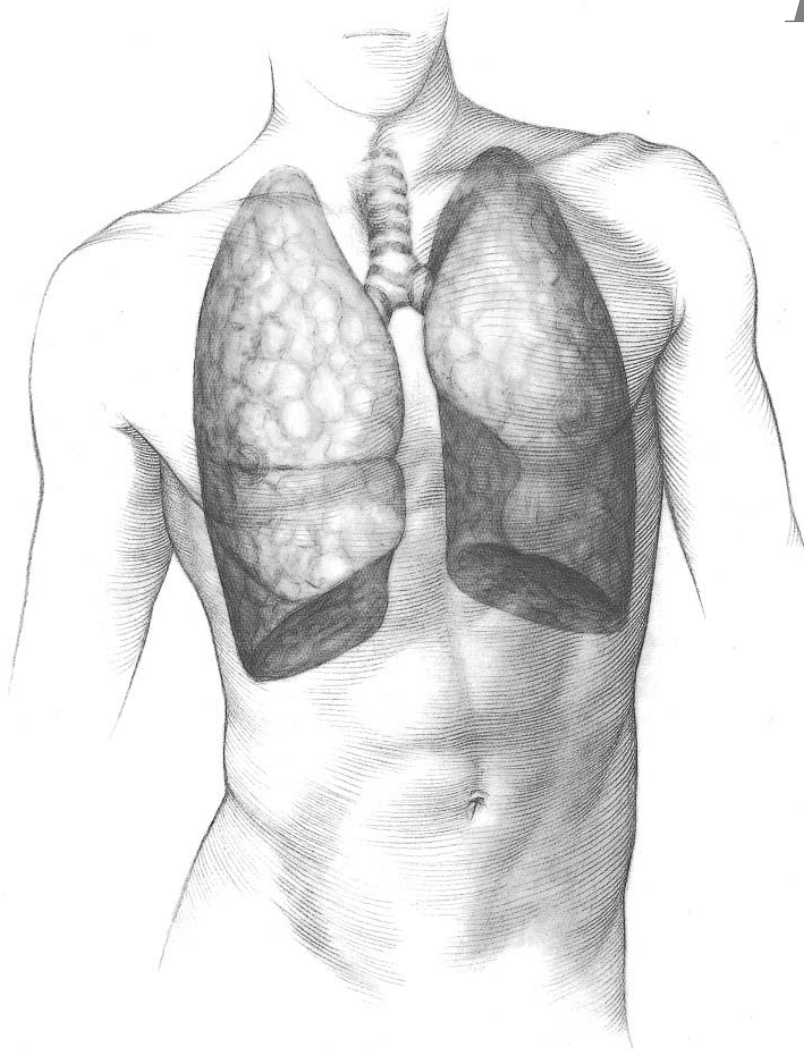


Lung Transplantation

a guide for patients

Part I



Duke Transplant Center
DUKE UNIVERSITY MEDICAL CENTER

Introduction

Lung transplantation is a sophisticated, effective therapy for end-stage lung disease. In this procedure, as its name implies, one or both of a patient's diseased lungs are removed and replaced with healthy lungs from a recently deceased organ donor.

The lung transplant program at Duke University Medical Center began in February 1992. Since then, we have performed more than 500 lung transplant procedures. Our work in this exciting field has also enhanced the prospects of lung transplant patients around the nation by contributing to advancements in transplant techniques and post-transplant treatments.

For most patients and families, the prospect of undergoing a lung transplant produces feelings of anxiety and uncertainty. This booklet has been designed to help alleviate these feelings by explaining what you may experience as a lung transplant patient at Duke. We have included information about the evaluation process, the surgery, and what to expect during your recovery.

This booklet is intended to answer many of your questions. However, you may find that you have several more. If so, we suggest that you write your questions in the space provided within this notebook to help you remember to discuss them with the members of the lung transplant team.

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Your Transplant Team

The Lung Transplant Team

The Duke Lung Transplant Team is made up of a diverse group of healthcare professionals, including physicians, social workers, dieticians, and physical therapists. Initially, these specialists will help you determine if a lung transplant is the right treatment for you. If and when you become a transplant patient, the same group of professionals will take care of you.

The following is a list of Lung Transplant Team members and a brief description of their roles. We suggest that you write down the names of your team members as you meet them to help you remember who they are.

1 Transplant Pulmonologist: This doctor specializes in lung disease and lung transplantation. He or she will evaluate your current lung disease and will discuss the option of lung transplantation with you.

Name: _____

2 Transplant Surgeon: This is the doctor who performs the operation. He or she will explain the lung transplant surgical procedure to you.

Name: _____

3 Transplant Coordinator: This nurse is your main contact person on the Transplant Team. He or she will discuss the overall course of events before, during, and after lung transplantation.

Name: _____

4 Social Worker: This specialist will help determine your ability to cope with the impact of lung transplantation on you and your family by asking you about your family life, social habits, and financial concerns. He or she will also be a resource person for information regarding insurance and disability.

Name: _____

5 Psychologist: A specialist in human behavior, your transplant psychologist will talk with you regarding the stress and anxiety you may feel during the transplant evaluation process. He or she may also ask you to complete questionnaires that will help determine how you might adjust to a lung transplant.

Name: _____

6 Transplant Clinical Pharmacist: This pharmacist will discuss with you how to take your transplant medications. He/she will use a pill box for instruction, and will provide written materials concerning your medications.

Name: _____

7 Physical Therapist: Trained to accurately evaluate your musculo-skeletal system and exercise capacity, this person may also recommend home exercise programs to increase your strength and endurance in preparation for surgery. preparation

Name: _____

8 Anesthesiologist: This physician will talk with you about how you will be put to sleep during surgery and how any post-operative pain you may experience will be managed.

Name: _____

9 Financial Coordinator: This member of the Transplant Team works closely with you and your insurance carrier to determine that your transplant is financially approved before you are placed on a waiting list for your new lung(s). He/she will also discuss specific expenses related to the entire transplant process

Name: _____

The members of the Lung Transplant Team want to help you as much as possible. Please feel free to ask us any and all questions you may have as they arise by contacting us through the Lung Transplant Office. The secretaries who answer your call can help you with many of your questions, or direct your calls to those who can.

Lung Transplant Office Address:

DUMC 3876

Durham, NC 27710

Telephone Numbers: 1-800-249-5864
(LUNG)
 or 1-919-684-2240

Transplant Team Members

(all area codes 919)

Transplant Coordinators

- Cindy Lawrence, R.N. 684-2240
- Jean Rea, R.N.. 684-2240
- Julia Curl, R.N.. 684-2240
- Karen Setliff, R.N.. 684-2240
- Tracie Parker, R.N. 684-2240

Transplant Pulmonologists

- Scott Palmer, M.D. 684-2240
- Mark Steele, M.D. 684-2240
- Mike Reidy, M.D. 684-2240
- Jerry Eu, M.D. 684-2240

Transplant Surgeons

- Duane Davis, M.D. 681-4760
- Sinan Simsir, M.D. 684-4694
- Shu Lin, M.D. 684-2890

Transplant Social Worker

- Ellen Stone, M.S.W. 681-5886

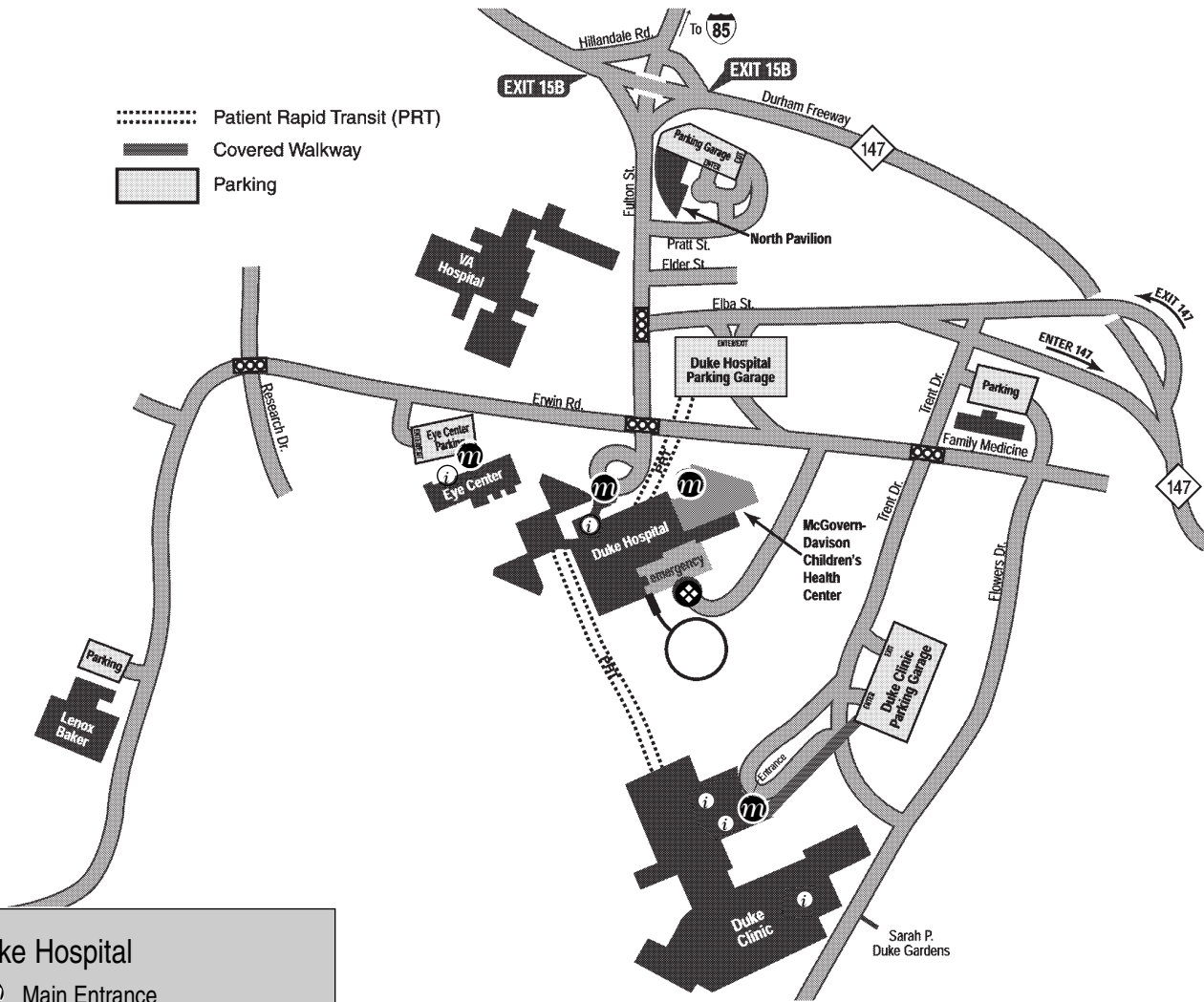
Directors of Pulmonary Rehabilitation

- Rebecca Crouch 660-6658
- Sheila Shearer 660-6660

Transplant Financial Coordinators

- Janet Tate 681-3562
- Julia Boatwright-Holden 681-4880

DUKE UNIVERSITY MEDICAL CENTER



Duke Hospital
 Main Entrance

Eye Center
 Main Entrance

McGovern-Davison Children's Health Center
 Main Entrance

General Information
 Information Desk
 Emergency Department

Duke Clinic
 Main entrance

All entrances are wheelchair accessible

Duke Clinic and Duke Hospital are served by two 24-hour parking decks. Clinic Parking is located on Trent Drive; Hospital Parking is on Erwin Road, at the corner of Fulton Street. The PRT (Patient Rapid Transit) offers quick, convenient transportation to and from Hospital Parking, Duke Hospital, and Duke Clinic.

Parking Fees

Parking fees are 75 cents per hour. Parking coupon books can be purchased at the Parking Office located in the Hospital. Valet parking is also available at the main entrance of the Duke Clinic and Duke Hospital for a fee of \$7 per day. Handicapped parking is available in both parking facilities.

Wheelchair Assistance

Wheelchair and escort assistance are available upon request to patients at the drive-up entrance of the Clinic and at the drive-up main entrance of the Hospital. Continuous shuttle service to and from the Clinic and Clinic Parking is available Monday through Friday, from 7:30 a.m. to 5:30 p.m., for those with disabilities or needing special assistance.

Information

During your visit, a patient representative is available in the designated information area of Clinic Parking to assist you with information and directions. For any questions or concerns that may arise during your visit to either the Clinic or Hospital, please contact our Patient and Visitor Relations representatives through the Patient Helpline at (919) 681-2020. Local area information, such as lodging, banking, and dining, is also available at all information desks.

Duke Consultation and Referral Center

The Duke Consultation and Referral Center was created to facilitate access to the physicians and services of Duke University Health System.

You can call the Consultation and Referral Center at 1-888-ASK-DUKE for

- Selecting a physician
- Information about Duke clinical services and programs
- Details on upcoming health education seminars and lectures
- Locations of Duke clinics in your community

Directions to Duke University Medical Center

Coming by I-85 from the south or north, take the Hillandale Road exit #174. Take a right at the top of the ramp. Follow Hillandale Road to Erwin Road. Turn left onto Erwin Road. Follow the signs for the clinics or the Emergency Room.

Coming by US 70 from the east or I-85 from the north, take Hillandale Road exit #174. Take a left at the top of the ramp. Follow Hillandale Road to Erwin Road. Turn left onto Erwin and follow the signs for the clinics or the Emergency Room.

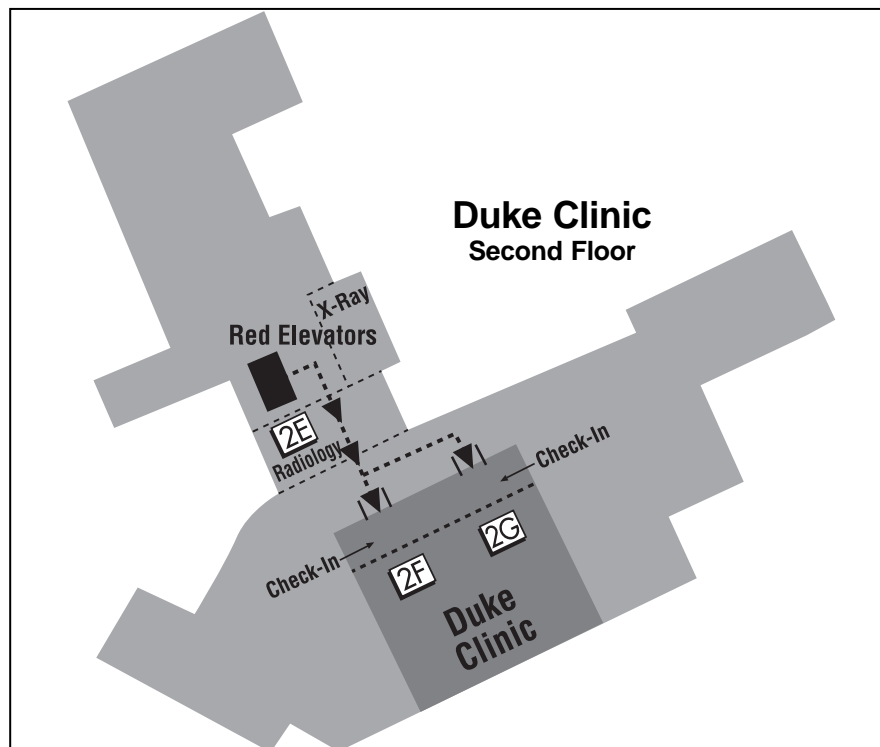
Coming by US 15-501 Bypass from the south, exit onto the Durham Freeway (Highway 147) eastbound, proceed to the Fulton Street exit, then follow the signs to Duke and VA hospitals.

Coming by Durham Freeway (Highway 147) from the east, follow the freeway into Durham. Take the Fulton Street exit and follow the signs.

Directions to the Duke Lung Transplant Clinic

(Duke Clinic, Zone 2F)

From the Duke Clinic parking garage use the second floor walkway to Duke Clinic. This will lead to the Transplant Clinic, located at zone 2F. If you need wheelchair assistance - go in main entrance of Duke Clinic and ask at the information desk. They will bring you to the clinic. Valet parking is available at main entrance at a cost of \$7.00, which includes your parking fee.



Before Your Transplant

About Your Lungs

The lungs are organs that provide your entire body with oxygen and remove carbon dioxide from your system. Located in the chest, they are protected and supported by twelve pairs of ribs, the intercostal muscles that lie between the ribs, the neck muscles, and the diaphragm.

Normally, people have two lungs. The right lung is divided into three sections or lobes: the upper, the middle, and the lower lobe. The left lung is divided into two lobes: the upper and the lower lobe. Each lung is surrounded by two protective layers of tissue called pleura.

The lungs are made up of bronchi, alveoli, and blood vessels. The bronchi are a series of highly branched, hollow tubes through which air travels. The alveoli are tiny gas exchange sacs located at the ends of the tiniest bronchi. There are approximately three million alveoli in the lungs, and it is within them that oxygen is absorbed into the body and carbon dioxide removed.

Reasons for Transplantation

Lung transplantation is indicated when lungs are so diseased that they can no longer perform their vital gas exchange function, and when the lung disease cannot be corrected in any other way.

The causes of end-stage lung disease vary. The following lung diseases can be indications for lung transplantation:

1. Chronic obstructive pulmonary disease (COPD).
This may include asthma, chronic bronchitis, emphysema, and/or Alpha 1 antitrypsin deficiency
2. Idiopathic pulmonary fibrosis
3. Sarcoidosis
4. Eosinophilic granuloma
5. Bronchiectasis
6. Cystic fibrosis
7. Pulmonary hypertension (both primary and secondary)
8. Lymphangiomyomatosis

Some other lung diseases are also possible indications for transplantation. Consult your lung specialist if you wish to learn more about transplantation as a possible therapy for your lung disease.

Evaluation for Lung Transplant

Before you become a transplant candidate, your condition and prospects for success with a transplant are thoroughly evaluated. Evaluation for lung transplantation may occur in the hospital or on an outpatient basis, depending on how well you are able to tolerate moving from one place to another and on the rules imposed by your insurance company. If your evaluation is to take place in the hospital, the length of stay will be approximately three days. If you are evaluated as an outpatient, the transplant team will schedule your evaluation with you.

During the evaluation, you will meet and talk with the various members of the transplant team. While examining you thoroughly, they will also be helping you become more knowledgeable about the impact a lung transplant will have on you and your family.

Testing Procedures

During your evaluation, you will be scheduled for some or all of the following tests. Your transplant team physician or nurse coordinator will summarize and explain the results to you after your evaluation is completed.

Heart catheterization: This test gives us information about arteries that supply the heart with blood and about internal heart pressures. Requiring about 45 minutes to one hour to perform, it is conducted in a specially equipped area called the Cath Lab. After numbing an area at the top of your leg, doctors insert a catheter through a large blood vessel and thread it through the vessel and into your heart. A special dye is injected through the catheter, and pressures are measured. Medication to help you relax may be given for this procedure if needed.

MUGA heart scan: This test shows the function of both the left and right sides of your heart. A substance which tags your red blood cells, given through a vein in your arm, travels to your heart. A large machine is positioned over you to record your heart function while you lie on a table.

Ventilation-perfusion lung scan: This test gives us information about both the blood supply and the air supply to the lungs. You will receive a small injection into an arm vein, then be asked to breathe oxygen through a mask. A large scanner will then record data while you lie on a table.

Pulmonary function tests: Familiar to everyone who has lung disease, these tests measure breathing capacity. You will be asked to breathe in and out as fully as possible while a technologist measures your lung volumes.

Blood tests: Many blood tests will be conducted to determine the function of your kidneys, liver, and immune system. We will also determine your blood type.

Echocardiogram: An ultrasound of your heart, this quick test bounces sound waves off your heart to give us information about its function and the condition of your heart valves. Clear gel is used to help the ultrasound wand slide easily over your chest.

Chest CT scan: This scan gives a three-dimensional picture of the inside of your lungs. You will be asked to lie very still on a table which moves you through a round, tunnel-like machine.

Gastric pH/Esophageal Manometry Testing: This procedure will show your doctor how the muscles in your esophagus (swallowing tube) work. The test is performed by a small catheter (tube) being passed through your nose into the esophagus and then into your stomach. Once the catheter is in place you will lie down and relax while the test is being performed. Please wear comfortable loose fitting clothes. During the test you will be asked to swallow water. To prepare for this test you cannot have anything to eat or drink for at least 6 hours prior to the test.

You may also be scheduled for a pH study on the same day. This is a test to determine how often acid from your stomach comes up into your esophagus. After your manometry study is completed we will place a very small tube through your nose and into your esophagus that will stay in overnight. You must come in the following morning to have the tube removed. Once the tube is in place you can eat and drink. You will be required to keep a diary while the test is in progress.

Other tests may be ordered as part of your lung transplant evaluation, depending upon individual circumstances. These will be explained to you by a member of the lung transplant team.

It will also be important to be sure all your vaccinations are updated prior to having a transplant. During the evaluation, we will ask you about pneumovax, tetanus vaccine, hepatitis B vaccine and flu vaccine (if in season.) Females should also have an updated PAP smear and mammogram.

During your evaluation, you will also need to consider financial, housing, and transportation needs. The transplant financial coordinator will contact your insurance company and inform you of the extent of your coverage. The transplant financial coordinator or the transplant social worker can also provide information on fundraising or applying for various forms of financial assistance.

When all test results are available, transplant team members will meet and discuss whether or not lung transplantation would be the best treatment for you. We will try to communicate our recommendations to you within a week following the completion of your evaluation.

Your Role in a Successful Transplant

New lungs mean new responsibilities. If we determine that a transplant would be the best treatment for your lung disease, there are many considerations to be aware of before making the commitment to a lung transplant.

Among the most important of these is your commitment to change harmful habits that may damage your new lungs. Our program does not consider patients for transplantation who are currently smoking or who are dependent on alcohol or other mind-altering drugs. We require potential transplant recipients to be substance-free for at least six months before being listed for lung transplantation.

The lung transplant team at Duke University Medical Center has ZERO tolerance for tobacco use once a patient has been listed for lung transplantation. Serum cotinine levels will be measured at each pre-transplant clinic visit, and patients are advised that ANY exposure to tobacco that would result in a positive serum cotinine measurement is grounds for immediate removal from our lung transplant waiting list.

There are also many issues to consider regarding follow-up care after your transplant. These include:

Medications: After a lung transplant, you will have many medications to take for the rest of your life. These medications are very expensive.

Monitoring: You will be asked to record your blood pressure, weight, temperature, and lung capacity each day.

Healthful habits: After the transplant, you will be expected to maintain a well-balanced diet and exercise regularly to keep yourself in good physical condition. You will also be expected to continue to abstain from the use of harmful substances.

Lung transplant recipients who resume smoking or any other form of tobacco use/abuse will not be considered for retransplantation.

Frequent check-ups: You will need to return to Duke frequently for outpatient tests and Lung Transplant Clinic visits. We will ask you to keep in close contact with us regarding changes in your health status.

In addition, if you are accepted for lung transplantation at Duke, you will be asked to sign a written contract verifying your agreement and commitment to the process. A sample contract is located after the “Preparing for Transplant” worksheet in this book. An individualized version will be prepared and given to you upon your acceptance into the program.

The following worksheet is designed to help you formulate a logical plan for dealing with the most frequently encountered concerns of the lung transplant process.

Preparing for Transplant

We want to help you and your family prepare for your transplant. Making plans to deal with your needs before your transplant can reduce the amount of stress you will have to cope with during the recovery process. You will probably have to make some changes in your plan over time as your situation changes. Please keep us up to date on changes as they occur.

When you are called to come to the hospital for your transplant, it is vital that you arrive at the hospital within a few hours. You need to have a reliable plan for getting to the hospital on very short notice within two hours. Once you have received your transplant and are ready for discharge from the hospital, you will be required to remain in the local area to participate in the outpatient Pulmonary Rehabilitation Program at Duke Center for Living. This program will help you recover more quickly and gives the transplant team an opportunity to monitor your progress closely before you go home. The rehab program lasts approximately four and a half weeks, from 12:30 to 4:30 p.m., Monday through Friday. It is important to plan for your needs during the outpatient rehab stay. Also, it is important to make plans for obtaining your medicines. You will need to have your prescriptions filled before you leave the hospital.

Following are questions to help you in planning for your transplant. Please complete each question as thoroughly as you can. Once you and your family have had a chance to discuss your plans, please schedule a time to discuss your plan and the resources you may need with your social worker. Please remember to update your plan if changes occur.

How will you get to the hospital when you are called for your transplant?

Will you need to relocate closer to the hospital on a temporary basis to be able to get to the hospital when it is time for your transplant?

Who will relocate with you and where will you stay?

Where will your family stay while you are in the hospital?

Where will you stay while you go to the outpatient rehab program?

Who will stay with you and help you take care of yourself?

Who will drive you to the Center for Living for daily rehab?

How will you pay living expenses for yourself and a family member while attending rehab?

Who will take care of your home while you are away (pay bills, maintenance, pets, etc.)?

Who will take care of your children while you are away from home?

Who will pay for your transplant?

- Insurance
- Medicare
- Medicaid
- Other _____

How much are your deductibles or co-payments? (How much will you be responsible for?)

Are there maximum limits on your coverage?

Will your coverage change or convert? (Please remember to notify the financial coordinator immediately of any changes in your insurance cover- age.)

Are you under a COBRA plan?

Who will pay for your medicines?

- Insurance
- Medicare
- Medicaid
- Other _____

How much will you have to pay for your medicines?

How will you budget for your co-payment or deductible?

What pharmacy will you use?

Are you registered with a transplant pharmacy
(if you plan to use one)?

If you hope to get your medications through the VAMC,
do you have a medical history number and a physician there?

List any areas of your plan that need more attention and who will work on completing that part of your plan.

Record changes to your plan here (remember to update at clinic visits or by phone).

Do you have other concerns about your situation or your family in preparing for your transplant?

What questions do you need answered by the transplant team?

Please sign this plan when it has been completed and reviewed.

Recipient/Date

Social Worker/Date

Primary Support/Date

Coordinator/Date

DUKE UNIVERSITY MEDICAL CENTER: LUNG TRANSPLANTION PROGRAM

You are being considered for lung transplantation at Duke University Medical Center. The success of the transplant procedure depends in part on your adherence to the transplant team's recommendations. Persons who receive lung transplants bear a special responsibility to care for themselves and their new organ in the best manner possible.

I, _____, understand that failure to care for myself in a healthy manner is reason to be refused organ transplantation. By signing this contract, I make a commitment to myself, my family, and the transplant team to care for myself in the following ways:

General Responsibilities

1. I will attend my scheduled clinic appointments, my laboratory tests, and my rehabilitation sessions.
2. I will read the transplant educational materials provided by the team and ask questions about any content that I do not understand.
3. I will take my medications as prescribed. I understand that this will include many medications related to my transplanted organs, as well as medications for general medical conditions that may arise during my care. I understand that some of my medications will require me to take them on strict schedule in order to get the maximum benefit and safety. Because transplant medications can interact with many other medicines, I will NOT take other medications, even if prescribed by a physician, without consulting with the transplant team.
4. I will follow the nutritional restrictions and guidelines prescribed by my clinical nutritionist.
5. I will not drink alcohol, smoke (tobacco, marijuana, pipes, or cigars), chew tobacco, or use any substance or drug not prescribed by my physician. I understand that exposure to these substances (including second-hand smoke) can injure my health and lead to failure of my transplanted organs. I am willing to have blood and/or urine tests to screen for drugs, nicotine, and alcohol. I understand that just one positive blood test for nicotine (smoking or other tobacco use) will result in removal of my name from the lung transplant waiting list at Duke University Medical Center. Evidence of any unhealthy behavior is a reason to be refused organ transplantation.

6. I understand that I will need to relocate to the Durham, NC area pre transplant, if I live farther than a 2 hour drive from Duke University Medical Center. I understand that I will need to live in the Durham, NC area for 6-12 weeks after transplantation for rehabilitation and close medical follow-up. This is a "best estimate" of time needed in Durham; some patients will need a longer stay, depending on response to surgery.
7. I understand that I will need a designated caretaker or set of caretakers to accompany me to Durham for transplant surgery and to assist me during the transplant recovery period. Caretaker duties will include helping me with medications and transportation to medical appointments and rehabilitation services.
8. I understand that I am responsible for the costs of transplantation. There are likely to be other costs to me, as few insurance plans cover all transplant expenses.
9. I understand that I need to stay in contact with the transplant team, to let them know of any change in my medical or life circumstances. I understand that if I break this contract that I may not be eligible for transplantation.
10. I understand that if I receive a transplant these requirements become a lifetime commitment.

My Specific Responsibilities

1. _____

2. _____

3. _____

4. _____

Signed: _____ Date: _____

Transplant Team Responsibilities

As your transplant team, we pledge to provide you with

1. the highest quality medical care,
2. open and honest communication about your medical condition,
3. clear recommendations about how to get ready for transplantation and how to take care of yourself after transplantation, and
4. support to you and loved ones during this difficult process.

Signed: _____ Date: _____

Complying with Transplant Treatment

Everyone who considers or receives a transplant is asked by their physician to follow certain recommendations in order to be listed or stay healthy. Depending on the type of transplant you need or receive, the things you need to do might include:

Scheduling & attending clinic appointments

Eating or avoiding certain foods

Taking medications on a daily basis

Losing weight

Monitoring your fluid intake & blood pressure

Stopping tobacco & alcohol use

Exercising or enrolling in rehabilitation

Psychological counseling

It can be hard to follow these recommendations and make lasting changes in your lifestyle. There are a lot of possible reasons why patients may not follow their transplant team's recommendations all the time. However, by NOT following these recommendations you can have serious health problems, such as:

Delays in getting on the transplant list

Your body rejecting your transplanted organ

Being taken off the transplant list

Poorer quality of life

Worsening of your physical health

Death

Recent research has revealed that 9 out of 10 patients who are noncompliant rejected their organ or died, compared with less than 2 out of 10 of those who took their medications as recommended. It's crucial for you to follow the advice of your transplant team as closely as possible.

If you are having trouble following your transplant team's instructions, it's important for you and the transplant team to understand what barriers may be getting in your way.

Here are few of the things that can get in the way of good compliance:

Medication side effects

Miscommunication between transplant team & patient

Anxiety, depression, or difficulty coping

Nobody at home to help with healthcare needs

Belief that the changes aren't really necessary

Work activities get in the way

Memory problems

Inadequate funds or insurance coverage

There are potentially many different barriers to sticking with long-term lifestyle changes and caring for a transplanted organ. Let's take a look at the hurdles that transplant programs see most often and the things that you can do about them.

Medication side-effects

Some of the medications you need before or after transplantation may cause changes in your body and discomfort. Depending on the medications, these changes can include:

Weight gain or loss / Appetite changes

Sleep problems

Irritability / Mood swings

Nausea / Diarrhea

Headaches

Restlessness

Changes in appearance / Hair growth

Confusion / Memory problems

Shaking

Bone loss / Fractures

Loss of sexual drive

Anxiety / Depression

You may feel discouraged with looking different, feeling ill, and dealing with the side-effects of medications. It's important to remember, however, that the medications make it possible for your body to accept your new organ.

If the medication side-effects are causing you problems, you should consider doing the following:

- ❖ Learn as much as you can about all of your medications, such as the common side-effects for each of them. Ask your transplant physician, coordinator, or pharmacist to tell you the side-effects to look for.
- ❖ Do NOT stop taking any of your medications without first talking to your transplant physician or coordinator! Let them know the side-effects you're having before you stop taking any medications.
- ❖ Ask your transplant physician or coordinator if there's anything you can do to make the side-effects better or more tolerable. Different types of medications will sometimes serve the same purpose and allow some relief from unpleasant side-effects.
- ❖ If you're not sure whether some changes in your body are due to the medications, ask your transplant physician, coordinator, or pharmacist about it. You may get good advice from fellow transplant patients, but it's always best to confirm that information with your transplant team!

Emotional Distress

Feelings of anxiety or depression can also get in the way of taking good care of yourself. Patients who are highly stressed or depressed have more problems concentrating and following their doctor's instructions. Also, when you're feeling depressed, it becomes harder to do all of the things that are expected of you. You may have less emotional and physical energy and you may not care as much about your future health. If you are feeling anxious or depressed, let your transplant physician or coordinator know. They may have you talk to the transplant psychologist or social worker, who can either work with you directly or help you find the psychological care that you may need near your home.

Miscommunication

It is not uncommon for miscommunication between patients and their healthcare providers. There are many reasons for miscommunication to occur, such as:

You feel uncomfortable asking questions

Too much information is being given to you at one time

You find it hard to give up control of your health care to others

Your health care providers use too much medical jargon

Your physician does not take time to ask about or understand your concerns

Your physicians don't agree on what you should do and you're not sure whose advice to follow

Establishing a good working relationship with your transplant team and making sure that the lines of communication are open and clear are very important. This can help to avoid confusion about what is expected of you and can also help to avoid unintentional non-compliance. For example, patients sometimes don't follow the instructions of their physician because they aren't sure what they are supposed to do. To make sure that miscommunication doesn't get in the way of your good compliance with your care, we recommend that you do the following:

- ❖ Before you come to each transplant clinic visit, take time to write down all of your questions for the transplant physician or coordinator. This will help you to remember what questions to ask and also show your transplant team that you are involved in taking good care of yourself.
- ❖ Your transplant physician and coordinator are busy, but be sure to take the time to ask all of your questions when you see them. Write their answers down or ask your caregiver to write the answers down for you.
- ❖ It is very common for transplant patients to be told to make changes in their medications, have some tests done, change their diet, etc. Because it's often hard for transplant patients who are having some concentration or memory problems, be sure to ask your physician or coordinator to write down any medical instructions for you.
- ❖ Share your list of medical instructions with your caregiver and, if needed, let them help you do the things that your transplant team wants you to do.
- ❖ Call your transplant physician or coordinator if you are not sure about what you should be doing. A quick phone call can clear things up and help to avoid misunderstandings.

Financial Problems

Transplantation can cost a lot of money for patients and their families. Some patients who become sick may lose their jobs or insurance benefits, and others may not qualify for certain government benefits to pay for transplant costs. Not having enough money or not having good insurance benefits can make it hard to:

- Fill your medication prescriptions on time**
- Participate in physical rehabilitation**
- Travel to the transplant center for all of your appointments**
- Get the psychological support that you need**

To make sure that financial problems don't get in the way of good compliance, we recommend that you do the following:

- ❖ Make sure you understand ALL of the costs you will have with your transplant, such as costs for transplant housing and transplant medications.
- ❖ Let your transplant physician, coordinator, or social worker know when you are having financial problems that might affect your health care. Transplant social workers are experts at helping patients find appropriate resources. They can also talk to you about how to raise money that you might need before and after your transplant.
- ❖ Talk to the transplant pharmacist. Some companies that make transplant medications have special programs for patients who have financial problems.

It is very important that you follow your transplant team's instructions carefully because not doing so can cause serious and possibly life-threatening health problems. It's a good idea to do a self-assessment of your compliance on a regular basis. Remember to:

- Identify whether there are any barriers to your good compliance
- Talk to your transplant physician or coordinator about these barriers
- Develop strategies to overcome these barriers
- Ask the transplant psychologist or social worker for assistance, if needed

The Transplant Process

Lung Donation and Selection

When the transplant team decides that you are an appropriate candidate for lung transplantation, your name is placed on a national transplant waiting list. All transplant candidates in the country are listed in a national donor computer system through the United Network for Organ Sharing (UNOS). Carolina Donor Services, our local organ procurement agency, works with UNOS to coordinate transplants in this area. Donor lungs are matched with recipients according to the following criteria:

size (height and weight);

chest x-ray measurements ;

blood type (O, A, B, or AB)

Quality of the donor lungs is of the utmost priority; they must be healthy and without evidence of damage or disease. Before the lungs are accepted for transplant, they are thoroughly evaluated. This evaluation includes examination of the donor's chest X-ray, medical history, social history, arterial blood gases, and bronchoscopy. Donors are also carefully tested to be sure that they have no transmissible disease, such as AIDS or hepatitis.

When donor lungs become available, they are given to the person on the waiting list who best matches the donor size and blood group.

Living Related Lung Donation

In rare circumstances, the transplant team may consider transplanting sections (lobes) of lungs from living relatives of very ill patients. This option will be discussed on an individual basis as appropriate.

Waiting for Your Transplant

Because of the small number of donors, the waiting period for a lung transplant varies; the average wait is about one year. This period is understandably frustrating, stressful, and even frightening.

It's important to remember during this difficult time that no one has any control over when donor lungs become available. We urge you to learn relaxation techniques and use all available resources to help yourself cope with the stress and uncertainty. You will also be seen regularly in the Lung Transplant Clinic during your pre-transplant waiting period. Please let us know if you need help managing depression or anxiety at any time during the transplant process.

While you are waiting, we require you to participate in a pulmonary rehabilitation program. Such a program of monitored physical exercise will help build your strength and endurance in preparation for your transplant, and increase your chances to do well afterward.

We will help you arrange to enter such a program, either at Duke or in your local community. Guidelines to help you select a pulmonary rehabilitation program follow.

Pulmonary Rehabilitation: What Should I Look For?

- **An Evaluation** prior to initiation of exercise to accurately monitor your progress throughout the program and upon completion of the program. Examples are: a treadmill, bicycle, or 6 minute walk tests while oxygen level, blood pressure, heart rate, perceived exertion, and ECG are monitored.
- **Reliable monitoring equipment**, such as a pulse oximeter to determine your SpO₂ (Oxygen saturation) and heart rate during exercise.
- **Provision of oxygen** if you need it while exercising. Ability to increase your oxygen during exercise if necessary to maintain your oxygen saturation 88%.
- **Instruction in various breathing exercises** and techniques, for example, diaphragmatic and pursed lip breathing, and coordinated breathing with exercise.
- **Exercises** that include 3 major components:
 - Muscle strengthening using resistive weights or therabands
 - Flexibility stretching exercises
 - Endurance activities such as walking for at least 20-30 minutes. Stationary bicycling for 20 minutes also helps to build endurance
- **Rehab sessions** should meet 4 to 5 times per week, or a minimum of 3 times per week.
- **Educational classes** and written material that explains lung disease and how to cope with it both practically and psychologically.

Duke University Medical Center Pulmonary Rehabilitation Program Physical Requirements prior to Lung Reduction or Transplant Surgery

The patient will be able to:

- (1) meet the walking requirements,
- (2) meet the bicycle physical requirements and,
- (3) meet the educational goals pre-operatively.

Treadmill walking is an added option but DOES NOT substitute for level surface walking.

These are the GOALS that each patient should work toward, accomplish, and strive to exceed. These goals should be accomplished with guidance from your local pulmonary rehabilitation program and on your own. It is strongly recommended that you attend pulmonary rehabilitation exercise classes at least 3 days/ week. If there are questions about these requirements, call the Duke Pulmonary Rehabilitation Program at (919) 660-6658.

WALKING:

Ambulate at least 20 minutes.

Must be able to walk at least 1000 feet in 6 minutes.

No restriction on ambulatory assistive devices (walker, cane, etc.).

No limit on the amount of oxygen used; however, you must roll or carry your own oxygen source.

No rest stops.

Distance covered must be $1\frac{1}{4}$ mile.

BIKE:

Bike on any type of manual bicycle (standard stationery bicycle, Airdyne, or recumbent bike).

Bike at least 20 minutes.

No rest stops.

No limit on the amount of oxygen used.

Bike load must be at least 0.5 kp.

TREADMILL:

2.0 mph

No rest stops.

No limit on the amount of oxygen used.

30 minutes.

STRENGTH TRAINING AND FLEXIBILITY:

Use dumbbells, cuff weights, therabands, or weight training equipment (i.e. Cybex) to strengthen upper and lower extremities and trunk.

Perform stretching exercises of all major muscle groups of the trunk and extremities.

EDUCATION:

- **Breathing exercises** – the patient will be able to perform diaphragmatic and pursed lip breathing independently and paced breathing with exercises.
- **The patient** will have a thorough understanding of medications that may be used pre- and post- operatively.
- **The patient** has been informed of the rehabilitation requirements pre- and post- operatively and has a plan for meeting those requirements.
- **The patient** will have realistic expectations of the outcomes following lung reduction or transplant surgery.

***These are minimum requirements**

**** Cessation of all nicotine and tobacco products is mandatory, e.g. cigarettes, cigars, chewing tobacco and nicotine gum.**

The Duke University Medical Center Pulmonary Perioperative Rehabilitation Program

What is the pulmonary perioperative program?

It is a program of exercise and education designed to improve your strength and stamina prior to or following your lung surgery. The Duke pulmonary surgical team strongly believes that rehabilitation before your surgery helps you prepare both physically and mentally to undergo surgery under the best possible conditions. Rehabilitation after surgery speeds your recuperation and helps you regain full independence.

Who is eligible to join the program?

All individuals who have been evaluated by the pulmonary surgical team **and** are preparing for lung reduction or lung transplantation surgery, **or** have had a lung reduction procedure or a lung transplant.

Where is the program located?

The perioperative rehab program is located in the Duke Center for Living, 1300 Morreene Road, Durham, NC. The Center for Living campus comprises three buildings: The Pepsico Fitness, Wallace Clinic, and Stedman Nutrition buildings. The pulmonary rehab program is located in the Pepsico Fitness Building.

When is the program held?

The program meets Monday through Friday from 12:30 to 4:30 p.m.

How long do I attend the program?

Upon entering the program, you will be evaluated by the rehab therapists and doctors. Recommendations will be made to the pulmonary surgical team regarding your physical status and how long you may need to attend the rehab program. Typically, patients participate in the program for four to five weeks.

Where will I live during the program?

If you live beyond commuting distance to Durham, your surgical team coordinator, transplant social worker, or the rehab secretary can provide a list of housing options for you to consider while attending the rehab program.

How much will the rehab program cost?

The program will be billed on a daily basis according to how long you are enrolled and what services you receive each day. All charges are submitted to third-party payers by the Duke Business Office.

How do I enroll in the rehab program?

You may call the pulmonary rehab office at (919) 660-6660 to arrange participation in the program.

Research Projects

Because we are continually trying to improve the outcomes of patients who undergo lung transplantation, we usually have a number of ongoing research projects. Although our rates of rejection and infections after transplantation compare favorably to other centers around the country and around the world, new medicines are constantly being developed to try and decrease posttransplant rejection and decrease the likelihood of infectious complications. In order to understand how to best use some of these newer medications, you may be asked to participate in a number of research studies either before, during or after your lung transplantation. Although we encourage everyone to carefully consider participation in any ongoing research studies, the decision is entirely up to you. We will provide you with the best care possible regardless of your decision to participate in any research studies.

When you are placed on our transplant list you may receive calls from a number of research nurses explaining some of the ongoing studies. At that time we can describe in detail the study design, treatments involved and potential side effects. You will also have an opportunity to discuss any research projects with your physicians or nurses when you come to your regular clinic visits. Ultimately, through research projects, our goal is to improve the long term quality of life and outcomes of all our lung transplant recipients.

Lung Transplant Readiness

When donor lungs become available for you, there is literally no time for delay. Therefore, you must be available to the lung transplant team members at all times. Your transplant coordinator will talk with you about obtaining a mobile phone or pager, so you can be reached even when you are away from home. While the actual amount of time that will be available for you to reach the hospital will vary, we generally ask that you be able to reach the hospital in two hours or less.

If you live farther away from Duke than a two-hour drive, you may be asked to relocate to Durham for the final period of your wait for a lung transplant. Should this happen, the transplant social worker can help you find appropriate housing in Durham.

When a donor lung has been identified for you, you will be called at home by the transplant coordinator. If there is no answer at your home number, you will be called on your mobile phone or pager. Please remember to keep your mobile phone or pager charged and with you whenever you are not at home. You will need to come to the hospital immediately as directed by the transplant coordinator.

Sometimes, after patients have arrived at the hospital and are ready for surgery, the transplant has to be cancelled because the donor lungs have deteriorated. We hope this will not happen to you, but if it does, we will continue to care for you and prepare you for another opportunity. Having your transplant tentatively scheduled, then later cancelled due to deterioration of the donor, has no negative effect on a future transplant.

Your Transplant

After you receive your phone call from the transplant coordinator, you must not eat or drink anything. You will normally be instructed to come to the Duke Hospital Emergency Room, where you will be taken directly to a hospital room.

Upon arrival at your room, you will be prepared for surgery. A chest X-ray, EKG, and routine blood tests will be done. After you are examined by the transplant team doctors and nurses, you will usually have a brief amount of time to spend with your family before you go to the operating room.

Your operation will probably last between five and nine hours. Your family will be shown where to wait and will be kept informed of your condition as necessary during surgery. You will be taken to the operating room on a stretcher. You will find that the operating room is cool and contains quite a bit of equipment. This equipment is used to monitor your heart and blood pressure during the surgery. You will also see many members of the team as they prepare you for the operation.

Single Lung Transplant

If you are having a single lung transplant, your incision will be on your side. This is called a thoracotomy incision. It will either be on your right or left side, depending on which lung is being replaced. Once the transplant surgeons are notified that the donor lung is good, they will begin to remove your diseased lung. The diseased lung is totally removed only after the donor lung arrives in the operating room.

Three connections, called anastomoses, attach the new lung. First, the donor's main airway, or bronchus, is attached to your bronchus. Then the blood vessels are attached: first the pulmonary artery, then the pulmonary vein. Once all the connections are made, your chest is closed and you are taken to the Intensive Care Unit. You will be asleep and supported on a ventilator for several hours after the surgery is completed.

Bilateral Lung Transplant

If you are having a bilateral lung transplant, your incision will be across your chest just at the base of your breasts. This is called a transverse sternotomy incision. The bilateral lung transplant is done by replacing each lung separately. As in a single lung transplant, the surgeons do not begin to remove your lungs until they know that the donor lungs are good.

When the donor lungs arrive in the operating room, your first lung (the one with the poorest function) is removed. Once this first lung has been removed, a donor lung will be attached. Again, there will be the same three connections for each lung.

After the first new lung has been attached, your second diseased lung is removed. The other new lung is attached in exactly the same manner as the first. Once the second lung is completely connected, your chest will be closed and you will be taken to the Intensive Care Unit.

After Your Transplant

The Intensive Care Unit

Immediately following your transplant surgery, you will be brought from the operating room to the Intensive Care Unit (ICU) in your bed. Once in the ICU, it will take approximately one hour for the nurses to do their initial assessments and help get you comfortable. The nurses will then call in your family members so that they may see you. You will still be asleep because the anesthesia will take several hours to wear off.

Once you wake up, it is normal to feel confused. Your nurses will tell you that your surgery is over, and they will tell you what day it is, what time it is, and where you are. You will have many IV lines and tubes, and you will be in a room with many monitors and machines. Your arms may be gently restrained until you are fully awake, in order to prevent you from pulling out any of your tubes. Most patients do not remember the first 12 to 24 hours after surgery.

You will have a breathing tube in your mouth and throat. This tube will be connected to your ventilator, which will breathe for you until you are able to breathe on your own. It will be impossible for you to talk as long as this tube is in place.

You will also have another small tube in your nose that goes to your stomach, called a nasogastric (NG) tube. This tube will drain your stomach contents and help prevent you from feeling nauseated. The NG tube will be removed after your anesthesia wears off and your stomach and intestines begin to work again.

You will also have a large IV catheter in a vein in the side of your neck. This will allow us to monitor your heart function closely. You may have an IV in your arm for fluid or medication and another in your wrist to continuously monitor your blood pressure.

Pumps by your bed will be supplying you with fluid from the IV bags hanging overhead. This fluid contains various medications to control your heart rate and blood pressure. You will also be receiving IV medications to prevent rejection of your new lung.

The drainage tubes you will have in your sides are called chest tubes. These tubes, designed to drain fluid and air from the space around the new lungs, will be connected to suction for a few days to help the lungs completely expand. Once the lungs are fully expanded and there is no longer any air or fluid draining from the chest tubes, the tubes will be removed.

You will also have a catheter in your bladder to drain your urine output. Your nurses will measure and record your urine output every hour to ensure that you stay in good fluid balance. In a few days, when you are able to go to the bathroom on your own, the bladder catheter will be removed.

Finally, you will have a small sensor on your finger connected to a machine at your bedside (called a pulse oximeter) to monitor your pulse rate and the oxygen level in your blood.

Every patient experiences pain after a major operation, but each person feels differently. You will probably have an epidural catheter in your back immediately after surgery. Medicine is given through this catheter to help numb the nerves which are causing the pain. Please let the nurses and doctors know if your pain is not being controlled, so that different treatment measures can be ordered.

Physical Therapy

While you are in the Intensive Care Unit, you will be asked to lie in certain positions in order to increase drainage from the transplanted lungs and help them expand more completely. You will begin physical therapy about 12 hours after the end of your surgery. You will receive physical therapy two to four times a day for 30 to 60 minutes each time.

First, you will have chest physical therapy, postural drainage, percussion and vibration. You will progress quickly to sitting on the side of your bed and dangling your feet, then to getting up in a chair after your surgery. You will likely be able to walk by the first or second day.

Keeping Your Lungs Clear

Transplanted lungs do not have the usual nerve attachments. Therefore, your new lungs will not feel irritation below the airway connection in the donor lungs. This means that you will not feel like coughing when you have secretions below the airway suture line. However, since it is common for the lungs to have many secretions after surgery, **it is extremely important to cough**. You must make yourself cough as deeply as possible and take deep breaths at least every couple of hours. You need to help your nurses and physical therapist keep your lungs clear and open.

Each therapy session will focus on the areas of your lungs that appear to be congested. You will also have frequent chest X-rays. Throughout your recovery, you will be taught various ways to help you maintain clear airways.

You will remain in the Intensive Care Unit until you are stable and breathing on your own. Most lung transplant patients stay in the ICU for several days.

Visiting hours in the Intensive Care Unit are flexible, depending on the condition of the patient. Generally, visitation can occur any time between 9 a.m. and 9 p.m., with the exception of 7 to 8 p.m., when nurses are changing shifts. Please note that visits must be cleared with the patient's nurse. Please request your visit by using the intercom located in the ICU waiting room.

Post-Transplant Therapy

When you are ready to leave the ICU, you will be transferred to the thoracic surgery step-down unit. On this unit, you will continue to recover and regain your strength. Again, each person recovers at his or her own rate.

As you recover, the IVs, chest tubes, and oxygen will be removed. Oxygen is usually not needed by two weeks after surgery.

Your physical therapy will continue to be a priority. You will walk at least twice a day, increasing your distance each time. Your deep breathing, coughing and chest physical therapy will also continue. Most patients are able to walk one mile per day by the third or fourth week after surgery, and can go back to supervised treadmill and/or bicycle therapy in even less time.

You can expect to be discharged from the hospital about one to four weeks after your operation, but you will need to remain in Durham to complete at least 23 sessions of the outpatient intensive pulmonary rehabilitation program at the Duke Center for Living. Your transplant social worker can help you arrange housing for yourself and a family member during this time.

Your Long-Term Outlook

While lung transplant represents the best hope for people with end-stage lung disease, various complications can occur after lung transplantation. These may include rejection, infection, technical complications, and recurrence of original lung disease.

During your hospitalization, we will teach you to monitor your lung volumes (FEV1 and FVC) daily. You will be given a hand-held machine called a microspirometer for measuring these lung volumes. Any changes in your lung function or other symptoms will be evaluated thoroughly. It is important that we carefully decide the cause of your symptoms so that we can treat you appropriately.

Part II of this educational manual goes into much greater detail about transplant complications. We recommend that you and your support person(s) spend time studying Part II while you are waiting to be called for transplantation. It will be very helpful for you to become familiar with post-transplant issues before actually becoming a lung transplant recipient. The transplant coordinator will review signs and symptoms of infection, rejection, drug side effects, and other complications with you before you are discharged from your transplant hospitalization.

While complications are always a possibility, it's important to remember that the single most important factor in the outcome of your transplant is **you**. Lung transplantation is a lifelong commitment, one with lasting impact on every aspect of your existence. So take your responsibility seriously—and take good care of yourself.

The Duke Lung Transplant Team knows that going through a major medical procedure like this can be a trying time, and we want very much to help you through this process. Please let us know of any way we can help ease your confusion and anxiety. We look forward to working closely with you.

Resource Directory

Resources

We want to help you and your family deal with concerns that may arise before or after your transplant. Your social worker, transplant coordinator, and physician can give you information on resources for your particular needs. In the following pages, you will find a listing of resources that may be useful.

Comprehensive Transplant Resources

Variety of Resources for Patients, Caregivers, and Donors

- AMERICAN DIABETES ASSOCIATION 800-342-2383
1660 Duke Street, Alexandria, Va 22314 www.diabetes.org
- AMERICAN HEART ASSOCIATION 800-242-8721
Information on heart healthy diet, www.americanheart.org
support and ventricular assist devices.
7272 Greenville Avenue, Dallas, TX 75231
- AMERICAN LUNG ASSOCIATION 800-548-8252
Information on smoking cessation, www.lungusa.org
local support groups
- AMERICAN ORGAN TRANSPLANT
ASSOCIATION 800-373-1646
Helps patients obtain and sustain www.a-o-t-a.org
transplantation.
1603 Oak Place Court, Pearland, Texas 77581
- ANGEL FLIGHT 800-446-1231
Free air transportation for financially (310)390-2958
eligible patients www.angel-flight.org
- CANCER INFORMATION SERVICE 800-729-6682
National education and information network www.cis.nci.nih.gov/
- CAROLINA DONOR SERVICES 919-489-8404
Information on organ donation network www.carolinaservices.org
3622 Lyckan Parkway, Suite 6002, Durham, North Carolina 27707
- CENTER FOR DISEASE CONTROL www.cdc.gov
Clearinghouse for illness and recovery information.

lung transplant

CHILDREN'S ORGAN TRANSPLANT ASSOCIATION 800-366-2682
Fundraising assistance for transplant patients. www.cota.org
2501 COTA Dr., Bloomington, IN 47403

CHILDREN'S TRANSPLANT ASSOCIATION (214) 287-8484
Private, nonprofit organization that assists with fundraising.
PO Box 53699, Dallas, TX, 75253

DUKE OUTPATIENT PHARMACY (919) 684-2908
Duke South/Clinics First Floor

DUKE UNIVERSITY TRANSPLANT CENTER

www.organtransplant.mc.duke.edu/transplant.nsf

Lung: 800-249-5864 or (919) 684-2240
Fax: (919) 681-9571
Lung_Transplant@mc.duke.edu

Heart: Voice: (919) 684-2651 Fax: (919) 681-8860
Heart_Transplant@mc.duke.edu

DURHAM VETERAN'S AFFAIRS MEDICAL CENTER (919) 286-0411

FOOD AND DRUG ADMINISTRATION

Ventricular Assist Devices.

[ww.fda.gov/hearthealth/treatments/medicaldevices/vad.html](http://www.fda.gov/hearthealth/treatments/medicaldevices/vad.html)

FRIENDS HEALTH CONNECTION 800-483-7436
Connects patients with same disease for support. www.48friend.com

HEART CENTER ONLINE. www.heartcenteronline.com.
*Up to date information available
by web-sitex*

JUVENILE DIABETES FOUNDATION 800-533-2873
432 Park Avenue, South, New York, NY 10016

LIFE IN LIMBO. www.life-in-limbo-com
Support for patients and caregivers.

MARCELINO PAN Y VINO INC. 703-820-7111

Provides financial, social and emotional support to Latino children needing transplants.

Fr. Jose Eugenio Hoyos, St. Anthony's Catholic Church

3305 Glen Carlyn Road, Falls Church, VA 22041

MEDIC ALERT. 800-432-5378

Offers membership and medic alert bracelets.

www.medicalert.org

2323 Colorado Avenue, Turlock, CA 95382

MEDICARE HOTLINE 800-672-3071

MEDSCAPE

*Comprehensive web-site for medical research
and abstracts.*

www.medscape.com

NATIONAL ASSOCIATION OF DISABILITY

REPRESENTATIVES 800-747-6131

PO Box 1303, Framingham, MA 01701

www.nadr.org

NATIONAL CLEARINGHOUSE FOR ALCOHOL

AND DRUG INFORMATION. 800-729-6686

www.ncadi.gov

NATIONAL CYSTIC FIBROSIS

FOUNDATION 800-344-4823 or (301) 951-4422

6931 Arlington Road, Bethesda, Maryland 20814

NATIONAL FOUNDATION

FOR TRANSPLANTS 800- 489-3863 or (901) 684-1697

Fundraising assistance for transplant patients.

www.transplants.org

1102 Brookfield Road, Suite 200, Memphis, TN 38119

NATIONAL ORGANIZATION FOR RARE DISORDERS. 800-999-6673

www.NORD-RDB.com

NATIONAL RESOURCES DIRECTORY. 800-238-7828

Stadtlanders Pharmacy

- NATIONAL TRANSPLANT ASSISTANCE FUND 800-642-8399
3475 West Chester Pike, Suite 230, Newtown Square, PA 19073 www.transplantfund.org
- NC DIVISION OF VETERAN’S AFFAIRS. (919) 733-3851
- NC DIVISION OF VOCATIONAL REHABILITATION
 (919) 733-3364
- NC GOVERNER’S ADVOCACY COUNCIL FOR PERSON’S
 WITH DISABILITIES. 800-821-6922
- ORGAN DONATION IN SUPPORT OF LIFE www.lifebanc.org
- PARTNERSHIP FOR CARING 800-989-9455
Information on advance directives. 1620 Eye St. NW, Suite 202, Washington, DC 20006 www.partnershipforcaring.org
- PHARMACARE 800-238-7828
Transplant mail order medication program. www.pharmacare.com
- RONALD McDONALD HOUSE. (919) 286-9305
Housing for pediatric transplant patients and their families. 506 Alexander Avenue, Durham, NC 27705 www.ronaldhousedurham.org
- SECOND WIND (888) 855-9463
PO Box 1915, Largo, FL 33779 www.2ndwind.org
- SOCIAL SECURITY ADMINISTRATION. 800-772-1213
Applications for retirement, survivorship, disability, SSI and Medicare benefits. www.ssa.gov
- SOCIAL SECURITY DISABILITY 800-772-1213
www.ssa.gov/disability
- SOCIAL SECURITY DISABILITY HOTLINE 800-638-6810
- TRIANGLE DISABILITY ADVOCATES, INC. (919) 350-8539
Fax (919) 350-5626

- TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION 800-874-6386
Support for transplant candidates, recipients, their families and donor family members. www.trioweb.org
 1000 16th Street, NW, Suite 602, Washington, DC20036
- TRANSPLANT SUPPORT GROUP DIRECTORY 800-753-5583
Updated annually.
 Chronimed Pharmacy, 13911 Ridgedale Drive, Minnetonka, MN 55305
- TRANSPLANT TIMES 800-893-1995
Newsletter of the transplant patient partnering program. www.tppp.net
 340 Kingsland Street, Nutley, NJ 07110
- UNITED NETWORK FOR ORGAN SHARING 804- 782-4800
 Post Office Box 2484, Richmond, Virginia 23218 www.unos.org
- UNITED PATIENT’S ASSOCIATION FOR PULMONARY HYPERTENSION 800-748-7274
Fellowship and educational support for persons with pulmonary hypertension.
- UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES
Comprehensive web-site on a wide range of healthcare issues. www.os.dhhs.gov
- US LIVING WILL REGISTRY
Medical power of attorney and living will/advance directives information. www.uslivingwillregistry.com
- VETERANS RESOURCE CENTER 800-606-2022
If you have served in the military and received an honorable discharge, you may be eligible for benefits, including immunosuppressant drugs.
- VENTRICULAR ASSIST DEVICES
www.sts.org/education/faqs/faqvassist.html

WE'VE BEEN THERE NATIONAL TRANSPLANT
FOUNDATION (866) 938-3233
Provide emotional and social support for *www.wevebeenthere.org*
young transplant patients 10-35 years old.
7713 Fontaine St. Potomac, MD 20854

WORLD CHILDREN'S ASSISTANCE FUND (818) 905-9283
Private, nonprofit organization dedicated to providing *www.wctf.org*
financial, social and emotional support.

Residential Reference Guide

This list of local residential facilities is provided as a reference guide. Most of the facilities are experienced in serving transplant patients and their caregivers. However, inclusion on this list does not imply a contractual relationship with Duke University Medical Center or your transplant team. Should service at any of these facilities be less than satisfactory, please inform your transplant social worker at (919) 681-5886.

BROOKWOOD INN DURHAM (919) 286-3111
 2306 Elba St
 DURHAM, NC 27705

BEST VALUE CAROLINA DUKE INN
 DURHAM (919) 286-0771
 2517 Guess Road
 DURHAM, NC 27705

BIRCHWOOD RV PARK (919) 493-1557
 5901 Wilkins Drive
 DURHAM, NC 27705

CANDLEWOOD SUITES RTP (919) 484-9922
 1818 E. Highway 54
 DURHAM, NC 27713

COMFORT INN: (919) 490-4949
 3508 Mount Moriah Road
 DURHAM, NC 27707

COURTYARD BY MARRIOTT (919) 484-2900
 301 Residence Inn Boulevard
 DURHAM, NC 27713

DAYS INN (919) 383-1551
 3460 Hillsborough Road
 DURHAM, NC 27705

DOUBLETREE GUEST SUITES - RALEIGH/DURHAM (919) 361-4660
2515 Meridian Parkway
DURHAM, NC 27713

DUKE TOWER RESIDENTIAL SUITES (919) 681-4444
807 W Trinity Avenue
DURHAM, NC 27701

EXTENDED-STAY DURHAM SO. SQUARE (919) 489-8444
3106 Tower Blvd
DURHAM, NC 27707

THE FOREST APARTMENTS. (919) 383-8504
800 White Pine Drive
DURHAM, NC 27705

FAIRFIELD INN BY MARRIOTT DURHAM (919) 382-3388
3710 Hillsborough Road
DURHAM, NC 27705

FAIRFIELD INN BY MARRIOTT
RESEARCH TRIANGLE PARK (919) 361-2656
4507 Highway 55
DURHAM, NC 27713

HAMPTON INN DURHAM (919) 471-6100
1816 Hillandale Road
DURHAM, NC 27705

HAWTHORNE INN & SUITES (919) 361-1234
300 Merdith Drive
DURHAM, NC 27713

HILTON DURHAM. (919) 383-8033
3800 Hillsborough Road
DURHAM, NC 27705

HOLIDAY INN HOTEL RALEIGH-DURHAM AIRPORT (919) 941-6000
4810 Page Road
DURHAM, NC 27709

- HOLIDAY INN EXPRESS HOTEL (919) 313-3244
 2516 Guess Road
 DURHAM, NC 27705
- HOMEWOOD SUITES RALEIGH DURHAM (919) 474-9900
 4603 Central Parks Drive
 DURHAM, NC 27703
- HOWARD JOHNSON..... (919) 477-7381
 1800 Hillandale Road
 DURHAM, NC 27705
- INNKEEPER DURHAM WEST..... (919) 309-0037
 3454 Hillsborough Road
 DURHAM, NC 27705
- KORMAN COMMUNITIES RTP (919) 484-1321
 300 Seaforth Drive
 DURHAM, NC 27713
- LA QUINTA INN & SUITES
 DURHAM/CHAPEL HILL..... (919) 401-9660
 4414 Chapel Hill Blvd.
 DURHAM, NC 27707
- MEDSTAY 877-633-7829
www.medstay.com
 (Free hotel reservation service at discount rates for patients and
 caregivers, not affiliated with Duke.)
- MILLENNIUM HOTEL DURHAM..... (919) 383-8575
 2800 Campus Walk Avenue
 DURHAM, NC 27705
- OAKWOOD AT SUMMIT SQUARE..... (602) 687-3322
 614 Snow Crest Trail
 DURHAM, NC 27707

- RESIDENCE INN (919) 361-1266
 201 Residence Inn Boulevard
 DURHAM, NC 27713
- RONALD MCDONALD HOUSE (919) 286-9305
www.ronaldhousedurham.org
 (Housing for pediatric transplant patients and their families.)
 506 Alexander Avenue, Durham, NC 27705
- STUDIO PLUS (919) 941-2878
 4610 S Miami Blvd
 DURHAM, NC 27703
- STUDIO PLUS (919) 361-1853
 2504 E Nc Highway 54
 DURHAM, NC 27713
- WASHINGTON DUKE INN GOLF CLUB (919) 490-0999
 3001 Cameron Blvd
 DURHAM, NC 27705
- WYNDHAM RALEIGH DURHAM
 AIRPORT GARDEN (919) 941-6066
 4620 S Miami Blvd
 DURHAM, NC 27703
- WELLESLEY INN & SUITES DURHAM (919) 998-0400
 4919 S Miami Boulevard
 DURHAM, NC 27703

Relocation Planning Guide

Use this guide as a reference to help you through the relocation process

STEP ONE: Develop Initial Budget Plan

- Rent
- Utilities
- Food
- Transportation
- Parking
- Medication
- Oxygen
- Incidentals

STEP TWO: Inspect Potential Residential Facilities

- “Transplant” Clean
- Feels Safe and Comfortable
- Weekly and Monthly Contracts Available
- Reasonable Distance from Duke
- Mail Delivery Available
- Wheelchair Accessible
- Roll In Shower
- Free or Pay Shuttle Service
- Full Kitchen Amenities
- Some Appliances Included
- Laundry Facilities On Site
- Utilities Included in Rent
- Swimming Pool
- Fitness Room
- Restaurant on Premises
- Social Activities
- Room Service 24 Hours
- Business Center
- Computer Data Port
- Designated Non Smoking Rooms
- Medical Discount Available
- Air Conditioning

- Cable Television/VCR
- Pets Allowed
- Children Welcome
- 911 Service Available
- Billing Options Identified
- Shopping Centers Nearby
- Security 24 Hours
- Housekeeping Available
- Distance From RDU Airport
- Availability Assured
- Guests Welcome Overnight
- Evening Desk Service

* Note: While no facility has every service available, identify which are the most important to you and fit your budget. Then, inspect two or three of the facilities before signing a contract. Remember, if you are not satisfied with your decision, you may always continue your search and move when your weekly or monthly lease requirements are fulfilled.

STEP THREE: Create a Moving Plan

- Make Apartment Deposit
- Have Car Serviced
- Arrange Oxygen Delivery
- Contact Local Pharmacy To Transfer Prescriptions
- Inform Medical Insurance Carrier
- Follow Medicare/Medicare Relocation Guidelines
- Inform Income Sources
- Collect Boxes for Packing
- Arrange for Van Rental If Needed
- Arrange for Pet Transportation
- Obtain School Information
- Identify Worship Center
- Locate Child Care Services
- Obtain Change of Address Information

STEP FOUR: Close Permanent Residence

- Defrost Refrigerator
- Unplug Major Appliances
- Disconnect Utilities
- Give Away Plants
- Cancel Deliveries
- Yard Care Plan
- Forward Mail
- Update Address Book
- Notify Important People
- Ask Trusted Neighbors To Inform You of Any Problems

STEP FIVE: When You Get To Durham

- Inform Your Transplant Coordinator
- Contact The Center for Living
- Identify Local Bank Branch
- Locate Local Veterinary Service
- Contact Cable Service
- Call Newspapers
- Keep Emergency Numbers Handy
- Contact New Utilities
- Obtain Local Street Maps
- Obtain Cell Phone
- Child and Pet Proof Apartment
- Test Smoke Alarms
- Save Receipts for Insurance
- Save Receipts for Taxes Purposes
- Notify Transplant Fundraiser
- Contact Local Pharmacy
- Contact Oxygen Company

