Lung Transplant
Information for Alberta & NWT Residents
Disclaimer

The information in this booklet is a guide and is meant to support the information given to you by your healthcare professionals. 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 a person is referred for assessment.
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For those suffering from severe lung disease, having a lung transplant may be their only option to survive. This can be intimidating and at the same time it can be difficult to acquire qualified information to help make informed decisions regarding treatment.

If you have been told that you need a lung transplant (or 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 is available to supplement the information available from other sources; more detailed or individually relevant information would be provided to you from the transplant team should you move forward with needing a lung transplant.

There are currently five hospitals in Canada that perform lung transplants. The only lung transplant centre in Alberta is located at the University of Alberta Hospital in Edmonton. There are currently no centres located in the Northwest Territories (NWT).

This document is intended for anyone who:

- has been told that lung transplant is an option for them
- has a serious lung condition and may need a lung transplant in the future
- would like to be able to pass on information about lung transplantation to others
In 2006 there were 38 double lung transplants, 3 heart-lung transplants and 1 living lobar lung transplant done at the University of Alberta Hospital.
What is air made of?
The air you breathe is not pure oxygen (O2) - in fact, it is only about 21% 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 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 (or 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 smallest airways are clusters of very thin-walled air sacs called alveoli (al-vee-oh-ly). 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, each having 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 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; they also may not be able to get rid of all the waste carbon dioxide. This can cause severe fatigue and the feeling of breathlessness. This can interfere with daily activities, and in severe cases it can ultimately lead to death.

A person with damaged lungs can be given extra oxygen to breathe in, but this is not always sufficient. In some cases, the only way to improve the breathing of someone with severely damaged lungs is to give them a lung transplant.

What causes breathing problems to develop?
Many things can cause breathing problems. Smoking, air pollution, chemicals, fumes, and dust can cause damage to the delicate lung tissues. Lung disease can also be inherited or can occur for unknown reasons.

High blood pressure in the lungs, also known as pulmonary hypertension, can also cause breathing problems.
The information in this section gives brief answers to frequently asked questions about lung transplants. You will be given more details about lung transplantation including the tests, surgery, recovery, and medications by the transplant team during your assessment.

What is a lung transplant?
When you have a lung transplant, your diseased or damaged lung(s) is removed and replaced with a healthy lung that is donated from another body (also called a donor lung). One or both of the lungs can be replaced depending on your condition.

What is a heart-lung transplant?
Some people have damaged lungs as well as a damaged heart. In this case, both the heart and lungs are replaced with healthy ones in a single surgery called a heart-lung transplant.

When did lung transplants first happen?
In the 1940s, lung transplants were attempted in animal experiments. The first attempt at a human lung transplant occurred in 1963, but it was unsuccessful. Between 1963 and 1983 there were another 40 unsuccessful attempts made to transplant lungs in humans.

The world’s first successful single-lung transplant was done in 1983, and the first double-lung transplant followed in 1986. Both were done in Toronto, Ontario.

When was the first heart-lung transplant?
The world’s first successful heart-lung transplant was done in 1981 in Stanford, California. The first heart-lung transplant in Canada was done in 1983 in London, Ontario.

Where are lung transplants done in Canada?
The five transplant centres in Canada that do lung transplants are (from east to west):

<table>
<thead>
<tr>
<th>Location</th>
<th>Hospital Name</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Montreal, QC</td>
<td>Centre hospitalier de l’université de Montréal - Notre Dame</td>
<td><a href="http://www.chumtl.qc.ca">www.chumtl.qc.ca</a> (514) 890-8000 ext. 25387</td>
</tr>
<tr>
<td>Toronto, ON</td>
<td>Toronto General Hospital</td>
<td><a href="http://www.torontotransplant.org">www.torontotransplant.org</a> (416) 340-3131</td>
</tr>
<tr>
<td>Winnipeg, MB</td>
<td>Health Sciences Centre</td>
<td><a href="http://www.hsc.mb.ca">www.hsc.mb.ca</a> (204) 787-3661</td>
</tr>
<tr>
<td>Edmonton, AB</td>
<td>University of Alberta Hospital</td>
<td><a href="http://www.albertahealthservices.ca">www.albertahealthservices.ca</a> (780) 407-8822</td>
</tr>
<tr>
<td>Vancouver, BC</td>
<td>Vancouver General Hospital</td>
<td><a href="http://www.vch.ca">www.vch.ca</a> (604) 875-4111</td>
</tr>
</tbody>
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**The BC Transplant Society should be contacted for any questions about transplants in BC.**

**The details about lung transplantation can also be acquired at Heathlink: 1-866-408-5465.**

www.transplant.bc.ca (604) 877-2240
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.
How many lung transplants are done each year in Canada?
The number of transplants done each year varies depending on the number of donor lungs that become available.

In 2006, there were 129 double-lung transplants, 35 single-lung transplants, and six heart-lung transplants done in Canada. (Source: International Guidelines for the Selection of Lung Transplant Candidates: 2006 Update). Of those, 38 double-lung transplants, three heart-lung transplants and a living lobar lung transplant were done at the University of Alberta Hospital (Source: University of Alberta Annual Lung Transplants 1986-2006). These numbers are continuing to increase as more research is completed and the procedure is refined.

Where do most 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, however the rest of the organs are healthy. 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 serious head trauma or a sudden bleed inside the brain.
What is a living lobar lung transplant?
Lobes of a lung can also be donated by healthy individuals. This is known as a living lobar lung transplant. In this case, two different people with healthy lungs each donate a lower lobe of one of their lungs. The donor will lose approximately 20% of their lung function. This is not necessarily harmful unless the donor develops lung disease later in life. Living lobar lung transplants have advantages including a shorter wait time as well as a better match; however, due to the potential risks to the donor, this surgery is only performed as a last resort.

Living donor lung transplants are extremely complex and rare. The University of Alberta Hospital in Edmonton is one of only two centres in Canada and only a few world wide where living-lung transplants are done, the other is located in 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 the size of the donated lung(s). Lungs that are too large for you can sometimes be trimmed down. A good blood type match is important to reduce rejection, however age, gender, and race are not important.

How long is the surgery?
The average amount of time for a lung transplant (single or double) or heart-lung transplant surgery is 6-8 hours. A double-lung or heart-lung transplant may take longer especially if complications occur. 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 will vary from person to person. Most people are in the Intensive Care Unit (ICU) for a few days to a week and they remain in hospital for about three more weeks after that. The hospital stay may be longer if post-surgery complications, such as infection, occur.

After getting out of the hospital, you must remain in the area of the transplant centre for at least two more months (a minimum of three months total from the time of surgery). Your doctor will not allow you to go home until you are stable enough.

Who might need a lung transplant or a heart-lung transplant?
Transplant surgery may be considered when:

- a severe lung condition is continuing to progress and when all other available treatments and medications are no longer helping
- And your life expectancy is in the range of one to two years without a lung transplant
- And it could result in a better quality of life
There is a long list of diseases that may lead to a lung transplant (or heart-lung), but the most common diseases for which the surgery is done include:

- chronic obstructive pulmonary disease (COPD)
- idiopathic pulmonary fibrosis
- cystic fibrosis
- alpha-1 anti-trypsin deficiency
- primary pulmonary hypertension
- Eisenmenger’s syndrome
- sarcoidosis
- bronchiectasis

*see glossary of lung diseases for descriptions (at the end of this booklet)*

**Single-lung, double-lung or heart-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. The majority of lung transplants done in Canada are double-lung.

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.

The decision to transplant the heart and the lungs together (heart-lung transplant) depends on the underlying disease and whether or not the heart is healthy. This surgery is not done very often.
Who might not be able to have a lung transplant?
Your doctor should contact a transplant centre to determine your eligibility for a lung transplant. The information given here is from the 2006 international guidelines, but keep in mind that the guidelines may change with medical advances.

There are a number of reasons a person might not be eligible for a lung transplant and these are called absolute contraindications and they include (as of 2006):

- cancer (except some skin and lung cancers\(^*\)) within 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 can’t 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 (that is: family, friends, others to help)
- using tobacco, street drugs, or excess alcohol now or within the past six months

The main medications used to prevent rejection in lung transplants are prednisone, cyclosporine, tacrolimus, and mycophenolate mofetil. Your transplant physician will decide which medications you will need and will discuss possible side effects.
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 it will increase the length of life.

Other factors are called “relative contraindications” and they may or may not mean that you can’t have a lung transplant. If several of the following are present at the same time, transplanting a lung or heart-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) or very underweight
- **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

Your transplant doctor and other members of the transplant team will discuss how your condition and psychosocial situation might influence your eligibility for transplant.

(Source: International Guidelines for the Selection of Lung Transplant Candidates, 2006)

**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 the body. In the same way, your body will attack any donor organ that has been transplanted into your body because your body will recognize the new lung as foreign. This attack that the body launches 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.

Nearly every recipient has 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 very rare cases, the recipient may need to have another lung transplant.
What do anti-rejection medications do?
Anti-rejection medications lower your body's immune response so it won't attack the new organ. 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 medication can often be reduced to a lower maintenance level.

Do anti-rejection medications have side effects?
Yes - all medications have some side effects. There are several anti-rejection medications that could be prescribed and their side effects will differ depending on the medication. A side effect of all anti-rejection medications is the increased risk of infection because the immune system is lowered.

Some other serious side effects 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. Also, you may have to take antibiotics or anti-viral medications to prevent certain lung infections for a certain amount of time after the transplant.

How close do you have to be to the transplant centre when waiting?
Because lung tissue is very fragile, 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 be within a 2 ½ hour travel distance (by land or by air) of the transplant centre so you can get to the hospital quickly when the call comes. Sometimes the transplant team will request that you and your support person re-locate to the Edmonton area, especially if you live too far away to get to the hospital in time. Other reasons might include your need for frequent clinic appointments to monitor your health while you wait.

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 may choose to live close to the transplant centre.

How long is the waiting time for a transplant?
The time spent waiting for a transplant varies greatly from person to person, and centre to centre. Available donor lungs are assigned based on the best match to someone waiting for a transplant and how sick that candidate is at the time. If you and someone else on the list are both a good match to an available donor lung, whoever 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 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.

In 2003, the average wait time for those listed as Status 1 was 11 months and for those listed as Status 2, was 38 days. At the end of June 2006, there were 252 people on active waiting lists for lung transplants across Canada (Source: Canadian Organ Replacement Register).

Do people die while on the waiting list?
Unfortunately, there are people who will die while on the waiting list for a lung transplant. In 2006, 36 people died waiting for a lung transplant down from 43 in 2005.

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. As of the end of June 2006, 44 candidates who were previously on the active waiting list were placed “on-hold” due to some other medical complication (Source: Canadian Organ Replacement Register).
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.

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

According to data from the Canadian Institute for Health Information (CIHI) website, “the 3 year survival rate has jumped from 60% in 1996 to 80% in 2006”. Additionally, in 2002, 4.4 transplants per million population were performed in Canada, compared to 3.7 in the US. Canada has consistently kept pace with the US in Lung Transplantation, even surpassing them from 2000-2002 and again in 2004.

Is it possible for the original lung disease to affect the transplanted lung(s)?
It is not likely to happen, but the transplant specialists will let you know whether or not this could be possible depending on your disease.

88% survive the first 3 months
85% survive the 1st year
80% survive 3 years
60% survive 5 years

(According to the Canadian Institute of Health Information; Treatment of End-Stage Organ Failure in Canada 1996-2005, 2007 Annual Report Published on February 28, 2008)
If you smoke you must quit before you can be referred to the lung transplant program.
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 for the rest of your life.

In order to receive your transplant, you may be required to make large lifestyle changes. You must also be willing to accept the large financial costs. 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 you might need a lung transplant?
Your family doctor may be the first to consider the possibility of a lung transplant as a treatment option. Those suffering from severe lung disease generally have already met with a pulmonologist or 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 a lung transplant.

If you are a smoker, before your information is sent to the transplant centre by your specialist or your family doctor, you must quit smoking, this includes smokeless tobacco and marajuana. Drug or alcohol misuse will also prevent a person from being referred to the transplant centre.
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 and occupational therapist
- a respiratory therapist
- a nutritionist
- other specialists if needed

How would I get onto the waiting list?
The path to 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 determine if your medical history is consistent with what is required to become a candidate and to determine your commitment to the surgery. They need to be confident that you will follow through with your strict medication regime and continue to make healthy life choices after the surgery. This meeting will also provide you with an opportunity to meet your transplant doctors and to learn more about your specific surgery.

Write down your questions, before the first meeting, so you won’t forget what to ask.

“Assessment Stage”
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 it includes tests that check overall 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.

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. The transplant team requires that you have a family member and/or support person with you during this week.

You are required to have a support person with you through every stage of the process.
“The Decision Stage”
Once the tests have been completed and analysed the transplant team will determine if you are a suitable candidate, it may be several months between the tests and when it is determined you are a suitable candidate you will be asked to attend the six-week physio program and some time during the six-week period you would be added to the wait list.

You must be within a 2 ½ hour travel distance (by land or by air) of the University of Alberta Hospital while you are on the transplant waiting list.

Sometimes the transplant team will request that you make certain lifestyle changes before you can be placed on the list, this is for your own safety. Examples include dental work or optimizing weight.

The lung transplant surgery is physically demanding and it is critical that you be in your best possible physical condition for the surgery. Therefore it is extremely important that you continue your physical exercise after the six-week program until the surgery to ensure you stay in your best shape.

You could be on the waiting list for a long time, you must continue your exercise program for the entire time.

What must I do while waiting?
During the waiting time, you will be working at staying as healthy as possible. You will continue your exercise program, receive advice about your diet, and have frequent appointments at the transplant centre to monitor 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 assist with your personal care 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 people 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 one (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 if you are required to move closer to the transplant centre. You will need a support person or team during the entire waiting time and for around the clock care while you are an inpatient at the hospital. They will also be required to stay with you for the two months after surgery until you are stable enough to leave Edmonton.

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, there is a chance that you may not be added to the waiting list. A support person is essential to the success of a transplant, speak to the transplant team if this is a concern for you.
Having a lung transplant is a very expensive process. Although the cost of the surgery itself is covered, there are many costs that someone having this surgery must be prepared to pay for themselves. It is important for potential recipients to consider what their plan might be for funding these associated costs.

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 Alberta Health and Wellness/NWT Health and Social Services?**

For residents of Alberta, all the tests done in hospital, appointments with health care professionals, the surgery itself, and the stay in hospital after the surgery are paid for by the Provincewide Service program through Alberta Health and Wellness.

In Alberta, Provincewide Services also provides coverage for the cost of immunosuppression medications for recipients of organ transplant.

In the NWT, you must be eligible for extended health benefits in order to be considered for drug coverage.
What is not covered?
In Alberta, The Provincewide Service program pays for anti-rejection medications only. 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.

In the NWT, if you are a non aboriginal all your medications must be paid for by yourself, or by your extended benefits, if you are eligible, or your private insurance. You should contact your insurance company to determine which medications will be covered. If you are First Nations or Inuit then you will be covered by FNIHB benefits. Please call your local Health or Band office, or the regional FNIHB Office for more information.

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 and neither Alberta Health and Wellness nor NWT Health and Social Services covers this expense.

You will be required to purchase personal medical equipment (detailed in a later section). The cost for this equipment is not covered by Alberta Health and Wellness or NWT Health and Social Services.

Any costs to travel to and stay in a city where the transplant centre is located are not paid for by the provincial/territorial government. You will also require transportation to and from the hospital, as well as parking. You will be required to have a pager or cell phone on you at all times while you are on the waitlist so that you can be notified if a suitable organ has been found. This is not covered. You will require a long term support person and their potential lost wages will not be compensated by the program either. Speak to the social worker about yours and your support persons’ financial concerns.

Are there assistance programs available?
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 that is not provided by the provincial/territorial government (see below).

The First Nations and Inuit Non-Insured Health Benefits Program (FNIHB) covers medical travel expenses and prescription medications for eligible First Nations or 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 1-866-522-2122 www.vac-acc.gc.ca

The Lung Association, Alberta & NWT Lung Transplant Assistance Program provides a gift basket to those with the most dire need of financial support. This program provides some funding for necessities like accommodations and food. Transportation, parking, and driving costs may also be covered depending on need through this program. Applications are made on behalf of lung transplant recipients (or candidates) by the social worker through the Lung Transplant Services Department at the University of Alberta Hospital. 1-888-566-5864 www.ab.lung.ca
Federal government employees covered by the Public Service Care Plan should check with their human resources to check on medical travel benefits and medication coverage.

What expenses should I expect?
You will face some major expenses before, during, and after a lung transplant. If you do not reside in Edmonton or surrounding area you will likely have two homes to maintain post surgery and it is likely that neither you, nor your support person, will be working during the time spent in Edmonton. The length of the waiting period is impossible to predict, and if there are complications after the transplant, you may be living near the transplant centre for much longer than the usual 3 months post-surgery.

This section describes some of the major costs you should expect, but there are likely other smaller costs that will accumulate 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.

DATS is a public transportation system available to those who cannot use the Edmonton Transportation System. Once you have had your surgery you will be unable to use public transportation to prevent your exposure to infection (colds or viruses). This service is available to non-Edmonton residents who are living in Edmonton temporarily. For more information DATS can be contacted at (780) 496-4567 or www.edmonton.ca/transportation and follow the Facilities and Accessibility link to Accessibility & DATS link.

Assessment Phase and six week physiotherapy program
There is a week long assessment for all potential recipients at the University of Alberta Hospital Transplant Program. This is to ensure that you are a candidate. You will have a variety of tests and procedures and will also meet with a number of members of the transplant team for other interviews. Once the assessment is complete the team will meet to discuss your eligibility for lung transplant.

If you are thought to be a suitable candidate you will be required to participate in a six-week pre-transplant physiotherapy program in Edmonton. Those not living in the Edmonton area will have to travel to the city for this 6 week period. Methods of transportation will vary depending on the distance you are planning to travel, your medical condition, the length of your stay, and your financial situation.

If you do not have friends or family in the area, you and your support person will likely have to stay in a hotel or some other type of accommodation. You will likely eat out during the weeks of testing. Again, these are costs that will not be covered.

Most people choose to stay 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. Call the hotel directly and ask if they have any special rates. Some hotels close to the transplant centre may offer a discount to people travelling for medical tests. When you are in Edmonton for your assessment you will meet with the social worker who will also provide you with some information and resources related to your stay in the city.
During the Waiting Period and After Surgery

You must always be within two to three hours travel time (by land or air) of the 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 following the transplant. Most people choose to live close to the transplant hospital to make it easier to attend the daily appointments at the hospital. You may also feel more secure being within a short distance from the hospital during the waiting time should any other complications arise.

As a lung transplant candidate, you have to be very careful that you do not contract any lung infections before or after the surgery. The risk for infection is higher once the surgery is complete due to the anti-rejection medications. For this reason, the transplant centre specialists do not want you living in a place where you will be sharing space with a lot of people. Avoid public transportation (such as a bus, streetcar, subway) during this time for the same reason, DATS bus service is available in Edmonton and may be more appropriate for your situation.

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 in the university area. 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, and some places require you to sign a lease.
You will also be paying for groceries and other things such as electricity, phone, transportation, and other personal expenses. By living close to the hospital you may avoid the need for a car and related expenses.

If you require home oxygen before the surgery that is covered by a private health insurance plan or government plan you will need to ensure that your provider will be able to accommodate you in Edmonton. Contact your home oxygen provider for more information about costs and how to arrange to have the oxygen set up in another city.

You will be required to purchase;

- A device called a micro-spirometer that is used to monitor your lung function every day at home after the transplant. This devise is usually available from the lung transplant team at the University of Alberta Hospital at a cost of $600.00, 
- A MedicAlert bracelet at a cost of approximately $100.00 for the first year and $40.00 / yr after that, 
- A digital thermometer at a cost of approximately $20.00 
- A digital weigh scale at a cost of approximately $40.00 
- And a digital blood pressure cuff at a cost of approximately $100.00.

There is a possibility you may require other additional equipment. The cost for all of this equipment is not covered by Alberta Health and Wellness nor most health insurance plans.

Long term follow up after the transplant
You will remain in hospital for approximately one month following the transplant. During this time you will require a consistent support person(s). Assuming there are no complications during this one month period, you will be discharged from the hospital, and will need to remain in the Edmonton area for a minimum of two additional months. Once you are discharged and have gone home you will continue to come back to the transplant centre at varying times so that the team can ensure you are doing well. Frequency of clinic appointments will vary between patients.

Monthly bloodwork can be done at a local lab, but you may have some travel costs depending on where you live.
Lotsa Helping Hands - The Lung Association, Alberta & NWT, partners with Lotsa Helping Hands to provide a unique and easy way to create an online caregiving community, made up of friends and family, who lend a hand to a loved one during their time of need.

Using a private calendar, a person (the caregiver or other coordinator) can outline the activities you and your caregivers or family need help with on a daily or weekly basis. These activities can be anything from meal delivery to providing transportation and everything in between. The caregiving community members (your family, friends, and coworkers) then sign up to lend a hand for specific tasks. This feature is especially helpful if you have had to relocate. Community members can sign up to mow your lawn, water your plants or even shovel your sidewalk to mention just a few tasks that get left behind.

The calendar makes it easy to organize volunteers and keeps them informed. The program even sends out notification emails to remind community members about the tasks they have signed up for. One of the favorite tools is a private bulletin board to share news about your condition and for others to offer their thoughts and well wishes.

Website: www.ab.lung.ca/lung/lotsa-helping-hands
Internet Resources

Alberta Lung Transplant Program
http://www.albertahealthservices.ca/4932.htm

Alpha-1 Antitrypsin Deficiency Canada Inc.
www.alpha1canada.ca
1-888-669-4583

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

British Columbia Transplant Society
www.transplant.bc.ca

Canadian Association of Transplantation
www.transplant.ca

Canadian Blood Services
www.bloodservices.ca

Canadian Cystic Fibrosis Foundation
www.cysticfibrosis.ca

Canadian Health Network
www.canadian-health-network.ca

Canadian Lung Association
www.lung.ca

Canadian Life and Health Insurance Association Inc.
www.olhia.ca

Canadian MedicAlert™ Foundation
www.medicalert.ca

Canadian Organ Replacement Register (CORR)
www.cihi.ca/corr

Canadian Society of Transplantation
www.cst-transplant.ca

Hospital for Sick Children Pediatric Academic Multi-Organ Transplant Program
www.sickkids.on.ca

Kidney Foundation of Canada
www.kidney.ca

Living with Pulmonary Hypertension
www.livingwithph.ca

Organ and Tissue Donor Information - Saskatchewan
www.health.gov.sk.ca/organ-and-tissue-donor-information

Pulmonary Hypertension Association of Canada
Southern Alberta Chapter
www.phasab.webs.com

Second Wind Lung Transplant Association (American)
www.2ndwind.org

The Lung Association, Alberta & NWT
www.ab.lung.ca

Trafford Publishing (books on lung transplantation available to order)
www_TRAFFORD.com

Transplant Manitoba
www.transplantmanitoba.ca

TransWeb: All about Transplantation and Donation
www.transweb.org
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 19 and under who are in need of organ transplants.

**Assured Income for the Severly Handicapped (AISH)**
http://www.seniors.gov.ab.ca/AISH/
Edmonton: (780) 415-6300
Calgary: (403) 297-8511
Other areas: (780) 310-0000 (request phone number for your location)
This program provides health benefits to assist low income clients, their cohabiting partners and dependent children with expenses related to their health. The disability must severely limit the ability to earn a living and must be permanent. Be advised that this is a lengthy process to determine eligibility.

**Alberta Works**
Edmonton: (780) 644-5135  
Other areas: 1-866-644-5135
The goals of Alberta Works are to help unemployed people find and keep jobs and help Albertans with low incomes cover their basic costs of living. You may qualify for additional money to help cover your travel expenses while attending the clinics or participating in physiotherapy.

**Canada Pension Disability**
www.servicecanada.gc.ca  
1-800-277-9914
The CPP Disability program’s primary role is to replace a portion of income for CPP contributors who cannot work because of a disability that is both severe and prolonged. The application takes three to six months to process and there is a requirement of medical documentation to support your claim.
Funding Uncovered 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. Don’t wait until the bills start piling up—ask for advice before you run into money problems. This section provides some general suggestions, but you should always ask an expert for advice about your personal situation.

Building a Budget

During the initial assessment you will meet with a social worker who will review with you the various means of funding that are available to you. You will then need to build a budget, this will help you better communicate to your fundraisers what kind of support you will need. This will also help you organize your finances so you won’t have any costly surprises.

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 options 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 current house 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 away on the waitlist. Although becoming a landlord may add extra stress to your life, it may dramatically help your financial situation. You should speak to a real estate professional, lawyer, or accountant to discuss these options.
Fundraising

Ask for help: There are many creative ways to fundraise, but not every idea will be successful in your community. Family and friends are usually more than willing to help with 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, and 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 licence 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 their time and the materials to make craft projects that 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 with a brief notice posted nearby that explains 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 consult their tax advisor regarding rules and regulations concerning this type of donation/fundraising.

A lottery licence or permit is needed for fundraising events that involve games with prizes (for example: bingo, raffles, Monte Carlo nights, etc.) and the maximum prize values may be limited by government rules. This type of permit or licence is only available to religious or charitable groups and fairs or exhibitions- so contact a service club or church for help in getting one of these permits/licences. Other large fundraising events may require a permit as well. For information on licencing contact the Alberta Gaming and Liquor Commission www.aglc.ab.ca

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 charitable organizations you may want to try include Lion’s Club, Rotary Club, Kinsmen Club, Shriners, Knights of Columbus, and Kiwanis Club, Royal Canadian Legions, Local Media Good Neighbor Club, among others.

Friends and Family: Your friends and family may organize a fundraising event or they may be able to help you financially. 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 could do a story about you to help 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.
Travel
Hope Air is a charitable organization with a mission “to help Canadians in financial need fly to necessary medical treatment”. You must be a Canadian citizen or landed immigrant, living in Canada, have a scheduled appointment for non-emergency medical treatment, and be able to demonstrate that you are in need of financial assistance. This program may also cover an escort if it is deemed medically necessary or if the client is 18 years or younger. Application can be made on-line or via telephone. Telephone: 1-877-346-4673 Call 9 to 5 EST 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®, President’s Choice PC® Points, Via Rail Preference Points™, etc. Even if you do not participate in a rewards program your family or friends can share their points with you in several rewards programs. It may be an opportunity for family members to provide support who could not otherwise provide financial or physical support. 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 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 two 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 can’t 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.

**PC Points®**: www.pcpoints.ca 1-866-727-6468
The cardholder can use points for their own travel or to get a ticket for someone else. Points can’t be transferred directly to another person’s account. Other rewards are available.

**Via Rail Preference Points™**: 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 can’t be transferred to another person’s account. Gift cards for travel can be purchased.
When booking a flight, you will need to give them the following information:

- your name, date of birth, address, telephone number, and email (if possible)
- your escort’s name, address, telephone number, and email (if possible)
- reason for travel and type of illness
- date, time, place and length of stay for medical appointment or treatment
- name, telephone and fax numbers of the referring transplant program/doctor (and email if possible)
- name, telephone and fax numbers of the treating doctor (and email if possible)
- details of any special needs (e.g. wheelchair, oxygen)
- your weight and your escort’s weight (not needed if flying with a commercial airline)
- telephone number where you will be staying during the medical treatment
- gross family income
Employment Insurance Compassionate Care Benefits—
for caregivers
A person may be eligible for Employment Insurance Compassionate Care Benefits if they must be away from work to provide care or support to a very ill family member who is at risk of dying within 26 weeks. Unemployed persons receiving Employment Insurance can also ask for these benefits. The benefits are paid for a maximum of six 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.

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 you may need to gather or save specific receipts or paperwork and that more than one year’s tax return will be affected.

To contact the Canada Revenue Agency (CRA) at www.cra-arc.gc.ca or check the Government Blue Pages of your telephone book under “Taxes.”
Allowable Medical Expenses

Expenses that you have 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 if your health insurance plan has or will reimburse you for them.

You may be able to claim costs you pay to travel to somewhere else for medical treatment that is not available where you live. There are two ways to do this:

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 drove for an entire 12-month period and how many kilometres you drove during that time specifically to get medical treatment. You have to keep receipts and records for all expenses related to your vehicle during the 12-month period. These expenses include fuel, oil, tires, licence fees, insurance, and maintenance and repair.

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

- all payments for medical professionals, hospitals, and prescriptions that are not covered or not paid for by a Health Services Plan
- the premiums paid under a Health Services Plan (may include the premiums for a private health insurance plan)
- 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 the home because of your health or disability

Disability Tax Credit

You may qualify for the Disability Tax Credit during your recovery from transplant surgery. You can obtain this credit by asking your physician to complete Form T2201 and then simply file it with your income tax return. If your impairment is permanent, it is not necessary to file a T2201 yearly.
This should be discussed thoroughly with your professional tax advisor, since 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 the disability tax credit.

**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. Quite 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 what is called a “pre-existing condition”. Coverage for medications and other services that you already use may be very difficult to get in this case. Alberta Blue Cross is available to all Albertan’s even those with a pre-existing medical condition. There is a three month wait for all new application approvals. Call Blue Cross for more details.
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 placed in a position of trying to guess what heroic measures or end-of-life care you would want while they are 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 about CPR, which is an attempt to restore breathing or heart function, or both. Basic CPR includes artificial breathing and chest compressions.

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 the centre of the chest to compress 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 and damage could be done to the teeth and windpipe 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 Resuscitate” order placed in their chart so that if their heart or breathing stops, no CPR will be done. Sometimes this order states exactly what actions the health care team should or should not take - for example: no chest compressions; only give medications; defibrillation only (electric shocks for the heart); do not intubate (put a breathing tube in), etc.

You may be asked if you would like this order (or some variation) to be put in your chart. This order does not affect the care you will receive. It only takes affect if you stop breathing or your heart stops beating on it’s own. Talk about this with your loved ones and ask your doctor to explain CPR, and anything you are unclear 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

You will be on life support immediately after surgery to temporarily support your body’s functions while you are recovering from this major surgery. If you develop a life-threatening condition that is no longer treatable, starting or continuing life support may not be appropriate.

You may want to ask your doctor or other health care professional 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 (those younger than 18). When someone dies without a Will in Alberta or the NWT, a court appoints 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 make up the papers to make sure their wishes are clear.

Enduring Power of Attorney
A written document called an Enduring Power of Attorney (EPOA) gives someone the authority (or power) to manage your property and finances on your behalf if you are not able to do so because of illness, disability, or mental incompetence. An EPOA may be written to give general or specific powers. You may need an EPOA to allow someone to take care of your affairs, such as ensuring your bills get paid, especially if it takes longer than expected for you to recover. You may wish to speak to either your banking institution or a lawyer to seek support in drafting an EPOA.

Personal Directive
This written document gives someone the power to make some or all decisions specifically related to your personal and/or health care if you are unable to do so. A personal directive does not cover property or finances. Personal care may include health care, consent to medical treatment, nutrition, shelter, and personal safety.

In Alberta a personal directive is a legal document that can be drafted without the assistance of a lawyer. If you would like further information on personal directives you can speak with The Office of the Public Guardian (Tel: 1-877-427-4525) or your transplant social worker. Legislation is online at www.qp.gov.ab.ca.

A “Do not resuscitate” order does not affect the care you will receive.
Alpha-1 Anti-Trypsin Deficiency
This is a genetic condition. Alpha-1 anti-trypsin (AAT) is a protective protein in the lungs which controls a natural enzyme called elastase. 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, causing COPD.

Bronchiectasis
This is a chronic disease which damages the walls of the airways and causes the airways 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.

Bronchioalveolar Cell Cancer
Bronchioalveolar cell cancer (BAC) is a relatively rare type of lung cancer that develops in mucus-producing cells of the bronchioles (very small airways) and alveoli. It spreads along the tissue that separate the alveoli, but it tends not to spread outside the lungs. This type of cancer causes a very large amount of watery mucus to be produced. Between 2% and 6% of primary lung cancers are BAC.

Chronic Bronchitis
People with chronic bronchitis have swollen airways that regularly produce large amounts of sticky mucus which blocks the airways. This disease 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. Chronic Bronchitis and Emphysema are forms of COPD. COPD is mostly caused by smoking, but it can also be caused by second-hand smoke, exposure to certain dusts and chemicals, or by alpha-1 anti-trypsin 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. The mucus blocks the ducts of the pancreas, making 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 then backs up into the lungs where it damages the blood vessels that supply the lungs, causing a high pressure to build up in these vessels. This high pressure is called pulmonary hypertension. The high blood pressure in the vessels of the lungs then causes heart failure to develop.

Emphysema

Emphysema is a form of COPD. The air sacs 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 anti-trypsin deficiency.

Pulmonary Fibrosis

Pulmonary fibrosis is a lung condition where the tissue between the 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 air sacs into the blood. Pulmonary fibrosis can be caused by other diseases that affect the lungs, inhaling asbestos or silica dust, and by certain medications. Often the cause is not known—this type of pulmonary fibrosis is called “idiopathic”.

Pulmonary Hypertension (PH)

Pulmonary hypertension (PH) is high blood pressure within the vessels that supply the lungs with blood (called pulmonary arteries). There are two types of pulmonary hypertension—primary and secondary. Primary PH develops for unknown reasons and it is much less common than secondary PH, which develops because of another problem or disease within the heart or lungs.

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 functions. 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.
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 or relocate to Edmonton 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
- Let provincial/territorial health care plan know when I move to Alberta 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 my home 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 check-up 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 home.
- 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 Alberta Blue Cross?
  - Alberta 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 the transplant.
- Find out about the disability tax credit.

**Legal Issues**
- Make an Enduring Power of Attorney & Personal Directive
- 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.

**Other Health-Related Concerns**
- Discuss my wishes with family and the person holding my Personal Directive
- Discuss any concerns or questions I have with family doctor, respiriologist, and/or members of the transplant team.
- Write down my questions before any appointments to make it easier 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 setup in apartment in my new location and during travel.
- Bring two or three 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 Lung Association, Alberta & NWT).
Acknowledgements

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We are pleased to offer you this complimentary copy of the Lung Transplant Handbook.

It is only through generous donations from the public that we are able to provide lung health resources.

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