



Lung Transplant Patient Manual



University Health Network

Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

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Foreword

This manual is written particularly for the patient and their caregivers as a resource for information regarding lung transplantation in the Toronto Lung Transplant Program. As you go through the lung transplant process it will provide a place for you to refer back to refresh your memory on important details related to lung transplantation and provide information regarding where our lung transplant team can be of further assistance to you.

This manual was put together by a multi-disciplinary team of members of our transplant program and we are greatly indebted to the dedication, passion and hard work that have been applied to the creation of this important resource for our lung transplant patients and their caregivers. We hope that you will find this helpful and we will also like to hear from you any suggestions you might have to improve the manual in time to come.

Yours Sincerely,

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Chapter 1

Welcome to the Multi Organ Transplant (MOT) Program & Your Lung Transplant Team

The Multi Organ Transplant Program at Toronto General Hospital is Canada's largest transplant centre performing a broad range of transplants. Recently, 80-100 or more lung transplants have been done at Toronto General Hospital each year.

It is important that you join us in our teaching programs and share this manual with your support persons and family. Transplantation is a team effort. We are your team and you are the most important member!

Our Philosophy of Care

- We believe that our work is possible because of the generosity of organ donors. Our work must honor these remarkable gifts from donors and their families.
- We believe that respect, dignity, integrity, and empathy drive care and support relationships. We expect courtesy and consideration in every interaction.
- We believe that the goal of the Multi Organ Transplant Program is to work in partnership with individuals, families, and the community to promote optimal health and quality of life for recipients through all phases of transplantation.
- We believe that transplantation is a very specialized area in health care. To succeed, we need the knowledge skill and ability of our multi-disciplinary team.

- We believe that all members of the health care team make an important and valuable contribution to the plan of care. Each member of the team is a dedicated professional who continually maintains a current knowledge base and consistently strives to advance the science and art of transplantation.
- We believe that all people are unique, with their own needs, goals, and abilities.
- We believe that people achieve their optimal state of the health in collaboration with the health care team.
- We believe that information and education provide recipients with knowledge to exercise their rights and responsibilities to make informed decisions about their health care.
- We believe that the best possible care is based on recipient needs, available resources, and ethical principles.
- We believe that all services must be provided in a safe environment that supports health goals and enables care to be delivered with comfort and efficiency.

Our Expectations of You

Throughout your transplant experience in the Multi Organ Transplant Program at The Toronto General Hospital you have the responsibility to:

- Work in partnership with the health care team to ensure the best possible treatment, rehabilitation, discharge planning, and follow-up care.
- Provide accurate information and to share any concerns with members of the health care team.

- Inform the team if you do not understand or cannot follow the health care instructions.
- Respect that the needs of other patients and families may be more urgent than your own needs.
- Treat staff, other patients and their families in a considerate, courteous, confidential, and cooperative manner.
- Understand the Toronto General Hospital's role as a teaching and research hospital and to partner with health care professionals in training.

Your Transplant Team

During your transplant journey, we will work together with you to help you care for your lungs, your health, and support you through this process.

Your transplant team includes:

- | | |
|---------------------------|--|
| ➤ Doctors | ➤ Nurses |
| ➤ Social Workers | ➤ Transplant Coordinators |
| ➤ Nurse Practitioners | ➤ Spiritual Care |
| ➤ Physiotherapists | ➤ Psychiatrists |
| ➤ Dietitians | ➤ Pharmacists |
| ➤ Occupational Therapists | ➤ Other health care professionals, and.... |

YOU

Some of the health care professionals that you will come in contact with are:

Respirologist

The *Respirologist* is a doctor who is highly skilled in the diagnosis and treatment of lung disease. This doctor, together with your family doctor, and referring respirologist will care for you before and after your transplant.

Lung Transplant Surgeon

The *Transplant Surgeon* is a doctor involved in your evaluation and selection. The surgeon performs the transplant operation and manages the post-operative recovery and the surgical care.

Transplant Assessment Coordinator

The *Transplant Assessment Coordinator* is a registered nurse who provides pre-transplant education and coordinates the transplant evaluation process. The Assessment Coordinator also helps manage your health while you are on the waiting list.

Transplant Coordinator

The *Transplant Coordinator* is a registered nurse who monitors you after transplant and arranges your follow up care. The transplant coordinator is able to put you in touch with the right people and the right services to meet your needs related to your lung transplant.

Nurse Practitioner

Nurse Practitioners (NP) are part of Toronto Lung Transplant Program team and work together with all team members such as physicians, surgeons, transplant coordinators, and other team members. They care for you while in hospital and as an outpatient. NPs are registered nurses with a Master's degree in Nursing who have specialized knowledge and skills in their chosen field enabling them to assess, diagnose and manage patients independently and/or together with the rest of the team.

Social Worker

The *Social Worker* meets with all transplant and candidates their families to review your situation and family supports. They will work with you and your support people to plan for your transplant. They can advise you about available resources such as transportation, housing and local accommodations, financial assistance and your medication coverage. They also provide supportive counseling for patients and their family before and after transplant.

Transplant Psychiatry

The *Transplant Psychiatry Team* includes *Psychiatrists* and *Psychiatric Nurses*. They are available to assist you and your support people throughout the transplant process. Many recipients meet with members of the team during their assessment, for support while waiting, during their hospitalization, and after the transplant to assist with the transition to their new life.

Physiotherapist

The *Physiotherapist* coordinates and monitors your exercise program. A physiotherapist is a health care professional trained in using exercise and physical activity to condition muscles and improve level of activity. Physiotherapists are trained to evaluate and improve movement and function of the body, with particular attention to physical mobility, balance, posture, fatigue, and pain.

Medical Secretary

The *Medical Secretary* is an administrative assistant who works closely along with the coordinators during the assessment and post transplant period. The Medical Secretary can relay concerns to the transplant team but is not qualified to give medical advice.

Dietitian

The *Dietitian* will provide nutritional information and counseling. A good nutritional program is important for preparation for and recovery following a transplant. They will recommend a well-balanced dietary

program that meets your particular needs before and after your transplant.

Inpatient Resource Coordinator

The *Inpatient Resource Coordinator* is a registered nurse who ensures you are ready for discharge from hospital and that a smooth transition is made from being a hospital patient to a clinic patient. The inpatient resource coordinator communicates with the outpatient transplant coordinator about the events of your hospital stay.

Spiritual Care

Spiritual Care Professionals are part of the team that provides care to patients and families in the transplant program. They seek to nurture and celebrate spirituality by providing assistance that is sensitive to cultural and religious diversity.

Pharmacist

The *Transplant Pharmacist* works closely with your doctors and the transplant team while you are in the hospital to make sure that you receive the most appropriate medication therapy. After your transplant, while still in hospital, you and your support person will attend a Self Medication Class taught by the Transplant Pharmacist to learn about your transplant medications. The Transplant Pharmacist also reviews all of your medications with you before you go home and answer any questions you may have. They will also provide you with a medication schedule to help you keep track of your medications and take them correctly at home.

Health Care Providers outside of the Transplant Team

Your *family doctor* and your *original respirologist* will always be a very important member of your healthcare team. It is important for you to have regular check-ups in addition to your visits with the transplant team. The transplant team and your local medical team will work together with you to provide care before and after your transplant.

Chapter 2

Why You Need a Lung Transplant

Your doctor has suggested that you may need a lung transplant. To understand why, it is important to know how the lung works.

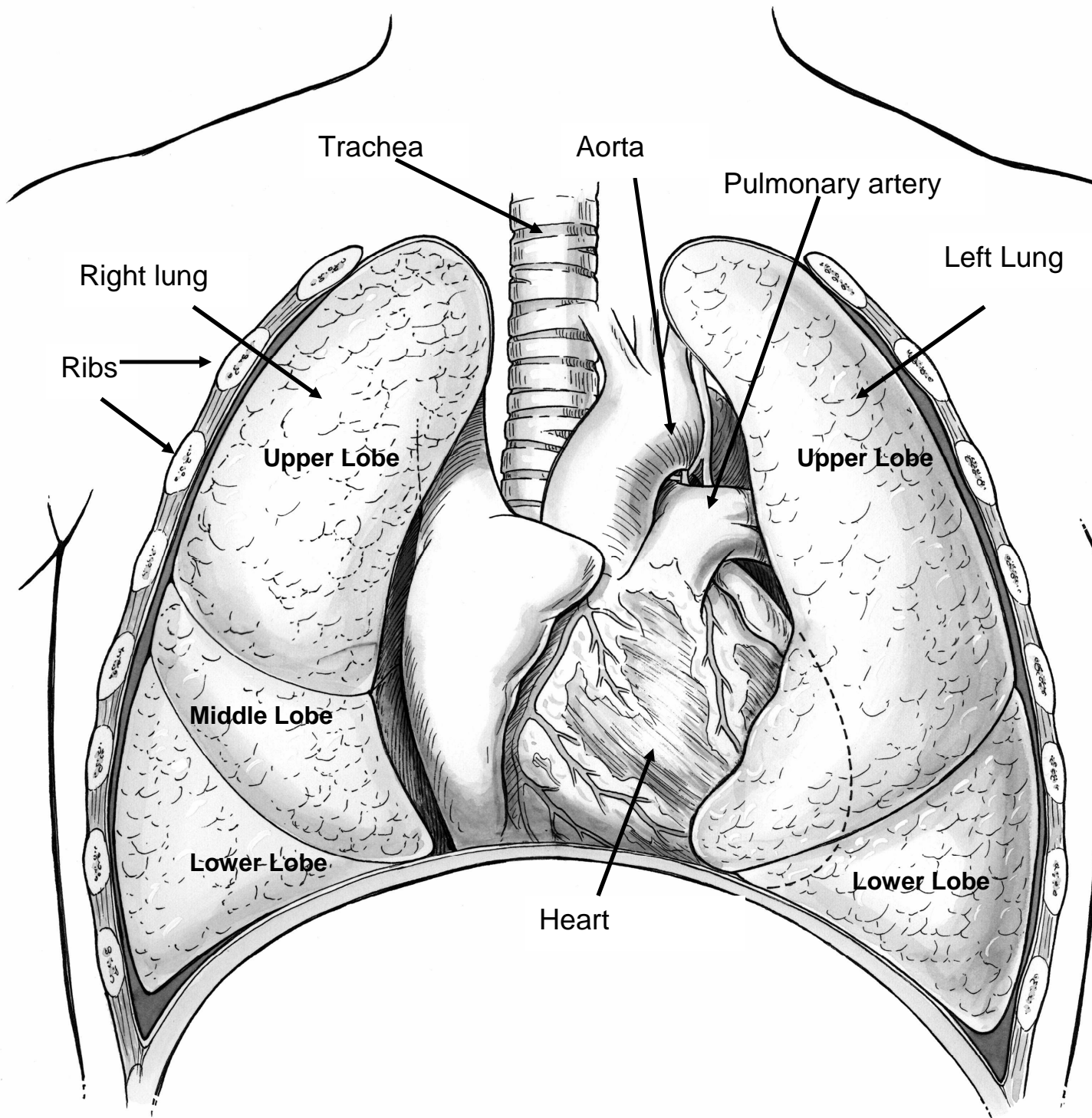
No organ or tissue can survive without oxygen. Oxygen is used throughout the body in chemical reactions to produce energy. The chemical reactions create carbon dioxide as a waste product. Carbon dioxide must then be removed from the body. This is called “gas exchange” (exchanging oxygen for carbon dioxide). The lungs perform both sides of this vital gas exchange for the entire body, both taking in oxygen and expelling carbon dioxide.

Normal lungs are soft and spongy. They are made up of elastic tissue that allows them to stretch. The right lung is divided into three lobes, the upper, the middle and the lower lobes. The left lung is divided into two lobes, the upper and the lower lobes.

The lungs themselves are made up of air passageways called bronchi. The airway branches look similar to those on a tree. Each branch becomes smaller and more numerous at each branching. The smallest of these branches end in the tiny gas exchange sacs called alveoli.

Where Are Your Lungs?

Your two lungs are located in the chest under the ribs. The lungs are protected and supported by the 12 pairs of ribs, the muscles which lie between the ribs, the neck muscles and the diaphragm. The location of your lungs is shown in the diagram below:



Recipients under consideration for lung transplant present with a variety of lung diseases. The following list outlines some of the lung diseases that may be referred for lung transplantation.

1. Chronic Obstructive Pulmonary Disease (COPD)

- Emphysema
- Alpha-1 Antitrypsin Deficiency
- Bronchiolitis
- Lymphangioleiomyomatosis (LAM)
- Eosinophilic granuloma

2. Interstitial Lung Diseases

- Pulmonary fibrosis
- Sarcoidosis
- Scleroderma

3. Airway Diseases

- Cystic Fibrosis (CF)
- Bronchiectasis

4. Pulmonary Hypertension

- Idiopathic
- Secondary: Eisenmenger's Syndrome secondary to a heart defect, or Interstitial lung diseases

Signs & Symptoms of Lung Disease

A diseased lung cannot carry out its normal functions. People with lung disease or lung failure can have the following signs and symptoms:

- Shortness of breath
- Cough
- Sputum

- Fatigue
- Dizziness
- Blue tinge to finger nails or lips

Please note that not everyone will experience the same symptoms.

Am I Eligible for a Lung Transplant?

Each recipient is assessed individually for his or her suitability for transplant. Basic requirements for lung transplant are:

1. Your transplant assessment shows that you:
 - a. have lung failure which is severe enough to require a transplant
 - b. are able to safely tolerate the surgery.
2. You want to have a transplant, and you understand and accept the responsibilities required before and after the transplant.
3. You have a family member or support person to help you through this process.

We will help you understand the benefits and risks of having a transplant. This will give you the information to make an informed decision. If a transplant is recommended, the decision to proceed is up to you. We will support your choice whether you go forward with transplant or not.

Our goal is to make your transplant as safe and as successful as possible. We will do everything we can to make your transplant work for you. We will work with you in making care decisions and help you to understand your treatments.

Having a transplant will change your life significantly. Before you make this choice you need to be prepared to make many life-long changes. This includes being part of your health care team, learning about your treatments, taking your medications, exercising regularly, and attending your clinic appointments.

Why do I need a support person?

All lung transplant recipients need to come to the Transplant Assessment with a support person. A support person provides help with day-to-day tasks such as cooking, cleaning, and transportation to hospital appointments. Pre-transplant the support person also assists with the exercise program. This carries on after the transplant. Early after transplant the support person may need to help with medications and follow your treatment plan.

The support person also provides emotional support and friendship. Everyone needs emotional support as they proceed along this transplant journey. The support person can also act as your advocate with the transplant team, speaking up for you when you are not able to do so.

The support person will receive his or her own information booklet.

Chapter 3

The Transplant Assessment Process

The transplant assessment process helps to determine if you are a transplant candidate and makes sure that it is safe for you to have a transplant. During your initial assessment for lung transplant, you will meet with many of the health care team members who will help decide if transplantation is the right option for you. The assessment also helps the transplant team advise you if this is the right time to be listed for transplant.

Sometimes your assessment will uncover a problem that makes transplantation a poor option for you. It could also identify a problem that may need correction before you become a candidate for a lung transplant.

Assessment testing also determines the condition of the recipient's heart. The heart and lungs work closely together; lung disease may affect the heart. The reverse is also true; years of heart disease may produce lung injury. It may be decided that some recipients may need both the heart and lungs transplanted.

Transplanting both lungs, one at a time, is used to treat recipients with chronic infections, such as Cystic Fibrosis or Pulmonary Hypertension. Either a single or double lung transplant may manage recipients with Emphysema or Interstitial Lung Disease.

Advantages & Disadvantages of Lung Transplant

Advantages

Many recipients experience:

- Less shortness of breath
- More energy
- Fewer restrictions
- A better quality of life

- A longer life with a transplant

Disadvantages

All recipients have:

- Transplant medications for the rest of their life to control rejection
- Follow-up transplant care for the rest of their life
- Side effects from the medications
- A greater risk for infection after transplant
- Other medical complications

The Transplant Work-Up

Several tests are done routinely during assessment. These include:

BODY PART	TEST	
LUNGS:	Pulmonary Function Tests	Pulmonary function tests are a group of tests that measure how well the lungs take in and release air and how well they move oxygen into the blood
	Chest X-Ray	Determines the extent of damage to lung tissue and looks at heart size
	Arterial Blood Gases	A blood test that shows how your lungs exchange oxygen and carbon dioxide.
	Ventilation-Perfusion Scan	This is done in a nuclear medicine lab. A small amount of a radioactive substance is injected into a vein. The test shows the amount of blood flow to each lung. This helps us to determine which lung needs to be transplanted. If you require a double lung transplant it helps inform us which lung should be transplanted first.
	CT, CAT Scan of Chest	A medical imaging method to obtain a more detailed picture of the lungs.
	Six Minute Walk	This is a self-paced test where you walk as far as you can in 6 minutes on a flat surface. This measures your exercise tolerance (endurance), muscle strength and oxygen needed for exercise.

	TEST	
HEART:	RNA-First-Pass and Exercise	Evaluates the function of the right and left sides of the heart. This is also done in a nuclear cardiology lab. A small amount of a radioactive substance is injected into a vein.
	Echocardiogram	Evaluates the effectiveness of heart valves as well as the pumping abilities of the heart's ventricles
	ECG (electro-cardiogram)	Shows the patterns of electrical activity in your heart.
	Thallium Persantine Scan	A radioactive substance is injected in your vein then pictures are taken of your heart. It assesses blood circulation to your heart muscle. Two sets of pictures are taken; one immediately following injection and one 4 hours after injection.
	Coronary Angiogram	An examination of the blood vessels using a contrast dye. It looks for narrowing or blockage that could increase your risk of a heart attack.
OTHER:	Blood tests	Helps to evaluate other systems such as kidney and liver function. Standard viral screening is also done.
	Urine tests	Helps evaluate your kidney function.
	Bone density	Looks for signs of osteoporosis and assesses your risk of fractures.

Consultation Interviews

As part of the assessment process, interviews will be arranged with several members of the transplant team. They may include:

- Respirologist or Nurse Practitioner
- Transplant Coordinator
- Anesthesiologist
- Social Worker
- Psychiatrist or Psychiatric Nurse
- Cardiologist
- Dietitian
- Pharmacy
- Physiotherapy

- Other: Other consultants or tests may be needed to assess further depending on your medical history or if something unusual shows up in the tests.

Living Donor Lung Transplant

Transplantation cannot occur without the generosity of others. Most people will benefit from a transplant through the kindness of strangers. Others may be able to have a living donor transplant.

Living donor lung transplant requires two donors. Donors donate one lower lobe of one of their lungs. The donors must have a compatible blood type to the patient. They must be healthy and will go through a full assessment.

This option is not appropriate for every patient, however if you have family members that are interested, they can call the assessment office and speak to one of the coordinators for further information.

After the Assessment Process

Once the tests and consults are finished, the transplant team will meet to review the results. There are several possible outcomes:

1. Too early to be listed.

Your lung disease is not yet severe enough to make the risks of transplant acceptable. You will be monitored regularly by your own respirologist and the transplant respirologist. They will follow your progress so that you can be listed at the right time.

2. Further testing required.

Sometimes the assessment uncovers other medical or surgical problems that need further investigation before a final decision can be made. The transplant team will arrange for further testing and

consults with specialists, either at the Toronto General Hospital or through your outside doctors if you are from out-of-town.

3. Transplant is too high risk.

The assessment may identify risks factors that which would lead to poor health or threaten your survival after a lung transplant. One of the most common reasons recipients are turned down for transplant is severe heart disease.

4. You are acceptable for transplant.

If there are no contraindications and you are prepared to go forward with a transplant, a meeting is scheduled for you with the lung transplant surgeon and transplant coordinator. The surgeon will talk with you and your family about the proposed transplant surgery. Your support person should also be present with you that day. The surgeon will tell you about the successes and risks of lung transplant as well as:

- Average chance of survival for this transplant surgery
- The possibility of a lung injury at the time of transplant
- Neurological and other complications
- Severe infections
- Prolonged ventilation and stay in Intensive Care Unit
- Need for re-operation
- The commitment of you and your family
- Introduction to clinical trials

Chapter 4

The Costs Associated with Lung Transplant

Medication Costs

- When you are discharged from the hospital after your transplant, you must be ready to pay for your medications.
- These costs can range from \$200 to \$4,000 per month.
- The Transplant Unit will **not** provide you with medications to take home.
- Toronto General Hospital **does not** have a drug assistance plan for Transplant recipients. Private drug coverage or provincial plans will cover most of the medication costs. There may still be some medications that you will need to pay for yourself.

The Ontario Trillium Drug Program

Many transplant drugs are expensive and unusual. These drugs can cost hundreds or thousands of dollars. Even the best insurance programs may not completely cover the costs of these medications.

The Trillium Drug Program, funded by the Ontario Government, is available to all Ontario residents, under 65 years of age, to help pay for such medications. The Trillium Drug Program also covers recipients who are on social assistance, Ontario Disability or have Home Care drug cards.

All Ontario recipients <65 years of age must register for the Trillium Drug Program **BEFORE** being listed for lung transplant.

If you do not register with Trillium you will be expected to pay for your medications by:

- Using your private insurance drug benefit card to directly bill your insurance company, if allowed
- Pay for the medications personally by:
 - VISA or MasterCard
 - Cash
 - Line of Credit

There is no cost to register with The Trillium Drug Program. The application takes only a few minutes to complete. Being registered with Trillium does not interfere with your private drug coverage. Trillium may assist you with drug costs that are not covered or only partly covered by your private drug plan.

You can get applications at any Ontario pharmacy, online, or through your social worker. Your social worker will provide you with further details about this program. The website to download the application for the Trillium drug program is:

http://www.health.gov.on.ca/english/public/forms/form_menus/odb_fm.html

As a transplant recipient, you **must** keep your registration active with Trillium. You must renew your registration with Trillium **every** year in August whether you are pre- or post-transplant.

Seniors

Recipients over the age of 65 years are covered automatically with the government drug plan under the seniors benefit plan.

Out-of-province Drug Coverage

Recipients from other provinces also need to have adequate drug coverage before they can be listed for lung transplant. Each province has different criteria. You will be provided with the specific information regarding your province when you meet with the Transplant Assessment Coordinator and Social Worker.

To find out what standard provincial drug coverage includes check the following website: www.drugcoverage.ca

Financial Information

Having a transplant has an impact on your finances. It is important for you to know this and plan ahead. Your income may change and you may have new expenses. Every situation is unique. Use the following information as a guide to see if there are opportunities for financial support.

Transplant recipients may be eligible for financial help from sources such as:

- Insurance – Employment or Illness benefits
- Employment and retraining funding
- Canada Pension disability plan (CPP)
- Ontario Works program
- Ontario Disability Support Program (ODSP)
- Provincial funding assistance. For example, Ontario residents have access to Trillium Patient Expense Reimbursement (TPER) if they are required to relocate.

These programs may provide you with financial support. Please contact your transplant social worker for details about these programs and see if you qualify.

Insurance

- **Employment Benefits**

Some transplant recipients are able to return to the job or position they had before transplant. Depending on your employer and the amount of time you are off sick, you may have **short or long term disability** benefits. Your employer will be able to tell you more about this.

- **Illness Benefits**

You might qualify for Employment Insurance (EI) illness benefits if your work does not have sick benefits or the

payment is low. EI illness benefit gives you up to 15 weeks of income. Your local EI office can give you information about qualifying or ask your social worker.

Employment and Retraining Funding

Some recipients may return to work after transplant but need to change their job. In this case, recipients may qualify for an Ontario government program for vocational assessment and rehabilitation. This program is for recipients who have physical problems that prevent them from finding or keeping their previous job.

Unfortunately, there is a long waiting list. Once you are accepted into the program, you qualify for financial assistance for retraining costs and a living allowance.

Private companies also offer vocational assessments, counseling and retraining for a fee. Some community agencies offer counseling free of charge or for a small fee.

Canada Pension (Disability) Plan (CPP)

If you are permanently unable to work for at least 12 months and you have paid into CPP, you can apply for CPP disability benefits. Drug benefits are not included.

Fill out an application as soon as possible. The Social Worker can provide you with this form. You must apply within 36 months of leaving your job or benefits will be denied. It can take up to several months to process the application. CPP approves your application based on the medical information that they receive from your doctor. Benefits are not retroactive to the date of your illness.

Ontario Works Assistance

You can apply for Ontario Works Assistance (OW) Benefits if you have a low income, few assets and are temporarily not able to work. Your total family income determines if you are eligible.

Drug benefits are included. The Social Worker can provide you with contact information.

Ontario Disability Support Program (ODSP)

If your doctor states you are permanently disabled and cannot return to work, you may qualify for the Ontario Disability Support Program (ODSP). This program is also for recipients with low family income and few assets. Drug benefits are included. The Social Worker can provide you with contact information.

Relocation – Housing

Some recipients are required to relocate closer to the hospital to wait for their transplant. Any recipient living more than 2 ½ hours away will be required to move. Ask your Transplant Assessment Coordinator or Social Worker if this applies to you.

Living closer to the hospital allows you to participate fully in our pre-transplant exercise program and come to the transplant clinic regularly. Being seen on a routine basis by the transplant team allows them to follow your progress closely. Recipients who are deteriorating more rapidly on the waiting list can be moved up the list.

You will meet with the transplant social worker to discuss relocation during the assessment. The Social Worker will provide you with information to help with this process.

Trillium Patient Expense Reimbursement (TPER)

If you are from Ontario and are required to relocate to the Toronto area to be listed for transplant, you may be eligible for some accommodation assistance. The Ontario government will pay up to \$650.00 per month for accommodations. Contact your Social Worker or Transplant Assessment Coordinator for details.

Applications for TPER can be downloaded from the Trillium Gift of Life Network website at <http://www.giftoflife.on.ca/> and are also available through the Transplant Assessment Office.

Out-of-Province Recipients

New Brunswick, Nova Scotia, Newfoundland, Quebec and British Columbia also provide some limited additional funding to help with the costs of relocation. Speak to your Social Worker for further information.

Other Financial Considerations

You will have other expenses related to hospital and clinic visits. These will be your own out of pocket expenses. We will describe a few of these below and offer some brief tax tips to help you recover some of these costs.

Parking

Parking near the hospital is expensive. The closer you park to the Toronto General Hospital, the more expensive it is. There are some parking lots a short walk from the hospital. It is worth looking at the costs of nearby lots if you will be coming to the Toronto General Hospital often. Consider taking public transit (TTC) or Wheel Trans whenever possible.

Wheel Trans

You can apply for Wheel Trans if you live in Toronto and are physically disabled. This service is available to people who are not mobile enough to use the regular transit system.

To get a Wheel Trans number, you need to go for an interview with the TTC. Call **(416) 393 – 4111** to set up an appointment. You **must** take a walking aid, such as a walker, or a wheelchair with you to the interview to get approved for Wheel Trans. Wheel Trans may provide you with transportation to the interview appointment if you are in a wheelchair or use a cane or walker to move around.

Travel

When traveling, you may need to pay for the cost of oxygen on a flight and upon arrival at your destination. You will need to confirm this with your airline in advance of your travel. Your local

respirologist will need to complete a medical form supplied by the airline. You need to give the airline 48-hours notice.

Notify your oxygen company of your travel arrangements. They can get a local oxygen company to provide you with oxygen at your destination. There may be an additional fee for this.

Ontario Residents

The Northern Health Travel Grant provides some financial assistance for travel to medical appointments for recipients living in northern Ontario. You must pay the cost of travel and then apply for reimbursement.

Bring the Northern Travel Form with you to your appointment. Complete the information in section 1. *Sign the form*. Your own local doctor will need to fill out the next section of the travel grant form. Bring this form to your Transplant Coordinator. Your transplant respirologist fills out their section. Your support person can fill in their information in the last section. Mail the Travel Grant form along with your receipts to the government.

Social assistance may help you with travel costs, no matter where you live. You need to apply at your local office for help.

Out-of-Province Recipients

HOPE Air *may* offer airfare at a reduced rate for recipients who live outside Toronto. You need to book at least 2 weeks in advance of your appointment. HOPE Air can be reached at **1-877-346-4673**. They will need to know the dates of your appointments, the doctor's name, and the phone number for your transplant coordinator.

Other Costs

There will be other costs during your transplant. You may need to buy special supplies that are not covered by drug plans.

For example, if you become diabetic, you will need testing equipment that may not be covered by your insurance plans. You may need to buy a blood pressure cuff if you have high blood pressure.

You will also require a **Microspirometer**. This device is often not covered by private insurance. The cost of the Microspirometer is approximately \$650.00. The transplant program sells you this, at cost, after you are discharged from hospital. You will need a personal cheque or money order to pay for the microspirometer. Cash, credit card or debit cannot be accepted. We can direct bill for the microspirometer if you have arranged with another funding source to pay for the microspirometer.

The Transplant Assessment Coordinator will provide you with a letter about the microspirometer at the time of your assessment. You can send the letter to your private insurance company to see if you have private coverage for this type of equipment.

We suggest that you also buy a **Medical Alert Bracelet**. This will be covered in a later section of the manual.

The physiotherapists may also recommend that you rent or buy equipment to help you around the home or with walking. Check your private insurance to see if you have coverage for this type of equipment. The physiotherapists can also help you find the equipment you may need.

You may need to have forms filled out or letters written by doctors in the program: for example, for insurance, employers and government programs. You will be required to pay for these services unless they are covered by provincial or private health insurance. Fees paid by you to have medical forms completed are tax deductible.

Tax Tips

Check the Canadian Revenue Agency Website or ask your accountant for information about deductions on your income tax related to your illness and your transplant. Check to web site at: <http://www.cra-arc.gc.ca/menu-e.html> for further information.

Here is a partial list that may be helpful. Remember to keep all your receipts for all your expenses. You cannot claim for anything if you have already received reimbursement, unless that reimbursement is claimed as income. You may need a medical letter to support your claim for some items.

Medical expenses that you ***may*** be able to claim include:

- Long distance telephone calls to the hospital
- Any diagnostic procedures you had to pay for
- Any payments you made to the hospitals not covered by your provincial health insurance
- Prescription drugs that you paid yourself, including any portion not covered by your private insurance or the Trillium Drug Plan
- Fees paid to doctors for completing medical or insurance forms
- Ambulances
- Parking for hospital and clinic visits
- Outside of Canada medical expenses – not covered by provincial health insurance
- Cost of housing, if you relocate, while waiting for transplant and immediately following your surgery. If you receive some funding for housing, you can only claim for the difference.
- The cost of the Microspirometer or other medical equipment you purchased, such as an oxygen concentrator or diabetic supplies.
- Home care services not covered by provincial health insurance
- Premiums paid to private or government drug plans
- Home help aids: hospital bed, bathroom aids (ie. commode), chair lift (including renovations)
- Mobility aids: wheelchair, walker, scooter

The list of eligible expenses is extensive and you should refer to the Revenue Canada web site for a full list.

You may claim expenses for yourself, your spouse and, with some limitations, your dependants. You can claim expenses for any twelve-month period ending in the current tax year.

Travel expenses:

- If you travel more than 40 km one way for medical appointments, you may be able to claim transportation costs: train, bus or taxi costs.
- If you use your own car, you can claim a reasonable amount for travel, approximately \$0.50/km. Check with Revenue Canada. This amount may change over the years and is different for every province.
- You will need to prove the number of trips you made to the hospital for appointments. Keep a travel log with mileage that you traveled. Have your health care provider sign and date it each time you come to the hospital.
- If you travel more than 80 km one way for medical appointments, you are also able to claim reasonable expenses for meals (\$51/day) and accommodation as well.
- Recipients living in some isolated northern regions can claim a Northern residents deduction

An accountant will be able to help you sort out your medical tax deductions. The accounting fees are also tax deductible.

Disability Tax Credit

- If you are disabled, as defined by Revenue Canada, you can ask your doctor to fill out a disability tax credit form. Include this in your yearly tax return.
- You may qualify for a credit of up to \$4,200.00, or you may qualify for the cost of care for a nursing home or a full-time attendant.
- Please note: Many transplant recipients do not qualify as disabled under the Revenue Canada definition after their transplant.

Chapter 5

Legal Information for Recipients

Advance Care Planning

Advance Care Planning is also known as advance directives and living wills.

There may be a time in the future when you are unable to make decisions about your medical care and treatment. This situation may be temporary or permanent. It could happen suddenly or gradually.

Advance care planning helps to clarify how you wish to be cared for and gives someone you trust the authority to act on your wishes. This person is known as a Substitute Decision Maker. This is the person we would ask to make decisions, in the event that you are unable to do so.

If you were unable to make decisions for yourself, there are two important things we need to know:

1. What are your specific wishes regarding your healthcare?
2. Who would you want to make decisions for you?

It is important to answer these questions now, while you are capable of making decisions. This helps to ensure that **your** wishes guide your care.

Please talk about your wishes with your family, your substitute decision maker, and anyone else who might make decisions for you in the future. We are always happy to answer any questions you have about advance care planning.

There are guides that you can use to help you with Advance Care Planning. Check the following web site:

<http://www.culture.gov.on.ca/seniors/english/programs/advancedcare/>

Your social worker will also be able to provide you with an Advanced Directives Guide booklet.

Powers of Attorney

It is important that you think about your situation and make plans for your powers of attorney. There are two basic forms of Powers of Attorney (PoA):

- Powers of Attorney for Personal Care
- Powers of Attorney for Finances

Powers of Attorney for Personal Care

A power of attorney (PoA) for personal care is a person that you choose to make decisions about your care when you are not able to make them yourself. This person is also called your Substitute Decision Maker (SDM). To appoint a PoA personal care, you need to create a legal document.

If you do not assign a PoA for personal care, the law states who may make these decisions on your behalf, in the following order of priority:

- Your spouse
- Adult children
- Parents
- Siblings
- Extended family members.

Sometimes recipients have a PoA for health care that is different from their usual substitute decision maker. If this applies to you, make sure this is clearly stated in your PoA document. Give copies of your PoA document to your Transplant team, the person named as your PoA and the hospital before you have your transplant.

If there is no one to make decisions for you, and you cannot identify anyone to be your PoA for personal care, the law can appoint a public guardian to make these decisions. This can be a long process. It is for your own benefit that you find a person to act as your PoA for personal care to avoid unnecessary delays.

Powers of Attorney for Finances

Your PoA for finances is a person that you choose to make decisions about your finances when you are not able to make them yourself.

This person is called a Power of Attorney for finances. To appoint a PoA for finances, you need to create a legal document.

This legal document states who will be responsible for making your financial decisions, payments, etc.

Powers of Attorney are powerful documents. They can have an impact on your care and finances. It is a good idea to get legal advice to set up a Power of Attorney.

Chapter 6

Waiting on the List

There are 2 goals for the waiting period for transplantation:

1. Maintain your health as you wait for transplant surgery
2. Identify and manage any new problems that may arise

You will have regular clinic appointments for the Pre-Lung Transplant clinic while you are waiting for lung transplant. You must keep these appointments. They are important opportunities for the transplant team to monitor your health and ensure your suitability for transplant. At the clinic visit we may adjust your medications and order additional tests.

The main goal of these clinic visits is to monitor your medical condition and fitness for transplantation. Care of your lung disease while you wait is a partnership between the lung transplant team and other respirologists involved in your care. If you are living at home while waiting, you should maintain regular follow up with your local respirologist. If you have relocated to the Toronto area, the lung transplant doctors may look after your lung disease while you are waiting or may refer you to another clinic for specialized care of your lung condition.

You will also require follow up as needed with your family doctor for other medical issues and general health maintenance; if you have relocated to Toronto, we can help you find a family doctor.

While you wait some of the assessment testing will be repeated every 3 to 6 months to keep your file as up to date as possible. Pulmonary function tests, CT scans, echocardiograms, blood tests, and 6-minute walk testing are commonly repeated for recipients on the waiting list.

If you are listed you will also meet the following people:

Thoracic Surgeon

Although you do not see the thoracic surgeon during your evaluation, they participate in the review of all your assessment tests. They will see you once you are accepted on the waiting list, and will discuss with you the operation and the risks of the surgical procedure.

Research Coordinator

The Toronto Lung Transplant Program is associated with the University of Toronto, and a world leader in transplant research. Recipients on the waiting list and post transplant recipients may be approached by our physicians and research coordinators to participate in research studies. Participation is always voluntary. The studies are reviewed and approved by the UHN Research Ethics Board. This is an independent review from the transplant team and protects your rights, privacy and confidentiality in performing clinical research.

There are always new and upcoming clinical trials, varying from life saving devices to new medications. For more information please contact the Lung Transplant Program and speak to our research coordinator.

Your Place on the Waiting List

The surgeon uses several criteria to match donors with recipients on the waiting list.

The most important two points are:

1. Blood type (ABO blood group)
2. Lung size (taken from your pulmonary function tests)

The first step to match a lung between a donor and recipient is a compatible blood type. The table below shows who can give you a lung by blood type.

If your Blood Type is	Can RECEIVE a lung from blood type:	Can DONATE to a recipient with blood type:
O	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	O, A, B, AB	AB

Other matching criteria used include:

3. If more than one recipient matches the donor blood type and approximate size, the surgeons will choose the recipient who is sicker. This is your “status code” on the list.
4. Lastly, time on the waiting list is used as a deciding factor who to transplant.

There is no “TOP” spot on the waiting list. Your status code may change as your health changes. The list is always changing. You will always be made aware if your status code changes. Coming to the clinic and pre-transplant rehab program helps the transplant program monitor your progress and increase your status if you become sicker. It is also important to remember that you may receive a transplant at any time, even if you are not very sick or unstable.

Unfortunately, not everyone who is listed will be transplanted due to a shortage of donated lungs. Some recipients’ health will get worse while they are waiting for a transplant and they will die before a suitable donor match is found for them.

IMPORTANT

The decision to move a recipient up the list is based on medical criteria and is a decision made by the transplant physicians. If you are approached or contacted by someone who offers to move you up

the list in exchange for money, please call the transplant program immediately.

The Role of Palliative Care in Lung Transplantation

Patients awaiting lung transplantation often need some degree of supportive care in addition to treatment for their underlying lung disease. The Palliative care team aims to improve the quality of life for patients and their families facing problems associated with a life-threatening or life limiting illness. The focus of palliative care is on the prevention and relief of suffering by means of early identification, assessment and treatment of shortness of breath, pain and other physical, spiritual and psychosocial issues associated with your illness. Some patients on the transplant waiting list are followed by the palliative care team, to help them have the best possible quality of life while awaiting transplant.

The palliative care team at Toronto General Hospital consists of a team of Physicians and an Advance Practice Nurse who work with your transplant team to provide the following services:

- assessment, counseling and care for those experiencing difficult symptoms associated with their illness
- provide relief from distressing symptoms such as pain, breathlessness and fatigue
- offer support systems and services to help you live at home as comfortably as possible, despite your symptoms
- assist with the co-ordination of home care supports for patients who are having difficulties with their activities of daily living
- continue to provide care for patients admitted to hospital
- End of life care and bereavement support for patients who are dying from their illness

Maintaining Contact

When a lung becomes available time is critical and we need to get in touch with you right away. You will have 2 ½ hours to get to the hospital from the time you are called.

We must know how to contact you at all times. Bell Mobility will provide you with a free pager so that we can reach you at all times. Your coordinator will arrange for you to get the pager. You need to provide your assessment coordinator with all your contact information:

- Home phone number & address
- Pager number
- Work number (if applicable)
- Cell phone numbers for you and your support person
- Close friends or relatives

Keep your contact information up to date at all times.

Please inform your coordinator immediately if:

- Any of these contact numbers change
- You will be out of reach for a period of time (e.g. unexpected travel)
- You are admitted to another hospital

While you are waiting

Waiting for a lung transplant can be difficult. It is normal to be experiencing many emotions during this time. There are many resources available to help you. A good place to start is with the members of your transplant team.

We don't know how long you will be on the waiting list. You do not have control over the wait list. There is no "top" spot on the list. Blood type and size are the first two considerations. Recipients who are quite severely sick may be given priority over recipients who are

stable and waiting at home. The list changes frequently based on how many recipients are listed and transplanted each month. This can be stressful and discouraging for you and your support person. Feelings such as fear, impatience, and even anger are normal.

The transplant team offers:

- Education and information before and after your transplant.
- Help with financial matters
- Counseling and emotional support. Talking helps.
- To introduce you to other transplant recipients and family members (mentors). These people have already been through the transplant experience, and can give you hope, courage, and information about transplant. Our mentors go through a volunteer training program at the hospital as well as an intensive training session with the transplant social worker to better help you.
- A support group for recipients and their caregiver/support person.

Lung Transplant Support and Education Group

The Lung Transplant Support Group is a mutual support and education group, the goals of which are

1. To provide an opportunity for lung transplant patients and their support people to meet each other on a regular basis, in order to offer mutual emotional support and encouragement as they experience the emotionally and physically taxing lung transplant process.
2. To provide ongoing education regarding various aspects of lung transplantation.
3. The opportunity to meet various members of the lung transplant team, who participate at various times

The group is not intended as a therapy group although there may be therapeutic value for those attending.

Membership and Attendance

Two staff members, the psychiatric nurse and social worker, co-facilitate the group. Pre-transplant patients and their support people

are strongly encouraged to attend the weekly meetings on a regular basis. Post-transplant recipients' attendance is welcome during their 3-month recovery period.

Under some circumstances, the Lung Transplant Assessment Committee may decide that a patient must attend the group as a condition of acceptance into the program. In such situations, the patient will be informed and staff will monitor that person's attendance for the period of time that has been agreed upon.

Due to the special infection concerns for cystic fibrosis patients, our cystic fibrosis patients are not allowed to attend and participate at group. However, their support persons are welcome and encouraged to attend and pass information back to our patients.

Meetings

Meetings are held once a week on Wednesdays from 11:00 am to 12 noon. The meetings are held in the *Astelles Conference Room, 11th floor in the Clinical Services Building*. A schedule for the meetings is circulated to the group members, listing the topics and any invited speakers for the meetings. Extra copies of the schedule are available in the Treadmill Room on the 12th floor.

Confidentiality

The Toronto General Hospital has a confidentiality policy, which prohibits staff from discussing details of any patient's situation with anyone who is not a member of the health care team. The members of the transplant team are only able to tell you if a patient is stable and able to have visitors. More detailed information will need to be obtained directly from the family or patient.

People attending group agree to respect confidential information, which may be shared within the group.

The Stress of Waiting

There can be significant stress associated with waiting for a lung transplant including:

- Experiencing deteriorating health and physical abilities
- The impact on family members
- The impact on finances
- Worry that lungs will not be available in time.

There is no right way to feel or react to stressful events. Everyone has a unique experience during the transplant process and copes in different ways. Some of the common reactions include:

Physical Reactions:

- | | |
|---------------------------|----------------------|
| • Fatigue | • Sleep disturbance |
| • Change in appetite | • Nightmares |
| • Muscle tension, tremors | • Startled reactions |
| • Headaches | • Dizziness |
| • “Butterflies” or nausea | |

Emotional Reactions:

- | | |
|---------------------------------|---------------|
| • Overly sensitive | • Self-doubt |
| • Feelings of helplessness | • Mood swings |
| • Fear or anxiety | • Anger |
| • Feeling numb and disconnected | • Frustration |

Changes in Thinking:

- | | |
|-----------------------------------|--|
| • Problems concentrating | • Forgetfulness |
| • Problems making decisions | • Slower thinking |
| • Difficulty with problem solving | • Isolation and withdrawal from others |

These reactions to stressful events are normal and understandable. If you feel overwhelmed or find that you are having problems with day-to-day coping, please contact the Transplant team for help.

Suggestions to help manage stress:

- Structure your time. Keep busy and try to keep your life on as normal a routine as possible.

- Talk to people. Sharing your feelings is helpful in reducing stress.
- Write your feelings down in a journal or diary.
- Reach out to others. Spend time with people you trust.
- Ask for help. People around you often want to help but don't know what to do. Let them know what would be helpful to you.
- Give yourself permission to feel sad and frustrated. Every one can have an "off" day.
- Do not use alcohol or recreational drugs to cope with stress. It may feel helpful at the time but it can cause problems.
- Exercise as much as possible.
- Eat regularly, get adequate sleep and drink plenty of water.

Stress Reduction Programs

- It is easier to cope with stress by having some practical tools to use during these difficult times.
- The Multi Organ Transplant Program can offer individual support for stress management as well as the Mindfulness-Based Stress Reduction (MBSR) Program. This may help you deal more effectively with stress. It can help you manage your anxiety and emotional responses better, even in moments of difficulty.
- **How to enroll?** Call the Transplant Psychiatry program or your Transplant Social Worker for more information.
- The course is free of charge. There is a small fee for the CDs that accompany the program.
- There are other stress reduction practices that you can learn. Please contact the Transplant Psychiatry team or your Transplant Social Worker for more information.

Managing Depression & Anxiety

Due to the physical and emotional challenges of transplant many patients experience depression and/or anxiety and panic. These conditions are **very common** and can be treated. It will not affect your status on the transplant list.

Symptoms of depression and anxiety are similar to those of stress:

Symptoms of depression may include:

- Irritability
- Frustration
- Fatigue
- Sadness
- Isolating self from others
- Changes in appetite
- Changes in sleep patterns
- Loss of hope

Anxiety may feel like:

- Persistent tension
- A feeling of dread
- Excessive worry
- Restlessness
- Feeling on edge

The symptoms of anxiety are associated with the lungs and breathing, and become worse with shortness of breath. Some patients experience panic attacks, which start quickly and can last a half hour or more. During these episodes patients feel as though their breathing is much worse, become highly anxious, feel like they are not able to cope, and may have a variety of physical symptoms including a pounding or racing heart, and bowel or bladder urgency.

Many patients benefit from referral to transplant psychiatry to learn various techniques to manage their symptoms, receive counseling and support, and for medications. As with any medical condition, sometimes medications are needed to ensure that patients are able to function at their best, perform physiotherapy, and optimize their quality of life. The transplant psychiatry team reviews all your medications to assess the compatibility and impact of these drugs to ensure their safety and effectiveness before and after the transplant.

Post transplant, depression and anxiety are also common. These problems may occur soon after transplant even while still in hospital or may occur several months to years down the road. Depression and anxiety can be treated with medication. The transplant psychiatric team is available to help. Please notify your transplant coordinator or physician if you need to be seen.

Spirituality

The Spiritual Care department at UHN recognizes that health care involves the whole person – mind, body and spirit. During times of illness, trauma, and loss, people often require more than physical

care to help them cope. Many find their spirituality helps them maintain health and provide support in the midst of life transitions.

Spiritual Care assists both the patient and the family:

- Explore the spiritual significance and meaning experienced in times of sickness
- Examine the implications in one's life, family and community as a result of the medical experience
- Provide bereavement support

The transplant program has a dedicated Spiritual Care Professional who is part of the Multi Organ Transplant Team. Please feel free to contact the service at any time. You can access a Spiritual Care Professional through your transplant coordinator, or on the in-patient unit.

Staying healthy while you wait

Vaccinations

Vaccinations are important for your health. We recommend:

- A flu shot every year in the fall. You can get this from your family doctor or local public health clinic.
- The Pneumovax vaccine every 3-5 years, based on current guidelines, which protects you from one type of bacterial pneumonia. Ask your family doctor about this.
- The Hepatitis B vaccine, or TwinRix (Hepatitis A and Hepatitis B combined). Except for recipients who have previously been exposed to or immunized for Hepatitis B. Check with your coordinator.
- Varicella vaccine (Chicken pox vaccine) is recommended for any adult who tests negative. You are tested at the time of your assessment. Ask your coordinator. This vaccine **MUST** be given before you are listed.
- HPV (human papilloma vaccine) is recommended for young men and women up to 26 years of age before they are listed.

Dentist

Good oral hygiene is important before transplant. Regular check ups and cleanings every 6 months with a dentist and dental hygienist is recommended. If you do not have a dentist, please notify your coordinator. You can be referred to the dental clinic at the Princess Margaret Hospital.

Smoking

All transplant recipients are required to be smoke free (tobacco and other substances) for a period of at least 6 months before they are listed. If you are having problems quitting and staying smoke free, speak with our social worker or psychiatry team who can recommend programs to help you.

Traveling / Out of town trips

You are required to stay within 2½ hours of the hospital while you are on the waiting list. We also realize that life events, such as a family issue, may take you away temporarily. If you need to travel outside of the 2½ hour range, please speak with your coordinator. You may need to go on “hold” on the list while you are away.

Over-the-Counter and other medications

Before starting any new medication, including over the counter and natural herbal supplements, it is important to speak with the Transplant team. Some medications may not be safe to use while you are waiting. Please update the team with any new medication you are prescribed by your family doctor or any other outside care provider.

Being Hospitalized

- During the waiting period your lung disease may get worse. Infections are also common. You may need to be admitted to your local hospital or the Toronto General Hospital for management of these problems.
- This does not necessarily mean that you are off the transplant list.
- Some infections or complications are severe enough that you are required to be placed on “hold” for a brief period.
- While in hospital the transplant team can evaluate your status frequently. Decisions about transplant will be made day-by-day.
- The recipient will be made “active” on the list when it is medically safe to do so.

- If you are admitted to another hospital, please have your support person notify your transplant coordinator immediately. The lung transplant team can speak to your care providers to provide advice, receive updated information about your condition, and decide whether transfer to TGH is necessary.

When is it important to call the transplant program?

- Increased shortness of breath
- Fever
- Increased cough
- Sputum that has increased in amount or changed colour
- Dizziness
- Changes in medications made by an outside physician.

Who to call?

- Monday to Friday 8:30 AM to 4:30 PM call the Lung Transplant Assessment Coordinator
- Nights, holidays, and weekends: Call your local chest doctor or family doctor or go to your local emergency room or call. Please leave a message with the transplant assessment office.
- Your transplant coordinator will follow up with the outside hospital and notify the transplant team.

A sudden increase in shortness of breath or chest pain is an emergency situation. Dial 911.

Physiotherapy and Exercise Pre-Transplant

Exercise is very important before and after your transplant. It is a ***basic requirement*** of our program.

Why do I need to exercise?

People requiring lung transplants are usually limited in their daily activities by shortness of breath, fatigue and muscle weakness. Often people are afraid to exercise or increase their activity level because they will get short of breath. As a result they may become weaker.

Exercise can increase your strength and give you more energy to manage your daily activities. It will help keep you as strong as possible before your transplant. Your physiotherapist will design a program based on your abilities. Exercise may involve using a bike or treadmill, stretching and using weights. Your physiotherapist will teach you how to exercise safely. They will also work with the doctors to ensure that your oxygen prescription is adequate for exercise and your activities at home. Your physiotherapists will also teach you how to use oxygen safely, breathing exercises and how to make activities easier at home.

How often & where do I exercise?

You will exercise in our physiotherapy exercise room at Toronto General Hospital before and after your lung transplant. Before the transplant, you will need to exercise **three times a week**. If you live outside of Toronto you may be able to exercise part of the time closer to home at a pulmonary rehabilitation program if they can accommodate you. This may occur after you are independent with your program, which usually takes about one month. Then you would be able to exercise two times a week closer to home but are still required to come to Toronto once a week. We will also encourage you to do some of your exercises at home.

Who designs my exercise program?

Your exercise program will be designed and supervised by physiotherapists. Physiotherapists are skilled in assessing and treating many conditions that affect the muscles, bones, circulation, breathing and the nervous system. Physiotherapists manage and prevent many physical problems caused by illness, disease and long periods of inactivity.

Should my support person help me exercise?

Your support people are important team players in your exercise program. Your physiotherapist will teach both you and your support people the exercises. Your support people may help by handing you weights, recording your exercises on your exercise card and by helping to monitor you when you exercise.

Diet and Nutrition Pre-Transplant

During your assessment you will meet with the dietitian. The purpose of this meeting is to determine if you are meeting the guidelines for healthy eating based on Canada's Food Guide. The second reason will be to determine your Body Mass Index (BMI). This is a measurement of body fat, based on height and weight. You and the dietitian will determine your BMI. If you would like to do this before the appointment, please refer to this website <http://www.nhlbisupport.com/bmi/>.

A healthy BMI for lung transplant recipients is between 17 and 27. We have found that outside these levels, recipients have poorer outcomes after lung transplantation. Recipients with greater weights before the transplant may have a longer recovery in the Intensive Care Unit. Recipients with a BMI higher or lower than these levels can also have more complications when compared to those patients who have healthy weights. During the assessment, the dietitian will provide you with an individualized diet program if you need to lose, or gain weight.

Recipients with a BMI over 30 will not be listed for lung transplant until they reach a BMI of less than 30. Recipients with a BMI under 17 will be given strategies to gain weight. This may include food supplements, such as Boost or Ensure, or even a feeding tube.

You will be instructed on a healthy weight loss diet. We will work together to decide the goal weight for you to reach a BMI of 30. This will be your first goal. The second goal will further weight loss to achieve a BMI of less than 27. The dietitian will provide you with all the necessary information for you to meet your goal weight. You can also review healthy eating guidelines on the Internet. The website for the Canada Food Guide is helpful, reliable and accurate. It can be found at http://www.hc-sc.gc.ca/fn-an/alt_formats/hpfb-dgpsa/pdf/food-guide-aliment/view_eatwell_vue_bienmang-eng.pdf

Some of the information from the website includes:

- Having the right amount and types of food

- Following the tips included in Canada's Food Guide will help you:
 - Meet your needs for vitamins, minerals and other nutrients.
 - Reduce your risk of obesity, type 2 diabetes, heart disease, certain types of cancer and osteoporosis.
 - Contribute to your overall health and wellness.

How to read a food label

The Nutrition facts Table is found on the packaging of most foods. All the information on the Nutrition Facts table is based on a specific serving size of food. This amount may be different than one serving from the Canada Food Guide.

You can use the Nutrition Facts table to:

- Compare products more easily;
- Determine the nutritional value of foods; and
- Help you choose a product with more or less of a particular nutrient.

Example:

The Nutrition Facts table tells how much fat, fiber, sodium or sugar is in different foods. There are 13 different nutrients mentioned on a standard food label.

Product 1		Product 2	
Nutrition Facts		Nutrition Facts	
Per 1 1/4 cup (30 g)		Per 3/4 cup (30 g)	
Amount	% Daily Value	Amount	% Daily Value
Calories 110		Calories 110	
Fat 0 g	0 %	Fat 0.5 g	1 %
Saturated 0 g	0 %	Saturated 0 g	0 %
+ Trans 0 g		+ Trans 0 g	
Cholesterol 0 mg		Cholesterol 0 mg	
Sodium 240 mg	10 %	Sodium 190 mg	8 %
Carbohydrate 26 g	0 %	Carbohydrate 24 g	8 %
Fibre 1 g	4 %	Fibre 5 g	20 %
Sugars 2 g		Sugars 3 g	
Protein 2 g		Protein 3 g	
Vitamin A 0 %	Vitamin C 0 %	Vitamin A 0 %	Vitamin C 0 %
Calcium 0 %	Iron 30 %	Calcium 2 %	Iron 30 %

For example, if you are trying to increase the amount of fiber you eat choose a product that has a high % Daily Value of fiber. Using the label above, Product #2 has a 20% Daily Value of fiber in $\frac{3}{4}$ cup serving compared to Product #1 which only has a 4% Daily Value of fiber in $1\frac{1}{4}$ cup. Choose products such as breads and cereals that are good sources of fiber.

For more information you can visit this website:

<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/choose-choix/grain-cereal/tips-trucs-eng.php#read>

Chapter 7

Is the Donor Suitable?

The Trillium Gift of Life Network (TGLN) is the organization that takes care of the organ sharing system in Ontario. They support donor families and organize the organ donation process with transplant centers in Ontario and throughout Canada.

Lung transplantation requires a deceased human donor. Lungs may be taken from “cadaver donors” or “non-heart beating donors”. Donors may die as a result of “brain death” or “cardiac death”.

- Cadaver donors are individuals who have recently died from severe brain injury resulting in brain death. Brain death occurs when the brain no longer functions at all due to severe brain injury.
- Non-heart beating donors are “donors after cardiac death”. This occurs when donors with some brain function die after being taken off life support.

Once a potential organ donor is identified, the donor’s next of kin is asked to consent for organ donation.

Transplantation is scheduled as soon as possible after death has been declared. Screening tests are done on the donor to ensure the organs are suitable and safe to use. Tests include testing for communicable diseases (such as HIV, hepatitis B & C, and West Nile virus), blood gases, x-rays, and bronchoscopies.

Donors must have good, functioning lungs, and be approximately the same height and weight as the recipient. The donor and recipient must have a compatible blood type. Race and sex of the donor have no bearing on the match. You will not develop any of the physical characteristics of your donor—with the exception of healthy lungs!

After testing the donor, the lung transplant surgeon selects the most appropriate recipient on the wait list for that particular donor on that day.

Organ Donation

Organ donation within Canada and the United States is an altruistic act, based on the kindness and generosity of the donor family. It is gift to you that is made by the donor's family with no strings attached. Donation is a decision made by the family in a time of profound grief and sadness.

The act of donation is confidential, as written into the Human Tissue Gift Act in Ontario. *You will not be given any information about the donor.* The Transplant Team, recipients and their families **MUST** respect the **privacy** of the donor family. The Human Tissue Gift Act of Ontario **prohibits** the Transplant Team or the Trillium Gift of Life Network from facilitating a meeting between donor families and recipients.

In accordance with the Ontario *Human Tissue Gift Act*, The Toronto General Hospital & the Multi Organ Transplant Program do not support or accept payment of any kind from recipients, organizations or any party for organs for transplantation.

It is against the law to buy, sell or otherwise deal in, directly or indirectly, any tissue for transplant, or any body part or parts of the body for therapeutic purposes, medical education or scientific research.

**If at any time you are approached by a person to purchase or sell an organ for transplantation, please immediately contact:
Patient Relations at (416) 340-4907.**

Chapter 8

The Call for Transplant

When a lung from a donor becomes available, we need to contact you right away.

Once you are chosen as the most suitable recipient, the transplant program's Recipient On-Call Coordinator will work to reach you by calling your contact numbers in this order:

1. Home phone number
2. Pager
3. Alternate phone numbers, such as a cell number

NOTE: ** Messages will be left where answering machines are available**

**Time is critical when an organ becomes available.
If the coordinator cannot reach you after 1 hour, another recipient must be selected.**

If you are paged, call the number that appears on your pager. If you get a wrong number on your pager, call the Transplant Unit at (416) 340-5163. Ask to speak to the Charge Nurse. Tell the nurse that you are waiting for a lung transplant and your pager went off. The charge nurse will put you in touch with the Recipient On-Call Coordinator.

Do not eat or drink anything from the time that you are called for transplant. If you are about to take your medications, you may do so with a small amount of water. It is OK to take your puffers. Diabetics should not take their insulin or diabetic pills before they come in.

It is very important that you follow these instructions.

Refusing to come in when called for transplant will mean that you are put on hold. The transplant team will contact you to discuss your situation.

Pagers

Bell Mobility will provide a pager for you free of charge. The pager will come by courier directly to your home. The transplant assessment office will fax Bell a request form.

Insert a fresh battery (AAA).

1. Test the pager when you receive it:
 - Dial the number assigned to the pager. This appears on the papers that come with the pager.
 - At the tone enter in a “test” page – this can be something as simple as 1..2..3
 - Within a minute or so the pager will start to make a noise. Press the main (largest) button to stop the noise. Press the button a second time. The “test” page should appear in the pager window. If the correct numbers appear, you know your pager is working.
2. Call your Transplant Coordinator with your pager number.
3. Read the instructions that come with the pager to delete your test pages.
4. Test the pager by paging yourself at least ONCE per week (see step two).
5. If the pager is not working, call Bell Mobility at 416-674-7243. Press #1 for English and #0 to speak with a person.
6. Always leave the pager on, even at home. NEVER turn it off.
7. You always want to be able to hear the pager. Never put the pager on vibrate. Read the pager instructions that came from Bell.
8. If you are in a noisy environment, the pager may be difficult to hear. In those settings, it may be helpful to set the pager on vibrate and wear it, so you can feel the vibration. However, do

not forget to turn the sound back on when you remove the pager".

9. The most recent message will always appear first. Messages cannot be deleted without you going through the proper steps.
10. If the battery runs low, the pager will beep and a message will appear in the window saying "low battery" or "low cell".
11. Take the pager with you where ever you go. When the pager goes off, call the number that appears in the window (10-digit number) and identify your self to the person on the other end. "My name is I am waiting for a transplant and my pager went off". You will be given instructions what to do.
12. If you get a wrong number, call the **Transplant Unit** at **416-340-5163** to check if someone was paging you. Ask to speak with the Nurse-in-charge.
13. If you get a bill for the pager, do NOT pay it. Bring it to your coordinator. We will notify Bell that you are still waiting for a transplant and to cancel the bill. When you are finished with the pager, you or your support person need to return the pager to Bell by **registered** mail to:

Bell Mobility, 200 Bouchard Blvd, Dorval, Quebec H9S 5X5

If you have any questions, please stop by the Transplant Assessment Office to speak with your coordinator.

Getting the Call

The call to come into hospital for transplant may come at any time of the day or night. The transplant coordinator will identify themselves and ask you a few questions. They will ask:

- How you are feeling?
- Do you have a fever or any flu symptoms?
- Are taking any antibiotics or have had any new medications prescribed?

If they have no concerns regarding your present condition they will ask you to come to hospital as soon as possible.

Do not eat or drink from this time on.

You may take medications that you require with a small amount of water. Diabetics should not take their insulin or diabetic pills before they come in because your blood sugar may drop without anything to eat or drink. Your blood sugar will be checked when you get to the hospital. It is OK to use your puffers.

Before you leave home, please remove all your jewelry. Please also remove all body piercings (ears, nose, tongue, belly button, etc.) before you leave home.

Coming to the Hospital

Once you are called in for a lung there is an urgent need to make sure you arrive quickly and are ready for surgery.

Getting to the hospital when called for transplant

- It is your responsibility to come to the hospital when called.
- You need to be able to arrive within 2 ½ hours of receiving the telephone call.
- If you live outside the Toronto area, specific plans need to be made ahead of time. You are responsible for arranging your own transportation to the hospital.
- If weather or traffic delays your trip to the hospital, call the transplant unit to advise them of the situation. The Transplant Unit can be reached at 416-340-5163.

We want you to arrive safely to hospital.

- If you are coming by car, do NOT drive yourself. Please have someone drive you.
- If you do not have a car, you can take a taxi to hospital.
- Do not call an ambulance as your first option to come to the hospital. If you chose to call an ambulance to get you to hospital you will have to pay for this service that the hospital **will not** pay for. There is no guarantee that the ambulance will be available when you want it. Do not use this as your first mode of transport.
- If you call an ambulance and have a false alarm you will have no way to get home. The Transplant Program will not pay for you to get home. You must arrange to have a family member or friend drive you to the hospital when you get the call. Your family can wait with you in the hospital until the transplant is confirmed, even if it is during the night.

Depending on the time that you are called to the hospital, you will either go to the Admitting department or the Emergency department. The Coordinator who calls you will tell you which entrance to use.

Between 7 am to 11 pm go to:

***Admitting Department
Toronto General Hospital
200 Elizabeth Street
Ground Floor, East (Eaton) Wing
Elizabeth Street entrance***

Between 11pm and 7 am, go to:

***Emergency Department
Toronto General Hospital
At the corner of Elizabeth St. and
Gerrard St.***

Once you arrive at the hospital, you will be admitted to the transplant unit (7 or 10 West) where the nurses will prepare you for surgery.

They will:

- Do blood tests, an ECG, and a chest x-ray
- Start an intravenous (IV)
- Not give you anything to eat or drink

False Alarms

A false alarm happens when you are called in for your transplant and then at the last minute, your surgery is cancelled. Even if all the preliminary testing on the donor is OK, there are still times when your transplant may not happen. The final approval must come from your surgeon after he has looked at the lung to be transplanted. You will not be put to sleep in the operating room until your surgeon is satisfied with the donor's lungs.

Your surgery can be cancelled for many reasons:

- We may have found a problem with the donor's lungs at the last minute.
- One of your tests may have an unusual result and the operation cannot safely proceed.
- In some cases, there may be an issue in matching an organ to a recipient.

Keep in mind that false alarms can happen. It gives you a chance to see what happens and you may be more prepared the next time you get called. Sometimes, people can have several false alarms. You and your family may have mixed emotions when this happens. If you, or any members of your family are having difficulties coping with the false alarm experience, let your social worker know. They will be able to refer you to someone who can help you.

What to Bring to Hospital

Bring these items with you to hospital:

1. Your Toronto General Hospital blue identification card
2. Your Ontario Health Card or Provincial Health Card if you are from another province.
3. Bring **ALL** your medications in their original bottles or packages.
4. A book or magazines to help you pass the time while you wait for your surgery.

After your surgery, you will go to ICU after your lung transplant. You do not need any of your personal belongings here, and we want to lessen the risk that such items are lost in hospital.

Personal belongings will not be needed until you are transferred back to the Transplant Unit. At this later time, your family may bring personal items to hospital, such as:

1. ***This manual***
2. Your drug card (if you have one)
3. Access to a credit card that you can use to pay for:
 - television and/or telephone,
 - your medications at the time of discharge,
 - your return trip home.
4. Toiletries: soap, shampoo, comb/brush, toothbrush, etc.
5. Dentures, hearing aid or glasses
6. A pair of sneakers to start your physiotherapy post transplant
7. Out of province recipients to bring appropriate drug cards and documentation

For safety reasons do not bring in:

1. Any valuables such as rings, watches, jewelry.
2. Large amounts of cash
3. Any large electrical equipment that needs to be plugged in (you may bring an electrical razor or hair dryer).
4. Laptop computers, i-pod, or cell phones unless you can give them directly to a family member for safekeeping.

Chapter 9

Your Transplant Surgery

Single lung transplant

- The operation can take 6 or more hours.
- People that have a single lung transplant will have one incision.
- The incision will be on your side. It is called a thoracotomy incision.
- The first step is for the surgeon to remove the diseased lung. We support your remaining lung by giving you oxygen through a ventilator during your surgery. Sometimes, your remaining lung may need extra help to give your body oxygen. If this happens to you, we will use a system called cardiopulmonary bypass.

During the surgery, your surgeon will put your donor lung in your chest in the place where your diseased lung was removed. There will be three connections, called anastomoses, where the new lung will be attached to your body.

1. The donor main bronchus is attached to your main bronchus.
2. The pulmonary artery is attached to the donor pulmonary artery.
3. The donor pulmonary veins are attached to the left atrium, a chamber of your heart

After these connections are completed, extra tissue is wrapped around the incision line on the airway to help with healing. Then your chest is closed and stitched up. You then leave the operating room and go the Intensive Care Unit (ICU).

Double Lung Transplant

When you have a double lung transplant, your surgeon will make a horizontal incision just below the middle of your chest. This is called a transverse sternotomy incision (also called a clamshell incision) that goes underneath your breasts. The bottom part of the sternum, or breastbone, will be cut during the operation. No other bones are cut.

- This operation can take up to 12 hours.

- Your surgeon does your double lung transplant by replacing one lung at a time. First the diseased lungs are removed. Then the new donor lungs are attached
- Just as with the single lung transplant, there will be three connections for each lung.
- You may also need support for your heart and lungs during this operation by using the cardio-pulmonary bypass machine. This is more common with a double lung transplant.
- After the transplanted lungs are connected then your chest will be closed and you will be taken to the ICU.

For all recipients:

During the surgery the surgeons will perform a bronchoscopy (fiber optic camera) to look at the new airways. They may also perform an echocardiogram in the operating room to examine the attachment of the blood vessels from the new lungs to your heart.

When the surgery is complete, the muscle layers of your chest are stitched together and the skin is closed with staples. The staples will be removed 2-3 weeks after surgery. You will also have chest tubes inserted beside the lungs. This helps the new lungs expand inside your chest and to remove any secretions or blood that builds up around the lungs. The chest tubes will be removed in 7-10 days.

While you are in the operating room, your family can wait in the surgical waiting room on the third floor of the New Clinical Services Building (West Elevators), or the ICU waiting room on the 10th floor (West Elevators). When your surgery is over, your surgeon will come there to talk to your family.

During the operation, the lung transplant surgeons cannot perform any other surgeries such as breast implants, liposuction or other cosmetic procedures. They will be concentrating on performing your lung transplant. If you had breast implants inserted before your lung transplant, these will need to be removed at the time of the transplant. The breast implants are in the area of the incision and can be a source of infection. They will not be reinserted when the transplant is over. As you can understand, our main focus is your transplant.

Chapter 10

Your Care after Lung Transplant

Once you've had your surgery, you can expect to be in the hospital for a minimum of 10 days, however many recipients are admitted to hospital for a longer period. Complications may extend your hospitalization until you are well enough to be discharged.

The Intensive Care Unit

From the operating room you will be taken to the **Medical/Surgical Intensive Care Unit (M/S ICU)** where there is specially trained staff to look after you. Recipients remain in the ICU until their lung function is stable and they are able to breath on their own. This takes anywhere from a few days to a week on average, but varies with each recipient, and can take several weeks.

The M/S ICU is located on 10 Floor West of the New Clinical Services Building. The waiting room for family is on the 10th floor near the elevators. During this time **ONLY** your **immediate** family members are allowed to visit for short periods, **TWO** people at a time.

We also ask that you designate ONE family member to act as family spokesperson, calling the ICU periodically for updates. Your nurse is busy looking after you. If many family members call, the interruptions may interfere with their ability to care for you.

While in the ICU you will hear and see many unfamiliar things. The descriptions of the following equipment and procedures may help you understand what is happening around you during your stay. You may not remember very much of your stay in the ICU. This is normal.

Heart Monitor and Blood Pressure Monitor

When you return from the Operating Room (OR) you will be connected to various machines that will help monitor your condition. A Heart Monitor is used to monitor your heart rate and rhythm. A cable from this machine, which has several smaller cables, is attached to your chest. There is a screen that shows the waveform

and a number display. Your blood pressure is also monitored and shown on the screen. There are some beeps and buzzers that will go off from time to time.

Ventilator and Ventilatory Care

Initially, you will have a tube through your mouth, down your throat, and into your trachea to help with your breathing. This is called an “endotracheal tube” or ET tube. Connected to this is more tubing from a machine called a ventilator. The ventilator breathes for you during your surgery and for at least the first few days after surgery.

At first, the ventilator will do all the breathing for you when you first come out of the OR and are still sound asleep. As you wake up, you will start to do some of the work of breathing for yourself. When the transplant ICU team feels you can breathe on your own, the tube will be removed, and you will be given oxygen by a facemask.

While you are attached to the ventilator, you will not be able to clear your lungs of any fluid or mucus. It will be necessary for the nurse to suction the secretions for you. Suctioning can be scary and sometimes uncomfortable. The nurses in the ICU are all specially trained to perform this task with a high level of skill.

If you require help with breathing for longer than 1 week, the team may consider inserting a tracheostomy (trache) tube in your neck. This is a small plastic tube inserted by a small incision in your neck into the trachea. This may make breathing with the ventilator more comfortable if you need it for a longer period. It allows easier clearing of secretions from your mouth and lungs as well as weaning from the ventilator. Once you are able to breathe without the ventilator, the trache tube will be made smaller until it is eventually removed. It will take a few weeks for the small hole in your neck to close, and you will be left with a small scar. The hole can be covered with a regular Band-Aid until it is healed.

Means of Communication

While the endotracheal tube or trache is in place, you will not be able to talk, eat, or drink. The nurses in the ICU have developed many ways to help with communication. Hand signals are used and we

have special letter boards. If you are well enough you can write notes for us to read. Patience is needed during this time.

Nasogastric Tube

You will not be able to eat or drink while on the ventilator. There will be another tube through your nose, which empties the acids from your stomach until you are able to eat and drink again. This tube is called a nasogastric tube. If for some reason it is a long time before you can begin eating and drinking again, you can be fed through your nasogastric tube. Normally however, it will be removed a few days after the surgery.

Incision Site

Your chest will be sore after the transplant because of the large incision made for the transplant. The skin is held together with staples that are removed after healing has taken place. There will be a large dressing over the incision that the nurse will change as needed.

Movement will be painful because of the incision site and chest tubes. The nurse will give you pain medication to keep you comfortable. Movement is important:

- 1) To protect your skin from pressure sores and
- 2) To help keep your lungs clear.

The nursing staff will assist you to move and make you as comfortable as possible.

Chest Tubes

You will have drainage tubes in your chest called chest tubes. These tubes drain fluid and air from the spaces around the lungs and the heart. These tubes will be connected to suction for a few days to help the lungs expand fully. Once the lungs are fully expanded and there is no longer fluid or air draining from the chest tubes, they will be removed.

Urinary Catheter

A urinary catheter, also known as a Foley catheter, will drain your bladder of urine. It will be inserted in the operating room when you

are asleep. The tube is connected to a collection bag. The catheter will be removed several days after transplant. Most recipients do not find a urinary catheter uncomfortable. The catheter does not restrict your movement and may be taped to your leg to help you move around. It is easily removed by deflating the balloon that holds it in place.

In your immediate post-operative period, keeping track of fluid intake and output is critical. The catheter will make it possible for nurses to accurately measure your urine output. Since you will be restricted to bed for a while after your surgery, the catheter will also help you pass your urine more easily.

Intravenous (IV)

An intravenous (IV) is a small catheter inserted in a vein. It is used for giving fluids and medications. You can expect to have a several different IV lines after your transplant. These IVs may be inserted in your wrist, hand, arm and neck. A pump delivers the IV fluids and medications so that you get the exact amount needed. As your condition improves, the IV lines will gradually be removed.

Pain Management

Recipients are often concerned about whether they will have pain after surgery and how that will be dealt with. Here are the answers to some of recipients' more commonly asked questions. Feel free to ask your nurse/transplant coordinator if you have any further concerns.

Will I have pain after surgery?

Yes, most recipients have pain after surgery. Pain medicine is a priority in your care. It will help relieve your discomfort. You can expect to feel pain in the area of the incision. You may also feel stiffness and aches in other areas. We encourage you to use the pain medicine. It will help you start moving around, sitting, and walking sooner. This is an important part of your recovery.

How will my pain be managed?

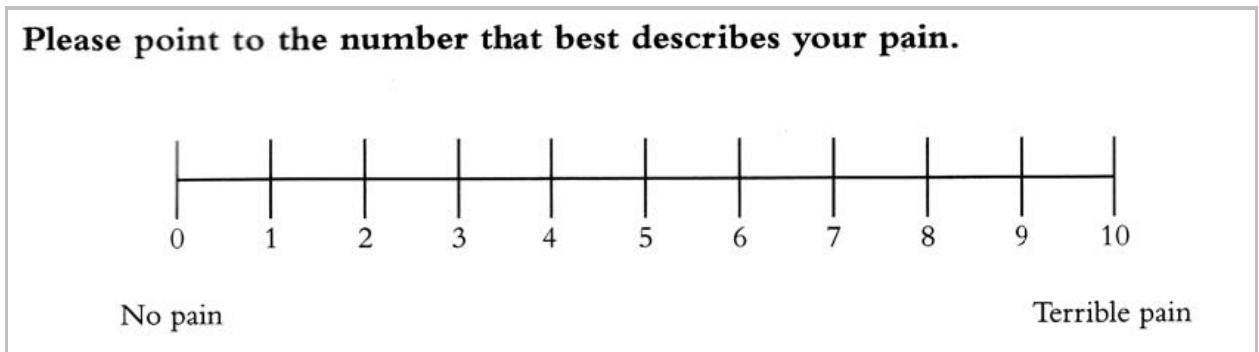
We will work with you to manage your pain. You must take the pain medicine regularly. Since you will be taking pain medicine only for a short period, you do not need to worry about becoming dependant on it. Listed below are a number of ways to receive pain medicine. Please discuss them with your doctor or nurse if you have any questions.

Are there side effects of pain medication?

Some recipients have side effects from pain medication. They can include nausea, vomiting, sleepiness or itching. If any of these happen to you, tell your nurse.

How do I tell my health care team how much pain I have?

We use a pain scale. It looks like this:



On this scale 0 means no pain and 10 is the worst pain you could ever imagine.

Other people describe the pain with words such as: mild, moderate or severe.

Type of pain management	Explanation of what it is
<p>Intravenous Patient Controlled Analgesia</p>	<p>If you have Patient controlled analgesia (PCA), we connect a PCA pump to our IV. This pump holds the pain medication. When you feel like you need something for pain you press the button attached to the PCA pump. The pump delivers pain medication through your IV.</p> <p>We suggest that you push your pain pump when you are:</p> <ul style="list-style-type: none"> • Starting to feel pain • Going to do your deep breathing and coughing exercises • Moving around in bed • Starting any activity that causes you pain <p>The pump gives you a small dose of pain medication each time you push the button. There are safety features that we set to stop you from getting too much medication. We program a safety timer called a lockout.</p>
<p>Epidural Patient Controlled Analgesia</p>	<p>An epidural is a small tube put into your lower back by an anesthetist doctor. It is the same tube that women have when giving birth. The tube stays in place and it taped to your back.</p> <p>We give you medication through the tube to help your pain. Usually the medication you get is a combination of pain medicine and local freezing. Sometimes this medication will make your legs feel numb. Please tell your nurse if this happens to you.</p> <p>We attach a PCA pump to your epidural. The pump gives you pain medication automatically. In addition, there is a button that you can press to get more medication if your pain is not in control.</p>

Type of pain management	Explanation of what it is
Intravenous Medication	With this method, your nurse gives you pain medication through your IV. It is important for you to tell your nurse when you have pain and if the medication is working for you
Medicine by Mouth	This is what you think of as a pain pill. Once you are able to drink fluids, we will give you pills to help control your pain. Pills take longer to work than IV medication. This means that it is important to tell your nurse when you beginning to feel uncomfortable.

Are there any other ways to control my pain?

Yes. In addition to medication there are several ways that you can control your pain. Some examples include:

Relaxation Breathing	Relaxation breathing gets the attention away from your pain because you are focusing on your breathing. You take slow deep breaths, in through your nose and out through your mouth.
Visualization	Visualization involves imagining yourself without pain. To begin, close your eyes and imagine yourself in a place or time that brought you happiness. It may be on a beach, at the cottage, or on a mountaintop.
Massage	Massage can help to decrease your pain. Massage is something your family or partner can do to help relieve your pain. Gently rubbing your shoulders, back, or arms can relieve tension.

Delirium

Because of the surgery, medications and hospitalization, it is common to experience sleep disturbance, restlessness, anxiety. These symptoms may progress to delirium with patients experiencing agitation, hallucinations, confusion, changes in memory and concentration, and problems with speech and movement.

There are often several causes of delirium, which may include:

- Medications
- Changes in blood chemistry
- Infection

Delirium is distressing for the patient, family and staff. It is a reversible condition with medications and treatment of the underlying cause. Delirium is a medical emergency. It is important for support people and visitors to notify the staff if they notice any changes in behaviour or thinking.

Physiotherapy and Exercise Post-Transplant

You will be assessed and treated by a physiotherapist throughout your hospital stay from the time you are in the intensive care unit until you are discharged from hospital. At that time you will return to exercise as an outpatient at the Toronto General Hospital.

Why should I exercise when I am in the hospital?

Exercise is very important to do in hospital after your transplant. You may be weak after the transplant because of your condition going into the transplant as well as the impact of the transplant on your body. Exercise can improve your breathing, circulation, sense of well-being, strength and ability to move. It may prevent further weakness during your hospitalization. Breathing and mobility exercises may also help to prevent common complications after transplants such as:

- Pneumonia
- Partial lung collapse
- Generalized muscle weakness
- Blood clots in the legs

When do I start physiotherapy in the hospital? What will I be doing?

Your physiotherapist will assess you daily starting in the intensive care unit. They will assess your lungs and teach you breathing exercises. The physiotherapist will help you cough up sputum and expand your new lungs. They will determine how much activity you are capable of doing and work with the nurses. You will gradually sit at the side of the bed, stand, sit up in a chair and walk. Your team will help to keep your pain under control so that you can do these activities.

A physiotherapist will continue to work with you when you leave the intensive care unit. They will help you improve your breathing, strength and independence with walking and daily activities. Occasionally people need to go to a rehabilitation hospital to get stronger before they can go home. Throughout your hospital stay your support people will be encouraged to help you with your exercises.

Do I need to continue to exercise when I go home from the hospital?

You will continue an exercise program after your discharge at the Toronto General Hospital. This will occur three times a week until approximately three months after the transplant. If you have a longer hospital stay you will need to continue to exercise for a longer period.

Diet and Nutrition Post-Transplant

If you have a long recovery in the ICU you may require a feeding tube to keep you healthy and give you the nutrients to help you heal.

In some circumstances, your stomach may not function properly and you may require additional feeding. This is called total parenteral nutrition (TPN). This is given intravenously. This type of feeding is short-term and you will be followed closely to make sure you are getting all the protein, calories, fat, vitamins and minerals you will need.

As you recover, your diet will gradually increase. You may begin to take food and drink by mouth beginning with ice chips, progressing to fluids, and then solid food. It is important to progress gradually. Eating or drinking too soon after surgery may cause nausea and vomiting. If you have been on the ventilator for a long time or have a tracheostomy, you may need to be seen by a speech-language specialist. They will assess your ability to swallow before eating or drinking safely. They may give you exercises to strengthen the muscles involved in swallowing before you can eat regular food again. If you cannot eat on your own, the nasogastric tube may be left in place for a period of time to feed you.

A dietary technician will visit you in hospital to make sure you get the diet you need. Once you are able to eat a regular diet, your family can talk to the staff about bringing in some of your favorite foods.

After the MSICU – Care in the Stepdown Unit

From the M/S ICU you will be transferred to the **Multi Organ Transplant (MOT) Step-down Unit** which is also referred to as the **Acute Care Unit (ACU)**. The ACU is on 10A West, across the hall from the M/S ICU. You will be admitted here for several days as your condition improves. The setup is similar to the ICU with private rooms however each nurse in stepdown cares for more than one patient.

What to Expect in the Stepdown Unit

Similar to the ICU, you will have several monitors and pieces of equipment attached. These include the heart monitor, IVs, pumps and urinary catheter. These will gradually be removed as you get better.

Visiting in the Stepdown Unit

Visiting is still limited to immediate family only, TWO people at a time. There is a designated rest period in the stepdown unit from 3 pm- 5 pm. No visiting is allowed during this time. Please refer to the signs posted on the doors. You are asked to check in at the nursing desk for security reasons.

After the ACU – Care on the Multi Organ Transplant Unit

You will complete your recovery on the **Multi Organ Transplant Unit (MOTU)** on **7 West A – NCSB**. The staff will help you recover, gain strength, and learn how to manage with your organ transplant.

Your Room

The MOT has private and semi-private rooms. Private rooms are first given to recipients based on medical needs. For example, if a recipient needs isolation, they will be given a private room first. Otherwise private rooms are given on a first come first served basis. Even if you have private coverage, this does not mean that you will be in a private room if none are available. Our priority is your medical needs. Your requests for accommodation will be taken into consideration whenever possible. Recipients who need a private room for medical reasons, but do not have insurance coverage, do not pay extra for their room.

Sometimes we need to move recipients from room to room. This can be unsettling and inconvenient for you. We move recipients only when we need to in order to meet the needs of all our recipients. We take the right precautions to make sure that all our recipients receive the best care possible.

Getting to know the Multi Organ Transplant Unit

The Multi Organ Transplant (MOT) Unit at Toronto General Hospital includes recipients who:

- Have recently had a liver, lung, heart, kidney and pancreas transplant
- Have been readmitted for various medical reasons
- Are waiting for transplant.

Staff of the Multi Organ Transplant Unit

Nurses

The nurses on the MOT Unit are specially trained to care for transplant recipients. They work 12-hour rotating shifts.

- Day shift: 7:15 am – 7:15 pm
- Night shift: 7:15 pm – 7:15 am

Medical Staff

The Respiriologist, Fellows and residents will see you each day while you are in the hospital. The doctors may change during your hospital stay.

Nurse Practitioners

Nurse Practitioners have advanced training and a graduate degree. They work with the transplant team to assist in your care and recovery.

Other Staff

You will meet other staff during your recovery on the Transplant Unit including a physiotherapist, social worker, and pharmacist. They are an important part of the transplant team in getting you ready for discharge home.

Planning for Discharge

Members of the lung transplant team will see you daily. You and your family will be advised several days in advance of your expected discharge date. Please make sure that all preparations have been made for you to go home.

Some patients may need a short time in an exercise rehabilitation program. We work closely with a rehab hospital, St. John's Rehab. St. John's provides a specialized transplant rehabilitation program specifically for our recipients. The Transplant team continues to monitor your condition closely while you are at St. John's Rehab.

Your discharge team will help the process of transfer, provide you with further information and answer any questions you may have.

Guidelines on the Transplant Unit

Visiting

- Visiting hours are from **10 am to 9 pm**.
- In the ACU, a patient rest period is enforced from **3pm to 5pm** to allow recipients uninterrupted time to rest.
Visitors are not permitted at this time.
- All visitors must sign in at the reception desk & wear a "visitor" sticker while on the unit. This is for patient safety.

- We recommend only **two** visitors in a recipient's room at one time. We encourage the recipient and family to focus on recovery at this time. If there are more people who would like to visit, this can be done in the visitor's lounge or another part of the hospital.
- Children under 12 are **discouraged from visiting** in the recipient's rooms because of the risk of infection to the child. An adult must supervise children who are visiting. If children are restless visitors will be asked to visit with the recipient in another part of the hospital.
- Staying overnight for family and friends is **not allowed** on the transplant unit.
- Visitors for recipients in isolation must fully respect the precautions in place to protect the recipient, themselves, and other people on the unit. This may mean wearing a gown, gloves and/or mask when entering the room.
- Visitors with signs of a fever or the flu are not allowed on the unit.
- Visitors are asked to wash their hands on entering and leaving the recipient's room and the Transplant Unit. Hand sanitizer is available throughout the hospital.
- Visitors may be asked to temporarily leave a recipient's room in order for staff to provide personal care or discuss confidential matters with the recipient. Visitors may also be asked to leave if the recipient in the next bed needs extra medical care.

Choosing a Spokesperson

- During your time in hospital, we ask that you **pick one person** to be your family spokesperson to protect your privacy and ensure patient confidentiality. Please advise the nursing staff of the name of your spokesperson.
- This person is responsible for calling to see how you are doing and passing this information along to family and friends.
- Nursing staff needs to take care of you and other recipients; they cannot be dealing with numerous phone calls.
- Please do not call before 9 AM for patient information.

Flowers

- Cut flowers or plants are **not allowed** on the transplant unit. They can carry a significant infection risk to transplant recipients.

Routines on the Unit

Blood Work

Blood work will be taken most days you are in hospital. The results tell us how you are doing and how your body is reacting to the new medications.

Your blood must be drawn **before** taking your morning dose of cyclosporine or tacrolimus medication.

Fluid Balance: Intake and Output Records

Fluid balance compares the amount of fluid you take in (drinks, IV, medications) with what you put out (urine, drainage, other tubes). We also call this your **Ins and Outs**.

Fluid balance is very important to monitor your progress. It is important that you measure everything that you drink and every time that you urinate. Your nurse will tell you how to keep track of your drinking and how to measure your urine output.

Daily Weight

Weighing you every morning is another method of checking your fluid balance.

Your Recovery after Transplant

After your transplant, we will focus on:

1. Monitoring lung function
2. Watching for signs of rejection and infection
3. Adjusting your immunosuppressive medications
4. Recovery and rehabilitation
5. Teaching you about living with a transplant

Monitoring Lung Function

Our first priority is making sure your new lung is working well. The lung transplant team will see you daily while you are in hospital.

Rejection happens when your body's immune system recognizes your new lung as foreign matter. The body will try to attack the new lung and this process can damage your new lung. Identifying the early signs of rejection is important so that this process can be stopped and your new lung can continue to work well for you.

When you are immunosuppressed, you are also at more risk for infections. The tests we do to watch for rejection also help watch for early signs of infection.

Biopsies, done by bronchoscopy, are also performed routinely. A tissue sample can be sent to the lab to look for signs of rejection. Rejection can start in the cells even before you feel sick. A culture sample will also be sent to check for infection.

Your transplant team will monitor and treat early signs of rejection and adjust your medication and therapy accordingly. We will also teach you the signs and symptoms of rejection and infection so that you know what to watch for at home. Further information about infection and rejection is discussed later in this book.

Adjusting your Immunosuppressive Medications

You will immediately start immunosuppressive drugs after your transplant. These help your immune system by preventing rejection of your new lungs. You may have many changes in the drugs or doses until we find the right combination for you.

We will adjust your dosages based on your:

- Blood test results
- Symptoms
- Side effects of the medication
- Biopsy results

Teaching

During your time on the transplant unit, you will get information about taking care of your new lung transplant. We also share this information with your family members and support persons.

Recovery

The nursing staff and the physiotherapist will help you to slowly increase your activity following the surgery. This is an important part of the healing and recovery process. Pain medication will help keep you comfortable during this time. It is essential that you work with us to do more and more each day.

Chapter 11

Going Home after Your Transplant

Your Transplant team is here to help you and your family to plan for your needs at home after your transplant. Having a solid plan for transportation and living arrangements can reduce stress while you are recovering from your surgery.

Clothing

Have your family bring a set of comfortable clothes and shoes to wear home.

Medications

Before leaving the hospital you will receive prescriptions for all of your new medications. One of the advantages of the Toronto General Hospital is that we have our own Outpatient Pharmacy that carries all of the products and medications that are unique to the needs of our lung transplant patients. If you choose to fill your prescriptions at our Outpatient Pharmacy, this will ensure that all of your medications will be available to your Transplant Pharmacist at the time they carry out your final discharge teaching. The Outpatient Pharmacy is located on the first floor of the Clinical Services Building. Bring a credit card with you to pay for the medications. If you have private insurance, bring your insurance registration cards. Ontario residents under age 65 must register with the Trillium Drug plan before going on the transplant list. This information is kept on file in the computer in the pharmacy. Out-of-province recipients will have met the pharmacy staff before they are listed to record their medication coverage.

Transportation

You will have many trips to the hospital immediately after your transplant. This can be very tiring. You will need to have someone drive you and assist you around the hospital.

Lung Transplant patients are not to drive at all for the first 3 months after transplant. You should not be driving if you take narcotics such as Percocet or Tylenol #3. You should not drive yourself to the hospital for procedures where narcotics are given, such as bronchoscopies, otherwise the procedure will be cancelled.

Wear a seat belt at all times.

Medical Alert

After your transplant, it is important to get a Medic Alert bracelet. Medic alert bracelets give important health information when you are unable to tell people yourself. Medic Alert bracelets can save your life and protect your transplant in an emergency.

If you already have a Medic Alert, you will need to update the information and get a new bracelet. When completing the form, include the file number from the old bracelet.

A Medic Alert pamphlet is included with this manual or is available from the Transplant Clinic. It is your responsibility to complete the form and mail it in. Your nurse can assist you with completing this form *before you are discharged*. It normally takes 6-8 weeks to get your bracelet. Once you get the bracelet/necklace, wear it at all times.

Chapter 12

The Medications

All transplant patients are required to take medications every day for the rest of their lives. This section details some of the special instructions that will need to be followed if you are taking these medications. It will also describe the various educational programs and tools that you can use to help you learn more about these medications. Information about the common drugs are included in Appendix 1 at the back of this manual.

Your Home Medications and Complete Medication History

When you are admitted to the hospital, your Transplant Pharmacist will speak to you to obtain a complete home medication history. It is important for you to bring in all of your home medications including all prescription medications and any over-the-counter products, eye drops, puffers, creams, etc. If you have a medication list, please bring this in as well. Your Transplant Pharmacist will review all of your home medications with you to make sure that everything you need is ordered for you in the hospital.

There may be many changes to your medication regimen after your transplant. Your Transplant Pharmacist will provide you with a medication schedule. They will review all the changes with you to help you understand how to take your medications correctly at home. You will receive prescriptions for any new medications. All of your home medications will be returned to you before you are discharged.

If you are re-admitted to the hospital for any reason after a transplant, it is still important that you bring in *all* of your home medications as described above. This will help your Transplant Pharmacist to ensure that you continue to receive all of the medications you need while in hospital.

The Self-Medication Program

After your transplant, you will be taking medications to help prevent rejection and manage other health issues. The Self-Medication Program is designed to help you learn more about your transplant medications so that you will be able to take them correctly and safely when you go home.

After your transplant you will attend a Self Medication Class taught by one of the Transplant Pharmacists. Your family members or support person need to attend with you. These classes are usually held on the Transplant Unit every Monday, Wednesday and Friday afternoon. You must attend a class before you can be discharged from the hospital after your transplant. During your recovery in hospital, your nurse and pharmacist will make sure you are scheduled to attend a class. Plan to attend a class as soon as you are transferred to the Transplant Unit.

In the Self Medication Class you will learn:

- The different transplant medications you will be taking
- Why you need to take these medications
- How to take them properly
- The side effects that may occur with each medication

In these classes the Transplant Pharmacist will answer any medication-related questions you may have.

Once you have taken the class, you will be responsible for taking some of your transplant medications on your own. You will be given a one-week supply of each medication to keep at your bedside. You will be given a special form to record when you have taken each dose. Your nurse and pharmacist will check your progress daily. This will help you to better understand your medications and get into a regular routine. At the end of the week, your medication bottles will be collected and refilled. When you are ready to leave the hospital, you will be given prescriptions for all of the medications you will need to take at home.

Completing the Self Medication Program is an important step towards going home. Your participation and input are important to your success.

The Transplant Pharmacy Website

There is a lot of new information to learn and process around the time of transplant. Important questions about the transplant medications may arise before transplant, while in hospital, and even long after your transplant. Your Transplant Pharmacist will answer these questions and assist you in learning about your new medications while you are in the hospital. We have also developed some online programs and tools. These can be accessed at any time on the UHN public internet site that will help you learn more about your transplant medications.

The **Transplant Pharmacy website** is located on the UHN public Internet site. To visit the website, please follow these instructions:

1. Go to www.UHN.ca
2. Click on the “Focus on Care” link on the left side of the page
3. Click on the “Multi-Organ Transplant” link
4. Click on the “Transplant Pharmacy” link on the right side of the page

Or, you can type the address for the Transplant Pharmacy homepage directly into the address bar of your web browser:

http://www.uhn.ca/Focus_of_Care/MOT/Transplant_Pharmacy/index.asp

On the website you will find answers to Frequently Asked Questions regarding Managing Your Medications and Life After Transplant. You can also watch a short video about Your Transplant Pharmacist: Caring for Your Medication Needs During Your Hospital Stay. This video will describe some of the services you can expect from your Transplant Pharmacist while you are in the hospital. In the Patient Toolbox area you can access information regarding prescription drug

coverage and download log sheets to help you manage common medical conditions such as high blood pressure or high blood glucose.

Transplant Medication Information Teaching Tool (TMITT)

The Transplant Medication Information Teaching Tool (TMITT) is an interactive internet-based teaching program to help you and your family or support person learn more about your transplant medications. This tool is flexible and designed to allow you to learn at your own pace by selecting the specific medications and material you want to learn.

Some of the features:

- Content is divided into brief and easy to follow 'lessons'
- Customize your own learning experience
- Unique audio-visual format
- Interactive quiz questions to test your knowledge
- Printable information summaries for each medication

The TMITT program can be launched through the Transplant Pharmacy website. To access this tool you may click on the link on the right side of any page. You can also go directly to the program by visiting www.TMITT.ca

Common Post-Transplant Medications

Information on common post-transplant medications can be found in **Appendix 1** at the back of the manual. Please refer to these information sheets for details regarding your specific medications. These are medications that *may* be prescribed for you after transplant. You may also need to take other medications that are not discussed in this manual.

Your Transplant Pharmacist will teach you about your transplant medications in the Self Medication Class. They will also review all of your medications with you when you are discharged from the hospital. The Transplant Pharmacist will give you a medication schedule to follow when you are at home.

You may also be prescribed other medications to prevent or manage side effects from the anti-rejection drugs. Medications to treat common conditions such as high blood pressure, osteoporosis, and diabetes are not described here.

While taking Immunosuppressive Drugs

Side effects from medications are common, especially right after your transplant. Your body is adjusting to the new organ, as well as many new medications. Everybody responds differently to the medications. It will take time for your transplant team to establish the right drug combination and doses for you.

While recovering from transplant surgery, it is normal for recipients to:

- Be tired
- Be confused and disoriented
- Have difficulty concentrating, and
- Have difficulty sleeping.

It is important to remember that your transplant team expects these side effects and are trained to deal with them. Adjusting your medications or adding another drug may help to reduce side effects. Talk to your transplant team if you have questions or concerns about your symptoms.

Drug Interactions

Many drugs can interact with your transplant medications. Before you take any new medications, including any over-the-counter products or medications prescribed by a non-transplant doctor, you **MUST** talk to your transplant team. For example, some antibiotics, non-prescription cold medications, or herbal remedies can interact with your transplant medications to cause unwanted effects.

If you would like to take a multi-vitamin or any herbal remedy (including herbal teas), please talk to your transplant team first. Herbal remedies are like drugs and may interfere with your medications so proper precautions need to be taken.

Pain Medications

Do not take pain relief medications known as NSAIDs (non-steroidal anti-inflammatory drugs). This includes ibuprofen (the active ingredient in Advil[®] and Motrin[®] products); naproxen, which is found in Aleve[®] and Naprosyn[®]; and also ASA or Aspirin[®]. If you are taking an 81mg 'baby' Aspirin[®] once daily to prevent heart attack and stroke, this is okay if it is on the advice of a doctor. If you need to take medication for pain or a headache, acetaminophen (**Tylenol**[®]) is usually a safe choice. Talk to your transplant team before taking any other pain medication.

Chapter 13

Possible Complications after Transplant

As you recover from your transplant, it is important that you learn how to take care of yourself. You need to know about complications that may occur. You will need to manage your health issues and follow instructions for regular check-ups such as bloodwork, clinic, etc. This section will help you begin to understand your health needs after your lung transplant.

You can expect to have complications after lung transplant. The transplant team monitors your recovery and responds quickly to treat these complications.

The two most common complications following lung transplantation are infection and rejection.

The Immune System and Your New Lungs

The immune system is the body's defense system. Immunity is the way the body protects itself from foreign matter. Foreign matter can be bacteria, viruses, and foreign tissue cells.

Rejection happens when your transplanted lungs are seen as invading cells and are attacked by your immune system. The purpose of immunosuppression is to prevent this response. Rejection can be mild, moderate, or severe. In order to prevent it from interfering with the normal function of your new lungs, it is important to detect rejection early and to treat it quickly.

Rejection

You are given anti-rejection medications, also called immunosuppression medications, after transplant. You will need to take these medications **every day** for the rest of your life. The medications work together in different ways to protect the new lungs.

You should know that:

- Rejection is *common*.
- Biopsy of the lungs (bronchoscopy) and careful monitoring for signs and symptoms help diagnose rejection.
- Rejection does not mean your lung will fail.
- Giving additional medications or adjusting your drugs can treat episodes of rejection.

It is important to detect and treat rejection **quickly**. You can help by monitoring your health and reporting changes. You will need to:

- Keep a record of your daily spirometry readings
- Know the signs and symptoms of rejection
- Report any unusual symptoms to the transplant team right away.

Signs and Symptoms of Rejection

Most of the time recipients do not have any symptoms of rejection. Recipients may experience only some of the symptoms mentioned below. If you do have symptoms, they may include the following:

- Fever. A temperature of 37.5° Celsius or more
Take your temperature every day at the same time – but not within 20 minutes after eating or drinking anything. Report a temperature of 37.5° Celsius or more.
- Fatigue
More tired than usual. Lack of energy.
- Shortness of breath
Any difficulty or change in your breathing pattern with rest or with exercise.
- Loss of appetite
No interest in food. Not wanting to eat.
- Decrease in FEV1 home spirometry readings

Perform spirometry readings twice daily at approximately the same time each day (not around meal time). If the reading is down by 10% for two days report it.

- Decrease in home exercise tolerance

Report any decrease in the amount of exercise you are able to do. For example, your endurance on the treadmill at home drops. (i.e. 20 minutes decreases to 15 minutes)

If you experience **any** of these symptoms, tell your transplant team **immediately**. These may be warning signs. A biopsy (bronchoscopy) is the only way to diagnose rejection. You may feel well yet still have rejection.

Infection Risks with Transplantation

Infections are an unavoidable risk of transplantation. They are one of the most common complications after transplant. The anti-rejection drugs given to you after transplant reduce the body's ability to identify and fight off early signs of infection. Bacteria, viruses, fungus, or other organisms can cause infections. We are most concerned about chest infections (pneumonia). Most infections can be successfully treated if caught in the early stages.

We try to minimize the risk and impact of infections by

- Giving anti-infective medications at the time of the transplant surgery and afterwards.
- Antiviral medication is given for at least 3 months after transplant and a low dose of antibiotics is prescribed lifelong to prevent one type of pneumonia.
- Monitoring and testing recipients closely in the transplant clinic.

You must remember that:

- Immunosuppressive medications decrease the body's ability to fight infection.
- The lungs are a very common site of infection.

- It is important to report flu-like symptoms immediately.
- Good oral and personal hygiene are important. Good hand washing is an important first step.
- Good nutrition, plenty of rest and regular exercise all promote higher resistance to infection.
- It is best to try and avoid people who might be infectious especially in the first three months after your transplant. Avoid crowded public spaces such as public transit for the first three months.
- If you come in contact with a person with an infection (e.g. chicken pox, measles, flu, etc.), contact the transplant team.
- The skin is a major defense against infection. If you have a cut or are injured, keep the area clean and dry. Watch for signs of local infection (tenderness over the area, redness, pus, and pain). Notify your family doctor if signs of infection are noted.
- Persistent sores, blisters, lumps, or growths in armpit, groin, or elsewhere should be examined by your family physician as soon as possible.

Signs and Symptoms of Infection

- Fever
Take your temperature every day at the same time. Do not take your temperature for 20 minutes after eating or drinking anything. Report a temperature of 37.5° Celsius or greater.
- Shortness of breath
Any difficulty or change in your breathing pattern at rest or with exercise.
- Change in your home spirometry testing
A drop of 10% in FEV1
- Persistent or prolonged cough
With or without secretions.
- Increased sputum production or change in sputum
Increase in the amount of sputum. A change in colour of sputum (green or yellow) or a change in odour.

- Fatigue.
Loss of energy.

Report these signs of infection to your transplant team ***immediately***. The transplant program is fortunate to have specialized infectious disease physicians working with us to help treat your infections as quickly and safely as possible.

Some, but not all, of the infection risks associated with transplantation are discussed below.

Cytomegalovirus (CMV)

CMV is the most common viral infection that recipients get after transplant. We screen you for this virus before you are listed for transplant. Most people have been in contact with this virus before their transplant. Pre-transplant, when you have a healthy immune system, you are not likely to experience any ill effects from this virus. Since CMV is common in the general population, you may also receive an organ from a donor that is positive for CMV. After your transplant, this virus may cause mild to serious infection.

In mild cases, the virus can make you feel like you have the flu. Other symptoms include:

- fever
- chills
- fatigue
- nausea
- vomiting
- diarrhea
- shortness of breath
- abdominal pain
- change in vision

If you experience these symptoms, please tell your transplant team ***immediately***. We can test for the virus to see if you have an infection and may start medication if necessary. Anti-viral medications work well to control the CMV virus. If left untreated, this virus can be very serious.

CMV is most serious in the first few months after your transplant, when your dose of anti-rejection drugs is highest. High-risk recipients are given preventative treatment with anti-viral drugs post-transplant for at least three months after transplant which is effective at preventing infections. CMV infection is most likely to occur after the preventative treatment is stopped. You will be screened for this virus periodically after transplant.

Multi-drug Resistant Bacteria

Multi-drug resistant infections are becoming more common in the community as well as in hospitals. These infections are resistant to standard antibiotics. Two examples are MRSA and VRE. Some specialized antibiotics may be effective in this situation. We try to reduce the problem of multi-drug resistant infections in our hospital by:

- 1) Isolation of patients at risk
- 2) Routine screening of all patients on admission to hospital.
- 3) Only giving antibiotics when absolutely necessary
- 4) Good hand washing

You can help reduce the risk of infection by:

- 1) Completing all antibiotic prescriptions given to you
- 2) Good hand washing
- 3) Obeying the isolation signs posted on the hospital doors.
You may need to wear masks, gloves or gowns.

Viral Hepatitis (Hepatitis B, C)

Donors are tested for evidence of hepatitis B and C viral infections. Organs from donors who have been exposed to the hepatitis B or C virus can be given to certain recipients who have also been previously exposed to this virus or immunized and have developed immunity.

You will be screened for immunity to these viruses at the time of your assessment. *It is important to protect yourself by getting immunized while you are on the waiting list. Your family doctor can immunize you for Hepatitis B (Energix or TwinRix vaccines).* No immunization is currently available for Hepatitis C.

Epstein - Barr virus (EBV)

EBV also causes flu-like symptoms. Rarely, it can cause a disease similar to a lymphoma (a type of blood cancer) called Post-transplant Lymphoproliferative Disease (PTLD). Fortunately, most people have been exposed to EBV and have immunity. Transplant recipients without any previous immunity will be given anti-viral medications to reduce the risks of EBV. You will be screened for immunity to this virus at the time of your assessment. You can get EBV from your donor.

PTLD can be difficult to treat. While treatment of PTLD may be effective, it can lead to problems with rejection in the transplanted lung.

West-Nile Virus

Most recipients with this infection have no symptoms or only minor symptoms. This virus is transmitted by insect bites, but can be transmitted through blood transfusions, or organ transplantation. Currently, blood products and organ donors are screened for this virus.

During the spring and summer, when the risk of mosquito bites is high, you will need to take precautions. Wearing insect repellent and long sleeved clothing, and avoiding high-risk times, such as the early morning and at dusk, can help reduce your exposure to biting insects.

New Infections

As new infections emerge, the transplant program will evaluate the risk to our recipients. We will advise you on the best practices to take to reduce your risk of infection. For example, with the H1N1 flu outbreak in 2009, all recipients were asked to get immunized for this virus in addition to the regular flu vaccine.

Travel can also expose you to other infections. Some countries you travel to may require that you get vaccinated in advance of leaving home. *Do this early in your travel planning and do not wait until the last moment.* These vaccinations can be arranged through a specialized travel clinic.

In Toronto you can call **416-730-5700** or check the web site at:

<http://www.medisys.ca/travel-health/index.htm>

There is a cost associated with this visit. Travel clinics are not covered under provincial insurance. If you live outside Toronto, check for a specialized clinic in your area.

You can also check the Centers for Disease Control (CDC) website listed below regarding travel precautions and infectious outbreaks.

<http://wwwnc.cdc.gov/travel/default.aspx>

Other Common Complications

Osteoporosis

Osteoporosis is a disease where the structure and strength of the bones are weakened. This may increase your risk of fractures. Several risk factors that contribute to osteoporosis include age, diet, and menopause. Transplant recipients have an added risk for osteoporosis. Prednisone increases the risk of developing osteoporosis.

Osteoporosis is detected by a special x-ray called a *bone density scan*. A bone density test is done before your transplant to provide a baseline assessment. Later scans, done every year after your transplant, can be compared to look for changes. Patients can also be referred to specialized osteoporosis clinics.

Today there are some effective treatments available. It is important to ensure that you eat a diet that contains enough calcium, such as dairy products. Calcium pills and vitamin D supplements are used after transplant to supplement dietary intake. Stronger bone building medications will also be prescribed. Exercise is helpful in decreasing the risk of osteoporosis, particularly weight bearing exercises, such as walking, and strength training exercises. The Transplant Physiotherapists will also provide you with an exercise program.

Diabetes

Some transplant recipients are diabetics before they receive their transplant. Others may develop diabetes after surgery. Some of the antirejection medications increase the risk of developing diabetes, or can make preexisting diabetes more difficult to control. These medications include prednisone, cyclosporine and tacrolimus. Diabetes is more common if you have had high blood sugar levels before your transplant. Diabetes is also more common in older recipients, if you have family members who are diabetic, if you are overweight, or have cystic fibrosis.

Diabetes is a disease where blood sugar levels are higher than normal. The treatment for diabetes depends on the severity of the problem. Treatment may include careful control of your diet, pills, or insulin.

Having high blood sugar may make you feel unwell and cause changes in your weight. Other symptoms of high blood sugar include feeling very thirsty, hungry, and urinating often.

There are complications of diabetes that can develop over time. Kidney damage, heart disease, changes in the circulation in your fingers and toes and changes to your vision can all happen with diabetes. Careful control of your blood sugars by whatever treatment is required is the important to reducing the risk of these complications.

Coronary Artery Disease

It is important to take care of your heart as well as your lungs after lung transplantation. Make sure you eat nutritious foods low in sodium, low in cholesterol, and low in fats. We also recommend that you do not eat a large amount of sweets. It is especially important that you reduce your risk, by maintaining your ideal weight and exercising. You should **never** smoke, and minimize the amount of alcohol you drink.

Hypertension (High Blood Pressure)

You will be asked to keep track of your blood pressure once you go home. You will find out what your blood pressure is while you are in hospital.

Some recipients experience high blood pressure before their transplant. It may also be related to other factors such as age and family history. After transplant, high blood pressure is a very common complication. It is a possible side effect of the anti-rejection medication. Other medications used after transplant can create a stress on your kidneys and give you high blood pressure.

Having extra salt in your diet will cause you to retain extra water and your blood pressure will rise. You can help control your blood pressure. Watch your weight, exercise, and avoid salty or pre-packaged foods that contain high levels of sodium.

If you develop high blood pressure, you may be prescribed medications in order to bring it down to normal levels. Left untreated high blood pressure can damage your heart, kidneys, and the blood vessels in your brain.

Blood pressure pills may have side effects. The drugs that work well for one recipient may not be ideal for others. Your doctor will adjust the drugs to find the right treatment for you. If you experience side effects that you feel are related to a blood pressure pill, always let your doctor know. *Never* stop or change *any* medication on your own.

High Cholesterol

Most people develop high cholesterol levels after transplant. If you already have high cholesterol before the transplant, these levels can become higher after transplant. This complication may be related to the side effects of prednisone and cyclosporine/ tacrolimus.

Other factors can affect your cholesterol levels. These include heredity, diet, and other medical conditions such as diabetes. Your cholesterol levels will be monitored after transplant. If they are

elevated you may be asked to see a dietitian. The dietitian can advise you to reduce foods in your diet that may be contributing to high cholesterol levels. Regular exercise and weight loss can help reduce cholesterol levels. Elevated cholesterol levels are associated with heart disease and stroke. If your cholesterol level remains high after dietary and lifestyles changes, you may need medication to help lower the levels.

Increased Risk of Cancer

Transplant recipients have an increased risk of developing certain types of cancer. The antirejection medications also suppress the ability of the body to fight off early cancer cells. The most common types of cancer seen are:

- One type of lymphoma, a cancer of the blood cells (called Post Transplant Lymphoproliferative Disease or PTLD).
- Skin cancer
- Bowel cancer
- Cancer of the cervix for women

These cancers may occur at any time after transplant.

PTLD most often occurs in the first few months after transplantation. It is sometimes, but not always, associated with the use of large amounts of medication for rejection episodes. Recipients who have never been exposed and developed immunity to the Epstein Barr Virus (EBV) may be at increased risk. You are tested for EBV at the time of your assessment. PTLD is a serious complication and the treatment usually involves antiviral drugs and a reduction of anti-rejection medications. Chemotherapy may be needed in some cases.

Skin Cancer is common. You can decrease the risk of this cancer by reducing your sun exposure. Skin cancer is easily treated if detected early. Your family doctor will help screen you for skin cancer and can refer you to a dermatologist if needed. Further information about risk prevention is mentioned later in this manual.

Cancer of the cervix in women begins as abnormal cells on the cervix. All female recipients should have regular Pap smears at least once a year through their family doctor's office. Pap smears help identify abnormal cells so that they can be treated quickly. Early detection usually makes this type of cancer curable.

Bowel cancer is more difficult to detect, but all recipients should report changes in their bowel habits to their family doctor. Important changes to report include alternating diarrhea and constipation, or the presence of blood in the stool. Early detection and treatment is important. Recipients with Cystic Fibrosis or a family history of bowel cancer are more at risk and may need screening (including a colonoscopy) at an earlier age. All other recipients over age 50 years need regular screening. Your family doctor can refer you to a specialist.

Other cancers: Transplant recipients may develop other cancers at similar rates to people who do not have a transplant. The treatment for any cancer can be more complicated because of the need to maintain immunosuppression to protect the transplant. Generally the earlier any cancer is detected, the easier it is to treat. In addition to the health practices described throughout this manual, we encourage everyone to be very aware of changes in their bodies that could indicate a problem and bring it to the attention of the family doctor.

Women should have breast examinations done through their family doctor and report any abnormalities immediately. Routine mammograms are usually started once a woman reaches age 50, or earlier in some cases. Women should discuss the need for mammograms with their family doctor.

Men should do monthly testicular checks for any abnormal lumps, and should report these immediately. Men over the age of 40 should also discuss the need for prostate cancer checks, including the PSA blood test and a physical examination with their family doctor.

Kidney dysfunction

The immunosuppressive medications used after transplant are cleared out of the body through both the liver and kidneys. Immunosuppressive medications may cause kidney damage. The transplant program monitors your kidney function through your routine blood tests. If kidney damage occurs, the transplant team will adjust the dose of your medication or try you on a new combination of drugs. They may ask for an opinion from a kidney specialist (nephrologist).

Kidney damage is not the same as kidney failure. However, some of the long-term survivors have eventually had kidney failure. Kidney transplant may be an option.

Chapter 14

Taking Care of Yourself after Transplant

Clinic Visits – Ambulatory Care

After you leave the hospital you will come for regular visits at the Ambulatory Transplant Clinic on 12th Floor NCSB. Regular clinic visits allow your transplant team to monitor your health and deal with any concerns or changes. As you recover you will not need to come to clinic as often.

How often you come for clinic visits depends on your health after your transplant. For the first 3 months, we will see you every 1 - 2 weeks.

Tips for clinic:

- It is your responsibility to schedule clinic appointments
- If you need help between scheduled clinic visits, please contact your transplant coordinator using Easy Call: 416-351-0793
- Prior to each clinic visit, it is a good idea to check Easy Call to see if there has been a change in your scheduled appointment

To get the most from your clinic visit, please follow these instructions.

- Bring your hospital blue card and provincial health card (OHIP) to each visit
- Check in with the transplant reception area
- Inform the receptionist if your phone number, address, or other contact information has changed.
- Inform the receptionist if you have a new cough, fever or diarrhea.
- Attend all scheduled appointments. If you are unable to make your appointment, call the receptionist and reschedule at: **416-340-4800 Ext. 4113**
- Have your bloodwork, chest X-ray and pulmonary function tests done before the clinic, as instructed by your transplant coordinator
- Bring all of your medications and/or a list of your medications to each clinic visit
- Bring a list of questions that you have
- Book your next clinic appointment before you leave

<u>Clinic Hours:</u>	Monday Afternoon, Wednesday Afternoon and Friday Morning.
<u>Clinic Location:</u>	12 th Floor, New Clinical Services Building, Toronto General Hospital. (Take the WEST elevators).
<u>Clinic Phone:</u>	Easy Call: 416-351-0793 Reception: 416-340-4800 ext 4113.

Clinic appointments are usually once a week for the first 3 months after transplant. If you are stable this may be decreased to once every 2 weeks.

Prescription Repeats

You will be given a 3-month supply of medications when you are first discharged from hospital. Please get your repeat prescriptions at your clinic appointment. Narcotic (pain medication) prescriptions will only be given in the clinic.

Please give us **3 working days** to respond to your phone requests for repeat prescriptions.

Prescriptions – first post-transplant year

Due to the frequency of patient visits in the first post-transplant year, the lung transplant program may write prescriptions for all medications during this year.

However, during the first post-transplant year, you may be directed to local care providers or specialists for prescriptions and treatment of issues that are beyond the expertise of lung transplant program staff, such as psychiatric care and management of chronic pain.

Prescriptions – beyond the first year post-transplant

The lung transplant program will only write prescriptions for transplant immunosuppressive medications (e.g. cyclosporine, tacrolimus, azathioprine, mycophenolate mofetil, and sirolimus). We will adjust the dosages of these medications. Other medications (e.g.

antibiotics) may be prescribed on an emergency basis or as needed for conditions that affect your transplanted lungs, or side effects of your immunosuppressive medications.

Prescriptions, refill requests and dose adjustments for all other medications will be the responsibility of the local care team, even if these medications were started in Toronto during the postoperative period. The lung transplant team should be informed of all new medications prescribed by an outside provider.

Please Note:

In order to get refills of your anti-rejection medication, you must have your regular blood tests and pulmonary function testing done at regular intervals as directed by the transplant team, and be seen in clinic or by Tele-health at least once a year.

Blood Tests

You will need to have blood tests done to check the levels of your immunosuppressive medication (i.e., Cyclosporine or Tacrolimus). You will be notified how frequently these are required.

Remember: Do NOT take your morning Cyclosporine (Neoral) or Prograf (Tacrolimus) dose before having your blood work done. Your blood work should be drawn 11-12 hours after your last dose of cyclosporine or tacrolimus.

You can get your blood tests done at LifeLabs or the Toronto General Hospital. LifeLabs are prepared to do the blood tests we need. You will be given a requisition to take to the lab. There are many LifeLabs throughout Ontario. You can call LifeLabs at 1-877-849-3637 or check the website:

http://www.lifelabs.com/Lifelabs_ON/locations/default.aspx

If you do not come to the Toronto General Hospital or go to a LifeLab, you will need to pay the courier costs to transport your blood to Toronto General Hospital for testing.

Preparing for Clinic

You will require a logbook and a calendar. Bring these with you to the clinic.

What you need to do BEFORE clinic:

- Bloodwork
 - Remember: Take your Cyclosporine/ Tacrolimus **AFTER** your bloodwork. You **DO NOT** need to fast for routine blood tests.*
- Pulmonary Function Test
- Chest x-ray
- Review your medication list at home. Do you need any repeats?

BRING to clinic:

- Blue Hospital Card
- OHIP card (or other provincial medical card)
- Medication list
- List of your Questions
- Your logbook or journal recording your temperature, blood pressure, and microspirometer readings
- Bring a calendar to record your next clinic appointment and tests.
- Bring a family member or support person

DURING your clinic visit:

- Ask Questions!
- Review your medication list with lung team. This is when you ask for refills.
- You can ask for your results and ask questions about your Bronchoscopy, tests and procedures.
- Report your health changes:
 - Fevers
 - Cough, sputum, colour of sputum
 - Shortness of breath
 - Weight gain or weight loss
 - Constipation or diarrhea

- Vomiting
- Difficulty urinating
- Bleeding
- Headaches
- Difficulty sleeping
- Changes in your mood
- Changes in your vision

When you LEAVE the clinic:

- Make your **next** clinic appointment with the Receptionist **BEFORE** you leave. The lung team will tell you when they want to see you again. **RECORD** the next appointment in your calendar.
- Book your next Pulmonary Function Test with the lab.

Your Transplant Logbook

You will need to keep a log or a diary of your health status. See the following example. Bring this with you to your clinic appointments. Please collect the following information:

Date: Enter the date you record the information

Temperature: Take your temperature once a day at the same time. Do not eat or drink anything for about 20 minutes before you take your temperature.

Call if your temperature is more than 37.5 degrees Celsius and report any other symptoms.

You may be asked to repeat your temperature in 2 hours.

Blood pressure (BP): You may need to buy a BP cuff to monitor yourself at home if you have high blood pressure. Your blood pressure may change because of medications or fluids.

FEV1: The FEV1 (forced expiratory volume in 1 second) is measured daily with your microspirometer. You will need to

purchase a microspirometer a few weeks after you are discharged. You be taught how to use this device. Record the **best** results into the log each day.

Comments: Record any symptoms, problems or concerns you may have in your logbook. Bring it with you to the clinic to discuss with your transplant team. You can also record your daily exercise in this space.

Ambulatory Instructions

The following is a list of routine testing you can expect after transplant. If you have complications, this schedule will be adjusted.

Bloodwork Schedule

Less than 3 months	Once a week and as needed
3-6 months	Every 2 weeks and as needed
6 months – 2 years	Monthly and as needed
More than 2 years	Every 3 months <i>IF</i> stable or as instructed

Chest X-rays

Medical Imaging, 1st Floor. Have a chest x-ray with every clinic visit, or as instructed.

Pulmonary Function Tests (PFT's)

Call 416-340-4800 ext. 4086 at the Toronto General Hospital to schedule. Please see the schedule of PFT below. You may go for regular pulmonary function tests at your local PFT lab beyond three months after transplant, or as instructed by the lung transplant team.

Less than 3 months	Once a week
3-6 months	Every 2 weeks
6 months – 2 years	Monthly
More than 2 years	Every 3 months <i>IF</i> stable or as instructed

Hand Held Microspirometer

What is a microspirometer?

The microspirometer is a hand held calibrated medical device that measures your lung function. The lung volume is called FEV1 (Forced Expiratory Volume in 1 Second). **ALL** lung transplant recipients are required to take daily measurement readings by using this machine. This is a part of your ongoing care of your new lungs. It is mandatory that you use the microspirometer on a daily basis for the ***rest of your life.***

Purpose of the Microspirometer:

This machine is **YOUR** early warning system of changes in lung function. The readings taken allow the lung transplant team to identify possible early rejection or infection. If you notice a drop in your FEV1, call your coordinator by using the Easy Call system.

A drop in your FEV1 readings by 10% for 2-3 days in a row may indicate rejection or infection.

Example of a 10% drop:

Usual reading is 2.5 liters

10% of 2.5 = .25 = FEV1 is now 2.25 liters

Therefore a drop by 0.25 liters or greater is of concern.

Your coordinator will want to know what has changed or what is different in the following:

1. FEV1 readings?
2. Shortness of breath?
3. Coughing?
4. Sputum? Amount? Change in colour? Any odor?
5. Fever?
6. Activity tolerance, energy levels?

These details will help the lung transplant team make the appropriate medical decisions and help them decide on the best treatment.

How to use the Microspirometer:

You will need to use your microspirometer at the same time every morning on an empty stomach. A full stomach will compress the diaphragm and decrease the readings. You will get the best results when you have had a good night's sleep. **Take 3 consecutive readings every morning.**

1. Use the same position every time. Sitting up straight, using good posture will help give you higher readings. Do not cross your legs.
2. Turn the microspirometer to the BLOW setting. Take a deep breath in with the machine turned away from your mouth. Put the mouthpiece in your mouth and blow as hard as you can until your lungs are empty. Turn the machine off and then repeat.
3. Do the readings 3 times and record the numbers down in the logbook. Record the HIGHEST number. Please bring the logbook of the highest readings to clinic.

Operation and Maintenance

You purchase the microspirometer from the Transplant program. Insert the batteries in the bottom. Keep an extra set of batteries at home. If the microspirometer becomes dirty, clean it with soap and water – do not submerge in water. Mouthpieces can be purchased at the Toronto General Hospital Pharmacy. You may continue to use the mouthpiece until it gets wet or dirty. Please change the mouthpiece if you have had an infection.

Tips for erratic readings:

1. Change batteries
2. Make sure you are not breathing in with the mouthpiece facing your mouth.
3. Make sure you are using the same position every time.

You are looking for a trend in your readings. As you record the numbers over time, you will see a pattern emerge and you will learn what is normal for you.

Post Transplant Rehabilitation Program (Treadmill)

Following discharge, you will exercise as an outpatient at the Toronto General Hospital in our physiotherapy exercise room. This will occur **three times a week** until approximately three months after the transplant. If you have had a longer hospital stay you will need to continue to exercise for a longer period. Call 416-340-4800 ext 3982 to schedule your program with the physiotherapist.

Exercise is vital at this point to build your strength and endurance so that you can return to regular activities. Your physiotherapists will give you an exercise program to do on your own at home. Exercise should be seen as a lifetime commitment to optimize your health and your lung function. Exercise is as important as your medications in maintaining your health after transplant.

Transplant Day Unit (TDU)

12th Floor New Clinical Services Building (NCSB)
Call 416-340-5773

The Transplant Day Unit (TDU) is located at the Toronto General Hospital on the 7th floor of the NCSB. It is open Monday through Friday, 7:15 am until 6:00 pm. Registered nurses from the transplant unit staff the TDU. They can provide various treatments, tests and procedures for outpatient recipients as required. For example, the TDU staff can provide first dose IV antibiotics before homecare can be arranged. Your outpatient transplant coordinator will make the arrangements if you need to be treated in the TDU.

Medical Forms

- Completion of medical forms may take up to 6-8 weeks
- *If possible have your family doctor fill out medical forms.*
- There is a cost for filling out forms that are not covered under the provincial health insurance plan
- Medical forms cannot be filled out during clinic visits

- Please complete the patient portion of the form with your name. You must *sign the medical release*.
- Give the forms to your Transplant Coordinator or the Administrative Assistant.

Guidelines for routine requests

Requests for letters, forms and prescriptions must be made well in advance. Same day service cannot be provided. Requests can be made as Easy Call messages.

Here are the guidelines that we use:

Prescription Renewals	3 Business Days Notice
Travel Letters	30 days before date of travel
Insurance Forms	6-8 weeks notice – ensure patient part with your name and date of birth is completed first. You will need to <u>sign the form</u> for release of information. Your family doctor may also be able to complete forms for you.

Telehealth Conference 2 years after Transplant

What does this mean?

Telehealth is a live 2- way video conference between you, your support person or family member, and members of the lung transplant team. The Telehealth program will decrease the time you spend in clinics at the hospital and the cost of traveling to Toronto. This appointment is meant to mimic a clinic appointment.

Who is involved?

Telehealth sees Ontario Lung Transplant recipients who live outside the 416 and 905 area codes. Recipients who are at least 2 years post transplant can be assessed this way. Instead of coming to Toronto for your yearly post-transplant assessment, you will be seen at your local

hospital through a Telehealth connection with the lung transplant team. Visits to Toronto may still be required for special problems that cannot be managed by Telehealth.

What happens at a Telehealth visit?

The Lung Transplant Coordinator and Administrative Assistant will set up the Telehealth appointment. An assessment package with all the instructions is mailed to your home. The address and instructions for the Telehealth facility close to your home is in the package. Once the appointment is made, it would be very difficult to cancel and rebook. *Please make sure you keep this appointment.*

The annual post-transplant tests will be arranged locally **BEFORE** the Telehealth visit. These include:

- Pulmonary function tests
- Blood gases
- Chest x-rays
- 6 minute walk
- Bloodwork

The transplant team will review all your tests during the Telehealth visit.

Regular communication between yourself and the lung team will not change. Easy call is still the main tool of communication.

How can I prepare for a Telehealth visit?

- Get all your testing done **before** the scheduled Telehealth visit.
- Have any questions or concerns written down so you can review with the transplant team during your visit.
- Review your medications at home before the Telehealth visit. Bring a list of your medications with you to the appointment. Inform your coordinator or doctor that you need repeats.

Bronchoscopy

After your transplant you will have regular bronchoscopies and biopsies to check for rejection or infection. A bronchoscopy is the only reliable way of diagnosing rejection.

Standard Bronchoscopy schedule post transplant

- 2 weeks (usually while still in hospital)
- 6 weeks
- 3 months
- 6 months
- 9 months
- 1 year
- 1½ year
- 2 years

If necessary, extra bronchoscopies will be booked, depending on your individual needs.

How is it done?

During the bronchoscopy the back of your throat will be frozen or numbed with medication. You will be given IV sedation that will make you sleepy. A small fiber optic probe (about the diameter of your baby finger) will be inserted, allowing the doctors to see inside your airways and lungs. There is a small tweezer attachment on the probe that can remove small pieces of tissue (a biopsy) if needed. The tissue can then be examined under a microscope to determine whether rejection is occurring. Rejection can start in the lung cells before you start to feel sick. It is also possible to collect specimens of fluids from the lungs during the Bronchoscopy to determine whether there is any infection.

Instructions for Bronchoscopy

- Do ***not*** have anything to eat or drink after midnight the night before.
- Take your morning Cyclosporine or Prograf with a sip of water.
- Take your blood pressure pills and medications for your stomach, such as Losec or Pariet, with small sips of water regardless of the

- time of the bronchoscopy. If you do not know which drugs these are, check with your Transplant Coordinator.
- Discuss with the transplant coordinator whether or not to take any other medications prior to your bronchoscopy.
 - ***You must have a family member or support person with you.*** You must be escorted from the Endoscopy Unit on the day of the bronchoscopy.
 - You will not be allowed to drive home after the bronchoscopy because of the sedation that is used. ***If you do not have transportation home, your bronchoscopy will be cancelled.***

Diabetics

- If you are on pills for your diabetes, please hold your morning dose of the diabetic pills before the bronchoscopy
- If you are on insulin, please take only a ½ your normal dose of the long-acting insulin. Do ***NOT*** take any short-acting insulin. If you are unsure, please check with your Transplant Coordinator.
- Do ***not*** have anything to eat or drink.
- Bring your blood sugar monitor to check your blood sugar after the bronchoscopy.
- Bring a snack to eat soon after the bronchoscopy is done to prevent a drop in your blood sugar.

Family Doctor

You ***must*** have a family doctor before and after transplant. We expect that you will stay in touch with your family doctor and see them about regular health issues not related to your transplant.

The transplant team will send your family doctor a booklet about taking care of transplant patients along with regular updates from your appointments. We work in partnership with the family doctor and are available to them if they have any questions.

Annual Checkups

You need to take care of your whole body, not just your new lungs and annual health examinations (“check-ups”) with your family doctor are very important.

Women require yearly gynecological check-ups with a Pap smear, breast examinations, and routine mammograms depending on age. Men should be checked yearly for testicular cancer and enlargement of the prostate gland, through both the blood test and physical examination for prostate cancer.

Colon cancer screening tests (stool testing with sigmoidoscopy or colonoscopy) needs to be performed regularly. Your immunosuppressive medications place you at higher risk for the development of some types of cancer. Early detection of cancer is very important.

A yearly bone mineral density test is also important to monitor for osteoporosis. We ask that your family doctor arrange this.

It is also important to have an annual eye exam by an eye doctor (ophthalmologist). Prednisone can increase your risk of developing cataracts. If you notice any changes in your vision tell your family doctor and make an appointment with an optometrist or ophthalmologist.

Referrals to other medical specialists for routine issues (e.g. cancer screening, aches and pains, etc.) will be the responsibility of your family doctor. The lung transplant program may send you to specialists for complicated problems which would be best managed at a transplant hospital. We are happy to speak to your family doctor or local specialists at any time to decide on the best course of action.

Vaccinations

Please see your family doctor for a record of your vaccinations.

Flu Shots

Taking anti-rejection drugs means you are more prone to common flu viruses. After your transplant, we strongly recommend that you and all the family members in your household get the flu shot each fall. The transplant clinic does not give the flu shot. Please arrange to have it at your family doctor's office. If you have just received your transplant and this vaccine is due, talk to your transplant team first.

If you have an allergy to eggs, do not get the flu shot. This vaccine has a protein ingredient very similar to the protein found in eggs.

Pneumovax

Transplant recipients are also encouraged to get vaccinated with Pneumovax for additional protection from pneumonia. Based on current guidelines, the Pneumovax vaccine should be received once before your transplant and then once every 3-5 years following that. Your family doctor can arrange for you to get this shot.

Tetanus

The tetanus vaccine is due every 10 years. Please arrange for this with your family doctor.

Hepatitis B

After your transplant, being protected against hepatitis B is important. The hepatitis B vaccination is a series of 3 shots given over 6 months. We will tell you to start these shots if needed as soon as you are on the waiting list for transplant. Your family doctor can give you these shots. If you did not complete the series of shots before your transplant, you will need to restart the shots after your transplant. Please wait 6 months before doing this. There may be a cost associated with this vaccine.

Human Papilloma Virus (HPV)

The HPV vaccine is suggested for young men and women less than 26 years of age. This vaccine may reduce the risk for women developing cancer of the cervix. This virus can be transmitted by men through sexual intercourse.

Live Virus Vaccines

Recipients who are immunosuppressed cannot receive vaccines that contain a live virus. There is a risk that you will catch the illness you are trying to prevent with the vaccine. The vaccine for chicken pox (varicella) is an example of a live virus vaccine. Please check with your doctor before receiving any vaccines. This is also important if you need vaccinations before traveling.

Dental Care

Dental hygiene is a very important part of managing your health. Eating a healthy diet will help maintain strong healthy teeth. Brush your teeth at least twice daily and floss at least once a day. Use a soft bristled toothbrush. Examine the inside of your mouth for any sores or swelling of your gums. Let your dentist or family doctor know of any unusual mouth sores, swelling, or bleeding of the gums.

Visit your dentist twice a year for cleaning and an examination. Tell your dentist that you have had a transplant and your immune system is suppressed. You may need additional antibiotics for some dental procedures. Some antibiotics, such as Erythromycin or others in that class (called macrolides), must be avoided because they interfere with Cyclosporine or Tacrolimus. The decision to use antibiotics is the dentist's choice. The dentist will provide you with a prescription for this. The dentist can call the lung transplant office for information or if they have any questions.

Chapter 15

A Healthy Lifestyle

Driving and Seat Belts

- Do not drive for 3 months after your transplant. Do not drive on days you are scheduled for a Bronchoscopy.
- Do not drive if you feel tired, are having dizzy spells, headaches or visual disturbances.
- You cannot drive while you are taking narcotics for pain control.
- Always wear your seatbelt when you are driving or riding in a vehicle. If your incision is tender, put a towel under your seatbelt to protect your incision.

Diet and Nutrition

“Eat food. Not too much. Mostly plants.”

Michael Pollan

Diet

Eat a healthy diet with a balance of protein, fat and carbohydrates. Be careful about portion size.

Remember: You *cannot* eat grapefruit or drink grapefruit juices after transplant. It interferes with the absorption of your immunosuppressive medications.

Overweight and Obesity

Recommendations for a healthy body weight:

- Eat a healthy balanced diet
- Decrease your portion size
- Exercise regularly

A healthy post-transplant BMI (Body Mass Index) is between 18.5 and 24. If you need help, the transplant dietitian is available to discuss these issues with you.

High Cholesterol

Your cholesterol will increase after the transplant due to the medications.

Recommendations to decrease cholesterol:

- Decrease portion size
- Decrease total fat intake
- Decrease intake of saturated fats
- Decrease intake of cholesterol (read food labels)
- Achieve a healthy body weight and a BMI within healthy guidelines
- Exercise regularly

You may require additional medications to help lower your cholesterol.

Osteoporosis

Some of the medications such as prednisone, cyclosporine and tacrolimus may cause changes that are needed for normal bone health. You may require additional medication to help protect your bones from these changes, such as calcium and vitamin D, and specialized bone building drugs called bisphosphonates, such as Fosamax.

Recommendations for healthy bones:

- Eat a healthy diet, with a good intake of calcium, magnesium, vitamin D and protein. You may ask the Transplant dietician for guidelines.
- Exercise regularly, especially weight bearing exercises
- Achieve a healthy body weight, with a BMI within healthy guidelines between 18.5 and 24

Diabetes Mellitus

The goal of nutrition management for patients who develop diabetes after transplant is to maintain good blood sugar control, appropriate body weight and healthy eating. You may need medication (pills or insulin) to help control your blood sugar in addition to healthy eating.

The general guidelines for healthy eating for patients with diabetes are:

- Eat three meals per day at regular times
- Limit sugars and sweets such as sugar
- Limit the amount of high fat food you eat
- Eat more high fiber foods
- Limit sugars contained in commercial drinks (pops and juices). If you are thirsty, drink water

Recommendations for diabetic management:

- Exercise regularly
- Monitor blood sugars regularly
- Achieve a healthy body weight with a BMI within healthy guidelines between 18.5 and 24

Recipients with cystic fibrosis should not restrict their food intake to manage high blood sugars.

You can find more information on the following Website:

<http://www.diabetes.ca/files/JTBcpg03.Pdf>

Supplements

Many patients ask about using other supplements such as vitamins and minerals. Please refer to the following guidelines:

Multivitamin and mineral supplementation: A daily multiple vitamin (such as Centrum) may be used.

Calcium: A total of 1000 mg elemental calcium per day. Take one-500 mg elemental calcium twice per day. Calcium carbonate 1250 mg contains 500 mg of elemental calcium in each tablet.

Vitamin D: While on Prednisone, you will need an additional vitamin D supplement, minimum 1000 IU per day. The transplant program may adjust these doses depending on your individual needs.

Vitamin E: do **NOT** take this vitamin as it can cause problems such as bleeding. This could be an issue during bronchoscopy or other interventions.

Complimentary Alternative Medications (CAM)

Recipients often ask about the use of CAMs. The most common questions are regarding the following products:

- St. John's Wort (Hypericum perforatum): do NOT take this supplement. It interferes with your immunosuppressive medication Cyclosporine and Tacrolimus.
- Echinacea (Echinacea purpurea): This is an immune booster and should NOT be used. We are trying to suppress your immune system after transplant, not boost it.
- Garlic (Allium sativum): This may cause bleeding and should NOT be used. This could be an issue during bronchoscopy or other interventions.
- Ginkgo (Ginkgo biloba): This may also cause increased bleeding. Do NOT take this supplement.
- Other CAMs: Very little research has been done on CAMs and the effect that they have on transplant medications. We recommend that you **do not take any** CAMs until you have discussed this with a lung transplant team member. The use of CAMs may interfere with your transplant medications and put your lung transplant at risk. We can review with you any information that is available and jointly agree if you should take the supplement.
- Probiotics: Many foods contain prebiotics and probiotics, known as functional foods. Eating foods with pre- and/or probiotics added may be beneficial. Taking a supplement (pill or capsule) with pre- or probiotics is not recommended. Not enough research is available to see how pre- and probiotics interact with your transplant medications. It may be helpful to eat yogurt with prebiotics added, when taking an antibiotic. This will help the 'good' bacteria to reform and help with regular bowel movements. However, there are no standards in the food industry regarding pre- and probiotics and the food you eat may not actually contain the ingredients on the label.

- Please note: Drinking ginger or other herbal teas in moderation, tea, sprinkling ginger on food as part of a recipe and using garlic in cooking are all acceptable. Our concern is when you are taking a concentrated source in a ***pill form***.

Travel

It is recommended that you do not leave the country for the first 6 months following your transplant. When you do plan a trip, it is very important that you talk to your transplant team before you travel. You need to plan carefully so that you can enjoy your trip.

Here are some tips for traveling.

- You might need vaccinations well in advance of your trip depending on where you are planning to travel. *Do this early and do not wait until the last moment*. These vaccinations can be arranged through a specialized travel clinic. You can check their web site at:
<http://www.medisys.ca/travel-health/index.htm>
In Toronto call **416-730-5700** or check with a travel clinic in your local area. There is a cost associated with this visit. Travel clinics are not covered under provincial insurance.
- Vaccinations containing a live virus ***must*** be avoided. Tell the travel clinic you are a transplant patient and immunosuppressed.
- It is very important that you purchase out-of-country health insurance. Your travel agent can help with this.
- We recommend that you purchase airline cancellation insurance. If you have a complication from your transplant you might have to cancel your trip.
- Ask your transplant coordinator to give you a ***travel letter*** 30 days before your trip. This letter includes a record of your medication, your most recent laboratory results and emergency contact numbers. This information may be important if you get sick in another city or country.
- Always carry your medication with you in your carry-on luggage in their *original* bottles and packages. ***Never*** put your medication with your luggage.

- Take an extra supply of medication in case your return trip home is delayed.
- Be prepared to return home if you become ill while traveling
- Ask about taking an antibiotic with you in case it is needed. Your transplant doctor or family doctor can give this to you.

Pets

A special concern for patients on immunosuppression is the possibility of catching infection from a family pet. For example, some pets, especially cats, could infect you with a disease called Toxoplasmosis. Birds can cause respiratory illness. Use these general guidelines to help decrease your chances of getting an infection from your pet.

Guidelines for contact with your pet

1. Wash your hands after handling your pet, especially before eating.
2. Keep your pet clean and have it groomed by another person.
3. Talk to your vet about flea and tick prevention.
4. Minimize contact with your pet's body fluids (vomit, feces, urine & saliva). Do not clean out the litter box.
5. Clean up pet fluids with a disinfectant. Have someone else do this if possible. If you have to do this wear gloves and a mask.
6. Do not let a pet lick any wounds, cuts, or your face.
7. Keep your pet's vaccinations up to date.
8. Take your pet to the vet at least once a year for a check up or more frequently if sick.

Talk to your transplant team for more information related to pets. Other animals are known to put you at greater risk for infection. We suggest that you stay away from such animals. They include:

- Stray or wild animals
- Exotic animals
- Sick animals

Sunscreens

As a transplant recipient you are at a much greater risk of developing skin cancer. Taking immunosuppressant medication increases the risk. Skin cancer is the most common cancer seen in long term transplant survivors. Prevention of skin cancer, by reducing your exposure to the sun, is recommended.

Prevention of Skin Cancer

- Applying a sunscreen with a SPF (sun protection factor) of at least 30. Protect your lips as well.
- Wear a hat, long sleeve shirts and pants when you are out in the sun.
- Avoid the sun when possible between the hours of 11:00 a.m. and 3:00 p.m.
- If you are swimming or sweating heavily, reapply your sunscreen after drying off or if still sweating. Even if you use a waterproof sunscreen you must reapply it regularly.
- On cool, cloudy or overcast days, 70-80 percent of the sun's ultraviolet (UV) rays still get through. You still need to be careful. Remember that sitting in the shade or swimming underwater does not protect you. UV rays go through water.
- Remember your sunscreen even in winter months if you are outside for a period (e.g. skiing, skating).
- UV light is reflected from sand, concrete, snow and water intensifying your exposure.
- Also note that exposure to UV light may cause cataracts: protect your eyes with UV-filtering sunglasses (both UVA and UVB filtering).

Examination of your skin and monthly checks for moles are a wise precaution. Use a mirror to check your back and the back of your legs. Look for any scaliness, changes in the colour or shape of moles, or any persistent itching or oozing. If you are worried about your skin or a mole, or in doubt see your family doctor. You may need to be seen by a dermatologist.

Sexual Activity

You may resume sexual activity as soon as you feel ready. You can ask your transplant coordinator if you have questions.

Many patients have a loss of interest in sex before transplant due to feeling physically unwell. Your interest in sex may return after the transplant, once you are feeling better.

Please note that some side effects from the immunosuppressant medication can contribute to decreased sex drive and erectile dysfunction. You can discuss this problem with the transplant team or your family doctor.

You must always remember that your immune system is suppressed and therefore you are at greater risk for contracting an infection. Everyone has to be concerned about sexually transmitted diseases such as HIV/AIDS (acquired immune deficiency syndrome), genital herpes, and Hepatitis B, and Hepatitis C. You must be aware of how to protect yourself. Sexually transmitted diseases are contracted through sexual activity, where there is an exchange of body secretions from one person to another. Using a latex condom along with contraceptive foam greatly decreases the risk of contracting a sexually transmitted disease or pregnancy. Discuss safe sexual practices with your partner.

Birth Control - Planned Parenthood

Pregnancy

Although pregnancy in transplant recipients is not encouraged, it is possible for young women to have children after transplantation. You should be aware:

- Your pregnancy may be complicated, requiring hospitalization.
- The incidence of birth defects in the baby is higher for immunosuppressed patients.
- The risk of rejection increases with pregnancy.

- If the disease that caused your lungs to fail is hereditary (such as Cystic Fibrosis), there is the risk you could pass along this disease or genetic defect to your child. Genetic counseling is strongly recommended.

If, after considering all of the possible health issues, you still wish to become pregnant, discuss this with the transplant team. We **strongly** recommend that you plan your pregnancy and consider the long-term impact this will have on your transplant and the rest of your family.

Contraception

For pregnancy prevention, using the double barrier method is recommended. This involves the use of condoms and contraceptive foam, or a diaphragm and contraceptive foam. The double barrier method is effective and has a low failure rate if used correctly. A woman must see a gynecologist to be fitted for a diaphragm. If you need more information regarding the proper use of condoms and contraceptive foam, please ask your family doctor or the transplant team.

The birth control pill may not be recommended for some transplant recipients. Women wishing to use a birth control pill should discuss this with the transplant team first. There is also a higher incidence of infection associated with the use of an IUD in transplant recipients. The risk is lower with newer types of IUDs, but this should also be discussed with the transplant team.

Exercise & Activity after Transplant

Before your transplant your illness made you weak and limited your activity. After transplant surgery, it will take time to heal and recover. Part of this process begins with activity and exercise.

Gradually you will be able to do more and more. Regular activity and exercise is important to stay healthy at all stages of your life after transplant. You will be exercising after your transplant in the physiotherapy exercise room. This will help you develop the “habit” of

exercising. It is essential to continue exercising once you return to your regular activities and are no longer in a supervised program.

We recommend 30 minutes of cardiovascular activity such as speed walking or biking 3 to 5 days per week. Your physiotherapist will provide you with guidelines for a home-based program.

Activity Post Transplant

Post transplant we hope that you return to a normal, active life. There are some activities that require special precautions and others that we may suggest you avoid all together for your long term health.

What ever activity you decide to do it is important to remember to think about your own safety. Wear the necessary protective equipment. For example, wear a properly fitting helmet when biking or skiing.

The long term use of prednisone and the effects on your bones may make some activities riskier if you fall. Broken bones may take longer to heal, may result in chronic pain and potentially affect your quality of life.

Below is a list of activities patients have asked us about in the past. If you do not see an activity listed here, please ask your transplant team.

Activities with extra caution:

Horseback riding: The grooming of a horse following a ride and the cleaning of the stall can increase your risk of infection. We suggest you use caution by using a mask and gloves.

Gardening: Wear a mask and rubberized gloves when gardening. Fungus spores in the soil can cause lung infections. If the soil is dry and dusty, consider watering it first to reduce the amount of airborne particles.

Spelunking or caving: Hiking, swimming or rappelling into caves should be avoided as there is a risk that you may inhale fungal spores which may result in an infection.

Swimming: Should be avoided until your chest incision heals. Use caution with swimming if you have open cuts or sores.

Hot Tubs: Use of a private hot tub is okay if it has been cleaned and maintained regularly.

Strength Training:

Strength training is important after your operation. Your physiotherapist will give your guidelines on the intensity of this type of exercise. Your incision needs time to heal. Bench pressing is especially straining on the chest. It should be avoided minimally for the first 3 months.

Activities to avoid post transplant

Tattoos/Piercings: The risk of infection from a tattoo or piercing is increased post transplant. We recommend that you avoid these.

Scuba diving: Scuba diving increases pressure on your lungs potentially creating problems. Caution must be used if performing this sport. Snorkelling is an acceptable activity.

Contact sports: Contact hockey, football, boxing, martial arts or fencing should be avoided post transplant due to the potential trauma to your chest.

If you have questions about other sports or activities, please speak with your transplant team.

Returning to Work

You may plan to go back to work after your transplant.

- Before you go back to work your transplant doctor needs approve your health status.
- The most important thing to consider is the physical activity and requirements of your job.

- You may need to modify your work schedule when you first start back at work.

You will be off work for several months after transplant.

- This gives you time to recover from surgery and adjust to your transplant.
- Acute rejection and infection are most likely to happen in the first 3-6 months after your transplant. It is important to wait until you have passed this high-risk period before you go back to work.
- You will be coming to the transplant clinic often during the first 3 months.

Chapter 16

If You Get Sick at Home

When you are discharged from hospital, you will be taught to watch for signs and symptoms of infection and rejection (Pages 84-87). If you get sick before your next scheduled clinic appointment, you need to call your transplant coordinator or Family Doctor. You may be scheduled for the next Transplant clinic or instructed to see your Family Doctor or go to the local Emergency Room.

Monday to Friday, between 8:30 a.m. and 4:00 p.m. you can leave a message through Easy Call:

416-351-0793

These calls are checked regularly during regular workdays. Please refer to your Easy Call instructions for more details.

If there are concerns that cannot wait until the next business day, the staff at Telehealth Ontario is available for further consultation. We have partnered with them and provided staff there with specific information about transplant. The service is free of charge and available to all our patients. The toll free number is:

1-866-797-0000

Your family doctor is expected to take care of minor problems or non-transplant related issues. Please notify your transplant coordinator if you have been started on any new medications.

In an emergency

*Sudden shortness of breath or chest pain is an emergency.
Dial 911 for an ambulance. You will be taken to your closest hospital emergency room.*

When you arrive in the emergency room, let the doctors know you are a lung transplant patient at the Toronto General Hospital. Call your

coordinator on Easy Call if you have been seen in an emergency room and sent home or are admitted to another hospital.

What to do if you have the following symptoms?

Outside of office hours you can use the chart below to help you decide what to do about different symptoms.

Symptoms	What to do
<ul style="list-style-type: none"> ▪ Sudden, severe shortness of breath ▪ Chest pain ▪ Excessive bleeding ▪ Unable to take your immunosuppressive medications for more than 1 day ▪ Continuous vomiting for a few hours or days ▪ Changes in level of consciousness or delirium 	<p>Dial 911 or go to your local Emergency Room</p>
<ul style="list-style-type: none"> ▪ Sore throat ▪ Gout or joint pains ▪ Severe new onset back pain ▪ Pain or burning with urination ▪ Constipation or diarrhea 	<p>Urgent: See your Family Doctor and notify your Transplant Coordinator</p>
<ul style="list-style-type: none"> ▪ Flu-like symptoms ▪ Redness, swelling, pain from incision site ▪ Persistent cough ▪ Change in colour of sputum ▪ More sputum than usual ▪ Fever 37.5 to 38 degrees 	<p>Call your Transplant Coordinator the next working day on Easy Call</p>
<ul style="list-style-type: none"> ▪ Any outside doctors visit or medical consults ▪ Any outside emergency room visits 	<p>Notify your Transplant Coordinator by Easy Call</p>

Chapter 17

The Easy Call System

Communication between you and your transplant coordinator is one of the most important parts of follow-up after transplant. To make this as easy as possible, the Transplant Program has a recipient voice message system called “**Easy Call**”.

The system has been designed to meet the special needs of the transplant recipients and their coordinators. It enables our growing number of transplant recipients to pick up and leave messages for their transplant coordinator quickly and easily.

You can use Easy Call any time you need to communicate with your transplant coordinator.

Easy Call features:

- Access 24 hours a day, 7 days a week
- Access from any touch tone phone
- Transplant Coordinator can contact recipient urgently
- Message access for other health care professionals
- Message cues available in six languages
- Recipients can repeat messages to ensure understanding
- Easy Call saves and archives all messages.

All recipients are encouraged to have touch-tone service on their phones so they can easily access the system.

Each recipient will be assigned a personal identification number to access his or her voice mailbox. This is called a PIN number. This number will also be used as your password for the Easy Call system.

If you have any questions, please speak with your transplant coordinator or their secretary. You will be given an information pamphlet as well as wallet cards to help you remember your Easy Call PIN number and the phone number to access the system.

The Purpose of Easy Call

- Easy Call is an efficient communication between you, your coordinator and your transplant program.
- **Messages are picked up regularly during on business days. (Monday to Friday) from 8:30 am to 4:00 pm.**
- Messages will be responded to via Easy Call as soon as possible depending on the urgency.
- Your Coordinator may still try to contact you over the phone for important discussion or information relating to medications, urgent appointments, etc.
- The Easy Call system can receive messages 24 hours a day, 7 days a week. You can access it from ANY touch-tone telephone.

Your message will be returned on the next business day if you call in the evening, on weekends or holidays.

Your PIN Number

- You will be assigned your own PIN number.
- Please write it down in your transplant manual.
- Make sure that anyone who will need to access your Easy Call messages, such as family members or support people, know your PIN number.
- Please remember to give important phone numbers to the transplant program (cell, cottage, work, or other contact numbers) to ensure that your Coordinator can reach you.
- If you change your address, phone number or health card, please let your coordinator know as soon as possible.
- Easy Call should only be used by you and your family. Family Doctors or pharmacies can reach the transplant program using other numbers.

How to Use Easy Call

- Please refer to the guidelines in the manual and in the pamphlet for:
 - Picking up messages
 - Leaving messages
 - Contacting reception for clinic changes

Access to Easy Call

To pick up or leave messages please dial **(416) 351-0793**

- You will hear the following voice message:
“Welcome to the Multi Organ Transplant Program of the Toronto General Hospital. If you have a Personal Identification Number or PIN number, please press the pound sign (#) now.”
 - Press the # key on your telephone keypad.
 - You will hear the following message:
“Using your touch-tone keypad, please enter your PIN number.”
 - Enter your PIN, followed by the # key. The system will then say your name.
 - You will hear:
“To confirm that you have accessed the correct mailbox, please re-enter your PIN number.”
 - Enter your PIN again, followed by the # key.
 - You have now accessed Easy Call.
-

The system will now give you **2** choices:

- “To listen to messages in your mailbox, please **press 1.**”
- “To leave a message, please **press 2.**”

To Pick Up a Message in Easy Call

1. After accessing Easy Call with your PIN, press “1”.
2. You will hear:
“You have ___ new messages. To review new messages, please press 1. To review old messages, please press 2.”
3. Choose to press either 1 or 2 to hear any new or old messages.
4. Sometimes the system will ask you to repeat a message that has been left by your coordinator. This ensures that you have heard and understood the message correctly.

In this situation, after hearing the message, you will hear:
“We need to make sure you have understood this message correctly, please repeat this message after the beep.”

5. In these cases, repeat the message, as you understood it. This allows your transplant team to make sure that important information is heard and understood correctly.

Tips:

- After listening to each message, you can listen to it again.
- Messages cannot be deleted. They are saved for a time before being stored and archived so that recipients can replay or review them if needed
- Once you are done listening to messages, press 9 to hang up.
- Easy Call can be accessed 24 hours/day and 7 days/week.

To leave a message in Easy Call

1. After accessing Easy Call with your PIN, press “2”.
2. You will then hear:
“If you have a message about a clinic appointment, please press 1. To leave a message for your transplant coordinator, please press 2.”
3. Choose to press either 1 or 2 depending on what you need.
4. If you choose 2, you will hear:
“Remember, messages left for your transplant coordinator will only be picked up from Monday to Friday, between 8:30 am and 4:00 pm. If this is a medical emergency, please go to your nearest Emergency Department, or hang up and dial 911. At the “beep”, record your message.”
5. Leave your message after the beep, and then hang up.

The Transplant program picks up Easy Call messages during regular workdays. Messages are not picked up on nights, weekends or Statutory Holidays.

Tips for Easy Call:

- Pressing “#” may shorten cues.
- Pressing “8” will return you to the previous menu.
- If you forget your PIN number, you can still leave a message on Easy Call by listening further into the menu and choosing your Coordinator’s name. Leave a message and the transplant office will call you directly to let you know your PIN number.
- As a new patient, you should check Easy Call daily – especially after clinic appointments.
- After 3-6 months, depending on your state of health, you should be checking messages weekly.
- Check before clinic visits in case you are advised to bring something or the clinic time or date has been changed.
- You should also check messages a few times after clinic appointments or tests for any information.

Hailing – Urgent Messages

- The Transplant office can “hail” a message to you – this means it will make your phone ring every hour, until you pick up the message.
- The Transplant office will hail a message to you if it is urgent. For example new appointments booked within the next week, reminders for biopsies, medication changes, or urgent test results will be hailed.
- After discharge the Transplant office will hail your Easy Call as a trial to ensure the system has the correct numbers inputted.
- When you access Easy Call for a hailed message you will hear the following:
 - “(your name)”, has an urgent message.
- Hails will continue until you pick up your message on Easy Call.
- Hails happen hourly between 08:30 am and 10:00 pm – the phone will not ring through the night, but will begin again the following morning until you pick up this message.

Emergency

- In an emergency DIAL 911
- For urgent matters **DO NOT** use Easy Call. **Call the Telehealth Ontario @ 1-866-797-0000** or go to your local Emergency Room.
- Messages are not picked up on weekends, evenings and holidays. Messages will be picked up on the next business day.

PLEASE MAKE SURE THAT ALL MEMBERS OF YOUR HOUSEHOLD KNOW ABOUT EASY CALL

Chapter 18

Feedback

We want to know what you think

As a transplant recipient, we care about what you think. Your feedback is important to help us improve the care we provide to our recipients.

If you have any suggestions regarding this manual, please speak with your transplant coordinator. If you have any problems or concerns regarding the care you received, please tell us. In the hospital, you can speak with the Charge Nurse or the Nurse Manager for the inpatient area. When discharged, you can speak with your transplant coordinator, the Manager of the Ambulatory Clinic or your physician.

If you would prefer, the Patient Relations Department can help you. The Patient Relations Department would be pleased to hear both your concerns and your compliments.

Patient Relations can be reached at:

Patient Relations Office
1st floor - Room 401
R. Fraser Elliot Building
Toronto General Hospital
Phone: (416) 340-4907

Saying “Thank You”

Transplant recipients often wonder how to say “Thank you” to their donor’s family. If you had a living donor such as a friend or relative, saying thank you can be done in the traditional way. When your donor is an anonymous person whose organs were donated by their family at the time of their death, a “Thank You” can be difficult.

You may want to write to the donor's family to express your thanks. Although it may be a challenge to write a letter, many transplant recipients welcome the opportunity to express their thanks. Thank you letters, or cards, may be a comfort to donor families as they deal with their loss.

There is no right or wrong time to write to the family. Some recipients feel that they want to write immediately. But you might need time to recover from your surgery before you are able to write.

Under the Human Tissue Gift Act, the government of Ontario requires we keep your identity and your donor's identity confidential. For this reason, we ask that you do not include your name, where you live, your cultural background, religious affiliation or workplace in your letter. Some things you may want to include are:

- How long you waited for your transplant
- How you felt while you waited
- How you feel now
- What you are looking forward to doing in the future.

When your letter is complete, give it to your transplant coordinator in an unsealed envelope so that it can be reviewed before being sent to the donor. Your coordinator will then forward your letter to the staff at the Trillium Gift of Life Network who will send your letter to the donor family.

Occasionally donor families will send correspondence to recipients through the Trillium Gift of Life Network. If this happens, your coordinator will let you know.

Chapter 19

Appendix 1

Common Post Transplant Medications

**CYCLOSPORINE
(Neoral®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
Cyclosporine Strengths: 10, 25, 50 and 100 mg capsules 100 mg/ mL oral solution	NEORAL®	Cyclosporine is an anti-rejection drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

- 1. INCREASED BLOOD PRESSURE**
 Your blood pressure will be monitored. You may require treatment with blood pressure medications.
- 2. HARMFUL EFFECTS ON THE KIDNEY**
 The level of cyclosporine in your blood will be closely monitored and the dose will be adjusted if needed. Your kidney function will be monitored with a blood test called creatinine.
- 3. TREMBLING OF THE HANDS**
 This is usually related to the level of cyclosporine in the blood. This usually subsides with time as blood levels are decreased.
- 4. SWELLING OF THE GUMS**
 Good mouth hygiene and regular dental check-ups can minimize this problem.
- 5. GASTROINTESTINAL UPSET**
 This may include stomach upset and diarrhea. The degree to which this occurs is variable and will depend on how your body reacts with the medication.
- 6. DIABETES (Increased blood sugar)**
 Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.
- 7. INCREASED HAIR GROWTH**
 Report this to the transplant team if it becomes bothersome.
- 8. INCREASED SUSCEPTIBILITY TO INFECTION**
 Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.
- 9. INCREASED RISK OF DEVELOPING CANCER**
 The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

CYCLOSPORINE (Neoral®)

DOSAGE ADJUSTMENTS

Cyclosporine is usually taken twice daily. Doses should be spaced twelve hours apart (e.g. 9:00 am and 9:00 pm) in order to maintain a consistent amount of drug in your body. You will be advised to adjust your dose up or down based on the amount of drug absorbed into your blood. Blood tests are usually done two hours after the dose is taken. Changes in dose are common so always check with your transplant team if you are unsure of your current dose.

STORAGE

Store this medication at room temperature. Do not expose to extremes of temperature (e.g. direct sunlight or refrigeration) as this may inactivate cyclosporine. Do not remove the capsules from their foil packaging until you are ready to take them.

INTERACTIONS WITH OTHER MEDICATIONS

- Many medications can change the level of cyclosporine in your blood. This may cause serious problems.
- Do not take **any** medications, including non-prescription drugs or prescriptions (given to you by anyone other than your transplant doctors), without first contacting your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase cyclosporine levels.

REMEMBER

Wear/carry identification (*i.e.* Medic-Alert) stating that you are immunocompromised.

This drug is available at no charge through a special program run by the Ontario Ministry of Health. In order to access cyclosporine free through this program it must be obtained from the Toronto General Hospital Outpatient Pharmacy.

CYCLOSPORINE PRODUCT INFORMATION

CAPSULES: Neoral®

- Usually supplied as 25mg and 100mg capsules (10 and 50mg also available)
- Dose may be any combination of these strengths – check strengths carefully
- Take with fluids e.g. water, juice, milk
- Avoid grapefruit as this can increase your blood levels of cyclosporine
- Capsules have an unpleasant skunk-like odour
- Remove capsules from the foil package **only when ready to take**

ORAL SOLUTION: Neoral®

- Supplied in a bottle with syringe
- Place syringe in bottle, draw up correct amount as indicated on scale: 100mg = 1 mL, 275mg = 2.75 mL, etc.
- Mix dose with ½ glass of milk or juice (use same type of fluid every time)
- Use only a glass, ceramic or china container (**no styrofoam, plastic or paper cups**) and only a metal spoon to mix (**no plastic spoon or straws**)
- Once opened use within 2 months

PROGRAF[®]
(tacrolimus immediate release)

GENERIC NAME	BRAND NAME	REASON FOR USE
Tacrolimus immediate release Strengths: 0.5 mg, 1 mg and 5 mg capsules	PROGRAF [®]	Tacrolimus is an anti-rejection drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. INCREASED BLOOD PRESSURE

Your blood pressure will be monitored. You may require treatment with blood pressure medications.

2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

This can include trembling hands, headaches, mood changes and trouble sleeping. This is usually related to the level of Prograf[®] in the blood and usually subsides with time as blood levels are decreased.

3. HARMFUL EFFECTS ON THE KIDNEY

The level of Prograf[®] in your blood will be closely monitored and the dose will be adjusted if needed. Your kidney function will be monitored with a blood test called creatinine.

4. GASTROINTESTINAL UPSET

This may include stomach upset and diarrhea. The degree to which this occurs is variable and will depend on how your body reacts with the medication

5. DIABETES (Increased blood sugar)

Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

6. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

7. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

PROGRAF® (tacrolimus immediate release)

DOSAGE ADJUSTMENTS

You will be advised to adjust your dose up or down based on the amount of Prograf® in your blood. Blood tests are done just before your morning dose. On the days you are having bloodwork, always remember to **delay your morning dose of Prograf® until after your blood is drawn**. Changes in dose are common so always check with your transplant team if you are unsure of your current dose.

STORAGE

Keep at room temperature. Do not expose Prograf® to extremes of temperature (direct sunlight or refrigeration).

INTERACTIONS WITH OTHER MEDICATIONS

- Many medications can change the level of Prograf® in your blood. This may cause serious problems.
- Do not take **any** medications, including non-prescription drugs or prescriptions (given to you by anyone other than your transplant doctors), without first contacting your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase Prograf® blood levels.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

TAKING YOUR MEDICATION

- Prograf® (tacrolimus immediate release) is taken twice daily every 12 hours, *e.g.* 9:00 am and 9:00 pm. This is to ensure that you maintain a consistent amount of drug in your body. Always take your doses at the same times every day.
- Always be consistent with respect to Prograf® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Avoid grapefruit and grapefruit juice as these can increase Prograf® blood levels.
- Do not get this medication confused with Advagraf® (tacrolimus extended release), which is a once-daily formulation of tacrolimus.

SIROLIMUS (Rapamune®)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Sirolimus Rapamycin Strengths: 1 mg tablets 1 mg/mL oral solution	RAPAMUNE®	Sirolimus is an anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. INCREASED CHOLESTEROL LEVELS

Your cholesterol and triglyceride levels may increase which can lead to atherosclerosis and heart disease. Dietary changes or medications may be required to bring your cholesterol levels down.

2. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. Inform your transplant team if you develop any symptoms of infection, if you feel very tired, or experience any unusual bleeding or bruising.

3. SKIN RASH, ACNE OR MOUTH SORES

A rash or acne may develop on your face or body. You may also develop sores inside your mouth. Inform your transplant team if these effects occur and are bothersome.

4. GASTROINTESTINAL UPSET

Stomach upset, diarrhea, or constipation may occur. The degree to which this occurs is variable and will depend on how your body reacts with the medication.

5. SLOW WOUND HEALING

Healing of wounds such as the incision from your surgery may be slow. Keep your incision site and any other wounds clean. If any signs of infection occur such as increased redness, swelling, or pus in the wound, report this to a doctor right away.

6. SWELLING OF THE HANDS, FEET, ANKLES OR LEGS

You may develop fluid retention and swelling of the extremities. If this occurs and becomes bothersome you should report this to your transplant team.

7. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

8. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

SIROLIMUS (Rapamune®)

TAKING YOUR MEDICATION

- Sirolimus is taken once a day. Try to take the dose at the same time every day in order to maintain a consistent amount of drug in your body. Tablets must not be cut, crushed or chewed.
- Always be consistent with respect to sirolimus dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Your transplant team will adjust your dose up or down based on the amount of drug in your blood. Blood tests are done just before your dose is taken. **Always remember to delay your dose of sirolimus until after your blood is drawn.**

STORAGE

- Store sirolimus tablets at room temperature – do not expose to extremes of temperature (direct sunlight or refrigeration).
- Store sirolimus oral solution in the **refrigerator**. Protect from light, **do not freeze**.

INTERACTIONS WITH OTHER MEDICATIONS

- **Sirolimus must be taken at least 4 hours apart from cyclosporine.**
- Many medications can change the level of sirolimus in your blood. This may cause serious problems. Do not take any medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors, without first speaking to your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase the level of sirolimus in your blood and lead to side effects.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

INSTRUCTIONS FOR SIROLIMUS ORAL SOLUTION

- Supplied as a 1mg/mL solution in a glass bottle with amber oral syringes and caps
- Keeping bottle upright, place syringe in the adaptor cap on top of the bottle and draw up the correct dose as indicated on scale: *e.g.* 3mg = 3 mL
- Add dose to ¼ cup of water or orange juice, stir well, and drink. Add another ¼ cup water or orange juice to container, stir well, and drink this rinse solution.
- Throw away the syringe after each dose.
- You may pre-fill your syringe to be used at a later time. Draw up dose as described above. Place a cap on the syringe and keep in the carrying case supplied. Dose may be kept at room temperature, but must be taken within 24 hours of preparation.
- Bottles should be stored in the refrigerator and used within 30 days of opening.

PREDNISONE

GENERIC NAME	REASON FOR USE
Prednisone Strengths: 5 mg and 50 mg tablets	Prednisone is a cortisone-like anti-rejection drug. This medication works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. STOMACH UPSET OR IRRITATION

Take prednisone with food or milk. An acid-reducing medication may be prescribed. Report any severe symptoms or blood in your bowel movements to a doctor right away.

2. WATER RETENTION

May cause swelling of the face, ankles or hands. You may need to restrict salt in your diet. A diuretic ('water pill') may be prescribed. This effect usually subsides as the dose is reduced.

3. FACIAL PUFFINESS

More common with higher doses. This usually subsides as the dose is reduced.

4. INCREASED APPETITE

Weight gain may occur if you overeat.

5. DIABETES (Increased blood sugar)

Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

6. SLEEP DISTURBANCES, NIGHTMARES, MOOD CHANGES

Take prednisone in the morning to minimize the effect on your sleep. These effects usually subside as the dose is reduced.

7. BRUISING

Your blood vessels may become more fragile which can cause easy bruising. Try to protect yourself from injury.

8. OSTEOPOROSIS (Thinning of the bones)

Your bones may become weaker which can increase your risk of fractures. You may be advised to increase calcium in your diet, do a weight-bearing exercise such as walking, or take calcium supplements or other medications to increase bone density.

9. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

10. OTHER SIDE EFFECTS MAY INCLUDE

Increased hair growth, acne, cataracts, or menstrual irregularities.

PREDNISONE

TAKING YOUR MEDICATION

- Prednisone is taken once daily in the morning.
- Prednisone should be taken with food or milk to prevent stomach irritation.
- The dose prescribed may be any combination of 5 mg tablets or half tablets.

Examples: 20 mg = 4 of the 5 mg tablets

15 mg = 3 of the 5 mg tablets

12.5 mg = 2½ of the 5 mg tablets

- Some patients who are taking larger doses may also be prescribed the 50 mg tablets.

Examples: 75 mg = 1½ of the 50 mg tablets

60 mg = 1 of the 50 mg tablets plus 2 of the 5 mg tablets

- Typically larger doses are prescribed initially, followed by a gradual dose reduction or 'taper'. Changes in dose are common so always check with your transplant team if you are unsure of your current dose

- **Never stop taking this drug suddenly.**

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are taking prednisone and that you are immunocompromised.

CELLCEPT®
(mycophenolate mofetil)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Mycophenolate mofetil MMF Strengths: 250 mg capsules 500 mg tablets 200 mg/mL oral suspension	CELLCEPT®	Cellcept® is an anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. DIARRHEA

This side effect is common especially at higher doses. It can often be managed by taking smaller doses more frequently throughout the day. This should only be done on the advice of your transplant team.

2. STOMACH UPSET

Nausea, vomiting, and abdominal pain can sometimes occur. These effects usually decrease with time. Report this to your transplant team if any of these become problematic.

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

4. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

5. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

CELLCEPT® (mycophenolate mofetil)

TAKING YOUR MEDICATION

- Take this medication twice daily. Doses should be spaced 12 hours apart in order to maintain a consistent amount of drug in your body, *e.g.* 9:00 am and 9:00 pm. Always take your doses at the same times every day.
- Always be consistent with respect to Cellcept® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Capsules and tablets should not be cut, crushed or chewed.

INTERACTIONS WITH OTHER MEDICATIONS

Cellcept® may interact with other medications including:

- Products containing iron such as ferrous gluconate, ferrous sulphate, ferrous fumarate or multivitamins plus minerals
- Products containing magnesium such as Maalox® or Milk of Magnesia®
- Cholestyramine (Questran®), a cholesterol-lowering agent

All of these medications can decrease the absorption of Cellcept® if taken at the same time. It is important that these medications be spaced at least 2 hours apart from Cellcept® (and at least 4 hours apart in the case of cholestyramine).

Please speak with your doctor, pharmacist or transplant coordinator before taking **any** new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors. Your pharmacist or transplant coordinator can help you plan your dosing schedule to avoid these interactions.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

MYFORTIC®
(enteric coated mycophenolate sodium)

GENERIC NAME	BRAND NAME	REASON FOR USE
Enteric coated mycophenolate sodium Strengths: 180 mg and 360 mg tablets	MYFORTIC®	Myfortic® is an anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. DIARRHEA

This side effect is common especially at higher doses. It can often be managed by taking smaller doses more frequently throughout the day. This should only be done on the advice of the transplant team.

2. STOMACH UPSET

Nausea, vomiting, and abdominal pain can sometimes occur. These effects usually decrease with time. Report this to your transplant team if any of these become problematic.

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

4. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

5. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

MYFORTIC[®] (enteric coated mycophenolate sodium)

TAKING YOUR MEDICATION

- Take this medication twice daily. Doses should be spaced 12 hours apart in order to maintain a consistent amount of drug in your body, *e.g.* 9:00 am and 9:00 pm. Always take your doses at the same times every day.
- Always be consistent with respect to Myfortic[®] dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Tablets should not be cut, crushed or chewed.

INTERACTIONS WITH OTHER MEDICATIONS

Myfortic[®] may interact with other medications including:

- Products containing iron such as ferrous gluconate, ferrous sulphate, ferrous fumarate or multivitamins plus minerals
- Products containing magnesium such as Maalox[®] or Milk of Magnesia[®]
- Cholestyramine (Questran[®]), a cholesterol-lowering agent

All of these medications can decrease the absorption of Myfortic[®] if taken at the same time. It is important that these medications be spaced at least 2 hours apart from Myfortic[®] (and at least 4 hours apart in the case of cholestyramine).

Please speak with your doctor, pharmacist or transplant coordinator before taking **any** new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors. Your pharmacist or transplant coordinator can help you plan your dosing schedule to avoid these interactions.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

AZATHIOPRINE
(Imuran®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Azathioprine Strength: 50 mg tablets	IMURAN® (and generics)	Azathioprine is an anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. STOMACH UPSET

Upset stomach or vomiting may occur but usually decreases with time. Report this to your transplant team if this becomes problematic. Take with food or milk to help prevent stomach upset.

2. ABDOMINAL PAIN

If you have abdominal pain which is severe or lasts for more than one day you should report this to a doctor or your transplant team. Although uncommon, this may be a sign of a serious problem called pancreatitis, or inflammation of the pancreas.

3. YELLOW COLORATION OF SKIN, DARK URINE

These symptoms are rare but may be a sign of liver damage. Report these symptoms to doctor or your transplant team as soon as possible.

4. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

5. BLEEDING AND BRUISING

Try to protect yourself from injury. Notify your transplant team of any unusual bleeding or bruising.

6. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

7. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

AZATHIOPRINE

TAKING YOUR MEDICATION

- Azathioprine is taken once daily
- Take with food or milk to prevent stomach upset
- The dose prescribed may be any combination of 50 mg tablets or half tablets.

Examples: 100 mg = 2 tablets
75 mg = 1½ tablets
125 mg = 2½ tablets

- Changes in dosage may occur. Always check with your transplant team if you are unsure of your current dose.

INTERACTIONS WITH OTHER MEDICATIONS

- Azathioprine may interact with other medications and cause serious problems. For example, **allopurinol** is a drug used in the treatment of gout which can cause severe side effects if taken with azathioprine.
- Always speak to your transplant team before taking any new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

COTRIMOXAZOLE
(Septra®)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Sulfamethoxazole/ Trimethoprim <u>or</u> Cotrimoxazole Strengths: Single strength tablet (400/80 mg) Double strength tablet (800/160 mg)	SEPTRA® (and generics)	This drug is a combination of two antibiotics. It is used to prevent or treat a type of pneumonia called PCP. You are more susceptible to this infection when your immune system is suppressed.

SIDE EFFECTS

1. SKIN RASH

You may be allergic to the ‘sulfa’ part of the drug. If this occurs, stop taking this medication and report this to your transplant team. A different drug may be prescribed.

2. SENSITIVITY TO SUNLIGHT

Your skin may burn more easily if exposed to the sun. Avoid excessive exposure to sunlight and wear protective clothing or sunscreen products on all sun-exposed areas, even in the winter.

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.

4. FEVER

A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team **immediately**. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol®) may be used to control the fever.

HOW TO USE THIS DRUG

- This medication may be taken with or without food.
- Take this medication exactly as your doctor has prescribed. This may be once daily, or only on certain days of the week, or in some cases twice daily. Always follow the instructions given to you by your transplant team.

DAPSONE

GENERIC NAME	REASON FOR USE
Dapsone Strength: 100 mg tablet	This medication is an antibiotic. It is used to prevent a type of pneumonia called PCP. You are more susceptible to this infection when your immune system is suppressed.

SIDE EFFECTS

1. SKIN RASH

This may be a sign of an allergic reaction. If this occurs, stop taking this medication and report this to your transplant team. A different drug may be prescribed.

2. SENSITIVITY TO SUNLIGHT

Your skin may burn more easily if exposed to the sun. Avoid excessive exposure to sunlight and wear protective clothing or sunscreen products on all sun-exposed areas, even in the winter.

3. YELLOW COLORATION OF SKIN, DARK URINE

These symptoms are rare but may be a sign of liver damage or a problem with your red blood cells. Report these symptoms to doctor or your transplant team as soon as possible.

4. FEVER

A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team **immediately**. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol®) may be used to control the fever.

HOW TO USE THIS DRUG

- This medication may be taken with or without food.
- Take this medication exactly as your doctor has prescribed. This may be once daily, or only on certain days of the week. Always follow the instructions given to you by your transplant team.

NYSTATIN

GENERIC NAME	BRAND NAMES	REASON FOR USE
Nystatin Strength: 100,000 units per mL oral suspension	NILSTAT® MYCOSTATIN® (and generics)	This medication is an antifungal. It is used to prevent yeast infections in the mouth (also known as oral thrush), which appear as white spots or patches.

SIDE EFFECTS

- Since this medication is not absorbed into the body, side effects are very unlikely.

HOW TO USE THIS DRUG

- This product is a suspension. Shake the bottle well before taking each dose.
- Measure the prescribed dose using the dropper supplied.
- Swish it around in your mouth for at least one minute then swallow.
- This medication needs contact time with the mouth and throat in order to be most effective. Do not eat or drink anything for 20 minutes after taking nystatin.
- Nystatin is usually taken 4 times daily. It is easiest to take your doses after meals and at bedtime.

**VALGANCICLOVIR
(Valcyte®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
Valganciclovir Strengths: 450 mg tablets 50 mg/mL oral solution	VALCYTE®	This medication is an anti-viral. It is used to prevent infections caused by viruses such as herpes virus and cytomegalovirus (CMV). It may also be used to treat infections caused by CMV.

SIDE EFFECTS

1. DECREASED BLOOD CELL COUNT

Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.

2. GASTROINTESTINAL UPSET

Diarrhea, nausea, vomiting, or stomach pain may occur. Taking the medication with food may prevent these side effects. If these symptoms are severe or last for more than one day, report this to your transplant team.

3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

This can include headaches or trouble sleeping. Report these symptoms to your transplant team if they become troublesome. Medications may be prescribed to help manage this.

HOW TO USE THIS DRUG

- If your doctor has prescribed a once daily dose of this medication it may be taken either in the morning OR the evening. Take the medication at the same time every day.
- If a twice daily dose of this medication has been prescribed, take it in the morning AND the evening, approximately 12 hours apart.
- Take this medication with food.

Your transplant team will adjust the dose of this drug according to your level of kidney function.

**PANTOPRAZOLE
(Pantoloc[®])**

GENERIC NAME	BRAND NAME	REASON FOR USE
Pantoprazole Strength: 20mg and 40mg tablets	PANTOLOC [®] (and generics)	This drug is used to prevent and treat heartburn, and stomach or intestinal ulcers, by decreasing the amount of acid produced by the stomach.

SIDE EFFECTS

- Side effects may include headache, constipation or diarrhea.
- Generally this medication is well tolerated. Contact your doctor if any side effects continue or are bothersome.

HOW TO USE THIS DRUG

- If your doctor has prescribed one dose of this medication every day it may be taken in the morning or at night. If you experience heartburn during the night you should take this medication at bedtime.
- If it is to be taken twice daily, take it in the morning and at night.
- Doses may be taken without regard to meals.

SPECIAL INSTRUCTIONS

- Swallow tablets whole with a glass of fluid such as water or juice.
- Tablets must not be chewed or crushed.

**RANITIDINE
(Zantac[®])**

GENERIC NAME	BRAND NAME	REASON FOR USE
Ranitidine Strength: 150 mg tablets	ZANTAC [®] (and generics)	This drug is used to prevent and treat heartburn, and stomach or intestinal ulcers, by decreasing the amount of acid produced by the stomach.

SIDE EFFECTS

- Side effects may include headache, dizziness, constipation, nausea and abdominal pain.
- Generally this medication is well tolerated. Contact your doctor if any side effects continue or are bothersome.

HOW TO USE THIS DRUG

- If your doctor has prescribed only one dose of this medication every day, it may be taken in the morning or at night. If you experience heartburn during the night you should take this medication at bedtime.
- If it is to be taken twice daily, take it in the morning and at night.
- Doses may be taken without regard to meals.

METHYLPREDNISOLONE (Solumedrol®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Methylprednisolone Sodium Succinate Strengths: Various (injection only)	SOLUMEDROL® (and generics)	This is an intravenous anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ. It may also be used to treat an episode of rejection.

SIDE EFFECTS

1. INCREASED BLOOD SUGAR LEVELS

This medication may cause high blood sugar (glucose) levels, which are difficult to control in patients with existing diabetes or those who are prone to developing diabetes. Your blood sugar levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

2. SLEEP DISTURBANCES, NIGHTMARES, MOOD CHANGES

These effects usually subside as the dose is reduced.

3. WATER RETENTION

May cause swelling of the face, ankles or hands. You may need to restrict salt in your diet. A diuretic ('water pill') may be prescribed. This effect usually subsides as the dose is reduced.

4. STOMACH UPSET OR IRRITATION

An acid-reducing medication may be prescribed. Report any severe symptoms or blood in your bowel movements to a doctor right away.

5. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

This medication is given through an intravenous (IV) line. It is commonly used in hospital right before and after transplant. Prednisone is a very closely related medication which is available in an oral tablet form. Most patients will receive a prescription to continue on oral prednisone therapy when they leave the hospital after transplant.

**RABBIT ANTI-THYMOCYTE GLOBULIN
(Thymoglobulin®)**

GENERIC NAMES	BRAND NAMES	REASON FOR USE
Rabbit anti-thymocyte globulin Strength: 25mg/5mL injection	THYMOGLOBULIN®	This is a potent intravenous medication that may be used in the first few days following a transplant to prevent rejection. It may also be used to treat an episode of rejection.

SIDE EFFECTS

1. ALLERGIC REACTIONS

This medication is derived from rabbit serum. Allergic reactions are unlikely, but if they occur the drug will be stopped and antihistamines and steroids will be given. Pre-medications are usually given before each dose to prevent allergic reactions.

2. FEVER AND CHILLS

This effect is more common during the infusion of the first dose. Pre-medication will be given and the drug will be infused very slowly in order to limit this effect. If fever or chills do occur the infusion will be slowed or stopped temporarily. These effects do not last long and will respond to treatment with acetaminophen (Tylenol®).

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be closely monitored while you are on this medication. If a decrease does occur the dose of this medication may be reduced or it may be stopped temporarily.

4. INFECTION

This medication is a powerful anti-rejection drug and that will cause suppression of your immune system. You will be much more susceptible to developing an infection, both during treatment and for a period of time after the medication has been stopped. To avoid the risk of serious infection this drug is used for the shortest period of time possible. Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team ***immediately***.

**BASILIXIMAB
(Simulect®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
Basiliximab Strength: 20mg/5mL injection	SIMULECT®	This is an anti-rejection medication. It is given intravenously in two doses following a transplant to prevent rejection of your transplanted organ.

SIDE EFFECTS

- This medication is very well tolerated and has minimal side effects
- Allergic reactions are very rare but if they occur the drug will be stopped and antihistamines and steroids may be given.

**GANCICLOVIR
(Cytovene®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
<p>Ganciclovir</p> <p>Strength: 50mg/mL injection</p>	<p align="center">CYTOVENE®</p>	<p>This is an anti-viral medication that is given intravenously to prevent and treat infections caused by the herpes virus or cytomegalovirus (CMV).</p>

SIDE EFFECTS

1. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. It may be necessary to stop or interrupt treatment until your blood cell counts recover.

2. PAIN AT INFUSION SITE

This medication is infused slowly through a large vein to limit this effect.

3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

This can include headaches or trouble sleeping. Medications may be prescribed to help manage these symptoms if they occur.

HOW TO USE THIS DRUG

- This drug is given intravenously (IV). In some cases treatment may continue for up to several months. If this is necessary, a special long-term IV (midline catheter or L-Cath) may be inserted so that you do not have to have multiple peripheral IVs inserted during the course of treatment.
- Many patients may be converted to a very similar medication called valganciclovir (Valcyte®) which is available in an oral tablet form. Your transplant team will determine if this is an appropriate option for you.

Your transplant team will adjust the dose of this medication according to your level of kidney function.

**ACYCLOVIR
(Zovirax®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
<p>Acyclovir</p> <p>Strengths: 200mg, 400mg and 800mg tablets</p>	<p>ZOVIRAX® (and generics)</p>	<p>This is an anti-viral medication used to prevent and treat infections caused by the herpes family of viruses, such as shingles or severe cold sores.</p>

SIDE EFFECTS

1. STOMACH UPSET, NAUSEA, VOMITING, DIARRHEA

Taking this medication with food can help to prevent these effects. If these symptoms are severe or last for more than one day, report this to your transplant team.

2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

Tiredness, headache, tremors or confusion may occasionally occur. While still uncommon, these effects are more likely with the use of higher doses of intravenous acyclovir. In rare cases acyclovir may trigger seizures in those who have seizure disorders.

3. ALTERED KIDNEY FUNCTION

This effect is rare and is more likely to occur with use of intravenous acyclovir. You may be instructed to increase your fluid intake while you are on this medication. If you experience any pain in your side (between ribs and hip) or kidney area of your back, report this to your transplant team.

HOW TO USE THIS DRUG

- This medication is usually taken 3 to 5 times a day. Always follow the dosing instructions given to you by your transplant team.
- This medication may be taken without regard to meals, although taking it with food can help to prevent stomach upset.
- You may be instructed to increase your fluid intake while you are on this medication.

Your transplant team will adjust the dose of this medication according to your level of kidney function.

Contacts Numbers

Contact	Telephone Number
Emergency	911
Easy Call	(416) 351-0793
<i>Your Easy Call PIN #</i>	
Pharmacy Toronto General Hospital	(416) 340-4075
Transplant Coordinator using Easy Call	(416) 351-0793
Transplant Clinic Reception	(416) 340-4800 ext. 4113
Tele-Health Ontario	1-866-797-0000