

PATIENT HANDBOOK

Multi-Organ Transplant Program, London Health Sciences Centre



Heart Transplant Program

HEART TRANSPLANT PROGRAM, LHSC MULTI-ORGAN TRANSPLANT PROGRAM

Patient Handbook

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Transplant Assessment

Assessment is the first step in the journey called transplantation.

You may have already received a copy of the *Patient Guide to Heart Transplant Assessment* when your assessment was arranged. If not, you will receive a copy of this booklet to help you understand the assessment process.

The assessment

The process of heart transplantation begins with the assessment of each potential recipient. You have been referred to our program 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 visit. You should expect to be in hospital for about 5 to 7 days, depending on the results of the tests. In some cases, it is necessary to keep a person in hospital longer, in order to get all of the information necessary for a complete assessment. The details of the tests can be found in the *Patient Guide to Heart Transplant 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 transplantation 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.

Waiting Period

Waiting, the hardest time for some...

Once you are accepted for heart 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. Because your position on the waiting list changes with your medical condition, you must inform the recipient coordinator if you are admitted to any hospital.

WAITING FOR
TRANSPLANT
IS ONE OF
THE MOST
DIFFICULT
STAGES OF
THE
TRANSPLANT
PROCESS.
IF YOU HAVE
QUESTIONS
OR
CONCERNS,
PLEASE
CONTACT A
MEMBER OF
THE
TRANSPLANT
TEAM

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.

You may have to wait from six months to a year for your transplant because donated hearts are in limited supply. There are too few donor hearts for many reasons:

- Not everyone can donate organs because suitable organ donors must die in hospital; they are attached to a ventilator, which circulates oxygen in the blood so organs can be used for transplant.
- Not all organ donors are acceptable heart donors. Strict criteria must be met before a donor's heart is used.
- There is an age limit for heart donors. Donors older than 60 years may not be acceptable because of coronary artery disease. A coronary angiogram may be required for older donors.

The transplant team realizes that patients cope better during the long 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 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.

However, you must wait in the London area if:

- you are medically unstable and require frequent monitoring at University Campus or
- your residence is more than three hours driving distance and there is no local airport.

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.

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.

REMEMBER...
IF YOU ARE
ADMITTED TO
HOSPITAL,
HAVE A
FAMILY
MEMBER OR
FRIEND PAGE
THE
TRANSPLANT
RECIPIENT
COORDINATOR

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). 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.

Transplant Surgery and Recovery

From the call through discharge from hospital.

Just as waiting for transplant can be difficult, the surgery and recovery period of the transplant process can be a stressful time as well. This chapter reviews some of the important points that you and your family should be aware of.

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 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 London Health Sciences Centre, University Campus.

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, electro-cardiogram, 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 two to three 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 Clinic on 4th floor.

Intensive Care Unit

After the operation, you are taken to the Intensive Care Unit where you will remain for a minimum of 1-3 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 ICU you are also 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. You are allowed to drink after the endotracheal 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.

Intensive Care Unit:

Treatment progresses from simple circulation exercises to sitting on the edge of the bed or in a chair.

Multi-Organ Transplant Unit:

A daily exercise program with specific exercises and short walks may be started. Rest periods are an important part of your program. As your recovery continues, you will exercise daily under the supervision of your physiotherapist. The program may include: stretching, posture, and strengthening exercises; walking; cycling; and stair climbing. You will be given a home exercise program to continue when you leave the hospital.

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.
- 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.

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. If you stop taking these medications, your body will know, and it will start to attack your new heart. There are many medications available to prevent rejection and to treat rejection. You will learn about your new medications, in great detail, while you are recovering from your transplant. The list below, gives examples of some of the more common medications.

Medication	Information
cyclosporine (Neoral®)	To prevent rejection of transplanted organs, this medication is taken for the rest of your life.
tacrolimus (FK506, Prograf®)	Similar to cyclosporine, it prevents rejection of transplanted organs. Given to patients who do not tolerate cyclosporine. This medication is taken for the rest of your life.
prednisone	Corticosteroid, naturally produced by the body, but given in higher doses as an immunosuppressant for transplant patients. This medication is usually taken for one year, then slowly discontinued.
mycophenolate mofetil (CellCept®, MMF)	Immunosuppressive agent given along with cyclosporine or tacrolimus to prevent rejection. This medication is taken for the rest of your life.
sirolimus (Rapamune®)	Immunosuppressive agent given to some patients who cannot tolerate cyclosporine or tacrolimus. If you are placed on this medication, it is taken for the rest of your life.

Life and Living after Transplant

Learning to live a normal life again.

Transplants are done in order to return patients to satisfactory quality of life. The goal of transplantation is to have recipients return to their normal lives and daily activities. A transplant recipient can generally do anything that they previously did (work, recreation, travel, family events, etc.) with few restrictions. The transplant team will provide guidelines and education to assist you in resuming a normal 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.

Rejection

The body's immune system recognizes and attacks foreign organisms such as bacteria and viruses. Unfortunately, your immune system also recognizes the transplanted heart as a foreign tissue and tries to get rid of your new organ through 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

If rejection is suspected, a heart biopsy is performed. Biopsy is the only reliable way to

REMEMBER:
SUCCESSFUL
TREATMENT
OF
REJECTION
AND
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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. Because the nerves to your heart were cut, you may not feel this symptom. 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

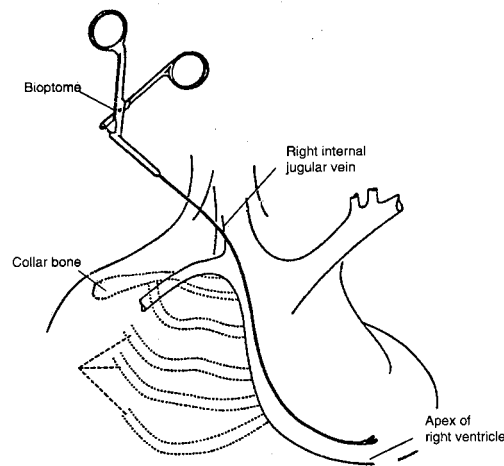


Illustration prepared by George Moogk, Education and Communication

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.

<p>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</p>	<p>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</p>
<p>Gastrointestinal tract Common symptoms of infection include: diarrhea nausea vomiting</p>	

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.

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.

Self-medication program

This program helps patients learn about their medications. 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.

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.

Resuming your lifestyle

TRANSPLANTS
ARE DONE IN
ORDER TO
IMPROVE A
PATIENT'S
QUALITY OF
LIFE:
THEREFORE,
YOU SHOULD
GET OUT AND
LIVE YOUR
LIFE

Quality of life

Most heart transplant recipients can look forward to leading normal lives. We encourage recipients to pursue good health habits.

Work and activity

You can expect an improved or normal activity level within three to six 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.

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.**

Driving a car

Most people can resume driving two to three months after transplant, but this is an individual decision. 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:**
Diets high in cholesterol and animal fat increase 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.

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.

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 six 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.

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

Thanking the 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 at any time through your social worker or recipient coordinator. Simply give your card or letter to the social worker or recipient coordinator and it will be sent to the donor's family.

Community follow-up

After the initial three-month 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 2 or 3 days, for your annual follow-up.

Appendix

Contact Numbers

Telephone Numbers (Area Code 519)**Cardiac Transplant Team**

Dr. J.E. Brown	685-8500	x33662
Dr. L. Chow	685-8500	x33992
Dr. B. Kiaii	685-8500	x33153
Dr. W. Kostuk	685-8500	x33263
Dr. N. McKenzie	685-8500	x33098
Dr. R. Novick	685-8500	x33159
Dr. P. Pflugfelder	685-8500	x33809
Dr. M. Quantz	685-8500	x33144
Jan Hoffman (NP/CNS)	685-8500	x35185
Grant Fisher (Transplant Coordinator)	685-8500	x33760
		(or to page: x13760)
Kelly Ariesen (Social Worker)	685-8500	x32484
Dale McIntyre (Dietitian)	685-8500	x35880
Prescription Centre	663-3231	
Pastoral Care	663-3070	
Physiotherapy	685-8500	x35365
MOTU Inpatient	685-8500	x33015
Outpatient Transplant Clinic	685-8500	x33818

www.lhsc.on.ca/transplant

