

Catch Your Breath!

A guide to lung transplant for
families and support people

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Introduction

You are embarking on a unique journey as a support person and caregiver for a lung transplant patient. We hope that this guide will help you along the way. This guide is the result of many conversations with and comments from many support people of lung transplant patients. It provides suggestions and information to help you get through the next period in your life. It is not intended to repeat the information provided in the patient's own transplant manual. This booklet is meant to address issues specific to your needs. Please also refer to the patient's own manual. This may answer other questions about the patient's experience. Most of all, we want to thank you for being a support person. You are a vital part of the process for lung transplant.

As a caregiver you have the right to:

- Acknowledge your feelings
- Recognize your limits of endurance and strength
- Take time out to learn caregiving skills and seek out accurate information
- Ask for help
- Receive appreciation and emotional support
- Take time out for your own health, spirit and relationships
- Provide care at home as long as you are able but remember, no one can be a caregiver forever
- Access available services that aid in caring
- Take pride in your accomplishments and applaud your courage
- Take care of yourself; this is not a selfish act
- Protect your individuality/identity
- **LAUGH!**

(Veterans Affairs Canada

<http://www.vac-acc.gc.ca/clients/sub.cfm?source=health/caregiving>)



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“My husband may have gotten the lungs, but we both got the transplant”

*- K. Keegan-Smith,
Lung Transplant support person*



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Who is a Support Person?

- At least one support person must be involved in the transplant patient's care. Often this person is the husband, wife, or parent of the patient.
- Other people can also take on caregiving roles for the patient or to help you. They may include brothers, sisters, parents, children and other relatives and friends. What they have in common is a relationship with the patient or yourself and a willingness to help.
- Some people may bring the patient to appointments or help care for them at home. Others may spend time with you or provide various forms of help, such as cooking meals or visiting.

Why is a support person needed?

- All lung transplant patients require a support person. The underlying lung disease progresses while waiting for the transplant and they cannot take care of themselves safely.
- A support person provides help with day-to-day tasks such as cooking, cleaning, and transportation to hospital appointments. This carries on for several months after the transplant until the patient is well enough to do these things on their own.
- The support person also provides emotional support and friendship. Everyone needs emotional support as they proceed along this transplant journey. Even support people need emotional support. This is addressed later in this booklet.
- As the support person, you are in a good position to notice changes in the patient's condition. Please bring these observations to the attention of the transplant team.
- Be an advocate. Ask the team to explain what is happening and any treatments and investigations the patient is having. Talk to the health care team about the patient's state of mind and level of comfort.

“There will always be more questions, no matter how prepared you think you are; the reality only sinks in when it happens and you learn to deal with the situation on a day-to-day basis.”

- J. Curtis, Lung Transplant support person





Taking Care of Yourself

- It is important to take care of yourself so that you can be at your best. Transplant is a marathon, not a sprint. Marathon runners get regular refreshment stops. You need these refreshment stops as well. You need to learn how to manage your energy and resources in order to go the long distance.
- You may experience many emotions. This could include feelings of isolation and loneliness, and an increased sense of responsibility as you care for a sick person. You may have fears about the future as you watch the patient becoming sicker.
- You may feel that your own life is on “hold”. This may leave you frustrated or angry and yet also feeling guilty for feeling this way. Many support people describe putting themselves last in many ways – sleeping, eating, and getting help for themselves – in order to care for the patient. From our experience, this does not work. The patient needs you to be healthy and whole.

How to take care of yourself

Some tips that may help:

- **Set up a support system for yourself.**
Think about who you can reach out to and rely on. Then look at this list and think about who is best able to provide practical help and who is best at giving emotional support. This can include family, friends, clergy, support groups, or professional counseling. Tell them what is most helpful to you and what you need from them. Support people who are able to receive help and support may be more able to find relief, increased strength, and sources of happiness.
- **Delegate tasks and accept help from others.**
Family and friends often want to help but are uncertain what would be most appreciated. They need to know that giving small things such as phone calls, taking you out for coffee, offering help with errands, giving a few hours of help or sharing a joke can be of help.

- **Create a communication system to update people.**
This will help reduce interruptions and help conserve your energy. This is addressed in more detail later on.
- **Keep track of medical information.**
This can help reduce confusion when meeting new individuals from various health care teams. Names, numbers, instructions, and questions can easily be recorded and helpful in future meetings. See the section on information management later on in this book.
- **Keep your own personal diary or journal.**
Write down your feelings – the “good”, the “bad”, and the “ugly”. Putting your feelings on paper is a powerful tool to decrease stress. Writing or journaling is not for everyone but give it a try.
- **Take time for yourself.**
Every support person needs some time to themselves. Include 10-15 minutes in your schedule each day for yourself – a walk, visiting with or phoning friends, or getting outside. This can re-energize your spirit. An alternate support person may need to be available to help out at this time.
- **Take it one step at a time.**
Focus on the present – one day, one hour, one moment – and measure progress in small steps. The unexpected can happen. Complications occur, which slows down recovery. There may be delays, setbacks, and surprises. Focus on what is important and what really matters. Try to maintain a positive outlook. Try not to get carried away with worrying about the future.
- **Plan for a journey.**
Caregiving carries on long after the patient leaves the hospital. Receiving the transplant is only the next step in the journey. Caregiving changes in the post-transplant period but it may be months before the patient is able to manage on their own.

“The best bridge between despair and hope is a good night’s sleep.”

-H. Ruby, Performer

Sleep

Despite the worry and stress that comes with the transplant it is important to make sure that you are getting enough sleep. People are at their best when they sleep about 8 hours every night. Sleep has many benefits. Among other things it improves your mood, mental alertness, energy, and well-being. Ways to promote sleep: Allow at least 1 hour to unwind before bed.

- Warm milk helps.
- Take a warm shower or bath before bed.
- Use relaxation techniques such as meditation, visualization, gentle stretching, and deep breathing to reduce muscle tension.
- Try to establish a bedtime routine and go to bed at the same time each night.
- Go to bed only when you feel tired. If you can’t fall asleep within 30 minutes, get up and do something relaxing until you feel drowsy.
- Make sure your bed and bedroom are quiet and comfortable.
- Exercise regularly, but not right before bed.
- Avoid taking naps, especially late in the day.
- Avoid caffeine, nicotine, alcohol, and heavy, spicy, or sugary food several hours before bed.
- Get plenty of morning sunlight; this helps regulate your sleep-wake cycle.

If you have difficulty falling or staying asleep, after trying these suggestions please see your family doctor or contact the Transplant Psychiatry Team. You may benefit from training in special relaxation methods or short-term medication.

Sometimes, sounds from the patient's oxygen tanks, coughing and breathing may keep you awake. If the patient cannot sleep, this may also disturb your sleep. Talk with the transplant team and they will try to improve the patient's sleep.

“A good laugh and a long sleep are the best cures in the doctor's book.”

~Irish Proverb

Healthy Eating for the Support Person

It is important to stay healthy while supporting your loved one through the transplant process. A healthy diet will help with your overall energy levels and health status. Eat regularly; eat nutritiously; drink plenty of water. The Canada Food Guide lists four food groups:

1. Fruit and Vegetables
2. Breads and Cereals
3. Milk and Milk Products
4. Meat and Alternatives.

Here are some tips recommended by Health Canada

- Eat at least one dark green vegetable each day (broccoli, romaine lettuce and spinach are some examples).
- Eat as least one orange vegetable each day (carrots, sweet potatoes, and winter squash are some examples).

- Have vegetables and fruit more often than juice
- Make at least half of your grain products whole grain each day (whole grain breads, oatmeal or whole wheat pasta are some examples).
- Choose grain products that are lower in fat, sugar, or salt (compare the Nutrition Facts table on the label).
- Drink skim, 1%, or 2% milk each day.
- Select lower fat milk alternatives (yogurt, cheeses, compare the Nutrition Facts table on the label).
- Try meat alternatives such as beans, lentils, and tofu.
- Eat at least two Food Guide servings of fish each week (salmon, trout and others).
- Select lean meat and alternatives prepared with little or no added fat and salt.

Smoking

- Smoking near someone with lung disease can be damaging to their health, as well as your own.
- Do not smoke while oxygen is in use.
- Quitting smoking will go a long way to support the transplant patient.
- Do not smoke inside the house, apartment, or car.
- Assistance with quitting smoking is available. Please speak with a member of the transplant program.

Infections

- Infection is a risk for patients waiting for their transplant and for patients who are immunosuppressed following the transplant. As the support person, you can take steps to control the risk of infection. Good hand washing is the **BEST** way to prevent the spread of infection. Hand washing requires soap and water, rubbing together for at least 15-20 seconds (sing yourself the “Happy Birthday” song). Don’t forget the backs of your hands too.
- Always wash your hands when returning to the patient after doing other activities.
- Wash your hands frequently, especially after using the bathroom, before preparing and eating food, and coming in from outdoors. Handwashing is especially important if someone in the home is sick.
- Antiseptic gel (such as Purell™) is an effective cleaner. This type of product can be bought at all major stores.
- Antiseptic gel can easily be placed near the door for visitors to clean their hands on arrival. Ask all family members and visitors to wash their hands on entering the home.
- Use paper towels instead of sharing hand towels, especially with visitors.
- Teach children to wash their hands frequently, especially before meals and when coming home from school or an outside activity.
- People in the home with a “cold” or the “flu” need to maintain a distance of at least one meter (just over 3 feet) from the transplant patient. Visitors who are sick with a cold or the flu should stay away until feeling better.
- Avoid close face-to-face contact with someone who is obviously sick, such as no hugs or kisses. Sleep in separate beds for the period of the illness.
- Get a flu shot every year in the fall. All family members living in the home, and others, who are frequent visitors, should also get the flu shot.

Intimacy

- There can be changes in a relationship when you take on care-giving responsibilities including changes in romance, affection, physical intimacy, and communication.
- Patients may experience changes in sexual function and desire due to medication side effects, fatigue, and physical problems.
- Birth control and safe sex practices need to be considered.
- Love and intimacy is not just expressed sexually, but in everything you do for your loved one, including emotional support and tending to their needs.
- Givers and receivers of care both need emotional support. Hugging, touching, holding, and kissing are ways of expressing this support.
- Sexual intimacy can be expressed in many ways and helps with feelings of closeness, comfort, connection, and pleasure.
- Be flexible in showing affection and being intimate with your partner.
- Touch can convey compassion, reassurance, safety, love, and provide relaxation. Touch creates a connection and eliminates feelings that the patient is fragile or undesirable.
- Communicate with your loved one and discuss ways to feel pleasure and be intimate.
- It is possible for you and your partner to have a healthy sex life after transplant.
- Please feel free to discuss these issues with the transplant team.
- Do small things each day with great love.

“Balance is the key to success. Always remember to think about today. You cannot control what happened yesterday or what will happen tomorrow but you can control what you do today.”

- T. Bolden, RN





The Transplant Team

The transplant team is available to provide you with guidance. You will be involved with the following people most often:

- **Transplant Coordinator:** The coordinator can advise you and the patient regarding any medically related issues.
- **Social Worker:** The social worker can provide advice on issues related to housing, finances, fund raising, drug related costs and government programs. **-Psychiatric Nurse Coordinator:** The transplant team is aware that being a support person can be a very challenging experience. The psychiatric nurse coordinator is able to assist you in getting the help you need.
- **Physiotherapists:** A regular scheduled exercise program helps the team monitor the patient. You will also be involved in the monitoring of their progress

Other members of the Transplant team include:

- Respirologists (Chest doctors)
- Surgeons
- Other medical specialists in areas related to transplant
- Advanced practice nurses/Nurse Practitioners
- Nutritionists
- Research coordinators
- Doctors, nurses, and other health care providers in training

You will have contact with a variety of members from the transplant team at different times in the transplant process. Keeping a record of the people you meet and their roles will help reduce anxiety as you become familiar with new faces.



Transition from a Pediatric Program

- Pediatric patients move from the Hospital for Sick Children (Sick Kids) to the adult transplant program at the Toronto General Hospital when they are 18 years old.
- As the young adult moves over to the new program they will be become more independent in their care. You may need to take on a more supportive role and less of a directive role. Transition is a process that takes time over several weeks or months.
- Leaving the close-knit program of Sick Kids can be difficult. Getting to know a whole new team at the Toronto General Hospital may take time. A transition process is set up between Sick Kids and the Toronto General Hospital to ease you through this process.
- The transplant coordinator is available to answer any of your questions.





When Relocation is Required

- Support people and patients who have to move from their homes to be closer to the hospital face a major change in their lifestyle. It is not easy to leave the familiar comforts of your home, family, and friends. Some people must also give up jobs and accept changes in family finances.
- During the assessment you and the patient meet with the transplant social worker to discuss relocation. The Social Worker will provide you with information to help with this process.
- Once you are here, you will find that there are other families such as yourself. You will meet other support people in the treadmill room, at the support group, and in the clinic.

Details to consider:

- **Who can help out with the planning?**

A social worker in your own community or through social services may be available. Family members may be able to help out with certain tasks.

- **Finances.**

The Transplant Social Worker will be able to provide you with some guidelines regarding some of the costs of relocation. Patients and their families often need to do some fundraising to help with these costs.

- **Where to live?**

You will be provided with a list of housing in the downtown Toronto region when you come for the assessment. Other useful sources include the Toronto Star classified ads (<http://www.thestar.com>) and Craig's list (<http://toronto.craigslist.ca/>).

- **Transportation.**

A car may be necessary if you plan on living outside the downtown area. Your driver must also be comfortable driving within the city.

Public transportation is a cheaper and sometimes easier way for you to travel. It may not be the best choice for the patient to use public transit because of access problems and infection risk. Local Toronto bus, streetcar and subway information is available at <http://www.toronto.ca/ttc/>

GO Train service information can be found at: <http://www.gotransit.com/>

Taxi may be an alternate choice if you do not have a car with you. You can enquire from cab companies about setting up accounts and a regular schedule of trips.

- **Arrangements to make before leaving home.**

Please refer to the relocation checklist provided by the Transplant Social Worker. If the patient is from another province, the Ministry of Health in your home province needs to be notified of your plans to relocate.

Medication and oxygen. It is very important that the medication and oxygen coverage is sorted out before leaving home. Please bring three months of medications for the patient when you relocate.

Dental Health: You and the patient should have a check up and cleaning with your dentist before leaving home. Dental follow-up in Toronto can be arranged through the transplant office if needed.

Banking and bill payments. The more you have organized in advance, such as on-line banking or automatic bill payments, the simpler it will be to manage when you move. Contact your local bank and billing agencies before you leave home to cancel unneeded services while you are away from home. Support is readily available through many sources. Please ask your transplant coordinator or social worker.



Information Management

- You may be the keeper of the patient's medical information. Remember to update the information regularly and carry it with you. Get business cards from the members of the transplant team.
 - Names and phone numbers of doctors, Transplant team members
 - Hospital admissions
 - Medications lists
- Keeping the information all located in one central place will mean that you can find this information easily. Get a notebook.
- Another way of keeping information organized is by using the patient passport which can be found on the following web site: <http://www.sickkids.on.ca/myhealthpassport/>
- Once the patient is listed, there will be several appointments in the first few months. Get a calendar so that you can organize this information in a clear manner.
- After the transplant, the routine changes. The first few months are the most demanding. Again, use a calendar so that you can organize this information in a clear manner.
- Please remind the patient to bring a list of all their medications with them to every appointment at the hospital.



Communication and Updates

During the transplant process it will be important to keep family and friends updated. There are ways to make communicating easier.

Have a plan. Provide family and friends with a way to receive information. It can be time consuming, tiring and even upsetting to have to repeat the same information many times.

- Designate a contact person. This person can be responsible for keeping everyone informed. This will also reduce the number of interrupting calls to you and the hospital.
- Use e-mail to keep family and friends up-to-date. This is a cost-effective and quick way to inform others of patient progress and changes. There is a computer for public use in the ICU waiting area on the 10th floor.
- Some families place messages on their voice mail so that people can phone in and listen to the update.
- CarePages are private, personalized Web pages provided to you as a free service by Toronto General Hospital. CarePages are secure, password protected and follow patient privacy rules.
- CarePages lets you:
 - Share information automatically every time you post a message.
 - Keep in touch before, during, and after the transplant.
 - Post messages about the patient's progress. Concerned family and friends can access the most recent news about the patient.
 - Friends and family may post messages at anytime, from anywhere. They can share words of support and encouragement.
 - Share patient information. The personal and secure CarePages contains important contact information and visiting hours.
 - Post photographs. Create a photo gallery to share with family and friends.

Ask your Social Worker or Transplant Coordinator about CarePages.



Physiotherapy

How to manage with Oxygen

- Oxygen is a drug which is prescribed by a doctor. A prescription is provided for various levels of activity such as sleeping, sitting, day-to-day activities, and exercise.
- The physiotherapists and the doctors will evaluate their oxygen needs regularly. If you have concerns about the patient's oxygen needs please talk to the transplant team. Do not adjust the settings on your own.
- Always make sure you have enough oxygen when you leave the house and for your trip to and from the hospital.
- If you have questions about ongoing maintenance of equipment or safety issues please talk to your home oxygen company. They should provide you with all of the supplies required to deliver the oxygen prescription provided by the transplant team.
- The most common oxygen delivery system in the home is the concentrator.
- Patients may have portable oxygen tanks for use outside the house. These carry either liquid oxygen or compressed gas in cylinders. We recommend that patients switch to liquid oxygen once they are listed. These type of tanks can be refilled when needed while at the hospital. Compressed gas cylinders (metal cylinders) cannot be refilled at Toronto General Hospital.
- Portable liquid oxygen tanks can be filled at the Toronto General Hospital:
 - Transplant assessment office 8:00 AM to 5:00 PM. (Room 12C-1217, NCSB)
 - Treadmill Room 9:00 AM to 4:00 PM. (Closed for lunch from 12:00 to 1:00 PM). (Room 12C-1376, NCSB)
 - After hours on the Respiriology floor (10 Eaton South by the EAST elevators). Ask at the desk.

Shortness of breath: If your family member is feeling short of breath, please do the following:

- Check to see if there are problems with the flow of oxygen.
 - is the hose attached?
 - is the oxygen tank turned on?
 - is the oxygen flow on the correct setting?
 - is there adequate oxygen in the tank?
 - is the oxygen coming out of the tank (or is it frozen)?

If necessary switch to a different tank. Have extra oxygen tubing or mask available.

- Some symptoms of too little oxygen can include:
 - confusion
 - shortness of breath and/or fast breathing
 - blue lips/fingers
 - flared nostrils
 - wheezing
 - grunting while exhaling
 - sweating
 - cool clammy skin
 - difficulty speaking a full sentence

Please call the Transplant Coordinator or speak with the physiotherapists so the patient can be evaluated.

IN CASE OF EMERGENCY DIAL 911

Pre-transplant Exercise Program

- Exercise is an important part of the patient's life before and after lung transplantation.
- Research and experience has shown that patients who are waiting for a lung transplant will benefit from regular exercise.
- It will be important for you to provide emotional support and reassurance throughout this experience.
- The physiotherapists will work with each patient to develop a program suited to his or her abilities and level of health. Exercise can help the body's ability to work at a better level within the limitations of the lung disease.
- It is important that the patient or support people let the physiotherapist know about changes in physical ability or general health. The physiotherapists meet regularly with the medical team to ensure that they are aware of any changes in each patient's health.
- In the treadmill room we welcome your assistance in guiding the patient through their program. Please let us know if you would like to help.
- It is also okay to drop off the patient and take some time to yourself to get a coffee or read a book.



Post transplant Exercise Program

- After the lung transplant, the physiotherapy team assesses the needs of each patient throughout their hospital stay. This begins in the ICU and continues on the transplant unit.
- Remember, the recovery phase will be different for each patient.
- You can also help by reinforcing the exercises that the physiotherapist has prescribed.
- Your help may be needed just as much by the patient once they return to the treadmill room immediately after the transplant. It will take time for them to regain their strength and independence.
- Please let us know if you have any questions or concerns about the exercise program.
- Throughout the exercise program, you can help by cleaning the equipment and handling the weights. It is also important to provide encouragement to other patients.
- It is in the treadmill room where friendships with other support people are made. Strength and comfort can be drawn from these relationships.

“It’s hard to understand the world from your armchair.”

~ Jeff Davison





Lung Transplant Support Group

- The group meets once a week at the Toronto General Hospital. It includes both patients and support people.
- A member of the transplant team leads the group. Guest speakers from the lung transplant team and other areas of the hospital are sometimes invited to speak to the group and answer questions. Other times, it will be a general discussion with patients and other support people.
- The group can help prepare support people to understand what to expect at the time of the transplant and during the recovery.
- The group provides the chance for support people to meet each other, develop important friendships, and share experiences.
- The group hosts social events such as a Christmas party, special recognition events, and other social activities.
- The group helps patients and support people to know that they are not alone.
- A schedule of meeting dates is available in the treadmill room.





Drug Coverage

- Transplant patients require life-long medications. This is discussed during the assessment.
- It is important for all patients to research their individual drug coverage situation. If a person is unable to do this, you may need to get involved to help them sort this out.
- The transplant social worker or the assessment coordinator can give you further guidance.
- Ontario residents under the age of 65 are required to apply to the Trillium Drug program even if they have private insurance.
- All out-of-province patients are asked to get their drug coverage sorted out in advance of moving to Toronto.
- On arrival, out-of-province patients and families are asked to meet with the pharmacist at the Toronto General Hospital outpatient pharmacy, to review their drug coverage before the transplant.
- For further information on drug coverage by home province you can check the following: <http://drugcoverage.ca/>



The logo features a stylized, circular arrangement of three overlapping leaf-like shapes in shades of green and yellow, positioned to the left of the title text.

The Family

Patients and support people who have young children are often concerned about the best way to help them. They wonder about how much to tell the children, how to protect them, and avoid frightening them.

The team's social worker is available to meet with you. They will discuss your individual situation and help you develop plans to support you and your children. There are other sources of help in the community, such as school counselors.

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

Managing Changes

- **Maintain Routines:** It is ideal to try to maintain children's routines as much as possible. Attempt to continue to eat, sleep, play, and live as normally as possible. Changes are going to happen, especially if relocation is required, but your family will handle changes best if routines can be continued.
- **Be Honest:** Children will sense that something significant is happening in your family. Be honest at their level.
- **Include The Whole Family:** Once the adults have discussed issues involving the whole family, children should be included in planning, when appropriate. Talk to children about how family life might change. Get their ideas on how to help. Try to include each family member in every step.
- **Have a Plan:** If you move the family, how will young children be cared for before the transplant, during hospitalization and recovery? It can be unfair to you and the children to expect to include them in all hospital trips.

- **Be Well:** Review each person's health, such as teeth, eyes, and yearly physical, before relocating (if applicable). Appointments are easier to arrange in your hometown and children will be more relaxed with doctors they know.

What Children Should Know

- Their parent or sibling will have been unwell for a time, but children must understand this next phase. Use pictures, examples, and simple terms to explain the sick person's condition and why the transplant is necessary.
- Reassure children that they are not to blame for the illness or the transplant.
- Discuss how family life will be affected. Will family members be moving? Will children live with someone else or move with the family? Will the home be sold or rented? Who will care for them? How will you keep in touch?
- Discuss the idea of organ donation and transplantation – how it happens, why there is a waiting time and possible outcome.
- Prepare the child for the first hospital visit after transplant. You and the patient may want to decide beforehand if the child should visit in ICU or wait until the patient is feeling better.
- It is important to talk about what the child will see — the room, equipment used, how the patient will look and whether the patient can speak. Also describe what they will hear such as machines, sounds from other patients and basic medical terms.
- Give children clear guidelines about behavior in the hospital setting. Teach the need for quiet and privacy.
- Prepare children not to expect immediate recovery. The patient is not instantly healthy

Remember that you cannot put everyone's life on hold – you must still live while you wait!

“We can do no great things, only small things with great love”.

~Mother Teresa





Managing Stress

Stress

- Preparing for, receiving and living with a lung transplant is stressful for patients, their families, and their support people.
- There is no right way to feel or react to stressful events. Everyone has a unique experience during the transplant process and copes in different ways.

Physical Reactions

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

Emotional Reactions

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

Changes in Thinking

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

These reactions to stressful events are normal and understandable. If you feel overwhelmed or find that you are having problems with day-to-day coping, please contact your family doctor or the Transplant Psychiatry team for help. Many support people get some professional help. This will not change the patient's status while on the waiting list or the care they receive after the transplant.

Burnout

- Caregiver burnout can occur if you feel emotionally and physically drained from your role as caregiver.
- Burnout can occur if you don't get the help you need, or if you try to do more than you are able to do.
- If burnout goes unnoticed, it can have an effect on the lives of your loved ones and yourself.
- Knowing what to watch for may help avoid this problem.
- The symptoms of burnout are similar to those of stress and depression. They include:
 - Withdrawal from friends and family.
 - Loss of interest in activities you previously enjoyed.
 - Feeling down, hopeless, and helpless.
 - Changes in appetite, weight, or both.
 - Changes in sleep patterns.
 - Getting sick more often.
 - Feelings of wanting to give up on yourself or providing care.
 - Emotional and physical exhaustion.
 - Irritability

Finding ways to help alleviate your stress may help address the problem.

Suggestions to help manage stress:

- Structure your time, keep busy and try to keep your life on as normal a routine as possible.
- Talk to people. Sharing your feelings is helpful in reducing stress.
- Write your feelings down in a journal or diary.
- Reach out to others. Spend time with people you trust.
- Do not be afraid to ask others for help. People around you often want to help but don't know what to do. Let them know what would be helpful to you.
- Help family and friends share their emotions and find out how they are feeling. You are not alone in what you are feeling.
- Give yourself permission to feel sad and frustrated.
- Do not use alcohol or recreational drugs to cope with stress. It may feel helpful at the time but it can cause problems.
- Exercise – even a walk around the block can be refreshing.
- Eat regularly and drink plenty of water.

You can have an “off” day. If the signs of stress and burnout occur regularly or are increasing, please ask for help from your family doctor, the Transplant Psychiatry team, or your Transplant Coordinator.

Stress Reduction

- It is easier to cope with stress by having some practical tools to use during these difficult times.
- The Multi Organ Transplant Program can offer individual support for stress management as well as the Mindfulness-Based Stress Reduction (MBSR) Program. This may help you deal more effectively with stress. It can help you manage your anxiety and emotional responses better, even in moments of difficulty.

- This program is geared for people who want to take an active role to maximize the benefits of their own health and wellbeing. You are asked to do one hour of homework nightly to practice the techniques taught in the course.
- **How to enroll?** Call the Transplant Psychiatry program or your Transplant Social Worker for more information.
- You will receive a package describing the program and an application form to be returned. The program is offered four times a year and is available during the day and evening.
- The MBSR Program runs for eight weeks; one three-hour class each week.
- The course is free of charge. There is a small fee for the CDs that accompany the program.
- There are other stress reduction practices that you can learn. Please contact the Transplant Psychiatry team or your Transplant Social Worker for more information.

“Light tomorrow with today.”

-Elizabeth Barrett Browning

Spirituality

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

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



Waiting for Transplant

Waiting Times

- Waiting times can be unpredictable. No one knows when the “call” for the transplant will occur. Matching with the donor depends on blood type, lung size, and other criteria.
- You will need to prepare yourself emotionally for the unpredictable nature of transplant.
- When the call comes for the transplant you and the patient will be given instructions.
- A “false alarm” may happen. The transplant patient is called about a possible transplant a few hours before the surgeon removes the lungs from the donor. Sometimes, on further inspection, the lungs are found to no longer be suitable. The transplant is cancelled.
- False alarms can occur at any time and can happen more than once. Patients will not be removed from the transplant list if they get a false alarm.
- False alarms may cause a variety of emotions. The transplant team is available to assist during this time.
- Ask the staff where you may wait during the surgery and how you can be contacted if needed.
- Is there another adult who can come and wait with you for support? It may not be appropriate at this stage to bring young children as the waiting time during surgery can be long. You will be waiting about 6 to 12 hours for the surgery to be completed and for the patient to be in the intensive care unit.

Get organized for “the call”:

- Make a checklist in advance of what you need to do and what to take with you. Follow your list when the call comes.
- Childcare: If you have young children, you will need to make plans for when the call comes for the transplant, either day or night. If they are in school, who will be responsible for them? Confirm these arrangements with the school in advance.
- Have a plan to get to the hospital. Who to call? Who will drive? How to get here?
- Taxi: get a few names and numbers for taxi companies and put these beside the phone.
- Practice your driving route. Know a few alternate routes in the event of traffic problems or rush hour traffic. Listen to traffic reports (680AM – every 10 minutes).
- Pack a small overnight bag for yourself with some personal belongings if you plan to stay near the hospital. Don't forget your glasses, pills, or any other necessary items.
- Bring extra cash or a credit card. These are helpful to pay for meals, parking, and a hotel if you are planning to stay close to the hospital.

“He who has health has hope; and he who has hope has everything.”

-Arabic Proverb Increasing responsibilities

Increasing Responsibilities

- Support people may need to take on more responsibility if the wait for the transplant is long.
- The transplant patient may be having problems doing simple everyday things. This may mean taking on more day-to-day tasks and also increased personal care for the patient.
- It is okay to ask for help from other people such as extended family and friends.
- Home care is available for Ontario residents. Please ask about this at the clinic.
- Some private insurance plans may also provide for home care services. Check private insurance plans as it may also cover for assistive devices such as a hospital bed, walkers, etc.
- The transplant program can provide the necessary documentation to get access to these services if you qualify. Please ask about them at clinic.
- Consider purchasing private services such as grocery or meal delivery, cleaning or transportation services to ease your workload.
- Read the Lung Transplant Manual along with patient.
- Encourage and accompany the patient to the weekly Lung Support Group Meetings held at the Toronto General Hospital.





Hospitalization

At any point in the transplant process, the patient may need to be admitted to hospital. Please do not visit the hospital if you are sick.

Pre-Transplant

- During the waiting period the patient's lung disease will progress. Infections are also common. They may need to be admitted to hospital for management of their problems.
- This does not necessarily mean that they are off the transplant list. Some infections or complications require that the patient be placed on "hold" for a brief period.
- While in hospital the transplant team can evaluate their status frequently. Decisions about transplant will be made day-by-day.
- The patient will be made "active" on the list when it is medically safe to do so.

When is it important to call the transplant program?

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

Often the patient will call about these issues, but if they are too unwell, you may need to report these changes. You will be provided with a list of phone numbers for the transplant program.

Who to call?

- Monday to Friday 8:30 AM to 4:30 PM call the Lung Transplant Assessment Coordinator

- Nights, holidays, and weekends: Go to your local emergency room or call your local chest doctor or family doctor. Please leave a message in the assessment office.
- The transplant coordinator will follow up with the outside hospital and notify the transplant team.

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

Have a plan:

- Keep a pen and paper near the phone to take down instructions
- Ask questions if you do not understand.
- Have an action plan. This may make things go smoothly in the event of an emergency or even when the “call” comes for the transplant.
- Plan for different events at different times of the day or night. Who will drive? How to get here?

What to bring:

- The patient only needs to bring their provincial health card, blue hospital card, and a list of their current medications. Personal belongings can come to the hospital at a later stage.
- You may want to pack a small overnight bag with some personal belongings if you plan to stay near the hospital. Bring extra cash or a credit card to pay for meals, parking or hotels.

During the Transplant

With the patient in hospital after the transplant, there may be a shift in priorities. It may also allow you to have a bit of a break from being a caregiver. Now many other people are managing the patient's care. This may leave you feeling relieved or perhaps even distressed as your role as the main caregiver has been taken away from you.

Outcomes of Lung Transplant

- It is hard to know how well someone will do after a lung transplant.
- Every person responds differently to the surgery and medications.
- The outcomes can be very different.
- The average patient may be out of hospital within a few weeks. Some people recover more slowly and may need to stay in hospital for several months. Don't get disheartened.
- The transplant team will keep you up to date on their progress on a regular basis.
- It is also important not to compare one person's recovery with another. It is not a race.

Medical-Surgical Intensive Care Unit (MSICU)

- The road to recovery can be long and difficult. Many factors enter into how long a patient's recovery is going to take. Recovery starts in the MSICU.
- The patient is brought to the MSICU when the operation is finished. There may be some delay getting into the MSICU to see them right away. The staff needs to do their own checks and some immediate tests as soon as they arrive from the operating room. They know you are eager to see the patient and will get you in as quickly as possible.

- Seeing your loved one in the MSICU with lots of different lines and tubes can be a scary experience. The MSICU nurses will do their best to make you feel comfortable and explain what all the equipment is for. Don't be shy about asking questions.
- The patient will be on a ventilator when they first come out of the operating room. Once they wake up, they will be encouraged to do more of the breathing on their own. The breathing tube is taken out as soon as it is safe to do so.
- While on the ventilator, with the breathing tube in their throat, they will not be able to talk. You can use other ways to communicate including written notes, lip reading, and preprinted boards in the MSICU.
- There is no definite length of stay in the MSICU. The time depends on each patient's progress. Try not to focus on the number of days in intensive care.
- Appoint a family spokesperson to communicate between the family and the MSICU. This will cut down on the number of interrupting phone calls.
- The Intensive care and Transplant teams will communicate with the family on a regular basis keeping everyone informed of the progress
- Confusion is common in patients after such a difficult operation. The medications and the unfamiliar environment in intensive care can contribute to the confusion. It is treatable with medications.
- Pain medication and sedation keep the patient comfortable but can also make them sleepy.
- The intensive care stay can be an emotional rollercoaster for families. Anxiety and fear are very common. It is important to try and keep with the present moment and not get caught up with worrying about the future. The Transplant Psychiatry team is available for help. There is also help from the Social Worker in the MSICU.

- During the hospital stay, patients can be sent back and forth from the transplant unit to the step-down unit or the MSICU if they run into complications.
- **Visiting hours** in the MSICU are from 11:00 AM to 8:00 PM daily. Visiting is limited to the immediate family, 2 people at a time. Please call from the waiting room each time before entering the MSICU to visit a patient. This is for patient privacy and security reasons.
- During critical periods, it is possible for families to visit at other hours with permission from the MSICU staff.
- Please do not visit if you are sick.
- During shift change at 7:00 AM and 7:00 PM it may not be possible to visit while staff get reports and start their shifts.
- After taking care of the patient before the transplant, watching others do this in the MSICU can leave you feeling unneeded. Ask the nurses if you can help by doing simple things to help such as washing the patient's face, combing their hair, giving them a hand or foot massage.
- If the patient's stay in the MSICU is for a longer than average period, it is helpful to think about what might help – bring in photos of family and friends, music, and cards.
- In certain situations, you may be asked to wear a gown or mask while visiting.



Post Transplant

- Regular monitoring is carried out after the transplant by the lung transplant clinic. Re-admission to the hospital is common, especially in the first few months after transplant.
- Infection and rejection, requiring more aggressive treatment are the most common reasons for admission to the hospital or the transplant day unit.
- Out-of-province patients may need admission since they are unable to access Ontario home care services.
- Please notify the Lung Transplant office if the patient is admitted to another hospital.
- Before discharge and in the clinic, you and the patient are taught the important warning signs to watch for after transplant. You may be the first person to notice a change. Early detection and early treatment of problems is important for a good outcome.

Rehabilitation

- Patients who have been in hospital for longer than average often need more exercise to regain their strength. A referral may be made to a specialized rehab program.
- The Transplant Program works closely with St. John's Rehabilitation Hospital in Toronto.
- Patients still attend appointments and follow-up at the Toronto General Hospital while in rehab.

“If life were predictable it would cease to be life, and be without flavor.”

~ Eleanor Roosevelt



Advanced Care Planning

- Advanced care planning is a process to help the transplant patient and family think about and express choices about future care.
- It helps ensure that the patient's wishes are respected in the event that they cannot communicate their choices.
- Patients and support people are encouraged to talk about which life sustaining treatments are wanted, and which are not.
- It is important that you are aware of these wishes as the support person. Once these choices have been made, sharing this information with other family members is important.
- **Advanced Directives** are written instructions that a patient gives for future medical care.
- There are two types of Advanced Directives:
 - **Living Will:** A written document that explains the patient's wishes about the medical care they want to receive.
 - **Power of Attorney for Personal Care:** A legal document naming someone to make decisions regarding medical care. The Social Worker with the transplant program will provide you and the patient with information about advanced care planning at the time of assessment.
- Many patients and support people are initially reluctant to consider contemplating advanced directives. Having this document done provides people with relief and comfort knowing their wishes.

*“Learn from yesterday, live for today,
hope for tomorrow.”*

-Albert Einstein

Funerals

- The majority of patients are successfully transplanted. Unfortunately, some people will die from their advancing lung disease while still waiting for the transplant. A small percent of patients die in the first few weeks following the transplant.
- Others may survive for some time before they succumb to either the long-term effects of the transplant or other life events.
- Discussion about funerals often happens with the discussion about advanced care planning. It is important to raise this issue if the patient's wishes are unclear.
- The funeral is a time for families and the community to gather together. There are many varied practices and traditions seen in different cultures, religions, and families.





Bereavement and Grief

- Grief and bereavement are the normal responses of sorrow – the emotions, thoughts, and behaviors that follow loss.
- Feelings of grief may be experienced throughout the time you care for someone who is ill, not just at the time of a person's death. Facing ongoing loss is one of the many challenges that you may encounter as you adjust to changes in the patient's health. With each change, you may experience feelings of loss.
- Grief is a unique process and is a natural part of life.
- It is important to note that everyone grieves in his or her own way and in his or her own time.
- An individual's experience of grief may be shaped by cultural, religious, and family traditions.
- There is no right or wrong way to grieve.
- Expressing your emotions is a normal part of the process.
- You will have made friendships with other support people and patients along the way. The death of another patient may also require a period of bereavement.

Suggestions that may help:

- Being with other people. Family and friends will be sharing in your sadness. Spending quiet time or talking with them may be helpful.
- Accept help from others. You do not need to do everything; family and friends are there to help.
- Rest and sleep. These will help you regain both your physical and emotional energy.
- Follow your regular routine as much as possible.
- Time is a great healer. Though things will never be the same, time will ease some of the pain and sadness you may feel.



Life After Transplant

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

Guidelines to consider:

- Identify yourself as the main support person and provide the transplant clinic with current contact information.
- Commit fully for at least the first three months post-transplant for all scheduled tests and appointments, as well as unexpected visits.
- Provide and/or arrange for translation services at clinic visits if needed.
- Function as the patient's "Personal Assistant":
 - helping with day-to-day activities and medications
 - transportation to hospital appointments
 - encouraging rest and exercise
 - promoting and assisting with proper nutrition.
- Maintain a log or journal and bring it with you to clinic appointments. General questions, concerns, and medication questions or refills can be addressed in the clinic.
- Early after transplant you may be the person in charge of managing the medications until the transplant patient recovers.
- Remind the patient to bring a list of medications to all appointments, including transplant clinics, bronchoscopy appointments, any other doctor's visits, the dentist, and even when traveling.

- Ensure proper understanding of various appointments, locations, and instructions. A calendar or day planner can help organize this information in a central spot.
- Assist the patient with the EZ call system.
- Read the Lung Transplant Manual along with patient.
- Encourage and accompany the patient to the weekly Lung Support Group Meetings during the first 3 months after transplant.
- Help sort out any financial issues – for example drug coverage and private insurance. Follow up with the Transplant Social Worker if needed.
- Provide feedback to the transplant team regarding the patient's mental state – alteration in mood, signs of difficulty coping, depression, or anxiety.
- Be prepared for a change in roles. As the transplant patient recovers and regains their strength they will become more independent and will not need your help as often. Congratulations!

“Every day is my best day; this is my life. I am not going to have this moment again.”

-Bernie Siegel





Coping *ABCs* for Caregivers

*A*sk the transplant team to explain any aspect of care you do not understand

*B*e realistic. Determine what is most important.

*C*onsult experts if you need help.

*D*on't overprotect your loved one.

*E*at right and Exercise safely.

*F*ind a good listener – someone with whom you can share your thoughts, feelings, and concerns.

*G*et enough rest.

*H*ave patience with your loved one.

*I*nsist on having some time for yourself each day.

*J*oin a support group.

*K*eep life as normal as possible.

*L*et your loved one resume former roles and responsibilities after the transplant.

*M*aintain your sense of humor.

*N*urture yourself.

*O*btain help when you need it.

*P*ost important phone numbers in a prominent place.

*Q*uell the temptation to accept responsibility for your loved one's decisions and behaviors.

*R*emain optimistic and think positively.

*S*et limits.

*T*ake care of yourself first.

*U*se a variety of positive coping mechanisms.

*V*anquish guilt.

*W*atch out for signs of caregiver burden.

*X*erox your loved one's medication list and other important medical information.

*Y*ell if you have to, when alone.

*Z*oom in on what is really important in your life.

(Adapted from: Cupples, S.A and Mize, J. Coping ABCs for Caregivers, *Progress in Transplantation*, 14 (2), 167-168).



Web Based Resources for Support People:

Web based resources for caregivers for transplant patients are scarce, especially those from Canadian sources. Many of the resources listed below deal with caring for the elderly and people with dementia. We have included them because some of the same issues apply regardless of the age or illness of the care recipient.

You might find some of these sources helpful.

Canadian Association of Retired Persons

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

Canadian Home Care Association

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

Caregiver Network

<http://www.caregiver.on.ca/>

Long Distance Caregiving

<http://www.howtocare.com/caregiving.htm>

Veterans Affairs – Caregiving

<http://www.vac-acc.gc.ca/clients/sub.cfm?source=health/caregiving>

Baycrest – Caregiving

http://www.baycrest.org/Health_Information/Caregiver/default.asp

Alzheimer’s Society – Caregiver Support

<http://www.alzheimer.ca/english/care/caregivers-intro.htm>

Alzheimer’s Society – Manitoba

<http://www.alzheimer.mb.ca/c.html>

Canadian Caregiver Coalition

<http://www.ccc-ccan.ca/>

Ontario Seniors' Secretariat – Caregiving

<http://www.citizenship.gov.on.ca/seniors/english/programs/seniors-guide/caregiving.shtml>

Region of Peel – Public Health, The Caregiver Role

<http://www.region.peel.on.ca/health/commhlth/caregiv/cgintro.htm>

Home Services Toronto – Services to purchase

<http://www.homeservicestoronto.com/index.htm> Family Caregiving
<http://familycaregiving.ca/>

Victorian Order of Nurses – Caregiving

<http://www.von.ca/caregiving.html>

HealingWell.com

<http://www.healingwell.com/>

How to Care

<http://www.howtocare.com/support.htm>

The complete aging and caregiving resource guide

<http://www.caregiver.on.ca/resource.pdf>

Caregiving with June Calwood

<http://www.caregiver.on.ca/nwnw.html#top> Resources

Notes



Contact Information

Please keep the following information close by:

Doctor's Name: _____

Phone Number: _____

Transplant Coordinator's Name: _____

Phone Number: _____

Alternate Contact:

Name: _____

Number: _____

Patient Information:

Toronto General Hospital Card # _____

Provincial Health Card # _____

EZ Call 416-351-0793 PIN# _____

(Post-transplant only)

**In an emergency Dial 911.
Notify the Lung Transplant Program.**
