Maalox, Amphojel, Gaviscon) with this medication. Antacids can make mycophenolate less effective. Antacids that contain calcium (eg. 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 MMF.
**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 dose 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, increased 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 (eg: always 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 1/2 hour of taking sirolimus, you should take it again. If you vomit more than 1/2 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 (eg: 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, report 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.

<table>
<thead>
<tr>
<th>Medications that increase your sirolimus blood level</th>
<th>Medications that decrease your sirolimus blood level</th>
</tr>
</thead>
<tbody>
<tr>
<td>diltiazem</td>
<td>phenytoin</td>
</tr>
<tr>
<td>verapamil</td>
<td>phenobarbital</td>
</tr>
<tr>
<td>fluconazole</td>
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<td>erythromycin</td>
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<tr>
<td>clarithromycin</td>
<td></td>
</tr>
<tr>
<td>cimetidine</td>
<td></td>
</tr>
<tr>
<td>grapefruit, grapefruit juice</td>
<td></td>
</tr>
</tbody>
</table>

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 (eg: 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-rejection 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 functioning. 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.
After your transplant, you must take anti-rejection medication for as long as you have your kidney. These drugs are expensive, but are covered by Trillium and most private drug plans in Ontario.

To be on the transplant waiting list, you must have proof of adequate drug coverage. In Ontario, there is assistance for drug costs from the provincial government through 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:

**Prograf (tacrolimus, FK-506)**
0.5mg caps DIN# 02243144
1mg caps DIN# 02175991
5mg caps DIN# 02175983

**Mycophenolate (CellCept, MMF)**
250mg caps DIN# 02192748

**Rapamune (rapa, sirolimus)**
1mg tab DIN# 02247111

**Valcyte (valganciclovir)**
450mg tab DIN# 02245777

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 to either:

Mary Anne Henry, Kidney Recipient Coordinator or Jennifer Cross, Nurse Practitioner
London Health Sciences Centre, University Hospital
339 Windermere Road
London, ON N6A 5A5
Apply to the Trillium Program immediately if you do not have drug coverage. 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 given 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.

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

**Delayed kidney function**

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®, OKT3®, intravenous immunoglobulin or plasma exchange. 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. You 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 (temp>38’)
- sudden weight gain
- decreased urine output
- swelling in ankles, feet or hands, puffy eyelids
- general feeling of ill health

**Infection**

Anti-rejection medications interfere 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 (an important cause of kidney transplant failure and, at present, there are few treatment options available)

Fungal (candida)

Bacterial (signs of bacterial infection include fever, cough, sore throat, burning sensation when voiding, redness, swelling or drainage around an incision)

If 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 annual health check-ups with your family doctor. It is recommended that women have a pap smear and mammogram annually, and stool for occult blood 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 skin changes to your physician. Always wear sunscreen when you are out in the sun. 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 glucose 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, Neoral, tacrolimus) can increase the risk of developing diabetes. Early signs and symptoms include tiredness, unusual thirst, weight loss, excessive production of urine, blurred vision and confusion. Monitoring of blood sugar (glucose) after your transplant is done to detect high levels of sugar. If you were taking insulin, after the transplant you may require higher doses and more frequent injections. 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 take 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.
**Peritoneal dialysis catheter & Perm cath removal**

The peritoneal dialysis catheter or perm cath is usually removed 2-3 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. This timing 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.
**Dental care**

As part of your transplant assessment, it is necessary for you to have a dental check-up. Any necessary dental work should be completed before your transplant. After your transplant, it is recommended that you see your dentist every 6 to 9 months if possible. You may need antibiotics before undergoing any dental procedure, such as deep cleaning, extractions, or oral surgery. Check with your transplant team or pharmacist before taking any antibiotics as there are many drug interactions with anti-rejection medications.

**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.

**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 or illness. 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.
# Kidney Transplant – Clinical Pathway
## Patient and Family Guide to Daily Events

<table>
<thead>
<tr>
<th>DAY OF SURGERY</th>
<th>“Before”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• No further eating or drinking, once called for surgery.</td>
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<tr>
<td></td>
<td>• Come to the hospital as soon as arrangements can be made.</td>
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<tr>
<td></td>
<td>• If you are on CAPD, please bring supplies for 3 exchanges.</td>
</tr>
<tr>
<td></td>
<td>• 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.).</td>
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<tr>
<td></td>
<td>• Please be aware of all your medications and dosages, or have a list prepared to bring with you.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DAY OF SURGERY</th>
<th>“After”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• The surgeon will contact your family after the surgery. The waiting room is across from the main elevators on 2nd floor.</td>
</tr>
<tr>
<td></td>
<td>• You will go to the recovery room for approximately 1-2 hours.</td>
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<tr>
<td></td>
<td>• Family may visit once settled back in your room.</td>
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<td></td>
<td>• Your vital signs will be checked frequently.</td>
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<tr>
<td></td>
<td>• The nurse will give you medication regularly to relieve your pain.</td>
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<tr>
<td></td>
<td>• An intravenous line will be coming from the right or left side of your neck.</td>
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<tr>
<td></td>
<td>• A tube called a “catheter” will be in your bladder to drain urine.</td>
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<tr>
<td></td>
<td>• You may need to wear oxygen in your nose.</td>
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<tr>
<td></td>
<td>• There will be a gauze bandage over your incision.</td>
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</tbody>
</table>

### DAY 1
#### After Surgery
• Every morning at approximately 5:00am, blood will be taken.  
• Your bandage will be removed.  
• You will go by stretcher for a renal ultrasound 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
• You will be weighed every morning prior to breakfast (expect a large weight gain after surgery).  
• 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.

### DAYS 3 & 4
• These days focus on returning to your regular diet and increasing your activity.  
• The bladder tube will be removed 4-7 days after your surgery.

### DAYS 5 & 6
• These days focus on your discharge plans.  
• 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.

### DAYS 7-10
• Signs and symptoms of infection and rejection are reviewed.  
• 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.
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 immunosuppressants that will allow transplanted organs to work better and last longer with fewer or milder side effects for transplant patients.

- 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 brand new drugs or new ways of using approved drugs.
- You can only participate in a clinical trial by volunteering 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:

1. Respond truthfully to the study questions.
2. Make every effort to follow the instructions of the study.
3. 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.
Contact information

<table>
<thead>
<tr>
<th>Contact Information</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>London Health Sciences Centre</td>
<td>519-685-8500</td>
</tr>
<tr>
<td>Outpatient Pharmacy (UH)</td>
<td>519-663-3231</td>
</tr>
<tr>
<td>Nephrology Outpatient Clinic</td>
<td>519-685-8500 ext. 33346</td>
</tr>
<tr>
<td>Urology Outpatient Clinic</td>
<td>519-685-8500 ext. 33188</td>
</tr>
<tr>
<td>Multi-Organ Transplant Unit</td>
<td>519-685-8500 ext. 33015</td>
</tr>
<tr>
<td>Mary Anne Henry, Recipient Coordinator</td>
<td>519-663-3851</td>
</tr>
<tr>
<td>Diane Smith, Case Manager Living Donor Program</td>
<td>519-685-8500 ext. 32331</td>
</tr>
<tr>
<td>Jennifer Cross, Nurse Practitioner</td>
<td>519-685-8500 ext. 35932</td>
</tr>
<tr>
<td>Lee Anne Breaton, Social Worker</td>
<td>519-685-8500 ext. 32411</td>
</tr>
<tr>
<td>Renay Ross, Team Assistant</td>
<td>519-685-8500 ext. 35778</td>
</tr>
</tbody>
</table>

For more information, please visit these websites:

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

Multi-Organ Transplant Program, London Health Sciences Centre
www.lhsc.on.ca/transplant

Trillium Gift of Life Network
www.giftoflife.on.ca
Appendix 3

Letter to all patients

Dear Patient,

I am writing to welcome you to London Health Sciences Centre. Our goal is to do everything we can to make your stay comfortable, and to provide the care and treatment that is medically necessary.

Our focus is not only your care and treatment while in hospital, but also your discharge from the hospital. The hospital is not the best environment for patients who no longer need acute hospital care. We start planning for your discharge as soon as possible. This helps ensure that we meet your needs on the day of your discharge, and that the appropriate services are in place, if needed, when you leave hospital.

LHSC is an acute care hospital and provides care to those who are most critically ill. We are committed to working with patients and their families to improve health and provide compassionate, high quality care.

Most patients return home when they are discharged. However, if you need more care, your health care team will work together with you and our community partners to plan for an appropriate discharge. This will ensure that your health care needs can be met when you leave the hospital.

We want to ensure that we provide the right care in the right place and the right time.

If you have any questions about discharge planning, please talk to your health care team. They will have a fact sheet for you with more information.

J. Kenneth Deane

Chief Operating Officer
London Health Sciences Centre
Kidney Transplant Program

Multi-Organ Transplant Program

Patient Handbook