



LUNG TRANSPLANT PROGRAM

Before your transplant



Duke Transplant Center

TABLE OF CONTENTS

The Duke Lung Transplant Program	2
The Lung Transplant Team	2
Transplant Pulmonologists	2
Surgeons	2
Transplant Coordinators	3
Transplant Program Specialist	3
Transplant Medical Secretaries	3
Transplant Clinicians	3
Transplant Social Worker	3
Medical Psychologist	3
Speech Pathologist	3
Transplant Clinical Pharmacist	3
Physical Therapists/Respiratory Therapists	3
Transplant Financial Coordinator	4
Transplant Dietitian	4
Reasons for Lung Transplantation	4
Preparing for the Evaluation	5
Evaluation Studies	6
Determining if You are a Candidate for Lung Transplantation	8
Requirements for Lung Transplantation	12
Pulmonary Physical Therapy Program	13
Challenges with Lung Transplant	14
Preparing for Listing as a Lung Transplant Candidate	18
Preparing for Relocation	18
Listing for Lung Transplantation	18
Waiting for a Lung Transplant	19
The Lung Transplant Procedure	22
Relocation Guide	26
Accommodations	27
Patient Contract for Lung Transplantation (Sample)	33
Patient Caregiver Contract (Sample)	35
Notes and Questions	39

THE DUKE LUNG TRANSPLANT PROGRAM

You have been referred to Duke University Hospital (DUH) to determine if lung transplantation may be the best treatment for your chronic lung disease. Lung transplantation is a sophisticated, effective therapy for end-stage lung disease. During transplantation, as the name implies, one or both of a patient's lungs are removed and replaced with healthy lungs from a recently deceased donor.

The Duke Lung Transplant Program began in February 1992. Since then, we have performed more than 1,600 lung transplants. 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 you understand more about the procedure and 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. By the end of the evaluation, we hope you can make an informed choice about your health care. Choosing transplantation involves a lifetime commitment to caring for yourself and your new lungs.

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 at the end of this booklet to help you remember to discuss them with the members of the transplant team.

THE LUNG TRANSPLANT TEAM

The Duke Lung Transplant Team is made up of a diverse group of health care professionals, including physicians, nurses, psychologists, social workers, dietitians, and physical therapists. Initially, these specialists will help determine if a lung transplant is the right treatment for you. If you are selected as a candidate for transplant surgery, the same group of professionals will take care of you.

The following is a list of the Lung Transplant Team members and a brief description of their roles in your care at Duke.

Transplant Pulmonologists

These medical doctors specialize in lung disease and transplantation. Your doctor will conduct a thorough exam, review your past medical history, and determine if a transplant is the best treatment option for you. They also will provide the majority of your post-transplant care.

Transplant Surgeons

Transplant surgeons perform the operation. Your surgeon will explain to you the procedure and risks related to the surgery and also help determine if transplantation is your best treatment option.

Transplant Coordinators

These nurses teach you and your family about the transplant evaluation, surgery, and recovery. They coordinate patient care before and after transplant and will be your primary contacts once the evaluation process begins.

Transplant Program Specialist

This team member coordinates and manages your referral to the Duke Lung Transplant Program. He or she will work with your referring physician to obtain all the necessary records for medical and financial clearance before your evaluation.

Transplant Medical Secretaries

These team members will help to facilitate communication between you and the rest of the transplant team. They will answer and triage phone calls and provide data entry for lab results.

Transplant Clinicians

These nurses assist with all your medication needs during the transplant process. This includes new prescriptions, refills, insurance authorizations, IV medications/ infusions, and PICC lines.

Transplant Social Worker

This provider will help determine your ability to cope with the impact of lung transplantation upon you and your family. He or she will assess your support network by asking you about your family life, social habits, and financial concerns; serve as a resource for information about local social services and counseling; and discuss your family's plans for relocating before the transplant and for recovery and rehabilitation after the transplant.

Medical Psychologist

This team member specializes in human behavior and will talk with you about your understanding of the transplant and behaviors that may impact your ability to have a successful outcome. He or she will consider your history of using substances such as nicotine, alcohol, and other drugs, and may use survey tools to determine how you might adjust to a lung transplant. In addition, team member also provides psychotherapy pre and post transplant as needed.

Speech Pathologist

This team member is trained to evaluate respiratory muscle and swallowing disorders before and after surgery. They may initiate pre transplant swallowing treatment to increase improvement and swallowing strength.

Transplant Clinical Pharmacist

This specialized pharmacist will teach you about the medicines you will take after your lung transplant and discuss medication safety and things you should report to your physician.

Physical Therapists

Trained to accurately evaluate your musculoskeletal system and exercise capacity, these team members may also recommend home-exercise programs to increase your strength and endurance in preparation for surgery. They direct the activity of your recovery in pulmonary physical therapy.

Respiratory Therapists

Specializes in assessing your oxygen needs while exercising as well as at home and in the community. They will ensure you have the proper equipment to remain as active as possible. They will also participate in caring for all your respiratory needs while attending your exercise sessions.

Transplant Financial Coordinator

This member of the transplant team will review your insurance benefits and provide you with information about any potential costs related to travel for appointments, medications, and home care expenses that you may be responsible for. This professional works with your insurance company to get prior approval for the transplant surgery before you are listed as a candidate for transplantation.

Transplant Dietitian

The clinical dietitian is available to advise you about your nutritional needs. A healthy weight at the time of the transplant will help your surgery be a success.

The members of Duke's Lung Transplant Team want to ensure that you understand all the aspects of your care. Please feel free to ask any questions you may have by contacting the program specialist or transplant coordinators.

REASONS FOR LUNG TRANSPLANTATION

Lung transplantation is considered when your 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 may cause your lungs to fail:

- Chronic obstructive pulmonary disease (COPD), which may include asthma, chronic bronchitis, emphysema and/or Alpha 1 antitrypsin deficiency
- Idiopathic pulmonary fibrosis
- Sarcoidosis
- Connective tissue disease-related pulmonary fibrosis
- Eosinophilic granulomatosis
- Bronchiectasis
- Cystic fibrosis (CF)
- Pulmonary hypertension (both primary and secondary)

- Lymphangiomyomatosis (LAM)

There are some other lung diseases that may also cause damage so severe that transplantation is considered.

Before you become a transplant candidate, you must have an evaluation. The evaluation includes consultations with transplant team members, physical examinations, studies, and blood work. The purpose of the evaluation is to decide if transplantation is the best therapy to improve your health—and whether you have any other health concerns that would affect your recovery or survival.

Evaluation for lung transplantation may occur in the hospital or as an outpatient over several days. The schedule depends upon how well you are and if you are able to tolerate activity. It may also depend on your insurance benefits. We will work with you to select a date to begin your evaluation.

PREPARING FOR THE EVALUATION

There are several things you should do to prepare for your transplant evaluation:

Choose a Date for the Evaluation

Your evaluation will be scheduled for one to five days, depending on the request of the transplant physician who reviewed your referral records. It is important to try to keep your appointment once it has been scheduled because it may take several weeks to reschedule it, if necessary. About 10 days before your evaluation, you will be sent a letter detailing your appointment schedule and any special instructions. You should make any necessary travel plans as soon as you choose your date.

Involve Your Family

The Duke Lung Transplant Team knows it is critical to educate families about their role in caring for lung-transplant patients, we ask that you have your primary caregiver with you during the entire evaluation. Family members can help you understand things that you are told during the transplant evaluation and, most importantly, they provide support for you during the evaluation. All patients are required to identify family members who will care for them during the evaluation. Please review the information on “Caregivers and Transportation for Lung Transplant Candidates” with your family, which begins on page 14.

Complete Routine Health Screenings and Vaccinations

It is important that you continue to maintain your health through routine health screenings and vaccinations. Please make sure that you have completed or scheduled the following:

- Pneumovax vaccine (within the last five years)
- Tetanus vaccine (within the last 10 years)
- Hepatitis B vaccine series (at least one of the series)
- Flu vaccine (annually)
- Tuberculosis (TB) skin test (within the last 12 months)

- Colonoscopy, if over age 50 (within the last five years). Please note that prior to undergoing any procedure, such as colonoscopy, you should discuss with your referring doctor to determine the safest place to have them done.
- Mammogram
- Pap smear
- Bone density test, if over age 50 (within the last 12 months)

Your primary care physician can assist you in obtaining and/or providing records from these screenings and vaccinations.

Plan Your Travel

You will need to plan for an overnight stay, meals, and transportation as needed. Some insurance plans provide travel assistance. Contact your insurer to find out about travel benefits, and see the enclosed information for area accommodations.

Plan for Oxygen Needs

If you use oxygen and are traveling to Duke from outside of the Durham, NC, area for your evaluation, you must notify your oxygen-supply company. The company should be able to arrange delivery just as it does when you are away from home for other reasons.

You will need to plan for enough oxygen to support you:

- While traveling from your home to Duke at the beginning of your evaluation.
- While traveling back and forth from the hospital/clinic, both in the morning and evening, each day of your evaluation.
- Overnight, in the hotel, each night of your evaluation.
- While traveling back home after your evaluation has been completed.

Oxygen will be provided at the hospital/clinic during your evaluation appointments and studies. We will also provide you with information for obtaining oxygen if you do run out while at Duke.

Please notify us as soon as possible if you will not be able to attend your evaluation or any appointment as scheduled. This includes notifying us if you are hospitalized.

EVALUATION STUDIES

We strive to obtain a great deal of information during your initial evaluation so we can make recommendations as quickly as possible about your ability to have a safe and successful transplant. The pre-transplant coordinator begins the week with a group class to explain details about the evaluation and what to expect. Then, you will have several appointments to complete studies and meet with members of the transplant team.

You will meet the members of the transplant team described previously in this booklet. These professional health care providers are only part of the evaluation. Clinicians from each area that performs studies will explain them to you—and may ask you to sign a separate consent form. Please keep in mind that the people who perform the studies do not tell you about the results; your transplant team physician or nurse coordinator will summarize and explain all results to you after your evaluation is completed. You will be scheduled for some or all of the following tests:

Blood tests: Many blood tests will be done, including those that identify your blood type and assess kidney, liver, and immune system function. We also check for viruses or other infections that could cause a problem after surgery.

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 the amount of air and the strength of your lungs.

Echocardiogram: This quick ultrasound 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.

Heart catheterization: This test provides information about arteries that supply the heart with blood and about internal heart pressures. 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 into your heart. A special dye is injected through the catheter that allows the physician to see your blood vessels and measure internal heart pressures. Medication to help you relax may be given for this procedure, if needed. The study usually takes 45 minutes to an hour and is conducted in a specially equipped area called the catheterization (“cath”) lab. After the study, you will need to lie flat for a while to prevent bleeding.

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

Chest CT scan: This radiology scan provides a three-dimensional image of the inside of your lungs and chest. You will be asked to lie very still on a table that moves you through a round, tunnel-like machine.

Esophageal manometry test: This procedure will show your doctor how the muscles in your esophagus work when you swallow. A small tube is passed into your stomach through your nose. When the catheter is in place, you 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. You will not be able to have anything to eat or drink for at least six hours prior to the test.

24-hour gastric pH test: This test, usually performed right after the esophageal manometry test, is performed to see how often acid from your stomach comes up into your esophagus. A small tube that measures the acid reflux you have is placed in your stomach through your nose and will stay in place overnight. Once the tube is in place, you can eat and drink normally, and you will be asked to keep a food and drink diary while the test is in progress. The following morning, the tube is removed in the endoscopy clinic.

Arterial blood gas analysis: This blood test measures how well the lungs bring oxygen into the blood and remove carbon dioxide from the blood.

Pulmonary physical therapy assessment: This evaluation by a rehabilitation physical therapist and respiratory therapist helps us to know about your tolerance of physical activity and oxygen needs for activity. We require participation in our rehabilitation physical therapy before and after your transplant to ensure physical readiness for a transplant. This evaluation includes exercise testing and a six-minute walk test.

Other tests may be ordered as part of your lung transplant evaluation, depending upon individual circumstances. Any additional tests will be explained to you by a member of the Lung Transplant Team.

DETERMINING IF YOU ARE A CANDIDATE FOR LUNG TRANSPLANTATION

Your evaluation results will be presented at a multidisciplinary transplant-selection committee that identifies patients who are eligible for transplantation. Committee members include the transplant professionals who met you during the evaluation. They will review the results of your physical studies and discuss your understanding of your illness, the transplant process, and how lung transplantation will affect you and your family. They will also decide if transplantation is the best treatment option for your disease.

Lung Transplant Selection Criteria

- The committee uses the following selection criteria to determine if patients are appropriate to be placed on the waiting list for lung transplantation.

Patients must:

- Have a chronic, end-stage lung disease that is failing to respond to the most complete and effective medical therapy or for which no effective medical therapy exists.
- Have limited life expectancy with continued maximal medical therapy.
- Be at least 14 years of age.
- Participate in pulmonary physical therapy.

- Have a consistent and reliable social support system.
- Be able to get to DUH within two hours of an organ offer (once listed for transplant).
- Abstain from nicotine-containing substances for at least six months prior to transplant and abstain completely after transplant.
- Be able to relocate to the Durham, NC, area to attend at least 23 sessions of post-transplant pulmonary physical therapy.
- Be able to meet the financial obligations of transplantation, projected immunosuppression medications, supportive therapies, and relocation.

The committee uses the following exclusion criteria which would prevent patients from being candidates for lung transplantation.

Patients must not:

- Have had a malignancy in the last two years, with the possible exception of localized malignancies such as certain types of limited lung cancer, cutaneous squamous, and basal cell carcinomas.
- Have untreatable advanced dysfunction of another major organ system (such as heart, liver, or kidney) unless the patient is a candidate for multi-organ transplant.
- Be older than 60 years of age for multi-organ transplants.
- Have an incurable chronic extra pulmonary infection, including chronic active viral hepatitis B, hepatitis C, and human immunodeficiency virus.
- Have a significant chest wall and/or spinal deformity.
- Be excessively obese or malnourished, which is generally defined as greater than 130% of ideal body weight (IBW) or less than 70% IBW, respectively.
- Have an untreatable psychiatric or psychological condition associated with the inability to cooperate or comply with medical therapy.
- Have documented nonadherence to medical therapies and appointments.
- Be addicted to substances, such as alcohol, tobacco, or narcotics, either currently, or within the previous six months.
- Be in critical or unstable clinical condition.
- Have a severely limited functional status with poor rehabilitation potential.
- Have a colonization of highly resistant or highly virulent bacteria, fungi, or mycobacteria.
- Have severe and/or symptomatic osteoporosis.
- Have chronic, active use of narcotics or benzodiazepines.
- Have severe esophageal dysmotility.

Heart–Lung Transplant Selection Criteria

The selection criteria above also apply for combined heart–lung transplant referrals. In addition, patients must have significant cardiac dysfunction that excludes isolated lung transplantation. Patients must be younger than 60 years of age to be considered for heart–lung transplantation.

Selection Committee Recommendations

After a thorough review of your medical history and the results of your evaluation, the lung transplant selection committee will decide the best way to move forward.

- The committee may decide that lung transplantation is not the best treatment option for your lung disease.
- The committee may decide that it is too early for transplant because you have not yet reached your “transplant window.” In this case, the team will continue to monitor you closely going forward to identify the best time for transplantation in the future.
- The committee may decide that more information is necessary to determine the best course of action, so you will be asked to complete additional studies or accomplish specific goals to improve your candidacy for the lung transplant procedure.
- The committee may decide that lung transplantation is the best treatment option at this time, and you will be approved for listing on the national lung transplant waiting list.

The lung transplant coordinator will contact you to tell you about the committee’s decision. You will also receive a letter with the outcome of your evaluation within 10 days of the selection conference.

Caregivers and Transportation for Lung Transplant Candidates

When you have a lung transplant at Duke, you are required to have a designated primary caregiver (a family member or friend), who will help you in a number of ways throughout the transplantation process. You will also need to have a designated secondary caregiver in place in the event that your primary caregiver is unable to meet all of your support needs. Both your primary and secondary caregivers will be asked to sign a written contract verifying their agreement and commitment to caregiving throughout the transplant process. A copy of the patient caregiver contract is on page 18. You cannot go through this surgery alone. Here is a list of how and when you’ll need help:

Transportation Needs

Your caregiver must be a licensed driver with a private car to transport you:

- To DUH for your transplant surgery (unscheduled, any time of the day or week).
- To the Croasdaile Commons for pulmonary physical therapy before and after your transplant, as scheduled.
- To your discharge location (your home or elsewhere) after surgery.
- To your pretransplant and post-transplant clinic appointments at DUH.
- To DUH for health care for any unexpected or emergency visits.

Discharge Teaching

It is critical that you and your caregivers learn how to care for you when you leave the hospital after surgery. It is best if your designated primary caregiver is one individual; however, we understand that, at times, this role may need to be shared. We request that your designated primary caregiver:

- Be present at the hospital and able to participate in discharge teaching during your hospital stay.
- Be available for case managers to contact and meet with.
- Be available for transplant coordinators to contact and meet with.
- Be available for the transplant pharmacist to contact and meet with.

Help at Home

Your primary caregiver must be prepared to stay at home with you to provide continuing post-transplant care and assistance during your recovery. The following are examples:

- Take care of family members and/or pets that typically rely on your help.
- Help you change bandages and care for your surgical wound.
- Help keep track of your health (vital sign records, appetite, weight, mood).
- Medications: purchase, organize pill box, keep schedule, administer.
- Finances: organize mail, deposit checks, pay bills, manage accounts.
- Nutrition: feeding tube, special diet, food preparation, feeding.
- Personal care: toileting, bathing, hair care, dressing.
- Chores: laundry, cleaning, shopping.

Coming to Appointments

Your primary caregiver must attend all pretransplant clinic and social work appointments with you. We encourage your secondary caregiver to attend all pre-transplant appointments, however this is not mandatory. If a secondary caregiver does not accompany the patient, a phone call will be requested from the secondary caregiver to confirm availability. In addition, one of your caregivers must also attend all post-transplant appointments until you are cleared to drive by your transplant physician.

REQUIREMENTS FOR LUNG TRANSPLANTATION

As a patient being considered for lung transplantation at Duke, the transplant team will ask you to meet certain requirements before being considered a suitable candidate for transplant. Some examples of these requirements are:

- Attending clinic appointments and pulmonary physical therapy.
- Taking your medications on time and as prescribed.
- Following the transplant dietician's nutritional guidelines/restrictions.
- Losing or gaining weight.
- Monitoring your fluid intake and blood pressure.
- Stopping the use of all tobacco products, narcotics, benzodiazepines, and alcohol.
- Attending smoking cessation programs, relapse prevention, and/or additional psychological counseling.
- Establishing a solid care plan.
- Relocating to the Durham area (if you live more than two hours away).
- Fundraising to assist with expenses that your insurance may not cover.
- Staying in contact, and communicating appropriately with the transplant team.

Your compliance with the transplant team's requirements greatly influences the success of your transplant. If you do not follow the transplant team's recommendations, it may result in negative consequences, such as:

- Termination of your transplant evaluation at Duke.
- Delays in transplant waiting list placement.
- Removal from the transplant waiting list.
- Rejection of your transplanted lungs.
- Poor physical health and quality of life.
- Death.

If you fail to care for yourself in a healthy manner, you will be refused as a candidate and we will not be able to offer you a lung transplant at DUH.

Smoking Cessation Programs

We require that you are substance-free for at least six months before transplant, complete a relapse prevention program, and remain completely substance-free after transplant. Smoking and the use of nicotine decreases your resistance to infection. Smokers are more likely to have wound infections after surgery, longer healing times, and problems with scarring. The chemicals in cigarette smoke also cause changes in your blood, making it thicker, stickier, and more likely to clot.

The Duke Lung Transplant Program has a ZERO-tolerance policy for tobacco use. It is important to keep your transplant doctor and surgeon informed about your smoking and when you quit. Blood tests, which reveal ANY exposure to tobacco, will be performed at each transplant clinic visit. A positive blood test is grounds for immediate removal from our lung transplant program.

If you are trying to quit smoking, here are some ways to get help:

- **Quit Now NC:** North Carolina's toll-free quit line has specialists available from 8:00 am to midnight every day for adults and youth. This service is available in English, Spanish, and TTY. Visit www.quitenownc.org or call 1-800-QUIT-NOW
- **NC Tobacco Prevention and Control Branch:** A web site for youth. Visit www.stepupnc.com. NCI Quit Line: Free counseling and resources from the National Cancer Institute. This service is available in English, Spanish, and TTY. Visit www.smokefree.gov or call 1-877-44-U-QUIT.
- **American Cancer Society:** Free counseling and resources for smoking and smokeless tobacco. Visit www.cancer.org or call 1-800-ACS-2345.
- **The Centers for Disease Control and Prevention:** This service is available in English and Spanish. Visit www.cdc.gov/tobacco.

Lung transplant patients who resume smoking or any other form of tobacco use or abuse will not be considered for retransplantation, under any circumstances.

Pulmonary Physical Therapy Program

Potential lung transplant candidates must enroll in a pulmonary physical therapy program. Pulmonary physical therapy is a program of exercise and education designed to improve your strength and stamina before and after your lung transplant. The Duke Lung Transplant Team strongly believes that pulmonary physical therapy is an important aspect of your lung transplant. Before transplant, pulmonary physical therapy helps to prepare you both physically and mentally and enables you to go into the surgery under the best possible conditions. After surgery, pulmonary physical therapy speeds your recovery and helps you to regain full independence.

We recommend attending pulmonary physical therapy a minimum of three days per week to prepare for transplant. Pulmonary physical therapy will be billed to your insurance company. If needed, a letter of medical necessity to continue in a pulmonary physical therapy program is available from our office at your request.

Duke Pulmonary Physical Therapy Program

When your disease is advanced to the point where transplant is needed, you will need to enroll in pulmonary rehab. You can contact them by using the information provided below and identifying yourself as a pre-transplant patient. Group therapy is held Monday through Friday from 12:30 pm to 4:40 pm. A monthly schedule of education classes is also available.

Duke Pulmonary Rehabilitation–Duke Medicine Plaza–Croasdaile

1821 Hillandale Rd. Suite 25B Durham, NC 27705

Phone: 919.660.6628

Choosing a Pulmonary Physical Therapy Center

If you are not a local resident, you should enroll in a pulmonary physical therapy center near your home. You can do so by contacting your referring physician and asking for a list of pulmonary rehabilitation centers in your area.

Here is a summary of what to look for in a pulmonary physical therapy center:

- An evaluation before you begin exercising to monitor your progress, such as a treadmill, bicycle or six-minute walk test performed while your oxygen level, blood pressure, and heart rate is monitored.
- Monitoring equipment, such as a pulse oximeter, to determine your oxygen saturation and heart rate during exercise
- Availability of oxygen, if you need it, while exercising.
- Ability to increase your oxygen during exercise, if you need it, to maintain your oxygen saturation of at least 88%.
- Instruction in various breathing exercises and techniques, such as diaphragmatic, pursed lip, and coordinated breathing.
- Therapy sessions that meet a minimum of three times per week; it is best to have rehab sessions that meet four to five times per week.
- Educational classes and written material that explain lung disease and how to cope with it physically and psychologically.
- Exercises that include three major components:
 - Muscle strengthening using resistive weights or Thera-Bands*
 - Flexibility stretching exercises.
 - Endurance activities to build endurance, such as walking for at least 20–30 minutes or stationary bicycling for 20 minutes.

Pulmonary Physical Therapy Requirements

Before surgery, you should be able to meet the walking requirements, meet the bicycle requirements, and meet the educational goals described below. You should work toward, accomplish, and strive to exceed these goals with guidance from your pulmonary rehab program. It is strongly recommended that you attend pulmonary rehab classes at least three days per week.

The physical requirements and goals that have been determined by the Duke Lung Transplant Program and should be achieved during pulmonary physical therapy before lung transplant surgery are:

Walking

- Walk for at least 20 minutes.
- Walk at least 1,000 feet in 6 minutes.
- No restriction on ambulatory assistive devices (i.e., 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 ½ mile (in 20 minutes).

Bicycle

- Bike on any type of manual bicycle (i.e., standard stationary bicycle, Schwinn Airdyne®, or recumbent bike).
- Bike for 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

- Walk for at least 30 minutes.
- No rest stops.
- No limit on the amount of oxygen used.
- Treadmill speed must be at least 2.0 mph.
- **Note:** Treadmill walking is not a substitute for level surface walking.

Strength Training and Flexibility

- Use dumbbells, cuff weights, Thera-Bands®, or weight training equipment (i.e., Cybex) to strengthen your upper and lower extremities and trunk.
- Perform stretching exercises of all the major muscle groups in your trunk and your upper and lower extremities.

Education

- You should be able to perform paced breathing with exercise, as well as diaphragmatic and pursed lip breathing on your own.
- You should have a thorough understanding of the medications that may be used before and after surgery.

- You should be informed of the pulmonary rehab requirements for before and after surgery and have a place to meet those requirements.
- You should have a realistic expectation of the outcomes following lung transplant surgery.

This is the outline used by the pulmonary physical therapy program at the Duke Croasdaile Commons. If you are enrolling in pulmonary physical therapy elsewhere, this information should be used to make sure that you will be able to meet our goals. If you have questions about these requirements, please contact Croasdaile Commons Cardiac and Pulmonary Rehab.

Lung Transplant Challenges

The ongoing evaluation period can often be a stressful and emotional time. The transplant team wants to ensure that nothing will prevent you from being able to care for yourself and follow the team's instructions to the best of your ability. If you are experiencing feelings of anxiety or depression, please let the transplant team know right away. They will make sure you receive the psychological care and coping skills that you may need during the transplant process.

It is very important to establish a good working relationship with the transplant team and to keep the lines of communication open and clear. This will help to make sure you understand exactly what is expected of you. To avoid miscommunication, we recommend the following:

- Before each clinic visit, write down a list of questions that you have and bring it with you to discuss with the transplant team.
- When you call the office, follow the voicemail prompts to leave a message for the appropriate person.
- For routine matters, allow at least one business day for a response from the transplant team.
- If you are unsure about how to meet the transplant team's goals, call your coordinator.

It is also very important to understand all of the costs that can be part of the transplant process, so that financial problems do not create a barrier for you. Some of the transplant costs include travel, housing, transportation, medications, and pulmonary rehabilitation. Our lung transplant financial coordinators are available to advise you about issues related to your insurance and the expected costs. If you encounter financial problems that might affect your health care, please contact a financial coordinator or social worker. These team members are experts at helping you find appropriate resources. They can also talk to you about how to raise the money that you will need before and after your transplant.

Food and Water Health

Food and water safety is important for everyone – but it is especially important for transplant patients who are uniquely susceptible to infections due to a compromised immune system.

In preparation for your transplant, we would like to make the following general suggestions:

- Avoid consuming undercooked or raw foods
- Do not drink or use untreated (and untested) well-water

- Avoid use of hot tubs or Jacuzzis
- Do not use tap water in nebulizers, inhalers, CPAP or for breathing treatments
- Keep fresh wounds or vascular access sites (including, PICC, and dialysis lines) clean and dry
- Do not clean unhealed wounds with tap water

After the organ transplant, while your immunity and your body are the weakest, Duke University Hospital implements and recommends additional precautions related to water until you reach certain milestones in your recovery.

PREPARING FOR LISTING AS A LUNG TRANSPLANT CANDIDATE

Before being listed for lung transplantation, you and your caregivers will need to establish and solidify a plan for each the following:

- Listed patients must carry a charged cell phone with them at all times.
- You must have transportation to and from the hospital.
- Your caregiver will need a place to stay while you are in the hospital.
- You must have coverage for your post-transplant prescriptions and be aware of any applicable co-payments and/or deductibles.
- If you will be relocating to Durham, you will need a relocation plan, including travel arrangements, housing, permanent residence maintenance, and child care, if applicable.

Preparing for Relocation

If you live further than a two-hour drive from DUH, you will be required to relocate to the Durham area before you can be listed. If you live within a two-hour drive of DUH, the transplant team will decide whether you will be required to relocate or if you will be allowed to remain at home. A variety of factors influence this decision, but you can be assured that the most important factor is what will be in your best interest. If you are allowed to remain at home, please be aware that you will still be required to attend pulmonary physical therapy and education classes at the Duke Cardiac and Pulmonary Rehab in Croasdaile Commons.

To assist you with relocation, a Lung Transplant Relocation Planning Guide is included on page 22 of this booklet. Information on Lodging and Transportation Resources has also been included.

Once you have relocated, you will attend pulmonary physical therapy five days per week at the Croasdaile Commons Cardiac and Pulmonary Rehab., attend transplant clinics, and be scheduled for any additional testing that may be needed before listing. At the Rehabilitation Center, you will be evaluated by a respiratory and physical therapist on a daily basis to determine your physical readiness for listing. Once you have met the pulmonary physical therapy requirements, the transplant team will move forward with listing.

Listing Requirements

The following items are required before you can be listed for transplant:

- Your evaluation testing must be complete.
- You must meet the pulmonary physical therapy requirements.
- You and your caregivers must attend all education classes at Croasdaile Commons Rehab Center and have read all transplant materials provided to you by the lung transplant team.
- Consents for listing must be signed.
- Financial approval for listing must be received.

- All members of the transplant team must be in agreement to move forward with lung transplant listing.

Listing for Lung Transplantation

Before you are placed on the national transplant wait list, the selection committee will review your current health, recent study results, your support system after relocation (if needed) and recommendations from the pulmonary physical therapy team. We will also ask your insurer to preauthorize your procedure. Once insurance approval is received, you will be placed on the transplant list.

Patients are prioritized for transplant by the national transplant wait list administered by the United Network for Organ Sharing (UNOS). Each candidate for lung transplantation receives a numerical value, the Lung Allocation Score (LAS), which is calculated based on his or her physical and laboratory data. Information about the LAS will be provided to you at your evaluation and can be found at www.unos.org. When a donor is identified, UNOS will identify the patients eligible for the organ and offer it to those patients based on their LAS, from highest to lowest.

Once you have met all these requirements, your name will be added to the national lung transplant waiting list maintained by the United Network for Organ Sharing (UNOS). The day you are listed, you will be notified verbally by one of the pretransplant coordinators. You will also receive a listing confirmation letter.

WAITING FOR A LUNG TRANSPLANT

We have no way of knowing how long you will be listed for transplantation. Currently, DUH offers patients one of the shortest waiting times in the United States. However, waiting times vary and may be prolonged if you have certain antibodies which may limit your donor pool. You may choose to be listed at more than one transplant center (multiple listing) and should speak with your transplant coordinator or refer to www.unos.org if you would like to learn more about multiple listing.

You should try to maintain the best health possible while waiting. You will be seen in the clinic on a regular basis and for any acute needs while waiting for transplant. Please inform us of any changes in your health – including new or recurring problems and/or hospitalizations – while you are listed

You should try to maintain the best health possible while you are waiting for your transplant. You will be seen in the clinic on a regular basis and for any acute needs. Please inform us of any changes in your health – including new or recurring problems and/or hospitalizations – while you are listed.

Organ Availability and Selection

All lung transplant candidates are listed on the national waiting list maintained by UNOS. Carolina Donor Services (CDS) is our local organ procurement organization (OPO) that coordinates transplants in North Carolina. Our program also considers organs from other OPOs, outside of North Carolina. Donor lungs are matched with recipients based on:

- Blood type (O, A, B, or AB)
- Size (height and weight)

- Chest X-ray measurements (actual lung size)

When donor lungs become available, they are offered to the patient with highest Lung Allocation Score (LAS) that also matches the donor's size and blood type. Please refer to the purple UNOS pamphlet distributed during your evaluation week for more information on LAS and the allocation of donor organs.

Before donor lungs are accepted for a transplant, the transplant surgeon evaluates the donor's medical and social history and examines the lungs. The most important consideration is the quality of the donor lungs. Donors are carefully screened for transmittable diseases, such as HIV and viral hepatitis, and organs are not accepted for transplant if any of these screens are positive.

Wait Time

Organ availability cannot be predicted, so the wait time for a lung transplant varies from patient to patient. The average wait time at Duke is about two weeks. This average is based on patients who are waiting for only one organ. If your chest cavity is particularly large or small, or you have antibodies directed against the cell markers of others in the population, you may have a much longer wait time. If you have to wait longer than the average time, we encourage you to learn relaxation techniques and use the available resources to help yourself cope with the stress and uncertainty of waiting. Resources are available at the Center for Living and through the transplant Medical Psychology department, upon request.

Research Projects and Studies

We are continually trying to improve the outcomes of patients who undergo lung transplantation, so we have a number of ongoing research projects. New medicines are being developed to improve post-transplant rejection and infectious complications, and many studies are focused on understanding, preventing, and treating BOS (severe post-transplant rejection). All lung transplant recipients are eligible to participate in these studies and will be contacted by a research coordinator with an invitation to enroll. The research coordinator will describe the study design, treatments involved, and potential risks and benefits. You will have an opportunity to discuss all research projects with your transplant physician. Participation in any ongoing research study is entirely voluntary, both before and after transplant.

YOUR ROLE IN A SUCCESSFUL LUNG TRANSPLANT

New lungs mean new responsibilities. If our team determines that transplantation is the best treatment for your lung disease, there are many considerations to be aware of before making the commitment to 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 transplant, complete a relapse prevention program and to be completely substance-free after transplant.

The Lung Transplant Team at DUH has a ZERO-tolerance policy for tobacco use. Blood tests, which reveal ANY exposure to tobacco, will be performed at each transplant clinic visit. A positive blood test is grounds for immediate removal from our lung transplant program.

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

Medication

After lung transplantation, you will have many medicines to take for the rest of your life to prevent rejection. These medicines are very expensive and may not be covered by your insurance. Our financial coordinator will review common pharmacy expenses with you.

Monitoring

You will be asked to check your blood pressure, weight, temperature, and lung capacity each day. You will also be expected to have blood work done at home and sent to our office monthly.

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 permanently abstain from the use of harmful substances, including smoking and/or tobacco use of any kind.

Frequent Check-Ups

You will need to return to DUH 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.

Primary Care Physician

You will need to maintain a relationship with your primary physician for your non-lung transplant related health care, including regular diabetes and routine health screenings.

THE LUNG TRANSPLANT PROCEDURE

We want to help you and your family prepare for your transplant. Making plans to manage your needs before your transplant can reduce the amount of stress you will have to cope with during the recovery process. It may become necessary to alter your plan because of changes in your situation. If this occurs, please let us know right away. Medical Psychology is also available to help you cope with the stress and anxiety that may accompany the transplant process.

When you are called to come to the hospital for your transplant, it is vital that you arrive at Duke University Hospital within two hours of the call; therefore, you must have a reliable plan for doing so. Most lung transplant patients relocate to the Durham area so they can be available. Relocating also allows patients to participate in our Pulmonary Physical Therapy Program before and after transplant.

Duke patients who receive lung transplants are hospitalized for an average of 16 days. How long you are hospitalized is based on your response to the surgery.

Your Lung Transplant Surgery

When donor lungs become available, a transplant coordinator will call you. The coordinator will instruct you to stop eating and drinking and to report to the hospital as soon as possible. They will instruct you to go to either Duke University Hospital Admissions or the Emergency Department once you arrive at the hospital, depending on the time of the call.

Admission to Duke University Hospital

Once you arrive at the hospital, you will be admitted and prepared for potential lung transplant surgery. A chest X-ray, EKG, and blood tests will be done, and you will be asked to sign the consent for surgery. At the same time you are completing the admission workup, the organ procurement team is traveling to the donor's location so the surgeon can exam the donor lungs. During this time, you will wait to hear if the donor lungs are good from the transplant coordinator. This often takes a significant amount of time, so you may be waiting for a long time.

Sometimes, a transplant has to be cancelled because the surgeon examined the donor lungs and discovered that they are not good quality. This is referred to as a "dry run." 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.

During Surgery

Once the surgery is confirmed, you will be wheeled 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 you during the surgery. The surgery can take anywhere from four to eight hours. Your family will be shown where to wait and will be kept informed through your surgery.

Your Duke cardiothoracic transplant surgeon will perform a double (bilateral) or single lung transplant based on your condition and what was decided by the transplant team during your evaluation. During your surgery:

- An incision will be made across your chest for a double (bilateral) transplant or along the side of your chest for a single transplant.
- A breathing tube will be inserted to help you breathe.
- A tube will be inserted through your nose and into your stomach to drain fluid.
- A tube will be inserted into your bladder to drain urine.
- Multiple tubes will be inserted into your chest to drain fluid.
- You will receive IV medications.
- Your lung(s) will be removed and replaced with donor lung(s).
- If needed, a feeding tube will be placed into your stomach.

After Surgery

Immediately following surgery, you will be brought to the Intensive Care Unit (ICU). Physical therapy/occupational therapy will begin about 12 hours after the completion of surgery with a goal of having you up and walking by day 2. Once you are stable, you will be transferred to the stepdown floor. You will continue physical therapy/occupational therapy and meet your new post-transplant coordinator.

Your post-transplant coordinator will establish a time to provide post-transplant teaching for you and your caregivers before you are discharged. You will also have a teaching session with our transplant pharmacist to explain all your transplant medications. Your medications will be ordered by your coordinator before discharge. It is very important that you establish a local pharmacy before your transplant and provide that contact information to your post-transplant coordinator while you are in the hospital.

Complications and Side Effects from Lung Transplantation

While lung transplantation has saved many lives, there are risks for complications and side effects that can occur after surgery. It is important to be aware of these possibilities when considering transplantation as an option for you. The following items come along with newly transplanted organs.

- Lifelong immunosuppression (antirejection) medications.
- Lifelong follow-up with the Duke lung transplant team.
- Increased risk of cancer due to the antirejection medications.
- Increased risk of a decline in kidney function or kidney failure due to the antirejection medications.
- Bronchoscopies on a regular basis to look for infection and rejection.

The following health issues are also common after transplantation:

- Being discharged on IV medications or needing IV medications at some point after your transplant.
- Monitoring your blood sugar and administering insulin due to medication-induced diabetes.

- Feeding tubes.
- Nissen fundoplication (stomach wrap surgery) to prevent chronic rejection.
- Possible infections, rejection, and re-admission to the hospital.

All these things will be discussed with you, in greater detail, along with the risks and benefits of lung transplant surgery during your clinic visits with the transplant team.

Discharge from Duke University Hospital

Once you are discharged from the hospital, you will enroll in pulmonary physical therapy at the Duke Cardiac and Pulmonary Rehabilitation at Croasdaile Commons. You are required to complete at least 23 sessions of pulmonary physical therapy before returning to your home city. During this time, you will also have regular clinic visits, pulmonary testing, lab draws, and bronchoscopies to check for rejection and infection.

The pulmonary physical therapy program lasts approximately four and a half weeks usually in the am for 4 hours, Monday through Friday. It is important to plan for your needs during the waiting period and during the post-operative period, as well as to make plans for obtaining your medications. You will need to have your prescriptions filled before you leave the hospital. It is not uncommon for patients to require the assistance of a home-care nurse for antibiotic and/or antirejection IV infusions.

Your long-term success depends on many things, including your adherence to recommended treatments and monitoring. Sometimes, a patient will do exactly as we ask and still experience problems. Our goal is to have you return to the best health possible as quickly as possible. You and your family are partners with us in achieving these goals.

Before discharge, the transplant team will provide you with a micro spirometer to measure your lung function at home. You will also need to have your own blood pressure cuff, thermometer, weight scale, and glucose monitor. All of these things can be purchased at your local pharmacy. We suggest purchasing these items at the time you are listed for transplant.

Requirements Summary

1. You must have adequate funding to cover transplant costs. This includes relocation expenses as well
2. You must have a caregiver plan that includes a primary and secondary (back-up) caregiver. These caregivers must be able to relocate to Durham for the duration of your stay here (average 6 months-but multi-organ and high PRA patients may stay up to a year) Your caregivers cannot smoke!
3. Patients are required to wean off certain medications such as: all Narcotics and Benzodiazepines- examples: Xanax, Ativan, Klonopin, Oxycontin, Hydrocodone, Percocet. We will ask that you wean off these drugs under the supervision of your local doctor.
4. You must be at a BMI between 17-27. This reflects a healthy weight goal. You may need to gain or lose weight to meet the above goal. We will refer you to our Dietician for assistance and recommendations.
5. You must be in a pulmonary rehab program a minimum of 3 days a week. If you have completed this, then you must continue a home program or a program at a local gym. You will be required to attend Duke's pulmonary rehab program-a minimum of 23 sessions but this is individualized per patient
6. You must have a functioning esophagus. Certain diseases affect the esophagus, causing silent aspiration. Aspiration causes inflammation in the lungs and can also trigger rejection in the transplanted lung/lungs.

LUNG TRANSPLANT RELOCATION PLANNING GUIDE

<p>Step 1: Develop a budget plan</p> <ul style="list-style-type: none"> <input type="checkbox"/> Rent <input type="checkbox"/> Utilities <input type="checkbox"/> Food <input type="checkbox"/> Transportation <input type="checkbox"/> Parking <input type="checkbox"/> Medication <input type="checkbox"/> Other living expenses 	<p>Step 3: Create a moving plan</p> <ul style="list-style-type: none"> <input type="checkbox"/> Arrange for oxygen delivery <input type="checkbox"/> Inform your medical insurance carrier <input type="checkbox"/> Obtain change of address information <input type="checkbox"/> Obtain a cell phone with NC coverage <input type="checkbox"/> Obtain school information for your children (if applicable) <input type="checkbox"/> Contact your local pharmacy to transfer your prescriptions
<p>Step 2: Inspect temporary residence possibilities</p> <ul style="list-style-type: none"> <input type="checkbox"/> Feels safe and comfortable <input type="checkbox"/> Clean environment <input type="checkbox"/> Close to Duke <input type="checkbox"/> Mail delivery available <input type="checkbox"/> Wheelchair accessible <input type="checkbox"/> Roll-in shower <input type="checkbox"/> Free or pay shuttle service <input type="checkbox"/> Off-street parking <input type="checkbox"/> Full kitchen amenities <input type="checkbox"/> Laundry facilities onsite <input type="checkbox"/> Business center <input type="checkbox"/> Designated nonsmoking rooms <input type="checkbox"/> Medical discount available <input type="checkbox"/> Air conditioning <input type="checkbox"/> Cable television/DVD player <input type="checkbox"/> 24-hour security <input type="checkbox"/> Distance from RDU Airport <input type="checkbox"/> Assured availability <input type="checkbox"/> Children welcome (if applicable) <input type="checkbox"/> Overnight guests welcome 	<p>Step 4: Close your permanent residence</p> <ul style="list-style-type: none"> <input type="checkbox"/> Cancel deliveries <input type="checkbox"/> Forward your mail <input type="checkbox"/> Notify important people <input type="checkbox"/> Ask a neighbor to keep an eye on your house
	<p>Step 5: When you get to Durham</p> <ul style="list-style-type: none"> <input type="checkbox"/> Inform your transplant coordinator <input type="checkbox"/> Keep emergency numbers handy <input type="checkbox"/> Contact a local pharmacy <input type="checkbox"/> Test the smoke alarms

ACCOMMODATIONS

Duke Transplant Center Recommended

To assist our patients and their family members who are in the evaluation, waitlisting and post transplant phases of care, the Duke Transplant Center contracts with the Hilton Garden Inn Durham/University Medical Center to set aside a **limited number of rooms** from Sunday through Thursday nights for a discounted rate of \$70 per night plus tax. Please contact the front desk and ask for Jennifer Watson regarding this Duke Transplant Center rate. If this rate is not available you will be offered the medical rate at \$119.00. At the time of check in you will need to provide the name of the transplant pulmonologist you will be seeing in clinic as well your clinic schedule.

The Hilton Garden Inn is conveniently located between Duke University Campus and downtown Durham. The hotel has complimentary self-parking and a free shuttle service to the Duke campus or to a location - such as the Croasdaile Pulmonary Rehab - within a five mile radius. The hotel is also located next door to grocery shopping, restaurants and the 9th Street district.

Hilton Garden Inn Durham/University Medical Center

2102 West Main Street, Durham, NC 27705

919.286.0774

Jennifer Watson 919 864 7102



While the Duke Transplant Center strives to make the accommodation information below as accurate as possible, the center makes no claims, promises, or guarantees about the accuracy, completeness, or adequacy of the information, and expressly disclaims liability for errors and omissions in the content of this information.

LODGING & TRANSPORTATION RESOURCES

Duke University Medical Center and surrounding area

Duke Medical Center is not affiliated with any facilities listed below, cannot recommend them or guarantee conditions. However, many facilities include transportation to Duke and shuttle service, additional amenities, as well as reduced medical rates. Many facilities allow pets. Contact individual location for full list of amenities.

HOTELS WITHIN 5 MILES OF DUKE

Aloft Durham Downtown 345 Blackwell St. 919-402-5656, 2 miles from Duke
www.aloftdurhamdowntown.com

Brookwood Inn 2306 Elba Street, 919-286-3111, walking distance to hospital,
www.brookwoodinn.com

Quality Inn Medical Park 1816 Hillandale Road, 919-471-6100 or 800-426-7866,
www.choicehotels.com

Courtyard by Marriott 1815 Front Street, 919-309-1500 or 800-321-2211,
www.marriott.com

Duke Tower Hotel 807 W. Trinity Ave., Durham, NC 919-687-4444 www.duketower.com

Durham Hilton 3800 Hillsborough Road, 919-383-8033 or 800-445-8667, www.hilton.com

Durham Marriott @ Civic Center, 201 Foster Street, 919-768-6000 or 800-768-6000,
www.marriott.com

The Durham Hotel, 315 E. Chapel Hill St., Durham, NC 27701 919-768-8830
www.thedurham.com

Hilton Garden Inn Durham/University Medical Center 2102 West Main St., Durham, NC 27705 919-286-0774 **Transplant Rate** may be available for Sun -Thurs, short term stays less than 2 weeks (provide name of patient's transplant doctor or transplant coordinator) www.Durhamuniversitymedicalcenter.hgi.com

Millennium Hotel 2800 Campus Walk Ave., 919-383-8575, or 800-633-5379, www.millenniumhotels.com

Residence Inn Durham McPherson/Duke Medical Ctr. Area 1108 West Main St. 27701 919-680-4440 Fully- furnished 1 and 1 bedroom suites with full kitchens. Breakfast is included. www.marriott.com/hotels/travel/rdudd-residence-inn-durham-mcpherson-duke-university-medical-center-area/

University Inn 502 Elf Street, 919-286-4421 or 800-801-3441, www.universityinnduke.com

21C Museum Hotel 111 Corcoran St., Durham 27701 919-956-6700 www.21cmuseumhotels.com/durham

Washington Duke Inn 3001 Cameron Blvd., 919-490-0999 or 800-433-5853, www.washingtondukeinn.com

HOTELS & MOTELS

Holiday Inn Express, 2516 Guess Road, 919-313-3244, www.hiexpress.com

LaQuinta Inn, 4414 Chapel Hill Blvd (Hwy 15-501), 919-401-9660 or 800-531-5900, www.lq.com

Quality Inn 3710 Hillsborough Road, 919-382-3388 or 800-228-2800, www.duke85.com

Red Roof Inn 1915 North Pointe Drive, 919-471-9882 or 800-843-7663, www.redroof.com

Residence Inn (Marriott) 201 Residence Inn Boulevard, Durham, NC 919-361-1266 or 800-331-3131, www.marriott.com

Wingate Inn RTP/RDU, 5223 Page Road, Exit 282 @ I-40, 919-941-2854 or 800-228-1000, www.wingatehotels.com

SUITE HOTELS/APARTMENTS/EXTENDED-STAY

Clairmont at Hillandale, 2901 Bertland Avenue, Durham, NC 27705 (888) 429-1315. 1.7 miles from Duke, 1,2,3 bedroom apartments, furniture rental available. Washer/dryer in each & attached garage. 3, 6, 12 mo. leases.

Colonial Village at Deerfield
910 Constitution Drive, 5 minutes from Duke
919-383-0345

Crosdaile Apartments, 2726 Crosdaile Dr. Less than 2 miles from Duke. 919-383-3437

DoubleTree Guest Suites, 2515 Meridian Parkway, 919-361-4660 or 800-222-TREE, 15 minutes to Duke, continental breakfast

Edinborough at the Park, 200 Edinborough Drive, (919) 941-9635, 1,2 and 3 bedroom apts, clubhouse, gated, swimming pool, 15 minutes from Duke

The Flats, at Mount Moriah, 5512 Sunlight Drive, 919-489-8788, 1, 2, & 3-bedroom corporate apartments. Mail concierge service, valet dry cleaning, lap pool, tennis courts, fitness center.

The Forest Apartments 800 White Pines Dr., 919-383-8504, 5 minutes from Duke. Fully furnished units avail.

The Hamptons at RTP Apartment Homes, 300 Seaforth Drive 919-484-1321 or www.thehamptonsapthomes.com Studio, 1- or 2-bedroom furnished

The Heights at LaSalle 500 South LaSalle Street, Less than 1 mile from Duke 919-309-1292 Short-term lease, furniture rental avail., pet friendly, pool, fitness center, elevators, washer dryer in unit

leasinglasalle@worthingse.com

Homestead Studio Suites, 4515 Highway 55 (RTP)), 919-544-9991 or 1920 Ivy Creek Blvd., 919-402-1700
Includes kitchen, pet-friendly

Homewood Suites, Exit 270 off I-40, 919-401-0610 or 800-225-4663

6 miles from Duke, full kitchens, free breakfast. Evening social hour/outdoor pool/exercise room, walking distance to shopping and restaurants.

Independence Park Apartments, 215 William Penn Plaza, Durham, 919/246-0800, furnished 1, 2 and 3 bedrooms available

Lofts at Lakeview 2616 Erwin Road Durham, NC 27705 919-382-8184. Short term lease available. Less than ½ mile from Duke. Washer dryer, rental furniture arrangements, parking garage.
www.loftsatlakeview.com

Oakwood Corporate Housing, 800-520-5288, 1, 2, and 3-bedroom apartments.

Bell West End 605 West Chapel Hill Street, Durham, 5 minute drive to Duke (919) 813-4301 Rates include furniture, internet and all utilities except electricity. Washer/dryer in unit. Short term lease and pets ok
www.605westapartments.com

RDU Furnished Housing-7 miles or less to Duke. 2 & 3 bedroom townhomes and single family homes, flexible leases, one rate includes all utilities, furnishings, linens,

cable/wireless, washer/dryer, TV in each unit, 773-931-4586

Staybridge Suites Durham/Chapel Hill
3704 Mt. Moriah Rd, Durham, NC 27707, (919) 401-9800 www.staybridge.com

Studio Plus, 2504 NC Highway 54, 919-361-1853 or 800-646-8000, Swimming pool, laundry, exercise room, fully equipped kitchens in all rooms, free local calls, data port, & extended cable.

Trinity Commons Apartments, 2530 Erwin Rd., Durham. 919-309-1409
www.trinitycommons.com 1-2bedrooms, rental furniture plans, pets ok, walking distance to Duke, parking, many amenities

West Village Corporate Lofts, 604 West Morgan Street, 919-682-3690 or
www.westvillagedurham.com Fully-furnished suites, cable & internet service, housekeeping, coffee bar, free local calls, business center, fitness center, laundry facilities, pets,

Wynne Residential 919-484-8999 or 800-477-6922 Offering fully furnished accommodations with washer & dryer

Nearby camping facilities:

Duke Oversized Parking, Garage II, 919-684-5773

Birchwood RV Park, 919-493-5573, 5901 Wilkins Drive, Durham

Spring Hill RV Park, 3500-1A Old Greensboro Road, Chapel Hill, NC 27516, Phone: (919) 967-4268 Toll-Free: (800) 824-8807

Jones Station RV Park, 2710 Jones Dr., Mebane, NC 27302

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

PARKING FEES

Hospital garage parking fees are based on an hourly rate. **Discounted validation passes may be purchased at** the Duke Clinic Customer Service Center beside the Medical Center Bookstore on lower level of Duke Clinic. Options are available for 5-use or 10-use scannable passes which save you money on parking. Please call the Medical Center Traffic Office at 919-684-7275 for more information.

Valet Parking

Valet parking service is available at Duke University Hospital, Duke Clinic, Duke Emergency Services, Duke Cancer Center and Duke Medical Pavilion. Discount parking passes **cannot** be used for valet parking.

- **Duke University Hospital:** Monday - Friday, 7 a.m. to 10 p.m., Saturday - Sunday, 10 a.m. to 6 p.m. \$9 per day.
- **Duke Clinic:** at Entry 1 (main entrance), Monday - Friday, 7:30 a.m. to 6 p.m. \$9 per day.
- **Duke Emergency Services:** Available 24 hours a day, every day. Free for ER patients.
- **Morris Cancer Clinic:** Monday - Friday, 7 a.m. to 6 p.m. Free for radiation/oncology patients.

Duke Transportation Options

Transport Services

Duke University provides free bus service to all campuses and the Medical Center for students, employees, patients, and visitors.

All routes served by Duke Transit are accessible to persons with disabilities. In addition, Duke's after-hours SAFE Rides program employs an on-call accessible van. Accessible Duke University buses can be identified by the international accessibility symbol on the side of each bus.

Transit Information

919-684-2218 or 919-681-4001

Safe Escort Service

919-684-SAFE (7233)

PATIENT CONTRACT FOR LUNG TRANSPLANTATION

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:

Patient Responsibilities:

1. I will attend my scheduled clinic appointments, my laboratory tests and studies, and my rehabilitation sessions.
2. I will read the transplant educational materials provided to me 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 organ(s), 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 a 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 organ(s). 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 (from smoking or other tobacco use) will result in the removal of my name from the lung transplant waiting list at Duke University Medical Center. Evidence of any unhealthy behavior is reason to be refused organ transplantation.
6. I understand that if I live farther than a two hour drive from Duke University Medical Center, I will need to relocate to the Durham, NC area before transplant. I understand that I will need to live in the Durham, NC area for six to twelve weeks after transplantation for rehabilitation and close medical follow-up. This is the "best estimate" of time needed in Durham, NC; some patients will need a longer stay, depending on response to surgery.
7. I understand that I will need a designated caregiver or set of caregivers to accompany me to Durham, NC for transplant surgery and to assist me during the transplant recovery period. Caregiver duties will include helping me with medications and transportation to medical and rehabilitation appointments.
8. I understand that I am responsible for the costs of transplantation, and that there are likely to be other costs to me, as few insurance plans cover all transplant expenses.

Lung Transplant Program

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.

Signature of Patient

Date

Transplant Team Responsibilities:

As your transplant team, we pledge:

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

Signature of Transplant Team Representative

Date

PATIENT CAREGIVER CONTRACT

You have been identified as the **primary caregiver** for _____, a patient at Duke University Medical Center (DUMC) who is being considered for lung transplantation.

Before we place patients on the United Network for Organ Sharing (UNOS) lung transplant waitlist, we require our patients to secure the commitment of at least two family members and/or committed friends who will provide patient care before, during, and after their transplant. In our experience, excellent caregiver support significantly increases the odds of positive patient outcomes. It is also in our experience that this level of support is not able to be provided by a hired caregiver.

As primary caregiver I also confirm that I do not smoke, nor do secondary caregivers involved in the patients care. I confirm I have a valid driver's license and will be able to transport patient as needed throughout their transplant course.

Please read this Patient Caregiver Contract carefully, and please sign it only if you feel absolutely committed to and able to undertake this task.

By signing this contract, I commit to the DUMC Lung Transplant patient listed above, and to the DUMC Lung Transplant Team, that I will fulfill my obligations as a primary caregiver.

Specifically:

1. During the pre-transplant period, and for duration of pre-transplant period, I or a secondary support person will accompany the patient to all clinic appointments as well as attend all appropriate lung transplant lectures and classes at the Duke Cardiac and Pulmonary rehab program which require caregiver's attendance.
2. During transplant hospitalization, I will be within the hospital setting on a daily basis. While patient is within the ICU setting I will stay informed of patients progress with my contact information available to hospital staff at all times. Once patient is moved to a step down floor within the hospital setting I will continue to be present within the hospital setting on a daily basis, available along with patient to obtain all discharge teaching instructions which patient may need. I understand this teaching will include medication teaching as well as any required home therapies that may be needed.
3. During transplant hospitalization, I will be visible in the hospital on a daily basis and communicate any needs to appropriate persons. I understand that it is not a reasonable expectation that a team member call me every day. If for any reason I am unable to be within the hospital setting to provide continued daily caregiver assistance I will make arrangements for our secondary caregiver to be present and remain available until my return.
4. I will have phone contact available for transplant team and physicians at all times so I can be alerted to any changes in the patient's clinical condition and/or notified of and prepared well in advance for patients discharge.
5. For the duration of the patients transplant process I will participate in transplant teaching, provide transportation back and forth from clinic, remain present within hospital setting as noted on daily basis and provide emotional support to patient during this period. I understand that a post-transplant hospital admission can vary depending on the patient's operative course. I also understand that the patient is required to participate in a pulmonary physical therapy program at the Duke Rehabilitation Center. I understand I will need to reside locally with patient for scope of entire transplant process.

Lung Transplant Program

6. When the patient returns home, I will continue to be available for post transplant care as needed, which may include driving the patient to and from clinic appointments and assisting the patient with their medications, until they are completely and independently functional.
7. I understand that I as primary caregiver must plan on remaining within the local Durham area for 3 to 6 months after transplant in order to assist patient with all post transplant care needs along with transportation. I understand this is an estimated time which could possibly be shorter than the estimated 3-6 months but which may also be a longer stay depending on patient's response to surgery.
8. Some patients may require ongoing care throughout their lifetime depending on their level of individual self maintenance. I understand that as primary caregiver I will remain involved to assist with ongoing care requirements as needed. If I am unable to provide such lifetime care, I will make suitable arrangements to meet patient's continued care needs.
9. I will mail this completed and signed contract back to the Lung Transplant Office
(DUKE University Health System, PO Box 102347, Durham, NC, 27710, Atten: Pre transplant coordinator. Appropriate to the context of my transplant course. I understand that a primary and secondary solidified care plan is imperative before the patient's evaluation can be considered complete and before the patient may be listed for transplant.

SAMPLE

Primary Caregiver:

(Printed name, address, contact# of primary caregiver)

Signature of primary caregiver)

Secondary Caregiver:

(Printed name, address, contact# of main secondary caregiver)

(Signature of main secondary caregiver)

SAMPLE

Additional Secondary Caregiver:

(Printed name, address, contact# of additional secondary caregiver)

(Signature of additional secondary caregiver)

DISCLAIMER: Each transplant patient is unique. While we have seen some patients heal rapidly and attain independent functioning quickly, we also have seen patients heal slowly and remain dependent on caregivers for an extended period of time.

Conclusion

The decision about lung transplantation is very important and affects all areas of your life. We want to provide you with the information necessary to make an informed decision about your health care. Here is a list of questions you may want to consider and/or discuss with your caregiver and family:

- Will you need to temporarily relocate to the Durham area for transplant?
- If so, who will relocate with you and where will you stay?
- Who will take care of your children/pets while you are away from home?
- How will you get to DUH within two hours after you are called for your transplant?
- Where will your family/caregiver stay while you are in the hospital?
- Who will stay with you to help you take care of yourself post-transplant?
- Who will drive you to the Duke Cardiac and Pulmonary Rehabilitation each day for post-transplant pulmonary physical therapy?
- Where will you stay while you attend pulmonary physical therapy?
- How will you pay for living expenses while attending pulmonary physical therapy?
- Who will take care of your home while you are away? (This includes paying your bills, doing home maintenance, caring for plants, etc.)
- How will you pay for the costs that come with lung transplant?
- How much are your deductibles and/or co-pays for clinic visits?
- How much are your deductibles and/or co-pays for medications?
- Is there a maximum or limit on your health insurance coverage?
- Will your health insurance coverage change in the near future?
- Which pharmacy will you use for your post-transplant medications?

Please let the transplant team know if you have questions or concerns about the transplant process and what it will require from you and your family.

