

B R E A T H E
the lung association

LUNG TRANSPLANT GUIDE

INFORMATION FOR NEW BRUNSWICK RESIDENTS



www.nb.lung.ca

Foreword

In New Brunswick, the number of individuals being evaluated for lung transplantation has been increasing year by year. The development of *Lung Transplant Guide: Information for New Brunswick Residents* was inspired by New Brunswickers who have called the Lung Association office over the past several years seeking information about lung transplantation. Already frightened and overwhelmed at the news that a transplant was their only remaining treatment option, those with life-threatening lung conditions had to expend precious time and energy searching for information and resources during an extremely emotional time. This booklet is meant as a guide to help those on this journey to better health.

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Introduction

For those suffering from severe lung disease, a lung transplant may be the only chance to have a better quality of life and possibly to live longer. Lung transplants are not done here in New Brunswick, so you will have to move to a major city in another province while you wait for “new” lungs to become available. The costs of living away from home while waiting may be very high.

If you have been told that you need a lung transplant (or that you may need one in the future), you likely have many questions about what happens next. Not knowing what to expect can create a lot of fear and worry. This booklet answers frequently asked questions, and provides information to help you prepare for a possible lung transplant.

You should read this information if:

- you have been told that you need a lung transplant;
- you have a serious lung condition and may need a transplant in the future; or
- you would like to be able to pass on information about lung transplantation to others.

Disclaimer

The information in this booklet is a guide and is not meant to be the last word on this subject. All information was current at the time of printing but things can and do change. The transplant centre team will provide much more information about lung transplants once you are referred for an assessment.

The Basics of Breathing

What is in air?

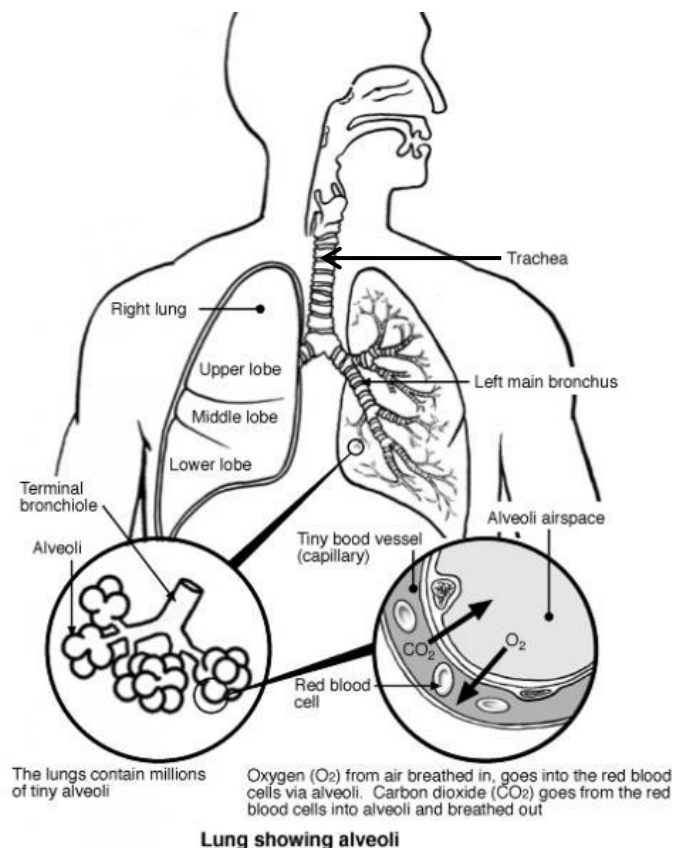
The air you breathe is not pure oxygen (O_2) – in fact, only about 21% of it is oxygen. The rest is mostly nitrogen with some very small amounts of other gases. The air you breathe out still contains about 16% oxygen.

What do lungs do?

You have two lungs (a right and a left), and each lung is made up of sections called lobes. The right lung is a bit bigger and has three lobes, while the left lung has two lobes. Air travels in and out of the lungs through passages called airways (bronchi and bronchioles) that get smaller and smaller just like the branches on a tree. The smallest airways are no wider than a strand of hair.

At the end of the tiniest airways are clusters of very thin-walled air sacs called alveoli. There are 300-400 million alveoli in the lungs. Tiny blood vessels called capillaries surround the alveoli. Oxygen and carbon dioxide pass easily between the capillaries and the alveoli.

The body is made up of billions of cells where each has a specific function. Each cell is like a tiny engine that uses oxygen for fuel and produces carbon dioxide as a waste gas. The lungs are responsible for getting fresh oxygen into the bloodstream where it is carried to the cells. The bloodstream then carries waste carbon dioxide from the cells back to the lungs so it can be breathed out.



What happens when the lungs are damaged or diseased?

When the lungs are not healthy, they may not be able to bring in enough oxygen to feed the body's cells or to get rid of all the waste carbon dioxide. This can cause severe fatigue, the feeling of being out of breath with the slightest effort, and may even shorten life.

A person with damaged lungs can be given extra oxygen to breathe in, but this is not always enough to fuel the activities of all the cells. Sometimes the only thing that will let someone with severely damaged lungs breathe with less shortness of breath is a lung transplant.

What causes breathing problems to develop?

Many things can cause breathing problems. Smoking, air pollution, and breathing in certain chemicals, fumes, and dusts can cause damage to the delicate lung tissues. Some people inherit diseases that damage the airways or air sacs in the lungs. Other people have lung disease that develops for unknown reasons.

Breathing problems can also be caused by an increased pressure in the blood vessels inside the lungs, which is called pulmonary hypertension. This disease can develop as a result of another condition or disease in the heart or lungs, or it may develop for unknown reasons.

General Lung Transplant Information

The information in this section gives brief answers to frequently asked questions about lung transplants. You will be given more information by the transplant team during your assessment about the tests, surgery, recovery, medications, and related issues.

While you are waiting for a lung to become available, you are a lung transplant candidate. Once you have had the surgery, you are a lung transplant recipient.

What is a lung transplant?

When you have a lung transplant, your diseased or damaged lung is replaced with a healthy lung that is donated from another body (called a donor lung). One or both of the lungs can be replaced if necessary.

When did lung transplants first happen?

In the 1940s, lung transplants were attempted in animal experiments. The first attempt to do a lung transplant in a person was in 1963, but it was not successful. Between 1963 and 1983, another 40 attempts were made to transplant lungs in humans.

In 1983, the world's first successful single-lung transplant was done in Toronto, Ontario. The first successful double-lung transplant was done in 1986, also in Toronto.

Where are lung transplants done in Canada?

There are five transplant centres in Canada that do lung transplants.

Lung Transplant Centres in Canada

Montreal, QC	Centre Hospitalier de l'Université de Montréal – Notre Dame http://www.chumontreal.qc.ca/	http://www.chumontreal.qc.ca/patients-et-soins/departements-et-services/transplantation-pulmonaire	(514) 890-8000 Ext. 25387
Toronto, ON	Toronto General Hospital	http://uhn.ca/Focus_of_Care/MOT/Lung/patient_info.asp	(416) 340-4800
	The Hospital For Sick Children	http://www.sickkids.ca/RespiratoryMedicine/What-we-do/Lung-transplant-program/index.html	(416) 813-1500
Winnipeg, MB	Health Sciences Centre	http://www.hsc.mb.ca/placecard10.htm	(204) 787-1521
Edmonton, AB	University of Alberta Hospital	http://www.albertahealthservices.ca/services.asp?pid=saf&rid=1005265	(780) 407-7559
	Stollery Children's Hospital	http://www.albertahealthservices.ca/services.asp?pid=saf&rid=1005265	(780) 407-8822

Vancouver, BC	Vancouver General Hospital	http://www.vch.ca/find_services/find_services/?program_id=13296	(604) 875-5182
	The BC Transplant Society	http://www.transplant.bc.ca/pre_lung.htm	(604) 877-2240

Where do the donated lungs come from?

Most donor lungs come from the body of someone whose brain has been so severely injured that there is no chance the brain will function again. This is called “brain death” and the body would die without machines to support breathing and medications to support the blood pressure. Brain death often happens because of some type of head injury or because of a sudden bleed inside the brain.

Some donated lungs come from living donors. In this case, two people with healthy lungs each donate a section (lobe) of their lung. Currently, the only Canadian transplant centres that do living-donor lung transplants are in Edmonton and Toronto.

What makes a donor lung a good match for me?

The two main factors that are considered for matching are the blood type of the donor and recipient, and the size of the donated lung(s). Lungs which are too large for you can sometimes be trimmed down. Your race and gender do not need to match that of the donor.

How long is the surgery?

The average amount of time for a single-lung transplant surgery is 6 hours or more and a double-lung takes 12 hours or more. Complications may cause the surgery to be longer. The transplant team specialists will give you more details on the actual surgery before your name is added to the waiting list.

How long is the recovery from surgery?

Recovery from transplant surgery depends on how well your body heals. Most people are in the Intensive Care Unit (ICU) for a few days to a week, and then in hospital for another 3-4 weeks. If there are complications, you may have to stay in hospital for a longer period of time.

After getting out of the hospital, you must remain in the area of the transplant centre for at least three months or until you are stable enough to return home to New Brunswick.

Who might need a lung transplant?

Transplant surgery may be considered when a severe lung condition is getting worse and when all other available treatments and medications are no longer helping the lungs to do their job. A lung transplant is considered when your life expectancy with the transplant is likely to be longer than it would be without it.

For some people, it is not clear whether or not a lung transplant would lead to a longer life. In this case a transplant might be done because it would result in a better quality of life.

There is a long list of diseases that may lead to a lung transplant but the most common diseases for which the surgery is done include*:

1. Chronic Obstructive Pulmonary Disease (COPD)
 - Emphysema
 - Alpha-1 Antitrypsin Deficiency
 - Bronchiolitis
 - Lymphangioleiomyomatosis (LAM)
 - Eosinophilic granuloma
2. Interstitial Lung Diseases
 - Pulmonary fibrosis
 - Sarcoidosis
 - Scleroderma
 - Hereditary Hemorrhagic Telangiectasia (also known as Osler-Weber-Rendu Syndrome)
3. Airway Diseases
 - Cystic Fibrosis (CF)
 - Bronchiectasis
4. Pulmonary Hypertension
 - Idiopathic
 - Secondary: Eisenmenger's Syndrome secondary to a heart defect, or Interstitial lung diseases

***see [Glossary of Lung Diseases](#) for descriptions (page 31) and *page 39 for information on the [Inspired Program](#). This is for people with Idiopathic Pulmonary Fibrosis (IPF) who will be taking the drug Esbriet.**

Single-lung, double-lung...how do they decide what someone needs?

In most cases, the decision to replace one or both diseased lungs depends on the number of donor lungs that become available and the medical needs of the person needing the transplant.

Those who have cystic fibrosis (CF) must have a double-lung transplant because they often have chronic lung infections that would infect a single transplanted lung.

Who might not be able to have a lung transplant?

Your doctor should contact a transplant centre before assuming that you are not eligible for a lung transplant. The information given here is from the 2006 International Guidelines, but keep in mind that the guidelines may change as medicine advances.

There are certain things that will stop you from being accepted as a candidate for a lung transplant. These are called **absolute contraindications** and they include (as of 2006):

- cancer (except some skin and lung cancers*) in the past two years; it is preferable to be cancer-free for at least five years;
- other diseases of the heart, liver or kidney that cannot be treated;
- non-curable chronic infections such as active hepatitis B, hepatitis C, and HIV/AIDS;
- significant problems with the shape of the chest wall or spine;
- not being willing or able to follow medical therapy;
- not having a reliable social support system (family, friends, others to help);
- current use of tobacco, street drugs, or excess alcohol, or use within the past six months.

***People with certain primary lung cancers (such as bronchioalveolar cell cancer**) can be considered for lung transplant** because the cancer tends to stay within the lung. In these cases, a lung transplant is not a “cure” because the cancer can return – but by that point, the person will have survived longer with the transplant than without it.

***see Glossary of Lung Diseases (page 31) and * for information on support for people with Idiopathic Pulmonary Fibrosis (IPF) who will be taking the drug Esbriet.**

Other factors are called **relative contraindications** and they may mean you will not be able to have a lung transplant. If several of the following are present at the same time, transplanting a lung may be too risky for you. These factors include:

- critical illness – for example: being on a mechanical ventilator (breathing machine) and/or needing powerful medications to support the blood pressure;
- severe obesity (very overweight);
- severe osteoporosis (very brittle bones);
- chronic lung infections due to a bacteria, virus or other organism that is resistant to medications, or one that can cause severe illness;
- other medical conditions that have not yet resulted in severe organ damage (some examples are diabetes mellitus and high blood pressure);
- very poor physical condition which would make the recovery after surgery extremely difficult.

Source: International Guidelines for the Selection of Lung Transplant Candidates (2006)
<http://www.jhltonline.org/article/PIIS1053249806002518/fulltext#section4>

What is rejection?

Your body's immune system tries to attack anything it thinks is an "invader". For example, when you are exposed to a cold virus, your body works to fight off the virus. The stuffy nose and cough that usually come along with a cold are the body's way of trying to surround and kill the virus and get it out of your body. In the same way, your body will attack any donor organ that has been transplanted into your body. This attack on the donated organ is called "rejection".

You will be given anti-rejection medications (also called immunosuppressants) after the transplant to suppress your immune system so it does not attack the new organ. At some point after a lung transplant you, like every recipient, may have an episode of rejection. This is usually a temporary and reversible problem called "acute rejection" and it is treated in the hospital with medications. Acute rejection is most likely to happen in the first six months after a transplant, but it can happen at any time as long as the donated organ remains in your body.

The transplant centre will give you lots of information on how to notice the early warning signs of a rejection episode so it can be treated as soon as possible.

Chronic rejection of a donor lung happens over a longer period of time and it is called "bronchiolitis obliterans syndrome". Chronic rejection is the most common reason for death in lung transplant recipients.

When the body chronically rejects the donated lung, the smallest airways inside the lung, called the bronchioles, become swollen and then scarred. The scarring causes the airways to become very narrow making movement of air in and out of the lungs more difficult. Chronic rejection is difficult to treat, and in some cases, the recipient may need to have another lung transplant.

What do anti-rejection medications do?

Anti-rejection medications lower your body's immune system response so the new organ is not attacked – however, because the entire immune system is working at a low level, you are more at risk of becoming sick than the average person would be. You will need to take anti-rejection medications for the rest of your life, but over time the amount of these medications can often be reduced to a lower maintenance level.

The main medications used to prevent rejection in lung transplants are prednisone, cyclosporine, tacrolimus, azathioprine and mycophenolate mofetil. Your transplant team will decide which medications you will need.

Do anti-rejection medications have unwanted effects (side effects)?

Yes – all medications have some side effects which differ depending on the medication. A side effect of all anti-rejection medications is the increased risk of infection because the immune system response is lowered.

Some other serious side effects of anti-rejection medications include: kidney damage, high blood pressure, increased cholesterol levels, increased blood sugar, and increased risk of certain cancers. The transplant team will give you more information about your specific medications and their side effects.

Are there other medications I will have to take after the transplant?

You may have to take medications to treat the side effects of the anti-rejection medications. As well, you may have to take antibiotics or anti-viral medications to prevent specific lung infections for a certain amount of time after the transplant.

How close do I have to be to the transplant centre when waiting?

Lung tissue is very fragile, so a donated lung has to be transplanted very quickly or else it becomes useless. When you are on the waiting list for a lung transplant you must live within a 2 ½ hour drive of the transplant centre so you can get to the hospital quickly when the call comes. The other reason for relocating is because the status of your lung condition must be closely monitored during the waiting period. You will be making many trips to the hospital for tests and appointments.

Most transplant centres are in the downtown area of major cities. In large cities, driving and finding parking is frustrating, time-consuming, and expensive. Public transportation is not recommended because being in crowded buses, streetcars or subways will increase your risk of infection. So, for these reasons you will likely choose to live close to the transplant hospital.

How long is the waiting time for a transplant?

The time spent waiting for a transplant varies greatly from person to person. Available donor lungs are assigned to the candidate who is the best match to the donor lung. If you and someone else on the list are both a good match to an available donor lung, the person who is sicker at that time will get the transplant.

You may get a transplant just a few days after your name has been added to the list, or you may wait more than two years. The majority of people get a transplant within 12 to 18 months of being put on the waiting list.

The status of your condition when your name goes on the list is another factor in how long you might wait. Status 1 means your condition is stable and Status 2 means it is rapidly getting worse. Your status on the list can be changed if your condition changes.

Do people die while on the waiting list?

Unfortunately, there are people who will die while on the waiting list for a transplant. Sometimes candidates must withdraw from the waiting list because of some other medical condition that must be treated before they can become a transplant candidate again.

How long can people live after a lung transplant?

How long someone will survive after a lung transplant is impossible to predict because every person's condition is different. Chronic rejection, infections, and side effects from anti-rejection medications affect survival.

Average survival rates (Source: Toronto Lung Transplant Program):

- 90-95% of lung transplant recipients survive the surgery and the first 30 days after
- 80% survive the first year
- 50% survive five years
- Close 40% survive 10 years
- 33% 15 years

For your particular health condition, age, stage of disease and transplant centre, these survival rates may vary. The transplant team will discuss this with you in more detail during your assessment.

Is it possible for the original lung disease to affect the transplanted lung(s)?

This could be possible depending on the disease but the transplant specialists will discuss this with you.

Can I still have a pet after having a lung transplant?

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 also cause respiratory illness.

If you do have a pet, it is very important to talk to your transplant team for more guidance. In general, these tips will help decrease your chances of getting an infection from 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). If you have a cat, have another person 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 checkup or more frequently if sick.
- Stay away from stray or wild animals, exotic animals and sick animals.

Becoming a Candidate

A lung transplant can treat life-threatening lung disease, but it is not suitable for everyone. A lung transplant involves major surgery that has a certain level of risk. Deciding to have a lung transplant means making a life-long commitment to follow a strict routine after surgery.

You will need to make big changes to your lifestyle and you may suffer financial hardship. During the referral process, the transplant team will decide if you are a good candidate for the surgery and you will get information to help you decide if having a lung transplant is the right choice for you.

Who decides that I might need a lung transplant?

Your family doctor may be the first to consider the possibility that you need a lung transplant. Because you have severe lung disease, you have likely been to see a lung specialist called a respirologist. Your family doctor or respirologist will send information to the transplant centre and ask the specialists there to decide if you are a good candidate for this treatment.

Is there a specific transplant centre for people from New Brunswick?

The majority of people in New Brunswick who need lung transplants go to Toronto, but a referral can be made to any transplant centre in Canada. New Brunswick Medicare will pay for the surgery as long as it is done in a publicly-funded Canadian hospital.

Who makes up the transplant team?

The transplant team includes:

- a respirologist who specializes in lung transplants
- a lung transplant surgeon
- an anaesthesiologist (the one who keeps you asleep during the surgery)
- a transplant coordinator (a registered nurse)
- a social worker
- a psychiatrist, psychologist, or psychiatric nurse
- a physiotherapist
- a respiratory therapist
- a nutritionist
- other specialists if needed

How would I get placed on the waiting list?

The path to getting on the waiting list may differ slightly between transplant centres, but the following section describes the general steps that will take place.

“First Meeting”

Once the specialists at the transplant centre receive your medical information from your doctor or respirologist, they arrange to have a preliminary or “first-step” meeting with you. This first meeting is to learn more about your medical history and how committed you are to doing all that is necessary to have a lung transplant, both before and after the surgery. You will also get more information about what happens before, during, and after the transplant.

The team will ask if you have a support person or team, and if you have a plan for funding expenses during the waiting time. This first meeting may be done by a teleconference if you live far from the transplant centre. The transplant team prefers that you have a family member and/or support person with you at this meeting.

Write down your questions before the meeting so you will not forget what you wanted to ask.

“Assessment”

If the transplant specialists believe that you could be a good candidate, they will ask you and your support person to come to the centre where you will have extensive tests. This takes about a week to do and include tests that check over all your body’s major systems, including your heart, lungs, liver, kidney, and bone strength. The staff at the transplant centre will explain how the tests are done and what they mean once you are at the centre.

If a patient is required by the hospital to stay as an out-patient in a city outside of NB during the assessment period for 3 nights or longer, and come in for scheduled work-up, tests, therapy etc., they and an escort qualify for accommodation expenses during that period and in accordance with the Medicare Hostel Policy.

You are encouraged to ask lots of questions and you may have a chance to meet with other candidates who are waiting for a transplant when you are at the transplant centre.

“The Final Stage”

Once all the tests have been looked at, the transplant team will decide if you would be a good candidate for the surgery. If everything looks good, they will call you to ask if you would like to go on the waiting list. This call may be a month or two after you have been through all the tests.

If you agree to go on the list, you will need to move with your support person to the city where the transplant centre is. Once you have moved, you will meet with the transplant surgeon and sign all the necessary consent forms to be placed on the list.

You should consider moving as soon as possible.

For your own safety, there may be things that the transplant team will ask you to do before you can be placed on the list. Examples include having dental work done or losing weight.

What must I do while waiting?

During the waiting time, you will be working on staying as healthy as you can. You will attend an exercise program, receive advice about your diet and you will have frequent appointments at the transplant centre to check on your condition.

Why do I need a support person?

A lung transplant is major surgery that affects all parts of your life, not just your body. Waiting for the call to come can be very stressful. You will go through many ups and downs before and after surgery. You cannot do it alone – you will need someone to support you and help you to remain optimistic. You also need someone to help you get to your appointments, get groceries, do the laundry, and care for you in your temporary home before and after surgery.

Who should be my support person?

Being a support person is very demanding and a full-time job during the waiting period and recovery time. A support person is often your spouse or a close family member. One or more persons can make up a support “team” so that they can share in the work to keep you on the transplant list.

A support person has to be able to tolerate hospitals since they will be spending a lot of time with you in hospital (for tests, appointments, during recovery). They will have to be able to leave their job temporarily and commit to being there for you during a very stressful time.

How long does my support person have to stay?

Your support person must move with you when you move close to the transplant centre. You will need a support person or team during the entire waiting time and for at least three months after surgery until you are stable enough to go home to New Brunswick.

What happens if I don't have a support person?

Unfortunately, if there is absolutely no one who can help you during the lung transplant process your name cannot be added to the waiting list. A support person is essential to the success of a transplant so the centre cannot consider you as a candidate without this support in place.

Preparing for the Expenses

Having a lung transplant is a very expensive process. There are many costs to prepare for. Before you can be placed on the waiting list, you need to have a clear plan in place as far as funding accommodations along with other living expenses and medications. This section gives a general idea of the major costs involved and provides some ideas about how to raise the needed funds.

What is covered by New Brunswick Medicare?

All the tests done in hospital, appointments with health care professionals, the surgery itself, and any stay in hospital before/after the surgery are paid for by the New Brunswick (NB) Medicare program. NB Medicare will pay for transplant surgery done in any publicly-funded Canadian transplant centre.

Lodging may be covered under certain circumstances if the patient is required to receive any sort of out-patient services on a regular basis. This must be officially confirmed by the hospital before being considered by Medicare since prior approval by Medicare is mandatory.

After the transplant, if the patient is required by the hospital to stay in that city to receive follow-up services on an out-patient basis, Medicare may approve payment for such in accordance with its Hostel Policy.

If you do not have any private health insurance or if your insurance plan does not cover anti-rejection medications, the New Brunswick Prescription Drug Programs will help patients with the cost of for anti-rejection medications.

For more information including contact information, please see "[New Brunswick Government Information](#)" (pg. 25) or call the **New Brunswick Lung Association for further information at 1-506-455-8961 Ext. 107**

What is not covered by New Brunswick Medicare?

Travel costs to and from the city where the transplant will be done, as well as transportation within that city, are not covered by Medicare.

The NB Prescription Drug Programs help with the cost of anti-rejection medications and other drugs as prescribed. All other medications needed to treat side effects from the anti-rejection drugs, or other conditions, will need to be paid for by either your private insurance or by yourself.

Private health insurance plans often require you to share the cost of prescription drugs. The part you pay is called a co-payment or deductible – NB Medicare will not pay this.

You will have to purchase a device called a micro-spirometer (sold to you at the Transplant hospital) that is used to monitor your lung function every day at home after the transplant. You will also have to buy a MedicAlert™ bracelet, a good thermometer, and possibly some other equipment for home monitoring – the cost for this equipment is not covered by NB Medicare.

For more information including contact information, please see "[New Brunswick Government Information](#)" (pg. 25) or call the **New Brunswick Lung Association for further information at 1-506-455-8961 Ext. 107**

Are there exceptions?

A person receiving social assistance from the New Brunswick Department of Social Development may be eligible for help with travel, accommodation, and medication costs. Their case manager will be able to provide more details. People may qualify for assistance (Health Card) even if they are not receiving social assistance. They could be gainfully employed, yet the medical bills may exceed their family income. Therefore, they should still check with the department of Social Development.

New Brunswick Department of Social Development
506-453-2001 (ask for your area's toll-free number)
www.gnb.ca Keyword: Families

Federal government employees covered by the Public Service Health Care Plan should check with their human resources department about medical travel benefits and medication coverage.

Under the *Canada Health Act*, the Federal Government has the responsibility for funding health care services for certain groups including: the Canadian Armed Forces (CAF), the Royal Canadian Mounted Police (RCMP), First Nations and Inuit, and inmates of federal prisons. Persons in one of these categories may be eligible for medical travel benefits and medication coverage.

The First Nations and Inuit Non-Insured Health Benefits Program (FNIHB) covers certain medical travel expenses and prescription medications for eligible First Nations and Inuit. For more information contact the local Health or Band office, the regional FNIHB office, or visit Health Canada at www.hc-sc.gc.ca.

Current members of the Canadian Armed Forces (CAF) and the Royal Canadian Mounted Police (RCMP) may be eligible for medical travel benefits and medication coverage. Members should contact their human resources department for details.

Former members of the CAF and RCMP may be eligible for benefits through Veterans Affairs. Benefits may be also be available to members/former members who have a disability related to their work. For more information, contact Veterans Affairs Canada at 1-866-522-2122 www.vac-acc.gc.ca .

What expenses should I expect?

You will face some major expenses before, during, and after a lung transplant. You may have two homes to maintain, and it is likely that neither you nor your support person will be working during the time spent outside New Brunswick. The length of the waiting period is impossible to predict. If there are complications after the transplant, you may be living near the transplant centre for much longer than the usual 3 months.

Listed below are descriptions of some of the major costs you should expect, but there are also likely to be other, smaller costs that will add up over time. The transplant program will provide you with more information on housing and relocation when you come for the assessment and meet the social worker.

During the Assessment (to see if you are a candidate)

The tests being done to see if you are a candidate for a lung transplant take about a week.

You will have to make your way from New Brunswick to the city where the transplant centre is located. Most transplant centres are in the downtown areas of major cities. You may be flying, driving, or taking a train depending on your medical condition, finances, and how long the trip is.

You and your support person will likely have to stay in a hotel or some other type of accommodation if you do not have friends or family in the area. You will likely eat out during the week of testing. Most people choose to stay in accommodations close to the hospital to make it easier to get to and from test appointments.

Talk to a travel agent or search the internet for a hotel/motel/bed & breakfast close to the hospital. Keep in mind that large hotels in the heart of major cities can be expensive. Ask if there are places to eat close to where you will be staying. Call the hotel directly and ask if they have any special rates. Ask specifically if they have lower rates for patients with a letter from their doctor.

Some hotels close to the transplant centre may offer a discount to people travelling for medical tests. Call the New Brunswick Lung Association for further information at 1-506-455-8961 Ext. 107

During the Waiting Period and After Surgery

You must always be within a 2 ½ hour drive of the transplant hospital during the waiting period so you can get there quickly when donor lungs become available. You will need to stay near the transplant centre for at least 3 months after you get out of the hospital following the transplant. Most people choose to live close to the transplant hospital to make it easier to get to frequent appointments. You may feel more secure being within a short distance from the hospital during this time.

As a lung transplant candidate, you have to be very careful that you do not get any lung infections before or after the surgery. The risk for infection is higher once the surgery has been done because of the anti-rejection medications you will be taking. For this reason, the transplant centre specialists do not want you living in a rooming house or some other situation where you will be sharing space with a lot of people. You should

also avoid public transportation (such as a bus, streetcar, or subway).

Most people waiting for a lung transplant will rent an apartment that they will share only with their support person. If your support person is your spouse, you may want to rent a one-bedroom apartment, otherwise, you will likely need one with two bedrooms. Apartments in major cities can be very expensive. You can expect to pay at least \$1500 to \$2000 per month to rent a furnished apartment. The rent may or may not include heat, depending on the building.

*You may have to pay first and last month's rent or a security deposit. Some places require you to sign a lease. **Call the New Brunswick Lung Association for further information at 1-506-455-8961 Ext. 107***

You will also be paying for groceries along with electricity, phone, transportation, and other personal expenses.

By living close to the hospital you may avoid the need for a car and related expenses.

Other expenses may include medications. The New Brunswick Prescription Drug Program does pay for prescriptions filled outside the province as well as most of the anti-rejection meds, and this may also be the case with private health insurance plans. If you have private health insurance that covers anti-rejection medications, you may still have to pay a portion of the costs.

Contact your home oxygen provider for more information about insurance coverage and how to arrange for oxygen set-up and delivery in another province.

You will have to purchase a micro-spirometer so you can measure your lung function every day after the transplant. This equipment currently costs about \$450 – you do not need to buy it until you have the transplant. **This cost is not covered by New Brunswick Medicare, nor is it covered by most health insurance plans.**

Routine check-ups after the transplant

Once you have gone home to New Brunswick, you will have to travel back to the transplant centre for routine assessments:

- every three months during the first year after your transplant
- every six months during the second year
- once a year for the rest of your life

The testing will take 2-3 days so you will be staying at a hotel or other accommodation for 2 or 3 nights plus travelling by car, plane, or train, depending on the distance from your home to the transplant centre.

Monthly blood work and lung function tests will be done at a hospital in New Brunswick, so you may have some travel costs depending on where you live.

Funding Uninsured Costs

Funding a lung transplant is not easy for most people. You will need to consider any and all sources of money and you may have to make some tough choices. Do not wait until the bills start piling up – ask for advice before you run into money problems. Consider any and all sources of money. This section provides some general suggestions but you should always ask an expert for advice about your own situation.

During the week-long assessment you will meet with a social worker who will go over the various means of funding that are available to you.

Bank or Credit Union

You might have savings, RRSPs, or other investments that can be cashed in. Some people get a line of credit or take out a second mortgage. Speak to your bank/credit union, an accountant, or a financial advisor to see what your choices are. Make sure you understand the consequences of cashing in any investments or insurance policies before you decide to do this.

Your Home

Some people decide that the best option is to sell their home and buy a smaller house, move into a smaller rental unit, or move in with family. Others may choose to rent out their home on a temporary basis while they are out of the province. Becoming a landlord may add extra stress to your life, and if you rent out your home, the rent you receive counts as income. You should speak to a real estate professional, lawyer, or accountant to discuss these options.

Travel

Hope Air

Hope Air accepts flight requests from Canadians of all ages and illness groups residing in Canada. Since 1986, they have helped thousands of people fly to healthcare resources across the country. Hope Air is not an air ambulance. Rather, it provides flights on both commercial airlines and on private planes from rural/remote locations to “the big city” and also from major city to major city.

The following eligibility criteria will be considered by Hope Air when reviewing your flight request:

- flying for an approved medical appointment (e.g. the cost of the needed medical treatment is being covered by your provincial health plan);
- you are in financial need and unable to afford the costs of an airline ticket; and
- your doctor confirms you are medically fit to fly in an aircraft and that you have a confirmed medical appointment.

If you have a scheduled medical appointment, simply call the National Office at 1-877-346-HOPE (4673) or complete the Flight Request Form at www.hopeair.org.

Reward Points Programs

You or someone you know may be able to book a flight or a train trip using collected “loyalty reward points” such as Air Miles®, Aeroplan®, and Via Preference Reward Program™, etc. Some programs have other reward options, including groceries and other merchandise, gift cards, gasoline, hotel certificates, etc. that can help with other expenses.

Points programs may end or change their rules without notice, so you should check with the program for current rules on redeeming or donating points. Contact details of some common programs are provided here as a guide.

Aeroplan®
www.aeroplan.com
1-800-361-5373

The cardholder can use miles for their own travel or to get a ticket for someone else. Miles can be shared with another cardholder for a cost of 2 cents per mile or miles can be donated to one of the listed charity pools. Other rewards are available.

Air Miles®
www.airmiles.ca
1-888-247-6453

The cardholder can use miles for their own travel or to get a ticket for someone else. Points cannot be given to someone else, but if both people have point collector accounts, the two accounts can be merged. One person will have to close his or her account in order to do this. Other rewards are available.

Via Rail Preference Reward Program™
www.viapreference.ca
1-888-842-7733

The cardholder can redeem points for their own travel or to get a ticket for someone else. Reward points cannot be transferred to another person's account. Gift cards for travel can be purchased.

Fundraising

Ask for help

There are many creative ways to fundraise, but not every idea will work in your community. Family and friends are usually more than willing to help with the fundraising efforts in whatever way they can.

Learn what works (and what does not) by asking others in your area what fundraising events they have attended or helped with. Ask what made these events a success or a failure.

Most communities have service clubs and church groups which can help to organize fundraising events. This help may include getting a lottery license or permit for the event, providing the use of a building, getting volunteers or donating supplies.

Ideas

Some groups hold dances, breakfasts or suppers, and charge admission or accept donations at the door. Others may have silent auctions, yard sales, raffles, Monte Carlo Nights, Bingo Nights, or 50/50 draws. Local businesses and community members can be asked to donate food, prizes, the use of a facility for the event, materials, items to be sold, their time to help, etc. Avoid trying to have any events that offer expensive prizes (a car, trips, etc.) as the money raised may not cover the cost of the prize.

Family and friends may donate materials and their time to make craft projects which can be sold to raise money. If a local fair, exhibition, or craft sale is planned for your area, see if your fundraising group can get a table where the donated crafts can be sold.

A small business that serves the public might agree to place a donation box on a counter. A brief notice can be posted nearby to explain what the money will be used for.

Some business owners may agree to donate a small portion of their profits during one day to your cause. The business owner would need to check with their tax advisor about the rules concerning this type of donation/ fundraising events they have attended or helped with games with prizes (for example: bingo, raffles, Monte Carlo nights, etc.) and the maximum prize values may be limited by government rules.

A lottery permit or license is only available to religious or charitable groups and fairs or exhibitions. Contact service club or church for help in getting one of these

permits/licenses.

Other large fundraising events may require a permit as well. Licenses and permits are available from the New Brunswick Department of Public Safety. (506) 453-3992 or www.gnb.ca Keyword: Public Safety

Bank or Credit Union

Some banks or credit unions can set up trust accounts for collecting donations in your name. Contact your local branch to see if this is an option in your area since each branch has its own policy on trust accounts.

Local Service Clubs and Churches

There are many service clubs and churches or other religious groups that may be able to help with fundraising. Some common service clubs in New Brunswick include: Lion's Club, Rotary Club, Kinsmen Club, Shriners, Knights of Columbus, and Kiwanis Club, among others.

Friends and Family

Your friends and family may organize a fundraising event or they may be able to help you with a cash donation. They might have rewards points they can use to get a ticket for travel (for you or your support person), groceries, a hotel certificate, etc.

Advertising

Contact your local newspaper, radio station, or television station to see if they would tell your story as a way to focus attention on your fundraising event(s). Take advantage of any free advertising available to announce public events. Check the websites of local media or call them directly to see what options are available.

Other Resources

David Foster Foundation

www.davidfosterfoundation.org

1-877-777-7675

This charitable foundation, based in Vancouver, BC, offers last-resort funding and emotional help to families of children 18 and under who need organ transplants.

Disability Benefits

For information about disability benefits programs in Canada, visit Canada Benefits at call 1-800-622-6232.

Benefits Finder site:

A customized list of benefits for which you may be eligible. The Benefits Finder may suggest benefits from federal, provincial or territorial governments, and does not collect or track your information.

<http://www.canadabenefits.gc.ca/f.1.2c.6.3z.1rdq.5.2st.3.4ns@.jsp?lang=en>

Employment Insurance Compassionate Care Benefits

A person may be eligible for Employment Insurance (EI) Compassionate Care Benefits if they must be away from work to care for or to support a very ill family member (at risk of dying within 26 weeks). Unemployed persons receiving EI can also ask for these benefits. The benefits are paid for a maximum of 6 weeks and can be shared among family members.

For information about Compassionate Care Benefits, contact Service Canada at 1-800-206-7218 or visit www.servicecanada.gc.ca.

Expedite™ Compassionate Drug Release for Prograf®

1-888-886-8999

This is a program designed to help transplant recipients who have private health insurance which covers the anti-rejection medication Prograf® (tacrolimus), but who are having problems affording their co-payment or deductible. You will need to wait to see if this medication is prescribed for you after your transplant.

New Brunswick Lung Association

www.nb.lung.ca

1-800-565-LUNG (5864)

The New Brunswick Lung Association can provide you with general information about lung transplants and can put you in contact other lung transplant candidates and recipients from New Brunswick via a Facebook Group (Lung Transplant NB Support Group: <https://www.facebook.com/groups/LungTransplantSupportGroupNB/> Being able to talk with someone who has been through a lung transplant can be very helpful for emotional support as well as for ideas on how to raise money. Once you are listed contact us to see how to receive \$500.00 from the NBLA.

Private Health Insurance Plans

Private health insurance plans offer different coverage for medications, travel, and other services depending on the company as well as the plan. Health insurance is available from a variety of insurance companies and some of the large banks. Often, group health insurance plans are available through employers. If you have private insurance, check to see what coverage your plan provides.

If you have a diagnosis of a serious health condition before trying to get insurance, you have a “pre-existing condition.” Coverage for medications and other services that you already use may be very difficult to get in this case. If health insurance is available, it will most likely be more expensive.

For more information about health insurance and to locate companies that offer it in New Brunswick, contact either:

Canadian Life and Health Insurance Association

www.clhia.ca

1-800-268-8099

or

Insurance Canada

www.insurance-canada.ca

New Brunswick Government Information

New Brunswick Medicare

www.gnb.ca Keyword: Health

1-888-762-8600

You should always carry your valid Medicare card with you. New Brunswick (NB) Medicare covers you for insured medical services (at the standard rate) while you are temporarily outside the province but still within Canada. You must present a valid Medicare card to receive these services; the bill then goes directly to NB Medicare.

However, in Québec, the doctor can choose to bill you directly. In that case, you have to pay the doctor and then submit a claim to NB Medicare. Sometimes the standard rate that NB Medicare will pay is lower than what the doctor charges, so you would have to pay the difference yourself.

Anyone who plans to be out of the province for more than a month should contact NB Medicare to make sure their coverage will continue during the time they are outside New Brunswick.

You should contact NB Medicare early in the referral process for a lung transplant and obtain a letter that verifies you are covered for the surgery and hospital tests etc. The transplant centre may need a letter from NB Medicare.

In addition, the costs for certain accommodations near each transplant centre may be eligible for reimbursement. Call the New Brunswick Lung Association for further information at 1-506-455-8961 Ext. 107

If there is a dispute about whether you are eligible to have your medical services paid for, or if you are unsure about your rights to coverage for medical services, you can contact the Client Advocate at 506-453-4227.

New Brunswick Prescription Drug Program

www.gnb.ca Keyword: Health
1-800-332-3692
506-867-4515 (outside NB)

The New Brunswick Prescription Drug Program (NBPDP) provides prescription drug coverage for eligible residents of New Brunswick. To have coverage under this program there are eligibility requirements to be met; therefore, not all residents of New Brunswick would be covered. Contact the program to see if you meet the eligibility requirements for one of the plans under the program.

Organ Transplant Plan (Plan R)

www.gnb.ca/0212/pdf/PDP-Forms/Organ-Transplant_Pamphlet-e.pdf
1-800-332-3692 (within NB)
(506) 867-4515 (outside NB)

NBPDP Organ Transplant Plan (Plan R) provides coverage for anti-rejection prescription drugs if you have no private health insurance or if your private plan does not cover anti-rejection medications. If you are prescribed a drug that is not covered under this plan, you may apply for coverage of that drug through the Special Authorization process. The drug must be directly related to your transplant condition and must be requested in writing from your physician. The written requests from the physician must detail the name of the medication, expected duration of therapy and any specific clinical and diagnostic evidence supporting the use of the medication.

Under this plan, you pay a co-payment of 20% of the cost for each prescription to a maximum of \$20 (maximum per year is \$500). There is a yearly registration fee of \$50. Prescriptions must be filled by a New Brunswick pharmacy once you return. NBPDP will reimburse eligible anti-rejection medications in the Province where your operation was performed

****You can pre-register for this program before you are placed on the waiting list.**

For more information, contact the New Brunswick Prescription Drug Program.

http://www2.gnb.ca/content/gnb/en/services/services_renderer.8936.

New Brunswick Department of Social Development

506-453-2001

www.gnb.ca Keyword: Families

This department provides social assistance (financial help) to eligible New Brunswick residents who have a very low income or who are unable to work. This department also provides health cards that are needed for certain plans under the New Brunswick Prescription Drug Program. It is possible for eligible residents to get a health card (that helps to pay for prescription drugs) even if they do not receive social assistance. To learn more, contact the department nearest you.

Income Tax Tips

Did you know that certain medical expenses related to organ transplants may be deductible from your income tax? You may also qualify for the Disability Tax Credit in some cases. Because each person's tax situation is different, it is important to contact an accountant or professional tax advisor to discuss what your options are. Do this as soon as you know you are going to be referred for a lung transplant. It is possible that tax returns for more than one year will be affected.

Canada Revenue Agency (CRA) - www.cra-arc.gc.ca

1-800-959-8281 (or check the Government Blue Pages of your telephone book under "Taxes")

Allowable Medical Expenses

Certain expenses that you will have to pay before the transplant, during the time spent in hospital, and during your recovery after the transplant may be allowed by the CRA. You are not allowed to claim any medical expenses which have been, or could be, reimbursed by your health insurance plan.

You may be able to claim expenses you pay to travel somewhere else for medical treatment that is not available where you live. There are two ways to do this - the simple method or the detailed method.

The simple method allows you to claim a flat rate for meals and mileage. Keep a diary of all trips that you must take for medical purposes. Write down the dates, the purpose of the trip, the distance travelled in kilometres, and the costs for accommodation, food, parking, etc. You do not need to keep receipts.

The detailed method is a bit more complicated. You must keep track of how many kilometres you drive for an entire 12-month period, and how many kilometres you drive

during that time specifically to get medical treatment. You have to keep receipts and records for all expenses related to your vehicle during this 12-month period. These expenses include fuel, oil, tires, license fees, insurance, and maintenance and repair.

The following expenses **may be** allowable under current CRA legislation (keep receipts):

- temporary housing costs, parking at the hospital and food if you have to relocate close to a designated hospital before and after the surgery (meals and accommodation for your support person may also qualify);
- non-prescription drugs prescribed by a physician;
- renovations/alterations to your home because of your health or disability.
- all payments for medical professionals, hospitals, and prescriptions that are not covered or not paid for by a Health Services Plan (such as New Brunswick Medicare or a private health insurance plan), and any premiums paid under a Health Services Plan

Disability Tax Credit

You may be able to qualify for the Disability Tax Credit before the transplant or during your recovery from transplant surgery. You can obtain this credit by asking your physician to complete Form T2201 and then simply filling it with your income tax return.

If your impairment is permanent, it is not necessary to file a T2201 every year.

The disability tax credit should be discussed thoroughly with your professional tax advisor. In some situations a person who is entitled to a disability pension under the Canada Pension Plan, Workers' Compensation, or under a private insurance arrangement may not be entitled to claim this credit.

End of Life and Legal Decisions

Although it is not something anyone likes to think about, you should give some thought as to what might happen if you do not survive the wait for a lung transplant, or if you have complications during or after the surgery.

Tell your family what your wishes are so they are not trying to guess what you would want while in a time of crisis.

This section mentions some of the key things you may want to consider, but for specific advice on your personal financial or legal situation you should consult a lawyer, accountant or another professional for advice. For medical advice, speak to your doctor.

CPR (cardio-pulmonary resuscitation)

You have likely heard of CPR, which is an attempt to restore breathing or heart function, or both. The New Guidelines for Basic CPR have made changes so that chest compressions only are performed in an out of hospital situation where a witnessed cardiac arrest is seen but the bystander has no formal training or is reluctant to perform mouth to mouth breathing. (2010, www.sja.ca)

Artificial breathing involves blowing air or oxygen into the lungs. In the hospital, the breathing is done with a face mask and a squeezable bag called a resuscitation bag. Often a breathing tube (called an endotracheal tube) is put into the windpipe (trachea) to make sure air goes directly into the lungs. This tube also helps to prevent stomach contents from getting into the lungs.

Chest compressions involve pushing on the centre of the chest to squeeze the heart between the spine and the centre chest bone called the sternum. Chest compressions keep blood flowing through the body. CPR might also include electric shocks (defibrillation) to treat certain heart rhythms, and medications to help the heart pump and to restore blood pressure.

CPR is not always successful and it can cause trauma to the body. Ribs can be cracked during chest compressions. Damage could be done to the teeth and vocal cords during the insertion of the breathing tube. Until blood flow and breathing are restored, the brain may not receive enough oxygen. This can result in permanent brain damage.

Some people choose to have a “Do Not Attempt Resuscitation” order placed in their hospital chart so that if their heart or breathing stops, no CPR will be done. Sometimes this order states exactly which actions the health care team should or should not take.

Examples include:

- no chest compressions
- only give medications
- defibrillation only
- do not intubate (insert a tube)

A “Do Not Attempt Resuscitation Order” does not affect the care you receive. You may be asked if you would like this order (or some variation) to be placed in your chart. Talk about this with your loved ones and ask your doctor to explain CPR (and anything else you are not clear about) before making this decision.

Life Support Measures

Life support is the use of therapies and equipment to keep someone alive when one or more systems in the body are failing. Life support measures may include the use of some or all of the following:

- a breathing machine called a ventilator;
- powerful medications that support the function of the heart, lungs, blood pressure or other organs such as the kidneys;
- kidney dialysis;
- a heart-lung bypass machine;
- a pacemaker;
- other equipment or medications

Often, life support measures are used to temporarily support the body's functions while someone is recovering from major surgery or a serious illness or injury. If someone has a life-threatening condition that is no longer treatable, starting or continuing life support may not be the best choice.

You may want to ask your doctor or other health care professionals to explain life support measures to you in more detail.

The Will

You should have an up-to-date Will if you want to have a say over who will receive your property and other possessions (your "estate"), and who will look after any minor children you have (those younger than 18) when you die.

If you die without a Will in New Brunswick, a court will appoint someone to decide how the estate will be divided and who will look after any minor children. The decisions will be based on rules set out by the *Devolution of Estates Act*. These choices may not be the same as the ones you would make.

You may want to get the advice of an accountant (or financial advisor) and a lawyer when you are making your Will. There are "do it yourself" Will kits, although most people choose to have a lawyer write up the papers to make sure their wishes are clear.

Power of Attorney

A written document called a Power of Attorney (POA) gives someone the authority (or power) to manage your property, finances and/or personal care on your behalf. The POA only applies if you are not able to make your own decisions because of illness, disability, or mental incompetence. A POA may give general or specific powers.

Power of Attorney for Personal Care

This is a specific type of Power of Attorney (POA) that gives someone the power to make some or all decisions specifically about your personal care if you are unable to do

so. This type of POA does not cover property or finances. Personal care may include health care, consent to medical treatment, nutrition, shelter, and personal safety.

If you do not have a POA for Personal Care, your immediate next-of-kin will be asked to make decisions on your behalf. If you do not want your next-of-kin to be involved in decisions about your health care or if they cannot be involved for other reasons (for example they live too far away), the POA for Personal Care gives you another choice.

You should make sure that your wishes for personal care are known to the person named in this document. A POA for Personal Care must be kept under seal in order to be valid, so it is a good idea to have a lawyer write it up.

Glossary of Lung Diseases

Alpha-1 Antitrypsin Deficiency

This is an inherited condition. Alpha-1 antitrypsin (AAT) is a protective protein in the lungs which keeps a natural enzyme called elastase in check. Elastase is normally helpful in fighting bacteria, but it will attack the walls of the alveoli (air sacs) if there is not enough AAT to balance it. The lack (or deficiency) of AAT allows the elastase to damage the alveoli, which causes emphysema to develop.

Bronchiectasis

This is a chronic disease which damages the walls of the airways and causes them to become stretched or widened. Pockets can develop in the widened airways and these pockets collect bacteria and become infected. These infections then cause more damage to the airways, which worsens the condition. Bronchiectasis is usually caused by a previous lung infection, but it can be inherited as well.

Cryptogenic Organizing Pneumonia (COP)

COP is a rapidly developing pneumonia-like illness characterized by lung inflammation and scarring that obstruct the small airways and air sacs of the lungs (alveoli). Its name is derived from the fact that it closely mimics pneumonia infections. The cause of COP is somewhat complex but it may be triggered by infections from bacteria, viruses and parasites as well as a number of drugs and toxic fumes. The disease usually begins between the ages of 40 and 60 and affects men and women equally.

Chronic Bronchitis

People with chronic bronchitis have swollen airways that regularly produce large amounts of sticky mucus. This mucus blocks the airways. Chronic Bronchitis is a form of Chronic Obstructive Pulmonary Disease (COPD) and is caused mostly by smoking.

Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is a lung disease where there is damage to the airways or air sacs, or both. The two major forms are chronic bronchitis and emphysema. COPD is caused mostly by smoking, but it can also be caused by second-hand smoke, exposure to certain dusts and chemicals, or by Alpha-1 Antitrypsin Deficiency.

Cystic Fibrosis (CF)

Cystic Fibrosis is an inherited disease that causes abnormally thick and sticky mucus to be produced in the lungs and the digestive tract. The mucus blocks the airways in the lungs and becomes infected with bacteria very easily. This can lead to life-threatening lung infections and lung damage. In the pancreas, the mucus makes it very hard to digest food and absorb nutrients.

Eisenmenger's Syndrome

This rare syndrome begins with an inherited heart defect (usually a hole in the wall between the two sides of the heart), which allows the blood to flow through the heart in the wrong direction. The blood flows backs up into the lungs where it damages the blood vessels that supply the lungs, and causes a high pressure to build up in these vessels. This high pressure is called pulmonary hypertension. Heart failure develops as a result of the pulmonary hypertension.

Chronic Obstructive Pulmonary Disease

The air sacs or alveoli in the lungs become damaged and over-stretched. Emphysema is mostly caused by smoking, but some people develop it because of an inherited disease called Alpha-1 Antitrypsin Deficiency.

Hereditary Hemorrhagic Telangiectasia (HHT)

Hereditary hemorrhagic telangiectasia (HHT), also known as Osler-Weber-Rendu disease and Osler-Weber-Rendu syndrome, is a genetic disorder that leads to abnormal blood vessel formation in the skin, mucous membranes, and often in organs such as the lungs, liver and brain.

Interstitial lung disease (ILD)

Interstitial lung disease (ILD) is also known as diffuse parenchymal lung disease (DPLD). It refers to a group of lung diseases affecting the interstitium (the tissue and space around the air sacs of the lungs). The term ILD is used to distinguish these diseases from obstructive airways diseases.

Lymphangioleiomyomatosis (LAM)

Lymphangiomyomatosis (LAM) is a rare lung disease that was first described in the medical literature by von Stossel in 1937. The disease is characterized by an unusual type of muscle cell that invades the tissue of the lungs, including the airways, and blood and lymph vessels. Over time, these muscle cells form into bundles and grow into the walls of the airways and blood and lymph vessels, causing them to become obstructed.

Localized pulmonary Langerhans cell histiocytosis (LCH)

Localized pulmonary Langerhans cell histiocytosis (LCH) (also termed pulmonary eosinophilic granuloma [EG]) is a rare pulmonary disease that occurs predominantly in young adults. The precise incidence and prevalence of pulmonary LCH are unknown, although studies of lung biopsy specimens from patients with interstitial lung disease identified pulmonary LCH in only 5%. Langerhans cell histiocytosis (LCH) describes a group of syndromes that share the common pathologic feature of infiltration of involved tissues by Langerhans cells.

Pulmonary Fibrosis

Pulmonary fibrosis is a lung condition where the tissue between the alveoli or air sacs (called the interstitium) becomes inflamed or swollen, which leads to a gradual scarring and thickening of this tissue. The scar tissue eventually makes it difficult for oxygen to be transferred from the alveoli into the blood. Pulmonary fibrosis can be caused by other lung diseases, smoking, inhaling asbestos or silica dust, and by certain medications. Often the cause is not known – this type of pulmonary fibrosis is called “idiopathic”.

Pulmonary Arterial Hypertension (PAH)

Pulmonary hypertension is abnormally high blood pressure in the arteries of the lungs. It makes the right side of the heart need to work harder than normal. When the small arteries (blood vessels) of the lung become narrowed, they cannot carry as much blood. When this happens, pressure builds up. This is called pulmonary hypertension. The heart needs to work harder to force the blood through the vessels against this pressure. Over time, this causes the right side of the heart to become larger. Not enough blood flows to the lungs to pick up oxygen. At this point, heart failure involves the right side of the heart. In many cases the cause is unknown. In this case, the condition is called idiopathic pulmonary arterial hypertension (IPAH). It used to be called primary pulmonary hypertension (PPH).

Sarcoidosis

Sarcoidosis causes tiny lumps of tissue to form for unknown reasons. If a lot of these lumps form in an organ of the body, they can affect how that organ works. Sarcoidosis can occur in almost any part of the body, but it usually starts in the lungs and lymph

nodes. It often affects the skin, eyes, and liver as well.

Scleroderma

Scleroderma is a group of rare, progressive diseases that involve the hardening and tightening of the skin and connective tissues, the fibers that provide the framework and support for your body. Localized scleroderma affects only the skin. Systemic scleroderma also harms internal organs, such as the heart, lungs, kidneys and digestive tract. Scientists estimate that about 250 people per million have some form of scleroderma. Scleroderma can run in families, but in most cases it occurs without any known family tendency for the disease. Scleroderma isn't considered contagious, but it can greatly affect self-esteem and the ability to accomplish everyday tasks.

PLANNING CHECKLIST

Support Person or Team

- Decide who is the best person, or team of persons, for this support role.
- Ask my support person if they can afford to leave their job, and for how long.
- Tell my support person to see if they qualify for EI
Compassionate Care Benefits.

Health Insurance

If I have a plan, check my coverage for:

- anti-rejection medications;
- other medications;
- medical travel expenses;
- oxygen (if needed);
- micro-spirometer; and other medical equipment.
- is coverage valid outside the province/ for how long?
- what is the co-payment or deductible?

If I don't have a plan:

- Can I get one with my "pre-existing" lung condition?
- Would a plan cover treatments and medications for my current lung condition?
- What are the premiums and co-payment or deductible?

Other

- Pre-register for the Organ Transplant Plan (Plan R), if I am eligible.
- Ask for letter from NB Medicare stating that they will pay for the transplant and other hospital services.
- Let NB Medicare know when I move outside the province to go on the waiting list.

Travel and Accommodation Costs*

*More information about finding an apartment and other costs will be provided by the transplant program social worker during the assessment week.

Add up the costs to travel between New Brunswick and the transplant centre:

- initial assessment week
- moving to go on waiting list
- regular check-ups**

**Remember, check-ups are:

- every 3 months the first year after the transplant;
- every 6 months during the second year; and then
- once a year

Add up the costs for accommodations for:

- the initial assessment (one week of tests)
- 2-3 days for each checkup after transplant
- apartment rental while on wait list (time unknown)
- first and last month's rent or deposit may be required (do I have to sign a lease?)

Add up the approximate costs for phone, cable, electricity (there may be others), including the initial hook-up fees.

Add up the approximate costs for food and other living expenses per month while living away from New Brunswick.

Decide how close I want to be to the hospital, and the best way to get to and from the hospital by car or taxi, or walking (if living close by).

Funding for Expenses

Write down all sources of income and savings or investments I have.

Am I eligible for benefits under:

- the New Brunswick (NB) Prescription Drug Program?
- NB Family and Community Services?
- federal government programs?
- Can I get disability benefits through:
 - the Canada Pension Plan?
 - my union?
 - other government programs?

Decide if I need to sell my house, downsize, or move in with family.

Discuss all my options for funding with:

- accountant;
- lawyer;
- real estate professional; and/or
- banking representative

Look into redeeming loyalty reward points (if available).

Think about having a fundraising event (ask service club or church to help).

Tax Issues

- Discuss my tax situation with an accountant or tax advisor.
- Keep receipts for renovations or equipment needed because of any disability.
- Keep a log of mileage and expenses for travel necessary to get medical care.
- Keep receipts for any expenses I pay for that are related to transplant.
- Find out about the disability tax credit.

Legal Issues

- Make a Power of Attorney / Power of Attorney for Personal Care.
- Make a Will (if not already done).
- Discuss any options and concerns with a lawyer.

End of Life Decisions

- Decide what life support measures I want or do not want.

- Decide if I want cardio-pulmonary resuscitation (CPR) if my heart or breathing stops.
- Discuss my wishes with family and the person holding the Power of Attorney for Personal Care.

Other Health-Related Concerns

- Discuss any concerns or questions I have with family doctor, respirologist, and/or members of the transplant team.
- Write down my questions before any appointments to make it to remember them.
- Have a dental check-up and get any needed dental work done
- Ask the doctor if I need to lose weight.
- If I use home oxygen – contact my supplier to arrange for set-up in apartment outside New Brunswick and during travel.
- Bring 2 or 3 months' worth of prescription medications when I move close to the transplant centre.
- Decide if I want to speak to someone who has already had a lung transplant (contact the New Brunswick Lung Association)

Resources

Alpha-1 Antitrypsin Deficiency Canada Inc.
www.alpha1canada.ca

Alpha-1 Antitrypsin Deficiency Canadian Registry
www.alpha1canadianregistry.com
1-800-352-8186

British Columbia Transplant Society
www.transplant.bc.ca/pre_lung.htm
1-800-663-6189

Canadian Association of Transplantation
www.transplant.ca

Canadian Cystic Fibrosis Foundation
www.cysticfibrosis.ca
1-800-378-2233

Canadian Institute for Health Information
http://www.cihi.ca/CIHI-ext-portal/internet/en/document/types+of+care/specialized+services/organ+replacements/release_18dec08

Canadian Lung Association
www.lung.ca
1-800-565-5864

Canadian Life and Health Insurance Association Inc.
www.clhia.ca
(416) 777-2221

Canadian MedicAlert™ Foundation
www.medicalert.ca
1-800-668-1507

Canadian Organ Replacement Register (CORR)
<http://www.cihi.ca/cihi-ext-portal/internet/fr/tabbedcontent/types+of+care/specialized+services/organ+replacement/s/cihi021362>

Health Canada
<http://www.phac-aspc.gc.ca/publicat/2007/lbrdc-vsmrc/transplant-greffe-eng.php#n121>

Hereditary Hemorrhagic Telangiectasia (HHT)

<http://hht.org/>

Hospital for Sick Children Pediatric Multi-Organ Transplant Program

www.sickkids.ca/RespiratoryMedicine/What-we-do/Lung-transplant-program/index.html

(416) 813-1500

Living with Pulmonary Hypertension

www.livingwithph.ca

New Brunswick Lung Association

www.nb.lung.ca

1-800-565-5864

- Lung Transplant NB Support Group:

<https://www.facebook.com/?sk=lf#!/groups/Lung.Transplant/>

New Brunswick Organ and Tissue Donation

<http://www.gnb.ca/0051/0217/organ/index-e.asp>

1-888-762-8600

New Brunswick Pulmonary Hypertension Society

www.nbphs.org

(506) 832-7618

Pulmonary fibrosis

<http://www.canadianpulmonaryfibrosis.ca/>

Québec-Transplant

www.quebec-transplant.qc.ca

Toronto General Hospital

www.uhn.ca/focus_of_care/mot/Lung/index.asp

(416) 340-3111

Transplant Manitoba

www.transplantmanitoba.ca

(204) 787-1521

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