

Acknowledgments

The Toronto Lung Transplant Program would like to acknowledge the contribution of many past and present team members who have contributed to this manual:

The Multi-Organ Transplant Program
The Thoracic Surgery Program
The Acute Pain Service

This is the 1st edition of The Toronto General Hospital, Living Donor Lung Transplant Manual.

(October 2002)

Table of Contents

An Introduction to Your Transplant Manual	5
Philosophy of Care.....	6
Patient Rights Statement	7
Transplant Program Expectations	8
Core Concept Definitions.....	9
<i>I - The Donor Evaluation</i>	11
Your Transplant Team.....	11
What Do Your Lungs Do?.....	13
Who Needs a Lung Transplant?	15
Why do we need a Living Donor Program?	16
Advantages	16
Disadvantages	17
Your Donor Evaluation.....	18
Lung Donor Selection.....	21
Emotional Issues and Living Organ Donation	23
Planning information for Organ Donors	28
Financial Information.....	28
Legal Information	30
Caregivers/Parents of Minors	31
Out-of-Province/Country.....	32
<i>II - Your Hospital Stay</i>	33
The Pre-Admission Visit	33
Your Hospital Stay	35
Your Surgery	38
Double Lung (Lobar) Transplant	43
The Thoracic Surgery Unit	43
Postoperative Care	44
Pain Management.....	47
Risks and Complications	51
Complications for Lung Transplant Recipients	58
<i>III -A Healthy Recovery</i>	60
Nutrition and your surgery	60
Thinking About Discharge.....	60
Following Discharge	61
Return Appointments	66
We want to know what you think	67
Suggested Reading and Viewing	68
Glossary	70
Notes.....	73

Contacts.....75

AN INTRODUCTION TO YOUR MANUAL

Transplantation cannot occur without the generosity of others. Most people will benefit from a transplant through the kindness of strangers. Others are able to have a living donor transplant. Your decision to be a donor is greatly appreciated not only by the patient and their family but also by the transplant program.

This manual has been designed by members of the Multi Organ Transplant Program of Toronto General Hospital.

It is intended to provide our donors and patients with reference and resource material to help them understand, prepare for, and assist them through the donation and transplantation process.

We realize that there is a lot of information given to you about the donation and the transplant and we hope that this manual will serve as a valuable guide.

Our aim is to help you to stay healthy and well informed.

In accordance with the Ontario *Human Tissue Gift Act*, The Toronto General Hospital and the Multi Organ Transplant Program do not support or accept payment of any kind from patients, organizations or any party for organs for transplantation. It is against the law to buy, sell or otherwise deal in, directly or indirectly, any tissue for transplant, or any body part or parts of the body for therapeutic purposes, medical education or scientific research. **If at any time you are approached by a person to purchase or sell an organ for transplantation, please immediately contact: Patient Relations at The Toronto General Hospital at (416) 340-4907.**

PHILOSOPHY OF CARE

We believe that our work is only possible through the generous act of organ donation and our efforts must honour these remarkable gifts from organ donors and their families.

We believe that respect, dignity, integrity and empathy drive all care and support all relationships, that courtesy and consideration are basic to every interaction.

We believe that the goal of the Multi Organ Transplant Program is to work in partnership with individuals, families, and the community to promote optimal health and quality of life for patients through all phases of transplantation and/or circumstances in their lives.

We believe that the field of transplantation is a unique and complex body of knowledge and is most comprehensively and best delivered with the participation and partnership of a multi-disciplinary health care team.

We believe that all members of the health care team make an important and valuable contribution to the plan of care. Each member of the team is a dedicated professional who continually maintains a current knowledge base and consistently strives to advance the science and art of transplantation.

We believe that all people are unique, with their own needs, goals, and abilities.

We believe that people achieve their optimal state of health in collaboration with the health care team.

We believe that information and education provide patients with knowledge to exercise their rights and responsibilities to make informed decisions about their health care.

We believe that the best possible care is based on patient needs, available resources, and ethical principles.

We believe that all services must be provided in a safe environment which supports health goals and enables care to be delivered with comfort and efficiency.

PATIENT RIGHTS STATEMENT

All staff of The Toronto General Hospital Multi Organ Transplant Program is committed to client-centred care and support the rights and responsibilities of patients and families.

Throughout your transplantation experience at The Toronto General Hospital Multi Organ Transplant Program, you can expect:

- to be treated with dignity, respect and courtesy;
- confidentiality;
- the most appropriate, planned and coordinated care that can be provided;
- to receive planned and coordinated care that encompasses your physiological, emotional, psychosocial, educational, physical, and spiritual needs in a timely fashion;
- to receive care in a culturally sensitive environment;
- to receive clear, honest answers to your questions and the information necessary to make informed choices;
- to be provided care in a safe environment;
- to consider participating in research because of its contribution to the provision of health care and the future of transplantation.

TRANSPLANT PROGRAM EXPECTATIONS

Throughout your transplantation experience at The Toronto General Hospital Multi Organ Transplant Program, you have the responsibility:

- for your own health;
- to work in partnership with the health care team to ensure the best possible treatment, rehabilitation, discharge planning, and follow up care;
- to provide accurate information and to share any concerns with all members of the health care team;
- to inform the team if you do not understand or cannot follow the health care instructions;
- to understand and respect that the needs of other patients and families may be more urgent than your own needs;
- to treat staff, other patients and their families in a considerate, courteous, confidential, and cooperative manner;
- to understand The Toronto General Hospital's role as a teaching and research hospital and to cooperate with health care professionals in training;
- to take appropriate health and safety precautions both in hospital and out in the community;
- to take care of your personal property and valuables and to respect the Hospital property and regulations;
- to take appropriate measures to ensure that financial obligations are met surrounding your current and future health care needs.

CORE CONCEPT DEFINITIONS

Health

The state of physical, mental and social well being and not merely the absence of disease.

Patient

The individual who receives physiological, psychosocial and spiritual care from the multidisciplinary team.

The multidisciplinary team recognizes that the patient is an integral part of a family unit, where family is defined by the patient.

Team

The team is comprised of multidisciplinary practitioners who work in collaboration with patients and their families and each other, to achieve optimal health for patients in all phases of transplant care.

Team members are committed to excellence in practice, teaching and research.

Environment

Physical, collegial and social conditions and processes which exist internally and externally to facilitate patient care and professional development.

The Donor Evaluation

YOUR TRANSPLANT TEAM

The Lung Transplant Team is a group of highly skilled professionals who work together to help the donor and the recipient have a successful transplant and recovery. Prior to your acceptance as a donor, each specialist evaluates your health, both physical and mental. Many tests will be performed including blood work, x-rays, and scans. The team will then decide if you are a suitable donor.

The members of The Lung Transplant Team include:

Respirologist

The *Respirologist* is a doctor who is highly skilled in the diagnosis and treatment of lung disease. The respirologist you meet will not be involved in the care and treatment of the person receiving the transplant. The respirologist will discuss the donation process with you, specifically the benefits and risks of being a donor making sure you are able to make an informed consent *BEFORE* proceeding with any further evaluation. Following the full evaluation, the respirologist will evaluate the results of all your tests before approving you as a potential donor.

Thoracic Surgeon

The *Thoracic Surgeon* is involved in the donor evaluation and selection. The surgeon performs the organ removal on the donor and participates in the transplant operation. The surgeon manages your post-operative recovery. He/she manages any surgical or medical problems and is always involved in your follow-up.

Anesthetist

The *Anesthetist* is a medical doctor who is involved in the donor evaluation and selection. The Anesthetist will evaluate the safety of putting you to sleep during the donor operation. The Anesthetist is also a member of the Pain Management team.

Transplant Assessment Coordinator

The *Transplant Assessment Coordinator* is a registered nurse who works with the transplant team to organize your evaluation and provide teaching and support through this process.

Social Worker

The *Social Worker* meets with all potential donors and their families to review each individual's situation and family supports. He/she will work with you and your support persons to plan for transplant, keeping your unique needs in mind. He/she will be able to advise you about any financial issues. In addition, your social worker will provide supportive counselling for you and your family, before and after the transplant. If you need assistance in dealing with other agencies and institutions, the social worker will be able to help you.

Dietitian

The *Dietitian* will provide nutritional information and counselling. A good nutritional program is important for preparation for and recovery from your surgery.

Psychiatrist and/or Psychiatric Nurse

The *Psychiatrist* and/or *Psychiatric Nurse* will see you during your evaluation. These professionals specialize in helping donors and families cope with the stress of organ donation and the emotions that may go along with it.

Physiotherapist

The *Physiotherapist* will evaluate you prior to donation and participate in your post-operative recovery. The physiotherapist will evaluate your exercise tolerance after you have recovered from surgery as part of your post-operative follow-up with the surgeon.

Nurse

Your *Nurse* will help coordinate the activities of your other health care team members, as well as caring for your needs during your hospital stay. He/she will prepare you for discharge. Your nurse will also keep the lines of communication open between you and the other team members.

Respiratory Therapist

The *Respiratory Therapist* will help manage and improve your breathing. They may use oxygen, humidity, and special breathing exercises as treatment.

The members of your Transplant Team have a special interest in caring for donors and have been specially educated to meet your needs. These health care professionals will be available to answer any questions you may have. The team will be there for you before your transplant, during your surgery, and after you've gone home.

WHAT DO YOUR LUNGS DO?

To better understand why lung transplants are recommended for some people, it is important to understand how the lungs function.

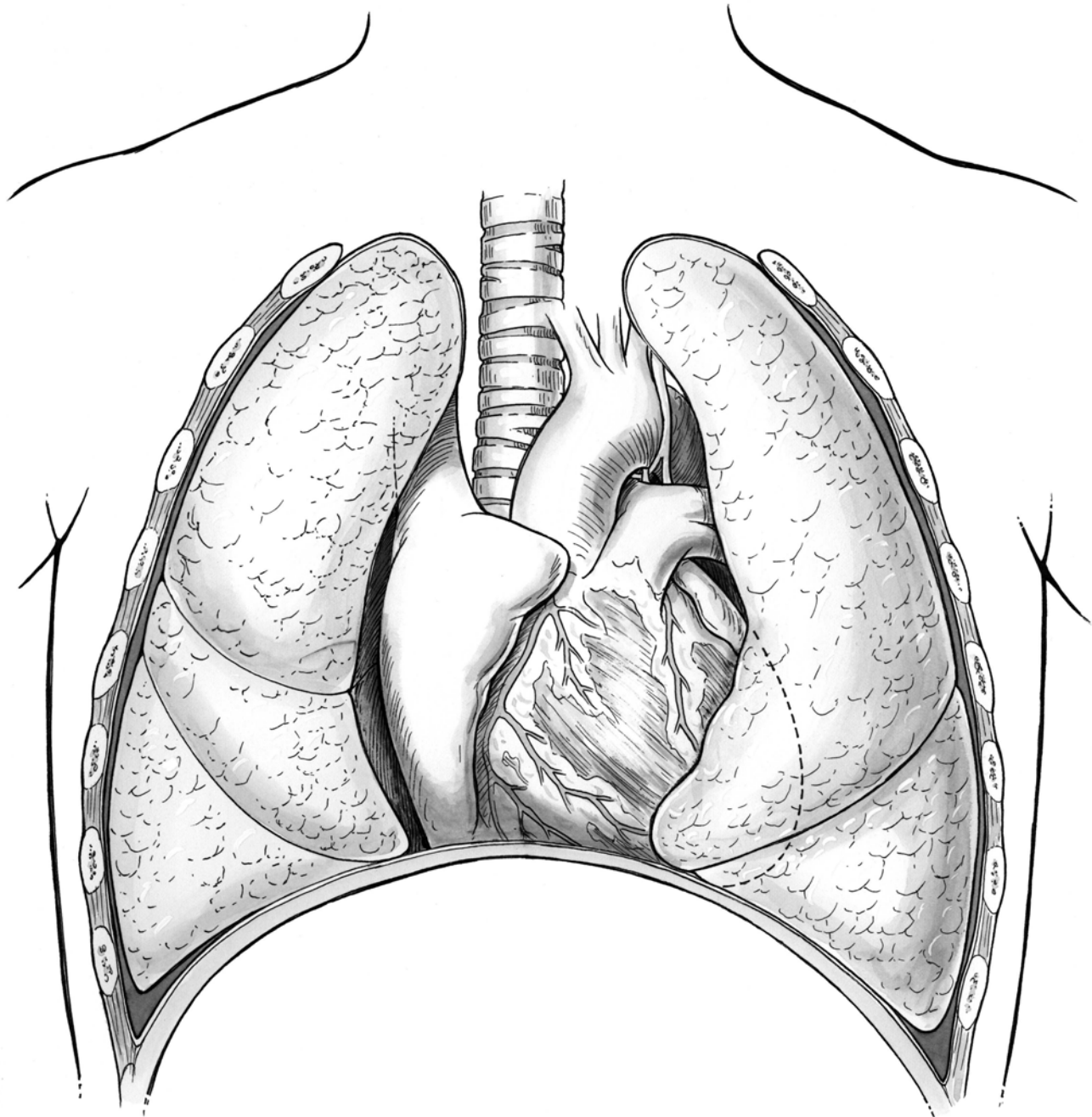
No organ or tissue can survive without oxygen. Oxygen is used throughout the body in chemical reactions to produce energy. These reactions create carbon dioxide as a waste product, and this gas must then be removed from the body. This is called a “gas exchange” (exchanging oxygen for carbon dioxide).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

The lungs are located in the chest under the ribs. The lungs are protected and supported by the 12 pairs of ribs, the intercostal muscles that lie between the ribs, the neck muscles and the diaphragm. You have two lungs. The normal lungs are soft and spongy. They are made up of elastic tissue that allows them to stretch and recoil. The right lung is divided into three lobes, the upper, the middle and the lower lobes. The left lung is divided into two lobes, the upper and the lower lobes. Two protective layers of tissue called pleura surround each lung.

The lungs themselves are made up of air passageways called bronchi, gas exchange sacs called alveoli and numerous blood vessels. The air passageways are made of a series of highly branched hollow tubes. The branches look similar to those on a tree. Each branch becomes smaller and more numerous at each branching. The smallest of these tubes end in the tiny gas exchange sacs called alveoli. There are approximately 300 million alveoli in the lungs. Tiny blood vessels or capillaries cover each alveolus. The oxygen in the alveoli crosses over the membranes and enters the blood vessels. The carbon dioxide in the blood then crosses the membranes and enters the alveoli so it can be exhaled.

Where Are Your Lungs?

The lungs are critical organs that provide your entire body with oxygen. The location of your lungs is shown in the diagrams below:



WHO NEEDS A LUNG TRANSPLANT?

The reason some people need a lung transplant is that the lungs can no longer perform their vital gas exchange function. The lung disease cannot be corrected in any other way. The causes of end-stage lung diseases vary.

Here is a list of the types of lung diseases that may be referred for Living Donor Lung Transplantation.

Airway Diseases

- Cystic Fibrosis
- Bronchiectasis

Interstitial Lung Diseases

- Idiopathic Pulmonary Fibrosis
- Secondary pulmonary fibrosis

Optimal transplant patients from a living donor will be between the ages of 12 to 25 years. This will take advantage of donors that are of appropriate size and health. Other recipients will be considered on a case-by-case basis.

Patient's referred for living donor lung transplantation must pass through an assessment of their own. They have to be suitable for a transplant regardless of where the donated organ comes from. Recipients who are malnourished, bedridden, have multiple resistant infections in their lungs or have pulmonary hypertension will not be considered. Patients who have had a previous lung transplant will also not be considered for living donor transplant.

WHY DO WE NEED A LIVING DONOR LUNG TRANSPLANT PROGRAM?

The most common way for a lung transplant to occur is through the donation organs following a person's death. These "cadaveric" donors are individuals who have suffered a fatal brain injury that results in "brain death". Just prior to their death, they were otherwise healthy. The next-of-kin must also give permission to use the organs for transplant. Only a very small percentage of people will die under such conditions. Of that small group, only 1 out of 5 donors have lungs that are suitable and healthy for transplant.

Each year, approximately 20% of patients waiting for a lung transplant will die before a suitable donor organ is found for them. Small patients, especially children, are even more disadvantaged as there are even fewer small donor organs available.

A live donor program will increase the total number of organs available for transplant and will save lives.

Living donation is a very common occurrence with kidney transplant. Over ½ of the kidney transplants done at the Toronto General Hospital are from living donors. Forty percent of those are from donors who are not blood relatives to the patient, the most common of these being between spouses. Living donor liver transplant has been done since 1989. It has been especially advantageous for infants and young children. Adult-to-adult live liver donation is slightly newer but is becoming more common. At the Toronto General Hospital we offer our liver transplant patients the option of living donor transplant.

Lung transplantation for the types of lung disease mentioned on the previous page requires a double lung transplant. For children and small adults, living donation will require TWO separate donors, each person donating the lower lobe of ONE of their lungs. To ensure that the lung volume is large enough for the recipient, donors will need to be at least 3-6 inches taller than the recipient. The larger of the two donors will donate the right lower lobe.

What are the advantages of a living donor program?

Several possible advantages have been identified:

- 1) A sense of satisfaction and a chance to contribute the health and well being of someone close to you.
- 2) A shorter waiting period for the patient receiving the transplant.
- 3) A transplant recipient in optimal health prior to the transplant. This takes advantage of the shorter waiting period.

- 4) Better quality of the donor organs. In living donation, the time between removal of the organ and transplant is shorter than when it comes from a cadaveric donor. The living donor has been thoroughly screened during the assessment phase. With cadaveric donation, sometimes the events that surround the donor's death can have subtle effects on the function of the lungs. These would not be seen with living donation.
- 5) Shorter hospital stay for the transplant patient. A better quality of organs and a recipient in optimal health prior to transplant may mean fewer complications.
- 6) If the donor and recipient are blood relatives, the genetic match may prove to be an advantage as is seen with living related kidney transplant. Since living lung donation is still a relative newcomer to transplantation, this has yet to be proven. These patients may need less anti-rejection medication and may experience fewer side effects.
- 7) Two genetically different donors may mean that if the patient experiences some rejection in one lung, the other lung may be spared.

What are the disadvantages of being a donor?

All surgery carries risks. Common complications of major surgery are:

- 1) bleeding from the incision or internally
- 2) infection in the wound
- 3) pneumonia in your lungs
- 4) blood clots in your legs
- 5) blood clots on your lungs
- 6) pain from the incision
- 7) complications with the anesthetic

Some of the other disadvantages related just to living lung donations are:

- 1) A permanent reduction in your total lung function of about 20%. The portion of the lung that is remaining will expand slightly. The reduction in lung volume will not interfere with most people's lifestyles.
- 2) Two separate donors are required for each transplant procedure.
- 3) All surgery carries a small risk of death. Removing part of someone's lung is a common operation but for other reasons. This operation that is performed for other reasons carries an operative mortality of approximately 1-3%. To date, with over 200 living donor transplants carried out in the world, there have been no deaths related to the surgery in the donors.
- 4) Rejection of the organ is still a possibility even if you are a blood relative of the recipient. The recipient's immune system will identify the lung as "foreign" tissue (that is, *not identical* to themselves). The immune system will

attempt to attack the lungs. Immunosuppressive medications can alter this natural response to some degree but there is always the possibility that rejection will occur. There are side effects related to the life long use of these drugs.

- 5) Stress is common especially if the recipient of the lungs is closely related to you. This can be increased if the recipient experiences complications or the transplant fails.
- 6) A transplant is NOT a cure. It is a treatment for a specific type of problem. As with all treatments, there are good outcomes that can be hoped for and some inherent risks.

The transplant evaluation can help reduce the risks of donation and transplant by careful assessment and screening of potential donors.

YOUR DONATION EVALUATION

A donor is someone between the age of 18-55 years. The donor is someone who is a family member of the recipient or has a long-standing relationship with the recipient and their family.

Your pre-transplant evaluation consists of a variety of interviews and medical tests with members of the transplant team. This evaluation process takes several days. The evaluation is to determine if lung donation is safe for you. Your willingness to donate will be carefully assessed. The evaluation gives us valuable information that we will use to care for you in-hospital and following your surgery.

During the evaluation process the potential donors and their family will be provided with information to assist them in making informed decisions about the operation and post-operative period. The donor and their family are encouraged to ask questions of the team members. The decision to go ahead and be living donor requires that we inform you of ALL the potential risks and benefits that your donation may involve. No one should feel pressured to be a donor. If at any time you change your mind, the transplant team will support your decision.

This evaluation will not only tell us the state of your lungs but is to make certain that there is nothing else wrong with any of your other organ systems that would increase the risk of lung donation. Sometimes the assessment will uncover a problem that makes donation a

poor option for you. If this turns out to be the case, you will be referred to a specialist to manage the problem that was identified.

You will be sent an information package about all the tests and appointments you will be having.

Tests for Assessment of Living Lung Donation

BODY PART	TEST	
LUNGS:	Pulmonary Function Tests	To measure how large the lungs are and how well they manage airflow.
	Chest X-Ray	Determines if the lungs are normal and looks at heart size
	Arterial Blood Gases	Bloodwork that shows how your lungs exchange oxygen and carbon dioxide
	Ventilation-Perfusion Scan	This is done in a nuclear medicine lab. A small amount of a radioactive substance is injected into a vein. This test can assess for the presence of blood clots in your lungs.
	CT, CAT Scan of Chest	A cross-sectional view of the structures in the heart and lungs
	Exercise Testing	Candidates for lung donation are asked to exercise with a physiotherapist who measures their exercise tolerance, oxygen content in the blood, heart rate and breathing rate. This test will be repeated 12 months after the donation to look at the effects of the removal of a lung portion on exercise tolerance.
HEART:	2D Echo with Doppler	Evaluates the pumping action of the heart and the valves that separate the chambers in the heart.
	ECG (electro-cardiogram)	Shows the pattern of electrical waves in your heart.

HEART:	Stress MIBI (Exercise test)	Performed on all donors >40 years and those with a history of heart problems. A radioactive substance is injected in your vein then pictures are taken of your heart while walking on a treadmill. This test assesses blood circulation to your heart muscle. Two sets of pictures are taken; one immediately following injection and one 4 hours after injection.
OTHER:	Urine tests	Assess kidney function. In women to test for pregnancy.
	Tissue Typing and Cross match	Genetic matching done between the donor and the recipient.
OTHER:	Bloodwork	Helps to evaluate other systems such as kidney and liver function. Viral screening for hepatitis and HIV is performed on all potential donors.
	Leg Doppler	An ultrasound of the large blood vessels in the legs looking for the presence of blood clots

The Transplant Team Members who consult on lung transplant evaluation are:

- Respirologist
- Psychiatrist
- Social Worker
- Transplant Co-ordinator
- Physiotherapist
- Anaesthetist
- Dietician

Thoracic Surgeon: Although you will not see the thoracic surgeon during your evaluation, he/she participates in the review of all your assessment tests. He/she will see you once you have finished the evaluation. The respirologist will review all of the test results and if acceptable to donor will be seen by the surgeon. The surgeon will discuss with you the operative procedure planned and the risks of this type of surgery.

LUNG DONOR SELECTION

PSYCHOSOCIAL EVALUATION

All donors are evaluated individually by members of the Departments of Social Work and Psychiatry. This part of the assessment is just as important in the final selection of the donor as are the medical tests. For lung donors, separate psychiatrists will see the two donors.

A suitable donor is someone who is a family member of the recipient or someone who has a long-standing relationship with the recipient and their family. Your decision to donate will be carefully assessed. The psychosocial evaluation is aimed to make sure that you have made this decision of your own free will and not because of coercion by the recipient or their family. The psychological stress of the donation will be discussed with you and how you deal with stress will be evaluated. The Team will help you to prepare for the possibility that the transplant is unsuccessful or the recipient dies.

The Team is also concerned that you have made plans for you and your family at the time of your surgery. A strong support network of your own at home is important for your recovery after this surgery. The practical aspects of your donation will be reviewed with the social work team. These are also discussed in the next section.

All donors must be physically and psychologically suitable to donate. The support network for the donor must also be in place ahead of time. The transplant may be postponed or canceled if all of these issues are not satisfactorily addressed before transplant. As well, donors may be refused for donation if the Psychosocial Team does not find them suitable to donate.

Sometimes, donors change their minds about donation. You are always able to opt out at any time in the assessment period. The Transplant Team will support your decision.

CONFIDENTIALITY

The results of your assessment belong to you. The information you receive from the Transplant Team will not be communicated with the recipient of the organ or their family. If you wish to share your results, that choice is yours. If you are found to be an unsuitable donor, the recipient and the family will not be told the reason, unless you chose to tell them. If you want to disclose this information to the recipient and the family but have difficulty doing so, the Transplant Team may be able to assist you.

PHYSICAL SUITABILITY

The donor lung must be compatible with the patient waiting for the transplant. The table below shows which blood types are compatible.

DONATING OR RECEIVING LUNGS BASED ON BLOOD TYPE		
Blood Type	Can Receive From:	Can Donate To:
O	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	O, A, B	AB

The size of the lung is important. This can be calculated from the pulmonary function tests. Since the patient is only receiving a portion of a lobe from the donor, to ensure it is large enough; the donor needs to be at least 3-6 inches taller than the recipient is.

The donor must be healthy. The assessment tests will provide us with the necessary information to safely select the best candidates to be donors. The anesthetist will evaluate the safety of putting the donor to sleep for the operation.

The surgeon will see all potential candidates for transplant, once they have completed all the needed tests. The surgeon will sign the consent with you for the operation once he/she has explained to you the nature of the surgery and the risks involved.

Once TWO acceptable donors are selected there will be a discussion regarding the timing of the donation and transplant. Living donor lung transplant is intended as a "back-up" for lung transplant. As long as the recipient is stable, we will wait for lungs from a brain-dead donor. If the recipient gets sicker while waiting for a transplant, living lung donation will be used.

If you fail to attend appointments:

If you do not attend appointments for the required tests or consults, these will be rebooked for you and you will be notified of the newly scheduled appointment by phone. This will be done on only 2 occasions. If you fail to attend for the same test or appointment a third time without notifying the Transplant Assessment Center, you will be notified by letter that you are expected to contact the Transplant Assessment Center within two weeks of the date on the letter. If you fail to contact the Assessment Center, this will be seen as an indication that you do not wish to proceed with donation. The assessment process will stop at that point and another donor will be evaluated if possible. The recipient will not be told the reason for your unsuitability.

EMOTIONAL ISSUES AND LIVING ORGAN DONATION

Donating a part of your body can result in number of different emotions. You may feel pride and joy, or the opposite feelings of worry and regret. Understanding the emotional aspects of living donation is just as important as understanding the physical aspects.

Members of the Psychosocial Team of the Multi-Organ Transplant Program are available to help you through the transplant process. They can be involved with you at any time during the donation process. They may be able to help you make your decision to donate. The Team is also with you during your hospital stay and recovery period at home. The Team consists of social workers, psychiatry nurses and psychiatrists. All of these professionals have special expertise in working with transplant donors and recipients. Different team members will see the donor and the recipient. This way the team members seeing you can focus on your needs and represent your interests.

Confidentiality: What you tell the Team will be kept in confidence. However, we cannot keep information confidential is if it threatens your health or the health of the recipient. If this situation was to happen, then the Team members will let you know that they need to discuss the issue with the other members of the transplant team. If you are worried about confidentiality, please speak with a Team member. They will do their best to answer your questions and concerns.

Donor Assessment and the Psychosocial Team

Psychosocial team members are usually involved in the donor work-up process. During the donor work-up process, you will meet with one or more members of the psychosocial team. They will ask you about your decision and motivation to donate. They will help you to anticipate any problems that may occur. They will help you to solve these problems when possible. Team members want to make sure that you are truly interested in donating and that you are not being pushed or pressured to donate by the recipient or other family members.

During your assessment you will be asked about your decision to donate including questions such as:

- Is this the right time in your life for you to donate?
- How do the people important in your life feel about your plans to donate?
- Do you think the recipient will look after the donated organ?
- Do you feel that you are giving your organ freely or do you feel that you are being forced to donate?
- Have you thought about how you might feel if the transplant fails?
- What do you expect to get back from the recipient in return for donating?

Team members will help identify any areas that might cause problems. A plan will be made to ensure a successful donation experience. Common examples of such problems include problems with finances, difficulties in getting time off from work, and need for practical or emotional support.

If you are taking antidepressant, anti-anxiety or sleeping medications, the team needs to know about this ahead of time. They will instruct you how to take these medications at the time of the surgery.

You will also be asked how you think you would cope in the unlikely event that the recipient does not do well or even dies. It is important to think about this question before the operation. It is important to think whether you would blame yourself for the failure of the organ or treat yourself harshly.

COMMON EMOTIONAL RESPONSES TO DONATING AN ORGAN

Prior to Organ Donation

- ***Pressured Feelings*** - Anyone facing the possible death of a loved one will feel some pressure to do whatever they can to help. Some people may have stronger feelings that upset them. Occasionally, people may be pressured by others to donate when it does not feel right to them. Strong feelings of pressure are hard to cope with and you may feel ashamed that you are uncertain about donating. There are many other ways of helping the recipient apart from donation. If you are unclear or worried how to handle these feelings or your family, we are here to help. We will treat what you tell us with confidence. There are times when it is best for a donor not to go through with the donation. If donation is not right for you, we can make sure the donor work-up process does not continue. The recipient will be told you are not a suitable donor and no further explanation or details will be provided to them.
- ***Anxiety***- There are many reasons to be anxious. Many people are anxious about having an anaesthetic, undergoing surgery and coping with post-operative pain. Most people are anxious about whether the transplant will be a success. You may also have worries about how other family members will cope with caring for both the donor and the recipient after surgery. Donors who have never had surgery before may worry about coping with the recovery period. You will be recovering from surgery when in other circumstances you would be helping to care for the recipient. While anxiety is common in the time leading up to transplant, it usually does not interfere with day to day activities for most people. If you find that your anxiety is interfering with your ability to do your usual activities, let your transplant coordinator or the Psychosocial Team members know and they will help you to deal with your anxiety.

- ***Sleep Problems*** - Many people describe difficulties falling asleep or staying asleep in the time leading up to transplant. This is understandable given the normal anxieties donors go through. The occasional poor night's sleep will not hurt you but if you are having troubles sleeping for more than a couple of nights, you should let someone on the team know - either your transplant coordinator or one of the Psychosocial Team members.
- ***Wish to Speed Up or Slow Down Time*** - The donor work-up and the wait for transplant may feel too quick or too slow depending upon your personality and current life situation. If you have strong feelings in this area, please share them with your transplant coordinator. We will try to accommodate your needs as best as possible.
- ***Doubts*** - Most people have doubts at some point in the donation process. It is important to remember that the transplant team would not be considering a transplant unless they felt that there was a good chance of success. The team would not approve you as a donor unless they felt that you were healthy. Some people may develop more serious doubts about their own wish to donate or how the intended recipient will care for the organ. If you have serious doubts, please discuss them with either your transplant coordinator or a member of the Psychosocial Team.
- ***Donor Expectations of the Recipient*** - Most people donating an organ have some expectations of the recipient. You may have expectations about how the recipient will behave after the transplant including how they take care of the organ. It is important to be clear about your expectations and to make sure that they are realistic. Donating an organ will likely improve the recipient's physical health but it doesn't change who they are or how they approach life. Donating an organ to the recipient may not change your relationship with them either.

While in the hospital

- ***Relief*** - It is a huge relief for most people to have their own surgery over and to hear that the recipient is recovering. Many people are surprised by how relieved they feel.
- ***Worry*** - Some people find it hard to focus on their own healing after surgery. They may have worries about the recipient and worries about their own recovery. If you are a worrier it is important to let a staff member know. If the recipient is having difficulties in the post-operative period, it is especially important that you get the information that you need. A plan for communication will be made with you before the surgery so you can have up-to-date information. Post-operative problems in recipients are common and even though they might sound serious, many are expected. Close monitoring of the recipient in the early days after transplant helps to identify these problems early so they can be treated quickly.

- **Blues** - Some people talk about a feeling of the blues or a sense of let down after the transplant. In some ways, this is like the “baby blues” woman may experience after childbirth. Once that the surgery is over the recipient is the focus of attention. All the build up to the transplant is now over. The donor may feel left out. This is a common experience. You should not be ashamed of these feelings. Donors and recipients who have had unrealistic expectations of how the donation will change their relationship may be saddened when things do not change. If you are feeling down, please talk about your feelings with your transplant coordinator or Psychosocial Team staff.

Recovery and Beyond

- **Pride, Satisfaction and a Sense of Accomplishment** - Many people describe feelings of pride and a sense of satisfaction and accomplishment that they were able to make this life-saving gift.
- **Surprise at the Recovery Process** - Everyone’s recovery is different. The most common experience is that people expect to feel better more quickly than they were told to expect. They are then disappointed if it is slower than what they want. Donating an organ is major surgery. Most people need at least 6 weeks before they begin to feel back to normal. If you have questions about your recovery process, please contact your transplant coordinator or surgeon.
- **Concerns about the Scar** - Some people see their scar as a “badge of honour” but others feel it is ugly and disfiguring. The scar will continue to heal slowly over time and become less noticeable.

UNCOMMON EMOTIONAL RESPONSES

While in hospital

- **Confusion and Disorientation** - These symptoms are uncommon. They are more likely to happen to the transplant recipient than to the donor. Post-operative confusion is also known as delirium. Delirium is the result of the effects of the pain medication and anesthetics on your brain. This may produce a temporary disruption in normal brain functioning. Delirium goes away over a few days. We can help it go away more quickly with a variety of different treatments. Delirium is more likely to happen to people who have had it before with other operations. If this was the case for you, please let the team know ahead of time. We can try and prevent the delirium from occurring. These symptoms are usually easily treated.

WHEN SHOULD YOU ASK FOR HELP

The Psychosocial Team is here to help. We are happy to meet with you at any point before or after the transplant. You can contact a team member that you saw during your donor

work-up or ask your transplant coordinator to contact the team. It is especially important for us to meet with you if you have any of the following concerns:

- *Feelings of being forced or pressured to donate*
- *Doubts that occupy a lot of your time and energy*
- *Anxiety interfering with daily activities*
- *Sleep problems*
- *Confusion or disorientation*
- *Low mood that lasts for more than a few days*
- *Poor outcomes with your recipient*

PLANNING MAKES A GOOD DONATION EXPERIENCE

Sorting out what you need and how to get it are important parts of making the donation process go smoothly. Please let the transplant coordinators and Psychosocial Team members know what we can do to help. We see donors as heroes, giving the most important gift one person can give another – the gift of life – and we want to do whatever we can to help you along the way.

PLANNING INFORMATION FOR ORGAN DONORS

FINANCIAL INFORMATION FOR ORGAN DONORS

The financial implications of organ donation will need to be considered by each donor. Donors will need to take several weeks off work, more if there are unexpected complications of surgery. Many will face a period of lowered income during this time. We recommend that donors estimate the financial loss, which they are likely to incur and ensure that they take this into consideration when planning surgery. It may impact the timing of the surgery. Some people have found that fund-raising in their communities was necessary to allay the loss of income.

Remember that the following information is not totally comprehensive. Each donor is in a different situation with regard to finances. Your various insurance policies, work or unemployment situations, asset mix and even your relationship with a partner, etc. will combine to make your particular status unique. This is an overview of some of our donors' more common situations and some of the more commonly used resources. Please think of this as a beginning point from which you can go on to obtain more individualized information.

BASIC FAMILY INCOME

Insurance

- **Employment and Illness Benefits**

Following a relatively short period of time off to recover from surgery, donors can expect to be able to *return to the job or position* they previously held. Depending on the length of the donor's recovery period and the type of benefit plan held by the workplace, he/she may qualify for *Short-Term Disability* payments. Most likely *Long-Term Disability* benefits will not be needed.

If such benefits are not available or are very low, it is usually possible to collect up to fifteen weeks' *Employment Insurance Illness Benefits*, provided the individual has paid into it sufficiently at work. Currently, it is necessary to have worked for 700 hours in the past 52 weeks in order to receive illness benefits.

Means Tested Income Sources

- **Short Term**

If you become *temporarily* unable to work, and have very low income and assets, you may apply for *Ontario Works Assistance (OW) Benefits* which are given based on total family income (drug benefits are included). Since you are not permanently disabled, you would not be eligible for the *Ontario Disability Support Program (ODSP)*.

- **Combined Types of Income**

Please note: Even if you have some insurance income such as short or long term disability from work or EI, an application to OW can actually take place at any time, if your total family income and assets are sufficiently low.

- **Exceptions**

It should be noted that there is one category of donors who are not entitled to Social Assistance: the recently sponsored immigrant. Because of the agreement with Canadian Immigration, the sponsor is responsible for maintaining the immigrant for a designated period of time.

PARKING

The cost of parking near the hospital can be very high. The most expensive lots at Toronto General Hospital are those closest to the building on the same city block. The covered lot on Elizabeth Street is less expensive and donors may obtain books of tickets at a lower cost, or arrange to pay monthly parking by talking to the attendant at the white trailer. Alternatively, other less costly parking is available within a short distance of TGH particularly for those who arrive early. It is worth looking at the costs of nearby lots if you will be making many trips to TGH.

HOUSING

Some donors and /or their families may wish to relocate to the Toronto area in order to remain close to the patient or for other reasons. A short-term housing brochure is included in this manual.

TRAVEL

The main source of assistance with travel for those living in Ontario's north is the Northern Health Travel Grant. Donors must make the initial outlay for their trip and then apply for reimbursement. Financial assistance for travel may also be available for anyone on social assistance, no matter where they live, but the application has to be made at the donor's local office.

Please note: Donors should have their local doctor fill out his/her section of the travel grant form, and then bring the partially completed form to the specialist at TGH so the specialist's part can be filled out.

For others who do not qualify for the Ontario Northern Travel Grant, travel to Toronto may be claimed as a medical expense (see Tax Tips below). However, this claim can only be made once a year after the donor makes the initial outlay.

TAX TIPS

We recommend that all donors contact Revenue Canada to obtain all the information they can regarding deductions they may make on their Income Tax related to their organ donation and any other medical expenses in their families. However, here are some general deductions available to keep in mind at tax time:

- Medical expenses include long distance telephone calls to the hospital, any diagnostic procedures you have paid for, payments to hospitals, drugs, premiums for private health service plans and parking. You must have receipts for all your expenses and you cannot claim anything for which you were reimbursed.
- You may claim expenses for yourself, your spouse and, with some limitations, your dependants.
- Out of Canada medical expenses can be deducted for the portion not covered by OHIP.
- You can claim expenses for any twelve-month period ending in the current year.
- If you travel more than 40 km one way for treatment, you may be able to claim transportation costs: train, bus or taxi costs. If you used your own car, you can claim a reasonable amount, i.e., \$0.38/km. You will need to prove the number of trips you made, which is best done by keeping your own mileage log and having a health care provider initial the date each time you come to hospital. If you travel more than 80 km one way, you are entitled to claim reasonable expenses for meals and accommodation as well.

If you have further questions regarding these issues, please contact your social worker.

LEGAL INFORMATION FOR TRANSPLANT DONORS

Powers of Attorney

There are two basic forms of Powers of Attorney (PoA): Powers of Attorney for Personal Care and Powers of Attorney for Finances. Although a full recovery in a short period of time is expected, it is important that each donor considers his/her situation and makes appropriate plans.

- **Powers of Attorney for Personal Care**

Powers of Attorney for Personal Care decisions are legal documents in which people state whom they would want to make health care decisions for them, should they become unable

to do so themselves. If there is no Power of Attorney signed and a patient is unable to act for him/herself, the Health Care and Consent Act, section 20 determines the substitute decision-maker in this order:

- 1) the guardian, provided the guardian has the authority to give or refuse consent to treatment
- 2) the Power of Attorney for Personal Care
- 3) a representative appointed by the Consent and Capacity Board
- 4) spouse or partner (a partner is defined as a person who has been living in a conjugal relationship of primary importance of 12 months or longer and recognizes same sex relationships)
- 5) child over 16 years of age or parent
- 6) brother or sister
- 7) any other relative.

If there is no one who can fulfil such a role, then a public official may need to be appointed. In cases where people want to have someone other than the usual substitute decision-maker become responsible for health care decisions, it is very important that they make their wishes known via a PoA. Copies of this document should be given to your physician, the person who will be acting as PoA, and a copy should be placed on the hospital chart at the time of surgery.

- **Powers of Attorney for Finances**

Powers of Attorney for Finances are legal documents in which the person who is to assume responsibility for making financial decisions, payments, etc. should you be unable to is named. There are various types of PoA's to meet the needs of a variety of situations.

Since all Powers of Attorney are powerful documents with far-reaching consequences, you are strongly advised to seek legal advice prior to signing one. It would be to your benefit to make sure that the Powers of Attorney being signed are set up exactly as you wish.

INFORMATION FOR CAREGIVERS/PARENTS OF MINORS

Donors who are caregivers to others, including minor children will need to plan carefully for their dependents during their absence from home and their recovery period. Substitute caregiver/s will need to be designated and their responsibilities clarified. Please remember that donors will not be able to be fully active for several weeks, so will need help during their own recovery. Although it is most unlikely that a donor would become seriously incapacitated, it is still the responsibility of the caregiver to plan for such a situation and name appropriate guardians for those in their care.

INFORMATION FOR DONORS FROM OUT-OF- PROVINCE/COUNTRY

Donors from outside Ontario can expect to have their medical and hospital expenses covered either by their own province or OHIP, depending upon the circumstances of their situations. Other expenses, such as transportation, accommodation and lost income are not covered and donors will need to make their own arrangements in their own provinces or countries to meet these costs (see Tax Tips).

Your Hospital Stay

THE PRE-ADMISSION VISIT

Once the date for transplant has been set, you will be seen in the Pre-admission Clinic at the Toronto General Hospital, not more than one month before the planned surgery date. You will be admitted to the hospital the day before your operation.

What can I expect?

A pre-admission visit involves a review of your assessment. It also helps to reinforce what you have learned about your surgery. This visit takes place at the hospital. The length of the visit may be from a few hours to all day. The visit takes place within a month of your surgery. Take any medicine(s) as usual unless otherwise instructed. Eat as usual on this day.

- During the pre-admission visit, the following **may** be carried out (depending on the date of any previous tests):
 - admitting process
 - blood work, ECG, chest x-ray & other tests
 - anesthetic assessment
 - nursing care assessment
 - you may meet the Thoracic Nurse Coordinator
 - you may be taken up to the ward (7ES) to see the Step Down Unit.
- Do not make any changes to the information on your health card or hospital card after your pre-admission visit.

What should I bring to the preadmission visit?

- your health card and hospital card
- information on coverage from your extended health insurance plan such as policy numbers
- your social insurance number if you have extended health insurance
- a credit card
- all of your medicines in their original bottles
- this booklet
- a lunch or lunch money if you are here for the day
- a book, knitting, a magazine...something to do if you should need to wait

If you do not come for your pre-admission visit your surgery will be canceled unless other arrangements have been made.

What is the purpose of the nursing care assessment?

The nurse will work together with you to identify areas in which you may need help as you recover. This will help the nurse and health care team to look after you better.

Details and information about the following will be discussed:

- preparing to come to hospital
- your surgery
- your care and what is expected of you to help you recover
- managing your pain and other symptoms
- exercises and types of activities you must do
- plans for your discharge home.

What happens if there is a change in the operating room schedule?

The operating rooms may be required for immediate life threatening emergency surgeries. We do not have any advance warning of this. If this occurs, your surgery may be affected. The time or date of your surgery may be changed. You will be notified as soon as possible of any changes. If your surgery is canceled, the Transplant Team will arrange a new date.

What special instructions do I follow before my surgery?

- **Follow all special instructions and preparations explained to you ahead of time. Your surgery could be canceled if you do not follow the instructions.**
- Your surgeon and anesthesiologist will discuss any medicines you take. Tell your surgeon if you are on blood thinners. Examples of blood thinners include coumadin (warfarin) or aspirin. Blood thinners may need to be adjusted or stopped.
- Remove all nail polish at home before surgery.
- Do not eat any food after midnight, the night before your surgery. You may have clear fluids to drink up to 5 hours before your surgery time. Clear fluids include juice, soft drinks, beef or chicken broth, and jello. Do not drink milk or eat solid food. Do not have anything to eat or drink after this time. This means no water, tea, coffee, candy, or gum. Do not smoke after midnight.
- You may brush your teeth or rinse out your mouth. **DO NOT** swallow any water.
- If you have been told by the anesthesiologist to take a medicine, take it with only a **SMALL** sip of water.

What happens if I do not feel well?

If there is a change in your health, notify the Transplant Team as soon as possible.

YOUR HOSPITAL STAY

On the day *before* your surgery, you will be admitted to 7 Eaton South, the Respirology and Thoracic Surgery Unit. The telephone number for 7 Eaton is:

 **416-340-3166**

What Should I Bring to the Hospital?

ALL patients are expected to bring:

- Your blue Toronto General Hospital identification card
- **Your Ontario Health Card (or other provincial health card if from another province)**
- This manual

Other items of a personal nature:

- An accurate list of all medications (names, doses, frequency) that you take, or bring the medications with you
- Your drug card, private drug insurance information (if you have one)
- A Telephone Calling Card if you want to use pay phones or to avoid paying a daily user fee for a phone in your own room
- A credit card which you can use to pay for a television and/or telephone
- Small change to cover the cost of newspapers, coffee shop, pay phone, etc.
- A *small* overnight bag
- All needed toiletry items: soap, shampoo, comb/brush, toothbrush, etc.
- Lip and skin moisturizer (the air in the hospital tends to be very dry)
- Mouthwash (if you use it on a regular basis)
- Glasses or hearing aid if needed
- A box of kleenex
- Bathrobe which opens all the way down the front
- Slippers with a closed-in heel and rubber soles, or running shoes
- A good book or magazine
- Your own pillow if you have specific needs (i.e., special neck pillow)

- Portable TV head phones if you have them at home and intend to rent a television while you are in hospital
- A change of loose, comfortable clothing

Do Not Bring

- Any valuables such as rings, watches, jewellery
- A large amount of cash (a maximum of \$20.00 may be locked up on the ward, any more than that must be locked in the hospital vault by security)
- Any large electrical equipment which needs to be plugged in (you may bring an electrical razor or hair dryer)
- A cellular phone (you cannot use this in the hospital)

What services are available while I am in the hospital?

- Television and telephone service may be purchased by completing a request card during the pre-admission visit. If you would like service once on the nursing unit, ask the ward staff for a request card. The sales person will visit daily. You must be in your room before the TV is installed. Payment can be made by cash, credit card, or cheque with identification.
- **A cellular telephone may not be used in the hospital as it interferes with medical equipment.**
- Semi-private and private rooms may be available at an extra cost per night unless you have insurance coverage.
- If you have semi-private coverage you may upgrade to a private room by paying the difference in cost.
- A gift shop.
- Hairdresser and barber.
- Pharmacy.
- A bank machine.

What will happen on the day of my surgery?

- Men will have their chest shaved. Your chest will only be shaved on the side of your surgery. A member of the shave team will shave you. The nurse will ask you to empty your bladder. A porter will escort you to the patient holding area. This is the waiting room outside the operating room. Most patients walk to the patient holding area. You will need to wear your slippers. If you cannot walk, you will be taken by wheelchair or stretcher.
- A relative or friend may wait with you on 7ES until you are taken to the holding area.
- The operating room is on the 2nd floor.

What will happen in the patient holding area?

A nurse and an anesthetist will see you. An intravenous (IV) may be started in your arm. You may be given something to help you relax. You will be taken to the operating room from here.

YOUR SURGERY

You will find that the OR is cool and there will be quite a bit of equipment. This equipment is used to monitor your condition during the surgery. You will also see many members of the team as they prepare you for the operation. You will be assisted onto the operating room bed. You will be covered with a warm blanket. You will have a blood pressure cuff put on your arm. An oxygen monitor will be placed on your finger. Your heartbeat will be registered on a heart monitor. A plastic mask will be placed over your face to give you oxygen.

Medicine will be given through an intravenous line. This will make you go to sleep. Once you are asleep, a breathing tube is inserted into your windpipe (trachea). This is usually removed before you leave the operating room.

You will have one incision after your surgery. The incision will be on your side as you discussed with the surgeon. This is called a thoracotomy incision. It will be either on your right or left side, depending on which lung lobe is donated. The larger of the two donors will donate the Right Lower Lobe. The other donor will donate the Left Lower Lobe. Both donors are in the operating room at the same time. The surgery itself may last 2-3 hours.

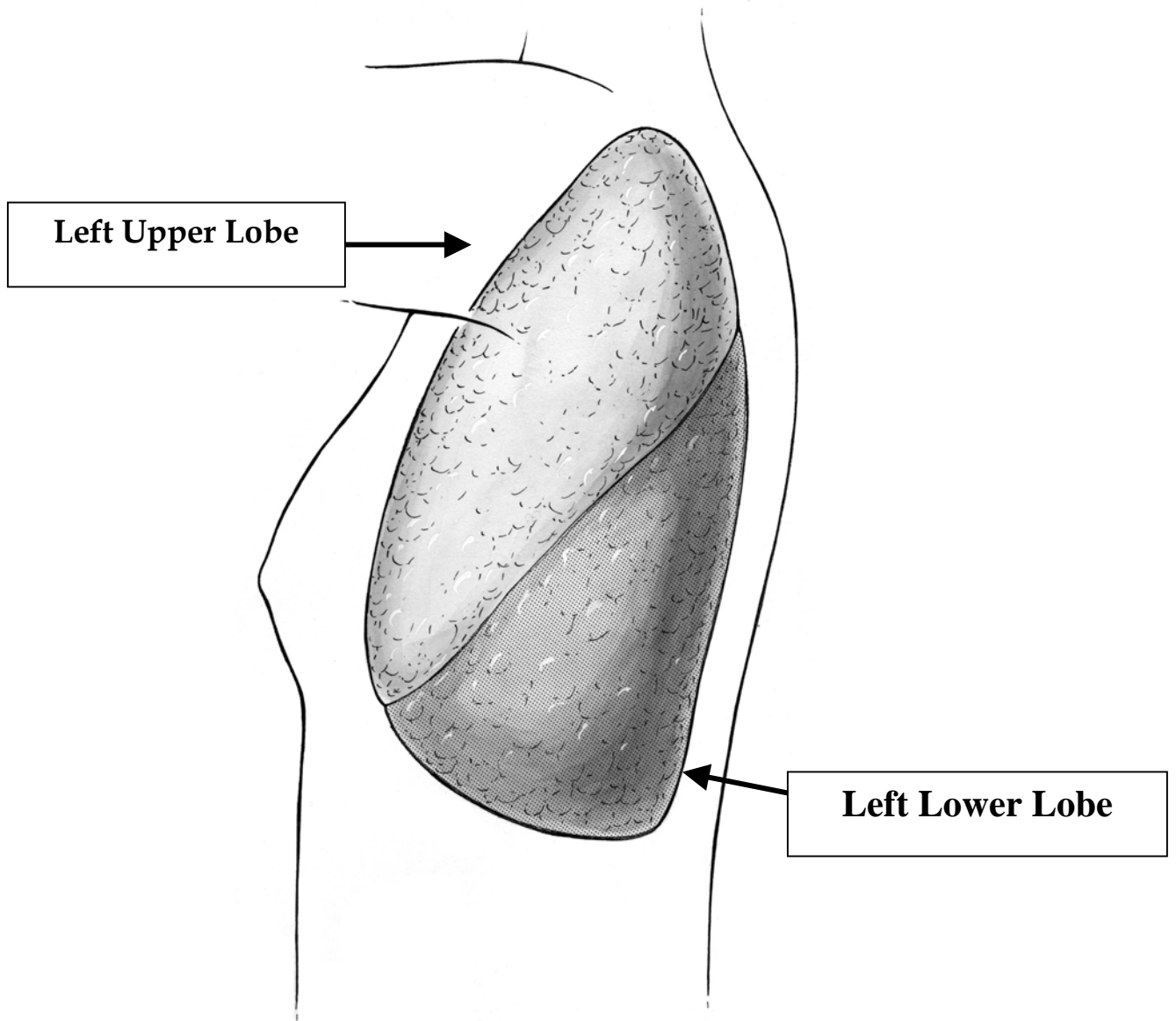
Bleeding is a risk during surgery. You may require a blood transfusion. You may donate some of your *own* blood *before* the scheduled surgery date and this blood will be given back to you if needed. This blood will not be given to anybody else if you do not require a transfusion. Ask your transplant co-ordinator about how to bank your own blood for your operation.

After your operation is finished, you will be taken to the **Post-Anaesthesia Care Unit (PACU)**. You will stay there for several hours until you are more awake. Then you will be transferred back to the 7th floor. You will have a chest X-ray done immediately after the operation in the Past Anaesthesia Care Unit. Your blood pressure, heart rate and breathing will be monitored frequently. You will be wearing an oxygen mask.

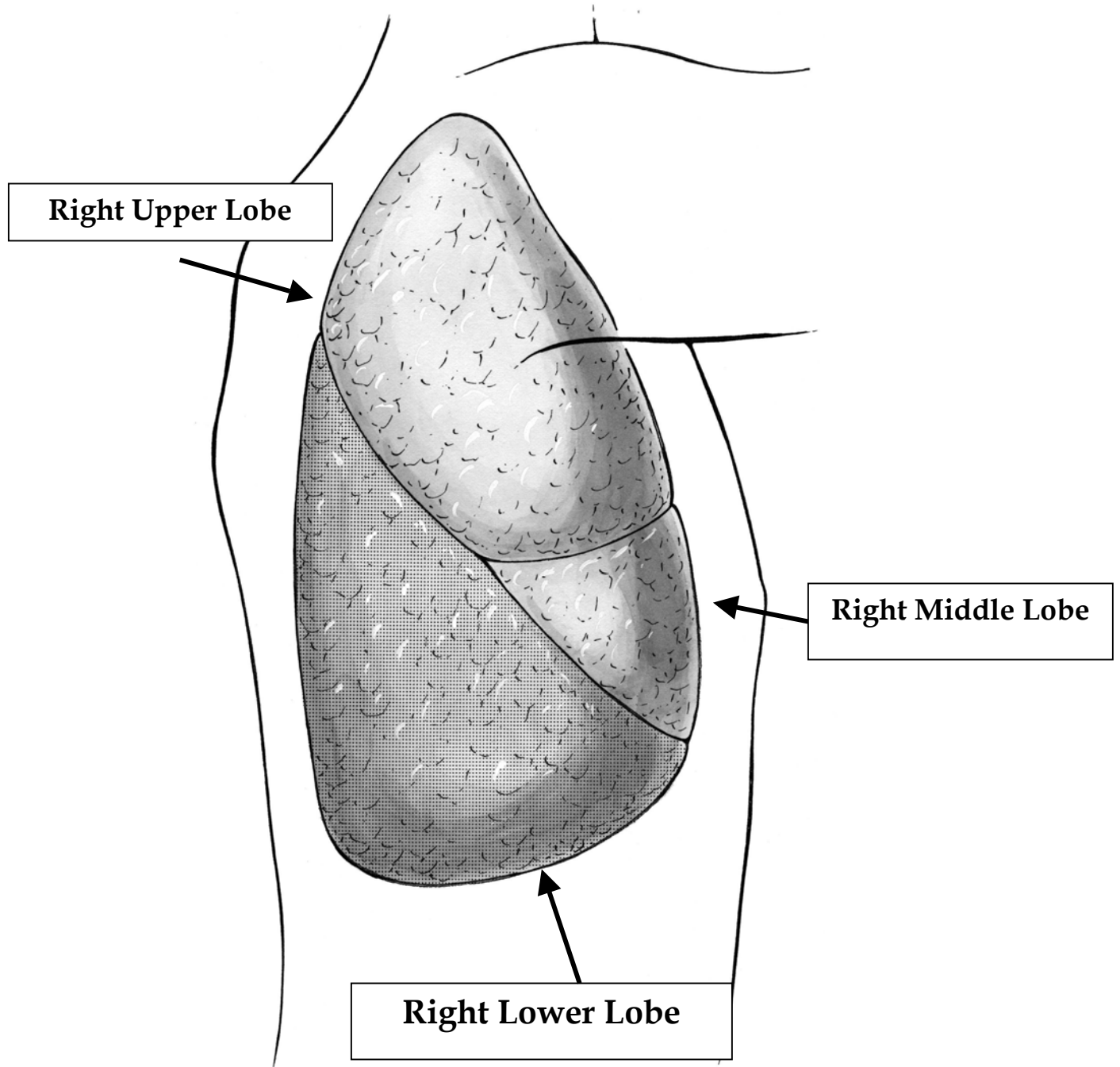
While you are in the operating room, your family can wait in the surgical waiting room on the 1st floor of the Eaton Wing. The waiting room is staffed with a hospital volunteer that can call for information while you are in the operating room and the Post-Anaesthesia Recovery Room. Your family can visit you once you have returned to the 7th floor. The surgeon will talk with your family after your surgery is completed.

The following pages show pictures of your lung and the incision both before and after the surgery. Remember, you will only have once incision, though both sides are shown here.

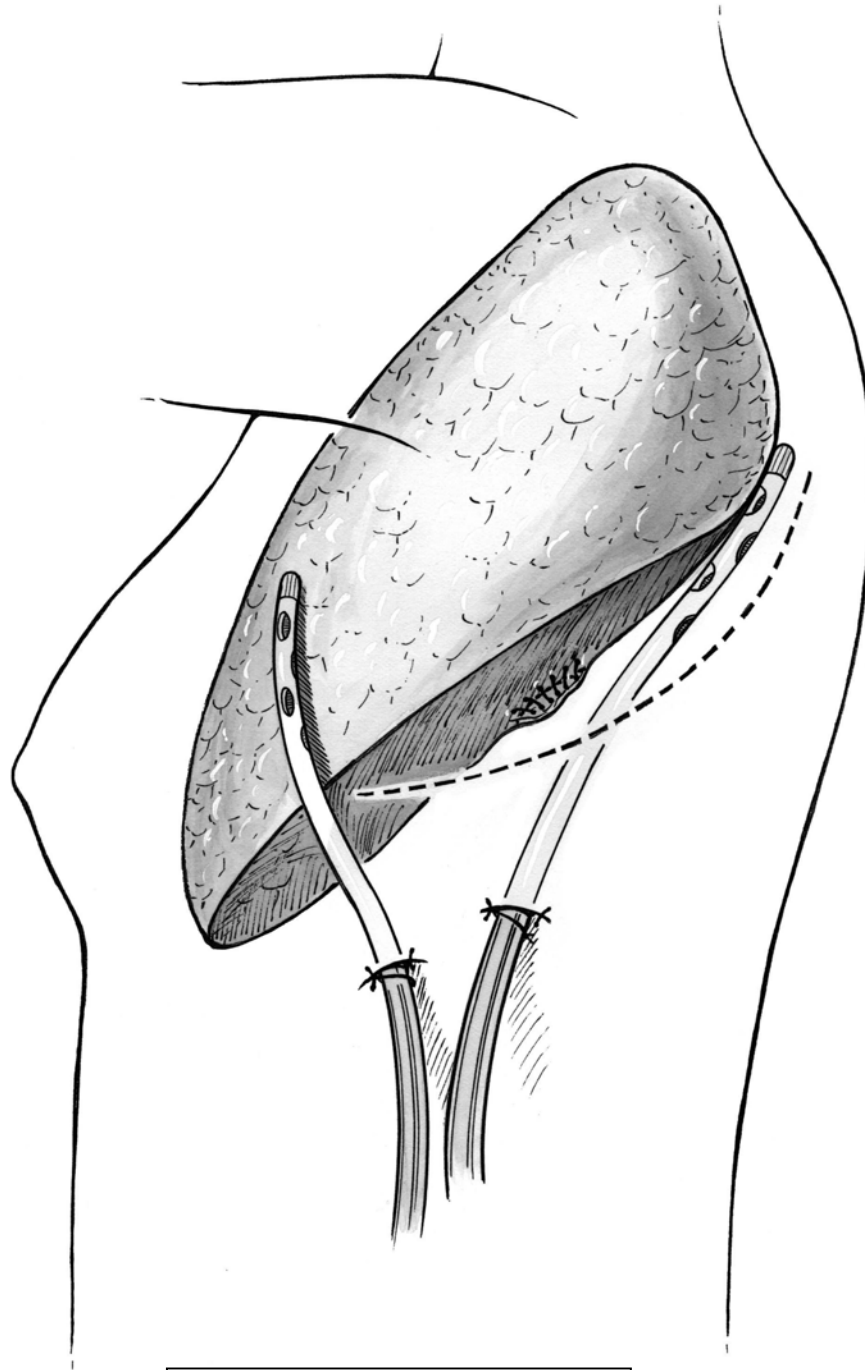
YOUR LUNG BEFORE DONATION



YOUR LUNG BEFORE DONATION

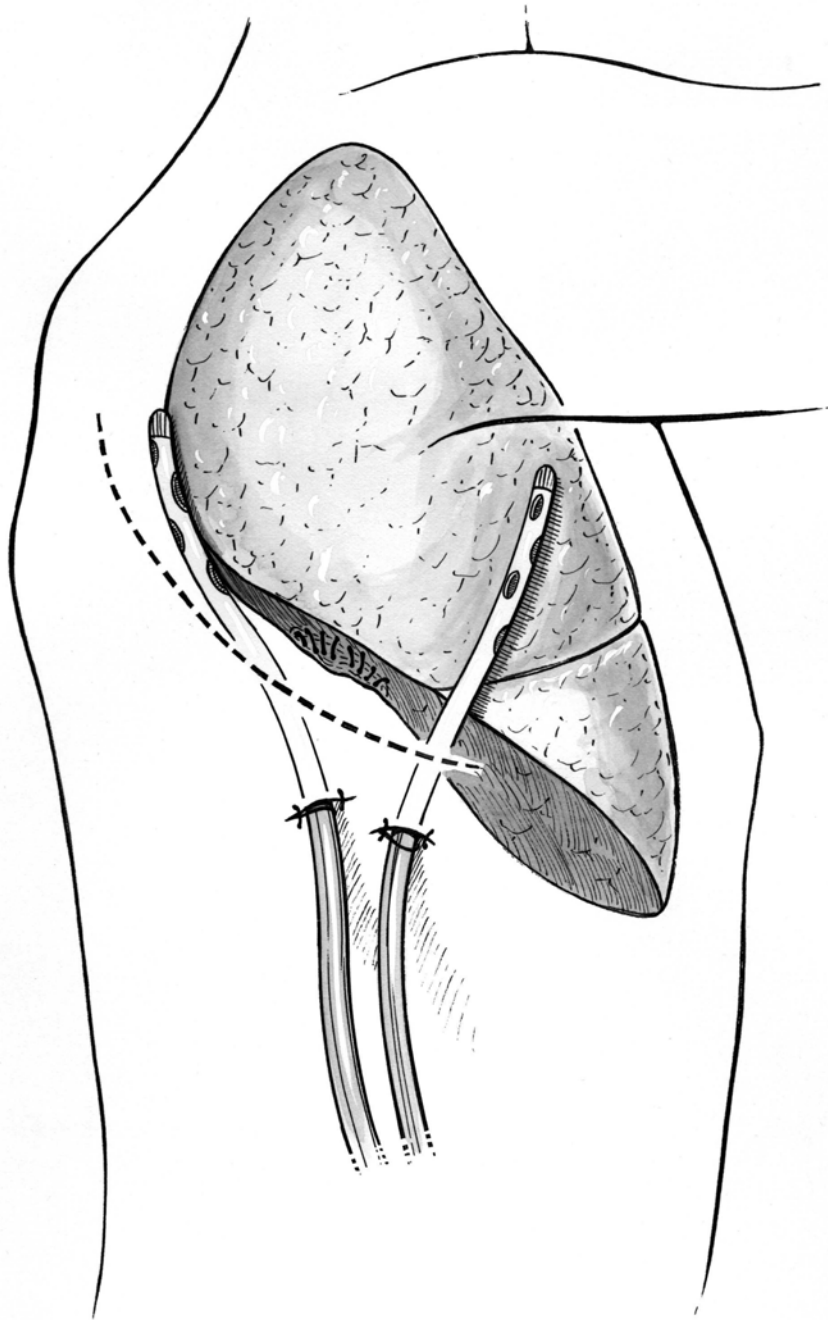


YOUR LUNG AFTER SURGERY THE INCISION



Left Lower Lobe Donor

YOUR LUNG AFTER SURGERY THE INCISION



Right Lower Lobe Donor

RECIPIENT SURGERY - DOUBLE LUNG (LOBAR) TRANSPLANT

Once the portions of the lung have been removed from both donors, they will be packaged up in sterile containers and taken to the operating room where the recipient is waiting for the transplant.

A double lung transplant is done through a transverse sternotomy incision. This incision is just at the base of the breasts going from the right to the left side through the breastbone.

The double lung transplant is done by replacing each lung separately. When the new lung lobes arrive at this hospital, the transplant recipient's first lung will be removed. The recipient will be ventilated on the remaining lung unless it is unable to exchange enough oxygen; in this case they will be placed on the cardiopulmonary bypass machine (*pump*). (The bypass machine is used in less than half of the cases). Even when they are using the pump, the heart will continue to receive and pump blood itself; this is called partial bypass.

Once the first lung is removed, one donor lung lobe will be attached. There will be 3 connections (anastomoses) for each lung. First, the donor bronchus is attached to the transplant patient's main bronchus. Next, the pulmonary artery is connected to the donor artery, and finally the donor's pulmonary vein is attached to the left atrium in the transplant patient. At this point, blood flow is restored to this first new lung.

The second diseased lung is then removed. The second new lung lobe is attached exactly as the first one was, except on the opposite side. Once the second lung is completely connected, blood flow is restored to it. The patient will be weaned from the cardiopulmonary bypass machine if it was used, slowly, by gradually letting the heart receive more of the blood volume, which it will pump to both new lungs to receive oxygen.

THE THORACIC SURGERY UNIT

Once you've had your surgery, you can expect to be in the hospital for about one week.

You will be cared for on the **Thoracic Surgery/Respirology Unit, 7 Eaton South**. Initially, you will be cared for in the **Step-Down Unit**. You will be there for 1-2 days. This intermediate care area is an open concept room consisting of several beds, a nursing station, and special equipment that is necessary to maintain your safety during the immediate post-operative period. Visiting hours are from 11:00 a.m. to 9:00 p.m. daily. In the Step-Down Unit there is a rest period from 1:00-2:30 p.m. daily when your visitors will

be asked to leave. Following your transfer from the step down unit; you will be nursed on the main nursing unit on 7 Eaton South.

We encourage your family to be involved in your care. Ways that your family may be involved include: sharing information, decision making, being present for tests and helping with your care. We also encourage your family to take care of themselves. Your relatives may become very tired while you are in hospital. The nurse may ask your family to take a break. This may mean going home for a rest. Each floor has a visitor's lounge. The visiting hours are posted. Only two people may visit at one time. If your family has any questions how they can help, please ask the nursing staff. You may have special needs after surgery that your family is not aware of.

Family can call for information while you are in hospital. Please pick one family member as a central contact person. Information can be given to the person you pick. This person can pass on the information to your family.

The 7th floor Eaton South Nursing Station (7ES) phone number is:

 416 - 340 - 3166.

POST-OPERATIVE CARE

There are well-established routines for caring for patients following the removal of part of their lung. You can expect the following:

- **Vital signs**

Your nurse will be checking your blood pressure, pulse, and temperature. The nurse will also be checking your heart, breathing and oxygen level.

- **Heart monitor**

You will be on a heart monitor. This does not necessarily mean you have problems with your heart. The monitor will record your heart rate and rhythm. This is the normal routine for patients with this type of surgery. You will be on the monitor while in the Step-Down Unit.

- **Oxygen Mask**

An oxygen mask will cover your nose and mouth. This gives you extra oxygen. You will need this for a short period after surgery. When your lungs are working well enough the oxygen will be taken off. The mask puts extra moisture into the air you are breathing. This will help to moisten lung secretions. More moisture will allow you to cough out the mucous.

- **Arterial Line**

You will have an arterial line. This is usually put in the opposite arm to the IV. This tube looks like an IV. It is placed in the radial artery in the wrist. It is used to take blood samples without having to

poke you with a needle. The arterial line will be in for 1-2 days while in the Step-Down Unit. The arterial line can be hooked up to a monitor to record your blood pressure.

- **Chest Tubes**

The lung is like a balloon filled with air. When the surgeon enters the chest cavity to remove the portion of the lung the remainder of the lung will deflate. Once the remaining lung is stitched up, chest tubes will be inserted to allow the remaining lung to re-expand. These tubes drain the space between the pleura of fluid and air. These tubes will be connected to suction for a few days to help the lung expand fully. The chest tubes are inserted through two small separate incisions. They are held in place by stitches. Chest X-rays are done to determine the position of the tubes and expansion of the lung. Once the lung is fully expanded and there is no longer fluid or air draining from the chest tubes, they will be removed. This occurs usually within 2-5 days after the surgery.

- **Urinary Catheter**

You may have a tube draining your bladder. This tube is also known as a Foley catheter. It will be inserted in the operating room when you are asleep. The tube is connected to a collection bag that your nurses will empty during their shift. The catheter will be removed several days after your surgery. Most patients do not find a urinary catheter uncomfortable. The catheter does not restrict your movement and should be taped to your leg to prevent irritation. It is easily removed by deflating the balloon that holds it in place. Since you will be restricted to bed for a while after your surgery, the catheter will also help make things easier for you.

- **Intravenous Lines (IV's)**

An intravenous (IV) line is a small catheter inserted in a vein in your arm, hand or neck. It is used for giving fluids and medications. The intravenous sites will be changed routinely every three days to prevent infection from developing at the intravenous site. You can expect to have some sort of IV for several days after your surgery. Once you are drinking fluids, the IV line will be removed.

- **IV Pumps**

An IV pump is a device that allows your nurse to administer an exact amount of medication or fluid to you via your intravenous lines.

- **Eating and Drinking**

You may feel nauseated and sick to your stomach after you wake up from the anaesthesia. Following surgery it is common for the stomach and bowels to be sluggish for several days. You will receive fluids intravenously, but will begin to take food and drink by mouth as well once your stomach and bowels start to move again. This will be assessed by placing a stethoscope on your abdomen. You will begin with ice chips and progressing to clear fluids, all fluids and then solid food. It is important to progress *gradually* as eating or drinking too soon after surgery may result in nausea and vomiting.

- **Participation**

Your participation during this phase of your recovery is essential and quite often is directly related to your length of stay in hospital. Deep breathing and coughing along with incentive spirometry is essential in preventing the development of lung infection. It is also very important to get up and sit in the chair, and go for walks. This may seem to be an impossible task with all the intravenous lines, tubes and infusion pumps, but you will be assisted by the physiotherapist and your nurse. Activities get easier to perform each day so it is very important to stay motivated.

- **Tests and Procedures**

Following your surgery, you can expect to undergo a number of tests, including chest x-rays and blood tests.

- **Activity**

Once you are transferred to the regular hospital room on the nursing unit, your activity level should increase gradually each day. Exercise is an important aspect of your recovery phase, to improve muscle tone, increase your appetite, and prevent complications associated with inactivity.

- **Physiotherapy**

It is common for lungs to have a lot of mucus after surgery. It is extremely important to remove the mucus from your lungs before they become infected or impair the exchange of oxygen and carbon dioxide. However, it will be painful to move and you must make a conscious effort to take deep breaths, cough and get up out of bed. You will be given medication to dull the pain, allowing you to take big breaths. The physiotherapists and the nursing staff will be able to assist you.

Your physical therapy will assist you with:

- leg exercises performed in bed (beginning right after your surgery to help prevent muscle weakness and the formation of blood clots)
- sitting on the side of your bed and dangling your feet
- getting up and sitting in a chair
- walking
- incentive spirometry

- **Incision Site**

Your chest will be sore post-operatively because of the incision made through the skin and muscles for removal of the donated lung lobe. The skin is held together with sutures (stitches), which are usually dissolved by the body. There may be a non-dissolving stitch where the chest tube was placed. It can be removed after a couple of days. Over the incision, there will be a dressing for the first few days. Any remaining sutures that need to

be removed can be removed either by your family doctor or the transplant coordinator if you are already discharged from hospital. This will be arranged with you before discharge.

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

- to protect your skin from pressure sores and
- to help keep your lungs clear.

The nursing staff will assist you to move and make you as comfortable as possible. Please refer to the following section on pain management.

• **Rooms**

On the nursing unit there are a limited number of private and semi-private rooms. These rooms are allocated based on medical need first. Some patients may require a single room because they must be in isolation and cannot safely be close to other patients. At times, patients may need a single or semi-private room because of the severity of their illness. Once these needs have been met, staff will then assign rooms based on individual health insurance coverage and the availability of rooms. Thus, patients should be prepared for the fact that they may not necessarily be able to be placed in a private or semi-private room even though they have the necessary insurance coverage. Patients who need private or semi-private rooms for medical reasons, but do not have the necessary coverage will not have to pay extra for their room.

At times it may be necessary to move patients from one room to another. Although such moves can be unsettling and inconvenient, they may occasionally be necessary in order to meet the changing needs of all of our patients. Staff would like you to be reassured that these measures are taken to protect all patients and to ensure that each receives the best possible care.

PAIN MANAGEMENT

Patients are often concerned about whether they will have pain after surgery and how that will be dealt with. Here are the answers to some of patients' more common questions. Feel free to ask your nurse/donor assessment coordinator if you have any further concerns. While in hospital you will be seen periodically by members of the pain management team.

Will I have pain after surgery?

Yes, most patients have some pain after surgery. You can expect to feel pain in the area of your surgery. You may also feel stiffness and aches in other areas. Pain medicine will help

to relieve some of your discomfort. We encourage you to use the pain medicine. It will help you start moving around, sitting, and walking sooner. Pain medicine will help you to get better sooner.

How will my pain be managed?

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

Pain Management Options:

Most patients are treated with only one of the options at any given time.

- **Intravenous (IV) Patient Controlled Analgesia (PCA)**

Patient controlled analgesia (*PCA*) involves connecting a PCA pump to your intravenous (*IV*). The pump contains pain medicine. When you feel like you need something for pain you should press the button attached to the PCA pump and the pump will give you pain medicine through your *IV*.

You should press the button:

- When you start to feel pain
- Before you do something that brings on pain
- Before deep breathing and coughing exercises
- Before you start to move or turn.

Do not worry about giving yourself too much pain medicine. The PCA pump is programmed to give you only a small amount of pain medicine each time you push the button. Also, the PCA pump has a safety timer called a *lockout*. The lockout time is between 5 and 10 minutes. If you press the button during the lockout time you will not receive more medicine. There is also a limit as to how much pain medicine you can have in any 4-hour period.

Only you should press the button. Visitors and family members should not press the button for you. Do not use PCA for gas pain.

- **Epidural Patient Controlled Analgesia**

An epidural is a small tube placed by an anesthetist into your back. The tube is the same as the one used by women during childbirth. The anesthetist will clean and freeze

an area of your back. A needle is placed into your back and a small tube is placed through the needle. The needle is removed and the tube is taped to your back. Medicine is given through the tube to provide pain relief. The medicine given is a narcotic (painkiller) and local anaesthetic (freezing). This medicine will help to take pain away. The medicine may make your chest and possibly lower down feel numb. Your nurse will check to see if this is a problem. A PCA pump will be attached to your epidural to give you pain medicine all the time. You should press the button attached to the PCA pump to receive more pain medicine if your pain is not under control.

- **Intravenous (IV) Medicine**

With this method, your nurse gives pain medicine through your IV. It is important to tell your nurse when you have pain.

- **Intramuscular (IM) Medicine**

You can receive pain medicine by a needle. The medicine is put into a muscle – usually the nurse will put it into your buttocks. Let your nurse know when you have pain.

- **Medicine by Mouth**

Once you are able to drink fluids you will be given pain medicine in a tablet form. Your nurse will give you pain pills when you need them. Pills take longer than IV medicine to work so it is important to let your nurse know when you need pain pills *before* the pain becomes severe.

Are there side effects of pain medicine?

Some patients may have some side effects from their pain medicine. The side effects can include nausea and vomiting, sleepiness, or itching. Tell your nurse if you have any of these side effects. Pain medication is commonly known to affect the normal functioning of the stomach and bowels. This can result in the nausea and vomiting mentioned and a slow return of gut function. Lack of appetite and constipation are not uncommon.

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

Tell your nurse or doctor if you are having pain. You can use a scale from 0 to 10. Where 0 is no pain and 10 is the worst pain ever. You can also use words such as “mild,” “moderate” or “severe.”

Are there any other ways to control my pain?

Other ways of managing pain include some of the following:

- **Relaxation Breathing**

This involves redirecting your focus away from your pain and concentrating on your breathing. Focus on your breathing by taking slow deep breaths in through your nose and blow breaths out through your mouth.

- **Visualization**

Visualization involves imagining yourself without pain. You begin by closing your eyes. Imagine yourself in a specific place or time that brought you happiness. It may be on a beach, at the cottage, or on a mountain top. Try to remember the sounds, the smells, and every detail of the experience.

- **Massage**

Gently rubbing your back, shoulders, or arms can relieve tension. This can help to decrease your pain. A family member can help you with this.

RISKS AND COMPLICATIONS

There are common risks associated with this type of surgery.

- **PSYCHOLOGICAL**

Stress is common for those who are facing any major operation, and may be more severe for donors who are closely related to a person receiving a life-saving organ transplant. Since donors are people who are “healthy” before this operation, it may be more difficult for them to be in a “sick” and dependant role for several weeks after surgery. Family dynamics and roles may be disrupted during the recovery period. Instead of being someone who cares for everyone else, you may be the one in need of care and attention. These changes can cause acute anxiety and emotional distress for some people. In addition, despite your donation and everyone’s best efforts, some recipients will not survive the transplant or may be very ill for some time afterwards. Psychological distress may delay your healing and return to health. We would like you to know that the Transplant Team and the Psychosocial Team is available to help you through this difficult time.

A primary concern of the Transplant Team is to protect all potential donors and to do everything possible to ensure their long-term health. During your donor evaluation, you will go through a number of tests and appointments. Any medical problems that are discovered will need closer evaluation. You will be referred to the appropriate specialists to carry out these investigations. Sometimes potential donors are not medically suitable to give an organ for a variety of reasons. In some cases a previously unknown medical condition may be revealed. Again, the Transplant Team and the Psychosocial Team are able to assist you with this outcome.

Should you be found to be a suitable donor and proceed to donate an organ, it will be several days until the chest tubes are removed from the suction, allowing you to travel off the nursing unit. Following your surgery the nursing staff on the unit and the Transplant Team will keep you up to date on how the recipient is doing. Once you are up walking around we will encourage and assist you to visit the recipient, including traveling to see those who have been transplanted at the Hospital for Sick Children.

Fatigue and difficulty sleeping are common after major surgery. Try to take a nap daily when first discharged from hospital. Feeling well rested will help you manage any of the emotional upheaval that may occur.

- **REDUCED LUNG FUNCTION**

When you donate a lower lobe of one of your lungs, you will experience a permanent reduction in your lung size by 20%. Most people do not use their complete lung volume when breathing and going about every day activities except serious athletes doing strenuous exercise. You should be able to carry on with your normal activities after

transplant however; it will be several weeks before you are able to partake in certain physical activities.

- **WOUND INFECTION**

The skin is the major barrier in the body against bacterial infections. When your skin surface is disrupted with a surgical incision, bacteria can enter the wound causing infections. The chest tube sites are also possible sites for infection.

The signs and symptoms of a wound infection are:

- Fever. You may become flushed and develop a temperature. A temperature over 38° C (Celsius) is significant.
- Redness around the site.
- Tenderness at the site. It may be puffy and warm to touch.
- Pus. You may notice yellowish discharge at the site or on your dressing. It may be foul smelling.

If you develop any of the signs of an infection, call your donor assessment coordinator or surgeon's office immediately.

- **PNEUMONIA**

It is common after surgery to have more secretions in your lungs. Pain from the incision will inhibit your ability and willingness to clear these away completely. Retained secretions can predispose you to pneumonia.

The signs and symptoms of pneumonia are:

- Fever. You may become flushed and develop a temperature. A temperature over 38° C (Celsius) is significant.
- Shortness of breath
- Cough producing sputum. The sputum may be yellowish-green tinged, may contain blood streaks and may be foul smelling.
- Chest tightness or chest discomfort on inspiration.
- Fatigue. You may feel very listless or tire easily.

If you develop any of the signs of pneumonia, call your donor assessment coordinator or surgeon's office immediately.

With the removal of part of your lung and cutting through the skin and muscles during the surgery, you will experience pain. This is to be expected. Pain management strategies cannot get rid of the pain completely but can make it more acceptable. It is important to have your pain managed within an acceptable level so that you will be able take deep breaths and cough on a regular basis.

Deep Breathing Exercises

- Take a deep breath in through your nose. Hold your breath for a second; breathe out.
- Take a deep breath in through your nose then take two sniffs in as if to smell some flowers; breathe out.
- A series of deep breaths gets air down deep to the bases of the lungs that could otherwise collapse. The movement of the air also helps to open the passages and move secretions out. This makes coughing easier.

Coughing

- Hug your pillow against your stomach.
- Take a deep breath in and *huff* it out. (Huffing is like pretending to create a mist on a pane of glass).
- Repeat this three times then take a deep breath, hold it a second and cough strongly.
- Try to cough every hour during the first few days after surgery.

Incentive Spirometry Exercises

You will be given an *incentive spirometer* by your physiotherapist or nurse. This device encourages you to take deep breaths. Use the incentive spirometer every hour and take at least ten breaths. To use the incentive spirometer correctly, put the mouthpiece in your mouth and close your lips. Draw air into your lungs by breathing *in* quickly and deeply. The ball in the machine will rise to the top of the column. Hold your breath for a few seconds, then breathe out *slowly*. Take a brief rest between each effort.

• **BLEEDING**

There is a small risk of bleeding from the incision site. If the bleeding is external, it will be seen on the dressing. If internal, the bleeding will be seen in the chest tubes. Excessive bleeding may mean another operation to find the source of bleeding. Before your surgery, you can bank your own blood to receive in the event you need a transfusion. Please ask your donor assessment coordinator or surgeon how this can be arranged.

• **AIR LEAK**

Your lung is like a balloon filled with air. When part of the lung is removed the remainder of that lung will need to be inflated after the area has been sewn up. This is done by a chest tube. The chest tube will attach to suction to assist with the re-inflation.

If the remaining lung has a leak, it will be seen in the chest tube apparatus. This may require the chest tube to be kept in place longer than usual until the leak heals. Daily chest x-rays will be done to determine the state of your lungs and if they are well inflated following the surgery.

- **IRREGULAR HEART BEAT (ARRHYTHMIA)**

The lungs and heart are intimately linked inside your chest by the blood vessels. Manipulation of these vessels with the removal of a portion of the lung may result in an irregular heartbeat. This can usually be treated with medications. A rapid irregular heartbeat is more serious as it may result in low blood pressure. Careful monitoring of your heart rate and blood pressure after the surgery will bring any problem to the attention of team as soon as possible.

- **PERICARDITIS**

The heart is contained within a sack in the chest called the pericardium. This sack may become inflamed following the manipulation of the blood vessels with the removal of a portion of your lung. It may also happen as the result of infection. Fluid may build up in the sack, impeding the pumping action of the heart. The signs and symptoms of pericarditis are:

- Fever
- Pain on deep inspiration
- Shortness of breath
- Rapid heart beat

Treatment for this complication depends on the underlying cause. This may take the form of antibiotics and anti-inflammatory pills.

- **BLOOD CLOTS**

All major surgery carries the risk of blood clots forming in the legs. A prolonged operation where you will be immobilized while under anesthesia predisposes you to clot formation. Remaining in bed for long periods after your surgery will increase this risk.

The situation is more serious if a clot from your legs travels up to the lungs. This can cause shortness of breath, cough, and chest pain and is potentially fatal. To reduce the chance of clot formation after your surgery you will receive a blood thinner called Heparin. This will be given to you by an injection twice a day in hospital.

The physiotherapist and nursing staff will have you up and out of bed the day after your surgery. Again, good pain management is needed to help you do this as comfortably as possible. While in bed, general bed exercises can keep the muscles moving. While in bed initially after your surgery, ankle pumping, hip and knee flexion, static quadriceps and arm raises are the most important, but once you are on the ward and up walking you should try to do all eight of the Bed Exercises. (See below).

BED EXERCISES

Remember:

- Do not hold your breath.
- Do exercises slowly and carefully.
- Try to do exercises regularly.
- Start with a low number of repetitions (5) and increase gradually.
- Decrease repetitions & rest between exercises if you find them tiring.

Starting position: Lie on your back with legs straight and knees pointing at the ceiling.

1. Ankle Pumping Exercises:

To improve circulation in your legs:

- Pump your ankle up and down.
- Make circles with your feet.

2. Hip & Knee Flexion:

To improve leg flexibility and strength.

- Bend one leg to bring your knee up towards your chest
- Lower and straighten your leg back onto the bed.
- Repeat with the other leg.

3. Static Quadriceps:

To strengthen anterior thigh muscles.

- With your leg straight, tighten the top of your thigh to push the back of your knee strongly down into the bed.
- Pull your toes up towards your head at the same time. Your heel should come slightly off the bed.
- *Do not* lift your leg.
- Hold the knee straight for 5 seconds.
- Repeat with the other leg.

4. Arm Raises:

To increase rib cage movement and shoulder mobility.

- Clasp your hands together in front of you down by your waist, straighten your elbows.
- While taking a deep breath in, lift your arms up and over your head.
- Hold your breath for about 5 seconds, then
- Gently breathe out while you lower your arms to your abdomen.

5. Bridging:

To improve your hip strength and bed mobility.

- Bend your knees and place your feet flat on the bed.
- Push down through your feet and lift your buttocks off the bed.
- Hold for 5 seconds, then relax.

6. **Knee Extension Over a Pillow:**

To improve thigh muscle strength.

- Place a pillow under your knees
- Pull your toes up and straighten your knee, to lift your heel off the bed.
- Hold your knee straight for 5 seconds, then relax.
- Repeat with the other leg.

7. **Straight Leg Raise:**

To improve your leg strength.

- Bend one leg up and place your foot flat on the bed.
- With the other leg, straighten your knee, pull your toes up and lift your heel about six inches from the bed.
- Hold for 5 seconds, if possible, then lower your leg to the bed.
- Repeat with the other leg.

8. **Rolling:**

To improve your bed mobility.

- Bend up both knees.
- Turn onto your left side by turning your head, rolling your knees and reaching with your arms to the left.
- Roll onto your back and then onto your right side in the same way.

• **CONSTIPATION**

Several areas in this section mention the need for good pain management to help you deep breath, cough and exercise. One of the most common side effects of pain medication is that it slows down the function of your bowels and can lead to constipation. This in turn can make you very uncomfortable and cause abdominal cramps.

Prevention is the best way of managing this complication. There are several easy ways to tackle this problem:

- While in hospital you will be given a stool softener called Colace.
- Get up out of bed and walk around as much as you are able to do.
- Once you start to eat and drink again after the surgery, you need to remember to drink plenty of fluid (a minimum of 6 cups per day).
- If you have no other diet requirements or special needs, add bran, high fiber breads and cereals, berries, dried fruit or prune juice to your diet.
- Continue to take the stool softener. You may also use a mild laxative if you need one.

Your normal routine should return once you stop taking the pain medicine. If you have further problems see your family doctor.

Your appetite will return to normal within a few weeks as your activity level improves. Constipation can hinder your appetite. If your appetite is poor, try smaller, more frequent meals. If a poor appetite persists, please see your family doctor.

- **ANESTHESIA**

Some patients do not tolerate the anesthetic drugs used to put them to sleep for the operation. Nausea and vomiting are common after surgery. You will see an anesthesiologist prior to your surgery to screen for potential complications and explain the risks of general anesthesia.

- **DEATH**

As with all major surgery, there is a small risk of death to the donor. These risks can be minimized with careful donor screening and evaluation. The overall risk of death for this type of operation but carried out for other reasons is 1-3%. However, to date, with over 200 donor operations done in the United States, no donor has died as a result of this operation. Compared to other patients, who need part of their lung removed for other reasons, living donors are in much better condition.

COMPLICATIONS FOR LUNG TRANSPLANT RECIPIENTS

In a perfect world, patients receiving a transplant would not experience any complications. However, it is very unusual to have a perfect situation and at least one complication is likely to arise. This is not a cause for panic, and a complication definitely does not mean a failure. This section of the manual is meant to acquaint you with the experience the recipient will be going through following your lung donation.

The two most common complications following lung transplantation are infection and rejection. Infection can occur because the immune system is being altered. However, it is necessary to alter the immune system to prevent rejection.

The Immune System and the New Lungs

The immune system is the body's defense system. The bone marrow produces white blood cells, which control and carry out most immune response. Immunity is the way the body protects itself from foreign matter. Foreign matter can be such things as bacteria, viruses, and foreign tissue cells.

The transplanted lungs are viewed as an invading protein, just like a virus, and come under attack by the immune system. This process is known as rejection, which can be mild, moderate, or severe. It is the normal response of the body. It does not mean transplant failure. In order to prevent it from interfering with the normal function of the new lung, it is important to detect rejection early and to treat it promptly.

- **Rejection**

In the transplant patient, anti-rejection medications (immunosuppressives) fool the normal immune response. These drugs help to prolong the time the transplanted organ is able to work in the body. The medications work in one of three ways:

- 1) Masking the transplanted organ as part of the recipient
- 2) Binding with the immune system so it cannot recognize the transplanted organ as foreign matter
- 3) Suppressing the immune system's ability to recognize all foreign matter.

The transplant patient must take the anti-rejection medications for the rest of their life.

Rejection is common after transplantation. The average recipient has 1 or 2 episodes of rejection. Rejection is determined by biopsy of the lung(s) (bronchoscopy) and careful monitoring for signs and symptoms of rejection. The recipient and their family will be taught this prior to discharge. Rejection does not mean the lung will fail. In the majority of cases it will not cause permanent damage. Episodes of rejection are treated by giving additional medications and/or adjusting medications.

- **Infection**

A major effect of the anti-rejection medications is an increased risk of infection. All lung transplant patients are put on preventative medications to reduce the chance of infection. Even with the use of these preventative drugs, infections can occur. They must be treated *promptly*.

FURTHER INFORMATION

The transplant recipient has a manual that explains in greater detail the potential risks and complications of lung transplant. Ask them to share their Lung Transplant Manual with you to help you better understand their situation. The Transplant Team is also available to answer your questions.

A HEALTHY RECOVERY

NUTRITION AND YOUR SURGERY

- **Nutrition Before Your Surgery**

Now that you have offered to be an organ donor, your nutritional preparation for surgery is important to optimize your recovery. You may see a dietitian before your surgery. During this time, the dietitian will ask you what you have been eating at home and he/she will talk to you about your weight. If you have diabetes, you should see a dietician to discuss healthy eating and to make sure your blood sugars are under control. If you are overweight, you should see a dietician to discuss healthy eating to keep your weight within normal guidelines.

The dietitian will make sure you are following Canada's Food Guide and eating food from the four groups: milk and milk products, breads and cereals, meat and alternates, and fruit and vegetables. A copy of Canada's Food Guide is provided for you in this manual. It is important that you eat a healthy diet, especially since you will be having surgery.

- **Nutrition After Your Surgery**

As previously mentioned, your bowel function may be slowed down after a major surgery and partly due to the effects of the pain medication. A diet high in fiber and fluids will help your bowel function return to normal. Physical activity also plays a part in normal bowel function. Please refer to the sections on constipation and activity for further information.

If you have persistent nausea, vomiting or diarrhea after you are discharged from hospital that interfere with your normal healthy diet, please contact you coordinator or surgeon's office.

THINKING ABOUT DISCHARGE

Patients coming into The Toronto General Hospital for living donation will need to think about their plans for discharge well in advance. You will meet with a social worker during your assessment for donation to start addressing these issues early.

Generally, all patients are responsible for arranging for their living arrangements and caregivers once they leave the hospital. Some information on accommodation in Toronto is available through your social worker if you are from out-of-town and intend to stay for a period of time. This not uncommon with living donation as donors are frequently related to

the transplant patient. The recipient themselves may not yet be out of hospital and they are also required to be in Toronto for follow-up clinics and evaluations for a period of time after their discharge. When you are ready to go home, arranging the return trip is also your responsibility.

If you have *any concerns* regarding your discharge, please let one of the transplant team members know as soon as possible so that we can assist you with planning.

On the day of your planned discharge, please arrange for a ride with a family member or friend. Discharge time is between 9:00 and 10:00 a.m. A prescription will be given to you at the time of discharge. A retail pharmacy is located in the Eaton Lobby at the Toronto General Hospital for your convenience. It is open from 8:00 a.m. to 6:00 p.m. on weekdays and Saturday from 9:00 a.m. to 2:00 p.m. Any outside pharmacy can also fill the prescription. If you have private drug insurance, please bring your benefits cards with you. You will have to pay for any medications at discharge if you do not have any other benefits.

FOLLOWING DISCHARGE

• CARE FOR YOUR INCISION

Shower daily with a mild soap when you get home. Let the water run over your incision. Carefully pat the incision dry with a towel. Do not rub it. Do not use lotions or creams on the incision until it is completely healed. If you notice any signs of infection, please contact the donor assessment coordinator or your family doctor.

• DRIVING

You should not drive until you are off the pain medicine. You must have full movement of your arm and shoulder before you drive. This is usually 2 - 3 weeks after surgery. The pain medicine you are taking may make you drowsy.

• ACTIVITY

For the first two months donors should avoid:

- lifting more than 10 pounds
- strong abdominal exercises, e.g., sit ups
- strong upper body exercises, e.g., push ups, pull ups, pushing or pulling heavy objects

You may feel that this is a long time, but it takes six weeks for the incision to heal. Ten pounds is not very much and, depending on the person, additional discussion may be necessary. For example, people with small children sometimes forget that the lifting restriction applies to lifting their child as well. This may require some additional planning

if the patient is a parent who is caring for a young child on their own all or part of the time, or if the person does not have enough support at home to help with grocery shopping and laundry. A heavy pet, such as a fat cat, can easily weigh more than 10 pounds.

- **EXERCISE**

Exercise after surgery is an important part of your rehabilitation. Benefits of an exercise program have been shown to be:

- increased muscle tone
- increased endurance
- improved heart rate and breathing response to exercise
- increased physical fitness, which will increase your tolerance for everyday activity
- reduced resting blood pressure and heart rate
- increased self-confidence and feeling of well being

Healing After Surgery: Skin and muscle tissue takes approximately 6 weeks to fully heal with strong scar tissue. Your incision may feel stiff or achy when you are active during the healing period.

Monitoring Exercise: Exercise should be done at mild to moderate level with no abnormal responses. You should be breathing comfortably enough to carry on a simple conversation as you exercise.

Stop exercising if any of the following occur:

- incisional pain
- excessive shortness of breath
- dizziness/lightheadedness
- palpitations (heart beating fast)
- excessive fatigue
- nausea

Warm up: It is important to do a long and progressive warm up. Warming up prepares your muscles and circulatory system for the activity. It prevents muscle pulls and strains as well. Your warm up should include 10 minutes of stretching and slow walking. Stretching helps prepare your muscles for the activity by increasing their blood flow as well as relieving muscular tensions. It is important to stretch out each of the muscles you will be using during your exercise session.

Cool Down: There should also be a long progressive cool down period (10 minutes) to allow the heart rate to return to resting level. Cooling down helps prevent blood from pooling in your legs. You assist this blood getting back to the heart by continuing to do slow walking and stretching. When the muscles contract they help pump the blood back to

the heart. Stretching after exercising also helps lengthen the muscles and eliminates some of the stiffness that may occur later on.

General Guidelines

- Do not hold your breath while exercising, rather exhale on effort.
- Allow yourself 2 hours after a large meal to digest your food before starting to exercise.
- Exercise should be avoided after drinking caffeinated beverages (coffee, tea, colas).
- Working with your arms above shoulder height is harder on your heart than with them at or below heart level.
- Saunas, whirlpools and hot baths/showers should be avoided.
- Avoid exercising in hot humid weather: $>27^{\circ}\text{C}$ or $>39^{\circ}\text{C}$ with humidex, and cool windy weather: -8°C or less.
- Try to plan your walking in a local indoor mall when the temperature prevents outdoor activity, and drink fluids before and after exercising.

Hints for Exercise

- Wear loose, comfortable clothing.
- Exercise on a regular basis.
- Breathing should be relaxed. Do not hold your breath. If you feel short of breath you are exercising too vigorously.
- Use the "talk test." You should be able to talk comfortably with a friend while exercising.
- Allow two hours after a large meal before starting to exercise. This allows your food to digest.
- Maintain balance and control—do your exercises carefully in a controlled, safe, manner.
- Progress your exercises gradually.
- Consult your physician or physiotherapist if any problems arise.

Walking Program

Walking is a gentle introduction to activity but an effective exercise for ALL people.

Guidelines for a walking program:

- Start with short walks frequently throughout the day, e.g., begin with 5 minutes, 6-9 times per day.
- Walk at a slow and relaxed pace on a level surface.
- Each day try to increase the length of time you walk, i.e., a one-minute increase per day.

- As you increase the time of each walk, decrease the frequency, i.e., walk 10 minutes, 3-4 times per day.
- Increase the distance or time walked rather than the speed at first.
- You should never feel breathless or “pushed” with your walking speed.
- If you find the progression too excessive, walk the same number of minutes for more days in a row before adding another minute to the length of your walk.
- Once you can walk for about 15 minutes at a time you should be increasing your walking pace to feel mild to moderate effort with your walk.
- *Always* warm up and cool down well with your walking program. This should include slow walking and general stretching.

Remember that a good brisk walk five to seven times per week can help to improve your total body fitness, decrease stress, and give you a feeling of well being.

Other Activities to Avoid During the 6-8 Weeks

In the first 6-8 weeks following discharge it is suggested that you **DO NOT** engage in any of the following activities. If you wish to do any of these activities at a later date, check with your surgeon at one of your post discharge follow-up appointments.

HOUSEHOLD ACTIVITIES

Vacuuming	Scrubbing floor
Polishing floor	Cleaning windows
Raking leaves	Mopping
Riding lawn mower	Pushing light power mower
Mowing lawn, heavy hand mower	Light carpentry
Gardening	Digging a garden, using a spade or hoeing
Picking up or carrying your pet (if over 10 lbs.)	Snow shoveling
	Picking up or carrying a child (if over 10 lbs.)

RECREATIONAL ACTIVITIES

Ice/roller skating (9 mph)	Bowling
Badminton	Tennis
Table tennis	Handball
Swimming 20 yards/minute	Dancing
Cycling at 5.5-13 mph	Horse back riding (even at a walk)
Squash	Racquet ball
Skiing	Volleyball
Golfing (including with power cart, pulling bag cart, carrying clubs)	Canoeing
Running (in place, jogging, cross-country)	

- **SEXUAL ACTIVITY**

You may resume sexual activity as before surgery. Avoid positions that cause strain on your incision.

- **TRAVEL**

We usually recommend that you do not travel overseas for 2 - 3 weeks after your surgery.

If there are specific activities that you might like to engage in, but which are not on any of these lists, such as scuba diving, please ask your surgeon or physical therapist about it before discharge.

IF YOU GET SICK AT HOME

Contact the Transplant Team for any of the following:

- any drainage or pus from your incision
- new redness or swelling around the incision
- increase in pain at the incision
- fever
- diarrhea
- nausea or vomiting
- weight loss or continuing poor appetite
- shortness of breath
- coughing out mucous that is yellow or green in color, or has a bad smell
- you suddenly start coughing up fresh red blood
- or anything else of concern.

If further questions arise once you go home, please call your surgeon's office or your Donor assessment coordinator.

RETURN APPOINTMENTS

You will see the surgeon at regular intervals following the surgery. These will be scheduled at 3, 6 and 12 months after discharge. You will have a chest X-ray at each appointment. Your pulmonary function tests and exercise testing will be repeated at one year after donation. This additional information will give us valuable data on the after effects of lung donation on your lung function and activity tolerance.

Before you leave the hospital make sure you have a date for your first return visit with the surgeon.

WE WANT TO KNOW WHAT YOU THINK

Your feedback is important to help us plan the care we provide our patients. Occasionally we ask some of our patients to complete questionnaires regarding the care they received. Please take the time to evaluate our work. At any other time, if you have any problems or concerns with the way in which your care was provided, please bring it to our attention. You can speak to the Nurse-in-Charge while in hospital, to your Transplant Co-ordinator or to the Nursing Manager. The hospital also has a Patient Relations Department that can help resolve issues. They can be contacted at:

Patient Relations Office
1st Floor, R. Fraser Elliot Building
Toronto General Hospital
Phone: 416-340-4907

Your compliments and concerns are equally valid.

SUGGESTED READING & VIEWING

Bach, R. **Illusions: The Adventures of a Reluctant Messiah.** New York, Dell Publishing Co. Inc. 1977.

The teachings of a modern-day philosopher.

Borysenko, Jean. **Minding the Body, Mending the Mind.** Bantam Books, 1988

Craven, J. MD & Farrow, S. OT. **Surviving Transplantation: A Personal Guide for Organ Transplant Patients, Their Families, Friends, and Caregivers.** Toronto, University of Toronto Press Inc.

Carlson, R. Ph.D. **Don't Sweat the Small Stuff....and it's all small stuff- simple ways to keep the little things from taking over your life.** Disney Press, 1997

Harris, Maxine. **The Loss that is Forever - The Lifelong Impact of the Early Death of a Mother or Father.** A Plume Book, 1993

Hart, Archibald. **The Anxiety Cure - methods of dealing with worry, stress and panic.** Word Publisher, 1999

Helmstetter, S. **What to Say When You Talk to Yourself.** Scottsdale, Arizona, Grindle Press, 1986.

Techniques to program yourself to achieve success and give yourself the kind of support you would give your best friend.

Kabat-Zinn **Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness.** Dell Publishing, New York, 1990.

Describes a program taught by the Stress Reduction Clinic of the University of Massachusetts Medical Center.

Kamin, Rabbi Ben. **The Path of the Soul - Making Peace with Mortality,** 1999.

Kerr, Margaret and Kurtz, Joann. **Facing a Death in the Family - caring for someone through illness and dying.** Wiley, John and Sons, Canada Ltd., 1999

Newman, M., Berkowitz, B., Owen, J. **How to Be Your Own Best Friend.** Brooklyn, New York, Lark Publishing Company, 1971.

A self-help manual, based on conversations between two leading psychologists.

Pitzele, S.L. **We Are Not Alone.** Minneapolis, Thompson & Co. Inc. 1985.

Chock full of valuable quotations from writers about learning to live with chronic illness.

Sandoz Pharmaceuticals Corp. **Looking Forward**

This film chronicles the anticipation and activities of four first-time renal transplant recipients and one second-transplant recipient.

Sandoz Pharmaceuticals Corp. **Coming Home**

All that it means to come home from the hospital after a successful transplant is told in this film through the words of two teenagers and one young man.

Saroyan, W. **The Human Comedy**. New York, Harcourt Brace Jovanovich Co. Inc. 1984.

A story about the joys & sorrows of one family in Smalltown, USA, as told through the eyes of the son.

Siegel, B. MD. **Love, Medicine, and Miracles**. New York, Harper & Row Publishers, 1986.

A story about healing, courage, love and how patients can take control and heal themselves.

Silverman, Phyllis Rolfe. **Never Too Young to Know - Death in Children's Lives**. Oxford University Press, 2000

Steinbeck, J. **Travels with Charley in Search of America**. New York, Bantam Books, 1986.

The author's rediscovery of his love affair with America while travelling with his dog.

Tolstoy, L. **Little Stores**. Nashville & London, Aurora Publishers.

A delightful collection of illustrated short parables.

GLOSSARY

<i>alveolus</i>	a tiny air sac within the lung where oxygen and carbon dioxide are exchanged
<i>anastomoses</i>	the connections that are made between your own organs or tissues, and the donor organs or tissues
<i>anesthetic</i>	an injection or inhaled gas that temporarily puts you to sleep for your surgery
<i>Anesthetist</i>	the doctor who puts you to sleep and takes care of you during surgery
<i>aorta</i>	the main artery. It carries oxygen-rich blood away from the heart to all parts of the body
<i>arrhythmia</i>	an irregular heart beat
<i>bronchus</i>	the main branch of the trachea
<i>catheter</i>	a tube that drains urine from the bladder
<i>chest tube</i>	a special drainage tube(s) which is put into your chest. It is inserted in the operating room while you are still asleep. This tube(s) will remove air and fluid from your chest cavity. It is put in the same side as your operation. This tube(s) is attached to a drainage machine. This machine is called a Pleurovac or Emerson Pump. The machine is attached to a suction source. It will be connected to a long extension cord. This way you can walk out in the hallway.
<i>consent</i>	a legal form stating that you understand the risks associated with a procedure. You will be asked to sign two of these during the live lung donation process; one to proceed with evaluation; and, one to have the surgery.
<i>discharge date</i>	the day you go home from hospital.
<i>dressing</i>	a bandage on your incision
<i>emerson pump</i>	the drainage machine that may be connected to your chest tubes after surgery.
<i>expiration</i>	the movement of air from the lungs out of the body to the outside (exhalation)
<i>immune system</i>	a defence system that our body has to act against invaders such as infection, foreign tissues

<i>incentive spirometer</i>	a breathing exercise machine. This machine will help you to fully expand your lungs. Use this before doing deep breathing and coughing exercises after surgery.
<i>incision</i>	the wound or cut made at the time of surgery.
<i>inspiration</i>	the movement of air from outside the body into the lungs (inhalation)
<i>intravenous</i>	see IV below.
<i>IV</i>	short for intravenous. This is a special line inserted into a vein. You will be given fluids and medicines through this line.
<i>metabolism</i>	all the physical and chemical activity that occurs in the body
<i>NPO</i>	Latin for "nil per os". This means you are not to have anything to eat or drink.
<i>OR</i>	short for operating room.
<i>PACU</i>	see post-anesthetic care unit below.
<i>PCA</i>	short for patient controlled analgesic. You may get your pain medicine through the intravenous. The intravenous is attached to a pump. The patient controls the pump by pushing a button. Pushing the button gives a small dose of the pain medicine. You should feel the effects of pushing the button within 2 to 3 minutes. Only the patient should push the button. Family members, friends, or health care workers should NEVER push the button.
<i>pericardium</i>	the sack that surrounds the heart
<i>PFT's</i>	short for pulmonary function test. This is a special breathing test to assess your lungs. You will have this done before surgery.
<i>pleurovac</i>	the drainage machine that may be connected to your chest tubes after surgery.
<i>Post-Anesthetic Care (PACU)</i>	you will go directly to the PACU from the operating room. You will be intensely monitored here as you recover from your anesthetic.
<i>post-op</i>	short for post-operative. This is the period of time after your operation.
<i>pre-admission</i>	the time before you are admitted to hospital for your operation.
<i>pre-admission visit</i>	an appointment to assess your health and prepare you for surgery.
<i>pre-op</i>	short for pre-operative. This is the period of time before your operation.
<i>pulmonary</i>	relating to the lungs

<i>pulmonary artery</i>	carries blood from the right side of the heart to the lungs
<i>pulmonary veins</i>	return blood from the lungs to the left side of the heart
<i>rejection</i>	a response that occurs when tissues in the body are seen as foreign
<i>sternotomy</i>	surgical incision of the breast bone
<i>Surgical Waiting Room</i>	this is on the first floor of the Eaton Building (East elevators, Room 1 - 300). This is where your family or friends can wait to speak to the doctor after the surgery is completed. Your family must check in with the volunteer when they arrive in the surgical waiting room. The volunteers will notify the surgeon they are there. This way, your surgeon knows that your family are waiting to speak with him / her.
<i>Step Down Unit</i>	a unit where you will receive special nursing care after surgery. You may be in this room the first night after surgery. Your health will be watched closely. Any changes will be reported to your doctor. A nurse will be with you at all times.
<i>sutures</i>	a word that means stitches. These are put in at the end of your operation while you are still asleep. They are used to sew up your incision. They will hold your skin together until it heals itself. They are sometimes dissolvable. This means that they will go away on their own. Sometimes, the sutures will need to be removed by the nurse or your family doctor. You will be told which type of sutures you have after surgery.
<i>thoracic</i>	having to do with the chest.
<i>thoracotomy</i>	surgical incision of the chest wall
<i>trachea</i>	the windpipe; it is a passageway for air exchange
<i>ventilation</i>	moving an amount of air in and out of the lungs
<i>ventricles</i>	the two lower chambers of the heart which are responsible for the major pumping of the heart
<i>vital signs</i>	blood pressure, heart rate, temperature and rate of breathing.
<i>voiding</i>	to empty the bladder of urine.

NOTES

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CONTACTS

7 Eaton South, Thoracic surgery/Respirology To receive <i>adult donor</i> information	(416) 340-3166
Medical Surgical ICU To receive <i>adult recipient</i> information	(416) 340-3601
Pharmacy, Toronto General Hospital (For any issue related to your medications, prescriptions, drug information)	(416) 340-4075
Multi-Organ Transplant Unit To receive <i>adult recipient</i> information	(416) 340-5163
Pediatric ICU, Hospital for Sick Children To receive <i>pediatric recipient</i> information	(416) 813-6486
Transplant Unit, Hospital for Sick Children, 6A To receive <i>pediatric recipient</i> information	(416) 813-6907
Transplant Assessment Center, Toronto General Hospital 10 th Floor Eaton Wing Center, Room 312	(416)340-4800 ext. 6834

