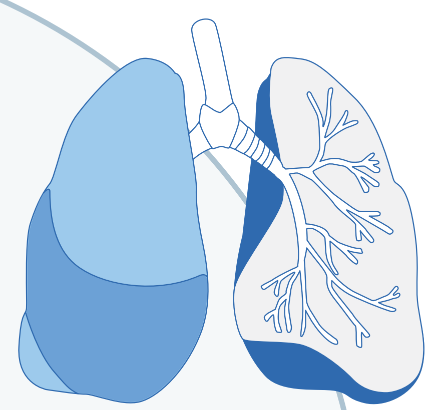

Your Lung Transplant Guide

The Toronto Lung Transplant Program

Toronto Lung
Transplant Program

publication date: December 2024

UHN Ajmera Transplant Centre

How to contact us

In an Emergency	Transplant Outpatient Pharmacy	Transplant Clinic Reception	Tele-Health Ontario	myUHN portal
911	(416) 340-4415	(416) 340-4800 ext. 4113	811 or dial 1(866)797-0007 or visit Health811.ontario.ca	myUHN.ca

login id

myUHN

username

password

We will help you be as prepared as possible for your transplant because **every journey is unique.**

Welcome

Welcome to the Toronto Lung Transplant Program at the Ajmera Transplant Centre. We are located at the Toronto General Hospital, part of the larger University Health Network. We are proud to be one of the largest lung transplant programs in the world. We have over 40 years of transplant experience, including many of the world's firsts in lung transplantation and we perform around 200 lung transplants each year. Our team provides exceptional patient care and we work hard to achieve excellent results for our recipients.

This guide has been designed to support you, your family, and your support network (more on this in the first section of the guide!) throughout your lung transplant journey.

We aim to provide you with as much information as possible about transplant, but each journey is unique so some of the content in this guide may not apply to your experience.

We work **together with you**, to support you through the lung transplant process.

Our Philosophy of Care

The goal of the Toronto Lung Transplant Program is to work as collaborative partners with you, your support people, and your local healthcare providers to promote good health and quality of life through all phases of your transplant journey. Each member of the team believes in practicing with respect, dignity, integrity, and empathy in order to provide patient-centered care of the highest quality. We are committed to providing you with the highest quality and excellence in care and take pride in our contributions to the field of transplantation.

We believe that all members of the healthcare team are an important and valuable part of the care plan – this includes you and those who are supporting you. At every step of your transplant journey, we want to hear from you, please share any concerns and questions you have with us. We will always work to provide you with the most up to date information and education so that you can make informed decisions about your health. We want to work together with you and your support people to make sure you have the best possible care and outcome after transplant.

Lung transplant is only possible because of the generosity and compassion of organ donors.

We honour these remarkable gifts from donors and their families through our pursuit of excellence in transplant care.

Your Lung Transplant Journey Guide

We have divided this guide into four sections that follow the transplant journey. We encourage you and your support people to explore the whole guide from start to finish at the beginning of your journey.

You can use this journey guide to “click” & “jump” to specific sections of the guide or you can scroll through the whole guide from start to finish.

Come back to this guide as you progress through your journey. The tools and tips are here to help along the way.

***Click** on the sections to explore the linked content.*

Is Lung Transplant for You?

- About Lung Transplant
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01

Is Lung Transplant for You?

A lung transplant is a treatment that involves a surgical procedure **to replace your sick lung(s)** with a donor's healthy lung(s).

About Transplant

You have received this guide because your doctor has suggested that you might benefit from a lung transplant. For many people this is part of a long medical journey, but for some it may be due to a sudden onset of a lung disease. To understand why a lung transplant has been recommended, it is good to know the basics of how your lungs work.

No organ or tissue can survive without the oxygen that fuels them. Our lungs take in oxygen that allows our body to produce energy and they get rid of the carbon dioxide that we produce when we use that energy.

A lung transplant is a treatment that involves a surgical procedure that replaces your sick lung(s) with a donor's healthy lung(s). It may be recommended when your lung function is severely impaired and there are no other effective treatment options available. A lung transplant involves much more than a surgery alone due to the significant commitment required while waiting for a transplant and the possible complications that can happen after a lung transplant. However, lung transplant can offer significant benefits for people living with advanced lung disease for both length and quality of life.

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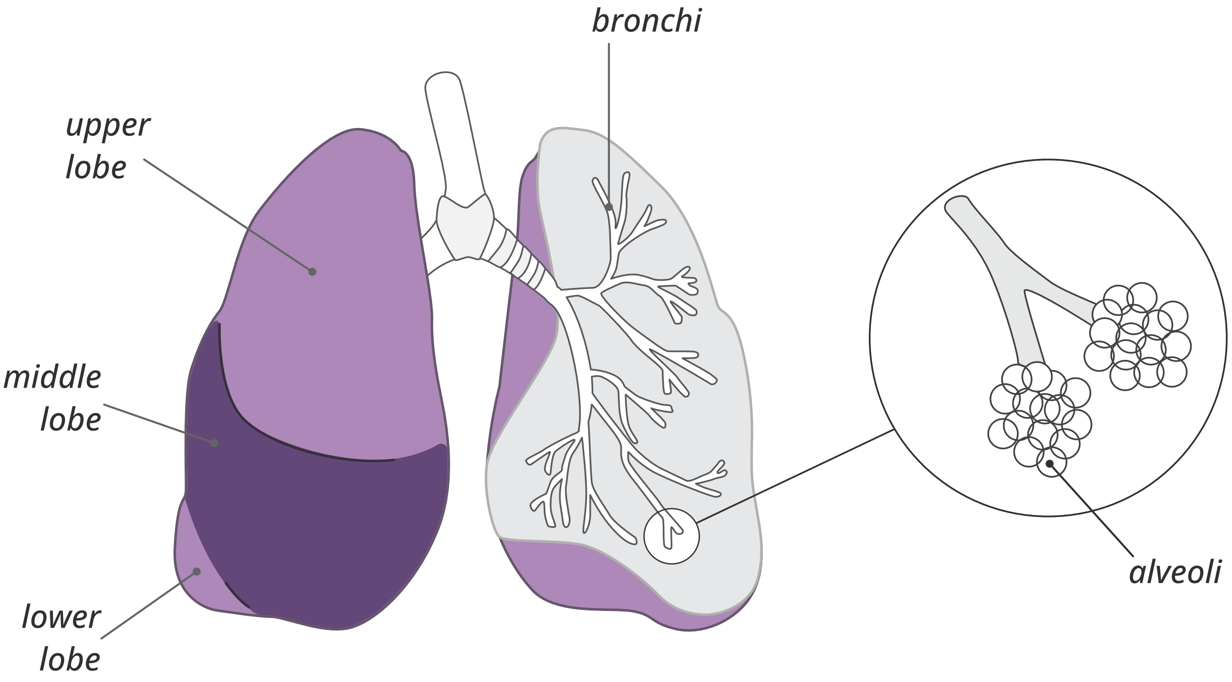

About your Lungs

Normal lungs are soft and spongy and made up of stretchy tissue that allows them to inflate or expand like a balloon and fill with oxygen. The lungs themselves are made up of passageways called bronchi that look similar to a tree. Each passage branches off into more and more smaller branches. At the end of the smallest branches are tiny sacs called alveoli. The alveoli exchange the oxygen and carbon dioxide through connections with blood vessels between the lungs and the rest of the body.

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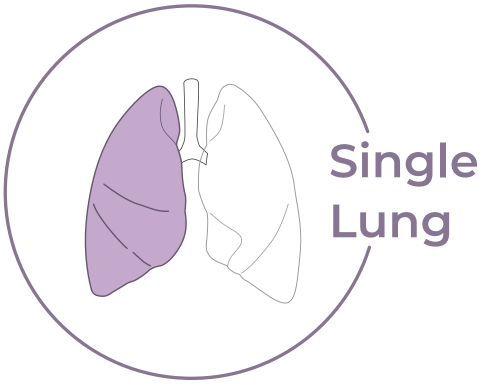

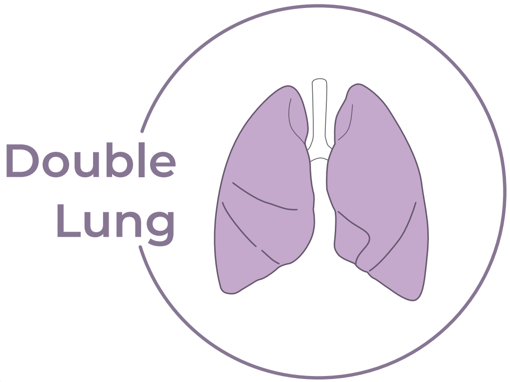

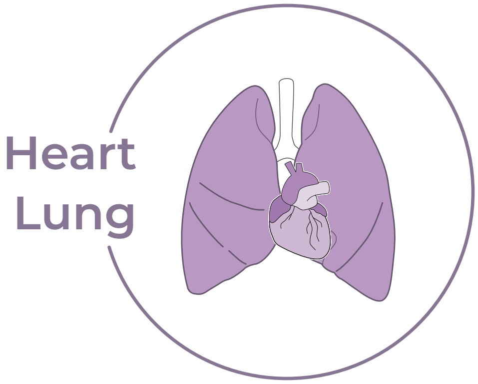

There are three main types of lung transplant:

- **A single lung transplant**; one lung, either left or right side is replaced with a donor lung.
- **A double lung transplant**; both lungs are replaced by two donor lungs form the same donor.
- **A heart-lung transplant**; both lungs and the heart are replaced by donor lungs and heart from the same donor.

The type of surgery you are eligible for will depend on several factors related to your lung disease and overall health. This is a medical decision made by your lung transplant care team

A single lung transplant can offer an excellent outcome in certain individuals, but may not be possible in all cases. A single lung transplant may be an easier operation to recover from. When only one lung is suitable for transplant from a particular donor (for example if the other lung has experienced damage) a single lung transplant in the right person will also eliminate the need to wait for another match.

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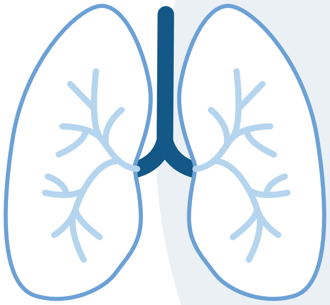
Lung transplant is a treatment option for many chronic lung diseases, such as (but not limited to):

- COPD (chronic obstructive pulmonary disease)
- Interstitial lung disease, the most common being IPF (Idiopathic Pulmonary Fibrosis)
- Bronchiectasis
- Pulmonary Hypertension
- Cystic Fibrosis

Less often, lung transplant is an option for acute conditions (such as infections), that lead to irreparable damage of the lung.

In most cases of lung transplantation, we aim to help improve how long you might live, and to improve your quality of life. Your care team will discuss the benefits of transplant that are unique to your situation.



Donor lungs come from people who have agreed to be part of the organ donor program prior to their death or whose families have agreed to organ donation.

Lungs are matched between donors and recipients primarily according to blood type and lung size. In rare cases, donor lungs may come from living donation, where 2 healthy individuals decide to donate part of their lungs to a recipient.

Is a Lung Transplant Right for You?

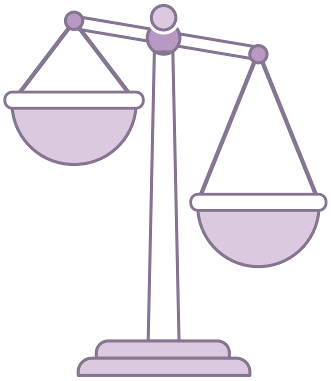
Lung transplantation is a complex process that includes pre-transplant assessment, the surgical procedure itself and post-transplant care.

Assessing if a lung transplant is the right treatment for you is one of the most important steps of the transplant process. It is important to understand that deciding if transplant is the right option for you is about understanding the balance between your need for a transplant and the risks that the transplant holds for you personally.

There are times when the Transplant Team feels that transplant would be too risky and not offer the benefits of improved survival and quality of life that a person is seeking. When this is the case a lung transplantation may not be offered as a treatment.

Needs

- How severe your disease is and the likelihood and rate of progression
- Symptoms
- Quality of life
- The absence of an alternative treatment



Risks

- Capacity to handle the surgery safely
- Pre-existing health conditions that might get worse with the surgery or the medications required after transplant
- Pre-existing health conditions or social circumstances that could jeopardize the outcome of transplant
- Risks of developing new health conditions after the transplant

We will help you understand the benefits and risks of having a transplant, give you the information to make an informed decision, and support you throughout the decision making process. Even if a transplant is recommended by our team, the final decision whether or not to proceed is yours. We will support your choice whether you go forward with a transplant or not.

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 an active partner with your health care team, learning about your treatments, taking and managing your medications, exercising regularly, monitoring your health at home, and attending your clinic appointments.

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.**

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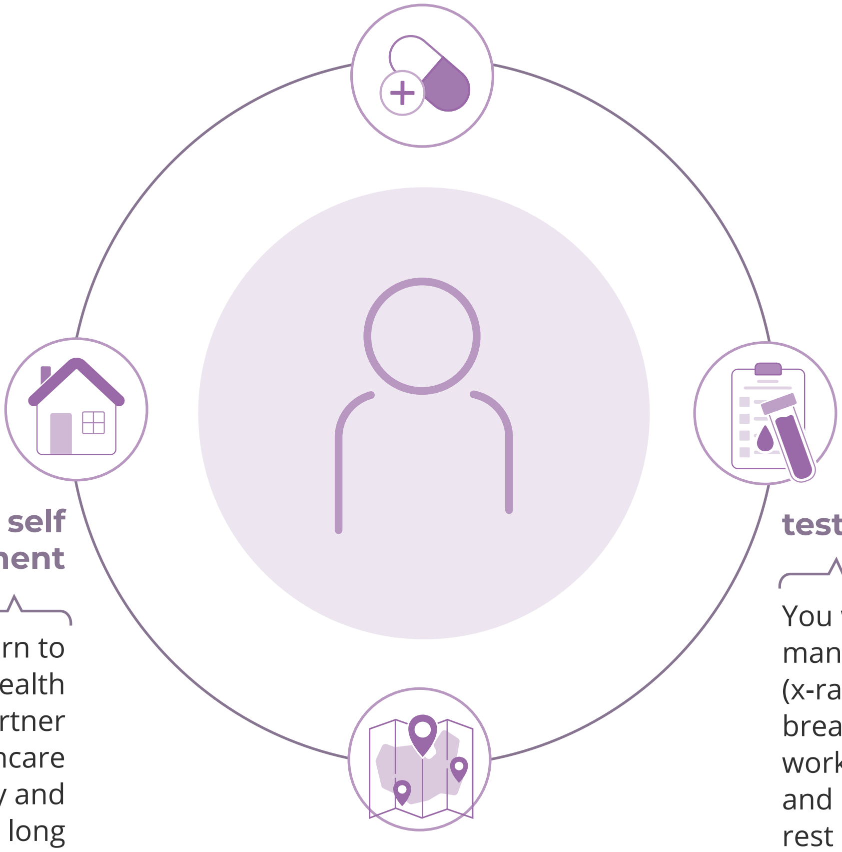
Ways Life Will Change After Transplant

medication

You will need to take medications for the rest of your life, this will include many pills several times a day.



self management

You will learn to monitor your health at home and partner with your healthcare team to try and achieve the best long term outcome after transplant.

testing

You will need to have many routine tests (x-rays, CT scans, breathing tests, blood work, bronchoscopies) and clinic visits for the rest of your life. Testing will be more frequent for the first few months after transplant.

relocation

You may be required to relocate closer to Toronto while on the lung transplant waitlist and during the first few months after your transplant.

The need to relocate is decided by your Transplant Team and is **based on your distance from Toronto General and ability to travel safely to the hospital several times per week before and after transplant.**

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Your Lung Transplant Team

The Lung Transplant Program works as a team. Your Transplant Team is made up of many different professionals who will be involved in your care and here to support you throughout your journey. Each team member plays an important role in your care.

Although each journey is unique, the following are some of the different members of the Transplant Team who you might meet along the way.

- **Transplant Respirologists**

  Medical doctors who are highly specialized in the diagnosis and treatment of advanced lung disease and transplant medicine. A Transplant Respirologist will care for you before and after your transplant.

Depending on your needs, you may also need to see other specialists before and after transplant to manage various health conditions.

Outside of the Transplant Team, **your Primary Care Provider and original Respirologist** (the one who referred you to the transplant program) **will still be essential healthcare providers for you**. The Transplant Team will work closely with them to provide care before, during and after your transplant.

- **Lung Transplant Surgeons**

  A Lung Transplant Surgeon is highly specialized in transplant operations. They will be the ones to perform your lung transplant surgery and help manage your post operative recovery and surgical care.

- **Registered Nurses (RNs)**

  RNs are healthcare professionals who will be involved with your care during every step of your transplant journey. A team of Nurses will provide you with care including helping you recover in the hospital after your surgery and acting as Transplant Coordinators throughout your journey.

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Transplant Coordinators

Transplant Coordinators are Registered Nurses with specialized training in transplant.

- *Pre-Lung Transplant Coordinator*

  Your guide through the transplant assessment process, from the moment you are referred to the Lung Transplant Program until your surgery if you are eligible for transplant. They will provide education and assistance to you and your support network to ensure a seamless process.

- *Discharge Coordinator*

  Once the Transplant Team has decided you are ready to go home after your lung transparent you will meet with your Discharge Coordinator. The Discharge Coordinator will work with you and your care team to ensure everything is ready for you to go home and that you have all the proper care instructions to have a smooth transition to outpatient care.

  If you need further care at an inpatient step-down rehabilitation facility before you go home your Discharge Coordinator will arrange this.

- *Post- Lung Transplant Coordinators*

  The Post-Transplant Coordinator is generally your first point of contact after transplant and will help to monitor you and arrange all of your follow-up care once you have returned home. They will put you in touch with the right people and the right services to meet any of your needs that are related to your lung transplant.

- **Administrative Assistants**

  Help to arrange your appointments. They can answer questions about your schedule and share messages to your medical team, but they are not clinical care providers and are not able to give you any medical advice. You will have the support of different administrative assistants during your journey

  - ***Pre-Lung Administrative Assistants***

    Work closely alongside your Pre-Lung Transplant Coordinator and Transplant Respirologist to arrange your appointments and assessment testing.

  - ***Post-Lung Administrative Assistants***

    Work closely with your Post-Lung Transplant Coordinator and Transplant Respirologist. They will arrange all of your follow-up testing and manage your routine assessment schedule.

- **Anaesthesiologists**

  Are medical doctors who perform the anesthesia during your surgery and can help manage postoperative pain. An Anaesthesiologist will meet with you before you are approved for transplant to help you understand the risks and plan for your surgery.

- **Social Workers**

  Are trained to support and counsel patients who are being assessed for lung transplant. Before you are approved for transplant, your Social Worker will meet with you and your loved ones to provide you with information about drug coverage, disability benefits, resources in your community, and ways to prepare for transplant. Social Workers can play an important role while you are in the hospital and after transplant as well.

- **Nurse Practitioners**

  Are Nurses who have additional education and experience. They assess, diagnose, and manage patients independently and work together with the rest of the Transplant Team. They will care for you while you are in the hospital on the transplant unit and when you are an outpatient.

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- **Physiotherapist**

  A healthcare professional trained in using exercise and physical activity to condition muscles and improve your 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. They will coordinate and monitor your exercise program both before and after your transplant surgery and while you are recovering in the hospital.

- **Pharmacists**

  Work closely with your care team to provide you with the right medications. After your transplant, a Pharmacist will teach you about managing all of your new medications and provide you with a schedule to help you keep track of them.

- **The Psychiatry Team**

  Includes Psychiatrists and Psychiatric Nurses. They will support your mental health and help you to cope with the stress and range of emotions related to transplant. The team may see you before, during, and after your transplant.

- **Dieticians**

  Provide you with information about your nutrition and diet. They will help you understand and design a good meal plan based on your weight, blood work results, and medications. This is important for your health, before and after transplant.

- **Spiritual Care Professionals**

  Can assist you, your family, and your support network. They will help you to explore any spiritual significance and meaning you might experience or question in your time of sickness. They can also help you to understand how your illness might impact your life.

- **Palliative Care Team**

  Provide treatments and support for managing symptoms of advanced lung disease with the aim of improving your symptoms and quality of life while waiting for transplant, and may continue to follow you after your transplant.

Your First Consultation

The first step in determining whether a lung transplant is a good treatment option for you is to meet with a Transplant Respirologist. This appointment will be made after your own Respirologist refers you to the Lung Transplant Program. The Transplant Respirologist will spend some time with you to learn your health history and help you understand what a lung transplant involves, including the risks and benefits.

It is helpful to write out your questions about transplant beforehand and bring this list with you to the appointment. You will have the opportunity to learn more about transplant at this initial visit and to ask questions.

Bring your questions with you to your appointment. You will have the opportunity to learn more about transplant and ask questions at this initial visit.

When you see this print icon throughout this guide it is telling you the page has been created as a printable resource for you to use!

After Your First Consultation

After your first consultation, there are a few possible outcomes:

- **A lung transplant seems like a reasonable option for you,** the team will connect with you to start the assessment process.
- **It may be necessary to do some additional tests or evaluations** to better determine if you should continue with the assessment process.
- **There are some barriers for transplant that need to be addressed before you are accepted to begin your assessment.** For example, if your weight is not within the ideal range you may need assistance in losing or gaining weight. If you seem to have lost fitness or muscle tone you may be required to participate in a physical rehabilitation program.
- **You may be too early in your disease course to consider transplantation –** if this is the case, the Transplant Respirologist may continue to follow you or they may discharge you back to your Primary Respirologist and see you again as your disease progresses.
- **Due to the risks involved, transplant is not a good treatment option for you.** If this is the case, you will be discharged back to your Primary Respirologist.
- **You may decide that you do not want to go through the assessment process** or proceed with exploring lung transplant at this time or in the future.

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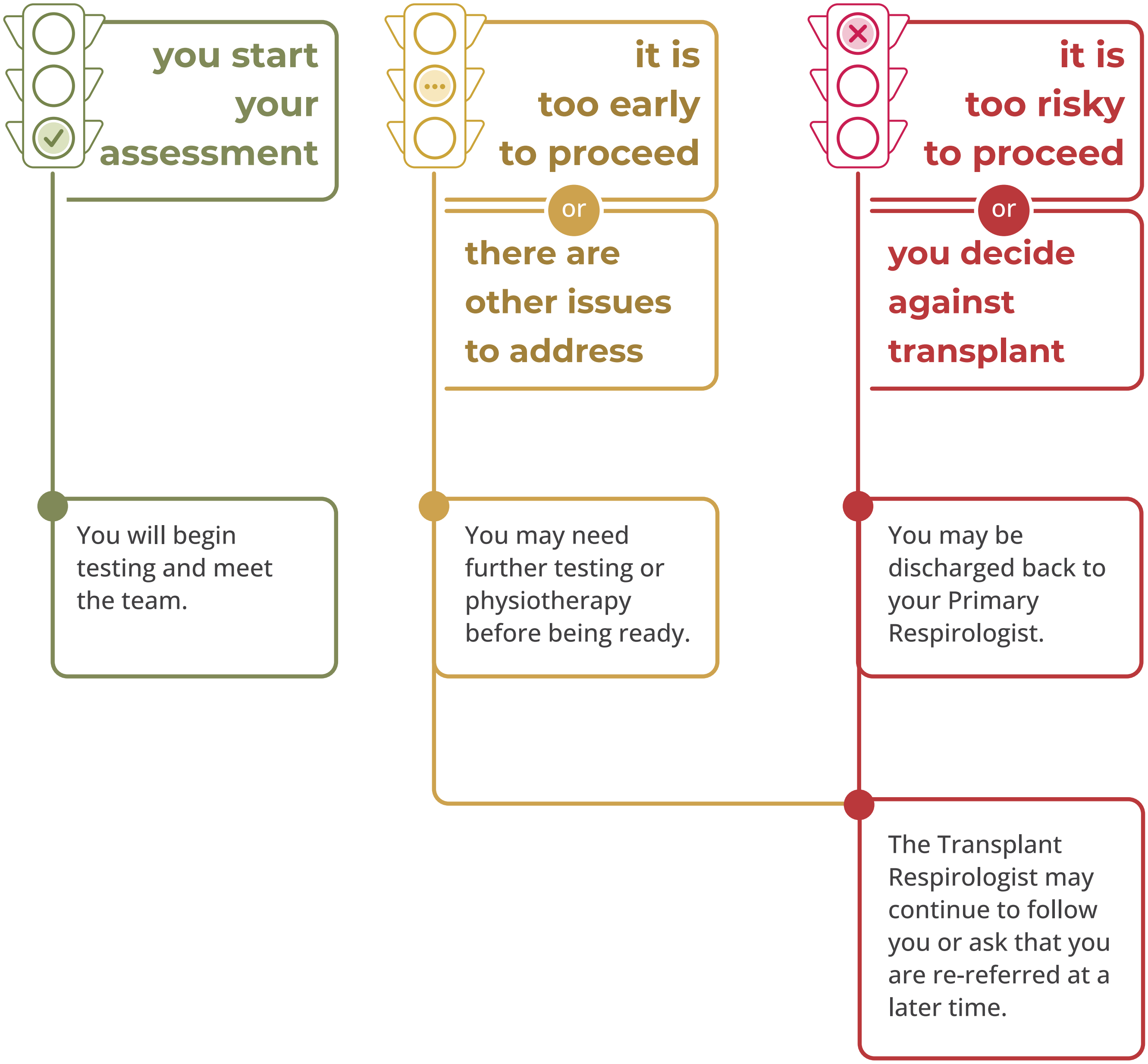
After Your First Consultation



you start your assessment

You will begin testing and meet the team.

it is too early to proceed

or

there are other issues to address

You may need further testing or physiotherapy before being ready.

it is too risky to proceed

or

you decide against transplant

You may be discharged back to your Primary Respirologist.

The Transplant Respirologist may continue to follow you or ask that you are re-referred at a later time.

The Assessment Process

If you, your family, your support network, and your care team decide to proceed after this first consultation, you will begin the transplant assessment phase of your journey.

During the assessment phase you will complete a number of medical tests and meet different Transplant Team members in person or virtually. This will help us to learn more about your general health, assess if a lung transplant is the best option for you, and tell us if you can go through a transplant surgery safely.

Although we will try to arrange for some tests in your local community, some testing and some in person consultations may be required at Toronto General Hospital.

You may be eligible for assessment testing through one of our satellite programs. You would also have some consultations done virtually or in person in Toronto along with the satellite care.

Before you come to your first appointment we will help you enroll in the **myUHN patient portal** if you are not already enrolled.

Through your patient portal, you will be able to track your appointments and communicate with your Transplant Team.

Later, if you move forward with transplant you will be able to use the portal to participate in our online exercise program, access additional transplant education resources, and participate in remote health monitoring programs.

If there are technological barriers, such as lack of access to electronic devices or access to the internet, we will work with you to overcome them as much as possible.

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We have created a checklist on the following pages to help you mark and track your progress through the assessment phase. You may not require all of the listed tests as they may not be needed in your case or they may have already been completed. Each test is listed alongside a description of what you can expect during the test.

Within the checklist we have included spaces for you to mark the dates and times of your appointments. There are also a few blank spaces at the end of the list where you can add any additional tests that are scheduled for you. These additional tests and/or consultations may be required based on your individual health needs.

In addition to the testing that is noted on the checklist you may meet with various members of the Transplant Team such as a Social Worker, Dietician, Physiotherapist, the Nurse Coordinator, Anesthesiologist, Palliative Care, and the Mental Health team as part of the assessment. They will all help assess your health and social situation to ensure transplant is right for you and that you are well educated and supported through the process. These discussions may be done virtually or in-person.

Additional tests and consultations may be required based on your individual health needs.

Please note, you will be scheduled for many appointments. If at any point you need to reschedule or cancel an appointment, please alert your Transplant Team as soon as possible.

We have many patients waiting for appointments, so the earlier we know about your need to reschedule, the more likely we are to be able to offer your time to someone else.

☐ PFT (Pulmonary Function Test)

You will be asked to blow air into a machine which measures how well your lungs move air in and out of your lungs and into your blood. This test also gives us information about the size of your lungs to help with planning your operation.

☐ 6–minute Walk Test

You will be asked to walk on a flat surface for 6 minutes while we monitor your oxygen saturation and heart rate with a pulse oximeter on your finger. We will measure the distance you can cover in the six minutes and note your endurance and the amount of oxygen you need for the exercise.

☐ CT (Computerized Tomography) Chest Scan

A CT or computerized tomography scan is a type of medical imaging that uses x-rays to provide a detailed picture of your lungs. For this test you will lay on a table that will move into a round open machine while the scan is done. Generally the test takes no longer than 10 minutes to complete.

☐ Lung Perfusion Scan

These are types of chest x-rays that use a small amount of radioactive substance to show how blood is distributed through your lungs. For the perfusion scan a radioactive substance is injected into your blood (through a small IV line) and it helps show the severity of disease in different areas of each lung.

☐ Bloodwork

A blood test allows us to evaluate how your kidneys, liver, and other organs are functioning as well as your immunity to various infections, or any active infections that need to be treated. Bloodwork involves a small needle being inserted into a vein to allow for the blood to be drawn. Most often blood is drawn from a vein in your arm.

☐ ABG (Arterial Blood Gas)

An ABG is also a blood test, however for this test blood is taken from an artery instead of a vein. An ABG measures the amount of oxygen and carbon dioxide in your blood and shows us how well your lungs exchange these gases.

☐ Sputum Culture

Sputum is a mixture of saliva and mucus that is coughed up from the respiratory tract. Your sputum will be collected and then sent to the microbiology lab to test for infections.

☐ TB (Tuberculosis) Skin Test

For this test you will receive an injection of a small amount of tuberculosis protein under your skin with a very small needle. The area is checked in 2-3 days for a reaction (positive test) by a healthcare professional. If you have a positive test more testing or treatment may be needed to reduce the risk of developing an infection with TB after transplant.

☐ ECG (Electrocardiogram)

Small electrode patches (stickers) will be placed on your chest, arms and legs, so that we can record electrical information from your heart.

☐ Echocardiogram

An ultrasound of your heart that helps assess the function of the major areas of the heart. It helps plan your operation and ensure your heart is healthy enough to support you through a transplant .

☐ Cardiac Stress Test

A test that helps determine how your blood circulates to the heart muscle during physically stressful situations. In most cases the “stress” will be created using medication or radioactive substances injected into your vein to mimic the effect of exercise. This test is used for patients aged 50 years or older, or younger patients with risk factors for heart disease.

☐ Coronary Angiogram and Right Heart Catheterization

A test that measures pressures in various parts of the heart so that we can better understand your heart function and plan your transplant surgery. A catheter will be inserted through an artery in your arm or leg and slowly moved through to your heart. Once the catheter has reached the heart, a dye is injected into the heart vessels that will highlight any abnormalities such as blockages or narrowing of your arteries.

☐ Arterial Doppler Ultrasound

A test that will evaluate the major blood vessels in your neck (the carotid arteries) and legs (the femoral arteries) to assess the risks of surgery for you and plan for your operation.

☐ BMD (Bone Mineral Density)

A type of x-ray used to measure the strength of your bones. This test is used to help understand your risk for fractures both now and with the medications needed after transplant and to plan treatments to protect your bones.

☐ Cancer Screening

Depending on your age and risk factors, you may need additional cancer screening, such as a colonoscopy, mammography, and PAP smear to make sure there are no underlying diseases that could worsen after transplant or that need treatment before transplant.

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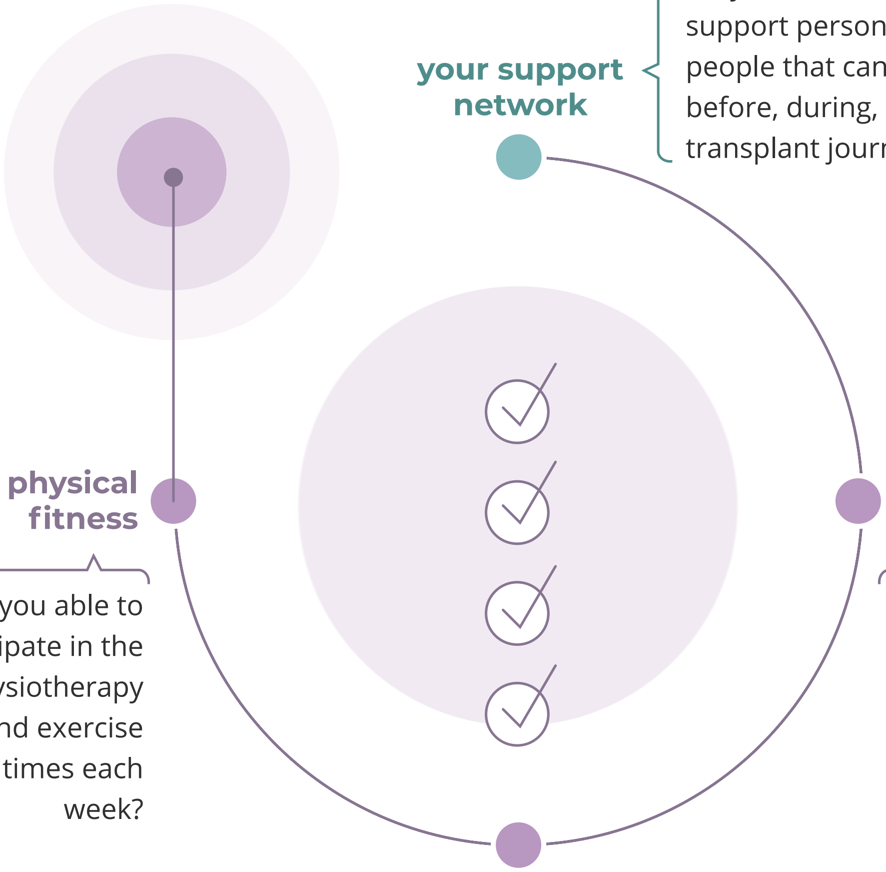
Additional Considerations for Listing

There are four additional considerations that we will explore before you can be placed on the lung transplant waitlist: your ability to assemble a support network, your location and access to the lung transplant program, your drug coverage, and your ability to exercise and build your physical fitness.

Your Social Work team will meet with you and help you understand your personal needs.



your support network

Do you have a dedicated support person or network of people that can support you before, during, and after your transplant journey?

your physical fitness

Are you able to participate in the physiotherapy program and exercise three times each week?

your location

Do you live within 4-5 hours of Toronto General Hospital?

Can you safely travel to the hospital when needed?

*Note: the need to relocate is decided by your transplant team.

your medication coverage

Do you have coverage to pay for all of your medications through a drug coverage plan?

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Your Support Network

Going through a transplant can be very challenging and having support throughout the process is critical.

Everyone needs physical and emotional support along their transplant journey. A dedicated support person or network of people is an essential component of successful transplantation. A support person **must** come with you to all of your appointments to help be an extra set of eyes and ears, you will need to take in a lot of information.

Before transplant you may need to rely on your support network to help you with day-to-day tasks such as cooking and cleaning, and with maintaining your exercise program. In the post-transplant period it is essential that you have a support person with you to help with your recovery.

The Social Worker will meet you and your support person or support network during your lung transplant assessment to discuss and plan for the psychosocial aspects of your transplant. This might include discussions around your home and family situation, substance use and mental health history, finances including time away from work for you and your supports, and reviewing the transplant support requirements as well as your own transplant support plan.

Your Social Work team will review your social support system with you and help you to build the right support network.

When you see this icon the message is for your support network!

At least one support person must be involved in each transplant patient's care and often this person is their partner, children, or parents. We encourage everyone to build a larger support network and include other relatives and friends who might be willing and able to help with tasks such as coming with you to appointments, care at home such as helping with meals, or just providing emotional support.

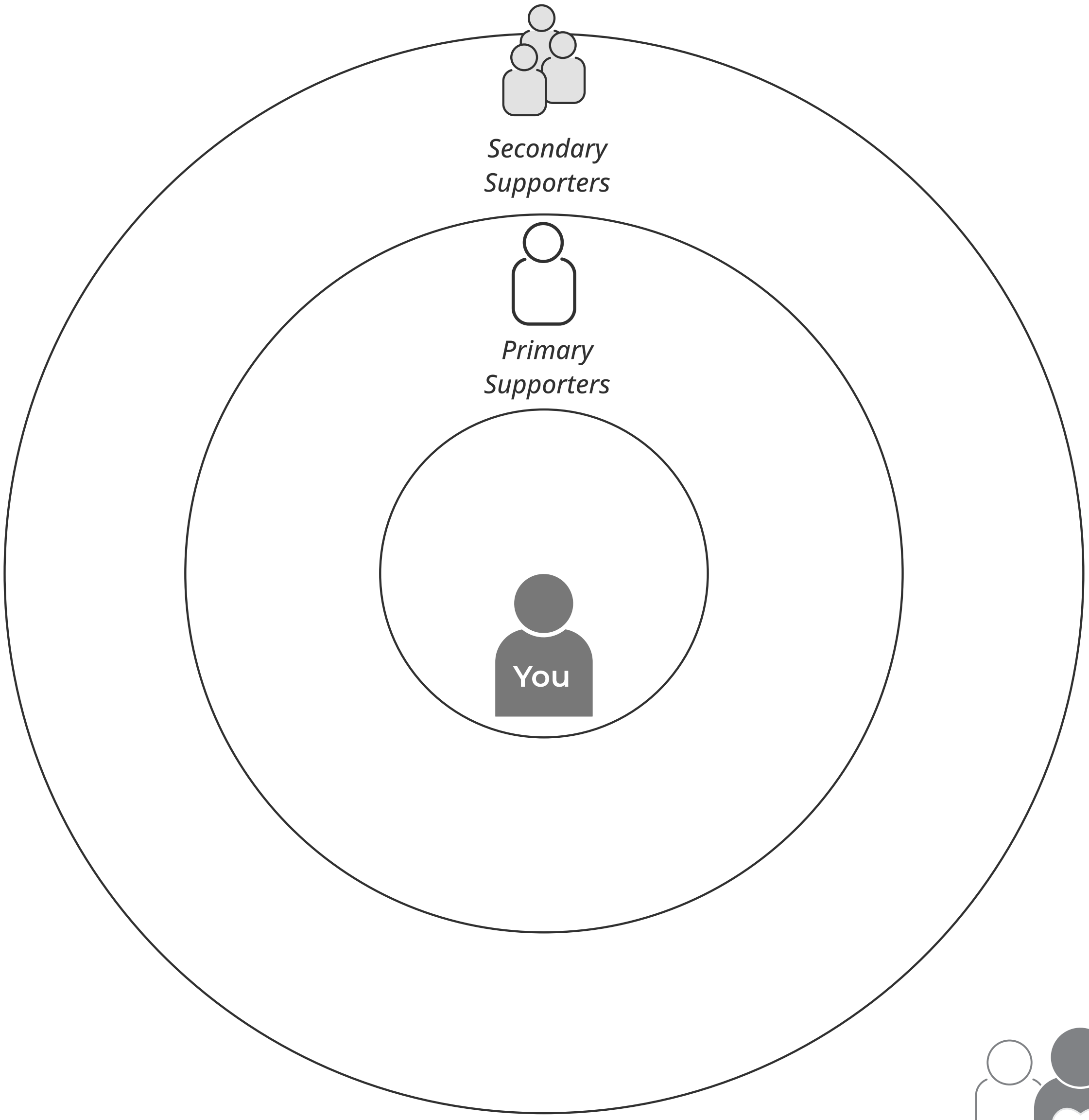
My Support Network

Your Support Network are people that have a relationship with you and a willingness to help. You will need:

- **At least one support person to be involved in your care.** Often this person is a partner, parent, or child.
- **Additional people who can also take on caregiving roles to help you.** This may include siblings and other relatives and friends.

Your Social Work team will meet with you and help you understand your personal needs.

You can use this space to make a list of people to approach as you build your support network.



Your Location

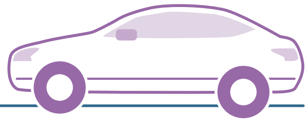
Due to the nature of organ donation and transplant logistics, things may need to move quickly if a lung transplant becomes available for you. **Depending on where you live and the status of your health you may be required to move closer to Toronto while waiting for a transplant.** People who reside up to 4-5 hours away might be able to wait at home for their lung transplant if it is safe and feasible to travel to Toronto General Hospital for physiotherapy sessions and medical appointments when needed. You may need to come to the hospital more than once a week while on the lung transplant waitlist. The decision about your need to relocate while waiting for transplant will be made by the Transplant Team at the time of your assessment. **This decision may change as your health needs change on the waiting list.**

After a lung transplant it is essential to be closer to Toronto General Hospital for at least 3 months after surgery. You will be recovering from a major operation and have frequent tests and clinic visits, as well as physiotherapy appointments. **You should be prepared to be within 2 hours or so from Toronto in the recovery period**. Many people find it beneficial to be even closer to the Toronto General Hospital during the early recovery phase. This will be discussed with you and your support people prior to being placed on the lung transplant waitlist.

You will meet with the transplant Social Worker to discuss any need for pre- or post-transplant relocation during the assessment. Your Social Work team will advise you about available resources such as transportation, housing, local accommodations, and potential financial assistance.

After your transplant, your Transplant Team will ask you not to drive for a few months (typically 3 months) , mainly because of potential side effects from your medications and the healing from your surgery. It is important to plan for how you will get yourself home after your transplant and how you will come back for regular appointments. You should reach out to your family members, friends, and community to organize a transportation and accommodation plan, and make sure that you always have backup options available. Your Social Worker can assist with this planning.

***Please Note:** Unfortunately the hospital can not offer transportation services, this is something that you must organize on your own.*



My Travel Plan

Use this space to make a list of people you might want to approach as you build your transportation plan.

Drivers

Routes to the hospital

option 1

travel time ☐

route info

option 2

travel time ☐

route info

Other Considerations

Your Medication Coverage

Taking your medications after transplant is very important, and you need to make sure you can pay for them through a drug coverage plan. If you cannot access your transplant medications, you will not have a successful outcome from transplant. Even the best insurance programs may not completely cover the costs of these medications. **The Transplant Team is unable to place you on the lung transplant waitlist unless you are able to access adequate drug coverage.**

There are two main sources of drug coverage: private coverage and government coverage. These two kinds of coverage can work together. Many people just have government coverage and it is usually enough to cover transplant medication costs. However, private and government drug coverage plans may not cover medications such as vitamins and minerals so these costs should be planned for in addition to any medications.

The Transplant Team is unable to place you on the transplant waitlist unless you are able to access adequate drug coverage.

You and your Social Worker will discuss your drug coverage one-on-one. They will provide recommendations and information to ensure you receive the right drug coverage.

Here are a few things to keep in mind:

- When you are discharged from the hospital, you must have drug coverage in place and be prepared to pay for any additional costs for medications.
- **These costs can range from $200 to $4,000 per month.**
- The Transplant Unit will provide you with prescriptions but not the actual medications to take home. Before you go home you will need to have your prescriptions filled at the Transplant Outpatient Pharmacy (TOP) at Toronto General Hospital. The team will help to facilitate this process. After going home you can decide if you want to switch to another pharmacy closer to home.
- Toronto General Hospital **does not** have a financial drug assistance plan for transplant recipients.
- Private drug coverage or provincial plans will cover most of the medication costs, however, there may still be some medications that you will need to pay for yourself.

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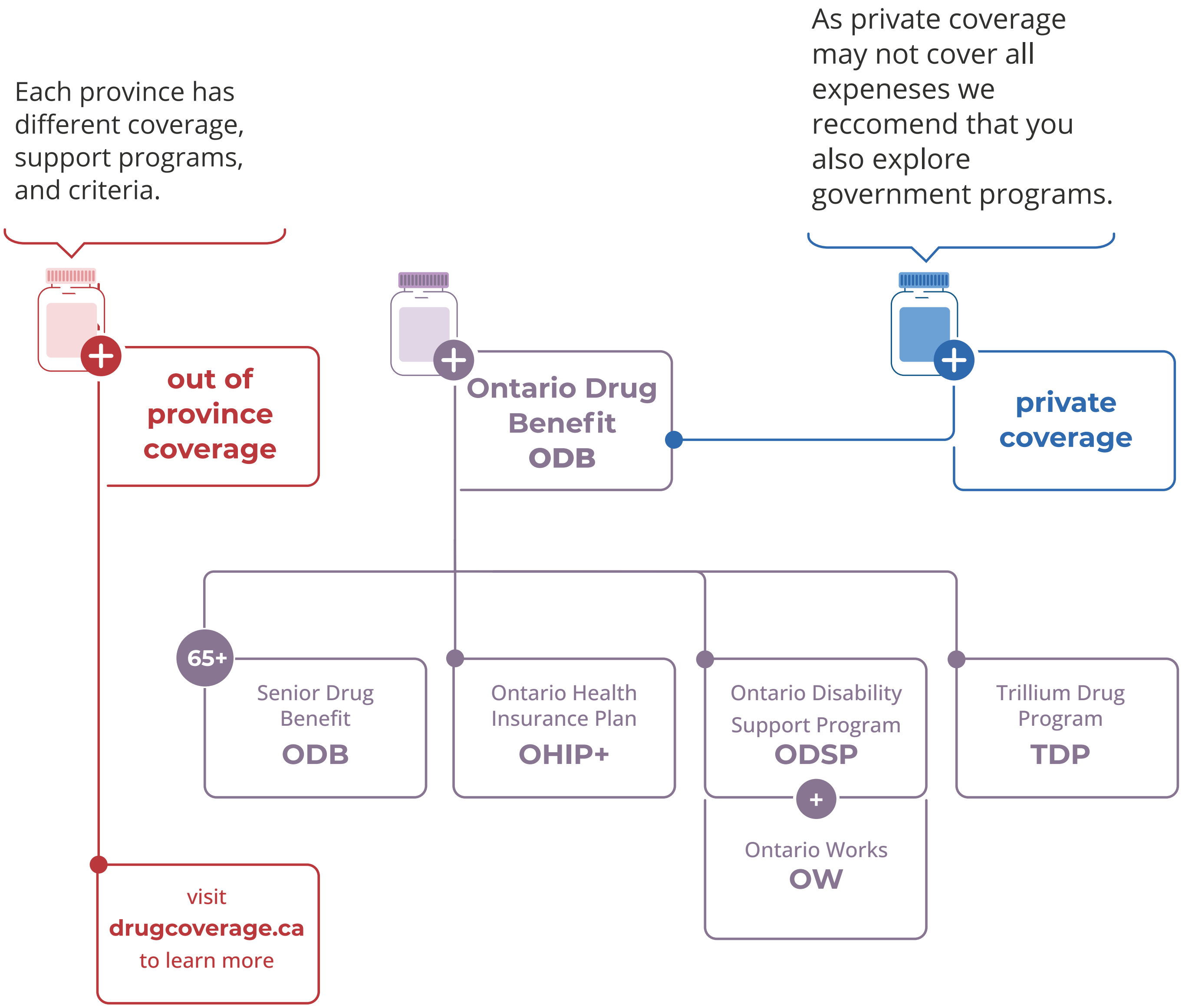
Your Drug Coverage



Each province has different coverage, support programs, and criteria.

As private coverage may not cover all expeneses we reccomend that you also explore government programs.

out of province coverage

visit **drugcoverage.ca** to learn more

Ontario Drug Benefit ODB

private coverage

Senior Drug Benefit **ODB**

Ontario Health Insurance Plan **OHIP+**

Ontario Disability Support Program **ODSP**

Ontario Works **OW**

Trillium Drug Program **TDP**

Private Drug Coverage

If you have private drug coverage, then you will need to ask your insurance carrier:

- What percentage of medication costs will be covered by your plan
- Whether there are yearly or lifetime maximums for drug coverage
- Whether your medications are automatically paid for by your insurance carrier at the pharmacy cash register or whether you need to pay for them yourself up-front and be reimbursed later.

A list of potential medications that you might be on and a list of questions to ask your insurance carrier **can be found here**. The list of medications is long, but this does not mean that you will be prescribed all of the medications on the list. Think of this list as all of the medication choices your doctor has for you. We need to be sure which ones are covered by your drug coverage plan before we prescribe anything.

Even the best private drug coverage plans may not completely pay for all of your medications, so you may need to apply to government programs for additional help.

If your private coverage covers less than 100% of your medication costs, you will also need a form of government coverage.

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. Discussions around out-of-province drug coverage will begin with the Social Worker, and you will also meet with the Medication Reimbursement Specialist, who will advise on out-of-province coverage and relevant processes.

To find out what standard provincial drug coverage includes you can check the following website: **www.Ontario.ca**

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Ontario Drug Plans

If you don't have private medication coverage or your private coverage covers less than 100% of your medication costs, you will also need to apply for some form of government coverage. Below is a list of the programs that are available in Ontario. Your Social Workers will help you find the coverage you need and determine what is available to you.

Ontario Drug Benefit (ODB)

The Ontario Drug Benefit (ODB) program is an Ontario government drug coverage plan which is the main source of help with high medication costs. Many of our transplant recipients get help with their medication costs through the ODB program. The ODB program pays for immunosuppression medications and all the medications on the ODB Formulary, so it will likely help with some of your other medication costs as well.

To qualify for the ODB program you must be an Ontario resident with a valid health card. You must bring your health card with you every time you purchase your medications as it must be swiped at the pharmacy. **Please make sure your health card is always up to date and not expired.**

Seniors-ODB

Recipients over the age of 65 are automatically covered by Seniors-ODB. For seniors with a valid Ontario health card, you are automatically covered starting the first day of the month following your 65th birthday. You do not need to apply.

If you are already covered by the Senior's ODB program, all you need to do is let your Pharmacist know that you are 65 years or older and show your Ontario health card. Each year on, or shortly after August 1st, when you fill prescriptions, you will need to pay around $100 to the Pharmacist towards the cost of your medications. This is called a **deductible**. Then you will need to pay a **co-payment** of a few dollars for each prescription.

These amounts may be subject to change over time. You may pay less than this amount if your pharmacy offers a discounted co-payment. If you want to know whether you qualify for a lower co-payment, **please click here to access the application form** from the Ministry of Health for the Seniors Co-Payment Program.

Ontario Health Insurance Plan Plus (OHIP+)

Recipients under the age of 25 (that are not covered under a private drug plan) are automatically covered by OHIP+, as long as OHIP coverage is active. Recipients under OHIP+ should transition to the Trillium Drug Program 6 months before your 25th birthday.

If you are under 25 years of age and have a private drug plan, OHIP+ does not apply to you. If your private drug plan does not cover 100% of your medication costs, you will have to apply to the Trillium Drug Program to receive full coverage. Also, if there is any reason to believe that your private drug plan may come to an end, for example, through loss of employment, it is best to apply to the Trillium Drug Program as a back-up measure.

Ontario Disability Support Program (ODSP) and Ontario Works (OW)

Recipients who are in receipt of ODSP and OW will have their medications covered through ODB. You will only need to apply to the Trillium Drug Program if your OW or ODSP is ending.

Trillium Drug Program (TDP)

All Ontario recipients that are under 65 years of age must register for the Trillium Drug Program BEFORE being listed for lung transplant, if there is not an alternate form of drug coverage available. Even if a patient does have an alternate form of drug coverage (e.g. private health insurance), registration with Trillium Drug Program would still be recommended as private health insurance plans might not cover all the necessary medication costs.

The Trillium Drug Program (TDP) can be a back-up to your private insurance plan or your only source of drug coverage. The TDP helps households with high medication costs. If you are under the age of 65, and are not covered by a private drug plan, or if your private drug plan does not cover 100% of your medication costs, you will have to apply to the TDP. Also, if you are on OW or ODSP, you will automatically have the ODB. You will only need to apply to the TDP if your OW or ODSP is ending.

About the Trillium Drug Program

In addition to applying for the TDP, you must renew your enrollment every year.

You do not need to pay a premium or any fees to be a part of the program. However, the TDP has a deductible that you must pay before the drug plan can cover the additional costs of medications. You never have to pay extra to have the TDP help with the cost of your medications; after you have paid a portion of your medication costs, the TDP covers the rest. This yearly deductible is based on your household's net income and is divided into four different payments over the year. After each quarterly deductible is paid, you may be asked to pay around $2 per prescription. Some pharmacies may waive this charge.

To ensure that there are no delays in getting your TDP application approved or renewed, you must keep your income tax returns up to date. The TDP obtains your net household income from the Canada Revenue Agency each year. For more information on the TDP program and how to apply **visit this link** or type www.ontario.ca/page/get-help-high-prescription-drug-costs in your browser search bar.

You can speak with your Social Worker about when you should apply to the TDP.

In most cases, you should have your TDP in place before you are placed on the lung transplant waitlist.

If you are on the lung transplant waitlist and have not been getting your health card swiped when picking up medications at your local pharmacy or sending in receipts to the TDP, then your TDP account may become inactive. If your TDP account has been inactive for more than 18 months, then the account will be terminated.

If the government sends you a letter of termination for your TDP account, you need to contact them right away to re-apply. To keep your TDP account active, renew the account each year before August 1st, swipe your health card every time you purchase medications at the pharmacy, and send out-of-pocket receipts to the TDP by sending it to the address shown here:

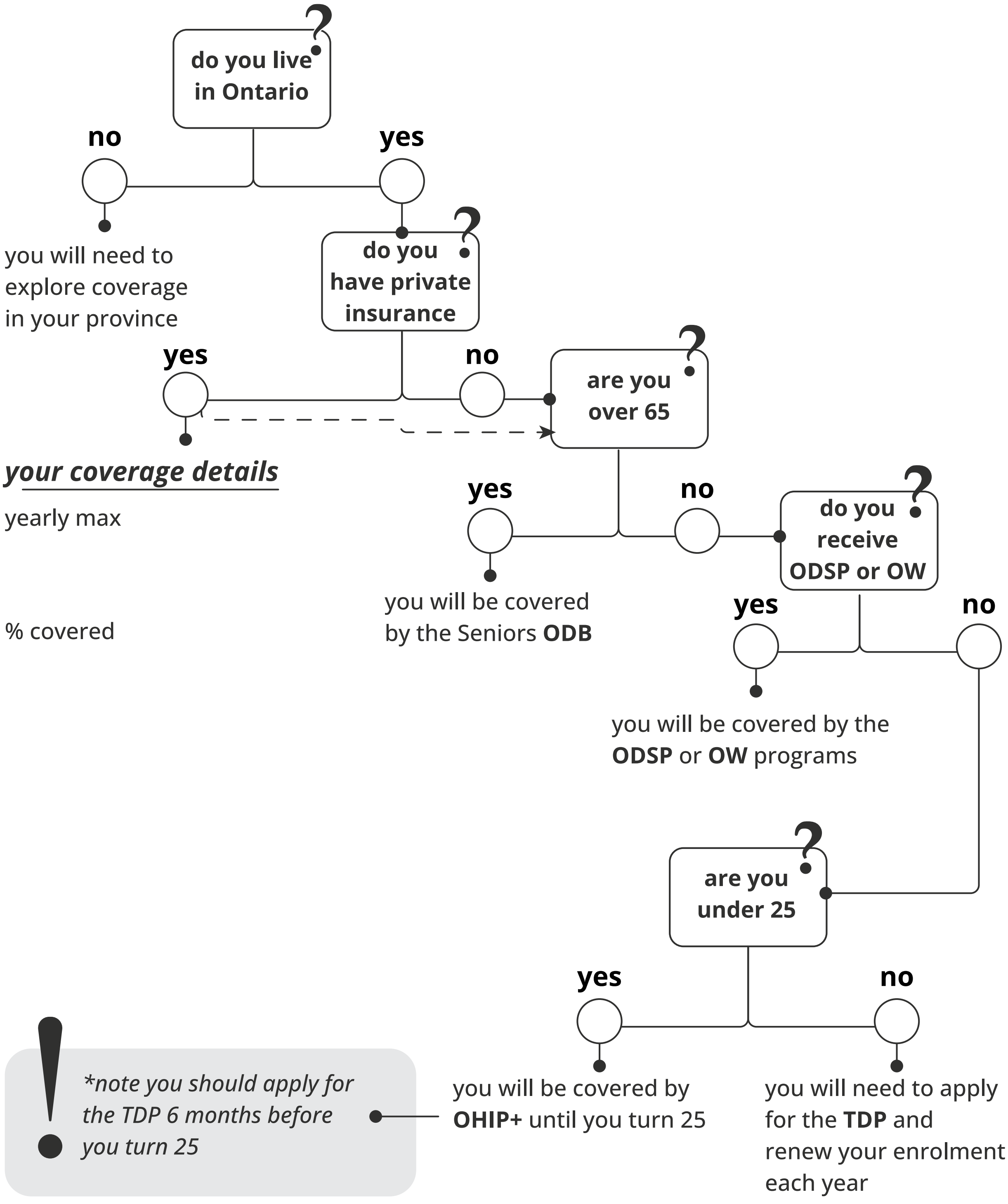
Ministry of Health
Trillium Drug Program
P.O. Box 337, Station D
Etobicoke ON M9A 4X3

There can be many considerations around the TDP that will require your attention so please review the website and prepare questions for your Social Worker.

Your Medication Coverage Worksheet

This worksheet has been developed to help you think about your coverage options.

You can use the open space on the page to note any questions that you have for your Social Worker.



your coverage details

yearly max

% covered

**note you should apply for the TDP 6 months before you turn 25*

Your Physical Fitness

Research and experience have shown us that patients who are waiting for a lung transplant benefit from regular exercise. Exercise helps to improve your fitness before your transplant and increases your ability to do well during and after surgery.

When you are listed for lung transplant you will be required to participate in a physical rehabilitation program supervised by an expert Lung Transplant Physiotherapy Team. **You will need to exercise at least three times every week while you are on the lung transplant waitlist.**

For the first few weeks on the waiting list the exercise sessions often occur at Toronto General Hospital to establish a good routine and ensure you are getting the right amount of oxygen (if you require supplemental oxygen).

After these first sessions the Transplant Team will support you with exercising at home and in your local community as much as possible (if an adequate rehabilitation program is available) along with some exercise sessions at Toronto General.

Our Physiotherapists will work with you to develop a program suited to your abilities and level of health. You should be prepared to come to Toronto General Hospital for your exercise sessions up to 1-2 times a week if it is deemed necessary by the Transplant Team.

After your lung transplant, you will begin post-transplant physiotherapy sessions while you are still in the hospital. These sessions will continue after you are discharged home for at least three months, three times a week as a mix of in-person and at home sessions.

Our physical rehabilitation program consists of both in-person exercise at the hospital and virtual exercise. We will adapt the program based on your individual needs and safety, such as replacing in-person visits with virtual visits.

The Costs of Transplant

In addition to the costs of medication, having a transplant will have an impact on your finances. There will be many costs during your transplant that are not covered by drug plans and these may be out-of-pocket expenses. 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.

You may need special devices and/or equipment, and care team members such as physiotherapists and occupational therapists may recommend that you rent or buy equipment to help you around the home or with walking. You may need to have forms filled out or letters written by health care providers in the program in the program such as forms 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.

Members of the your Transplant Team such as Coordinators and Social Workers will help you find support when needed.

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** (OW) 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

Your Social Worker can provide details about these programs and help to see if you qualify.

You can also consider speaking with Service Ontario or Service Canada to learn more about the programs.

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Funding for Transplant

Government Programs

Ontario government programs

Ontario Works Assistance
OW

Based on income level, assets, and temporary inability to work.

Ontario Disability Support Program
ODSP

For those permanently disabled and unable to return to work.

The Trillium Patient Expense Reimbursement
TPER

For Ontario residents who need to relocate for transplant.

Canadian government programs

Employment Insurance
EI

Contact a local office to learn more about disability benefits.

Canadian Pension (Disability) Plan
CPP

For those under 65, who are no longer able to work and have paid into CPP.

retraining funds & grants

Provincial and federal funds are available for those who are unable to find new or keep previous work due to illness.

Other Programs

out of province programs

Some provinces offer additional funding for relocation.

private programs

Check with your employer to see if you have any benefits or coverage related to medical expenses.

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Insurance

Employment Benefits: Some transplant recipients are able to return to their job or position they had before transplant. Depending on your employer and the amount of time you are off sick, you may also have access to 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 benefits can give you up to 26 weeks of income. Your local EI office will have 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.

Once you are accepted into the program, you qualify for financial assistance for retraining costs and a living allowance. Unfortunately, there is often a long waiting list for government programs. Private companies also offer vocational assessments, counseling and retraining for a fee or some community agencies can offer counseling free of charge or for a small fee.

Canada Pension (Disability) Plan (CPP)

If you are under the age of 65, are permanently unable to work for at least 12 months and you have paid into CPP, you can apply for CPP disability benefits. This will not include drug benefits.

If you feel this might be appropriate for you, fill out an application as soon as possible. Your Social Worker can provide you with the necessary 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.

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Ontario Works Assistance (OW)

You can apply for Ontario Works (OW) Assistance 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 in this program. Your Social Worker can provide you with contact information to learn more.

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 in this program. Your Social Worker can provide you with contact information to learn more.

Trillium Patient Expense Reimbursement (TPER)

If you are from Ontario and are required to temporarily 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 $2500.00 per month for accommodations (as of 2024). This funding applies only to accommodation costs. A rental agreement and rental receipts are required for reimbursement. If this applies to you, this will be discussed when you meet with your Social Worker.

Applications for TPER can be downloaded from the Trillium Gift of Life Network website at **www.giftoflife.on.ca/** and are also available from your Transplant Team. If this applies to you, the application form and program brochure will be provided to you following your social work assessment.

Out-of-Province Recipients

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

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Parking

Other costs to consider relate to hospital and clinic visits. Our virtual care and remote monitoring program helps reduce these costs by providing care in your own home whenever it is safe to do so, however you will be required to attend many visits in-person. Parking at and near the hospital in Toronto can be expensive. Patients and their families can purchase discounted hospital parking passes from the **TGH parking office** to help reduce some of these costs.

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 book with WheelTrans, you can visit their website at **mywheel-trans.ttc.ca**. You will need to apply for the service, if you are interested, speak with your Social Worker.

Travel

If you are flying with oxygen to Toronto for your lung transplant assessment or other visits, your local Respirologist will need to complete a medical form supplied by the airline.

Notify your oxygen company of your travel arrangements. They may be able to help get a local oxygen company to provide you with oxygen at your destination, however there may be an additional fee for this.

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Northern Ontario Patients

The **Northern Health Travel Grant** provides some financial assistance for travel to medical appointments for recipients living in Northern Ontario. However, you must pay the cost of travel up front and then apply for reimbursement.

To facilitate your application to this grant, bring a pre-filled **Northern Health Travel Grant Form** with you to your appointment. Be sure to complete the information in section 1 yourself and sign the form. Your own local doctor will need to fill out section 2 of the form. Give the pre-filled form to your Transplant Coordinator who will have your Transplant Respirologist complete their section.

Your support person will need to complete 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 regardless of where you live, however you will need to apply at your local office for help.

If you need to fly to Toronto for lung transplant care

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. More information can be found on their website at **hopeair.ca.**

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After the Assessment Process

After you have completed all the required tests and appointments, our team will review your results to make our decision and build your plan. Each patient is discussed in a weekly multidisciplinary team meeting that includes Surgeons, Respirologists, Physiotherapists, Dieticians, Social Workers, and others. The full team is part of every decision.

The full team is part of **every decision!**

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you are a suitable candidate

The team will move forward with placing you on the waitlist.

you are too early to be listed

Your lung disease is not severe enough for you to benefit from transplant at this time.

your are not yet ready for listing

Further testing or treatment is needed before you can proceed.

or

lung transplant is too high risk for you

The risks of transplant are too high to give you a good outcome.

< back to the menu

There are four possible outcomes from the assessment process:

1. **You are a suitable candidate for transplant.**
   If you are medically suitable and you feel prepared to go forward with a transplant, the team will move forward with placing you on the lung transplant waitlist. Your first step following this decision will be to meet with a Lung Transplant Surgeon to sign a consent for transplant (more on this in the next section) and then with your Pre-Transplant Coordinator to discuss the next steps and what to expect while you are on the lung transplant waitlist.
2. **You are too early to be listed.**
   It might be too early to put you on the lung transplant waitlist for transplant, usually this is because your lung disease is not severe enough to make the benefits of transplant worth the potential risks. If this is the case, you will be monitored regularly by your own Respirologist and your Transplant Respirologist. They will follow your progress so that you can be listed when the time is right. As time passes, you may need to come to the hospital and repeat some of the assessment process before being listed.
3. **Further testing or treatment is needed.**
   Sometimes the assessment uncovers other medical or surgical problems that need further investigation or treatment before a final decision can be made. We can arrange for further testing or make a treatment plan, after which the team will look at your case again.
4. **A transplant is too high risk and not an option for you.**
   The assessment may identify risk factors that would lead to poor health or threaten your survival after a lung transplant, making transplant not an option for you. If this is the case for you, our team will help you understand the reasoning behind this and discuss what your options are.

It is okay to decline or say you don't want to be put on the transplant lung transplant waitlist right now. This is ultimately your decision and you should let us know if you do not feel that transplant is the right treatment option for you. If you decide that transplant is not the right treatment for you, you will still be supported by your medical teams and may be able to revisit this decision in the future.

It is okay to decline or say you don’t want to be put on the transplant waitlist right now.

This is ultimately your decision and you should let us know if you do not feel that transplant is the right treatment option for you.

If you decide transplant is not right for you now, you may be able to revisit this as a treatment option in the future.

02

Waiting for Your Lung Transplant

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What to Expect

on the Lung Transplant Waitlist

Meeting the Lung Transplant Surgeon

If you and the Transplant Team decide that you are a good candidate for lung transplant, you will meet with a Lung Transplant Surgeon to get more information about lung transplantation and the surgery in particular, and to sign the consent for surgery.

The Surgeon will also discuss your eligibility for a single or double lung transplant. There are three possible outcomes:

1. The first possibility is that you are **only eligible for a double lung transplant**. This may be the case for you if your lung disease makes the risk of a single lung transplant too high. This may be the case for people with lung infections, high pressures in the heart (pulmonary hypertension) or other structural factors.
2. The second possibility is that you are **only eligible for a single lung transplant**. Because of your lung disease and health status, a single lung transplant is preferred.
3. The third possibility is that you may benefit from **either a single or double lung transplant**. This flexibility can increase your chances of receiving a lung transplant offer.

The type of surgery you are eligible for is decided by a team of Transplant Respirologists, Surgeons, and Anesthesiologists, not by any single healthcare provider. This decision is made when the Transplant Team agrees that you would benefit from a lung transplant.

If after this discussion you choose to sign the consent, you will officially be added to the waitlist for a lung transplant.

After your conversation with the Lung Transplant Surgeon, if you are ready to sign consent, **you will officially be added to the waitlist for a lung transplant.**

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Understanding Priority Status

When you are listed for transplant, you will be assigned a priority status on the lung transplant waitlist. The priority status is a number from one to three that identifies the level of urgency for transplant, with a higher number reflecting greater urgency. Your priority is initially determined at the time of listing and will be reassessed after every clinic visit or with changes in your condition while you are listed.

Here is a summary of what the numbers mean, with further explanation later in this guide:

- **Status 1** is for people who need a lung transplant but who are relatively stable.
- **Status 2** usually includes people with rapidly progressing lung disease who may require high amounts of oxygen or are deteriorating in other ways.
- **Status 3** is assigned to patients who have a high risk of dying without a lung transplant in the coming weeks.

priority status

1 low urgency

For those who are relatively stable.

2 moderate urgency

For those with rapidly progressing disease and moderate oxygen needs.

3 high urgency

For those who are very unwell and have high oxygen needs.

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Participating in Research

The Transplant Surgeon will also talk to you about research studies and your options to participate. One of the reasons why we are one of the world's leading lung transplant programs is because people have participated in research and given us feedback. Research is always optional and it is never required that you participate, but by getting involved you can help us keep improving the quality of care we provide.

While you are on the waitlist and after transplant you may continue to get requests from other members of the Research or Transplant Teams to join in on research projects.

A bit about consent and privacy:

- **Participation in research is always voluntary.** You will be given the same high-quality care whether or not you consent to participate and it is okay to say "no" part way through, even if you agreed to take part and then changed your mind later.
- **All research studies are reviewed and approved by the UHN Research Ethics Board,** which is an independent group of staff at the hospital that ensures patients' rights are protected.
- **Your personal information will be private and confidential.** There are hospital policies, as well as provincial and federal laws, that protect the privacy of your information. All your information will be secured within the hospital's computer systems and will not be shared outside UHN unless you give us permission.

Staying Healthy on the Waitlist

There are 2 main goals during the transplant waiting period.

1. **Maintaining your physical fitness through structured rehabilitation.**
2. **Identifying and managing health issues as they arise.**

The time spent on the lung transplant waitlist is highly variable. It can range from a few short days (rare) to a few months. Some people will even wait over a year for a lung transplant. While waiting for transplant, it is likely that your condition will worsen over time.

You will be seen in our Pre-Transplant Clinic every 1-2 months by a member of our Transplant Team to help monitor your health and detect issues. These appointments may be conducted in-person or remotely over video conference. It is essential that we see you in person regularly to best assess your health status. We will also arrange for periodic testing that may include blood work, chest imaging, lung function studies, walk tests, and cardiac testing. You will also be enrolled in the Transplant Physiotherapy Program which allows very close monitoring of your condition.

If your condition worsens or changes, we may need to change your priority status on the lung transplant waitlist. For example if you get an infection, we may need to put you “on hold” until the infection resolves. If you develop a permanent condition that would make your transplant too high risk, we may have to remove you from the list.

If you already live close to Toronto, the Pre-Transplant Clinic does not replace seeing your local Respirologist or Primary Care Provider. If you have temporarily relocated to Toronto, our Pre-Transplant Clinic may act as a substitute for your local Respirologist only for the time that you are away from home. Our team will be in communication with your local Respirologist to ensure that they remain informed about your care, as they will continue to follow you when you move back home after transplant.

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If you have temporarily relocated to Toronto for your transplant, you should ensure you remain connected with your own Primary Care Provider while you have relocated as they may be able to assist you with primary care issues from a distance.

While you are on the lung transplant waitlist **you must inform your Pre-Transplant Coordinator immediately if you will be out of reach or difficult to communicate with** even if it is for a short period of time (for example, unexpected travel).

Also let your Pre-Transplant Coordinator know if you are admitted to any hospital other than Toronto General Hospital so that our team can be in touch with that hospital's team.

Increasing Responsibilities

As a support person you may need to take on more responsibility if the wait for transplant is long and the health of the person waiting for lung transplant continues to decline. If you are feeling stretched there are resources available to you.

If you feel that you need any additional support at home or access to particular services, please contact your Social Worker for more information.

We need to be aware of your current health status and be able to get in touch with you easily.

Your Place on the Lung Transplant Waitlist

In Ontario, donor lungs are allocated by a matching and prioritization method. The donor lungs are matched with potential recipients by blood type and lung size, and then given to the patient with highest priority and the longest wait time. To summarize the 4 factors involved in matching and allocation:

1. **The first factor is blood type.** The donor blood type must be compatible with your blood type. If they are not matched your immune system will think the transplanted lung is foreign and attack it.
2. **The second factor is lung size.** If the donor lungs are too large or too small, they may not function properly or there can be complications. Depending on the circumstances, it might be possible to reduce the lung size surgically to provide a better size match. The lung size you require is determined primarily through pulmonary function tests.
3. **The third factor is priority status.** If more than one potential recipient matches the blood type and lung size of a donor lung, the lung is prioritized for the person who is sicker. Your priority status may change as your health changes and we will let you know if this happens. Patients with any priority status can be called for transplant at any time so do not worry if you have a low number.
4. **The fourth criteria is time on the lung transplant waitlist.** If more than one potential recipient matches the blood group, lung size, and they have the same priority status, we will then prioritize whoever has been on the lung transplant waitlist for the longest time.

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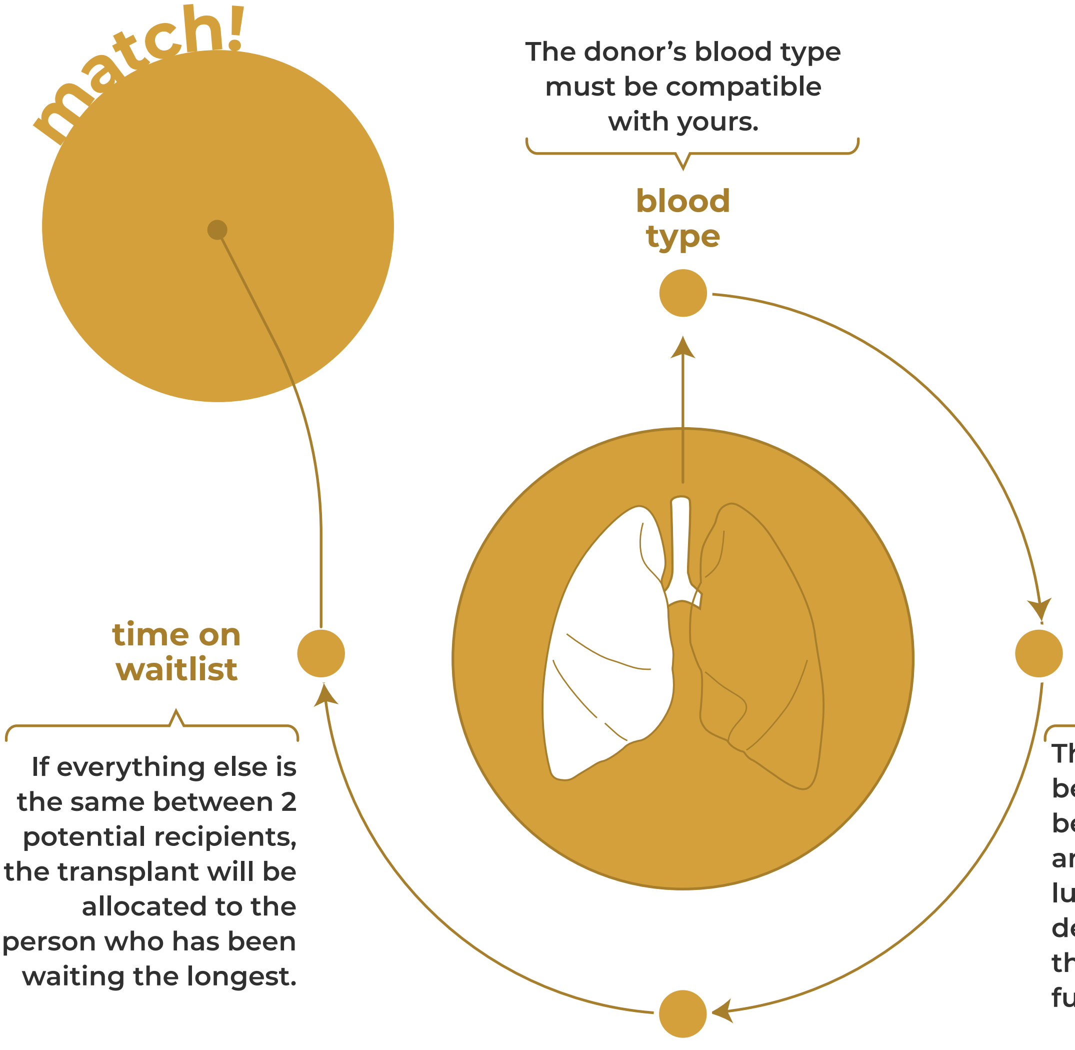
The Matching Process



blood type

The donor’s blood type must be compatible with yours.

lung size

The lung size must be well matched between the donor and recipient. Your lung size will be determined primarily through pulmonary function tests.

priority status

1 low urgency

For those who are relatively stable.

2 moderate urgency

For those with rapidly progressing disease and moderate oxygen needs.

3 high urgency

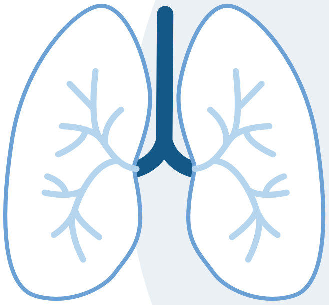
For those who are very unwell and have high oxygen needs.

time on waitlist

If everything else is the same between 2 potential recipients, the transplant will be allocated to the person who has been waiting the longest.

There are four other important points to remember:

1. **There is no "TOP" spot on the lung transplant waitlist** because patients have different blood groups and different lung sizes. In addition, patients' priority status is updated when their health changes, so priority is always changing.
2. **You may be called in to receive a donor lung at any time**, even if you are prioritized as status 1. You may be the only recipient on the lung transplant waitlist that is a match for the donor lung.
3. **The Transplant Team does not know exactly how long you will need to wait** before receiving a lung offer. There is some element of chance in finding a blood type and size match for you.
4. **Priority status 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 or other goods, please know that this is fake and tell the transplant program immediately.



Unfortunately, not everyone who is listed for lung transplantation will be transplanted due to a shortage of donated lungs and the progressive nature of most lung diseases.

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The Pre-Transplant Exercise Program

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

Often when you need a lung transplant you are not able to manage all of your daily activities because you get tired easily, feel weak, and have shortness of breath. You might be afraid to exercise or increase your activity level because you get out of breath easily. But this can actually lead to feeling even more tired, weak and out of breath.

Exercise can help to build your strength, give you more energy and help you to feel like you can breathe more easily. An exercise program will help keep you as strong as possible before your transplant, improve your chances of having an easier time with the transplant surgery and help you get out of the ICU faster, with fewer complications after your surgery.

Your Physiotherapist will design a program based on your individual abilities. Your exercises will often involve using a bike or treadmill, stretching, and using weights. Your Physiotherapist will teach you how to exercise safely and will work with your Doctors to ensure that you have enough oxygen prescribed for exercise and your activities at home.

Your Physiotherapists will also teach you how to use oxygen safely, and teach you breathing exercises that will make activities easier at home.

Helping to Manage Oxygen

Patients may have portable oxygen tanks for use outside the house. These carry either liquid oxygen or compressed gas in cylinders. We recommend that patients switch to liquid oxygen once they are listed. These types of tanks can be refilled when needed while at the hospital. Compressed gas cylinders (metal cylinders) cannot be refilled at Toronto General Hospital.

Portable liquid oxygen tanks can be filled at the Toronto General Hospital:

- Treadmill Room 9:00 AM to 4:00 PM. (Closed for lunch from 12:00 to 1:00 PM). (Room 12C-1376, Peter Munk Cardiac Building)
- After hours on the Respirology floor (6B Peter Munk Building). Ask at the front desk.

Before your transplant and once you are discharged after your transplant you will exercise in our physiotherapy exercise room, the “**Treadmill Room**” at Toronto General Hospital.

Before your transplant, you will come to the Treadmill Room 1-3 times per week the whole time you are on the lung transplant waitlist. You will also be given a home exercise program with exercises that you will be asked to record in your myUHN patient portal for your home exercise sessions.

In order to exercise effectively at home, it is best if you have access to exercise equipment at home such as a treadmill, bike, weights, and a finger pulse oximeter (a small device you slide on your finger to measure your oxygen saturation level and heart rate in your body while you are exercising).

The Physiotherapy Team will advise you and the rest of the care team on how often you need to come to Toronto to exercise vs. how often you may exercise at home and/or in a local exercise program. Every patient has different needs but should be prepared to be required to do in-person exercise in Toronto up to three times a week.

Supporting Exercise

Physiotherapists will include you in their teaching and show you how you can help such as setting up the oxygen, helping with weights, recording exercises on either an exercise card or in the myUHN patient portal, and helping to monitor heart rate and oxygen levels during exercise.

It is important to let the Physiotherapist know if you notice any changes in physical ability or general health of the transplant patient. The Physiotherapy Team meets with the Transplant Medical Team regularly and will share any changes in each patient’s health.

Although your help is welcomed, once the routine is set it is also okay to sometimes just drop off the patient and take this opportunity to have a moment to yourself and grab a coffee or read a book.

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Other Ways to Stay Healthy

There are some other things you can do, in addition to exercise and monitoring your health, that you will help you to stay healthy while on the ung transplant waitlist:

Get your vaccines

Vaccines train the immune system to recognize and fight off viruses and bacteria, and they are important for your health.

Your Transplant Team will review your vaccination history to see which ones you are missing and need to get before your transplant. It is ideal to receive these vaccines before your transplant because after transplant, you will be required to take medications that suppress your immune system. This means that some vaccines will be less effective and possibly even dangerous.

After transplant, you should avoid all live virus vaccines, such as the chickenpox vaccine, because there is a risk that you might catch the illness you are trying to prevent with the vaccine. Please check with your Transplant Team if you are unsure about which vaccines are necessary and safe.

Practice good dental hygiene

Taking care of your teeth is also an important part of your health before and after transplant. This means brushing your teeth at least 2 times a day, flossing at least once a day, and checking the inside of your mouth for unusual mouth sores, swelling, or bleeding of the gums.

You should visit your Dentist 2 times a year for regular checkups and cleaning. If you do not have a dentist, the Transplant Team can help you find an appropriate provider.

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Stay smoke free

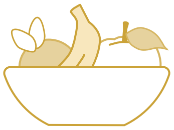
Everyone who is listed for lung transplant is required to be smoke free for a period of at least 6 months before they are placed on the lung transplant waitlist.

Being smoke free means not smoking tobacco or cannabis, and not using e-cigarettes or other vaping devices for any substances. If you are having problems quitting and staying smoke free, speak with your Transplant Team, who can recommend programs and strategies to help you.

Avoid unsafe herbal remedies and medications

Before starting any herbal remedies and medications, it is important to speak with the Transplant Team.

Many herbal remedies, over-the-counter medications, and prescription medications can interact with your current medications and are not safe to use while you are on the lung transplant waitlist. You must talk to the Transplant Team first before taking any new herbal remedy or any new medications, even if they are recommended and prescribed by another doctor outside the Transplant Team.



Eat a healthy diet

It is important to have the right amount and right types of food, so that you can meet your needs for vitamins, minerals, and other nutrients; reduce your risk for obesity, type 2 diabetes, and other diseases; and maintain your overall health and wellness.

You will be able to discuss your diet with your transplant dietician and come up with a plan based on the Canadian Food Guide.

Based on research and experience, patients have better outcomes after lung transplant if their Body Mass Index, also known as BMI, is between 17 and 27. This number is determined by your height and weight, and a dietician on the Transplant Team will help you calculate your BMI and work with you to find strategies to help you lose or gain weight if necessary.

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Being a Supporter

As the support person, you are in a good position to notice changes in the lung transplant patient's condition. Please bring these observations to the attention of the Transplant Team.

Some ways you can be an advocate:

- Talk to the Transplant Team about the state of mind and level of comfort of the person you are supporting.
- Ask questions about what is happening, including any treatments and investigations the transplant patient is having.

It is also very important to take care of yourself so that you can be at your best throughout this journey. **Transplant is a marathon, not a sprint.** Marathon runners get regular refreshment stops. You need these refreshments stops as well. You will need to learn how to manage your energy and resources in order to go the long distance. You may experience many emotions including isolation, loneliness, and an increased sense of responsibility as you care for a sick loved one.

You may also have fears about the future as you watch them becoming sicker.

Here are a few things to keep in mind:

- **Eat healthy**
  A healthy diet will help with your overall energy levels and health status. Eat regularly, eat nutritiously, and drink plenty of water.
- **Avoid smoking**
  Smoking near someone with lung disease can be damaging to their health, as well as your own. Do not smoke while oxygen is in use. Do not smoke inside the house, apartment, or car. Quitting smoking will go a long way to support the transplant patient.
- **Avoid infections**
  Infection is a risk for patients waiting for their transplant and for patients who are immunosuppressed following the transplant. Take steps to control the risk of infection including using good hand washing, antiseptic gel, teaching children to wash their hands frequently, avoiding people with "cold" or "flu-like" symptoms and close face-to-face contact, and get your recommended vaccinations, including the flu shot.

Managing Stress on the Waitlist

There are a lot of reasons to feel stress while waiting for a lung transplant. Worrying about a decline in health and physical abilities, the impact on your family, support network, and finances, and the worry that you may not receive a transplant in time all can weigh heavily. There is no right way to feel or react to stress because everyone has their own experience and copes in different ways.

Stress can cause physical reactions such as fatigue, headaches, change in appetite, and problems sleeping. Stress can also cause emotional reactions, such as fear, anxiety, anger, frustration, and mood swings. Sometimes stress can even cause changes in thinking, such as difficulty concentrating and making decisions, forgetfulness, and withdrawal from others. These reactions to stressful events are normal and understandable. If you begin to feel overwhelmed at any point about the transplant process or have problems with day-to-day coping, please contact your Transplant Team for help.

The following are a few ways you can try to manage your stress while waiting for transplant.

- **Structure your time.** Keep busy and try to keep your life on as normal a routine as possible.
- **Talk and share.** Being open about your feelings with your loved ones can be helpful in reducing stress. You can also participate in the Lung Transplant Support Group or talk to your Transplant Team.
- **Give yourself permission to feel sad or frustrated.** This is a life-altering time, and everyone can have an “off” day.
- **Avoid alcohol and drugs.** Do not use alcohol or recreational drugs to cope with stress. This can cause more problems and harm your ability to successfully get a transplant.
- **Practice self-care.** Exercise as much as possible, eat well, get adequate sleep, and do something that makes you happy.

Because of the physical and emotional challenges of transplant, **many patients may feel depressed and/or experience anxiety.**

Feeling depressed and/or dealing with anxiety is very common. This can be treated, and does not necessarily affect your status on the lung transplant waitlist. Symptoms of depression and anxiety are similar to those of stress. If you are experiencing depression you may feel irritated, frustrated, fatigued, and/or sad. You may try to isolate yourself from others and have changes in your appetite and sleep patterns.

If you are experiencing increased anxiety you may feel restless, tense, on edge, and have a sense of dread. Some people may even experience panic attacks, which can last a half hour or more. For someone with trouble breathing panic attacks can be particularly upsetting as you may feel as though your breathing is much worse and your heart may feel like it is pounding or racing.

If you or your support network are experiencing depression and anxiety you might benefit from seeing the Transplant Psychiatry Team. The team can help you learn about different ways to manage your symptoms, provide counselling and support, and prescribe medications if needed. Depression and anxiety can also occur after transplant, so please let your Transplant Coordinator or doctor know if you need help.

Spiritual Care

Another resource for patients during this time is Spiritual Care at UHN. At UHN, health care involves the whole person – the mind, body, and spirit. During life transitions and times of stress, attending to your spiritual needs may be helpful.

A Spiritual Care Professional who is part of the Transplant Team can help you and your support network to:

- Explore spiritual significance and meaning experienced in times of sickness.
- Examine the implications in one's life. as a result of the medical experience
- Cope with death, dying, and sickness.

Please let your Transplant Coordinator know if you would like to see a Spiritual Care Professional.

It is common to experience stress, depression, and anxiety while going through your transplant journey. Please let your Transplant Coordinator or Doctor know if you need help. The Transplant Team includes Psychiatrists and Spiritual Care Professionals who can support you in this process.

Taking Care of Yourself

As a support person you too may experience stress and you may feel that your own life is on "hold". This could leave you feeling frustrated, angry, or even guilty for feeling this way. Many support people describe putting themselves last in many ways in order to care for soemone else. From our experience, putting your own needs on hold such as sleeping, eating, and getting help for yourself does not work. The transplant patient needs you to be healthy and whole.

Some tips that may help you to manage your own health and wellness are:

- **Set up your own support system.** Think about who you can reach out to for both practical help and emotional support. This can include family, friends, clergy, support groups, or professional counseling. Be sure to tell them what is most helpful to you and what you need.
- **Delegate tasks and accept help.** Family and friends often want to help but are uncertain what would be most appreciated. They need to know that giving small things such as phone calls, taking you out for coffee, offering help with errands, giving a few hours of help or sharing a joke can be of help.
- **Create a communication system.** During the transplant process it will be important to keep family and friends updated. Creating a phone tree or other communication plan will help reduce interruptions and conserve your energy.
- **Keep track of medical information.** This can help reduce confusion when meeting new individuals from various health care teams. Names, numbers, instructions, and questions can easily be recorded and helpful in future meetings. If you are on the MyUHN portal you can use this tool to for tracking.
- **Take time for yourself.** Every support person needs some time to themselves. Include 10-15 minutes in your schedule each day for yourself – a walk, visiting with or phoning friends, or getting outside. This can re-energize your spirit. We recommend that you build a support network because sometimes an alternate support person may need to be available to help.

Transplant Support Groups

You and your support network will have access to a virtual Lung Transplant Support Group that meets regularly.

The group is organized by our Social Worker and mental health Nurse and helps address questions and stressors that commonly affect individuals awaiting transplant. It is a venue for patients to share their experiences, offer mutual support, and receive education. It is not intended to be a therapy group, although there may be some therapeutic value for those attending.

People attending the group must agree to respect confidential information, which may be shared during these meetings. **What happens in the group stays in the group.**

Support Group Time & Link:

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A few more ways to take care of yourself

- **Keep a diary.** Keep your own personal diary or journal. Write down your feelings – the "good", the "bad", and the "ugly". Putting your feelings on paper is a powerful tool to decrease stress. Writing or journaling is not for everyone but give it a try.
- **Take it one step at a time.** Focus on the present – one day, one hour, one moment – and measure progress in small steps. The unexpected can happen. Complications occur, which slows down recovery. There may be delays, setbacks, and surprises. Focus on what is important and what really matters. Try to maintain a positive outlook. Try not to get carried away with worrying about the future.
- **Plan for a journey.** Caregiving carries on long after the patient leaves the hospital. Receiving the transplant is only the next step in the journey. Caregiving will change in the months following transplant but it may be some time before the patient is able to manage on their own.

Palliative Care

Patients awaiting lung transplant often need some degree of supportive care in addition to treatment for their underlying lung disease.

The Palliative Care Team aims to improve quality of life for patients and their families facing problems associated with a life-threatening or life-limiting illness.

The team will assess and help to treat shortness of breath, pain and other physical, spiritual and psychosocial issues associated with your illness. Most patients on the transplant waitlist are followed by the Palliative Care Team, to help them have the best possible quality of life while waiting for their transplant.

> The focus of palliative care is the **prevention** and **relief of suffering** through early identification.

The Palliative Care Team may be able to assist with:

- **Providing relief** from distressing symptoms such as pain, breathlessness, and fatigue.
- **Coordinating home care support** to help you with things such as cooking, cleaning, bathing, dressing etc. so that you can live at home as comfortably as possible, despite your symptoms.
- **Advanced care planning** to ensure your values and wishes for your health and personal care are shared with those around you if you can not speak for yourself.
- **End of life care and bereavement support** for you and your family and friends if your condition or illness worsens to a point that this support becomes appropriate.

Family Needs

For those patients and support people who have young children they are often concerned about the best way to help them throughout this journey and the best way to share information with younger children. They wonder about how much to tell the children, how to protect them and avoid frightening them. The Social Work Team is available to meet with you and will discuss your individual situation and help you develop a plan to support you and your children. They may also connect you with other sources of help in the community, such as school counselors.

Everyone in the family is affected by the waiting, surgery, and recovery from transplant. Children of every age will know that family life is different and will need support, understanding and processing what is happening.

Here are a few tips for how you can support children and help them manage during these changes:

- **Maintain routines:** Try to maintain a child's routines as much as possible. Attempt to continue to eat, sleep, play, and live as normally as possible. Changes are going to happen, especially if temporary relocation is needed, but your family will handle changes best if their routines can be continued.
- **Be honest:** Children will sense that something significant is happening in your family. Be honest but be sure to share details at their level.
- **Include the whole family:** Once the adults have discussed issues involving the whole family, children should be included in planning, when it is appropriate. Talk to children about how family life might change. Get their ideas on how they can help. Try to include each family member in every step.
- **Have a plan:** If your family needs to move temporarily, how will young children be cared for before the transplant, during hospitalization and recovery? It can be unfair and unrealistic to expect to include children in all of your hospital trips.
- **Stay healthy:** Keep up to date on everyone's healthcare including yearly physicals, dental, and eye check-ups. If you have to move temporarily be sure to review each person's health before the move. Appointments are easier to arrange in your hometown and children will be more relaxed with doctors they know.

Talking to Children About Transplant

As a family you will need to decide how much information is appropriate to share with your children and how you will prepare them for what is ahead. Although a parent or sibling may have been unwell for some time, children need to have some understanding of how transplant will change things. Be sure to decide before surgery if it will be appropriate for them to visit the ICU or if it will be better for them to wait until you are feeling better to see you in the hospital.

If children are young, try to use pictures, examples, and simple terms to explain why a transplant is needed. Be sure that children understand that they are not to blame for the illness or the transplant and don't make promises you can not keep, for example avoid saying "everything will be fine". Be sure to give space for children to ask questions and don't be afraid to say "I don't know".

Here are a few topics to consider discussing:

- **Changes in family life:** Talk with children about how regular family life could change. If you might need to move temporarily, talk about why and when, or if someone new is coming to stay for a while, talk about who and why.
- **Organ donation and transplantation:** Share how transplant works, in very basic terms appropriate to the child's level and why there might be a long wait. It is good to also talk about all the possible outcomes.
- **What to expect in a hospital:** It is important to prepare a child for what they will see if they are visiting a patient after surgery including the room, any equipment used, how the patient will look and whether the patient will be able to speak. Be sure to also add details about what they will hear such as the machines, sounds from other patients and even some basic medical terms.
- **Recovery times:** Make sure children understand that recovery will not be immediate. The transplant will not make the patient instantly better, it is going to take some time.

Remember that life is not on hold – things may be different but life goes on and **you must still live while you wait!**

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Dealing with burnout

Burnout and physical 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 your Primary Care Provider or the Transplant Psychiatry Team for help. **Your Pre-Transplant Coordinator can help you navigate this.**

Many support people get some professional help. This will not change the patient's status while on the waiting list or the care they receive after the transplant.

Burnout can occur if you feel emotionally and physically drained from your role as a support person and caregiver when you don't get the help you need, and try to do more than you should. If burnout goes unnoticed, it can have an effect on the lives of your loved ones and yourself. Knowing what to watch for may help avoid this problem.

Symptoms of burnout can be similar to those of stress and depression and might include:

- Withdrawal from friends and family
- Loss of interest in activities you previously enjoyed
- Feeling down, hopeless, and helpless
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Getting sick more often
- Feelings of wanting to give up on yourself or providing care
- Emotional and physical exhaustion
- Irritability

Everyone has an "off" day but when the signs of stress and burnout start to occur regularly or get worse, **please ask for help.**

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More about dealing with burnout

Finding ways to help alleviate your stress may help address the problem. The following are a few ways to manage your stress and avoid burnout:

- **Structure your time:** Keep busy and try to keep your life on as normal a routine as possible. Don't give up everything that makes you who you are and don't feel guilty for taking a moment for yourself.
- **Talk to people:** Sharing your feelings can be helpful in reducing stress. Reaching out and spending time with people you trust can help you to see that you are not alone in what you are feeling.
- **Journal:** Write your feelings down in a journal or diary. Give yourself permission to feel sad and frustrated.
- **Ask for help:** Do not be afraid to ask others 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.
- **Avoid self-medication:** Do not use alcohol or recreational drugs to cope with stress. It may feel helpful at the time but it can cause more problems later on.
- **Keep healthy:** Exercise – even a walk around the block can be refreshing, eat regularly and drink plenty of water.
- **Get proper sleep:** People are at their best when they sleep about 8 hours every night. Sleep has many benefits including mood improvement, mental alertness, energy, and well-being.

Remember to ask for help if the signs of stress and burnout begin to occur regularly or are increasing, talk to your Primary Care Provider, the Transplant Psychiatry Team, or your Transplant Coordinator. It is easier to cope with stress when you have 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 and help you manage your anxiety and emotional responses better, even in moments of difficulty.

To learn more about the MBSR program call the Transplant Psychiatry Team or your Transplant Social Worker.

Advanced Care Planning

Advanced Care Planning might also be referred to 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 and it could happen suddenly or come on gradually.

Advance Care Planning ensures that your wishes for how you want to be cared for are known to your full care team and gives someone you trust the authority to act on these wishes. The person you identify is known as your 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 are unable to make decisions for yourself, there are two important things your care team and family and friends need to know, your wishes for what type of care you want and who can make decisions for you.

You can use the worksheet on the next page to document your values and wishes for your care.

It is important to answer these difficult 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.

Advance Care Planning Canada has some online resources that can help you with your planning. Got to **www.advancecareplanning.ca**.

Your Social Worker will be able to provide you with an **Advanced Directives Guide booklet.**

Advanced Care Planning Worksheet

Advanced Care Planning might also be referred to 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 and it could happen suddenly or come on gradually.

You can use the following worksheet to document what you would like people to know about your wishes and preferences.

What are your specific wishes regarding your healthcare?

Who would you want to make decisions for you?

If you need support creating your advance care plan talk to your talk to your Social Worker or Palliative Care team, and visit **AdvanceCarePlanningCanada.ca** *to find a comprehensive planning guide.*

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Powers of Attorney

A **Power of Attorney (PoA)** is a legal document stating who has the authority to manage your money and property or make personal decisions on your behalf if you become unable to do this for yourself. The person you appoint in your powers of attorney does not need to be a lawyer.

A substitute decision maker is the person you have appointed to make your healthcare decisions and the PoA is the legal documentation stating who you have appointed to make those decisions.

The PoA can also provide the authority to make decisions about personal care, such as clothing, housing, nutrition, etc.

It is important that you think about your situation while you are relatively healthy and make plans for your powers of attorney.

There are two basic and separate forms of PoA:

- Power of Attorney for Personal Care
- Power of Attorney for Property

If you do not chose someone for this role the law will prioritize decision-makers:

1. **Spouse**
2. **Adult children and/or Parents**
4. **Siblings**
5. **Extended family**

personal care

Someone you choose to make healthcare decisions when you are not able

property

Someone you choose to make financial decisions when you are not able

These decisions can affect your care and your finances.

Power of Attorney for Personal Care

A PoA for personal care is someone 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.** To appoint a PoA for 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:

1. Your spouse
2. Adult children (over 16) and/or Parents
3. Siblings
4. Extended family members

Sometimes patients 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 and your designated PoA 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; however, 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 in receiving the care you would wish to receive.

Power of Attorney for Property

Your PoA for property 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 PoA for property.

To appoint a PoA for property, you need to create a legal document that 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 PoA.

03

Getting Your Lung Transplant

Getting the Call for Transplant

When a donor lung becomes available to you, we will call you. The call for a transplant can come at any time of the day or night.

Getting the call for transplant can be exciting and stressful.

If you do not pick up the call, the Transplant Coordinator will leave a voicemail for you and try to contact your support network. It is very important to let us know if you change your contact numbers. Please pick up your phone, even if you do not recognize the number or if you see a private or unknown caller. If you see that you missed a call from the hospital, dial back the number that was provided in the message.

Timing is critical for the function of the lung transplant, so if we cannot reach you within an hour, the lung will be offered to the next patient on the lung transplant waitlist.

During the call, the Transplant Coordinator will identify him or herself and briefly ask you about any recent changes in your health, new symptoms, medications, etc. They may also ask questions to confirm your medical history and allergies.

If there are no concerns you will be asked to come to the hospital. At this time, the Transpolant Coordinator will tell you when you need to stop eating or drinking if you need to take a shower, and when to come to the hospital.

You should know that **you can decide not to come in for transplant**, however in that case **you will be placed "on hold"** on the lung transplant waitlist, and then will speak with your Pre-Lung Transplant Coordinator about your situation and next steps to make sure you are ready for transplant.

If you are coming by car **do not drive yourself**, please have someone else drive you. You should always have a back-up person who can drive you in case your primary support person is unavailable when you get the call. Your **transport plan** should be made in advance so that you are ready to put everything into action when you get the call.

Getting the call for transplant can be **exciting and stressful.**

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Being Ready for "The Call"

- **Make a checklist in advance:** Make a list of what you need to do and what to take with you.
- **Plan for childcare:** If you have young children, you will need to make plans for when the call comes for the transplant, either day or night. Make sure there is someone to pick them up or care for them and confirm arrangements in advance.
- **Transportation:** Have a plan for getting to the hospital. Know who is going to drive, who is the back up and the route you will take to get to the hospital. It is also a good idea to practice your route.
- **Pack a small overnight bag:** Pre-pack a few personal belongings for yourself, particularly if you plan to stay near the hospital. Don't forget your glasses, pills, phone chargers, or any other necessary items.
- **Bring extra cash or a credit card:** You may need to pay for meals, parking, or even a hotel if you are planning to stay close to the hospital.

What to Bring to the Hospital

This worksheet will help you plan what to pack for the hospital.

Do Not Forget

It is very importatnt to remember to bring:

Your Ontario Health Card or Provincial Health Card if you are from another province.

A list of all your medications including the drug names, dosages, and frequencies. If you do not have a medication list, you will need to bring all your medications in their original containers and packages.

You may bring your cellphone and charger. Your support person or the nursing staff can keep it safe for you while you are in the operating room.

For after your surgery

Your family or support person can bring you some things to make your stay at the hospital more comfortable. Ask the nursing team when the right time is to bring these items in. Here are a few suggestions:

Toiletries (soap, shampoo, comb/brush, toothbrush)

Dentures, Hearing Aids, and/or Glasses

A pair of sneakers to start your post-transplant physiotherapy.

Do Not Bring

For safety reasons, when you are called in for transplant
please do not bring:

Any valuables such as rings, watches, and jewelry.

Large amounts of cash.

Any large electrical equipment that needs to be plugged in.

Laptop computers or tablets unless you can give them directly to a family member for safekeeping.

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At the Hospital

At the hospital, you will be seen by Doctors, Nurse Practitioners and the Nursing Team who will examine you and get blood tests, x-rays, and other tests to ensure you are well enough for the surgery. If the team feels your health status is adequate for a successful surgery and the donor lung or lungs are suitable, the nursing team will prepare you for surgery.

Please understand that **it is possible that your transplant surgery could be cancelled** if the donor lung(s) is/are found to be unsuitable, or if your tests show changes in your health that mean the surgery cannot be done safely. These “false alarms” or “cancellations” happen relatively frequently. This is one of the more upsetting things that can happen while you are on the lung transplant waitlist.

Having your surgery cancelled can feel shocking and disappointing for you and your family. **Sadness and all these feelings are normal.** Please remember that the team is still supporting you and looking for the right match for the best chance at a successful transplant.

Having your surgery cancelled can feel **shocking and disappointing**

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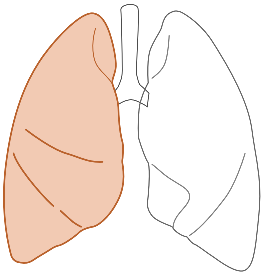
About Your Surgery

During your surgery, while you are in the operating room, your family and/or support person can stay in surgical waiting room, or the ICU waiting room, someone will show them where to go. They can also choose to wait elsewhere such as your local accomodations or home if it is nearby.

When your surgery is over, your Surgeon will come to the waiting room to talk to your family and/or support person or call them if they have gone home to rest or wait.

There are a number of options for how your surgery might be done, the following section will give you a bit of information for each surgery.



Single lung transplant

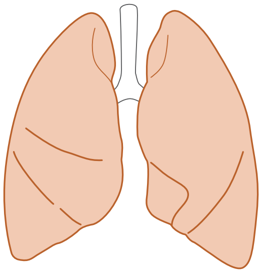
A single lung transplant will likely take 6 hours or more. You should only need one incision on your side, however, in some cases the incision may be larger and go across your sternum or breastbone.

Your Surgeon will remove the diseased lung. Your other lung will be supported during surgery by giving you oxygen through a ventilator. You might also be supported with other types of life support to help keep you stable.

Once the unhealthy lung is removed your Surgeon will put your donor lung in your chest and make three connections to attach the new lung. Your Surgeon will attach:

- Your main bronchus (airway) to the donor lung bronchus
- Your pulmonary artery (blood vessel) to the donor lung pulmonary artery.
- The donor lung pulmonary veins (blood vessels) to the left atrium of your heart

Once all these connections are completed, extra tissue is wrapped around the incision line on your airway to help with healing.



Double lung transplant

When you have a double lung transplant, your Surgeon will make a horizontal incision just below the middle of your chest. The bottom part of your sternum, or breastbone, will also be cut during the operation.

A double lung transplant can take up to 12 hours. Your Surgeon will replace one lung at a time, first removing the unhealthy lung and then attaching the new healthy donor lung. 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 with more advanced life support. This is more common with a double lung transplant.

For Everyone

Regardless of the type of lung transplant you are having, certain things will be the same for everyone. During surgery your Surgeon will perform a bronchoscopy (the insertion of a fiber optic camera down your throat) to look at your new airways. They may also perform an echocardiogram in the operating room to check on the attachment of the blood vessels from the new lungs to your heart.

Sometimes your Surgical Team will need to adjust the size of the donor lung(s) to better match the size of lungs that you require. This is called volume reduction. Some people will also benefit from having only parts (lobes) of a donor lung transplanted for the best size match. This is called a lobar transplant. Size matching is very important for a good outcome from lung transplant.

Once your surgery is complete, the muscle layers of your chest will be stitched together and the skin will be closed with staples. **Your staples will be removed 2-3 weeks after surgery.** You will also have chest tubes inserted beside the lungs to help drain any fluid or air as the new lungs settle in. **The chest tubes will typically be removed within 7-10 days.**

Your Hospital Stay

The average length of stay in hospital after a lung transplant is about 21 days, or 3 weeks. Complications may extend your hospitalization significantly, requiring some people to be transfered to an in-patient rehabilitation facility before discharge, while other people have a more straightforward recovery and leave the hospital sooner.

The ICU - Intensive Care Unit

Peter Munk Building 10th floor

From the operating room you will be taken to the Medical/Surgical Intensive Care Unit (MSICU). Most patients are sedated with medications and are on a ventilator with a breathing tube in place. Your care team will assess how well your lung(s) are functioning and work toward getting you awake and breathing on your own so that the breathing tube can be removed.

This may happen as quickly as the day of the surgery but often takes more time, as the lungs may require time to function well after a transplant, and other complications can happen that prolong your time on the ventilator and in the ICU.

While you are in the ICU, visits will be limited (usually 2 visitors at a time). ICU Nurses can call and be called for updates. Ideally please have one designated person to get these calls.

While in the ICU you will hear and see many unfamiliar things. You might feel sleepy all the time and it is normal to feel disoriented. You may also not remember very much of your stay in the ICU after you fully recover. This is normal.

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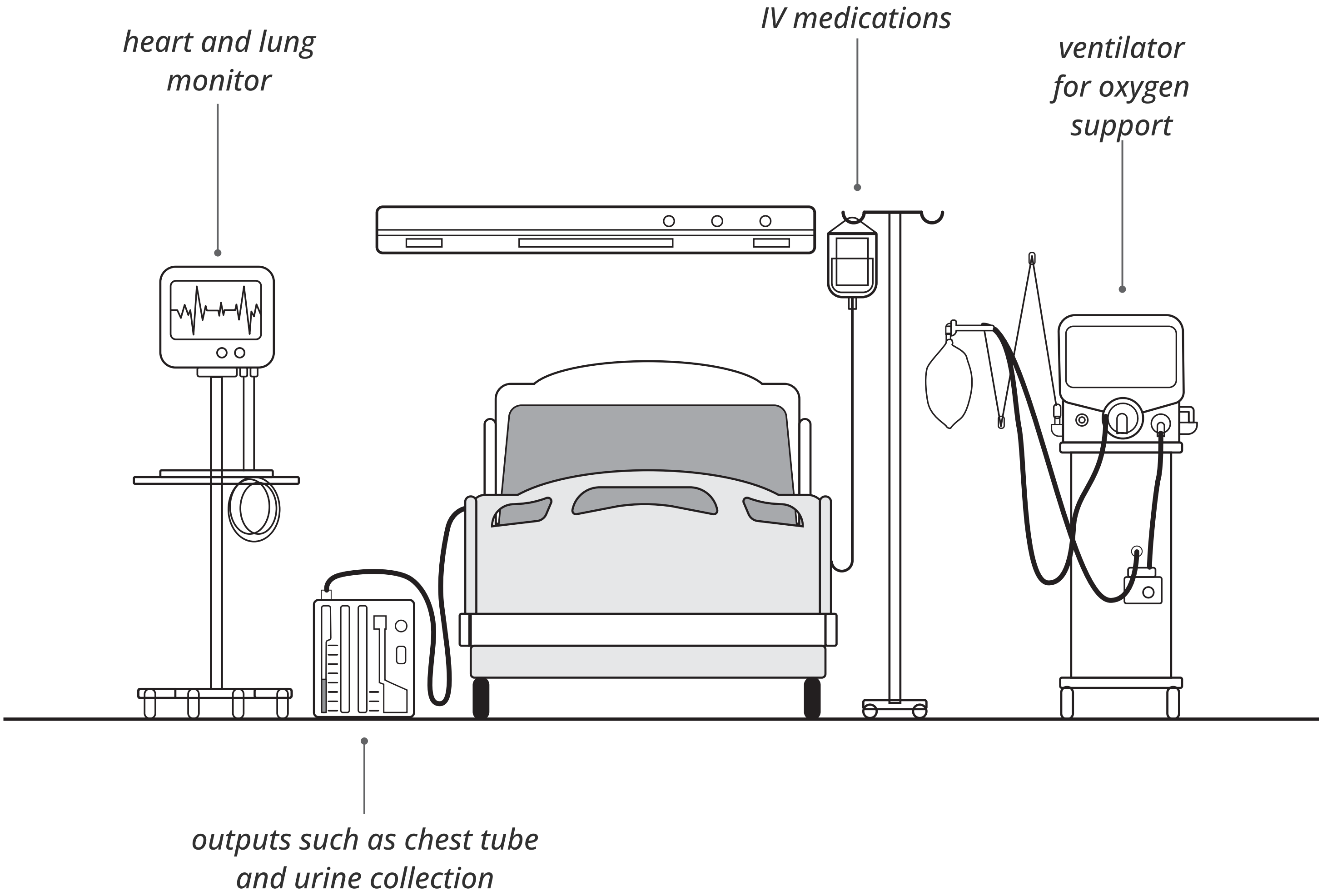
While in the ICU you will hear and see many unfamiliar things.
You might feel sleepy and disoriented.
This is normal.

Your Hospital Room



After your surgery you will have a new incision in your chest from the surgery. The skin is held together with staples that are removed after healing has taken place. You will also have tubes in your chest that help drain extra fluid and air after the surgery. You might feel pain from your incision and chest tubes. We will manage this with medication. The chest tubes will be removed once there is no more air and fluid coming out, usually over the course of the first week or so. Sometimes they need to stay in longer or be re-inserted once removed.

While your breathing tube is in place, you will not be able to talk, eat, or drink. There are many ways to help with communication, such as hand signals, special letter boards, and if you are well enough you can write notes for us to read. Everyone will help you to communicate with us and make their best effort to help you understand what is going on.

When the medical team feels you can breathe on your own, the breathing tube will be removed and you will be placed on supplemental oxygen with a plan to wean you off oxygen over time.

While you are attached to the ventilator, it will be more difficult to clear your lungs of any fluid or mucus. It will be necessary for the Nurse or Respiratory Therapists to suction the secretions for you. Suctioning can be scary, noisy, and sometimes uncomfortable. The team in the ICU are specially trained to perform this task with a high level of skill.

If you require help with breathing from the ventilator for longer than one week, the team may consider inserting a **tracheostomy (trach) 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 and can reduce the risk of lung infections, as well as make weaning from the ventilator easier.

Once you are able to breathe without the ventilator, the trach tube will be made smaller until it is eventually removed. It may take a few days or weeks for the small hole in your neck to heal closed, and you will be left with a small scar.

The MOTU - Multi Organ Transplant Unit

Peter Munk Building 6th and 7th floors

When you leave the ICU you will be transferred to the Multi Organ Transplant Unit (MOTU). You will likely first spend a few days in the step-down unit which is also referred to as the Acute Care Unit (ACU).

The setup in the ACU is similar to the ICU with close monitoring, however each Nurse in stepdown cares for more than one patient.

Similar to the ICU, you will have several monitors and pieces of equipment attached to you and these will gradually be removed as you get better.

Visitors on this unit are permitted but limited to 2 at a time. Please ask the unit about the current visiting hours, and any restrictions that may be in place at the time of your stay.

When you are ready you will be transferred to a general ward bed on the MOTU. As your condition improves, the need for monitors and intensive care decreases (which is a good thing!).

During your time in the transplant unit, we will provide you with information about taking care of your new lung(s) and give you opportunities to practice taking care of yourself. We will also share this information with your support network to make sure you are all learning and preparing for going home together.

While your loved one is in hospital after the transplant, there may be a shift in priorities for their support network. You may find you are able to take a break from being a caregiver while the Transplant Team is managing your loved one's care. This could make you feel relieved but also distressed as you are not the main caregiver right now. Shifting from fulltime caregiver to observer can leave you feeling unneeded.

Ask the Nurses if you can help by doing simple things such as washing your loved one's face, combing their hair, giving them a hand or foot massage. **You are still needed.**

This is also a time when you can take a step back, rest up and restore your energy reserves knowing that your loved one is well cared for and safe. Once your loved one is discharged you will need to resume your role as main caregiver.

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The transplant unit 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. This means that even if you have private coverage you may not be placed in a private room if none are available. Your requests for accommodation will be taken into consideration whenever possible but our priority is your medical needs. If you need to be moved to a private room for medical reasons, but do not have insurance coverage, you will not be charged extra.

Sometimes we need to move patients from room to room several times during their stay. Although this can be unsettling and inconvenient for you, the goal is to make sure that everyone receives the best care and the care they need.

The transplant unit provides care for many different patients including:

- **Recent transplant patients**; lung, liver, heart, kidney and pancreas transplants
- **Readmitted patients**; for various medical reasons

Staff of the MOTU

You will meet many health care professionals while on the transplant unit, here are a few of the staff your might meet:

- **Nurses:** The Nurses on the transplant 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
- **Physicians and Surgeons:** The Respirologists, Surgeons, Fellows and Residents will work as a team to see you each day while you are in the hospital. The doctors may change during your hospital stay and other specialists may be involved in your care (for example kidney, infectious disease, or heart specialists)
- **Nurse Practitioners:** Nurse Practitioners have advanced training and a graduate degree. They work with the Respirologists and Surgeons to play a key role in your care and recovery.
- **Other Staff:** You will meet with other staff during your recovery on the transplant unit including but not limited to Physiotherapists, Social Workers, Dieticians, and Pharmacists. They play an important part in getting you ready for discharge.

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Routines on the Transplant Unit

A typical day in the ward starts early in the morning with blood work before your breakfast and medications on most days. Nurses will check in on you soon after your blood work is complete. They will monitor your vitals signs (blood pressure, oxygen level, heart rate) and take other measurements such as your fluid intake and output and daily weight.

During the morning and early afternoon you can expect to see a lot of staff and have more tests done. Some of the things you can expect are:

- **Physiotherapy:** They will encourage you to move and walk as soon as you are able to. This may be hard at first, but it is fundamental for your recovery.
- **Dieticians:** They address your dietary concerns and preferences and adjust your diet to your progress
- **The Transplant Medical Team:** Surgeons, Respirologists and Nurse Practitioners will visit and ask you how you are doing, examine you, discuss your progresss and results of tests with you and your family, and try to address all your issue and questions.
- **Chest x-rays and blood work:** These will happen daily for the first week or more and then may be done less frequently

You may also have other tests done such as swallowing tests, heart studies and bronchoscopies, but not on a daily basis. The team will discuss the need for these with you during your stay. Recovery varies significantly from person to person, so we will tailor care to your needs.

Pain Management

You might be concerned about whether you will have pain and how that will be dealt with after transplant. The truth is most people have some pain after surgery and pain medicine will be a priority in your care. It will help to relieve your discomfort.

You can expect to feel pain in the area of your incision and you may also feel stiffness and aches in other areas. We encourage you to use pain medicine we prescribe because it will help you start moving around, sitting, and walking sooner.

You will only be taking pain medicine for a short time period, so you do not need to worry about becoming dependent on it or addicted. Some recipients have side effects from pain medication which can include nausea, vomiting, constipation, sleepiness, or itching. If any of these side effects happen to you, tell your team.

There are many options for pain medication. We will adjust your pain medications throughout your recovery to ensure we are providing the most appropriate and effective pain treatment.

There are a number of ways we can provide pain medications:

- **Intravenous:** either administered by your nursing team or self-administered through a button that you control (Patient-Controlled Analgesia, or PCA) :
- **Epidural:** a small tube inserted into your lower back by an anesthetist doctor that delivers medication to the areas that need it most, and is used most commonly in the ICU
- **Oral (by mouth):** taking tablets which can be given on a regular basis or as needed.

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Medicinal Pain Management

medication

intravenous (IV)

Patient Controlled
You will have a button that allows you to add pain meds when you need them to avoid increased pain.

Nurse controlled
Pain meds are injected directly into your IV by your nurse.

by mouth

Traditional Pills
Once you are able to drink fluids you will be given pain pills.

Pills will take longer to work than an IV, so be sure to notify your nurse when you are beginning to feel any pain.

epidural

Patient Controlled
Pain meds are administered through a tube inserted into your lower back and controlled by the patient thought a pump.

You will have a button in case you need more meds.

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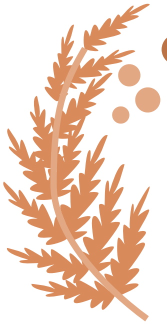
Other ways to manage pain

In addition to medication there are several non-medication related ways that you can take control of 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.



relaxation breathing

- Focusing on your breathing can shift your attention away from your pain.
- Take slow deep breaths, in through your nose and out through your mouth.

visualization

- Imagining yourself without pain can also help to shift your focus.
- 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

- Gentle 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.

Complications

During the Early Post Transplant Period

It is difficult to cover all the possible things that can happen after a lung transplant. Your team will provide education on the risks and benefits of transplant along with this material. **Remember that lung transplant is a very complex treatment that goes beyond just a surgery.** Most people have some complications and they cannot all be predicted. Some people have many complications that impact their outcome from transplant in the short and longer-term. We will talk more about infections, rejection and longer-term complications in the final section.

Because we want you to be informed and understand the process, here is a brief overview of the more frequent things that can happen in the days and weeks after transplant or even once you go home. There are other less common early complications that can arise after transplant that may not be described here:

Infections: Infections are very common after a lung transplant and can occur in the lungs and outside of the lungs (for example at the incision site, or in the urine or blood). Everyone is given antibiotics after transplant and these are changed/tailored based on what infections may be found. Infections can be successfully treated or may be more difficult to treat due to the immune suppression drugs that are started right after transplant.

Rejection: Rejection can happen when your body's immune system recognizes your new lung(s) as foreign, and tries to "attack" the foreign material. We try to prevent this with the use of antirejection medications but it is still very common in the early post transplant period. Rejection may lead to shortness of breath, coughing, or a need for more oxygen. Sometimes there are no symptoms, but we can see it in your test results. If rejection is found we will assess how best to treat it, typically with more anti rejection medication or other specialized treatments. Acute rejection may cause permanent dysfunction of the transplanted lungs despite treatments. If detected early there will likely be a better response to treatment.

Surgical Complications: As with almost any surgery, there may be issues with infection at the incision site, bleeding, or wound healing. You may need to be taken back to the operating room to address these issues or the team may manage them without additional surgeries.

Kidney injury: Your kidneys are very sensitive to changes in blood flow and side effects of medications. Kidney injury is a frequent complication after lung transplant and may be mild with full recovery, but in some cases, your kidney function may need to be supported with machines (dialysis). This may be a temporary measure, with most people eventually recovering to come off of dialysis. However, some individuals end up on dialysis permanently or require assessment for a kidney transplant down the road. Kidney dysfunction can impact how long you stay in hospital and your outcome from transplant.

Arrhythmias: Heart rhythm abnormalities are very common after lung transplant surgery given the proximity and connections of the heart and lungs and changes in fluid and electrolyte levels in the blood. The complications can vary from an overly fast heart rate (tachycardia) to other arrhythmias where the electrical system of the heart gets a bit confused. We usually treat these with medication to improve the heart rate or rhythm which can be given through your IV or orally. You may also need blood thinners to prevent blood clots in the heart that can occur with arrhythmias. Blood clots in the heart can break up into pieces and those pieces may travel up to the brain through your blood vessels, causing a stroke.

Stroke: The risk of a stroke after major operation like a lung transplant can be 1-2% or higher, depending on the individual. Risk factors for stroke include pre-existing problems such as heart disease or blood vessel blockages, different types of life support that may be required before, during, and after your transplant, as well as arrhythmias as described above. Many people may recover well from a stroke if it is more minor but others may be left with significant disability.

Swallowing issues: You may develop trouble swallowing safely after the surgery, sometimes related to the breathing tube or other factors. A Speech Language Pathologist with expertise in assessing and managing swallowing issues will help ensure you are swallowing safely and advise when it is not safe for you to swallow all or some liquids and foods. You will have a nasogastric tube placed into your nose that goes into your stomach at the time of the surgery. If your swallowing is abnormal the tube will stay in place to allow you to get nutrition and medications safely until you can swallow on your own.

Gastrointestinal issues: Nausea, vomiting, constipation and diarrhea all are quite frequent after lung transplant and may be caused by medications, infections, or the recovery from surgery itself. We will treat your symptoms and potentially adjust your to make you as comfortable as possible and avoid complications.

Delirium: The combination of your surgery, medications and hospitalization can lead to a condition called delirium, which is a sudden and sometimes severe change in brain function that causes a person to appear confused or disoriented, or to have difficulties maintaining focus, thinking clearly, and remembering recent events, typically with a fluctuating course. Older patients, over 65 years of age, and people with some other medical conditions are at highest risk for developing delirium. Some patients appear visibly agitated, while many others may be quietly confused. Delirium can be very upsetting for patients and families however it is a common and reversible condition with time.

Deconditioning: A prolonged hospital stay and other medical complications can cause you to become weaker than before your transplant. Improving your functional status may take a long time if you have more complications and a longer stay in hospital. Our team will work with you and help provide rehabilitation to improve things as much as possible. You may need to be transferred to a rehabilitation centre such as the Toronto Rehab Institute for more intensive physical therapy once you are medically well enough.

Elevated blood sugars: This is mostly related to the medications you are given and sometimes we will need to give you insulin to manage this issue. Some people will need to go home from the hospital on insulin with close monitoring of blood sugars at home, as well as follow up by a specialist Physician, Endocrinologist, or Nurse Practitioner

Fluid retention (edema): It is quite common to retain fluids after your surgery. This typically improves with time and your may be given water pills (diuretics) to help you eliminate the extra fluid through your urine. Sometimes you need to take those pills for some time after you go home.

Physiotherapy and Exercise

Post-Transplant During Your Hospital Stay

You will be assessed and treated by Physiotherapists throughout your hospital stay from the time you are in the intensive care unit until you are discharged from hospital.

Exercise is essential to do in the hospital after your transplant. You may feel very weak after the transplant because of the impact of the transplant on your body but also because of your condition before surgery. **Exercise can improve your breathing, blood circulation, sense of well-being, strength and ability to move.** Improving your strength will allow you to have a better outcome from the transplant.

Breathing and mobility exercises may also help to prevent some common complications after transplants such as:

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

Your Physiotherapist will assess you daily starting in the intensive care unit (ICU). They will assess your lungs and teach you breathing exercises, help you cough up sputum and expand your new lungs. Your Physiotherapists will also work with the Nurses to determine how much activity you are capable of doing and help you to slowly increase your activity following the surgery.

Movement and exercise is an important part of the healing and recovery process. It is essential that you work with the Physiotherapy and Nursing Teams to do more and more each day. You will gradually sit at the side of the bed, stand, sit up in a chair and walk. Don't worry, your team will give you pain medication to help keep you comfortable and reassess your oxygen needs to ensure you can feel confident to do these activities. It is important to work with us to build your strength.

A Physiotherapist will continue to work with you when you leave the ICU and move to move to the transplant unit. They will help you improve your breathing, strength and independence with walking and daily activities. Once you leave the hospital after your surgery you will return to exercise as an outpatient at the Toronto General Hospital.

Occasionally people need to go to a rehabilitation hospital to get stronger before they can go home. Throughout your hospital stay your support network will be encouraged to help you with your exercises.

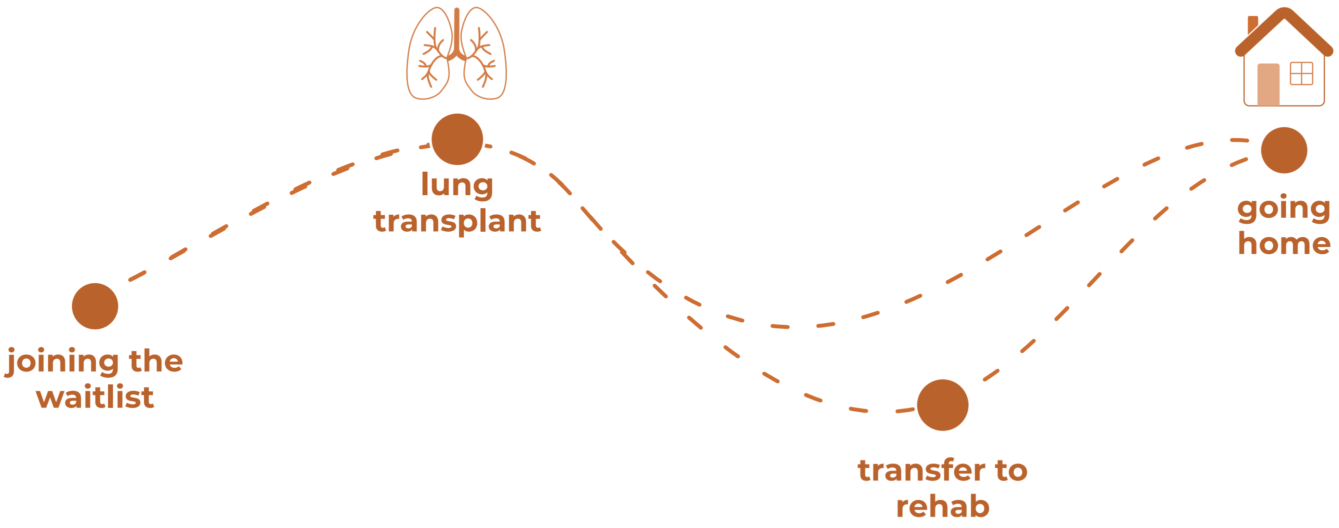
InPatient Rehabilitation

Some patients may need to transition from Toronto General Hospital to an inpatient rehabilitation program before going home.

We work closely with several rehabilitation hospitals who will provide a specialized transplant rehabilitation program specifically for our lung transplant recipients.

You may require a short stay in rehab (1-2 weeks) or a longer stay if your post-transplant course is more complicated and you develop significant deconditioning. If you Transplant Team decides that it would be best for you to continue care on an inpatient rehabiliation unit, you will be provided with more information at that time so that you know what to expect.

The goals of rehab are for you to gain functional independence so that you can have the best outcome possible from your lung transplant and manage safely at home. The Transplant Team continues to communicate and collaborate with the interdisciplinary team at the rehab centre to manage your care.



You will be given physiotherapy and exercise information that will support you after you are discharged home.

Diet and Nutrition

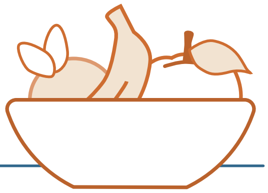
Post-Transplant

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. As described in the complications section, swallowing issues may prevent you from being able to safely swallow and a feeding tube may need to stay in place for some time. If it takes or is anticipated to take a long time (weeks) for your swallowing to get better, the team may talk to you above moving the feeding tube from your nose (nasogastric) directly into your stomach through a small surgery called a percutaneous gastrostomy so that you are more comfortable and could potentially go home or to rehab to continue to recover.

In some rare circumstances, your gastrointestinal tract may not function properly after the transplant and you may require a different route for nutrition. This type of feeding is called total parenteral nutrition (TPN) and is given intravenously. This is a short-term supplemental treatment 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 much 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 Dietician will visit you in hospital to make sure you get the diet and nutrition you need. Once you are able to eat a regular diet, you and your support network can talk to staff about bringing in some of your favorite foods.



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 while you are still in hospital, you will attend a Self Medication Class taught by one of the Transplant Pharmacists. **Your family members or support person must attend with you.** These classes are usually held in the transplant unit every Monday, Wednesday and Friday afternoon and **you must attend a class before you can be discharged from the hospital after your transplant.**

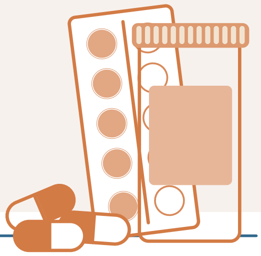
In these classes the Transplant Pharmacist will answer any medication-related questions you may have.

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 and 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 and you or your support person will need to pick them up at the pharmacy.

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

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



Going Home

You and your family and support network will be advised several days in advance of your expected discharge date. Once you know you are going home, have your family and/or support network bring you some comfortable clothes and shoes. It is also important that your support network makes sure that all of the needed preparations have been made for you to go home including who will drive and accompany you to appointments and who will be staying with you for support.

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 Transplant Outpatient Pharmacy (TOP) that carries all of the products and medications that are unique to the needs of our lung transplant patients. Filling your prescriptions at TOP will ensure that all of your medications will be available to your Transplant Pharmacist at the time they carry out your final discharge teaching.

TOP is located on the 12th floor of the Peter Munk Building in the outpatient transplant clinic area. If you have private insurance, be sure to bring your insurance registration cards. You will also need to bring a credit card with you to pay for any costs that are not being covered by either private or government programs. All of your health coverage information will be 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.

As a reminder, all Ontario residents under the age of 65 must register with the Trillium Drug plan before going on the transplant list, this should have been covered by your Social Worker during your pre-transplant assessments, you can review this information in the first seciton of this guide.

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Before you go home you will be contacted or seen by:

- **Discharge Coordinator and Administrative Assistant** to help you understand what to expect for your outpatient care, needs at home and upcoming outpatient appointments
- **Pharmacist** to review all your medications, how and when to take them and answer any questions you might have.
- **The Transplant Medical Team** that you see daily to make sure all is in place for you to go home
- **Other medical specialties** if needed

You will need to make sure you understand all the next steps including:

- Clinic visits and tests that need to be done such as
  - blood work
  - pulmonary function testing
  - xrays
- When and where these take place
- How to contact the outpatient lung Transplant Team
- What to do in case of emergencies

You should have your medications ready to take home and ensure everything is organized at home (or the place where you will stay for now) for your safe discharge.

Before you are discharged be sure to **have your medications ready** to take home and **have everything organized at home**

Going Home Notes

You can use this worksheet to take notes and make sure you are ready to go home.

I have spoken to:

Before going home make sure you have checked in with the following people:

The Discharge Coordinator or Administrative Assistant

The Pharmacist

The Transplant Medical Team

Any other medical specialties

My next clinic visits & tests

You can use this space to note any upcoming clinic visits and tests (this information is also available to you in your myUHN patient portal):

Who to contact & how

If you have questions:

In case of an emergency:

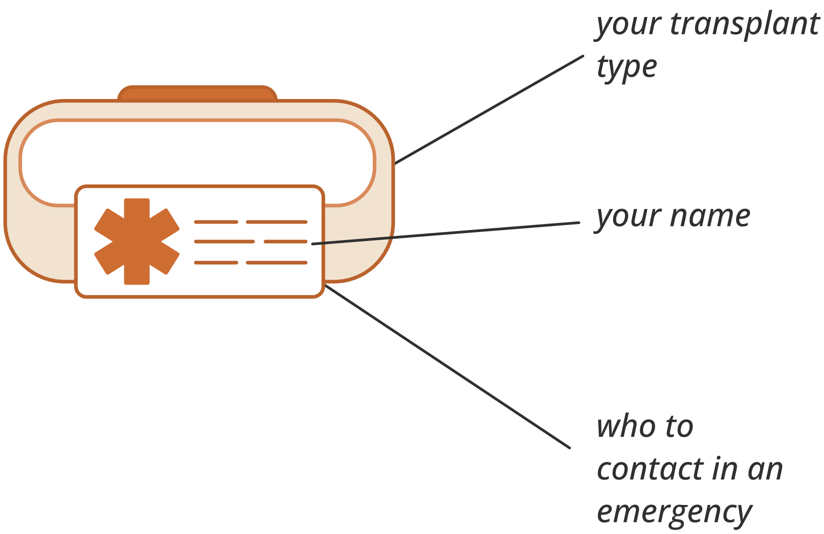
Medic Alert

After your transplant, we recommend that you get a Medic Alert bracelet or necklace. Medic Alert bracelets can relay important health information when you are unable to tell people yourself and can save your life and protect your transplant in an emergency.

If you already have a Medic Alert bracelet, you will need to update the information and get a new bracelet. When completing the form to update your information be sure to include the file number from your old bracelet. You can access the **Medic Alert application form here**. Or type www.medicalert.ca/sign-up into your browser search bar.

You can get more information on obtaining a Medic Alert bracelet from your Post-Transplant Coordinator when you come to the transplant clinic. It is your responsibility to complete the form and mail it in. Your Transplant Coordinator can assist you with completing this form if you need help.

To contact Medic Alert go to medicalert.ca or call 416-696-0267 or 1-800-668-1507



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After Your Lung Transplant

Follow-up Care

After your transplant you will be required to continue to get testing done regularly to ensure you are managing well. It is important to be involved in your care and be committed to attending all appointments.

After you leave the hospital you will come for regular visits at the **Ambulatory or Outpatient Transplant Clinic on the 12th Floor of the Peter Munk Building.** Your first clinic appointment will be scheduled for the week after you are discharged. You will meet your Post-Transplant Coordinator during this visit. Your Post-Transplant Coordinator is your primary point of contact to ask questions and communicate issues to after your lung transplant.

You should communicate with your Post-Transplant Coordinator primarily through the MyUHN Portal patient messaging system. Messages are reviewed within one business day but are not answered after hours or on weekends and holidays. **If you feel you are having an emergency you should call 911 or go to your nearest emergency department.**

In the first 3 months after your transplant, we see you in the clinic very frequently. This may be once a week or every other week if you are recovering well. You will get bloodwork and lung function testing once a week and occasionally require a chest x-ray.

You will also need to participate in the outpatient lung transplant physiotherapy program. Depending on your needs, your exercise sessions may be done in person at TGH one or more times a week, with some exercise being done at home. The Physiotherapy Team will work with you on a schedule that optimizes your recovery. It is likely that you may need to come to TGH more than once a week in this early post-transplant period.

At about 3 months after transplant, you will have a comprehensive assessment. These assessments are described in detail below. If you have temporarily relocated to Toronto, your Transplant Team will need to review all of these results and see you in the clinic to let you know if it is safe for you to return home.

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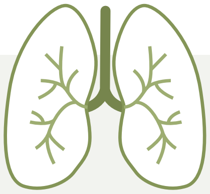
During your first three months post-transplant you will come into the clinic 2-4 times a month, depending on your health status. You will also have other visits with Physiotherapy and may see other specialists, so be prepared to come to the hospital more frequently than once a week. Regular clinic visits allow your Transplant Team to monitor your health and deal with any concerns or changes as they might arise. As you recover you will not need to come to the clinic as often.

Please do not communicate with any of your care team members over email. All messages should be sent through the MyUHN patient portal or over the phone if you are not able to use the portal. If team members are away, your messages in the portal will still be seen and answered. Email messages will not be reviewed if the team member you sent the message to is away and this will introduce potentially dangerous delays in your care.



About the Lung Transplant Clinic

Lung Transplant Clinic Days:

Your clinic appointments will be scheduled on the day(s) of the week that your rimary Lung Transplant Doctor is working in clinic. We may also be able to see you in our urgent care clinic if required.

Clinic Location

Toronto General Hospital, 585 University Avenue, Peter Munk Building, 12th Floor. Use the Munk Elevators.

Clinic Phone:

Reception: 416-340-4800 ext 4113.

Note: the best way to contact your Transplant Team is through the Patient Portal (MyUHN) messaging system. You will be able to connect with your Transplant Coordinator and receive a reply within one business day. Both the MyUHN messaging system and the clinic reception number are for non-urgent inquiries only and are monitored during business hours, not on weekends or holidays.

You will receive instructions on how to use the portal messaging system from your Transplant Team

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Preparing for Clinic

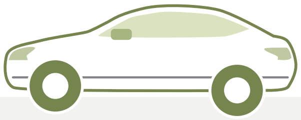
Transportation

You will have many trips to the hospital immediately after your transplant. Coming to the hospital for appointments can be very tiring and you will need to have someone not only drive you but also assist you around the hospital.

Once you are more than three months post-surgery you can begin to drive if you feel well enough and your Transplant Team does not have any concerns with you driving at that time point. However, you should never drive yourself to the hospital for procedures where sedating medications are given, such as bronchoscopies. If you drive yourself to the hospital for a procedure where you will be given sedating medications the procedure will be cancelled.

****Please remember if you need to reschedule or cancel your appointment, let us know as soon as possible.**

Even if you are not coming for an appointment, be sure to update the Transplant Team if there are changes in your health status, medications, contact information, or home address.



A few things to keep in mind about driving:

- Do not drive for at least **three months** after your transplant.
- **Do not drive on days you are scheduled for a bronchoscopy** as you will receive sedating medications that will impair your judgement and function .
- Do not drive if you feel **tired**, are having **dizzy** spells, **headaches** or **visual disturbances.**
- **You cannot drive while you are taking narcotics** such as morphine or hydromorphone 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.

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Regular Post Transplant Blood Tests

Before coming to the clinic for your post-transplant visits and in between visits, you will need to have blood tests done to check the levels of your immunosuppressive medication (i.e., tacrolimus (Prograf) or cyclosporine (Neoral)) as well as to monitor other aspects of your health.

When you are getting bloodwork done that includes monitoring of your tacrolimus or cyclosporine trough levels, it is essential that you get the bloodwork done in the morning **BEFORE** you take your tacrolimus or cyclosporine so that your Transplant Team gets an accurate blood level result.

For the first 3 months it is best that you get your bloodwork done at Toronto General. After that, your Transplant Coordinator will help you figure out what the best place is to get regular bloodwork done in your local community and provide you with a requisition for the bloodwork that you need.

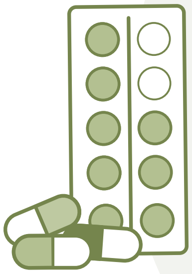
- **LifeLabs:** If you are able to access LifeLabs, this is the best option outside of Toronto General as it allows us to get results very quickly and automatically into our hospital records. There are many LifeLabs throughout Ontario. You can find the lab closest to you by calling LifeLabs at 1-877-849-3637 or checking their website: **www.lifelabs.com**
- **Toronto General Hospital:** come to the Diagnostic Test Centre/Blood Collection Lab. The lab is located in the Eaton Building on the ground floor, Room 455 (EG-455), in the Diagnostic Test Centre near the Elizabeth Street entrance. Their contact information is included here:
  Phone Number: 416-340-LABS (5227) or 1-866-865-LABS (24-hour Call Centre)
  Hours: Monday – Friday, 7:00 am – 3:00 pm
  Closed on Saturdays, Sundays and Public Holidays
  Current information about the lab can be found here: **uhn.ca/Labs/Labs_Tests/Blood_Drawn**
- **Other community or hospital based labs:** if testing at another lab is your only option, we will ensure that we get the results as quickly as possible. Please ensure that you are also informing the lab that the results should be sent to your Transplant Team, which will be outlined on the requisition.

A typical blood testing schedule

You will be notified how frequently blood tests are required based on your own circumstances, but here is a guide for the typical frequency of testing:

Bloodwork after lung transplant

Up to 3 months	3-6 months	6 months - 2 years	Over 2 years
Once a week (and as needed)	Every 2 weeks (and as needed)	Monthly (and as needed)	Every 3 months or as instructed



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

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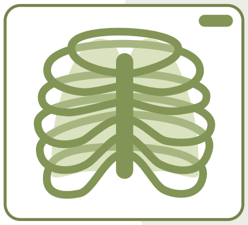
Chest X-rays

You will need to have regular chest x-rays every time you come to the clinic, or as instructed by your Post-Transplant Coordinator. You do not need an appointment to get your chest x-ray. The order will be in the UHN system and patients are taken on a walk-in basis.



To have a chest x-ray go to the **Medical Imaging Department on the 1st Floor at Toronto General Hospital** and check in at the Reception Desk.

Physiotherapy Assessments

You will also have reassessments over time by our Physiotherapy Team, **including 6-minute walk tests** which allow us to assess your functional status and oxygen levels with exertion.

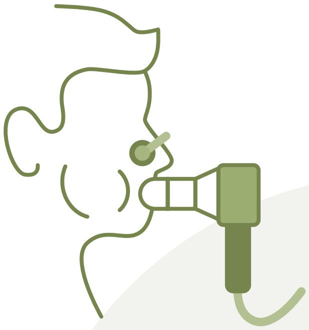
These assessments are generally done with your regular comprehensive assessment visits, and may be repeated as needed.

Pulmonary Function Tests (PFTs)

You will need to have regular Pulmonary Function Tests (PFTs) following your transplant as an essential way to monitor your lung health. For the first 3 months after transplant and when you come back to TGH for assessments, you will have PFTs done at TGH.

Once you are beyond three months post transplant you may be able to go for regular PFTs at your local PFT lab, or as instructed by your Transplant Team. Your Post-Transplant Coordinator will help arrange this testing.

Below is a typical schedule for PFTs post-transplant but you will be notified by your Post Transplant Coordinator how frequently you need to book your tests.



To book your PFT at Toronto General Hospital call the Pulmonary Lab at 416-340-4800 ext. 4086 and press #4.

PFT testing post transplant

Up to 3 months	3-6 months	6 months - 2 years	Over 2 years
Once a week	Every 2 weeks	Monthly	Every 3 months or as instructed

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Post Lung Transplant Comprehensive Assessments and Routine Testing

You will have a comprehensive assessment at 3 months, 6 months, 12 months, 18 months, 24 months and then once a year around the time you had your transplant surgery. You will be expected to participate in your annual assessment every year. Many people require additional visits with the Transplant Team to address issues in between assessments.

Between your comprehensive assessments you will continue to have routine testing to help us monitor your health. How often you need to get testing generally decreases with time. But remember It is very important to keep doing the routine tests, even after many years post transplant.

Routine assessments will be done IN-PERSON at Toronto General Hospital for at least the first 12 months. This face-to-face interaction allows us to better evaluate your condition, especially if there are issues to address.

Most people will also be having a bronchoscopy done as part of the assessment. Virtual clinic appointments may be offered in between comprehensive assessments, in the longer-term, and to review test results or complete discussions on specific topics.

3 Month Assessment

*Your **3 MONTH ASSESSMENT** is the most extensive assessment. For your 3 month assessment you will need to do the following:*

Assessment Blood work: more extensive than routine blood work to check cholesterol, average blood sugar levels, and antibodies in the blood.

CT Chest Scan of the chest

Chest X-ray

Full PFT (pulmonary function test): more extensive than a routine PFT (45 minutes)

Six Minute Walk Test

24-hour pH study and esophageal motility study

Gastric Emptying Study

Bronchoscopy

Assessment Clinic Appointment: in person

3-month Coordinator teaching: Your Post-Lung Transplant Coordinator will see you in the clinic to give you some important information about monitoring yourself, transitioning to less frequent clinic visits, and transitioning your routine testing to closer to home.

Once you have completed your 3 month assessment, taking into account your situation and health status, you have the option to conduct certain tests at local hospitals in your hometown and labs that are more conveniently located for you. We will collect and review the results.

6 Month Assessment

The test listed here are the routine expected tests. ***Additional tests or consultations may be required.***

Assessment Bloodwork

CT Chest Scan of the chest

Chest X-Ray

Full PFT

Six Minute Walk Test

Bronchoscopy

Assessment Clinic Appointment: in person

9 Month Assessment

Assessment Bloodwork

CT Chest Scan of the chest

Chest X-Ray

Full PFT

Six Minute Walk Test

Bronchoscopy

Assessment Clinic Appointment: in person

12 Month Assessment

The tests listed here are the routine expected tests. ***Additional tests or consultations may be required.***

Assessment Bloodwork

CT Chest Scan of the chest

Chest X-Ray

Full PFT

Six Minute Walk Test

Bronchoscopy

Assessment Clinic Appointment: in person

18 Month Assessment

Assessment Bloodwork

CT Chest Scan of the chest

Chest X-Ray

Full PFT

Six Minute Walk test

Assessment Clinic Appointment: in-person or virtual depending on your care needs and location

2 Year Assessment

At you two year anniversiary you will have the following check-in.

Assessment Bloodwork

CT Chest Scan of the chest

Chest X-Ray

Full PFT

Six Minute Walk Test

Assessment Clinic Appointment: in -person or virtual depending on your care needs and location

The tests listed here are the routine expected tests. ***Additional tests or consultations may be required.***

Annual Assessment

Your annual assessment will happen
EVERY YEAR

Assessment Bloodwork

Chest X-Ray

Full PFT

Six Minute Walk Test

Assessment Clinic Appointment: in -person or virtual depending on your care needs and location

The tests listed here are the routine expected tests. ***Additional tests or consultations may be required.***

Bronchoscopy

After your transplant you will have regular bronchoscopies that include lung biopsies to check for rejection or infection and to assess how your airways are healing after the transplant. **Our protocol is to do a bronchoscopy at 4-6 weeks, 3, 6, 9, and 12 months.** Additional bronchoscopies are commonly needed for clinical indications outside of this protocol schedule.

A bit about Bronchoscopies

A bronchoscopy is a procedure that involves inserting a small flexible tube through your mouth. The tube acts as a camera and is able to carry pictures back to a video screen. This shouldn't cause any pain, but it can be uncomfortable. To help with this discomfort, we will have you gargle a numbing medication (anaesthetic) before starting the procedure, and spray some of this medication into the back of your throat.

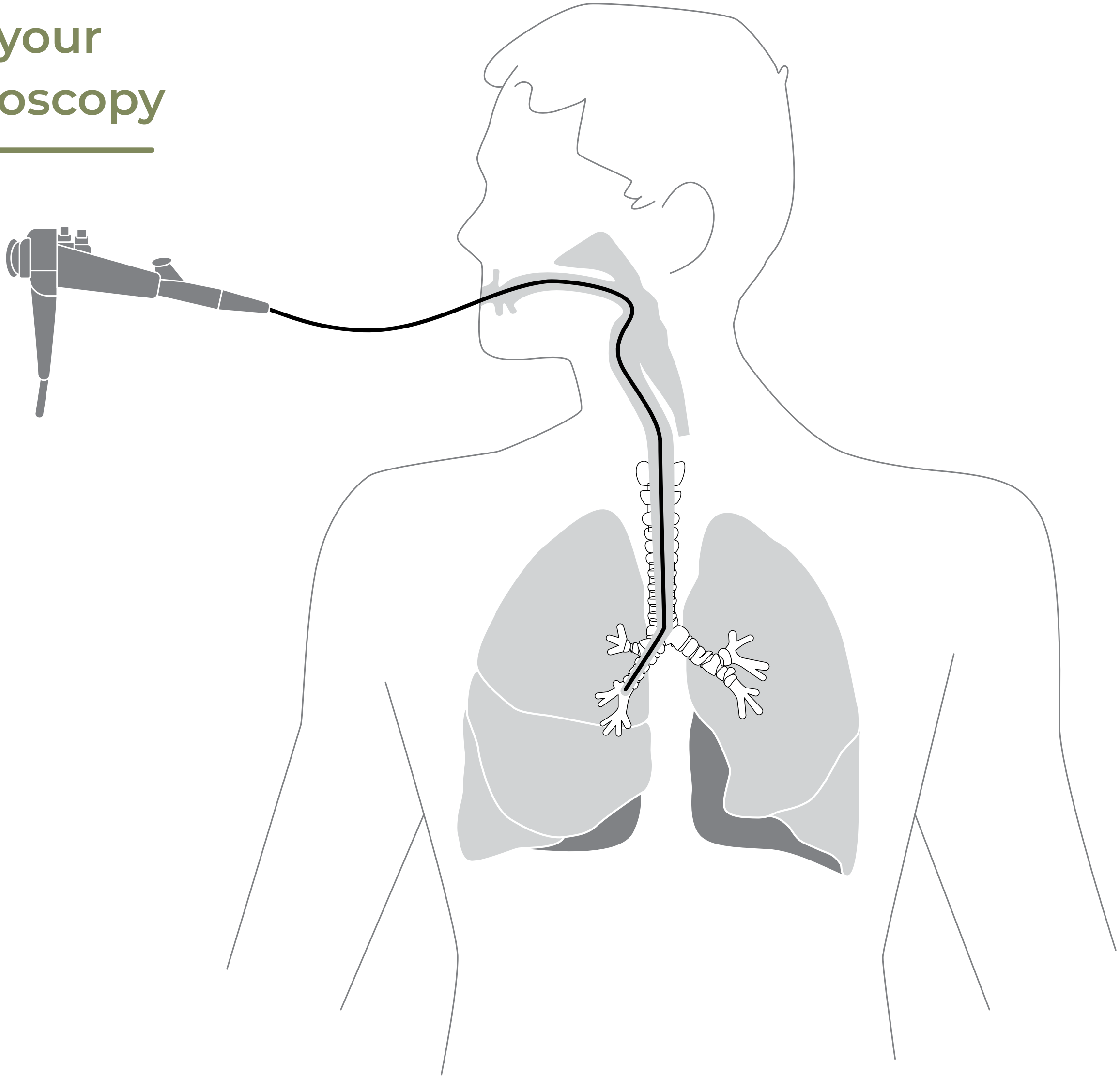
You will also be given IV medication that will make you sleepy. We are aiming for "conscious sedation", meaning that you don't have to be fully asleep during the procedure. In fact it is ok to be awake during the whole procedure; the main goal is for you to be comfortable. This level of sedation allows comfort balanced with safety, so you are still breathing well and maintaining a good oxygen level.

We will ask you to bite on a mouthpiece (a bite block) to prevent you from accidentally biting the scope. Once you are comfortable, the scope will be inserted through your mouth. We will take a look at the airways (bronchi) of both lungs, check the sutures where the new lung(s) were attached, and remove secretions if there are any.

Once we have looked through your airways we will perform some fluid washings in the lung. This involves injecting some saline through the bronchoscope and suctioning it back out. The fluid will be collected in a container that will be sent to the lab for analysis to look for any signs of infection or inflammation.

The last part of the procedure involves taking small biopsies of the lung tissue to assess for any signs of rejection. We pass a small biopsy forceps through the bronchoscope and take several biopsies. We use an x-ray machine (fluoroscopy) to help guide where we take the biopsies from. Sometimes it is not safe to take biopsies. The Transplant Doctor performing the procedure will discuss this with you. We can still get very helpful information from the bronchoscopy if biopsies cannot be done.

What will happen during your Bronchoscopy



You will be sent detailed instructions on how to prepare for your bronchoscopy prior to each time you have one.

Please pay close attention to the instructions as they help make the procedure safe.

Ask your Transplant coordinator if you have any questions about the instructions.

The Risks

What are the potential risks of bronchoscopy?

- **Fever and shortness of breath:** The fluid that is put down for washings can lead to some irritation of the airways. You may experience mild shortness of breath and fever for 24-48 hours after the procedure. If these symptoms are persisting or worsening you should contact the Transplant Team or seek medical attention if you feel it is an emergency
- **Reduced oxygen:** Your oxygen level will be continuously monitored during the procedure using a pulse oximeter. The level of oxygen in the blood may fall during the procedure for several reasons. It may be due to the sedating medications or fluid washings, and rarely due to more serious complications from the procedure. This drop is usually mild, and the oxygen level usually returns to normal without treatment. If your oxygen level remains low, you will be given more oxygen and the procedure may be stopped early for safety.
- **Air leak from the lung:** The biopsies can cause a small hole in the lining of the lung, leading to an air leak (pneumothorax). This means air comes out of the lung and gathers in the space around it, which can limit how well the lung expands. This problem is not common but may happen in 1-2% of bronchoscopies with biopsies. If there is a large or ongoing air leak, it may need to be drained with a chest tube. Many of these air leaks resolve on their own. You will have a chest x-ray done after a bronchoscopy with biopsies to check for a pneumothorax before you go home from the procedure.
- **Bleeding:** Bleeding can occur after a biopsy. Bleeding can also occur if the airway is already inflamed or damaged by disease. Usually bleeding is minimal and stops by the end of of the procedure without intervention. Sometimes the doctor will need to put some medications down the scope to stop the bleeding and may stop the procedure early to prevent further bleeding. Very rarely, bleeding can lead to severe breathing problems, hospitalization or death.
- **Infection:** While equipment used is cleaned before and after use, there is a small risk that a germ could be introduced into the airways (for example from your mouth) that could cause infection.

Home Spirometers

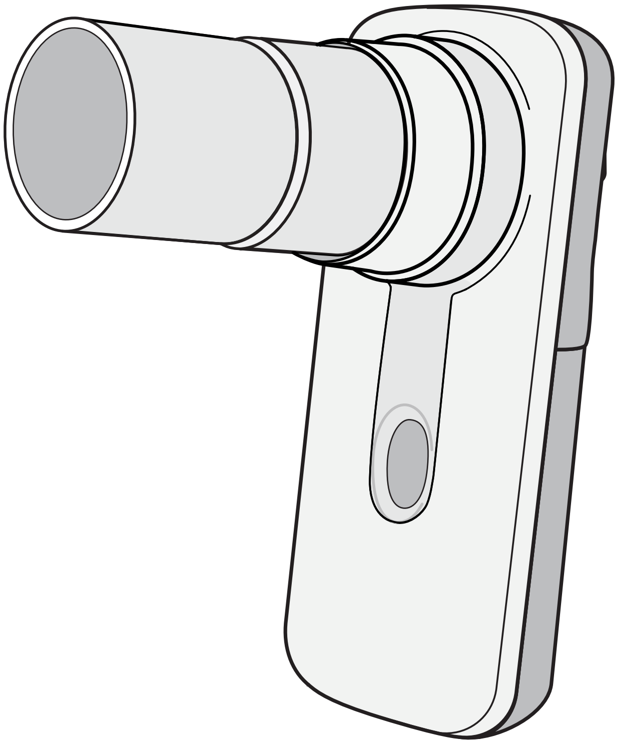
A home spirometer is a small device that allows you to measure your lung function at home, so that you can monitor how your lungs are working.

You will be required to have a spirometer that you can use at home after your lung transplant. This device is essential to monitor the health of your lungs in between PFTs or clinic visits. Think of it like checking your blood pressure at home. **The earlier you detect possible complications, the more likely they can be treated.**

Your Transplant Team will help you make the arrangements for you to purchase your own device after your transplant. The spirometers are typically ordered online and delivered to the hospital for you to pick up. If you have private insurance your Transplant Coordinator or Social Worker can give you a letter for you to submit to the insurance company to see if they will cover the cost. If you receive Ontario Works, ODSP, WSIB, or NIHB, your device might be covered and your Social Workers will help you send a letter to verify this.

If you are from out of province and have a government support program in place, you can consider submitting this as a claim to confirm if it would be covered. If you do not have any private insurance or government income support programs in place, this will unfortunately be an out of pocket expense.

Your Transplant Coordinator will teach you how to use your device, and you will be provided with detailed educational materials that can be viewed as needed on your patient portal.



A bit about Home Spirometers

Here is some important information on measuring your lung function at home:

- **This device measures how much air you blow out during expiration.** The most important measurement that is recorded is the Forced Expiratory Volume in 1 Second (FEV1). Changes in your FEV1 help identify signs of possible complications. We encourage you to do daily readings as part of your home routine. Daily measures help us to see trends. As time goes on you can transition to measuring a few times a week or weekly, and with any changes in your symptoms. Your Transplant Team will guide you on the right frequency.
- **Small variations in your daily readings are expected and common**, this could be due to how the reading was taken, the device calibration, or even the room temperature. A small variation (less than 10%) in just one measurement, may not mean much, especially if you are feeling well. We suggest you take 3 readings everyday (especially if you notice changes in one of those readings). These readings can be taken at the same time.
- **You should consider a 10% difference between two measurements, as significant.** If you notice a drop in your FEV1, bring this to our attention. Please contact your Transplant Coordinator through the myUHN patient portal. Please make note if you are experiencing any new symptoms such as shortness of breath, coughing, sputum production, fever or fatigue because we will ask you about these.

A drop in your FEV1 readings by 10% for 2-3 days in a row may indicate rejection or infection. Here is an example of what a 10% drop might look like:

- Your usual reading is 2.0 liters
- Your reading is now 1.8 liters, which is a 10% drop
- Therefore a drop by 0.20 liters or greater is of concern based on your usual level.

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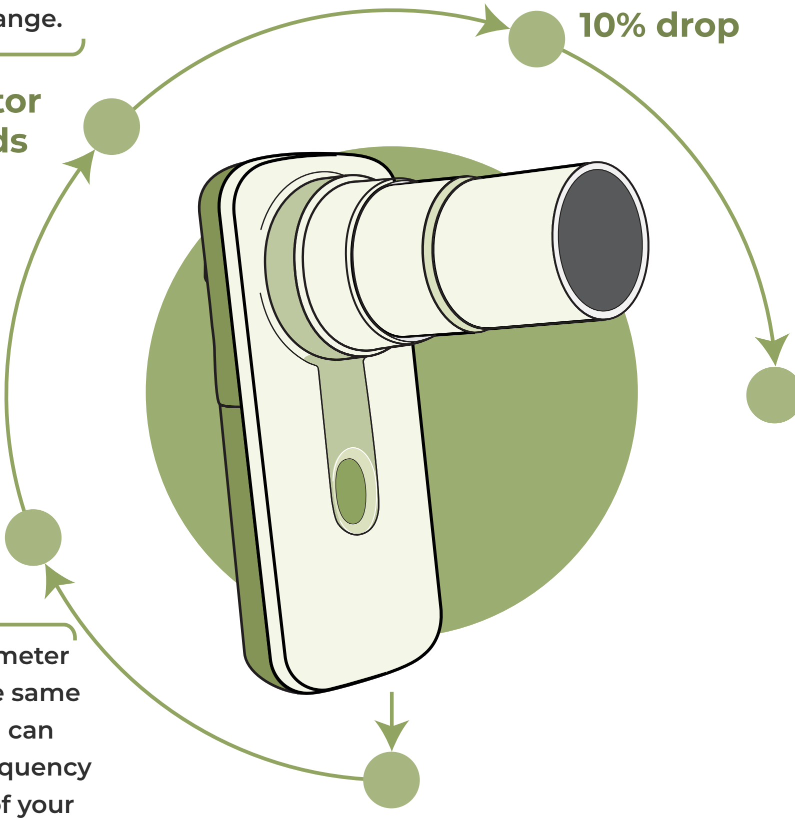
Taking a reading with your Home Spirometer



monitor trends

Observe your readings over time to find your normal range.

watch for a 10% drop

A 10% drop for 2-3 days may be a signal of rejection, infection, or other problems with your lungs.

communicate change

Report any changes of symptoms to your Transplant Coordinator.

take measurements

use daily

Use your spirometer every day at the same time, and you can decrease the frequency on the advice of your lung transplant team in the longer-term.

1 take a reading

- Turn on the spirometer and take a few breaths.
- Inhale **AWAY** from the machine.
- Tighten your mouth around the mouthpiece and blow **FORCEFULLY** until your lungs are empty.

2 repeat

- Reset the spirometer.
- Repeat step one.
- Take **THREE** readings in a row at the same time of day.

3 record

- Record the **HIGHEST** number in your logbook or tracking record.

Remember
We 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.

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What to expect during clinic

Here is some of what you can expect during your clinic visit. You will:

- Review your medication list with your Post-Transplant Coordinator or Physician. You should know what medications you are on and why. If you do not know your medications, bring them or an accurate list with you. **Ask for refills if you need them.**
- Review your results and ask any questions about your tests and procedures.
  ** results will be available on your myUHN patient portal.

Ask Questions!

- Report any health changes such as:
  - 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

At the end of the clinic visit the Transplant Team will tell you when they want to see you next.

Some Tips for Clinic

- Be prepared for what might be a long day. You may need multiple tests before seeing the lung Transplant Team. Your appointment may be delayed as the Doctors and Nurses are doing their best to look after other patients who may have high care needs. We do our best to stay on time
- If you need non-emergency help between scheduled clinic visits, **please contact your Transplant Coordinator through your myUHN patient portal.**
- Prior to each clinic visit, it is a good idea to check your myUHN patient portal to see if there has been a change in your appointment, or any new messages from your Transplant Team.

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

- Bring your provincial health card (OHIP or other) to each visit (it is also a good idea to make note of your seven digit MRN or medical record number).
- Check-in at the transplant reception desk when you arrive.
- 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, contact your Transplant Team through the portal and work with them to reschedule.
- 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.
- Ensure you ask for all your required prescription renewals.

Your Clinic Checklist

You can use this checklist to help you make sure you have done all of your needed pre-tests and are prepared for your clinic visit.

Before Clinic

Be sure to do the following before each of your clinic visit:

Bloodwork

****Remember: Take your tacrolimus or cyclosporine AFTER your bloodwork. You DO NOT need to fast for routine blood tests. Your Coordinator will let you know if any tests need to be done while fasting.**

PFT (Pulmonary Function Test)

**** Try to book your next test when you are in the Pulmonary Function lab.**

Chest X-ray

Review your medication list at home and check if you need any refills.

What to bring to the clinic

Health Card (OHIP card, or other provincial medical card)

Review and correct your medication list in the myUHN patient portal before each clinic visit or bring your medication list to the clinic to ensure we have the most up to date information

A family member or support person

A list of your questions

Notes: *****you can use the space provided here to make note of any questions you may have.***

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Using the MyUHN Portal to Track your Health at Home

Your Transplant Team will set up a reminder system through the MyUHN patient portal this tool is called the Care Companion. This tool will allow you to track daily home measurements of your lung function (spirometry), blood pressure, heart rate, and oxygen saturations. These will be visible to your care team.

While we may get an alert if you enter an abnormal result, you should also message your Transplant Coordinator if you notice that your measured home lung function or other values are outside of your typical range or if you are concerned about them at all. A normal value may mean something different from one person to the next, so talk to your Transplant Team about what you should consider as normal for you.

You will also be able to log your home exercises for the Rehab Team to review. You will be provided a comprehensive guide on how to enter all of this information before and after transplant.

The MyUHN portal Care Companion is also where you will be able to access helpful educational content (like this guide) and resources such as information for your dentist or upcoming travel.

Your Medications

You will need to take many new medications after your transplant. These include medications to suppress your immune system to reduce the risk of rejection of the lung(s), and medications to prevent infections. All medications have side effects, and these might include causing other health conditions that need more medications, such as high blood pressure, high cholesterol, diabetes, and osteoporosis. Some people may require more or fewer medications as time goes on. You will learn more about these complications later in this section.

You will receive information about why, how, and when you take your medications before discharge from hospital. Your Transplant Coordinator and Doctor or Nurse Practitioner will provide you ongoing education about your medications and any changes needed after the transplant. It is important to try to learn as much as possible about these medications so that you understand why they are needed and what the possible side effects are.

Anti-Rejection Medications

The main medications required to keep your new lungs healthy are anti-rejection medications. These function by suppressing your immune system to prevent your body from recognizing and “attacking” the new foreign lung(s). The doses of these will vary after transplant based on blood levels of the drug, your individual risk for rejection, side effects, and how long it has been since your transplant. It is essential to understand that these medications cannot ever be stopped unless there is a medical indication to do so that is identified by your Transplant Team. Please do not stop medications on your own as it can seriously jeopardize your health. You may have side effects that start early after your transplant and as you adjust to the new medications, or sometimes they take some time to develop.

Your blood tests will measure your tacrolimus or cyclosporine (and some other) drug levels. Based on these levels the Transplant Team will make adjustments to your medications. It is common for your medications to be adjusted frequently, even weekly, in the first few months after the transplant.

Drug Interactions

Always ask if it is safe to take any new medication, either prescribed or over the counter!

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 healthcare provider, 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.

Pain Medications

Do not take pain relief medications that are part of the non-steroidal anti-inflammatory (NSAID) class.

These include ibuprofen (the active ingredient in Advil® and Motrin® products) and naproxen, which is found in Aleve® and Naprosyn®. Aspirin should not be used as a pain relief medication but can be used in low doses for various heart and other conditions if required.

If you would like to take a multivitamin 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 these should be reviewed carefully before taking.

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 when you have gone home. Your Transplant Pharmacist can answer your 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 that will help you learn more about your transplant medications and find answers for yourself. These tools can be accessed at any time on the UHN public internet site.

The Transplant Outpatient Pharmacy (TOP) website has some quick links to information to help manage your medications as well as information about the services at TOP, the TMITT website (more on this below) and the patient toolbox. These resources can be accessed at any time by visiting **www.uhn.ca/Transplant/TOP**.

The Transplant Medication Information Teaching Tool (TMITT) is an interactive internet-based teaching program to help you and your family and support network 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 materials you want to learn. The TMITT program can be accessed by visiting **www.TMITT.ca**

Some of the features of TMITT are:

- Content that is divided into brief and easy to follow 'lessons.'
- A customizable learning experience.
- Information provided in a unique audio-visual format.
- Interactive quiz questions to test your knowledge.
- Printable information summaries for each medication.

Here are a few specific medications you may want to explore:

- **Tacrolimus**
- **Cyclosporine**
- **Azathioprine**
- **Myfortic/Cellcept**
- **Prednisone**
- **Septra**
- **Valganciclovir**

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Prescription Management

You will be given a prescription for a three-month supply of medications when you are first discharged from hospital. As noted earlier, please discuss any prescription refills you need with your Transplant Coordinator at your clinic appointments. Pain medication prescriptions (narcotics) will only be given in the clinic. Outside of clinic visits please give us at least three working days to respond to your requests for prescription refills.

Due to the frequency of patient visits and complexity of care in the first post-transplant year, the lung transplant program may write prescriptions for some medications not directly related to your transplant. However, you may be directed to local care providers or specialists for prescriptions and treatment of issues that are beyond the expertise of Transplant Team, such as psychiatric care and management of chronic pain.

After the first year post-transplant the lung transplant program will only write prescriptions for transplant immunosuppressive medications (e.g. tacrolimus, cyclosporine, azathioprine, mycophenolate mofetil, and sirolimus). We will adjust the dosages of these medications and may prescribe other medications (e.g.antibiotics) on an emergency basis or as needed for conditions that affect your transplanted lungs, or side effects of your immunosuppressive medications. However at this time all other prescriptions, refill requests and dose adjustments for non-transplant related medications will be the responsibility of your local care team, even if these medications were started by the Transplant Team during the postoperative period. These may include medications for your blood pressure, cholesterol, bone health, or other general medical conditions. These conditions are often best managed by your primary care physician in the longer term, and are within their scope of practice. **Although we will not be the prescriber, the Transplant Team must be informed of any new medications prescribed by an outside provider. We are also available to speak with your other medical care providers about questions and concerns around prescription medications.**

Please Note: *In order to get refills of your anti-rejection medication, you must have monitoring through blood tests and pulmonary function testing done at regular intervals as directed by the Transplant Team, and be seen in clinic in person or virtually at least once a year after the first 2 years.*

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. We will help you understand how to manage your health issues and follow instructions for regular check-ups such as bloodwork, lung function testing, clinic, and other ways to maintain your health. You can expect to have complications after lung transplant. The Transplant Team continues to monitor you life-long, and along with monitoring your own health this allows us to work together to respond quickly to address complications whenever possible. The two most common complications following lung transplantation are infection and rejection.

Acute Rejection

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 foreign and are attacked by your immune system. The purpose of immunosuppression is to try to prevent this response. Rejection can be mild, moderate, or severe.

In order to prevent rejection from interfering with the normal function of your new lungs, it is important to detect rejection early and to treat it quickly. You will be 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 your new lungs.

If you experience any symptoms of rejection, **tell your Transplant Team immediately.**

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You should know that:

- Rejection is common after a lung transplant.
- Acute rejection can be caused by a type of immune cell-mediated inflammation in the lung (Acute Cellular Rejection – ACR), or by proteins called antibodies that your body can produce that recognize the transplanted lung as foreign (Antibody-Mediated Rejection – AMR). Sometimes it is a combination of both ACR and AMR.
- Biopsies of the lungs (done through bronchoscopy), blood tests, and careful monitoring for signs and symptoms help diagnose rejection.
- Rejection does not necessarily mean your lung will fail but it can damage the transplanted lung.
- Giving additional treatments to reduce rejection-related inflammation or remove antibodies from the blood and other adjustments in your immune suppression 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 spirometry readings at home based on the schedule given to you by your team
- Know the signs and symptoms of rejection
- Report any unusual symptoms to the Transplant Team right away.

We will review the most common signs and symptoms of rejection in the following pages.

A Note About Warning Signs

Before discharge and in the clinic, you will be taught the important warning signs to watch for after transplant. You may be the first person to notice a change. Early detection and early treatment of problems is important for a good outcome.

Signs and Symptoms of Rejection

Many lung transplant recipients may not have any symptoms of rejection, which is why monitoring of your lung function is so important. Recipients may experience some or all of the symptoms mentioned below:

- **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.
- **Fatigue or decrease in exercise tolerance:** Feeling more tired than usual. Lack of energy.
- **Shortness of breath:** Any difficulty or change in how your breathing feels at rest or with exercise.
- **Loss of appetite:** No interest in food. Not wanting to eat.
- **Decrease in spirometry readings:** Perform home spirometry readings as instructed by your care team, around the same time each day (not around meal time). If the reading is down by 10% for two days, report it to your Transplant Coordinator along with any other symptoms you may have.

If you experience any of these symptoms, tell your Transplant Team immediately. These may be warning signs.

The Transplant Team will work to assess the best next steps to figure out the cause of your symptoms.

Rejection is common after a lung transplant.

Be sure you know the signs and symptoms of rejection

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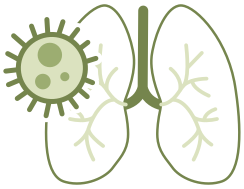
Common Infections After Lung Transplantation



Infections are the most common complication after lung 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 try to minimize the risk and impact of infections by:

- Giving anti-infective medications at the time of the transplant surgery and afterwards.
- Giving antiviral medication for several months after transplant.
- Prescribing a lifelong low dose of antibiotics to prevent a common fungal infection.
- Monitoring your health closely in the clinic and between clinic visits.

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.
- **Your 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).
- Persistent sores, blisters, lumps, or growths in armpit, groin, or elsewhere should be examined by your Primary Care Provider as soon as possible, and inform your Transplant Team.

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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, but it rarely causes severe infection in people who are not immune suppressed so most people are never aware that they ever had it. CMV remains in your body in an inactive state after an initial infection. 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, the CMV virus may start to replicate and can cause serious problems including infection of the transplanted lungs and other organs in your body.

Most people will not experience any symptoms with an early CMV infection. Symptoms may also be mild or non-specific, such as feeling like you have the flu.

Symptoms can include:

- Fever and/or chills
- Fatigue
- Muscle aches
- Nausea/vomiting
- Diarrhea
- Shortness of breath
- 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. Antiviral 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. Depending on your own risk of CMV infection, you will be prescribed preventative medication such as valganciclovir for 6 months or longer to reduce the risk of infection.

Once the preventative medications are stopped there is a risk of CMV infection. After stopping the preventative medication you will be asked to get regular blood work to check CMV levels in the blood (CMV PCR test) weekly or every other week. **It is extremely important that you get these tests done and that the Transplant Team reviews them so that any infection can be detected and treated early before it causes serious problems.** Most people can be treated for CMV at home with oral or intravenous medications, but some infections will require admission to hospital.

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Pneumonia (lung Infection)

Infections in the transplanted lung are very common because of the immune suppression medications and the direct contact of the lung with the outside environment. Lung infections can be caused by bacteria, viruses, or fungi.

Infections may not have typical symptoms or any symptoms at all early in their course. It is important to monitor for any symptoms that may indicate a lung infection, such as:

- Fever
- Shortness of breath
- Change in your home spirometry testing a drop of 10% in FEV1 or more on 2 or more readings
- Coughing: persistent or prolonged cough, with or without sputum
- Sputum: increase in the amount and/or a change in colour of your sputum
- Fatigue

Report these signs of infection to your Transplant Team immediately.

You may need some additional testing to figure out the cause of the infection symptoms, such as:

- Sputum sample for bacterial and fungal culture
- Nasopharyngeal swab for viral testing (influenza, COVID, RSV, other viruses) – some viruses have treatment options, especially for lung transplant recipients
- Chest x-ray or chest CT scan
- Blood tests
- Bronchoscopy

Treatment for a lung infection will depend on the type and severity of infection. Some infections can be treated with a few days of medications and some may require several months of treatment.

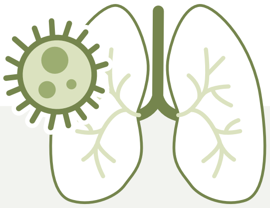
If treatment is started by a care provider outside of transplant you should inform your Transplant Coordinator so that the Transplant Team can ensure you are on the correct medications and have the correct follow up.

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 (Methicillin-resistant Staphylococcus aureus) and VRE (Vancomycin-resistant Enterococcus). Some specialized antibiotics may be effective in this situation.

We try to reduce the problem of multidrug resistant infections in our hospital by:

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



You can help reduce the risk of infection by:

- Completing all antibiotic prescriptions given to you.
- Ensuring you are always practising good hand washing.
- Following the isolation signs posted on the hospital doors. You may need to wear masks, gloves or gowns.

Other Infections

Infections after lung transplant are not limited to the lungs. Other areas of the body can develop infections, such as:

- **Urinary tract:** change in urination frequency, pain when urinating, change in urine colour or odour, blood in urine
- **Bowel:** diarrhea, cramping
- **Skin:** redness, swelling, warmth around the transplant incision or in other areas of the skin

Other infections are possible and they cannot all be described here. The most important thing is to track your overall symptoms and your home measurements such as **temperature, heart rate**, and **blood pressure** to help detect signs of an issue.

Protect yourself by being up to date with vaccinations, avoiding others who are known to be sick, and following good hand hygiene and food preparation practices. Avoid mosquito and insect bites by using insect repellent, long sleeves and pants, and avoiding high risk times (dawn, dusk) and environments (standing water) to minimize risk of infections such as West Nile virus.

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 such as immunizations and other measures such as preventative medications and precautions for travel or contact with others.

Travel can also expose you to infections. Some countries you travel to may require that you get vaccinated in advance of leaving home. These vaccinations can be arranged through a specialized travel clinic or through your Family Physician. Remember that **you must not get any live vaccines after transplant**.

Contact your Transplant Coordinator before you travel out of the country if you have questions about precautions or medications while travelling.

You can check the HealthCanada website to learn more about travel precautions and infectious outbreaks **www.travel.gc.ca/travelling/health-safety/vaccines**

You must not get any live vaccines after transplant.

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Chronic Lung Allograft Dysfunction (CLAD)

Chronic rejection, or chronic lung allograft dysfunction (CLAD) is a major complication after lung transplant that affects about half of patients who reach five years post transplant.

Bronchiolitis Obliterans Syndrome (BOS)

There are different forms of CLAD but **bronchiolitis obliterans syndrome** (BOS) **is the most common type.** BOS usually occurrs more than five years after a transplant but it can happen even just a few months after your surgery.

BOS is involves damage to your small airways and narrowing and scarring of the airways in your transplanted lung(s). This scarring will cause you to have a progressive decline in the function of your transplanted lung(s). After transplant you and your care team will regularly measure your lung function at the hospital and at home. Over time you will come to know what your "**best**" or "**baseline**" lung function is, base on your FEV1 measure. With BOS your FEV1 may continue to decrease over time, but may also decline initially and then stabilize for some time.

Restrictive Allograft Syndrome (RAS)

Another form of chronic rejection is restrictive allograft syndrome (RAS). RAS is characterized by damage and scarring of the air sacs (or alveoli) within your transplanted lung.

In the case of RAS the scarring leads to a decline in lung function values, including not only the FEV1 (as in BOS) but also the forced vital capacity (FVC) or total lung capacity (TLC).

A CT scan of the chest revealing RAS may show new changes consistent with lung scarring.

Unfortunately, RAS is typically a more aggressive form of chronic rejection compared with BOS.

Early detection
and **reporting**
is key.

Diagnosing CLAD

Knowing your baseline FEV1 after transplant is important, because a decline in your FEV1 or other spirometry numbers may indicate there is a problem with your lungs and your Transplant Team will perform a workup to determine the cause. Before CLAD can be diagnosed, other causes for the decline in function such as infection and other forms of acute rejection must be ruled out. When a drop in lung function persists despite investigating and treating possible other causes, then CLAD may be the diagnosis.

Initially you may not experience any symptoms, and there may be a decline in lung function prior to any symptoms. This is why monitoring of lung function after transplant is essential. As time goes on common symptoms may develop such as:

- Shortness of breath (especially with activity)
- Fatigue
- Cough, sometimes with increased mucus production

These symptoms can be similar to those that develop during an infection. **This is why it is important to report any new symptoms or problems to your Transplant Team so that a proper diagnosis can be made.**

Prior to diagnosing CLAD, some additional testing will likely be required and may include:

- **Lung function testing:** this testing will be repeated to look for trends such as improving, stable, or declining
- **Chest x-ray or chest CT scan:** to assess for signs of infection or structural issues. Sometimes CLAD will be evident on imaging such as a CT scan but it is not always visible
- **Bronchoscopy:** may be done to take samples from the lung to check for infection or types of acute rejection.
- **Blood work:** to check for signs of infection, inflammation, or antibody-mediated rejection.

Your Transplant Team will work with you to figure out what tests are needed. The final decision about a diagnosis of CLAD is based on the Transplant Team's assessment and the results of testing to exclude other potential causes of the decline in FEV1.

If there is no infection or other forms of rejection and your lung function does not recover or continues to decline, the diagnosis is likely CLAD. The severity of your diagnosis is determined by comparing your current FEV1 to the your best FEV1 or a combination of lung function testing and imaging.

Risk Factors for CLAD

It is not clear why some patients who receive a lung transplant develop CLAD. Some of the factors that are thought to play a role are things in the environment that irritate or damage the lungs, such as infection, air pollution, or tobacco smoke, and your immune response to the transplanted lung(s). Some known risk factors for the development of CLAD include:

- **Primary graft dysfunction:** This is when the transplanted lung does not function properly early after transplant and can be caused by many different factors related to the donor, the recipient, and the transportation and storage of the lungs before implantation.
- **Acute cellular rejection or antibody-mediated rejection:** Prior episodes of these forms of acute rejection can predispose an individual to develop CLAD later.
- **Gastroesophageal reflux disease (GERD)**: This is when fluid from the stomach (either acidic or non-acidic) comes back to the throat and gets into the lung. This is a frequent problem in people who have lung transplants and needs to be treated to reduce lung injury.

Certain infections increase the risk of CLAD. These include but are not limited to:

- **Bacteria**: Pseudomonas aeruginosa
- **Viruses:** Cytomegalovirus (CMV) and common respiratory viruses
- **Fungus:** Aspergillus

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Treatment for CLAD

The most important treatment for CLAD is prevention through trying to reduce the risk factors as much as possible. It is also especially important to act quickly when lung function starts to drop. Your Transplant Team will work with you to:

- Promptly treat any bacterial, viral, or fungal infections.
- Promptly treat any acute rejection episode.
- Effectively diagnose and treat GERD. You will have testing for GERD and other stomach issues around 3 months after transplant and as needed to guide any necessary treatments. Sometimes medications are not effective enough and your Transplant Team may recommend an anti-reflux surgery or other procedure to help protect your lungs.
- Some people may be prescribed long-term azithromycin, an antibiotic that may reduce inflammation, which may help slow or reverse the decline in lung function.
- Always take your prescriptions. All transplant patients receive anti-rejection medications (immunosuppressants) and it is important to be sure to take them. as prescribed. If you develop CLAD while on one immunosuppression medicine, sometimes switching or adding a different immunosuppressive medication can help to prevent any further damage.

Additionally, your Transplant Team may offer you clinical trial options. There are new treatments for being developed everyday and research to prevent and treat CLAD.

Sometimes despite best efforts CLAD continues to progress, and your lung function continues to decline. Some people with advanced CLAD may be evaluated for a second lung transplant. This is a high-risk procedure and cannot be offered in many cases.

Unfortunately, CLAD is life-threatening, and in some cases, people may not survive after a lung transplant. If further treatment options are not available, your Transplant Team will continue to support you in all possible ways.

Some people will develop CLAD and with treatment can remain stable for a long time. There is no straightforward way to predict the course of CLAD over time for everyone.

Close follow-up and excellent communication with your lung Transplant Team is very important.

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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.

If you get sick before your next scheduled clinic appointment, you need to contact your Transplant Coordinator or Primary Care Provider. You may be scheduled for the next transplant clinic or instructed to see your Primary Care Provider or go to the local emergency room.

It is very important that you continue to see your Primary Care Provider, who should provide ongoing care for non-lung transplant programs. The Transplant Team is always available to provide advice to other Physicians as needed.

If there are concerns that you feel cannot wait until the next business day, patients in Ontario can access health advice from a Registered Nurse through Health811. You can call 811 or visit **health811.ontario.ca** to chat online

Certain issues that arise are emergencies and you should seek urgent and immediate care for them.

If you experience shortness of breath 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. Inform your Transplant Coordinator if you have been seen in an emergency room and sent home or admitted to another hospital. Outside of office hours you can use the chart below to help you decide what to do about different symptoms.

On the next page we have created a general guide – you and your support network should use your judgement and seek urgent care if you feel it is necessary.

Sudden shortness of breath or **chest pain** is an **emergency**.

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Symptoms/Situations	What to do
- 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	**! EMERGENCY** **Dial 911** or go to your local **Emergency Room.**
- Gout or joint pains - Severe new onset back pain - Pain or burning with urination - Constipation or diarrhea	**! URGENT** **See your Primary Care Provider and notify your Transplant Coordinator as soon as possible.**
- Flu-like symptoms - Redness, swelling, pain from incision site - Persistent cough - Change in colour of sputum - More sputum than usual - Fever	**myUHN** **Message your Transplant Coordinator on the myUHN portal.** *The portal is monitored Monday - Friday and the response time is typically one business day.*
- Any outside doctors visit or medical consults - Any outside emergency room visits	**myUHN** **Notify your Transplant Coordinator via messaging on the myUHN portal.** *We will reach out to obtain the records as needed.*

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Other Complications After Transplant

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, menopause and some medications such as prednisone, which is used after lung transplant.

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 one to two years after your transplant, can be compared to look for changes. Osteoporosis can be managed by your Primary Care Provider, and some recipients are referred to specialized osteoporosis clinics.

Calcium and vitamin D supplements are used after transplant to supplement dietary intake and when needed other bone maintaining or building medications will be prescribed. Exercise is helpful in decreasing the risk of osteoporosis, particularly with weight bearing exercises, such as walking, and strength training. Prevention and treatment of osteoporosis is important to help reduce the risk of bone fractures. Fractures can impact your health by causing chronic pain and functional disability.

High Cholesterol

Many 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 tacrolimus or cyclosporine.

Other factors can affect your cholesterol levels. High cholesterol can also be hereditary, related to diet, or related to 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 lifestyle changes, you may need medication to help lower the levels. The Transplant Team will likely be the initial prescribers of these medications. Similar to high blood pressure, your Primary Care Provider can take over the management of high cholesterol after transplant and reach out to the Transplant Team as needed.

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Diabetes

Some transplant recipients are living with diabetes 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, tacrolimus, and cyclosporine. 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 important to reducing the risk of these complications. 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 candies.
- 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.

Other general recommendations for blood sugar management:

- Exercise regularly.
- Monitor blood sugars regularly.
- Aim to achieve a healthy body weight, generally considered by guidelines to be a BMI of 18-24.

Recipients with cystic fibrosis should not restrict their food intake to manage high blood sugars. Your CF or Endocrine team will continue to help manage your diabetes with you.

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Hypertension (High Blood Pressure)

It is important to keep track of your blood pressure at home and report your measurements to the Transplant Team.

High blood pressure can be a common complication from some of the medications that are necessary after a lung transplant (such as prednisone and tacrolimus or cyclosporine). Even if you did not have high blood pressure before transplant, there is about a 50% chance of needing treatments for high blood pressure after transplant.

You can help control your blood pressure by maintaining a healthy weight, exercising, and avoiding excess salt such as pre- packaged foods.

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.

The Transplant Team will likely be the initial prescribers of blood pressure medications. Your Primary Care Provider can then take over the management of your blood pressure, especially once you are further out from transplant. If they have questions about the best blood pressure medications to use, the Transplant Team is available to give advice. **Never stop or change any medication on your own.**

Kidney Dysfunction

Immunosuppressive medications may cause kidney damage with longer-term use. The Transplant Team monitors your kidney function through your routine blood tests. If kidney damage occurs, the Transplant Team may adjust the dose of your medications 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 people do experience progressive kidney dysfunction that requires more specialized treatment, such as dialysis or kidney transplant. It is important to get your regular blood tests done and monitor your health, even if you are feeling well, so that kidney problems can be detected early

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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:

- Lymphoma, a specific type of cancer of the blood cells called Post Transplant Lymphoproliferative Disease or PTLD
- Skin cancer
- Bowel cancer
- Cervical Cancer (for women)

These cancers may occur at any time after transplant.

PTLD most commonly occurs early after transplant (in the first post-transplant year), but some people can develop it many years after a lung transplant. 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. The treatment usually involves a reduction in anti-rejection medications and may include antiviral medications. Chemotherapy may be needed in some cases if the PTLD is more extensive or not getting better with reduction in your other medications.

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 Primary Care Provider 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 guide.

Bowel Cancer may be more difficult to detect, but all recipients should report changes in their bowel habits to their Primary Care Provider. Important changes to report include alternating diarrhea and constipation, or the presence of blood in the stool.

Early detection and treatment is important. You may be screened for colon cancer before lung transplant if you are over the age of 50. People living 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. After transplant the recommendation is to have colon cancer screening with a colonoscopy starting at 3 years after transplant, and likely every 3-5 years after that depending on your risk.

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Cervical Cancer in women begins as abnormal cells on the cervix. All female recipients should have regular PAP smears at least once a year through their Primary Care Provider's office. This is more frequent than what is recommended in the general population. Pap smears help identify abnormal cells so that they can be treated quickly. Early detection usually makes this type of cancer curable.

Other Cancers: Transplant recipients may develop other cancers at similar rates to people who have not had 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 your health care providers.

Women should also have breast examinations done through their Primary Care Provider and report any abnormalities immediately. Routine mammograms are usually started once a woman reaches age 40, or earlier in some cases. Women should discuss the need and timing of mammograms with their Primary Care Provider.

Men should do monthly testicular self 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 Primary Care Provider.

Regular cancer screening **is an important part of your ongoing healthcare.**

We have shared a great deal of information about the possible short and longer term complications after lung transplant throughout this guide. Although nobody experiences all of these complications, the majority of people living with a lung transplant experience some of them. **This is why transplant is not a perfect cure, but rather a treatment for lung disease.**

Most people want to know how long they can live after a lung transplant but this can be hard to predict. **Survival after lung transplant is getting better and better over time**. We talk about survival as a statistic, which will not apply to every person but it is one way to put things into perspective.

The median survival after a lung transplant as of 2024 is about 6-7 years. This means that if 100 people get a lung transplant today, in 6-7 years 50 of those people will still be alive. Survival may be longer if you can get through the first year after transplant, which tends to come with the highest risks.

There are long-term survivors after lung transplant, for example 40% of people are still alive after 10 years. **Understanding how a lung transplant can impact how long you live and how well you live (your quality of life) is very important.** You will have individualized discussions with your transplant physicians about this, and are encouraged to ask questions around these outcomes.

Taking Care of Yourself after Transplant

Physiotherapy at Home

Before your lung transplant, your illness may have 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.

Once you are discharged from hospital you will continue a supervised exercise program at Toronto General hospital that is tailored to people recovering from a lung transplant. You will exercise here until approximately three months after your transplant. Your Physiotherapist will also give you daily home exercises to do. If you have a longer hospital stay you can often continue to exercise in the physiotherapy exercise program for a longer period of time.

Gradually you will be able to do more and more. Your exercise in the Treadmill Room 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. Exercise is vital following transplant to build your strength and endurance so that you can return to regular activities and should be seen as a lifetime commitment to optimize your health and lung function. Exercise is as important as your medications in maintaining your health after transplant

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.

Exercise is vital following transplant to build your **strength and endurance.**

Giving Support After Transplant

The support network role after lung transplant is important in maintaining and promoting a healthy recovery and state of wellness. It is key for you to help the patient navigate through the post-transplant period, and the first 3 months after transplant are the most intense.

Here are a few things you should do:

- Identify yourself as the main support person and provide the transplant clinic with current contact information.
- Commit fully for at least the first three months post-transplant for all scheduled tests and appointments, as well as unexpected visits.
- Function as a “Personal Assistant” for example helping with day-to-day activities and medications, providing transportation to hospital appointments, encouraging rest and exercise, promoting and helping with proper nutrition.
- Maintain a log or journal of any questions or concerns, including medication questions or refills that might be needed and bring it with you to clinic appointments.
- Early after transplant you may be the person in charge of managing the medications until the transplant patient recovers.
- Remind the patient to bring their list of medications to all appointments, including transplant clinics, bronchoscopy appointments and any other doctor’s visits, the dentist, and even when traveling.
- Ensure proper understanding of various appointments, locations, and instructions. A calendar or day planner can help organize this information in a central spot.
- Help sort out any financial issues – for example drug coverage and private insurance. Follow up with the Transplant Social Worker if needed.
- Provide feedback to the Transplant Team regarding the patient’s mental state – mood changes, signs of difficulty coping, depression, or anxiety.

Be prepared for a change in roles. As the transplant patient recovers and regains their strength they will become more independent and will not need your help as often.

Activities you can do 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: Avoid the use of hot tubs due to infection risks even later post transplant.

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. If these are important to you, discuss them with your Transplant Team to better understand the risks.

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.

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Medical Forms

Requests for letters, forms and prescriptions must be made well in advance. Same day service cannot be provided so please plan in advance if you need a medical form, letter or renewal. Contact your Transplant Coordinator to make a request.

Here are some things to keep in mind:

- If possible, have your Primary Care Provider fill out medical forms.
- Completion of medical forms may take up to 6-8 weeks, and your Transplant Physician may not be able to fill out all forms. Your Transplant Physician will not be able to fill out forms in the longer-term after transplant, particularly if the forms are not related to a specific issue realted to your transplant.
- 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 if applicable.
- Give the forms to your Transplant Coordinator or the Administrative Assistant.

Please note that as you progress through your lung transplant journey, much of your care is coordinated by your Primary Care Provider. You will need to go to them for most form completion.

If you are submitting a request for forms to your Transplant Team, please be sure the patient portion with your name and date of birth is completed. You will also need to sign the form for release of information.

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timelines for receiving forms

prescription renewals	travel letters	insurance forms
Allow 3 business days.	Allow 30 days before your travel date.	Allow 6-8 weeks.

Living a Healthy Lifestyle

Maintaining Your Health After Transplant

You need to take care of your whole body, not just your new lungs. Annual health examinations ("check-ups") with your Primary Care Provider are very important. You must have a Primary Care Provider before and after transplant. We expect that you will stay in touch with your Primary Care Provider and see them about regular health issues not related to your transplant.

The Transplant Team will be available to speak with your Primary Care Provider to share information and answer questions about looking after transplant patients along with sending regular updates from your appointments. We work in partnership with Primary Care Providers to share in your care. Your Primary Care Provider will be the person to ensure that you are getting appropriate cancer screening and other check ups to maintain your health, as well as your vaccinations.

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

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

Referrals to other medical specialists for routine issues (e.g. cancer screening, aches and pains, etc.) will be the responsibility of your Primary Care Provider. 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 Primary Care Provider or local specialists at any time to decide on the best course of action.

Vaccinations

Vaccinations will be managed by your Primary Care Provider, please see them for a record of your vaccinations.

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 chickenpox (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.

The following is a list of vaccinations that should be updated both before and after transplant.

- **The Flu Vaccine:** Taking anti-rejection drugs means you are more prone to common respiratory viruses like influenza or the flu. After your transplant, we strongly recommend that you **and all the family members in your household** get the flu vaccine each year, typically when it comes out in the Fall.
    - Please note: The transplant clinic does not give the flu shot. Please arrange to have it at your Primary Care Provider's office, or at a local pharmacy. If you have just received your transplant and this vaccine is due, talk to your Transplant Team first as we may suggest waiting at least 3 months after your surgery.
- **The Pneumococcal Vaccine:** This vaccine protects you against the many types of pneumococcal bacteria that can cause serious and life-threatening disease, such as:
    - **Meningitis:** infection of the lining that covers the brain
    - **Pneumonia:** infection of the lungs
    - **Septicemia:** infection of the blood
    - Lung transplant recipients should make sure they are up to date with the current available pneumococcal vaccinations through their Primary Care Provider's office. Note that the Pneumovax-23 and Prevnar-13 vaccines are being replaced with Prevnar-20. Your Primary Care Provider can review the right timing for Prevnar-20.
- **Tetanus:** The tetanus vaccine is due every 10 years. Please arrange for this with your Primary Care Provider.
- **Hepatitis B:** After your transplant, being protected against Hepatitis B is important. **The Hepatitis B vaccination is a series of 3 doses given over 3-6 months**. You will be tested for Hepatitis B immunity prior to transplant. If you are not immune the Transplant Team will recommend that you get vaccinated by your Primary Care Provider while under evaluation or on the waiting list. If you did not complete the series of vaccines before your transplant, you will need to restart the whole series after your transplant. **We generally advise waiting at least 3-6 months after transplant before updating your hepatitis B vaccine.**

- **Human Papilloma Virus (HPV):** The HPV vaccine is suggested for men and women less than 26 years of age, and can be considered in older individuals at risk for exposure to HPV. This vaccine protects you against cervical cancer, anal cancer, and genital warts which are caused by HPV, the most common sexually transmitted infection.
- **Shingles:** Shingrix® is a non-live vaccine that can protect you against shingles (herpes zoster), which is caused by a virus called varicella-zoster. Shingles cause a painful skin rash with blisters that may last for 2 to 4 weeks, and it can cause more serious infection in other organs. About 1 in 3 individuals will get shingles in their lifetime. It is more common in people over 50-years-old or those with a weakened immune system. The Shingrix® vaccine is strongly recommended for transplant recipients who are 50 years of age or older.
- **Meningococcal Vaccine:** The quadrivalent meningococcal vaccine protects you against the 4 most common types of meningococcal bacteria - A, C, Y, and W. Meningococcal infection is spread from person to person through coughing, sneezing, or face-to-face contact. It can also be spread through saliva. Although rare, it can cause serious and life-threatening infections, including infection of the blood and the brain. Complications of infection can be serious.

It is very important to **AVOID LIVE VACCINES** after lung transplant. Common examples of live vaccines include:

- Tuberculosis BCG Vaccine (Oncotice®)
- Intranasal Influenza Vaccine (FluMist®)
- Measles, Mumps, Rubella (MMR, Priorix®)
- Oral Typhoid Vaccine (Vivotif®)
- Chickenpox Varicella-Zoster Vaccine (Varivax®, Zostavax®)
- Yellow Fever Vaccine (YF-VAX®).

If you are not sure whether a vaccine is safe to take after your transplant, reach out to your Transplant Team and ask!

Avoid live vaccines after lung transplant.

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Skin Care

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.

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 any doubt see your Primary Care Provider. You may need to be seen by a Dermatologist. It is recommended that your Primary Care Provider or Dermatologist review your skin from head-to-toe every 6-12 months.

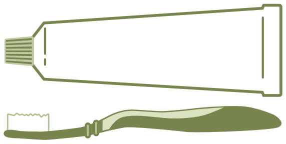
Some tips for the prevention of skin cancer include:

- Apply sunscreen with a SPF (sun protection factor) of at least 30.
- Protect your lips with a lip balm that has a SPF of 30 or higher.
- Wear a hat, long sleeve shirt, and pants when you are out in the sun.
- If you are swimming or sweating heavily, reapply your sunscreen regularly. Even if you use a waterproof sunscreen you will need to reapply it regularly.
- Wear sunscreen all year long (even in the winter months) if you are going to be outside for any length of time (e.g. skiing, skating).
- Wear UV blocking sunglasses. Exposure to UV light may also cause cataracts so remember to protect your eyes with UV-filtering sunglasses (both UVA and UVB filtering).

It is important to remember that even on cool, cloudy or overcast days, 70-80 percent of the sun's ultraviolet (UV) rays still get through. Sitting in the shade or swimming underwater does not protect you, UV rays go through water. In fact UV light is reflected from sand, concrete, snow, and water intensifying your exposure. **You should always take proper sun precautions.**

Always wear sunscreen with a SPF of **at least 30.**

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 Primary Care Provider 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.

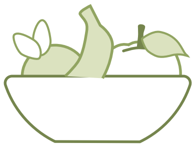
Some antibiotics, such as Erythromycin or others in that class (called macrolides), must be avoided because they interfere with cyclosporine or tacrolimus. The decision to use antibiotics will be up to your Dentist. The Dentist will provide you with a prescription for this. The Dentist can call the lung transplant office for information or if they have any questions.

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 recommended intake of calcium is 1000mg of "elemental calcium" per day. As an example, calcium carbonate 1250mg is commonly prescribed, and contains 500mg of elemental calcium in each tablet. Dietary sources of calcium can be reviewed with your Transplant Coordinator or Dietician.
- **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:** You should not take vitamin E supplements on your own, as they can increase your risk of bleeding. If a healthcare provider recommends that you should take vitamin E, inform your Transplant Team.

Diet and Nutrition



It is important to eat a healthy diet with a balance of protein, fat and carbohydrates and appropriate portion sizes.

Maintaining a healthy post-transplant BMI (Body Mass Index) is very important to support your new lung(s) and remain healthy. You may find maintaining a healthy weight to be challenging long term. If you feel you need help maintaining a healthy weight, the Transplant Dietitian is available to discuss any concerns with you and support you in building a healthy meal plan.

Some of your transplant medications may increase your blood cholesterol levels. You may require medications to lower cholesterol after transplant. Your Transplant Team can help you and your Primary Care Provider manage cholesterol with medications.

Here are some things aside from medications that you can do to manage your cholesterol and maintain a healthy weight:

- Eat a healthy balanced diet.
- Decrease your 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.

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

Complementary Alternative Medications (CAM)

Recipients often ask about the use of 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.

The most common questions we hear are regarding the following products:

- **St. John's Wort (Hypericum perforatum):** Do NOT take this supplement. It interferes with your immunosuppressive medication such as cyclosporine and tacrolimus.
- **Echinacea (Echinacea purpurea):** This is an immune booster and should NOT be used.
- **Garlic (Allium sativum):** This may also cause increased bleeding risk. and should NOT be used. This could be an issue during bronchoscopy or other interventions.
- **Ginkgo (Ginkgo biloba):** This may also cause increased bleeding risk. Do NOT take this 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.

Please note: Drinking ginger or herbal teas in moderation, and using ginger and garlic in foods are acceptable. There is only potential concern if taking concentrated amounts in pill form.

Getting Back to Living

Returning to Work

You will be off work for several months after transplant, to give you time to recover from surgery and adjust to your transplant. Once you are feeling better you may plan to go back to work. However your Transplant Physician will need to approve your health status before you are able to return to work.

Here are a few things to consider as you make your decision about returning to work:

- The physical activity and requirements of your job.
- Whether you will need to modify your work schedule when you first start back at work.
- 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. You will need to make sure any work schedule will not impact your follow-up care.

Be sure to check in with your Transplant Team **when you think you feel ready to return to work.**

Travel

It is recommended that you do not leave the country for the first 6 months following your transplant. When you 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.

- **Vaccinations:** 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 travel clinic in your area.
    - There is typically a cost associated with visiting a travel clinic. 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.
- **Health Insurance:** It is very important that you purchase out-of-country health insurance. Your travel agent can help with this.
- **Cancellation Insurance:** We recommend that you purchase airline cancellation insurance. If you have a complication from your transplant you might have to cancel your trip.
- **Travel letter:** Ask your Transplant Coordinator to give you a travel letter 30 days before your trip. This letter includes a record of your medication and emergency contact numbers. This information may be important if you get sick in another city or country.
- **Medications:** Always carry your medication with you in your carry-on luggage in their original bottles and packages. Never put your medication in your checked luggage.
- **Back-up Medications:** Take an extra supply of medication in case your return trip home is delayed.
- **Infection Prevention:** Ask about taking an antibiotic with you in case it is needed. Your Transplant Physician or Primary Care Provider can give this to you.

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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

- Wash your hands after handling your pet, especially before eating.
- Keep your pet clean and have it groomed by another person.
- Talk to your vet about flea and tick prevention.
- Minimize contact with your pet's body fluids (vomit, feces, urine & saliva). For example, do not clean out the litter box.
- 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.
- Do not let a pet lick any wounds, cuts, or your face.
- Keep your pet's vaccinations up to date.
- 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:

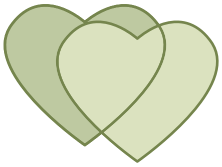
- Stray or wild animals
- Exotic animals
- Sick animals

Sexual Activity

You may resume sexual activity as soon as you feel ready. Contact your Transplant Coordinator if you have questions. Many patients have a loss of interest in sex before transplant due to feeling physically unwell. However, 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 Primary Care Provider.

You must always remember that your immune system is suppressed and therefore you are at greater risk for contracting an infection. You must be aware of how to protect yourself from sexually transmitted diseases such as HIV/AIDS, genital herpes, Hepatitis B, and Hepatitis C. Using a latex condom along with contraceptive foam greatly reduces the risk of contracting a sexually transmitted disease or pregnancy. Be sure to discuss safe sex practices with your partner.



Pregnancy

Although pregnancy in transplant recipients is not encouraged, it is possible for young women to have children after transplantation. There are also potential alternatives to pregnancy that can be explored, such as surrogacy or adoption.

You should be aware of some risks associated with pregnancy after lung transplant:

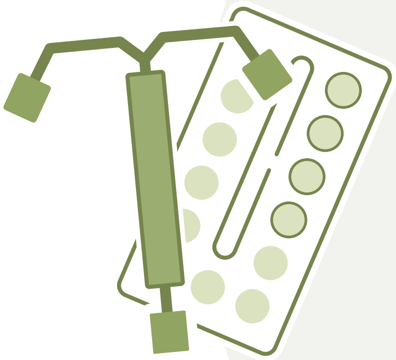
- Your pregnancy may be complicated, requiring hospitalization.
- The incidence of birth defects in the baby is higher for immunosuppressed patients.
- The risk of rejection increases with pregnancy.
- If the disease that caused your lungs to fail is hereditary (such as Cystic Fibrosis), there is the 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. We are here to support you in any way that we can.

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 Primary Care Doctor.

A Special Note for Women



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 may be a higher incidence of infection with certain intrauterine devices (IUDs). These can still be safe and effective. Talk to your Transplant Team if you have questions about the safety of birth control medications or IUDs.

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 loved ones agreed to organ donation at the time of their death, a "Thank You" can be difficult. Many recipients feel they want to write to the donor's family to express their thanks

Under the Human Tissue Gift Act, the government of Ontario requires we keep your identity and your donor's identity confidential. We cannot provide you with your donor's contact information but we can help you by delivering a letter. Although it may be a challenge to write a letter, many transplant recipients welcome the opportunity to express their thanks and thank you letters, or cards, can be a comfort to donor families as they deal with their loss.

Due to the need for confidentiality, 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.

There is no right or wrong time to write to the family of your donor. 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. If you decide to write a letter, once 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 Transplant 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 letters or responses to recipients through the Trillium Gift of Life Network. If this happens, your Transplant Coordinator will let you know.

Feedback for the Transplant Team

The Transplant Team is here for you. We want to hear about the patient and caregiver experience.

If you have any suggestions regarding this guide, please speak with your Transplant Coordinator. Did we miss something? Should we remove something?

Also, 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 or Outpatient Clinic or your Transplant Physician.

If you would prefer to go outside of the Transplant Team, 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

Online: **forms.uhn.ca/PatientRelations/**

Email: patientrelations@uhn.ca

Phone: 416-340-4907

Mail:
Patient Relations
University Health Network
200 Elizabeth Street
Toronto, ON
M5G 2C4

This guide was created by the Toronto Lung Transplant Program in partnership with Healthcare Human Factors to support lung transplant patients and their caregivers.

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