

Lung Transplant Patient Education Handbook

Lung Transplantation Program
Charles O. Strickler Transplant Center



UNIVERSITY
of VIRGINIA

Lung Transplant Patient Education Handbook

Lung Transplant Program
Charles O. Strickler Transplant Center

UVA Health System | PO Box 800413
Charlottesville, VA 22908

844.296.8070 | Fax: 434.243.9540

Emergency Phone Number: **434.924.0000**

(ask operator to page the Heart/Lung Transplant Coordinator on call)



Table of Contents

Introduction	5
Why do I need a lung transplant?	6
Principles of lung function	6
Obstructive airway diseases	6
Interstitial lung diseases.....	7
Airway diseases.....	7
Vascular diseases	7
Are you a transplant candidate?	7
The evaluation process	8
Members of the transplant team.....	8
Tests and evaluations during your transplant work up.....	9
Financial.....	11
Medicare.....	11
Medicaid.....	12
Insurance.....	12
Financial responsibilities.....	12
Relocation.....	12
Pulmonary rehabilitation and physical therapy	13
Nutrition: a key to successful lung transplantation	14
Nutritional goals prior to lung transplantation.....	14
Dietary changes.....	15
Waiting	17
The lung transplant selection committee	17
Where do lungs for transplant come from?.....	17
The Lung Allocation Score (LAS).....	17
Staying healthy.....	17
Becoming “deactivated” on the wait list.....	18
Reasons for deactivation	18
The Transplant Support Group & Mentor Program.....	18
The time of surgery	19
Getting “the call”.....	19
Transportation	19
Arriving at the hospital	19
The transplant surgery.....	20
Single lung transplant.....	20
Double lung transplant	20
False alarms.....	20



Post operative period.....	21
The Intensive Care Unit.....	21
The Step-Down Unit.....	22
Nutritional goals during your hospitalization.....	22
Going home	22
Clinic visits	23
Complications after lung transplant.....	24
Infections following lung transplant	25
Precautions	25
Types of infections and how to prevent them	25
Viral infections.....	25
Bacterial infections.....	25
Fungal and mold infections	25
Lung transplant rejection	26
Acute rejection.....	26
Chronic rejection and bronchiolitis obliterans.....	26
Other complications	27
Bronchoscopy	28
Instructions to follow.....	28
Transportation and travel after transplant	29
Driving	29
Traveling.....	29
Airplane travel	29
Emotional concerns	30
Sexuality after transplantation.....	31
Reaching out to the donor's family	32
Health maintenance	32
Cancer screening.....	32
Vaccinations.....	34
General remarks	34
List of vaccinations.....	34
Labs	35
Nutritional goals at home after your lung transplant	36
Discharge medications	39
Background	39
Medications to take home	39
Insurance	39
Options for prescriptions.....	39



Taking your medications	41
Selected transplant medications	42
Generics	42
Tacrolimus (Prograf)	42
Mycophenolate (Cellcept , Myfortic).....	43
Azathioprine (Imuran)	43
Prednisone (Deltasone).....	44
Cotrimoxazole (Bactrim)	44
Clotrimazole Troches (Mycelex).....	45
Valganciclovir (Valcyte).....	45
Voriconazole (Vfend)	46
Anti-ulcer and Anti-heartburn Medicines	46
Over the counter medications	47
Non-steroidal anti-inflammatory drugs (NSAIDs).....	47
Lodging	48
UVA Hospitality House	48
Lodging options close to UVA.....	49
UVA patient rights and responsibilities.....	50
Rights.....	50
Responsibilities.....	50
Resources.....	52



Introduction

Since 1983, more than 35,000 lung transplants (both single and double) have been done in the United States and Europe. Approximately 3,000 lung transplants are done annually in the United States. The most common reason for lung transplant is obstructive lung disease. Other reasons include pulmonary fibrosis, pulmonary cystic fibrosis, pulmonary hypertension and other rare pulmonary disorders.

The first lung transplant at UVA was performed in 1990. We have now completed over 400 lung transplants and average 20 to 25 lung transplant operations each year.

Patients undergo extensive evaluation prior to being listed. Following listing, most patients wait 12–24 months before receiving a transplant. The major reason for long waiting time for lung transplants remains the limited supply of donors. Unfortunately, some patients die from their underlying disease before they can be transplanted.

While lung transplant is a high risk procedure, most patients achieve a significant increase in their functional ability. Most patients are able to come off oxygen and function very well on room air. Many are able to return to work and engage in full time activities. The present average survival following a lung transplant is approximately 80 percent at one year, 65 percent at three years, and 50 percent at five years. The current one-year survival at UVA is 94 percent. Survival is affected by the underlying disease, age, and activity level prior to transplant. Survival is also affected by the ability of the transplant recipient to follow instructions, including taking medications as ordered after transplantation.

Our transplant team consists of pulmonologists (lung doctors), cardiologists (heart doctors), cardiothoracic surgeons, nurse coordinators, social workers, psychologists, dietitians, pharmacists, physical therapists, financial counselors and respiratory therapists. Our team will work together and communicate with your primary doctor about your evaluation.

If you have questions at any time during your evaluation, feel free to use our toll free number: **1.844.296.8070**. Always remember that transplant is a treatment **OPTION** and you do not have to undergo lung transplant. You can refuse transplant or change your mind at any time during the process.



Why do I need a lung transplant?

Your doctor has suggested that you may need a lung transplant. It may help you to understand why if you know some basic principles of how the lungs work.

Principles of lung function

No organ in the body can function without oxygen. Oxygen is used in chemical reactions throughout the body that produce energy for cells to function. These reactions produce carbon dioxide as a waste product. The lungs function to absorb oxygen from the air we breathe in and transport it into the blood stream, and they expel carbon dioxide when we exhale. These two basic functions are called gas exchange. The gas exchange takes place in tiny air sacs called alveoli. Alveoli are surrounded by blood vessels that carry oxygen and carbon dioxide.

The air we breathe reaches the alveoli through a system of air passageways called bronchi. The airway branches look similar to those on a tree (for that reason, we also call it the “bronchial tree”). The branches become smaller and more numerous at each branching.

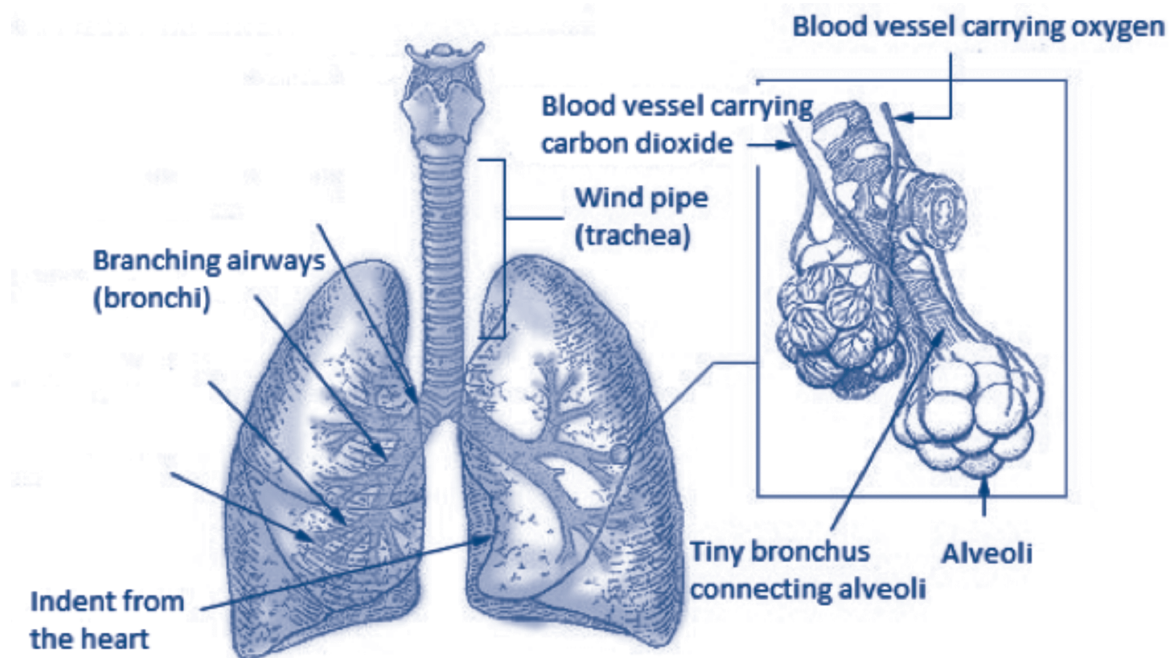
Lung disease may affect the function of the lungs in different ways. Many lung diseases affect several different lung functions simultaneously.

Obstructive airway diseases

Chronic inflammation inside the airways causes the bronchi to narrow and become obstructed. This makes it much more difficult to move air inside the lung, and the work of breathing increases.

Diseases that present with obstruction of the airways include:

- COPD (Chronic Obstructive Pulmonary Disease)
- Alpha-1 antitrypsin deficiency
- Lymphangioleiomyomatosis (LAM)
- Eosinophilic granuloma
- Cystic fibrosis



Interstitial lung diseases

The space around the alveoli is called the interstitium. In interstitial lung disease, the normal lung tissue in this space is replaced with scar tissue (also called fibrosis). This causes the lung to stiffen and shrink, and it gets harder to breathe and expand the lungs.

Diseases of this category include:

- Pulmonary fibrosis
- Sarcoidosis

Airway diseases

Thick mucus in these diseases tends to plug the airways, and they become chronically inflamed and infected. This causes the airways to “wear out” and lose their elasticity. They become “ectatic”, and it becomes more and more difficult to clear mucus effectively.

These diseases include

- Cystic fibrosis
- Bronchiectasis

Vascular diseases

Certain diseases can change the normal structure of the blood vessels inside the lungs, which causes those vessels to narrow. When the same amount of blood is pumped through a system of narrowed blood vessels, it causes the blood pressure inside these vessels to increase (pulmonary hypertension). Pulmonary Hypertension can develop by itself (“idiopathic”), or it may happen as the result of another underlying disease, such as advanced chronic lung disease (“secondary”).

Many different lung diseases cause the normal lung architecture and the alveoli to be destroyed. This means that the lung’s capacity to exchange oxygen and carbon dioxide will decrease.

Are you a transplant candidate?

We will conduct an extensive evaluation to assess your suitability for lung transplant. The purpose of the evaluation is:

1. To determine whether your lung disease is severe enough to require a transplant.
2. To determine whether there may be less invasive alternatives to transplant.
3. To determine whether you will be able to tolerate a lung transplant safely. Are there any co-existing conditions that will increase your risk of not doing well with a transplant?
4. To determine whether you actually want a transplant. Do you understand and accept the responsibilities required before and after transplant?
5. To ensure that you have adequate social and emotional support from a family member or another support person before and after transplant.
6. To evaluate your insurance status and your financial resources.

We will help you to understand the risks and benefits of lung transplantation, so you can make an informed decision. Having a lung transplant is a life-changing event, and it takes a commitment being part of our team, getting educated about treatments, taking your medications, exercising regularly, and attending your appointments. We will support you no matter what your decision. Remember, we are here to help you.



The evaluation process

The evaluation process is usually done on an outpatient basis, and involves several visits to UVA Medical Center.

We will be doing many tests to determine your medical and surgical risks for transplant. All of your organ systems will be evaluated.

Members of the transplant team

You will meet with many members of a multidisciplinary team during your evaluation. These members include:

Transplant nurse coordinator

The transplant nurse coordinator provides education regarding the transplant evaluation process, listing for transplant, and patient responsibilities before and after transplant. The coordinator is your advocate throughout the process and will work to ensure your needs are met. Meeting with the coordinator is intended to provide you with an opportunity to ask questions and become fully informed about the lung transplant process. After transplant, the coordinator is your contact person for any questions or problems.

Transplant surgeon

The transplant surgeon's role is to assess your readiness for transplant based on the information obtained during your evaluation. The surgeon also discusses details about the procedure and the risks/possible complications associated with surgery. The surgeon is responsible for your surgery and your immediate post-operative care and management.

Transplant pulmonologist

The transplant pulmonologist meets with you to discuss many of the disease processes that have contributed to your lung failure. They review your medical history to determine medical tests that should be performed in addition to the standard evaluation tests required during the evaluation. They will discuss alternative treatments to transplant. The transplant pulmonologist will also see you in the pulmonary clinic after you are discharged from the hospital.

Social worker

The transplant social worker's role is to evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan, both before and after transplantation. The social worker will ask questions about your development, family history, employment, and family relationships. As a transplant can be an emotionally stressful time for both the patient and family, the social worker will be available to answer questions, provide support and connect you with helpful resources in your neighborhood.

Neuropsychologist

The psychologist will evaluate how you can best process information; assess your mental well-being and your ability to deal with stress.

Financial coordinator

The financial coordinator will discuss with you the costs associated with transplant and which medications are required after transplantation. If you live far away from Charlottesville, we may need you to re-locate for a period of time to ensure you have easy and adequate access to care early after the transplant. The financial coordinator will help you to identify the costs that are associated with re-location and develop a financial plan with you. They will help you understand your insurance coverage and what costs may not be covered by insurance. They will ensure there is a solid financial plan in place prior to placing you on the transplant list.

Dietician

The transplant dietician will provide nutritional assessments, education and support for you and the transplant team.

Pharmacist

The transplant pharmacist will provide medication assessments and recommendations to the transplant team and physicians. Pharmacists help to ensure that medications are adequately dosed and alert the team to potential interactions between different drugs if necessary.

Tests and evaluations during your transplant work up

Below is a description of the various assessments/ tests you will be having done:

Lung function testing

This test measures your lung capacity. Arterial blood gas may be drawn to measure the oxygen and carbon dioxide in your blood.

Six-minute walk exercise test

This test evaluates your exercise ability and need for supplemental oxygen when exercising. You will be instructed to walk for six minutes. If you get tired or have trouble breathing, you may rest or slow down. You may be given oxygen to help you. The results can guide us in recommendations for pulmonary rehabilitation.

Blood testing

We test patients for past exposure to hepatitis, the AIDS virus, and several other viruses. We will also be able to assess the function of your kidneys and liver. A 24-hour urine collection will also help us measure your kidney function. If we do find abnormalities, such as the presence of infection; the presence of HIV; or significant other abnormalities, we will discuss these results with you confidentially.

Perfusion lung scan

This specialized lung scan, done in the X-ray department, measures the blood flow (perfusion) to each lung. A small amount of radioactive material will be injected into a vein in your arm. This information helps us decide which lung to transplant (in case of a single lung transplant) or which lung to transplant first (in case of a double lung transplant).

Echocardiogram

This sound wave test allows us to see the heart size, the heart valves, and how well the heart muscle is working.



Abdominal ultrasound

This is another sound wave test which allows us to look at the liver, gall bladder, kidneys, pancreas, and the aorta to make sure they are all normal.

Bone density test (DEXA scan)

This test measures how strong your bones are. Patients with lung disease often have thinning of the bones (osteoporosis). Medicines such as prednisone that are needed after transplant can cause worsening osteoporosis, and may result in bone fractures. If we find you have osteoporosis, we will refer you to a doctor who specializes in this problem so that we can build up your bones before transplant.

Chest CT scan

This is a special computerized X-ray test that shows a more detailed picture of the lungs. It can help rule out any cancers, and determine if there is disease of the lining of the lungs which might make surgery more difficult.

Cardiac catheterization

This procedure is performed in the hospital and may require an overnight stay. We assess the heart function, coronary arteries, and heart pressures. Heart catheterization is almost always performed through the right leg blood vessels. There are two major blood vessels in the groin region which provide easy access to your heart. After this area is scrubbed and cleaned, the doctor will numb the area. A catheter is introduced into the vein and the artery. The blood pressure inside your heart is measured. Occasionally during this part of the test you will be asked to breathe oxygen or will be given a medicine in order to change these pressures. This is followed by taking pictures to assess the function of the major chambers of your heart and the vessels around your heart. When the test is completed (this generally takes about 45 minutes), the catheters will be removed from your leg and pressure will be placed on your leg for approximately 15–20 minutes to stop any bleeding. You will then be asked to lie on

your back for four hours while this area heals. You will need to have someone drive you home after this test procedure.

Neuropsychology testing

When you meet with the neuropsychologist, he or she will talk with you and then you will take a written test. This portion of the evaluation will take approximately four hours. Please make sure you bring an adequate oxygen supply to get you through the evaluation. Unfortunately, the neuropsychology offices do not have oxygen hook-ups. The purpose of this test is to determine how well you cope with the stresses of your illness and to help us find the best way to help you learn about your medications after the transplant. We will also provide appropriate supportive and coping techniques to allow you to deal better with the transplant process.

24-hour pH probe and esophageal manometry

Gastro-esophageal reflux disease (GERD) is a common condition in patients with chronic lung disease, and it does not always cause symptoms like heartburn. In patients with GERD, stomach content is regurgitated back into the food pipe (“esophagus”). Some of the regurgitated stomach content may end up in the lungs and contribute to inflammation and destruction of lung tissue. GERD is one of the known factors that can contribute to chronic rejection. For that reason, we screen every patient for GERD. Currently, the most sensitive test to detect GERD is the 24-hour pH probe. A very small-bore catheter will be inserted through one of your nostrils into the esophagus and is secured in place. The catheter can measure the amount of acid in the esophagus that is coming from the stomach. The catheter will be connected to a small recording device for 24 hours, since reflux tends to occur in episodes.

If it turns out that you do have reflux, a different kind of probe will be used to measure the muscle contractions in your esophagus. This information is important to determine if the reflux can be treated with a certain type of surgical procedure.

Financial

Organ transplantation is an expensive undertaking and life-long commitment. It is very important to fully understand your insurance coverage and financial responsibility for transplant. You will be assigned a transplant financial coordinator who will partner with you and help you develop a financial plan for transplant.

It is essential that you maintain uninterrupted insurance coverage and that you discuss any changes in your financial situation or insurance coverage with your transplant financial coordinator. Ultimately, you are financially responsible for the medical services that you receive.

The role of the financial coordinator is to obtain transplant pre-authorization from your insurance company, determine the extent of coverage under your insurance plan, and investigate the likelihood of continued coverage for immunosuppressive (anti-rejection) medications.

Due to the high cost of organ transplant, verified financial resources are required prior to acceptance as a transplant candidate. Without insurance coverage, few options are available to assist in funding transplantation.

Medicare

Medicare is administered by the Social Security Administration. Medicare may be available to individuals 65 or older or to anyone who is declared disabled by the Social Security Administration. Disabled individuals have a 24 month waiting period before Medicare eligibility begins. To determine Medicare eligibility, contact the Social Security Administration at **800.772.1213**.

UVA is a Medicare-approved facility for transplant. To be eligible for immunosuppressive (anti-rejection) medication coverage, you must be enrolled in Medicare Part A at the time of transplantation,

currently enrolled in Medicare Part B, and receive a transplant in a Medicare-approved facility. Immunosuppressive medications such as tacrolimus, mycophenolate, sirolimus (Rapamune) and prednisone are reimbursed by Medicare Part B at 80 percent as long as you remain eligible for Medicare.

Original Medicare which is administered directly by the federal government has two parts:

- **Part A (Hospital Insurance)** covers most medically necessary hospital, skilled nursing facility, home health and hospice care.
- **Part B (Medical Insurance)** covers 80 percent of the costs for anti-rejection drugs, most medically necessary doctors' services, preventive care, durable medical equipment, hospital outpatient services, laboratory tests, X-rays, mental health care, and some home health and ambulance services. You pay a monthly premium for this coverage.

If you are on Medicare, you must have Part B coverage to be eligible for lung transplantation at UVA.

- **Part D (Prescription Drug Insurance)** is the part of Medicare that provides outpatient prescription drug coverage not covered by Part B. Part D is provided only through private insurance companies that have contracts with the government—it is never provided directly by the government (like Original Medicare is). Part D is optional for most people.

Medicare Part D is not mandatory to become eligible for lung transplantation at UVA. However, due to the fact that many transplant drugs are very expensive, you will incur substantial out-of-pocket costs to pay for the 20 percent of your medication costs that are not covered under Medicare part B. It will be very important to develop a financial plan to cover those expenses in this situation.



- **Part C** is not a separate benefit. Part C is the part of Medicare policy that allows private health insurance companies to provide Medicare benefits. These Medicare private health plans, such as HMOs and PPOs, are sometimes known as Medicare Advantage plans. If you want, you can choose to get your Medicare coverage through a Medicare private health plan instead of Original Medicare. Medicare private health plans must offer at least the same benefits as Original Medicare (those covered under Parts A and B) but can do so with different rules, costs and coverage restrictions. You can also get part D as part of the benefits package if you choose. Many different kinds of Medicare private health plans are available. You may pay a monthly premium for this coverage, in addition to your part B premium.

Medicaid

Medicaid is administered by your state's Department of Social Services. Medicaid may be available to individuals with disabling medical conditions who meet specific financial guidelines. To determine if you are eligible for Medicaid, contact your city or county's Department of Social Services.

Commercial insurance

Commercial insurance coverage for transplantation varies depending upon the policy. It is important for transplant patients to be fully aware of the specifics of their insurance benefits as plans may have caps or limitations on coverage for transplant-related services.

Medication coverage

Immunosuppressive (anti-rejection) medications are critical in maintaining the transplant organ. If you receive a transplant, you will be on immunosuppressive drug therapy for the rest of your life. During the first year following transplantation, the estimated cash price for immunosuppressive medication is \$1,500 - \$1,800 per month. You will also be prescribed other costly medications. Your financial coordinator will help you understand your coverage and estimate out of pocket costs for medications after transplant.

Relocation

Depending on how far away you live from UVA, we may ask you to re-locate to the Charlottesville area after your surgery. We do this with your safety in mind to ensure that you have ready access to adequate specialized care in the period where you are most vulnerable to developing medical or surgical complications. Depending on your individual situation, you may have to re-locate for at least eight weeks. Your insurance company may cover some of the expenses that are associated with relocation. Our financial coordinator will help you estimate the expenses that you will incur and develop strategies to cover these costs.

Pulmonary rehabilitation and physical therapy

Exercise is beneficial in all the phases of lung transplant. There is good evidence from the medical literature that patients in good physical shape have a higher likelihood of doing well during and after their lung transplant surgery.

Benefits of exercise before your transplant:

- Helps you maintain your ability to function in your home and community
- Improves and maintains your exercise capacity
- Decreases hospital admissions
- May help in weight reduction

Most people with severe lung disease have an abnormal response to exercise, so exercise should be supervised to ensure safety.

It is mandatory for every patient who is being considered for lung transplantation at UVA to enroll in a pulmonary rehabilitation program and to participate regularly. The lung transplant coordinator will help you find a suitable pulmonary rehabilitation program in your area and make a referral if necessary.

The University of Virginia has its own outpatient pulmonary rehab program that is available to patients who live in the Charlottesville area.

Some of the goals of pulmonary rehabilitation include:

- Improvement of general body strength and endurance
- Strengthening of upper and lower extremities
- Optimizing breathing and airway clearance techniques
- Optimizing techniques using inhalers and nebulizers
- Achieving a six-minute walk distance of at least 150 meters, which is the minimum requirement for lung transplantation at UVA
- Developing strategies to cope with breathlessness and anxiety

After your lung transplant

After lung transplantation, most patients report that their breathing feels better, but their legs are weak and tired. It will take several weeks to months for your muscles to catch up with your new lung function.

The physical therapy team will evaluate you and start working with you shortly after you had your surgery. It is important that you cooperate, even though you may feel weak and tired.

After discharge from the hospital, you should return to your pulmonary rehabilitation program. Exercise is the best way to make the most of your new lungs. You should make a life-long commitment to exercise. Exercise can:

- Improve your endurance
- Help keep your lungs free of secretions, decreasing your risk of infections
- Increase your sense of well-being
- Make activities of daily living easier
- Reduce stress by relieving tension
- Assist the body's natural immunity to fight infection
- Assist with weight, blood sugar and cholesterol control
- Help counteract some of the side effects of some of your transplant medications, such as osteoporosis (thinning of the bones), hypertension and high cholesterol



Nutrition: a key to successful lung transplantation

Good nutrition is an important piece of all parts of the lung transplantation process, both before and after transplant.

Because your nutrition is so important, a registered dietitian is part of your transplant team and will work with you before transplant, during your hospital admission for transplantation, and after you go home from your transplant.

Nutritional goals prior to lung transplantation

Prior to lung transplantation, it is important to be in the best nutritional health as possible. You will work with the dietitian and transplant team to reach the goals you set together. Below we will discuss some nutritional topics of importance during this time.

Body weight

Being under-nourished (*malnourished*) or over-nourished (*overweight or obese*) can be dangerous and increases risks during transplantation, which can be fatal. So, it is important that you are a healthy body weight when you receive your transplant.

Body mass index (BMI)

The BMI is a broad measure used to estimate how much body fat you have and determine if you are a healthy weight. See the chart below to see what a specific BMI means:

To be eligible for lung transplantation at UVA Health System, you must have a BMI of 18-30.

- What is your BMI? Knowing it before you come to clinic for your transplant evaluation can help you to get started in making necessary changes prior to your visit.
- You can use the online BMI calculator provided by the National Heart, Lung, and Blood Institute to calculate your BMI. All you need to know is your current weight and height.
- Visit nhlbisupport.com/bmi to learn more.

BMI	Weight Classification	Intervention Needed
Less than 18.5	Underweight	Weight Gain Needed
18.5 to 24.9	Healthy Weight	Maintain Current Weight
25.0 to 29.9	Overweight	Weight Loss Needed
30.0 or higher	Obese	Weight Loss Needed

Dietary Changes

Below are some healthy ways you can start to improve your diet:

- **Eat more fruits and vegetables.**

- At all meals, make half of what you eat fruits and vegetables. Fruits and veggies are also good snacks.
- Choose fruits and veggies of all different colors.
- Fruits and vegetables are power foods and can help protect you from many different diseases.

- **Reduce unhealthy fats and focus on eating healthy fats.**

Unhealthy Fats: Saturated and Trans Fats

Examples: butter, lard, vegetable shortening, animal fat (high fat beef, pork, and dairy), baked goods, cream

Healthy Fats: Monounsaturated and Polyunsaturated Fats

Examples: nuts and seeds (any kind), fish, avocados, olives, canola oil, olive oil

- Eat fish at least 2 X per week.
- Reading nutrition labels can help you to see if the foods you are eating contain the unhealthy fats.

- **Limit sodium intake. Limit to 1,500-2,000 mg per day.**

Where does sodium come from?

- 1 teaspoon of table salt contains approximately 2,400 mg of salt.
- Processed foods like frozen dinners, soups, canned foods, deli meats, gravies, snack foods, condiments (soy sauce, ketchup, Worcestershire sauce), seasonings (poultry and fish seasonings) are high in sodium.
- Restaurant food and fast-food contains very high amounts of sodium.

How can I reduce my intake?

- The fresher you buy food, the less sodium it will likely contain. Buy less processed foods.
- Have more home-cooked meals. Limit meals eaten at restaurants or fast-food places.
- Cook with spices, juices, vinegar, and herbs to season your food rather than using salt.

- **Choose whole grains rather than white grains.**

- Whole wheat products have higher amounts of dietary fiber, which can help to improve your heart health and help keep your digestive system healthy.
- Examples of whole grains include: whole wheat breads, whole wheat pastas, brown rice, oatmeal and popcorn.
- Fiber also comes from fruits and vegetables

- **Limit sugar-sweetened beverages.**

- Sodas and juices add many unnecessary, empty calories to your diet.
- Reduce use of these beverages and increase your consumption of water and fat-free or low-fat milk products.

- **Eat breakfast, lunch, and dinner every day.**

- Skipping meals does not help with weight loss and can actually promote weight gain.
- When you are hungry between meals, it is ok for you to have a healthy snack.

- **Need to gain weight? If so, here are some tips that you may find helpful:**

- Eat frequent snacks between your meals – aim for three snacks daily.
- Drink beverages with calories like: milk, nutrition supplements (Ensure®, Boost®, Carnation Instant Breakfast®, or their store-brand versions), or make a homemade smoothie (yogurt, milk, fruit and peanut butter).
- Have higher-calorie snacks like hummus, trail mix, nuts, peanut butter, avocados or dried fruit.
- Add calories to what you are already eating like: nut butters, cheeses, oils, dried milk powder, nuts, oils and bean spreads.
- Occasionally, we may recommend a feeding tube to improve your nutrition. This allows us to give you high-calorie liquid nutrition at night.



- Start reading nutrition labels to help learn how much fat, sodium, fiber, and calories are in the foods and beverages you eat and drink.
 - Start by looking at the serving size. All the nutritional information listed is based on that serving size.
 - Look at the nutrient(s) of concern.
 - Comparing several products' nutrition labels next to each other will help you to choose the healthiest product.

Diabetes

If you have diabetes, follow a consistent carbohydrate diet and take your medications. The transplant dietitian can help you learn about how to follow a consistent carbohydrate diet. Many local hospitals often have a diabetes education program you can also attend or contact.

Vitamins, minerals, and herbal supplements

Many vitamin, mineral, and herbal supplements are widely available for purchase without a prescription. Unfortunately, many herbal supplements or vitamin and mineral supplements can interact with medications, vitamin and mineral levels in your body cause toxicity or in extreme cases, can be fatal. You are encouraged to use caution with these substances.

If you are eating a well-balanced diet, you likely do not need any supplementation. Should you require supplementation, your physician will prescribe it or recommend a reputable brand for you to purchase.

Problems with these supplements:

- They are not regulated like medications.
- It can be hard to identify the ingredients – many do not contain what it actually says it contains or in the amount it says it contains.
- Some have been found to contain traces of antibiotics, heavy metals and pesticides.
- No, little, or unclear research to support that their use actually improves health.
- Lack of research to support that use is not harmful.
- For a supplement to be banned after it is on your local grocery shelf, it has to be proven to be unsafe – this can take years before this is found, after many consumers have already gotten ill from it.
- You may think that more of a vitamin or mineral may not be harmful, but it can be and has been shown to be. More isn't always better.
- If you do take a daily multivitamin with minerals, please ensure it contains no more than 100 percent of the recommended amounts of the Dietary Reference Intakes (DRI) (this is the percentage you will see on the food label next to each nutrient).

Waiting

The lung transplant selection committee

Once the evaluation is complete, your test results will be presented to the transplant selection committee. This committee consists of pulmonologists, cardiothoracic surgeons, lung transplant coordinators, a neuropsychologist, a financial counselor, a social worker, a pharmacist and a nutritionist. The group will again discuss your entire case and decide jointly whether or not you are a candidate for lung transplantation. The committee will also decide which type of transplant procedure is best suited to treat your condition (transplantation of the left or right lung only versus transplantation of both lungs). If accepted for listing, you will be listed on a local and national list according to blood type and general body size.

Where do the lungs come from?

Lungs for transplantation are obtained from patients who are brain dead due to illness, accident or injury. The families of these patients have agreed that the patient would wish to give his/her organs. Donors are carefully screened through a health history, physical exam, and blood tests. Although it is natural to be very curious about the donor, information about the donor is confidential and we cannot tell you any details about your donor. You will, however, be given the opportunity to write your donor's family after the transplant if you desire.

Lungs at the University of Virginia Health System are obtained through Lifenet, the organ procurement agency that covers a large part of Virginia. Lungs from other areas in the country are sometimes offered if not needed in their locale.

The Lung Allocation Score (LAS)

Lung offers are made to lung transplant candidates by assigning each candidate a Lung Allocation Score. This score is based on each candidate's particular medical information. It reflects both the seriousness of each candidate's medical status before transplant, and the likelihood of a successful transplant. The LAS is a number between 0 and 100. The highest

score is given to very sick patients who are expected to have a high chance of living longer with a lung transplant. While you are waiting on the list, we will periodically ask you to repeat certain blood tests or do pulmonary function testing to update your LAS.

Bear in mind that the LAS is just one of several variables that will decide how soon you will receive an organ offer. Your blood type, height, listing status (single versus double lung transplant) and availability of organs will also affect your individual time on the transplant wait list. There is no "TOP" spot on the waiting list, and the list changes frequently. You may receive a transplant at any time, even if you are not very sick or unstable.

The average waiting time is approximately 12-18 months. We understand that this will be an emotionally difficult time for you and your family. We strongly encourage you to attend our support group, which meets on the 4th Thursday of every month from 11:30 a.m to 1:00 p.m. The support group will give you the opportunity to meet other patients and their families, both pre- and post- transplant. It can greatly help if you share your feelings with others who have been through similar experiences. Our social worker is also available to meet with you on an individual basis.

Staying healthy

While you are waiting, we will need to see you in the pulmonary clinic at UVA about every three to four months. During these visits, we will evaluate you to confirm that you remain a candidate and to prepare you for life after transplant. We will keep in contact with your referring doctor during your waiting time.

You will be expected to participate in a pulmonary rehabilitation program from the time you are listed until several months after your transplant. Exercise in this type of program improves quality of life prior to transplant, and enables patients to recover more rapidly after surgery.



Being severely under or over weight increases the risks involved during and after surgery. Our transplant dietician is available to help you with any of these issues. During your evaluation and the waiting period, we will let you know of any concerns regarding your weight or nutritional status.

It is very important that you remain as healthy as possible during your time on the waiting list.

Becoming “deactivated” on the wait list

It is possible that you may be taken off the active lung transplant waiting list (“deactivated”) for various reasons. If you are deactivated, you will not be offered a lung. We will discuss this with you before deactivation.

Reasons for deactivation

- Illness that would increase your risk of a bad outcome after transplant
- You decide that you do not want to have a transplant
- Use of any tobacco products, alcohol or drug abuse
- Loss of financial coverage for the transplant or medication
- Failure to participate in your exercise program
- Infection
- Failure to keep your clinic appointments
- Severe malnutrition (BMI less than 18)
- Obesity (BMI greater than 30)
- Loss of social support system
- You travel and would not be able to come to the hospital for transplant if you received a call

Depending on the circumstances, patients may either be deactivated temporarily, or removed from the list. Your physician and coordinator will always discuss this with you prior to making any changes.

The Transplant Support Group & Mentor Program

The transplant program offers a monthly meeting for patients and family members awaiting transplant. The group offers waiting patients the opportunity to meet transplant recipients, ask questions and gather insightful information from a recipient’s point of view. The group is held on the fourth Thursday of each month from 11:30 a.m. to 1:00 p.m. All patients and family members are encouraged to attend.

Many transplant recipients report that the most challenging aspect of transplantation is the waiting period. The uncertainty of not knowing when a donor lung(s) may become available coupled with the adjustment of living with a disabling condition can have significant emotional consequences for the patient and family. Over half of family members of transplant candidates may experience moderate to high levels of stress. If not dealt with appropriately, these stressors can “pile up” causing excessive emotional burden making the wait for transplant even more difficult. Studies have shown that transplant candidates and family members who participated in a support group had overall better adjustment and less emotional stress during the waiting period.

The time of surgery

Getting “the call”

We need to be able to contact you at all times in case lung(s) become available.

It is mandatory that you contact the Transplant Office if you change your address or telephone number, go out of town, are admitted to a hospital, or are being treated for an infection, illness or injury.

PLEASE do not install a “Call Intercept” on your phone. This may keep you from getting calls from the Transplant Office.

The transplant nurse coordinator will call you when it is time for your transplant.

If you have recently been ill or running a fever, please let the coordinator know when she calls. If you are on a blood thinner (Coumadin or Heparin), you should also alert the coordinator. You should not take any more doses after receiving the call.

You are not to have anything to eat or drink after we have called, except a small amount of water in order to take your normal medications.

On rare occasions, we call patients for stand-by, meaning if the lung would not be appropriate for one patient, it may suit another patient. For example, if we call a patient in for a double lung transplant and we then learn that only one lung is suitable, we would then use a single lung recipient.

Transportation

You are responsible for providing your own transportation on the day or night of your transplant. If you are more than three and one half hours (3 hours) away by car, you may need to make flight arrangements. If needed, our social worker can assist you in finding transportation. Contact your local airport for a list of private pilots. There are some pilots who provide this service for the cost of the fuel only. Once you have made your travel arrangements, please notify the nurse coordinators so that we may include the information in your chart.

Arriving at the hospital

The coordinator who calls will tell you where to enter the hospital. Do not bring valuables to the hospital. Bring a current list of all your medications and a list of any allergies you have to medications or food.

Once you are admitted to a room, you will be prepared for surgery. This will be a very busy time. Your operation will take up to eight hours, sometimes more depending on your individual case. During the surgery, your family will be able to wait in a family and visitor waiting area. The surgeon will speak with your family as soon as possible after the surgery.

You should discuss with your family in advance where they plan to stay during your hospitalization. UVA Patient and Guest Services at **434.924.1299** may be able to assist you in making reservations. Our transplant social worker will also be available to help you find a place to stay.



The transplant surgery

Below is a brief description of how a lung transplant is performed.

Single lung transplant

The surgery usually takes six hours or more. The surgeons will make an incision on the side of your chest to gain adequate access to your lung.

First, your diseased lung will be removed. During that time, only the opposite lung will do all the breathing with the help of a ventilator, which is usually not a problem. Sometimes, however, it is not possible for just one lung to do all the work. In these situations, the surgeons use a system called “cardiopulmonary bypass” which is a machine that transfers oxygen into the bloodstream outside the human body. Next, the transplant lung will be put in your chest in the place where your diseased lung was removed. Three connections, called “anastomoses”, will be made to connect the transplanted lung to your body:

1. The main airway of the transplant lung will be connected to your own airway.
2. The pulmonary arteries will be connected.
3. The pulmonary vein of the transplant lung will be connected to the left atrium, which is a chamber of your heart.

The chest will be closed, and you will be taken to the Intensive Care Unit (ICU) for observation.

Double lung transplant

The surgery can last up to 12 hours. In case of a double lung transplant, the surgeons will make an incision across your chest below your breasts, called “clamshell incision.” This allows good access to both lungs. One lung is replaced at a time, and the sickest lung will be replaced first. Just as with a single lung transplant, three connections will be made on each side. In case it is not possible to support your body with just one lung breathing, it may be necessary to use the cardiopulmonary bypass machine. After your chest is closed, you will be taken to the Intensive Care Unit (ICU) for observation.

False alarms

When we call you in for a transplant, we are quite certain that we will actually go forward with the surgery. The donor lung(s) will be assessed on site with comprehensive blood work, X-rays, and bronchoscopy. However, there is still a potential that the transplant will have to be called off at the last minute. Sometimes, organs have to be rejected when our surgery team goes out to inspect the donor lungs on site. It is also possible that the condition of the donor lungs changes rapidly, which would cause an organ to be rejected for transplant that looked good initially.

A false alarm can be a very frustrating and even traumatizing experience for someone who is anxiously awaiting a transplant. However, when we call a transplant surgery off at the last minute, we are doing so with your best interest and safety in mind. Our team will do its best to support you in this difficult situation.

Post operative period

The Intensive Care Unit

After your transplant, you will be in the TCV (Thoracic and Cardiovascular) post-op unit. The average length of stay in the intensive care unit is two days to one week, followed by one to two weeks in the hospital on the general surgical floor. You will have many tubes and IV lines and will be very closely monitored.

When you wake up, you will have a breathing tube in your mouth and a ventilator will be breathing for you. This is called intubation. Because of this tube, you will not be able to talk at first. As you become more awake and can do more of the breathing on your own, the nurses and respiratory therapists will start weaning you from the ventilator. You will need to be awake for this, but you will receive pain medication to keep you comfortable. Many patients report that they don't remember this phase. When you are able to breathe on your own, you will be taken off the ventilator and the breathing tube will be removed. You will be on oxygen following surgery, which will be weaned as able when you are ready.

After surgery, coughing and deep breathing are very important to help expand your new lung. You will receive an incentive spirometer to help you do some of the breathing exercises. Because the nerves to your transplanted lung are cut, you will not feel the mucous build-up. The nurses will remind you to cough and breathe deeply. Your incision may be sore when you take deep breaths. If you are having pain, it is important that you tell the nurses so they can give you pain medication. Don't be afraid to take the pain medicine. It will be easier to do your breathing exercises if you are comfortable. Our UVA Acute Pain Service Team will also be visiting you to make sure you are getting the appropriate pain medicine to help you cough, take deep breaths, and walk.

You will have several tubes. You will have two to four tubes in your chest to drain excess blood and fluid from the space around your lung that accumulates during surgery. You will have a bladder catheter that

will drain your bladder. These will be removed a few days after your surgery. You will also have an IV line in your neck and arm so that you can receive medicines intravenously.

It is possible that you will also have an epidural catheter placed into an area near your spine by an anesthesiologist who is a member of the UVA Acute Pain Service Team. This small catheter will give you small amounts of pain medicine via a pump to numb the area around your incision and the chest tubes. This catheter will only be placed if your surgeons feel it is suitable for you. If placed, it will be removed when your chest tubes are removed.

Visiting hours are restricted in the intensive care unit to allow you to get the rest you need and to minimize your exposure to infection. Only family members and significant others will be allowed to visit. If anyone has a cold or infection, they should not visit until they are better.

Sometimes a bronchoscopic exam (or "bronch") is necessary to look at the connection in your bronchus (or windpipe) or to take a small sample of lung (biopsy) for examination under a microscope. During this procedure you will be mildly sedated. The bronchoscope is a long tube with a light at the end that is inserted into the windpipe through the nose or mouth. This procedure is used to check for rejection and infection and to check for any narrowing of your anastomosis (the surgical connection of the donor lung and your natural lung). Patients who receive a transplant will have scheduled bronchoscopic exams after discharge. Your post-op coordinator will discuss this with you.



The Step-Down Unit

When you are ready, you will be transferred to a room on 4 West on the TCV Step-Down Unit. You will be in a private room. The visiting hours will be longer but it is still wise to keep visitors to a minimum to prevent exposure to infections.

The average length of stay in the regular hospital room is five days to two weeks. You may still have supplemental oxygen and IV lines for a while. You will begin more activity on your own and will start doing exercises with a physical therapist to regain your strength. It is also very important to continue your breathing exercises. Remember that your new lung will not know when you need to cough to clear mucus. As before, if you are having any pain, let the nurse know so you can get your pain medicine.

This is a time when you will be asked to learn more about your medications and transplantation. The nurse coordinator and nursing staff will begin teaching you about your medicine and your daily routine (lab work, how to prevent infections, signs and symptoms of rejection, etc.) after transplant. You can be prepared by familiarizing yourself with your immunosuppressive medications and with information in this booklet before your transplant. We strongly encourage you to begin to learn this information now, so you can learn it in a less stressful situation. It is also helpful if you investigate what local pharmacy you will work with after your transplant.

Nutritional goals during your hospitalization

During the first four to six weeks after lung transplantation, your body will require extra calories and protein to help you recover. Getting enough nutrition is an important part of recovery and can:

- Improve wound healing
- Increase your ability to fight off infections
- Give you energy

Often times, getting enough nutrition in the first few weeks after surgery can be difficult as you may not have an appetite, may not be able to eat immediately, or may have nausea or abdominal discomfort. It is important that you think of your nutrition after surgery as one of your medications to help you get well. Without proper nutrition you will get behind. The transplant dietitian and transplant team will work with you to help ensure you receive enough nutrition after surgery. Some of these interventions may include:

- Drinking nutrition supplements (like Ensure[®], Boost[®] or Carnation Instant Breakfast[®])
- Eating snacks frequently between meals
- Receiving tube feedings
- Starting vitamin or mineral supplementation
- Recommending gastrointestinal medications

As with any surgery, your individualized hospital course may be very different than another transplant patient, so your team will work with you to cater to your individualized needs.

Going home

When your doctors and nurses believe you are ready, you will be discharged from the hospital to your home, a local apartment/hotel, or an inpatient rehabilitation facility. This will depend on your individual condition after surgery.

Transplant patients and a care giver should be prepared to remain in the Charlottesville area after their transplant for a minimum of two to four weeks or longer.

If you live far away from UVA, we may require you to stay in the Charlottesville area for at least a month. This is mainly to ensure your safety and access to adequate care during a period where patients are known to be particularly vulnerable to complications. If you fall into this category, our financial coordinator will help you to develop a plan for covering expenses that are associated with a temporary relocation to Charlottesville.

Transplant recipients are not permitted to stay in the UVA Hospitality House in the first year following their transplant. Cost and availability of lodging in the greater Charlottesville area varies. In most instances the cost of lodging, transportation and food is not covered by insurance companies. All patients should be prepared to pay out of pocket in the range of \$1,500-\$2,000 or more for lodging, food and transportation. The transplant social worker can assist you with lodging resources. It is the patient and family members' responsibility to secure adequate lodging arrangements prior to the patient's hospital discharge. Please plan accordingly.

Post-transplant patients have to follow a strict medication and care regimen to keep their organ healthy. It is essential to take medications as directed and follow other instructions that your team provides you. If you do not follow instructions regarding your medication and care after transplant, you greatly increase your risk for not having a good outcome from your transplant, and your risk for developing infections, rejection or other fatal consequences.

You may feel overwhelmed with all that you must do once you return home. That is normal. We do expect a lot from you, but we will work with you daily in the hospital to prepare you for discharge home.

Remember: there is always someone you can turn to for help. Once you go home, the staff in the Heart-Lung Transplant office will talk to you regularly to discuss your lab work, your medications and your general well-being.

The Heart-Lung Transplant office telephone number is **1.844.296.8070**. After 4:30 p.m., for emergencies, you can reach the pulmonary transplant nurse coordinator on call by dialing **434.924.0000** and asking for the cardiopulmonary transplant nurse on call or call **1.844.296.8070** and follow the prompts that will connect you with the UVA hospital operator.

Any changes in medication, lab work or treatment will always come through the Heart-Lung Transplant

office. If a physician, other than the Heart-Lung Transplant team, wishes to make a change, instruct them to contact the Heart-Lung Transplant office first.

In your home, you do not have to take any special precautions. You do not have to sleep in a different room from your spouse. You do not have to eat from a different set of dishes. You do not have to wear a mask inside or outside your home. We do recommend that during the cold and flu season you avoid crowds and always avoid people who are obviously ill.

Clinic Visits

After you are released from the hospital, you will come for regular follow-up visits to ensure you and your lungs are doing well. You will be seen by the transplant pulmonologist and a transplant coordinator. We will see you more frequently in the first two months after transplant and then gradually lengthen the intervals in between visits. How often you need to be seen will also depend on your health after transplant.

Time after transplant	Frequency of visits
0-2 months	Once a week
2-4 months	Once every 2 weeks
4 months to 1 year	Once every month
Past 1 year	Once every 3 months

Typical visit schedule:

At each clinic visit, we will get pulmonary function tests and discuss the results with you. You may occasionally need to have a chest X-ray, blood work or perhaps a bronchoscopy during your visits.

Please bring your transplant booklet to your clinic visits. We will review your medications, vital signs, lab results, exercise program and diet with you during each scheduled visit.



Phone surveillance

To ensure your well-being after transplant, the transplant coordinators will contact you three times per week on Mondays, Wednesdays and Fridays for the first year after your surgery.

Once you are past one year post-transplant, the coordinators may decide to call you on a weekly basis between visits if you are sick or if you recently had to be admitted to the hospital.

During each phone call, the coordinators will go through a set of questions, including:

- Questions regarding respiratory or infectious symptoms
- Review of your medications
- Questions regarding breathing exercises and physical activity
- Questions regarding appointments for clinic visits and blood work

Complications after lung transplant

The two most common complications in lung transplant patients are infections and rejection (acute and chronic). Following your instructions and taking your medications exactly as prescribed will help to minimize the risk of complications. Unfortunately, many complication events happen unexpectedly and are beyond your and our control.

Infections following lung transplant

If you have any of the following symptoms please notify the transplant coordinators:

1. Persistent cough
2. Fever greater than 100° F
3. Cold/flu-type symptoms
4. Decreased exercise tolerance
5. Burning with urination
6. Persistent nausea, vomiting or diarrhea

Always call or page a coordinator if you are seen in an emergency room or hospitalized.

Your immune system is responsible for fighting infections. It is weakened with the immunosuppressive drugs that are used to prevent rejection. You receive the highest level of anti-rejection medicines immediately after transplant, and although this is a high risk time of developing infection, it is a risk that lasts for your lifetime. Infections after transplant can be life-threatening and must be taken seriously.

You should understand that while most infections are treatable, it is extremely important to diagnose and treat them promptly before the symptoms become too severe. If you have any questions concerning your symptoms, please contact the transplant coordinators.

Precautions

- For the first three months, we ask that you wear a mask when out in an area where there are many people in an enclosed area. This includes the hospital, waiting rooms, church, movie theatres, etc. It is best to avoid these areas if possible during cold and flu season.
- It is essential that you practice good hand hygiene. Anyone visiting you must wash their hands (or use hand sanitizer), as many infections are passed through hand-to-hand contact. You must avoid people with colds or flu if at all possible. Anyone with a cold or flu should wear a mask if they are in the room with you. People who have a fever or are very sick should NEVER visit you.
- Once you return home it is not necessary to wear masks or gloves in your home. Some patients continue to wear masks during winter months, especially in crowds or clinic waiting rooms.
- If someone in your family or household has a cold or flu, use separate drinking glasses, make sure they cover their mouth/nose when coughing or sneezing, and wash their hands frequently. Carry a bottle of hand sanitizer with you, which is helpful when you are away from soap and water.
- If you are exposed to a child with active chicken pox please notify the transplant coordinators.
- Skin abrasions should be treated promptly. You can treat these using a mild soap and water rinse and applying an over-the-counter antibacterial ointment, and cover with a band-aid or gauze. If you have signs of redness, swelling or drainage please notify the coordinators. Wound healing occurs more slowly because of the immunosuppressive medicine.
- Pets: If you own a cat, we will ask you to never change the cat litter (another house member will need to take over that job). Toxoplasmosis, a parasitic infection found in cat's stool, can cause problems with immunosuppressed patients.
- Our program does not transplant patients who have pet birds. Birds are a source of serious infections for post-transplant patients.

Types of infections and how to prevent them:

Viral infections

CMV (Cytomegalovirus infection)

CMV is a very common virus in the general population. It does not usually cause problems in healthy people, but in transplant patients it can be a very serious, life-threatening illness. If you had evidence of CMV prior to transplant, it may reactivate following transplant. If you did not have CMV and receive lungs from someone who had CMV, you may develop CMV infection after transplant. You will receive medicine to prevent this from occurring or receive medicine if you develop CMV infection. Unfortunately, the medication is not 100 percent effective in preventing infection. Signs of CMV infection may include fever, fatigue, nausea, vomiting, diarrhea or shortness of breath. Because these signs are also common with other infections, you need to call the coordinator to report these symptoms.

Influenza (FLU)

The flu can cause serious illness and even death after transplant. All patients must receive a flu shot every year, and avoid others who are sick. Family members must also receive a yearly flu shot, as they often can carry the virus to the transplant patient.

Bacterial infections

There are many different bacteria that are present in the environment that can cause infections such as bronchitis, pneumonia or meningitis. Good hand washing is important in preventing bacterial infections. Avoiding people who are ill is also important to avoid infections. We recommend the pneumonia vaccine prior to transplant, and a booster in five years.

Fungal and mold infections

Fungal infections are also very serious and sometimes life-threatening infections after transplant. Some of the more common fungal infections are due to aspergillus. Fungus lives in the soil and our environment. For this reason, we



ask patients to avoid areas where there is a lot of construction that stirs up the dirt and causes the fungus to be released into the air. If you are doing any type of gardening or yard work, you must wear a snug mask and gloves. You should also avoid any area that smells musty or has visible mold. If there is any doubt, a mold test can be performed in your home. Please let the coordinator know.

Lung Transplant Rejection

Acute rejection

Your transplanted lung is considered foreign by your body's immune system. Therefore, the body attempts to reject, or "attack" this organ. In order for your immune system to tolerate this new organ, your body's immune system must be suppressed. Immunosuppressive medicines are taken to prevent rejection of your transplanted organ.

Despite these medications, many patients undergo several episodes of acute rejection.

The incidence of rejection declines after the first year, but the risk never completely disappears.

Symptoms of rejection may include fever, cough, shortness of breath, and a decrease in exercise capacity. Unfortunately, these symptoms may also be seen with infectious episodes. For that reason, we usually require a lung biopsy to determine if you are undergoing a rejection or infection.

Chronic rejection and bronchiolitis obliterans

A potential long-term complication of lung transplant is bronchiolitis obliterans or "chronic rejection." It occurs in 30-50 percent of lung transplant recipients. Bronchiolitis obliterans is a process in which the bronchioles (small airways) of the lungs become swollen or inflamed and are eventually replaced by thick fibrous (scar) tissue. This makes it difficult for the lungs to absorb oxygen and remove waste products from the blood stream. The lungs may also have difficulty with increased mucous production. This process, called chronic

rejection, usually happens one to two years after lung transplant and may have a slow and subtle course. Lung transplant physicians at many centers are trying to discover a cause, treatment and how to detect it early. Presently, there are no definitive answers.

Acute rejection episodes, infections and gastric reflux may trigger bronchiolitis obliterans. Fortunately, many patients who have rejection or infections will never develop bronchiolitis obliterans.

The symptoms associated with bronchiolitis obliterans are often subtle and may include cough with mucous production and worsening shortness of breath. We can detect it by observing a decline in the pulmonary function tests. Sometimes it may be seen on lung biopsy (bronchoscopy), but bronchiolitis obliterans is much more difficult to see on a bronchoscopic biopsy than acute rejection. Follow-up appointments in the pulmonary clinic are crucial for chronic rejection screening.

Some patients have normal fluctuations in their pulmonary function tests that are not a sign of bronchiolitis obliterans.

Treatment of bronchiolitis obliterans (chronic rejection)

In an attempt to slow down or stop the progression of chronic rejection, we may decide to change your immunosuppression drugs or adjust the dose.

We may start you on a medication called azithromycin three times per week. You may know this medication from taking it as an antibiotic. We are actually not using it as an antibiotic, but because it has effects on the immune system that may help to slow down chronic rejection.

In addition, we may start you on a steroid inhaler to reduce inflammation within the airways.

Gastro-esophageal reflux disease and chronic rejection

We know from the medical literature that gastro-esophageal reflux disease (GERD) can contribute to bronchiolitis obliterans. Small particles of stomach content may spill over into the lungs and cause damage to the tissue. Medications for GERD alleviate symptoms, but they do not prevent the reflux itself from happening.

When we diagnose you with chronic rejection, we may decide to work you up for GERD, possibly even when a prior work up has been negative (see page 11 for a description of the 24-hour pH probe and esophageal manometry).

If we find that you have reflux disease, you may benefit from an endoscopic keyhole surgery called fundoplication. A piece of stomach is wrapped around the junction between the stomach and your esophagus to prevent GERD.

These interventions are not a cure and may not reverse any lung damage that has already occurred. However, they may stop the chronic rejection and prevent further damage to the lung tissue. Many patients continue to experience a good quality of life after treatment despite their new limitations.

If you have any questions about bronchiolitis obliterans, please ask the transplant coordinator or physician.

Other complications

It is impossible to discuss every possible complication of lung transplantation with you in detail. However, there are some that you should know about:

Medication side effects

Specific side effects from the different medications that you will be on are discussed in more detail later in this booklet (see section on medication). However, it is very common for patients to experience some degree of GI side effects, mainly nausea and diarrhea. The degree to which this happens is

variable. These symptoms can usually be controlled with medications or dietary modifications. In most patients, these symptoms will improve over time

Gastro-esophageal reflux disease (GERD)

As mentioned earlier, GERD is a common condition in patients with advanced lung disease. GERD symptoms may worsen in patients with pre-existing GERD, and some patients who never had GERD will develop it after lung transplant. Some of this has to do with the medications that you need to take. Sometimes, a certain nerve in the chest cavity can get damaged during surgery, which increases the risk of GERD. For this reason, we re-evaluate all transplant patients for GERD about a month after surgery with a 24-hour pH probe. This test is described earlier (please see page 11).

Cancer

The drugs that you will be on to suppress your immune system and prevent rejection of the transplanted organ unfortunately increase the risk of certain types of cancer. For that reason, it is important that you stay up to date with all your health maintenance exams like colonoscopies, mammograms and PAP smears.

We recommend that you see a dermatologist at least once a year to do a thorough screening exam of your entire skin, especially if you already have a history of cancerous or pre-cancerous skin lesions. It is important for you to use proper precautions when you are out in the sun.

Osteoporosis

Osteoporosis is a disease where the structure and strength of your bone weakens, which increases the risk of bone fracture. Certain drugs that you will be on increase the risk of osteoporosis, especially prednisone. It may be necessary for you to start therapy for osteoporosis, and we may have to supplement you with calcium and vitamin D to prevent bone disease.



Diabetes

Some of the drugs that you will be on, especially prednisone, increase your risk of becoming diabetic. If you already have diabetes, your glucose levels may increase, and it may be necessary for us to adjust your medication regimen.

Hyperlipidemia

Some of the medications you will be on can affect your lipid metabolism. Your cholesterol or triglyceride levels may increase, and it may be necessary for you to get started on medication for this.

High blood pressure (hypertension)

Some of the medications that you will be on can increase your blood pressure. It may be necessary for you to start blood pressure medications, or we may have to adjust the regimen that you are already on.

Renal failure

Certain medications that we need to treat your transplant can be toxic to the kidneys over time. We will regularly measure your kidney function with blood tests after transplant. Renal failure usually does not cause any symptoms, and it is usually slowly progressing over time. It is rare for transplant patients to require treatment with an artificial kidney (dialysis). We may have to adjust medications to minimize toxic side effects to the kidneys.

Bronchoscopy

It is very difficult and oftentimes impossible to diagnose acute rejection or an infection inside your transplanted lung based on clinical symptoms, X-rays and laboratory results. One of the most useful tests to help with establishing the correct diagnosis is bronchoscopy.

We schedule surveillance bronchoscopies at 1 month, 3 months, 6 months and 12 months after your transplant surgery. Additional bronchoscopies may be necessary depending on your course after transplant.

Bronchoscopies are usually done as an outpatient procedure. The procedure will be done under “conscious sedation.” We will give you two separate drugs for sedation purposes, so you will likely be very sleepy during the procedure but can still breathe on your own.

The procedure itself takes about 30 to 45 minutes to perform. We will use a small flexible scope to do a thorough inspection of your airways. We will then use a certain amount of sterile saline to wash out some cells from within your lung (bronchoalveolar lavage or BAL). Lastly, we will take several small biopsies from one of your lungs under X-ray guidance. Since the lungs are not supplied with any pain nerves, you will not feel any pain when we take those biopsies.

The bronchoalveolar lavage is a very sensitive test to look for infection in the lungs. The transbronchial biopsies are very helpful for diagnosing acute rejection. It may take several days for all the results of the bronchoscopy to become available.

Instructions to follow

- Since you will be receiving sedative medications, it is mandatory that you have a support person with you who can drive you home and observe you after the procedure. You will not be allowed to drive yourself home after your procedure.

- You are not allowed to eat or drink anything after midnight on the day your procedure is scheduled. However, you may take your medications in the morning with a sip of water.
- If you are a diabetic and your diabetes is controlled with pills, don't take those pills on the morning of your procedure.
- If you are on insulin, take half the normal dose of your long-acting insulin in the morning. Do not take any short-acting insulin on that day.

Transportation and travel after transplant

We want your life after transplant to be as close to a "normal life" as possible. For many, this includes the ability to travel, something that you may not have been able to do prior to transplant. While we certainly want you to be able to travel, there are some precautions that we need you to follow.

Driving

You will not be able to immediately drive on your own following transplant. The individual time that it takes until you are safe to get behind the wheel is variable and will depend on your individual course. Most patients are not able to drive by themselves for the first three months after transplant.

You are not allowed to operate a vehicle as long as you are on narcotic pain medications or any other drug that can affect your ability to drive safely. Remember that when you are under the influence of those medications, you are not only a risk to yourself, but you are also a risk to others. There are very strict laws that prohibit you from driving under these circumstances.

Always wear a seatbelt. It is wrong to assume that the seatbelt may damage your transplant lungs; not wearing a seatbelt can kill you.

Traveling

While it is certainly OK to take short day or weekend trips after your transplant, we generally ask you not to travel outside the region for the first six months after your surgery. Your status of health in this period will be particularly vulnerable, and you will have to come to Charlottesville for multiple clinic appointments. Once you become more stable, you may be able to go on longer trips and travel further away.

Please always notify your coordinator if you plan to leave the region or will be away for longer periods of time.

It will be important to ensure that you have an adequate supply of your medicines. Have spare medication available for a few days to account for any unexpected delays in your travel plans. If you plan to go away for longer, it may be important to develop a back-up plan with your coordinator in case you get sick and need help with transplant-related issues. It is always a good idea to keep a list of your medications and a health summary with you.

Airplane travel

We generally ask people not to fly for the first six months after transplant. Ask your coordinator when and if it is safe for you to travel by plane.

Since the air inside the plane is re-circulated and you will be in a tight space with lots of other passengers, you must wear a mask for the entire duration of the flight. Use hand sanitizer to protect yourself from the spread of germs, especially when you are using the bathroom on board the plane.



Emotional concerns

Following your transplant, you will be busy adjusting to a new lifestyle with frequent trips to see your physician, learning new medications, and participating in physical rehabilitation. Once you are feeling better, you may begin to reflect back upon the significance of the surgery. Some of the stresses that predated your transplant may still be present. In addition, you may have new questions about your new organ and life. Questions like, “Will this new organ change me?” or “Does it matter if the organ came from a man or woman?” These factors can worsen existing stressors making you feel as if you are on an “emotional roller coaster.” If you experience these emotions, don’t panic. These feelings are very common for transplant recipients. Remember that the key to successful adjustment following transplant lies in your ability to recognize these feelings and seek appropriate support.

The use of positive coping strategies is your best defense against the “emotional roller coaster.” Suggestions to help manage stress include:

- Structure your day and try to keep yourself busy. Develop a daily routine. This will prevent you from ruminating too much about the things that may worry you.
- Socialize with family and friends.
- Share your feelings. It helps to alleviate stress when you talk to a family member or someone else who you trust. Do not try to “sweep your problems under the carpet”. This may cause stress to “pile up” and become much more difficult to handle.
- Write your feelings down. Keep a journal or diary. This structures your thoughts and helps you process your feelings.
- Ask for help. People around you often want to help, but feel insecure and don’t know what you may need. Be specific about the type of assistance you need.
- Exercise regularly. This is a great way to alleviate stress, and it also keeps you healthy.
- Maintain a healthy diet and make sure you are getting enough rest and sleep.
- Never try to drown your feelings with alcohol or drugs.
- Remind yourself that it is OK to feel frustrated sometimes.

Seek feedback from others who have been in the same situation. The monthly transplant support group meeting is a great way to make contacts and get emotional support.

Share your feelings with your coordinator and your transplant physician. If your emotions become overwhelming and it is too much for you to handle, it may be necessary to refer you to a psychologist or a psychiatrist, or to start you on treatment for depression or anxiety.

Remember that emotional changes are not only common in the transplant recipient, but in family members as well. Recognize when your family member is overwhelmed or is experiencing undue stress. Offer your support by acknowledging their stress, actively listening to their concerns and offering assistance. Frequently “check back” with your family member to see how they are doing.

Most importantly, do not “sweep your problems under the rug.” Avoiding difficult issues only leads to an eventual build-up of stress.

Sexuality after transplantation

Intimacy and sexuality are basic human needs that sometimes become compromised after transplant. Relationships can become altered because of fear, lowered sexual desire, impotency related to new medications, and lower self-body image. Some patients actually experience several of these problems after transplant.

Some couples feel that they need to protect the newly transplanted organ, and are fearful that sexual activity will be too stressful. This is not so. Kissing, intimacy and sexual activity are safe. However, be careful to avoid strain across your incision for at least six weeks after surgery and make sure your partner doesn't have any open sores on their mouth or genitals. It is strongly recommended that you use condoms. Because of the medications that you will be taking after transplantation, you are at a higher risk for sexually transmitted diseases. These diseases behave aggressively in transplant recipients due to their low immunity.

People's reactions to drugs vary a lot from person to person. Your transplant team can tell you specifically which drugs may be affecting your drive and your natural ability to lubricate. For instance, blood-pressure medications can cause depressed sexual desire, impotence, as well as vaginal dryness. Antibiotics can cause decreased sperm density, and antifungals can cause impotence and reduce interest in sex. Steroids can also decrease sexual desire. Sometimes, antidepressants cause an increased sexual desire just because depression has been alleviated.

Sharing feelings and concerns about changes that have occurred to your body can help you and your partner work through any alteration in body-image and help you regain your previous level of intimacy. Patience is important in overcoming this difficulty.

Finally, adequate birth control must be ensured before engaging in sexual activity. Condoms are very safe and effective, and they offer protection against sexually transmitted diseases. Many female patients take birth control pills after transplant. Check with your doctor or transplant coordinator if there are any concerns in regards to interactions between birth control pills and your other medications.



Reaching out to the donor's family

You have received the gift of life. While it is natural to want to reach out to your donor's family and express your gratitude, contacting a family that has been through a tremendous loss can be very difficult. If you're having trouble finding the right words to express how you feel, consider the following suggestions provided by the Second Wind Lung Transplant Association:

- Include a few words on how the transplant has changed your life. What can you do now that you couldn't do before?
- Describe your transplant experience. Include a brief description of your illness. What the wait was like for you and your family?
- Talk about yourself (first name only) and your family. What are your hobbies or occupation?
- Describe special events that you would not have experienced without a transplant such as marriage, an anniversary or graduation.
- Remember to be sensitive to the donor family's loss and extend your sympathy along with your thanks. Since you don't know their religious beliefs, it is best to keep any religious comments to a minimum.
- Keep your letter anonymous. Sign your first name if you wish, but don't include any identifying information such as your address or phone number.
- Send the letter or card in an unsealed envelope to your transplant coordinator. Be sure to include a separate piece of paper with your full name and date of transplant so that we can ensure it is delivered to the correct family.

The transplant coordinator will pass your letter on to the organ procurement organization (Lifenet). They will notify the donor family about the letter. While some families may not be ready to receive the letter, most welcome it and find that it provides comfort for them knowing how they have helped save a life. If the family isn't ready, the letter will be held for them.

Any response from the donor family will be treated in the same method, and you will be given the choice of receiving any response. Confidentiality is always maintained for both parties. In some circumstances if both recipients and donor families are agreeable, they may meet a year following transplant.

A link to submit a letter to the donor family can also be found on the Lifenet Website: lifenethealth.org.

Health maintenance

Staying in good health is important after lung transplant. This includes regular check-ups to screen you for cancer and making sure you stay current on all your recommended vaccinations.

Cancer screening

Both women and men:

For prevention or early detection of skin cancer:

- Avoid too much exposure to the sun.
- When you work outside, or spend time in the sun, make sure you cover up exposed skin.
- Wear clothing that covers head, arms, neck and legs.
- Use an SPF lotion or cream of at least 15.
- Do not use tanning beds or sunlamps.
- Report any birthmarks, moles, or other spots on your skin that change in appearance or size to your healthcare provider
- Since some of your transplant medications increase the risk of skin cancer, we recommend a complete skin exam by a dermatologist once a year, especially if you have a history of skin cancer or precancerous skin lesions.

For prevention or early detection of colorectal cancer:

- Eat food which is low in fat and high in fiber
- Report any bleeding from the rectum, any blood found in your stool, any persistent change in your bowel movements, or any cramping in your abdomen to your healthcare provider

If you are age 50 or older, have one of the following:

- Colonoscopy every 10 years
- Sigmoidoscopy every 5 years
- CT colonoscopy ("virtual colonoscopy") every 5 years
- Double contrast barium enema every 5 years
- Stool screenings for occult blood every year

You may have to start screening for colorectal cancer earlier and may need screening exams more frequently if you are considered to be at high risk.

Women:

For prevention or early detection of breast cancer:
(Age 20-39)

- Do a self- breast exam every month.
- Have a clinical breast exam by a health care professional every three years

You may have baseline mammogram at age 35-36.

(Age 40 and over)

- Do a self- breast exam every month.
- Have a clinical breast exam by a healthcare professional every year.
- Have a mammogram every year.

For prevention or early detection of cervical cancer:

The American Cancer Society changed their guidelines for cervical cancer screening in 2012. We recommend more frequent screening based on the increased risk of cancer in patients with a weakened immune system:

- Age 21 to 30: Have a Pap smear every year
- Over 30: Have a Pap smear every year or Pap smears plus HPV DNA test every 3 years.

- Over 30: After 3 normal Pap smears in a row, you may space out screening to every 2 to 3 years.
- If you had your uterus and cervix removed for reasons not related to cancer, you do not need to get screened for cervical cancer.

For prevention or early detection of endometrial cancer:

- Report any abnormal spotting or vaginal bleeding. Women who are in high-risk categories should have a tissue sample or biopsy taken from the endometrium at menopause.

Men:

For prevention or early detection of prostate cancer:

- Report to your healthcare provider if you have painful or burning urination, if you have blood in your urine or if you are unable to urinate or have difficulty starting urination
- Over 50, have a digital prostate examination and prostate-specific antigen blood test every year.
- Men at high risk (family history, African-American) should begin testing at age 45.

For more information, call the American Cancer Society toll free at **1.800.ACS.2345** or visit the internet at **cancer.org**



Vaccinations

General remarks

Taking drugs that suppress your immune system after transplant will increase your risk of acquiring infections like the flu or pneumonia. Infections also tend to be more severe in transplant patients and in patients with chronic lung disease prior to transplant.

Vaccinations can protect you against certain types of infections, but the level of protection is not 100 percent.

Vaccinations with “live vaccines” (vaccines that contain a weak strain of a live virus) are not allowed after transplant since they may cause infections in patients with a suppressed immune system.

If you are not sure whether it is safe for you to have a certain type of vaccination, ask your transplant doctor or your coordinator.

- Generally, no vaccinations should be given within the first three months after transplant: The high dose of immunosuppression in this period usually causes vaccinations to be ineffective.
- The level of protection from a vaccine is generally lower in patients after transplant.
- Household members should be vaccinated to prevent disease transmission to the transplant patient.

List of vaccinations

Flu vaccine

- Safe for patients pre and post transplant
- Should be given every year in the fall (October, November)
- Each member of your entire household should receive a flu vaccine every year
- If you are allergic to eggs, you should not receive the flu vaccine

Pneumococcal vaccine (Pneumovax)

- Vaccine status should be up-to-date prior to transplant
- Safe for patients pre and post transplant
- Repeat once after 5 years

Tetanus

- Should be updated prior to transplant
- Combination vaccine - also contains vaccine against diphtheria
- Needs to be renewed every 10 years
- OK to give post transplant, but level of protection may be lower
- Available at your primary care physician’s office. We do not stock the tetanus vaccine in our clinic.

Hepatitis B

- Should be given prior to transplant
- Patients who have no immunity against hepatitis B (no prior exposure, never vaccinated) will need a series of 3 vaccines, which will be given over a period of 6 months
- If you did not complete your series prior to transplant, you will need to complete it after your surgery
- Patients with prior vaccination will have their antibody-levels checked to ensure that protection is still adequate (re-vaccination may be necessary)
- Some patients may need more than one vaccine series to achieve adequate protection. We will determine this based on antibody levels
- We cannot give the hepatitis vaccine to you in our clinic. Please ask your primary care physician to take care of this for you.

Varizella vaccine (Chickenpox)

- We will check your immunity to chickenpox prior to transplant
- If you have no immunity to chickenpox, you need to get vaccinated before your transplant
- **The varizella vaccine is a live vaccine. It is not safe for patients after transplant**

Zoster vaccine (Shingles)

- Recommended for patients aged 60 or older, regardless of prior history of shingles
- Needs to be given prior to transplant
- **The Zoster vaccine is a live vaccine. It is not safe for patients after transplant**

Labs

Your post-transplant care will involve regular blood work. In the first several months after surgery, we will have to obtain blood tests every week. Once your body stabilizes more, we can decrease the frequency of your lab work to twice monthly and eventually once a month.

A very important lab test will be your Tacrolimus (or Prograf) level. We use the level to ensure that you have an adequate amount of medication in your blood stream to prevent rejection. High levels can lead to over-immunosuppression and possible infection, and low levels may lead to rejection.

For the Tacrolimus level to be reliable, the blood has to be drawn **BEFORE** you take your Prograf.

If you forgot and take your medicine, you should call the transplant office and arrange another date for checking your level.

In addition to the Prograf level, lab tests also monitor blood count, clotting, kidney function, liver function, and electrolytes.

Tests for blood count:

- **WBC** (white blood count) tells if your white blood cells have increased (a sign of infection), or decreased (a side effect of some of the medications that would cause a lower defense against infection).
- **Hemoglobin** measures the oxygen-carrying pigment in your blood. When your hemoglobin level is low, you have anemia.
- **HCT** measures the hematocrit, which is the percentage of red blood cells in your blood. Red blood cells carry oxygen to all parts of the body. When your HCT is low, you may feel tired or have little energy.
- **PLT** measures the level of platelets. Platelet cells form a blood clot when your body is injured. Low platelet levels may cause you to bruise easily and to bleed for a longer time when injured.

Tests for kidney function:

- **Creatinine and BUN** tell how well your kidneys work by measuring levels of creatinine and blood urea nitrogen (BUN), waste products normally removed from the blood by the kidneys.

Tests for liver function:

- **Bili** measures the level of bilirubin, a normal byproduct when hemoglobin from red blood cells breaks down. The liver removes bilirubin from the blood and excretes it into the bile. When the liver is not functioning normally, bilirubin levels can increase, often resulting in jaundiced (yellow) skin and eyes.
- **Alk phos** measures alkaline phosphatase, which is made in the bones, liver, pancreas, and intestines and removed from the blood by the liver.
- **AST, ALT** test enzymes that are made in the liver. These tests tell how well your liver is working.



Tests for Electrolytes (dissolved minerals):

- **Ca** measures calcium, which is necessary for strong bones and teeth, blood clotting, and heart and nerve function.
- **PO₄** measures phosphate, which works closely with calcium to strengthen bones.
- **Mg** measures magnesium, which is necessary for normal functioning of muscles and blood clotting.
- **K** measures potassium, which is needed for normal heart and muscle function.
- **Na** measures sodium, which helps maintain the balance of salt and water in the body.

Nutritional goals at home after your lung transplant

At the end of your hospitalization, the transplant Dietitian will educate you on your individual post-transplant nutritional needs and dietary changes that will need to be made.

In addition to a verbal education session with the transplant dietitian, you will also be provided with a packet of information called “Nutrition and Diet after Transplant.” The dietitian will also be available to meet with you during your outpatient appointments as needed after hospital discharge.

It is particularly important that you are aware of two nutrition-related issues.

- **Food-medication interactions:** You will be asked not to eat or drink grapefruit, pomegranates, or star fruit after receiving your transplant. These items (the fruit or juice) can interfere with your transplant medications, which can be dangerous.
- **Food safety:** When certain disease-causing bacteria or pathogens contaminate foods, they can cause foodborne illness which can cause

nausea, vomiting, diarrhea, abdominal pain, and even death. After organ transplantation, you are at higher risk for getting a foodborne illness because you will be on medications that suppress your immune system. It is very important for you to know about and start practicing safe food-handling behaviors.

The foods that are most likely to contain pathogens are uncooked fresh fruits and vegetables, and animal products such as unpasteurized milk, soft cheeses, raw eggs, raw meat, raw poultry, raw fish, raw seafood and their juices. The risk these foods may pose depends on its origin or source and how it is processed, stored and prepared.

This chart can help you make smart choices by selecting foods at lower risk for causing foodborne illness.

Type of Food	Higher Risk	Lower Risk
Meat and poultry	<ul style="list-style-type: none"> Raw or undercooked meat or poultry 	<ul style="list-style-type: none"> Meat or poultry cooked to a safe minimum internal temperature Tip: Use a food thermometer to check the internal temperature
Seafood	<ul style="list-style-type: none"> Any raw or undercooked fish, such as sushi or ceviche seafood Refrigerated smoked fish Precooked seafood (i.e. shrimp and crab) 	<ul style="list-style-type: none"> Smoked fish and precooked heated to 165° F Canned fish and seafood Fish and seafood cooked to 145 °F that is firm and flaky
Milk	<ul style="list-style-type: none"> Unpasteurized milk 	<ul style="list-style-type: none"> Pasteurized milk
Eggs	<ul style="list-style-type: none"> Foods that contain raw/undercooked eggs, such as: Caesar salad dressings, homemade raw cookie dough, homemade eggnog Soft-boiled or “over-easy” eggs, (the yolks are not fully cooked.) 	<ul style="list-style-type: none"> At home: Fully cook eggs until firm. Use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs Tip: Most pre-made foods from grocery stores, such as Caesar dressing, pre-made cookie dough, or packaged eggnog are made with pasteurized eggs.
Sprouts	<ul style="list-style-type: none"> Raw sprouts (alfalfa, bean, other sprouts) 	<ul style="list-style-type: none"> Cooked sprouts
Vegetables	<ul style="list-style-type: none"> Unwashed fresh vegetables, including lettuce/salads 	<ul style="list-style-type: none"> Washed fresh vegetables, including salads
Cheese	<ul style="list-style-type: none"> Soft cheeses made from unpasteurized milk, such as: Feta, Brie, Camembert, Blue-veined cheese, Queso fresco 	<ul style="list-style-type: none"> Hard cheeses, Processed cheeses Cream cheese Mozzarella Soft cheeses that are clearly labeled “made from pasteurized milk”
Hot dogs, deli meats, Pâtés	<ul style="list-style-type: none"> Luncheon meats that have not been reheated Unpasteurized, refrigerated pâtés or meat spreads 	<ul style="list-style-type: none"> Hot dogs, luncheon meats, and deli meats reheated to steaming hot or 165° F Canned pâtés or meat spreads



In addition to selecting lower risk foods, how you prepare them can also further decrease your risk for foodborne illness.

Have clean hands and surfaces. Bacteria can spread throughout the kitchen and get onto cutting boards, utensils, counter tops, and food. Wash and sanitize your hands, cutting boards, and cooking utensils well.

This includes thoroughly rinsing all fruits and vegetables prior to eating with clean water.

Don't cross-contaminate. Cross-contamination occurs when bacteria are spread from one food product to another. This is especially common when handling raw meat, poultry, seafood, and eggs. The key is to keep these foods — and their juices — away from ready-to-eat foods.

Cook food to proper temperatures. Foods are safely cooked when they are heated to safe minimum internal temperatures. To ensure that your foods are cooked safely check the temperature using a food thermometer:

Minimum Cooking Temperature	Food
145 °F	Steaks & roasts, fish, seafood
160 °F	Ground beef, pork, egg dishes
165 °F	Ground poultry, chicken breasts, whole poultry

When cooking in a microwave oven, cover food, stir, and rotate for even cooking.

Refrigerate food promptly. Cold temperatures slow the growth of harmful bacteria. Keeping a constant refrigerator temperature of 40°F *or below* is one of the most effective ways to reduce risk of foodborne illness.

Never thaw food at room temperature, such as on the counter top. It is safe to thaw food in the refrigerator, in cold water, or in the microwave. If you thaw food in cold water or in the microwave, you should cook it immediately.

Divide large amounts of leftovers into shallow containers for quicker cooling in the refrigerator.

Discharge medications

Background

Following transplantation, you will be very busy learning how to best care for yourself. This can be a very overwhelming time. We want to help minimize some of the worries by helping you prepare in advance.

After you receive a transplant, you will have to take new medications, called immunosuppressive drugs, to keep your body from rejecting your lung(s). These drugs are not regularly stocked in most pharmacies.. Having a good understanding of how to get the drugs and pay for them prior to transplant will eliminate the need to worry about it while you are recovering from surgery.

There are several ways you can get your medications after you leave the hospital. You can continue to use your pharmacy at home, you can use the pharmacy at the University of Virginia, or you can use one of several transplant mail order pharmacies that send medications to your home.

Please feel free to talk to your transplant coordinator and social worker to determine which program may be best for you. Transplant medications are expensive; a month's supply can cost between \$1,500 - \$1,800.

If you have any questions about your insurance coverage for these medications, please call the Transplant Office and ask to speak with a financial advisor.

Medications to take home

The medications your doctors prescribe to control rejection must never be forgotten or missed for any reason. When you leave the hospital, it is important that you have a supply of drugs to use the evening you arrive home. You should choose a pharmacy before leaving the hospital. Prior to discharge from the hospital, the transplant team will give you prescriptions to be filled at the pharmacy of your choice.

Each insurance plan differs in the amount of money a patient must pay to fill their prescriptions. We recommend you contact your insurance company to determine your specific prescription coverage. For patients with Medicare Part A and B prior to transplant, Medicare will pay 80 percent of the cost of the immunosuppressant medications. The patient must pay the remaining 20 percent. Medicare does not pay for other prescription medications.

Our financial coordinator will be able to answer questions regarding your individual prescription drug coverage and develop a financial plan to cover co-payments if necessary.

Options for prescriptions

You may have several options where to get your medications. Some insurance companies require you to get them from certain pharmacies, which will limit your choices. A summary of useful facts is listed below.

Local pharmacies

Advantages:

Pharmacies that are located in your community can be convenient for filling prescriptions and the pharmacists may already have a list of the medications you have been taking.

Your pharmacist should know your personal history and will be available to answer questions. Your local pharmacy will know your insurance program if you have received drugs from them before.

Disadvantages:

The drugs you will be prescribed may not be stocked at a community pharmacy. The immunosuppressive drugs you will take are expensive and local pharmacies usually carry them only after a patient brings in a prescription.

This may cause a delay in getting your medications unless you and the transplant team communicate with the pharmacy in advance.



You may find the prescriptions filled by a local pharmacy more expensive because your pharmacist will not order a large enough supply to receive a significant discount.

Many community pharmacies are not familiar with Medicare reimbursement procedures and may require that you complete the necessary paperwork for Medicare payment yourself.

UVA Outpatient Pharmacy

The UVA Barringer Outpatient Pharmacy is located on the first floor of the University Hospital West Complex on 1300 Jefferson Park Avenue.

Phone: **434.243.3886**

Fax: **434.982.4197**

Advantages:

- UVA Pharmacy offers bedside delivery of transplant medications through our specialty medication services group. Additionally this service will follow up with the patient for subsequent refills and or questions regarding medication therapy.
- UVA Pharmacy stocks most of the drugs transplant patients must take.
- The average cost of medication may be less than at other pharmacies.
- The University can work with patients who do not have adequate insurance and can help work out arrangements for payment.
- UVA offers mail order services with no shipping charge. We can get your credit card payment over the phone
- Patients can also call ahead and leave a message for refills and then come to pick them up at Barringer pharmacy. The University pharmacy will also complete the necessary paperwork for Medicare payment for you.

Disadvantage:

- Pharmacy hours are limited to Monday through Friday from 8:30 a.m. to 5:00 p.m. The pharmacy is closed on weekends and holidays.

Mail Order Pharmacies

Several mail order pharmacies have been established to supply transplant patients with their specialty medications. Brochures for specific pharmacies are available for you to review if you decide this choice is best for you. We suggest you call these pharmacies through their “800” numbers to determine if they meet your needs.

Advantages:

Mail order pharmacies specialize in filling prescriptions inexpensively and shipping them to you very quickly.

Many pharmacists have specific knowledge of your medications and can be asked questions at any time.

Mail order pharmacies pay close attention to your prescriptions and will contact you about refills if you have not already called in your request.

Mail order pharmacies work closely with insurance plans and will help you file for reimbursements.

Many companies offer blood pressure cuffs or medicine boxes as incentives to use their services.

Disadvantages:

Prescriptions are usually filled and received at your home within 48 hours. Prescriptions must be called in several days before your discharge from the hospital to ensure a continuous supply of medications.

If you run out of important drugs, an emergency shipment is possible, but a delay will occur.

Most mail order pharmacies offer support to patients who cannot afford drugs, but this type of generosity is limited.

Some available transplant mail order pharmacies:

- Amber Pharmacy | **888.370.1724**
- Walgreen's Specialty Pharmacy | **800.888.5753**
- Express Scripts/ Medco | **877.429.8414**

Taking your medications

You are responsible for taking the medications that have been prescribed for you. At home, you'll continue taking most of the medicines you began in the hospital after your transplant surgery, especially the anti-rejection medications. Anti-rejection medications such as Prograf®, Cellcept®, and Prednisone® are lifetime medications. They help prevent your body's immune system from attacking your transplanted lung.

The other medications that have been prescribed for you also play an important role in maintaining the health of your transplanted lung.

Three keys to success:

1. Do not stop taking your medications without first contacting your transplant coordinator.
2. Do not start any new medications without first contacting your transplant coordinator (including medications prescribed by another doctor).
3. Do not take any OTC medications or herbal supplements without first contacting your transplant coordinator.

The following are additional important reminders about your medications::

- Take your medication every day at the scheduled time.
- Take only the exact dose that has been prescribed for you, and follow a written schedule.
- Do not run out of medications.
- Notify the Lung Transplant Coordinator as soon as you notice your supply is running low.
- Do not cut or crush a tablet unless you are advised to.

- Changes are made in your medications only through the Heart/Lung Transplant Coordinator or transplant physician. If your doctor at home (or consulting doctor) wants to change one of these medications or add a medication, please have him/her call us first.
- Store all medications in a cool, dry place away from heat, direct light, and moisture. Don't store your medications in a bathroom cabinet where they will be exposed to moisture. Moisture can make medicines lose their strength.
- Do not allow liquid medications to freeze.
- Do not store medications in the refrigerator unless your pharmacist advises you to do so.
- Report all side effects to the Transplant Coordinator.
- If you miss or vomit a dose - notify the Transplant Coordinator - do not double the dose.
- Keep medications out of reach of children.
- Do not store your medications in a hot car.

Notify your transplant coordinator if you...

- Have nausea, vomiting, or diarrhea that lasts more than one day or prevents you from taking your medication
- Think the directions on the label are different from what you were told
- Have trouble removing child-resistant caps
- Need to take over-the-counter pain relievers other than Tylenol
- Need to take "cold pills"
- Feel you are having a reaction to your medication.
- Have a change in health or eating habits
- Have a new prescription from your local doctor or a change in a current prescription
- Have any unusual symptoms, as they may be related to the medications you are taking



Selected transplant medications

Generics

When a pharmaceutical company develops a new drug, they will patent it to ensure that a competitor can't copy the drug and sell it at a lower price. After a certain time period, the patent will expire, allowing other companies to use the same ingredients and bring their version to the market. These drugs are called "generics" and they are usually, but not always, sold using the name of the main ingredient of the drug. The developer usually keeps the right to sell the drug under the "brand name."

Even though generic drugs and brand name drugs usually have different names, the ingredients and dosage forms will be very similar if not identical.

Prescription drug plans will encourage you to use generic drugs whenever possible, since they are usually a lot cheaper than the brand name counterpart.

In most cases, there will be no difference between taking the generic versus the brand name version of one particular drug.

If you are switched over from a brand name drug to a generic, the pill may look different depending on the manufacturer.

If you have any questions or concerns about generic drugs, talk to your pharmacist, coordinator or your transplant physician.

Comment: *The following images and descriptions of drugs are only examples. The exact shape and color of the drug will depend on the manufacturer.*

Tacrolimus (Prograf®)

Other name: FK-506



Tacrolimus 0.5 mg (yellow capsule)

Tacrolimus 1 mg (white capsule)

Tacrolimus 5 mg (pink capsule)

Generics available: **yes**

Purpose:

Tacrolimus is used to prevent rejection of your transplanted organ.

How to take it:

- Take tacrolimus by mouth two times per day, 12 hours apart. It is important to take your pills at the same time each day.
- Tacrolimus can be taken with or without food, but it is important to take the medication in the same way every day. This means if you take the medication with a certain food or by itself, then you should continue to do this. This helps with absorption of the medication.
- Do not take tacrolimus with cranberries, cranberry juice, grapefruit, grapefruit juice, pomegranate, or pomegranate juice, as this can increase the level of the medication in your blood.
- In the first few months after your transplant, you will have your blood levels checked frequently.
- On the morning of your blood draws, do not eat any food or take your medication until after your blood is drawn.
- Your dose is adjusted according to your laboratory values, tacrolimus blood level, and how long it has been since transplant.

Common Side Effects:

- Kidney injury
- Headache, tremors, or tingling in hands/feet
- Nausea/vomiting
- High blood sugars/diabetes
- High blood pressure
- High cholesterol
- High potassium levels
- Low magnesium levels
- Hair loss
- Vivid dreams

Mycophenolate (Cellcept®, Myfortic®)



Mycophenolate mofetil (Cellcept) 250 mg (pink and light blue capsule)

Mycophenolate mofetil (Cellcept) 500 mg (pink tablet)

Mycophenolic acid, delayed release (Myfortic) 360 mg (light orange, oval shaped tablet)

Other names: Mycophenolate Mofetil, MMF, Mycophenolic Acid

Generics available: **yes**

generic mycophenolate mofetil is available, however there is no generic for Myfortic (not for Myfortic/ Mycophenolic acid)

Purpose:

This medication prevents rejection of your transplanted organ

How to take it:

- The initial dose of mycophenolate mofetil (Cellcept) is usually 1000 mg by mouth two times per day, 12 hours apart, at the same time as your other medications.
- The initial dose of delayed release mycophenolic acid (Myfortic) is 720 mg by mouth two times per day, 12 hours apart, at the same time as your other medications. It is important to take your pills at the same time each day.
- Many patients find convenient to take Mycophenolate together with Tacrolimus.
- Mycophenolate can be taken with or without food, but many patients find it easier to take mycophenolate with food to prevent side effects such as nausea and vomiting.

Common side effects:

- Nausea, vomiting
- Diarrhea
- Low white blood cell count
- Low platelet count
- Elevated cholesterol
- Rash

Azathioprine (Imuran®)



Azathioprine 50 mg (light yellow or off white tablet)

Generics available: **yes**

Purpose:

This medication prevents rejection of your transplanted organ. It is sometimes used in patients who cannot tolerate mycophenolate.

How to take it:

- Azathioprine should be taken by mouth once per day, at the same time as your other medications.
- You may need to cut along the line if your dose requires a 25 mg pill

Common side effects:

- Nausea and vomiting
- Mild loss of hair which usually returns later
- Liver injury
- Low platelet count
- Low white blood cell count



Prednisone or “steroids”



Generics available: **yes**

Purpose:

This medication prevents rejection of your transplanted organ. It works together with the other anti-rejection medications.

How to take it:

- Take prednisone by mouth at the same time every day in the morning.
- Always take prednisone with food or after meals to prevent stomach upset.
- Prednisone is available in several different strengths. Make sure you take the adequate dose as prescribed by your doctor.
- You may have to cut the pill in half in order to achieve the correct dose.
- We will gradually lower the dose of prednisone after your transplant.
- Higher doses may be needed if you have an acute rejection episode.
- Take your Prednisone at the same time every day in the morning.
- Always take Prednisone with food or after meals to prevent stomach upset.

Frequent side effects:

- Swelling and fluid retention Increase in appetite leading to weight gain
- High blood sugars/ diabetes
- High blood pressure
- High potassium levels
- Fat deposits on the face, upper back, and abdomen
- Acne on the face and upper back
- Increase in skin oiliness and breakdown
- Heart burn
- Stomach ulcers
- Bone weakening
- Muscle weakness
- Vision changes including: cataracts/blurred • Mood swings, nervousness
- Excitability
- Insomnia

Sulfamethoxazole/ trimethoprim (Bactrim®)



Bactrim DS (800/160 mg) (white, oval tablet)

Other names: Septra®, Trimethoprim sulfamethoxazole

Generics available: **yes**

Purpose:

This medicine is used to prevent and treat PJP (Pneumocystis jiroveci pneumonia. The risk of PJP is increased for transplant patients because of the anti-rejection drugs that suppress the immune system.

How to take it:

- Take this tablet with plenty of fluids of sulfamethoxazole/ trimethoprim by mouth three times per week, at the same time as your other medications in the morning)
- The usual dose is one double strength tablet three times per week
- Do not take this medicine if you are allergic to sulfa drugs.

We will start alternative drugs if you are allergic to this medication.

Frequent Side effects:

- Nausea and vomiting
- Diarrhea
- Loss of appetite
- Sensitivity to the sun
- Skin rash
- Decreased white and red blood cell count

Clotrimazole Troches (Mycelex®)



Mycelex 10 mg (white, round tablet)

Generics available: **yes**

Purpose:

This medication helps prevent yeast infections in your mouth and throat

How to take:

- Dissolve one lozenge in your mouth four times a day after meals.
- Do not swallow tablet whole.
- Look at your mouth and tongue every day to check for white patches. If you see any, call the transplant coordinator.

Common side effects:

- Nausea, vomiting, diarrhea
- Metallic taste
- Unpleasant mouth sensations

Nystatin swish and swallow

Nystatin suspension 100,000 units per ml

Generics available: **yes**

Purpose:

This medication helps prevent yeast infections (“thrush”) in your mouth and throat

How to take:

- Swish 5 ml or 1 teaspoonful of nystatin suspension around your mouth and swallow after meals and before bedtime (total of four times per day)
- Do not eat or drink anything for 15 to 20 minutes after taking
- Look at your mouth and tongue every day to check for white patches. If you see any, call the transplant coordinator.

Common side effects:

- Nausea, vomiting, stomach pain, diarrhea

Valganciclovir (Valcyte®)



Valganciclovir 450 mg (pink, oval-shaped tablet)

Generics available: **no**

Purpose:

Prevention and treatment of certain viral infections, including CMV (Cytomegalovirus) infections

How to take:

- Take valganciclovir 900 mg (two tablets) by mouth once daily, at the same time as your other medications in the morning.
- Doses will be higher for treatment of an infection as compared to preventing CMV infections
- Dose may be adjusted if you have kidney disease

Common side effects:

- Nausea, vomiting, diarrhea
- Low blood counts
- High blood pressure



Voriconazole (Vfend®)



Voriconazole 200 mg (white, oval-shaped tablet)

Generics available: **no**

Purpose:

Prevention and treatment of fungal infections

How to take:

- The usual dose is 200 mg (one tablet) by mouth twice daily, at the same time as your other medications
- Will usually be given for the first 4 months after transplant
- Voriconazole interacts with tacrolimus (Prograf®) and increases the amount of tacrolimus in your blood
- When you are about to stop the voriconazole, contact your transplant coordinator, so we can adjust your tacrolimus dose
- If you have to go back on voriconazole, we may have to lower your tacrolimus dose

Common side effects:

- Nausea, vomiting, diarrhea
- Blurred vision, increased sensitivity to light, or other visual changes
- Liver injury
- Swelling or fluid retention

Anti-Ulcer and Anti-Heartburn Medicines



Common names:

Famotidine (Pepcid®), Ranitidine (Zantac®), Omeperazole (Prilosec®), Lansoprazole (Prevacid®), Esomeprazole (Nexium®)

Generic available: **yes** (for most)

Pepcid® 40 mg *Diamond-shaped, rose tablet*

Zantac® 150 mg *Diamond-shaped, rose tablet*

Prilosec® 20 mg *(purple capsule)*

Prilosec® 40 mg *(purple and pink capsule)*

Nexium® 40 mg *(purple capsule with yellow stripes)*

Purpose

These medicines lower the amount of acid in the stomach and are used to prevent or treat stomach ulcers and heartburn.

How to take:

Your transplant team will determine the proper medication, dosage and length of time for you to take this medication.

Common side effects:

- Nausea, vomiting, and diarrhea
- Constipation
- Gas

Over-the-counter medications

The following is a list of common problems and recommended over the counter medications that you can take. Please check this list before taking any over the counter medication. Remember the addition of any other medications or change in your current medications must be made through the transplant team.

Constipation

Increase fluids in your diet

Increase fiber in your diet (bran, fresh fruits, and vegetables)

Increase Colace® to 2 capsules three times daily

If constipation remains a problem, be sure to report it to your transplant coordinator.

Diarrhea

Increase fluids to prevent dehydration

Do not take your Colace® until diarrhea goes away

You may take Imodium after checking with the transplant coordinator.

If the diarrhea lasts for more than one to two days, notify the transplant coordinator.

Headache, muscle aches, general aches and pains

You may take Tylenol®, but first check with your transplant coordinator to see if your prescription pain medication has Tylenol in it.

Non-steroidal anti-inflammatory drugs (NSAIDs)

You must not take any medication that contains NSAIDs.

These medications are VERY common ingredients in over-the-counter pain and cold medicines. Many cold medicines contain a combination of different drugs.

NSAIDs can interact with your immunosuppression-drugs, and they can hurt your kidneys.

The following medications contain NSAIDs and must be avoided. This list is NOT complete.

Ibuprofen, Motrin-IB®, Advil®, Nuprin®, Bayer Select Pain Relief®, Haltran®, Menadol®, Wal-Profen®, Midol®, Ketoprofen, Orudis-KT®, Acton®, Naproxen, Aleve®, Aspirin.

Allergies / cold Symptoms

Call the transplant coordinator if symptoms persist or worsen. Medicines that you may take include Actifed®, Sudafed®, and Robitussin®.



Lodging

Occasionally, it may be necessary for you or your family members to spend the night in Charlottesville. Here are some lodging options close to UVA.

UVA Hospitality House

UVA Health System offers Hospitality House and apartments as homes away from home for our patients. Guests who stay at any of our lodging facilities must get a referral from a UVA Social Worker.

You must not stay at the Hospitality House during the first six months after transplant surgery to avoid contracting infections from other people. The Hospitality House does not accept patients who are on isolation precautions for any reason.

The Hospitality House is located on 14th Street, close to “The Corner.” It is a short walk or shuttle bus ride from the hospital and close to restaurants. Amenities include:

- Bedrooms furnished with two twin beds
- Shared bathrooms
- Towels and toiletries
- Kitchen and pantry with donated non-perishable food
- Living rooms with cable TV
- Small library with books and games
- Laundry facilities

Free parking is available in the Lee Street or 11th Street parking garage (no on-site parking available).

Fee: \$10 per night per person

Hospitality House is limited to a maximum of two adults for each patient. Unfortunately, no one under 18 is allowed. Guests must be independent and able to manage all of their own care needs.

Call **1.800.543.8814** and a social worker can assist you with making a reservation

Lodging options close to UVA

Distance from UVA (miles)	Facility Address	Phone	City Bus Access	Breakfast included	Laundry Facility	Restaurant Access	Shuttle Service to/from UVA	Rate per night*
0.1	Red Roof Inn 1309 W Main St	434.295.4333	X			X		\$59-90
0.2	Courtyard Marriott 1201 W Main St	434.977.1700	X		X	X		\$150-200
0.3	Hampton Inn 900 W Main St	434.923.8600	X	X	X	X		\$150-200
0.6	Cavalier Inn 105 Emmett St North	434.296.8111	X	X	X	X	X	\$65-80
1.2	Budget Inn 140 Emmet St North	434.293.5141	X	X	X	X		\$49-55
0.7	Econo Lodge 400 Emmet St North	434.296.2104	X	X		X		\$42-49
0.9	Omni 235 W Main St	434.971.5500	X		X	X		\$157-247
1.3	Residence Inn 1111 Millmont St	434.923.0300	X	X	X	X		\$154-239
1.5	Holiday Inn Monticello 1200 5th St sw	434.977-5100			X	X		\$73-82
1.5	English Inn 2000 Morton Dr	434.971.9900	X	X		X		\$100-160
1.5	Sleep Inn 1185 6th St SW	434.244-9969		X	X	X		\$76-111
2.5	Days Inn 1600 Emmet St	434.293.9111	X		X	X	X	\$50
2.5	Quality Inn 1600 Emmet St	434.971.3746	X	X	X	X		\$65
2.7	Comfort Inn 1803 Emmet St North	434.293.6188	X	X	X	X	X	\$85
3.0	Holiday Inn 1901 Emmet St North	434.977.7700	X		X	X		\$118

***Disclaimer:** The quoted nightly rates were researched in November of 2012 and are estimates only.

Additional information about lodging can be found on the Charlottesville Bureau of Visitors Website: visitcharlottesville.org



UVA Patient Rights & Responsibilities

Rights

Quality care:

- Access to quality medical and psychosocial care regardless of ethnic background, national origin, religion, or age
- Access to transplant physicians, nurses, social workers, and other specialists as needed
- Coordination of effort between your transplant team and your referring and primary care physician

Respect and personal dignity:

- To be treated with respect, dignity, courtesy, compassion, and cultural sensitivity
- To have privacy and confidential handling of all medical records and communication

A voice in decision-making:

- To be consulted for my view of “quality of life”
- To participate as a full partner with my healthcare team and to have my opinions heard and valued in the development of a plan of care
- To have treatment options, possible complications and self-care requirements explained in an understandable manner, with sufficient time to ask questions and have them answered
- To appeal decisions made by a physicians, hospital staff, managed care plan, or other healthcare provider
- To obtain a second opinion and/or accept or refuse medical treatment
- To be able to change physicians

Information:

- To have family members or significant others, people that I designate, be kept informed of my medical condition during hospitalizations
- To know the identity and profession of any individual providing a service to me
- To receive timely communication regarding lab work results, medical tests, and advice of my medical team, and to have access to all medical records
- To receive a complete explanation of the total bill for services rendered

Emotional Support:

- To have feelings respected and, when appropriate, addressed by my healthcare team
- To have a comprehensive psychosocial plan developed and updated by an appropriately trained mental health provider
- To have correspondence forwarded to the family of my donor, provided the donor family has expressed a willingness to receive communication from the recipient

Responsibilities

Maintain long-term health:

- To schedule appointments and tests at appropriate intervals with the transplant team
- To be prompt in attending appointments and when canceling, to give notice as early as possible of the need to reschedule
- To adhere to transplant medical instructions and to inform the transplant team when unable to do so
- To learn the names, dosages, and reasons for taking all prescribed medications and to report all adverse reactions to the transplant team
- To learn and identify signs and symptoms of rejection and infection and know when to report such signs and symptoms.

- To maintain my primary healthcare needs (dental, gynecology, dermatology, etc.) and to know when to report any abnormalities
- To ask questions and obtain clarification to ensure understanding of all communication from the transplant team

Provide information:

- To inform the transplant team if my address, insurance or phone number change
- To inform the transplant team about any changes in my health condition including: desire to take new medication (including herbal, vitamins, alternative, or over-the-counter); any change in my daily activity (such as stopping or starting exercise regimen); or any other situation that may have an impact on my emotional or physical well-being
- To provide information from other treating physicians to the transplant center by giving written permission for records to be sent to the transplant office
- To provide the transplant team with the names and contact information of designated family or significant others who should receive updates on my medical and psychosocial condition
- To request results of my medical and lab tests if these are not provided in a timely fashion
- To provide the UVA Health System with a copy of my advanced directives and/or durable power of attorney for healthcare

Display mutual respect:

- To treat all healthcare professionals with respect and courtesy
- To cooperate and follow UVA Health System rules regarding patient conduct

Meet financial obligations:

- To understand that UVA will NOT pay for my medical care or medications needed after transplant
- To give UVA any information needed for insurance to pay for my transplant
- To apply, if needed, for financial help to pay for the cost of transplant and for medical care after transplant
- To submit any financial verification information required by assistance agencies (State or private)
- To understand if insurance and/or Medicare does not pay for the cost of my transplant or for the drugs after transplant that the I am responsible for paying for all of these costs
- To understand that changing my health insurance may mean that a new insurance will not cover pre-existing conditions such as transplant medications, etc.
- To understand the limits of Medicare and/or other insurance (including deductibles and co-payments)
- To notify the transplant office of any insurance changes before or after transplant
- To accept responsibility for the cost of transplant surgery if insurance denies coverage due to my failure to notify UVA of insurance changes



Resources

Here are some links to websites with further information on transplant-related topics:

American College of Chest Physicians

This professional organization of chest physicians offers educational materials for patients about different lung diseases.

chestnet.org/accp/patient-guides

Diabetes Resource

The University of Virginia Health System provides Certified Diabetes Educators and a Diabetes Management Program. Our program is certified by the American Diabetes Association.

Our program provides:

- One-on-one and group sessions
- Training and support for insulin pump use
- Foot care tips
- Workshops and classes
- Support for women with gestational diabetes

For more information please contact the Diabetes Education and Management Program at **434.924.DOCS** or **800.251.3627**.

LifeNet

LifeNet is the Organ Procurement Organization (OPO) that manages our region. Their website contains information on organ donation and provides links to submit a thank-you letter to donor families.

lifenethealth.org

Nutrition

- A brochure with information on weight loss can be found at win.niddk.nih.gov/publications/PDFs/Myths.pdf
- Tips for healthy nutrition from the United States Department of Agriculture can be found at choosemyplate.gov/

Scientific Registry of Transplant Recipients (SRTR)

The SRTR supports the ongoing evaluation of the status of solid organ transplantation in the United States. Transplant centers are required to report their outcome data, and the SRTR publishes reports that allow comparing outcomes from different transplant centers.

srtr.org

Second Wind Lung Transplant Association

This international organization is mainly run by lung transplant survivors. Educational resources about lung transplantation and links to network with lung transplant recipients can be found at 2ndwind.org

United Network for Organ Sharing (UNOS)

UNOS is a non-profit organization that manages the Organ Procurement and Transplantation Network in the United States. The website has education resources for patients regarding organ donation, organ allocation, and life after transplant.

unos.org

For more information about Charlottesville, the Charlottesville Bureau of Visitors offers information on area attractions and lodging at visitcharlottesville.org

Lung Transplant Program | Charles O. Strickler Transplant Center

UVA Health System | PO Box 800413

Charlottesville, VA 22908

844.296.8070 | Fax: 434.243.9540

Emergency Phone Number: **434.924.0000**

(ask operator to page the Heart/Lung Transplant Coordinator on call)

