Multi-Organ Transplant Program

# Heart Transplant Program

London Health Sciences Centre

# Patient Handbook

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This handbook provides information about the Heart 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: Angela received her heart transplant in 2007,*
*and she enjoys many social and leisure activities with her husband and children.*

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# Contents

# Transplant Assessment

To determine if you are a candidate for heart transplantation, a comprehensive assessment of your current health is needed. The transplant team will decide if transplantation is the most beneficial option for you.

## The assessment

You have been referred to our program for a heart transplant assessment by your heart specialist. After our cardiologists review the information provided, an appointment will be made for your assessment visit. The process of assessing a person for heart transplant involves many tests, some of which you may have had in the past. Because of the number and nature of some of the tests, your assessment is done as an inpatient. You should expect to be in hospital for about five to seven days, depending on the results of the tests. Occasionally, it is necessary to keep a person in hospital longer, in order to get all of the information necessary for a complete assessment. Not everyone who is assessed will be listed for transplantation. Sometimes, a person is too well or there are other options for treatment before transplantation. Sometimes, a person is too sick to undergo surgery. For some people, there are other health problems that need to be addressed before the team can decide if transplantation is the correct choice of treatment.

## The transplant team

During your inpatient assessment, you may meet:

- cardiologists (doctors who specialize in heart disease)
- transplant surgeons (doctors who perform the transplant surgery)
- advanced practice nurse (a nurse specialist who follows your care in hospital and in the heart function clinic)
- recipient coordinator (a nurse who coordinates your care, provides education and information about transplantation, and is your contact person throughout the transplant process)
- social worker (the social worker provides you and your family with emotional and practical support throughout the transplant process)
- dietitian (the dietitian provides a comprehensive review of your nutritional state and can provide information to improve your diet, if needed)
- physiotherapist (the physiotherapist assesses your physical ability and prepares an individualized exercise program for you)
- nurses (nurses in Cardiac Care and in the Transplant Unit monitor and assess your daily health while you are in hospital)
- laboratory and technical staff (these staff will assist you with specific tests that you need during your assessment)

## Medical tests

Certain tests will be required to evaluate your health. The following tests are usually done during an assessment, but additional tests or consultations with other health care professionals may be necessary to obtain a complete picture of your health.

- blood work (assesses your general health and the function of your organs; screens for antibodies and viruses)
- chest x-ray (assesses the general condition of your chest, including your heart and lungs)
- electrocardiogram (ECG) (measures the rate and rhythm of your heart)
- echocardiogram (an ultrasound that shows your heart's structure and provides information about how well the valves function and how efficiently your heart pumps blood)
- treadmill test or stress test (evaluates your heart function while you are exercising)
- wall motion scan (enables the team to see the walls of your heart in motion and to see how efficiently your heart is pumping)
- right heart catheterization (allows the cardiologist to measure pressures within your heart)
- Holter monitor (provides a continuous recording of your heart rhythm for a 24-hour period)
- abdominal ultrasound (examines the structure of your liver and kidneys as well as blood vessels)
- carotid ultrasound (provides an image of the major arteries in the neck)
- pulmonary function tests (breathing tests to determine your lung function)
- chest CT (provides an image of your chest if you have had previous chest surgery)
- physiotherapy assessment and 6-minute walk test (determines your baseline function and helps in developing a home exercise program for you)

Depending on which tests you need, you will be given more detailed information at that time. The heart transplant process is very stressful so we recommend that you have someone with you for support. They'll be able to provide the company and comfort during this important time in your life. It's also very important that you and your family understand the risks and benefits of transplant surgery, and these will be explained to you during the assessment by members of the transplant team. The team is available to answer any questions that you have.

## Results of assessment

Once all the tests have been completed, the transplant team meets to discuss the results and determine if the patient is a candidate for transplantation. Not all people who are assessed for transplant are accepted on the waiting list. You will be informed of the results of the assessment in person (if you are still in hospital) or by phone (the transplant coordinator will call you at home).

There are three possible decisions:

1) You are a good candidate for transplant.
2) It is not time for transplant yet.
3) You are not a candidate for transplant.

Each of these will be discussed with you during your assessment. If a transplant is recommended and you are emotionally ready for heart transplantation, then you will be asked if you wish to be placed on the transplant waiting list.

## Questions

You can jot down any questions or concerns that you have so you can discuss with the transplant team.

# Waiting Period

Once you are accepted for transplantation, your name is placed on the heart transplant waiting list, and an active search begins for your new heart. You will be assigned a “status number”, which describes your medical condition. Your position on the waiting list changes with your medical condition; therefore, **you must inform the recipient coordinator if you are admitted to any hospital**.

## Waiting for the transplant

The waiting period ends when a suitable donor is found for you. The donor will have the same blood type as you and be a similar size (i.e. weight). Other factors, such as your current health and waiting time, are also considered.

**Waiting for your transplant is one of the most difficult stages of the transplant process**. The waiting time varies, and you may have to wait anywhere from a few weeks to more than a year for your transplant because donated hearts are in limited supply.

The transplant team realizes that patients cope better during the waiting period in their own home. Every effort is made to make this possible for you. Whether or not you can wait at home depends on your current health and where you live. You must wait in the London area if you are medically unstable and require frequent monitoring at University Hospital. You may wait at home if:

- you are medically stable and
- your residence is within three hours driving distance from LHSC or
- your residence is more than three hours driving distance, but there is an airport with an air ambulance to transfer you to LHSC within four hours.

**Remember, if you are admitted to any hospital at any time, have a family member or friend page the recipient coordinator**.

While on the waiting list, you will receive medical and nursing care through the Transplant Outpatient Clinic. The frequency of your visits to the clinic depends on your health and where you live. If you live in the London area or within driving distance, you will come to the clinic at least once a month. If you live further away, your local doctor will take care of you. If there are any changes to your health status, such as increased fatigue, shortness of breath or weight gain, please contact the clinic or recipient coordinator so that you can be assessed at the Heart Function Clinic.

## Compliance

The transplant team expects that **all patients** on the waiting list will comply with medical advice, which includes clinic appointments, sodium and fluid restrictions, treatment requirements, and refraining from smoking and consuming alcohol.

No matter where you are waiting, we recommend that you participate in an exercise program. Exercise, along with your diet and medications, will help keep you in the best possible health before transplant. The healthier you are before transplant, the faster you will recover after transplant. During your assessment, the transplant physiotherapist would have designed a home program for you, and you should continue to follow it.

## Your responsibilities while you wait

- do not drink alcohol
- do not smoke
- take your medications as prescribed by your doctor
- do not use herbal preparations or illegal drugs, including marijuana
- exercise regularly
- follow your recommended diet
- inform your recipient coordinator of any changes in your health
- inform your recipient coordinator if your phone number or address changes
- keep all clinic appointments
- have your blood work taken monthly or as requested
- see your family doctor regularly
- apply for provincial drug coverage (Trillium Drug Program, see Appendix 1)
- plan for financial expenses (such as travel, accommodation and food)

## Costs and accommodations

Some recipients are fortunate and live close to the transplant centre, but most patients must travel for their transplant. Travel can be expensive, especially if separate visits are required for assessment, transplant, and outpatient clinic appointments. As well as maintaining your permanent residence at home, you will need funds to afford temporary accommodation near the transplant centre. Additional costs include food, personal expenses such as medications, and travelling to medical appointments. Patients travelling to London from Northern Ontario for medical treatment are eligible for the Northern Travel Grant Allowance. More information is available by calling 1-800-461-4006 or 1-705-675-4010.

During the waiting period, we encourage you to think about who will accompany you to the hospital at the time of transplant, where they will stay, and the cost to you once you are discharged from the hospital. Family members and friends who stay in London should budget a minimum of $2,500 a month. This budget covers only the basic cost for food, accommodation, and local travel expenses. You also need to budget for transportation back home.

Once you're discharged from hospital, you will be required to stay in London for some follow-up care before returning home. During this time, you will also be responsible for your own costs, which you should include in your budget. A variety of accommodation is available in London, ranging from hotels and motels to furnished apartments and bed-and-breakfast lodging. An extensive list of possible places to stay can be found at www.londontourism.ca or visit our transplant website, www.lhsc.on.ca/Patients_Families_Visitors/MOTP/Accommodations/index.htm.

## Parking at University Hospital

Visitor parking is available on site. The parking garage is located at the North end of the hospital, and is operated by Standard Parking of Canada Ltd. This is an automated system, which charges by the hour. Passes are available, however, by the day, week, or month. Depending on the number of appointments and the length of your stay, you may want to purchase a pass. The parking office, located on the ground floor of the parking garage, is open 24 hours a day, seven days a week.

## Benefits eligibility

Financial needs can place an enormous strain on your family budget. It's very important that you and your family prepare for the expenses that are an inevitable part of the transplant process. There are some resources that can help lessen the financial burden. Depending on your financial circumstances and geographic location, you may be eligible for assistance with travel, income, and the cost of medications. Assistance programs exist at the municipal, provincial, and federal levels of government. Benefits provide long-term financial assistance to people who are unable to be fully employed for an extended time because of illness.

**All transplant candidates are strongly encouraged to register with their provincial drug program even if they have private drug plans (Appendix I)**. You may need to know the DIN number of prescribed drugs to determine possible coverage ahead of time. Also, there are some local and regional organizations across Canada that provide financial assistance to patients and families who must travel to other cities or provinces for medical treatment. For more information about benefits and financial assistance, please contact your social worker, Kelly Thomas (519-685-8500 ext. 32484).

The Ontario Ministry of Health has the TPER (Transplant Patient Expense Reimbursement) Program, which is available to assist heart, heart-lung and lung patients who need to relocate to a different city while waiting for or recovering from their transplant. The aim is to assist patients with some of the financial burden of relocating. For more information about this program, you can contact TPER by phone (1-888-977-3563; 1-416-619-2342), by e-mail (TPER@giftoflife.on.ca) or by Trillium Gift of Life Network's website (www.giftoflife.on.ca/).

## Self-care while waiting – nutrition

Maintaining good nutrition can be a concern for individuals who have symptoms of heart failure. At the time of transplant, almost all heart patients will have experienced some degree of malnutrition.

An emphasis on optimizing nutrition with each meal and snack will help to keep you as well nourished as possible. Good nutrition combined with an exercise program will help you maintain an improved quality of life during the waiting period. Patients who are able to maintain better nutrition generally have fewer complications with a shorter recovery time.

You may be experiencing symptoms associated with your heart disease. A diet that is specific to you may include restricting sodium (salt), fluid, fat and cholesterol. You may also require modifications to adjust your intake of calories and protein to prevent undesirable weight changes or muscle loss. Nutritional strategies can help address various symptoms that you may be experiencing, such as poor appetite, nausea and taste alterations. The cardiac care dietitian, Jennifer-Anne Meneray, is available to provide education and assistance to optimize your nutritional health, suggest strategies for managing your symptoms, and help you comply with your diet.

## Self-care while waiting – exercise

Physical fitness is very important as you wait for your heart transplant. It is difficult to remain active when you're feeling poorly, but this remains a priority. Patients who are in better condition generally have shorter recovery times and fewer complications following surgery. "Working out" at a gym may be beyond you now. Light exercises, using cans of soup or small weights, are a good way to get some exercise done at home. Even more important is your cardiovascular fitness. While on the waiting list, walking is the best exercise to maintain your cardiovascular fitness. You can start by going for a five to ten minute walk outside or in a nearby mall. Aim to increase the time you spend walking by one minute every day you walk. Try to walk at a pace that gets you slightly short of breath, but still able to talk.

This level of activity is safe for people with health problems, including heart and liver disease. Don't walk immediately following a big meal, or on days that are extremely cold, hot or humid. Stop exercising if you feel dizzy, nauseated, unusually short of breath, or generally unwell.

Maintaining your physical health is important before transplantation. You'll benefit physically and mentally by keeping your body in good shape. Try your best to fit exercise into your daily routine by getting your family and friends to join you. Perseverance now will pay off later. Physiotherapist Nancy Howes (519-685-8500 ext. 35365) can also provide more specific information about exercises that can help you maintain your health while waiting for transplant.

## Patient Education Centre

Located in the Transplant Unit, many patients and family members find the resources in the Education Centre to be helpful. There are books related to nutrition, exercise, healthy lifestyles, and the transplant process, including some personal narratives. Other resources include videos, pamphlets, and newsletters as well as a computer centre so you can search the Internet for the latest information.

## Contacting the transplant team

Despite the uncertainty of the waiting period, we encourage you to lead as normal a life as possible. The recipient coordinator will contact you intermittently to see how you are doing and to answer your questions. **You may, however, contact any member of the transplant team at any time (Appendix II)**. Continue to see your local doctor or specialist who can also communicate with our transplant team in order to provide you with the best care. **Please remember that you or a family member must inform a recipient coordinator of any admission or discharge from hospital**.

The waiting period during the transplant process can be a difficult time. Clear, direct, and honest communication among all family members will help reduce frustration and tension. If you or your family experience significant difficulty with coping during the waiting period, please get help from a local, qualified health professional or contact the transplant team's social worker.

# Surgery and Recovery

Just as waiting for transplant can be difficult, the surgery and recovery period of the transplant process can be a stressful time as well. Here we review some of the important points of which you and your family should be aware.

## The call

When a heart becomes available for transplant, the selected recipient is the next patient who has the same blood type and is a similar size as the donor. Once selected, the recipient coordinator will contact the patient by telephone or pager.

As soon as you are informed about the transplant surgery, **do not eat or drink anything. You should be prepared to leave home within 60 minutes if you are driving to the hospital**. If you must fly to London, arrangements will be made by the recipient coordinator. You are responsible for getting yourself to the local airport, and paying for the taxi trip from the London airport to University Hospital, London Health Sciences Centre (Appendix III).

## What to bring

Here are some suggested items that you should pack for your stay in London:

- medications
- provincial health card
- private insurance card or information
- toiletries (toothbrush & paste, brush, scent-free deodorant)
- soap, shampoo, razors & shaving cream (all scent free)
- pyjamas, housecoat and slippers (non-skid)
- underwear and socks
- loose-fitting pants (such as sweatpants)
- tops that are easy to get on and off
- books, magazines or hobbies to pass the time

## Surgery

After arriving at the hospital, report to Patient Registration on the main floor. When your paperwork is completed, you will go to a hospital room to be prepared for the surgery. You will meet the nurses as well as the transplant surgeons, and have some tests such as blood work, chest x-ray, electrocardiogram, and urine tests. The transplant surgeon will discuss possible risks of your transplant.

Remember, most transplants are successful; however, complications may occur. These complications can include:

- dying during the operation
- poor function of the transplanted heart after transplant
- bleeding
- infections (wound or other)
- long ICU stay
- the need for support such as medications or dialysis

While you are being prepared for surgery, the transplant team is retrieving the donated heart. **It is possible the heart will not be suitable for transplant; in this case, the surgery is cancelled. If this happens you will return home. The cost of your trip home is your responsibility**.

Once confirmed that the heart is suitable for transplant, you will be brought to the operating room. The transplant surgery usually lasts six to eight hours, and you will likely require a blood transfusion. During surgery, your family and friends can wait in the ICU waiting room on the second floor. The surgeon will speak to them once surgery is completed.

## Recovery

Recovery from a heart transplant operation is different for each patient. Your recovery depends on your health before the transplant and whether or not you had any complications. Be prepared to stay in the London area for **at least three months** after the operation for your inpatient and outpatient care. The inpatient stay is usually for three to four weeks, but it may be as short as two weeks. As an inpatient, you will be cared for in two different units: the Intensive Care Unit (ICU) and the Multi-Organ Transplant Unit (MOTU). Your outpatient care includes daily physiotherapy, regular blood tests, heart biopsies, and weekly clinic visits. These will be arranged through the Transplant Outpatient Clinic on 4th floor.

## Intensive Care Unit

After the operation, you are taken to the Intensive Care Unit where you will remain for several days (or longer, if needed). You will be connected to various monitors and will have tubes in your chest and bladder as well as intravenous lines in your neck and arm. While in the ICU, you will also be connected to a breathing machine called a ventilator. This machine is connected to your lungs by a tube (endotracheal tube) through the mouth into the windpipe. You are well sedated to lessen discomfort from the tube. When your lungs work satisfactorily, you will be weaned from the ventilator and the tube is removed. As the endotracheal tube presses on your voice box, you will not be able to speak. Your nurse is available to help you communicate and you are able to write down messages if needed.

The ICU is a very busy place. The noise from various machines and monitors may interfere with rest and sleep. Unfortunately, this situation cannot be avoided, but every effort is made to move you from the ICU as soon as you no longer require the intensive care and monitoring.

## Multi-Organ Transplant Unit

When you have stabilized, you are moved to the Transplant Unit. You still have intravenous lines in your neck and your arm and you are attached to a heart monitor. You still need some extra oxygen but, as your lung function improves, this will be discontinued.

You will be able to get out of bed, sit in a chair, and have short walks with help from a nurse or physiotherapist. The physiotherapist checks your lungs to see how well they're working and assesses your strength after transplant. You are allowed to eat a normal diet as soon as you can tolerate it. As you become stronger, you will become more involved in your own care and begin the process of learning what you need to know after transplant, such as:

- increasing your strength, mobility, and coordination through physiotherapy
- learning about infection and rejection
- taking medications
- checking your weight, temperature, and pulse
- keeping records of this information.

## Physiotherapy

After your transplant, the physiotherapist will see you each day. She will listen to your lungs and instruct you on deep breathing and supported coughing exercises. The physiotherapist will also develop an appropriate exercise program that progresses throughout your hospital stay. In the Intensive Care Unit, treatment progresses from simple circulation exercises to sitting on the edge of the bed or in a chair.

In the Multi-Organ Transplant Unit, a daily exercise program with specific exercises and short walks will be started. As your recovery continues, you will exercise daily in the Physiotherapy Gym with other transplant patients. The program may include: stretching, posture, and strengthening exercises; walking; cycling; and stair climbing. You will be given a referral to a local Cardiac Rehabilitation Program or a home exercise program to continue once you leave the London area.

## Denervation of the heart

The heart has many nerve connections to the central nervous system. These nerves control your heart rate. During the transplant operation, these nerves are cut and usually do not grow back. Recently, some studies have shown that nerves to the heart can grow again over time. Because your new heart is denervated, you will experience:

- a faster heart rate (your heart rate will likely be around 90-110 beats/minute instead of the normal 70-80 beats/minute) and
- a slower increase and decrease in heart rate when exercising.

Neither of these changes is harmful, but it is important to warm up before exercise and to cool down after exercise.

## Infection

Your immune system will be suppressed from the anti-rejection drugs that you must take. Although your body is still able to fight infections, you will be more prone to infection especially during the first few weeks after transplant. A fever can be the first sign of infection. Although it’s helpful to take your temperature when you don’t feel well, it’s not necessary to take it on a routine basis. Signs of infection include fever (38°C/100°F or higher), cough or sore throat, burning sensation when you urinate, or redness, pain, swelling or drainage around the incision. If infection is suspected, you should call your doctor.

## Rejection

Your immune system protects you from infection (bacteria and viruses) by recognizing and attacking foreign substances. The transplanted heart is seen as a foreign tissue so your body tries to reject the new heart. Many patients experience rejection episodes in the first few weeks. Rejection is usually easily controlled by adjusting your anti-rejection medications. Rejection is less likely to occur as time passes, but the risk is always present.

## Anti-rejection medications

After transplant, **you must take anti-rejection medications for the rest of your life**. These drugs keep your body from rejecting the new heart. There are several anti-rejection drugs, including tacrolimus (Prograf®), cyclosporine (Neoral®), sirolimus (Rapamune®), mycophenolate (CellCept® or Myfortic®) and prednisone. The pharmacist and your nurse will teach you about your medications as soon as you are well enough. You will learn:

- the purpose of each medication
- their side effects
- directions to take medications safely and properly after discharge.

A supply of your medications will be left at your bedside. You will take your medications as prescribed and record this information. Your nurse will supervise you until you are thoroughly knowledgeable about your medications. You can find more information about anti-rejection drugs at our website: www.lhsc.on.ca/Patients_Families_Visitors/MOTP/Pharmacy/index.htm.

The use of alternative therapies, such as herbal remedies, is not recommended. Interactions between these drugs and your prescribed anti-rejection medication can affect your blood levels. You want to maintain your blood levels as consistently as possible, without becoming too high (with side effects) or too low (with possible rejection). Discuss any use of alternative therapies with a member of the transplant team.

## Discharge

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 to ensure 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 usually 11:00 in the morning.

Your hospital stay may be as short as two weeks. You may be discharged directly from the Transplant Unit or from the general ward. You will need to stay in London for approximately three months for the surgery and recovery before returning home. During this period, you will attend physiotherapy, teaching sessions, and the Transplant Outpatient Clinic. Before discharge, you will be given a calendar with your scheduled appointments, along with an information booklet that contains specific follow-up care for you.

# Resuming Your Lifestyle

The goal of transplantation is to have recipients return to their normal lives and daily activities. A transplant recipient can generally do anything that he or she previously did with few restrictions. We encourage recipients to pursue good health habits. The transplant team will provide guidelines and education to assist you in resuming your lifestyle. You must always be aware of monitoring your health after transplant, but you must not let this monitoring take over your life. The following sections provide information on some of these guidelines.

## Work and activity

You can expect an improved or normal activity level within six to twelve months after surgery. Your tolerance for activity will depend on how ill you were before surgery. As your energy level rises, you will be able to return to your former activities. You should be able to return to work after the first year. As a general policy, patients are considered to be fully recovered by six to twelve months following heart transplantation, and do not qualify for long-term disability or illness pensions, unless there are special situations.

## Driving a car

Most people can resume driving two to three months after transplant once their cardiologist or surgeon approves this and gives permission. Remember, you are still required to wear a seatbelt. If the belt bothers your incision, place a towel or blanket between you and the seatbelt.

## Smoking

Do not smoke. Second-hand smoke is just as harmful. Smoking damages the delicate lung tissue and can lead to mucus buildup, coughing, and breathing problems. Because you are taking immunosuppressive drugs you are already at risk of developing lung infection and coronary artery disease (CAD). Smoking adds to this risk. Smoke also constricts the blood vessels and robs the heart of oxygen and may lead to CAD.

## Nutrition

After transplant, your diet must be low in animal fat, cholesterol, and salt. The dietitian will provide a diet plan for you based on your weight, food preferences, and lifestyle. It is very important to follow these guidelines:

- Achieve and maintain ideal weight:

  Ideal weight is important so that you have enough fat and protein reserves during periods of infection, rejection, or other complications. Once your ideal weight is reached, it is very important to stay within this range as excess weight strains your new heart. Excess weight also increases blood sugar, cholesterol, triglycerides (fat), and blood pressure. It is very easy to gain weight after transplant. To avoid weight gain, eat low-calorie snacks and exercise regularly.

- Lower the animal fat and cholesterol in your diet:

  A diet that is high in cholesterol and animal fat increases the risk of coronary artery disease. Your diet must be low in cholesterol and animal fat to protect the coronary arteries in the transplanted heart.

- Restrict sodium intake:

  To avoid fluid retention, a no-added salt diet is recommended. You can add salt during cooking but not at the table. You should avoid food and liquids with high salt content.

- Limit alcohol:

  You may drink alcohol in moderate amounts. Moderate use is 4 ounces of wine, 8 ounces of beer, or 1.5 ounces of liquor each day. Do not take alcohol with medications especially cyclosporine. You may drink alcohol one hour before or after taking your cyclosporine.

## Dental care

You should see your dentist every six to nine months. Dental procedures can be performed as necessary after consultation with a physician. You must take antibiotics before undergoing some dental procedures such as probing, deep cleaning, extractions, or oral surgery. You will receive information to give your dentist regarding the antibiotics you should take.

## Sexual activity

There are no restrictions on sexual activity after heart transplantation. You may resume activity whenever you and your partner feel comfortable. Previously non-menstruating women may resume menstruation and become pregnant. It is important to use birth control. The use of birth control pills is reasonable, but you must inform the transplant team if you intend to use oral contraceptives. These are not recommended for the first six months after heart transplantation as your body is adjusting to new medications and healing. We recommend using a double barrier method for birth control: either condoms and contraceptive foam or diaphragm and contraceptive foam. Any member of the transplant team is available to discuss family planning and birth control with you. Although many women have given birth to healthy babies after a heart transplant, **it is recommended that women do not become pregnant for the first year following transplant. If you are considering having children, discuss this with the transplant team before becoming pregnant**.

## Travelling

You are able to travel as often as you wish after the transplant, although it's recommended that you do not leave the country for the first nine months to a year. Always discuss your travel plans with your physician. Your doctor may be able to give you the names of physicians in the area or region to which you are travelling. Some countries require that you are vaccinated. Please discuss this issue with the transplant team prior to receiving any vaccines. Do not take vaccines made from live viruses. It is important that you obtain medical insurance, bring your own supply of medications, and store the medications in your carry-on luggage. Always take extra medications with you in case of emergency or delay. You should be prepared to return home if you become ill during your vacation.

## Immunization

The flu vaccine is allowed. Anti-rejection drugs suppress your immune system; therefore vaccines prepared with "live" vaccines should not be taken. If in doubt, ask your transplant physician or recipient coordinator.

## MedicAlert

In an emergency, a MedicAlert bracelet or necklet shows others that you are a heart transplant patient. We recommend that you buy a MedicAlert bracelet or necklet as soon as possible. Application forms are available at London Health Sciences Centre and at most drug stores. You can also find more information at the MedicAlert web site (www.medicalert.ca). Your bracelet or necklet should be engraved: Heart Transplant / Immunosuppressed.

## Medication guidelines

It is important to understand your medications: their name, dosage, purpose, and side effects. Follow these guidelines:

- Know both generic and brand name(s) of each medication.
- Take all your medications as directed.
- If you miss a dose, take it as soon as possible. If it is almost time for your next dose, do not take the missed dose or a double dose.
- Do not take other medications unless prescribed by or discussed with your doctor, especially over-the-counter drugs and herbal medications.
- Store all your medications away from heat and direct light. Do not keep medicine in the bathroom cabinet as heat and moisture may cause changes in the drug.
- Keep your medications in their original containers. The labels on these containers specify the drug prescribed and expiry dates, the prescribing doctor, and directions for taking the drug.
- Notify your physician immediately of severe or continuing nausea, vomiting, diarrhea, or any possible side effects or new symptoms.
- Do not run out of medications.

## Rejection

Despite taking anti-rejection drugs, rejection remains a problem after transplant. Rejection can occur at any time, but the risk is greatest during the first three months after your transplant. Most episodes are mild and you may not have any symptoms. These warning signs of rejection should be reported:

- fever (above 38°C)
- irregular or fast heart rate
- progressive weight gain of about one kilogram a day with ankle swelling
- shortness of breath on mild exertion, such as climbing one flight of stairs
- loss of energy and appetite

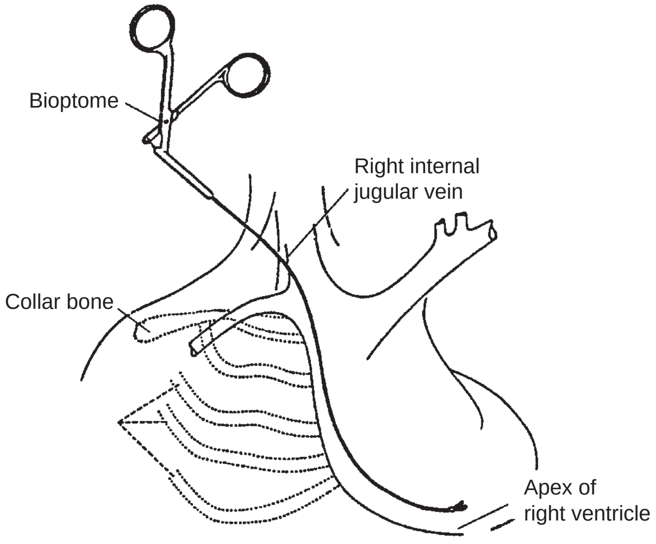
**Remember:**
**Successful treatment of rejection and infection depends on early diagnosis and treatment.**

If rejection is suspected, a heart biopsy is performed. Biopsy is the only reliable way to diagnose rejection. You will have a weekly biopsy for the first month and then every other week for the next two months. In time, the risk of rejection decreases and biopsies are done less frequently. Rejection episodes are usually treated successfully with an increased dose of prednisone, a type of anti-rejection drug.

In some patients, the coronary arteries may narrow, reducing the blood supply to the heart muscle. Angina is a warning sign that the blood flow to the heart is not enough. You may not feel this symptom because the nerves to your heart were cut. For this reason, you will have a coronary angiogram at least every two years to check the condition of the arteries in your new heart.

## Heart biopsy

Biopsy is a safe procedure with minimal discomfort or risk. It takes 10-15 minutes during an outpatient visit. After adequate freezing, a needle is inserted into a vein in the right side of the neck (right internal jugular vein). A wire is placed through the needle and a plastic catheter is passed over the wire into the vein. The wire is then removed and the bioptome is inserted into the plastic catheter. Using x-ray guidance, the bioptome is advanced to the apex of the right ventricle. To obtain the biopsy (a tissue specimen of the heart), the open jaws of the bioptome are pressed against the inner muscle of the heart (endocardium) and then closed using the forcep handles. Four or five very small specimens are taken. You will feel a slight tugging sensation, but it is not painful. At the end of the procedure, the biopsy instrument is removed and pressure is applied over the puncture site to minimize bleeding. Complications are very rare, but it is important to report any chest pain, shortness of breath, or palpitations to your nurse or doctor.



## Infection

You are susceptible to infection because your anti-rejection drugs suppress your immune system. You do not have to follow elaborate precautions to protect yourself, but it is important to recognize symptoms of infection and report these promptly. Successfully treating infection depends on early diagnosis. This section describes common sites of infection, its symptoms, and ways to reduce infection.

### Lungs

Symptoms of lung infection should be reported promptly:
persistent cough; fever (above 38°C); green, yellow or brownish sputum; shortness of breath; increased pulse rate

## Urinary tract and genitals

Common symptoms of infection include:
burning or stinging sensation when urinating; frequent urination; cloudy or foul smelling urine; sores in the genital area.

## Gastrointestinal tract

Common symptoms of infection include diarrhea, nausea, vomiting.

## Mouth

To reduce the risk of infection, practice meticulous mouth care and visit your dentist at least once a year. You should receive an antibiotic before and after any dental work. Sores around the lips and inside the mouth are common after transplant. They are caused by the herpes virus and are commonly called “cold sores”. If you have them, tell your doctor so that an anti-viral medication may be prescribed. Do not expose cold sores to direct sun.

## Help reduce the risk of infection

- Have enough rest – do not get run down.
- Eat a nutritious and balanced diet.
- Do not smoke and avoid second-hand smoke.
- You, and others who have contact with you, should wash hands frequently.
- Avoid potential sources of infection, such as individuals with colds and contagious diseases, including sexually transmitted diseases.
- Avoid crowded, poorly ventilated, smoke-filled places.
- Avoid public whirlpools.
- Avoid activities that may cause a break in the skin.

## Monitor for infection

Check your temperature once daily, in the morning before breakfast. If your temperature is 38°C, check it again after four hours. If it is above 38°C, inform your doctor. Temperature above 38°C is a fever. Be alert to symptoms of infection and promptly report them to your doctor, the Transplant Clinic, or your recipient coordinator.

## Cancer prevention

You are at a slightly higher risk of developing cancer as a result of taking anti-rejection medications. Skin cancers are commonly found on the back, calves, arms, ears and the back of the neck. Inspect these areas frequently and report any new moles or skin changes to your physician. Avoid sun tanning, and always wear sunscreen (with a minimum SPF 30) when you are in the sun. Don’t forget to apply lotion to your ears, face, and nose. Re-apply the sunscreen frequently especially if sweating or after drying off from a swim. It’s important that you have yearly check-ups and cancer screening through your family physician.

## Writing to your donor family

Expressing gratitude to the donor family is commendable. The Transplant Program always sends a “thank you” to the donor’s family. If you wish, you can send your thanks **anonymously** through your social worker or recipient coordinator. The decision to contact your donor family is a personal choice. It may help knowing that donor families are comforted by the correspondence they receive from the recipients of their loved one’s organs. There is no time limit for corresponding – you may write at any time. However, you may want to wait three months before writing as this will give the donor family some time to initially grieve the death of their loved one and allow you, the patient, to finish your initial three-month recovery phase.

If it is more comfortable, you may choose to send a card during the holidays, or a ‘thinking of you’ card instead of a letter. Simply give your card or letter to the social worker or recipient coordinator and it will be sent to the donor’s family. In either case, remember that you cannot include your name, address or any identifying information, including the name of the transplant centre. For specific suggestions and guidelines, read the brochure “Writing to your Donor Family”, which is available at www.lhsc.on.ca/Patients_Families_Visitors/MOTP/Social_Work/index.htm.

## Community follow-up

After the initial recovery period in London is over, you can return to your home community. If you have any questions, please contact any of the members of the transplant team. Information on your surgery and recovery will be sent to your family doctor and your heart specialist. We would like you to arrange to see both of these doctors within the first two weeks after your return home. You will also be given a schedule for blood work and a return appointment for your six-month follow-up in London. After your six-month appointment, you will need to return once a year, for two or three days, for your annual follow-up. You will also need blood work done every three months to monitor your general condition.

# Appendix I

## Ontario's Trillium Drug Program

Dear Ontario Resident,

Our Transplant Program often uses tacrolimus (Prograf®) and mycophenolate (CellCept®, Myfortic®) to prevent rejection. These medications are extremely costly, and are not covered by the Ontario health plan (OHIP). You are responsible for the payment of these expensive medications.

You may have a private or work-related drug insurance plan. Some drug plans may not pay for new, expensive medications. Some plans may require that you pay a portion of the cost of the drug every year. If you have a plan, you should check if there is an annual or lifetime maximum amount that you can claim. You should also ask your company whether your drug plan covers tacrolimus and mycophenolate mofetil. You may also want to check for sirolimus and valganciclovir. The DIN number has been included for your reference.

Prograf® (tacrolimus) 0.5mg (#02243144); 1mg (#02175991); 5mg (#02175983)

CellCept® (mycophenolate mofetil, MMF)
- Brand product 250mg (#02192748); 500mg (#02237484)
- Generic product (Teva) 250mg (#02364883); 500mg (#02348675)

Myfortic® (mycophenolate sodium) 180mg (#02264560); 360mg (02264579)

Rapamune® (sirolimus) 1mg/ml liquid (#02243237); 1mg tablet (#02247111)

Valcyte® (valganciclovir) 450mg tablet (#02245777)

For Ontario residents, assistance is available from the provincial government through the Trillium Drug Program. This program helps Ontario residents who must spend a large part of their income on medications by paying a portion of the drug costs. All Ontario residents are eligible for this program. There is a deductible that you are required to pay. The deductible, however, varies from patient to patient based on household income and the number of family members with whom you live.

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. The form is easy to complete and there is no fee to apply. **Please complete the form and mail it as soon as possible**. This application form must be renewed **EVERY YEAR**.

London Health Sciences Centre and its Heart Transplant Program are not responsible for providing medication funds; therefore, we ask you to apply to the Trillium program immediately, even if you do not have enough receipts to reach your deductible yet. This has benefits for you. Because you are at home, you will have access to all your income and prescription information. You and your family may also be able to take advantage of the Trillium program for pre-transplant drug costs.

If you need help to complete the form, there is a telephone help line. If you are still having difficulty completing the form, please contact the social worker at your local hospital. If you are unable to get help, contact the social worker at the transplant centre. You are responsible for your drug costs after transplant. The province has created the Trillium Drug Program to help you, but it is your responsibility to apply for this help.

# Appendix II

## Contact Information

| | |
|---|---|
| Transplant Program's general number | (519) 685-8500 x 33354 |
| Transplant Inpatient Unit | (519) 685-8500 x 37015 |
| Transplant Outpatient Clinic | (519) 685-8500 x 33818 |
| Transplant Physiotherapy Gym | (519) 685-8500 x 35365 |
| Prescription Centre | (519) 663-3231 |
| Pastoral Care | (519) 685-8500 x 35310 |

| | |
|---|---|
| Dr. Chu | (519) 685-8500 x 33593 |
| Dr. Davey | (519) 685-8500 x 33428 |
| Dr. De | (519) 685-8500 x 33428 |
| Dr. Goldraich | (519) 685-8500 x 33428 |
| Dr. Nagpal | (519) 685-8500 x 38822 |
| Dr. Quantz | (519) 685-8500 x 33144 |
| Dr. Smith | (519) 685-8500 x 33428 |
| Recipient Coordinator-Grant Fisher | (519) 685-8500 x 33760 (or page 13760) |
| Social Worker-Heather Sadler | (519) 685-8500 x 35331 |
| Physiotherapist-Kristin Morris | (519) 685-8500 x 35365 |
| Physiotherapy Assistant-Tracy Fuller | (519) 685-8500 x 35365 |
| Dietitian Jennifer-Anne Meneray | (519) 685-8500 x 35880 |

**For more information, please visit these websites:**

**EatRight Ontario**

www.eatrightontario.ca/Doorway.aspx

**Heart & Stroke Foundation of Canada**

www.heartandstroke.ca

**Multi-Organ Transplant Program, London Health Sciences Centre**

www.lhsc.on.ca/About_Us/MOTP/

**Trillium Gift of Life Network**

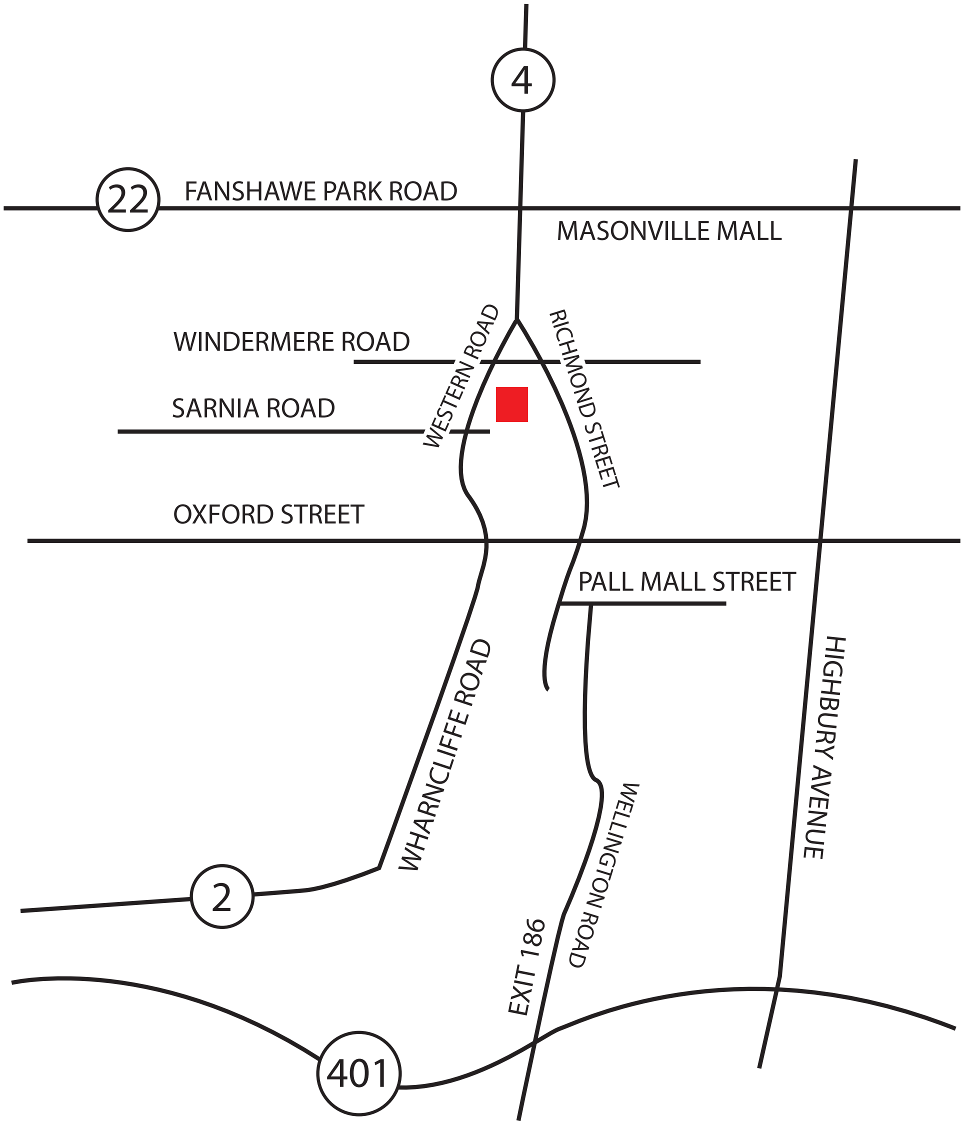
www.giftoflife.on.ca

**Transplant Patient Expense Reimbursement (TPER) Program**

www.giftoflife.on.ca/page.cfm?id=6C26FA7F-D610-4ED2-9A1B-2FFB4AEBDBE0

# Appendix III

London Health Sciences Centre
Multi-Organ Transplant Program



🟥 London Health Sciences Centre
University Hospital

# Appendix IV

## Exceptional Distribution and Increased Risk Donors

No donor heart is transplanted if the Cardiac Transplant Team believes it is not of good quality (function) and/or if it poses a major risk to the recipient's health. All donor hearts are screened for diseases such as HIV and Hepatitis C and B. A complete medical-social history is also obtained about the donor from their family and friends in order to determine if the donor engaged in activities that would put them at risk for passing on infections like HIV and Hepatitis. When we have the complete medical-social history and negative blood tests for infections, the transplant team (and YOU) can be very confident that no infections will be passed on.

There are potential donors that we cannot obtain a complete medical-social history or they have events in their life that might increase the risk of passing an infection on to the recipient. These donors can still donate their heart for transplant under a strict set of guidelines AND if the recipient and transplant team feel the risk is low. These donors are identified as EXCEPTIONAL DISTRIBUTION (ExD) and/or INCREASED RISK DONORS (IRD).

The most common reason for ExD donation is that we do not have a complete medical-social history. Remember that we are relying on friends and family to answer questions about the donor's sexual history, drug use and other activities such as tattoos and piercings. The family and friends may not know every single detail. In this case, if we have bloodwork that shows the donor is HIV negative, Hepatitis negative and has no other infections then we can be very confident that there is no increased risk for infection. We would disclose this information to you and ask if you would take a heart from an ExD donor. If you agree to this heart, we would sign a consent with you that says you have agreed to this donation and that we feel there is no significant increased risk to you. You may also decline the offer without penalty.

ExD donation can also occur due to other factors. Some (but not all) donor factors are listed below:

- Unknown sexual history
- Intravenous Drug use
- Travel to certain parts of the world (increased risk of infection)
- Having sex for money
- Having sex for drugs
- Having been in prison or jail
- Snorting cocaine
- Infection in the donor that is easily treated if passed on (i.e. Donor has a urinary tract infection)

**We do not use donor hearts from HIV positive donors**

**Remember that we would not use a heart for transplant if the risk to you was greater than the benefit to you.**

Now the part that can be confusing…

We **can** use donor hearts from donors that are Hepatitis C or Hepatitis B positive.

## Increased Risk Donors

As odd as it sounds, a donor who tests positive for Hepatitis C or Hepatitis B can still donate (Heart, Liver, Kidneys, Lungs) organs for transplant!! In fact, our program has successfully transplanted organs from Hepatitis positive patients into recipients over the past number of years. We can do this because of advances in drug therapy that effectively get rid of the Hepatitis Infection. We would transplant you and then give you the treatment for the form of Hepatitis that the donor had. You would also be followed by our Liver specialists at our hospital to ensure your full care and treatment.

In the case of Hepatitis B, if you have been immunized against Hepatitis B (we test you as part of the assessment) then we may not even have to treat you for anything as you body will have immunity.

These donors are classified as both ExD and Increased risk donors (IRD) because we know we are passing an infection on to you. The situation would be explained and you would be informed of this history. You may consent to the transplant or turn the offer down without consequence.

For either the ExD or IRD donors, we want to be fully open about the donor history and any potential risk to you. Our team would never offer a heart to you or your loved one that we did not believe was safe to do so. We also do not want to force anyone to do something they do not feel comfortable about doing. The reason for telling you about these types of donors is to get you thinking about this situation and talk with your family about what you would be willing to do. We do not want the first time you hear about this to be at the time of your transplant.

At the time of an offer, if it is an ExD or IRD donor, one of our doctors will explain the situation and get your consent to use the heart OR you can decline the offer and keep waiting for another heart offer.

# Notes

# Notes

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London Health Sciences Centre
Multi-Organ Transplant Program

Heart Transplant Program