Now that you have had (or will have) your lung transplant, you need to have a good understanding of the care you will require, including your follow-up visits, medications, lab values, and other lifestyle issues.

The following pages will help you and your family to learn how to care for your new lung and your general health after transplantation.
Candidates for lung or heart-lung transplantation are severely impaired in their daily activities. They are without the possibility of alternative medical or surgical therapy and, left untreated, have a poor outlook for long-term survival. Unfortunately, not all of these individuals will benefit from transplantation. Those who have severe systemic diseases or active infections and those who cannot comply with regular follow-up care after transplant should not undertake the operation.
Evaluation for Lung Transplant Surgery

As soon as your own pulmonologist decides that lung transplantation is a possible treatment option for you, he or she will contact the NewYork-Presbyterian Center for Lung Disease and Transplantation at Columbia University Medical Center. The first goal of the program is to determine whether lung transplantation is the best and only option for each patient. The latest alternative treatment strategies can sometimes enable patients to defer or, if possible avoid transplantation. Once it has been confirmed that you have received optimal treatment with no significant success, then the next step is to evaluate whether you are a suitable candidate for lung transplantation.

Not everyone with end-stage pulmonary disease can be considered for lung transplantation surgery. First of all, you must

- be between ages 16 and 65
- not have acute and/or critical illness
- not have significant other organ dysfunction, such as severe heart, kidney or liver disease
- be cancer-free for at least two years
- have abstained from cigarette smoking and alcohol and drug addiction for at least six months
- have a track record of compliance with follow-up visits and medications
- have no significant and active psychiatric problems
- have a current body weight that is more than 70% or less than 150% of ideal body weight
- be able to pass a standard six-minute walk test and participate in pulmonary rehabilitation program
- be HIV and hepatitis negative
- not be infected with certain difficult-to-treat microorganisms

Initial Screening

Your physician will send all your medical records and a letter outlining your case to the program's Medical Director, a pulmonologist. He and a transplant coordinator will review your records. Your physician should send this information to:
The transplant team will contact you and your referring physician by telephone or letter following the chart review. If it has been determined that you could be a possible candidate for lung transplantation, an appointment will be scheduled for your initial evaluation within the following four weeks.

Initial Consultation

For your pre-transplant evaluation – as well as all your pre-transplant and post-transplant care – you will go to the new state-of-the-art Beverly & Arthur Shorin Comprehensive Transplant Outpatient Center at Columbia University Medical Center.

The initial consultation will last several hours. During that time, you will meet with six members of the lung transplantation team: the pulmonologist, surgeon, coordinator, social worker, psychiatrist and financial counselor. The purpose of this consultation is twofold: 1) to determine if you are a suitable candidate for transplantation and 2) to educate you and your family about all aspects of lung transplantation.

You can expect the following during this consultation:

- You will be examined by the transplant pulmonologist, surgeon and physician's assistant who will also take a detailed medical history and review your medical records as well as recent chest x-ray films and other relevant test results, such as CT scans.
- The social worker and psychiatrist will each conduct a basic psycho-social evaluation. At that time, the social worker will look into the extent of your social support system – those people who can assist in your care at home following your surgery.
- The financial counselor will evaluate your medical insurance and determine if the plan provides coverage for your lung transplantation. Often, in collaboration with your social worker, the counselor will work closely with you to ensure that all possible expenses, including cost of your many medications, will be covered, perhaps through new or additional insurance — or sometimes alternative sources.
- You and your family will learn about the evaluation process, organ allocation, the potential risks and benefits of lung transplantation, the surgery itself, the post-operative recovery period and the inevitable lifestyle changes, and the mandatory medications you'll be taking for the rest of your life. You will have the opportunity to discuss any concerns you may have.
A letter summarizing the results of this initial evaluation will be sent to your referring physician.

**Outpatient Testing**

If the initial evaluation indicates that you may potentially benefit from lung transplantation, then you will be required to undergo a battery of tests. These tests will be performed over two to three days at Columbia University Medical Center within four to six weeks following the initial consultation. The tests will include:

- Chest x-ray and, in selected patients, CT scan
- Quantitative ventilation-perfusion lung scan
- Echocardiogram and electrocardiogram
- Complete pulmonary function tests and arterial blood gas
- Six-minute walk test and cardiopulmonary exercise study
- Right heart catheterization; in patients above age 45 and with risk factors for coronary artery disease — left heart catheterization for coronary angiography
- Cardiac stress test in selected patients
- DEXA (dual energy x-ray absorptiometry) to measure bone density
- Blood and urine testing
- Testing for blood and tissue type
- Antibody testing to measure the immune system’s level of activity
- Barium upper gastrointestinal series in selected patients
- PPD and anergy testing for tuberculosis
- Dental evaluation

And, as part of general health maintenance:

- **Women**: Gynecologic evaluation with PAP smear (if have not had this test within a year)
- **Women over 40**: Mammography (if have not had this test within a year)
- **Men over 40**: PSA (prostate specific antigen)
- **Patients at average risk for colorectal cancer over 50**: Three-sample fecal occult-blood testing and sigmoidoscopy if have not had these in past five years – or a colonoscopy if have not had this test in ten years
- **Patients with risk factors for colon cancer**: A colonoscopy if they have not had one at an interval recommended by a physician
Patients with bronchiectasis: Sputum culture

If necessary, you will be referred to other medical services such as gastroenterology and cardiology for further evaluation.

Post-Evaluation Decision

Once all your tests and medical consultations have been completed, the multidisciplinary lung transplantation team will review all your data at its weekly meeting and determine whether transplantation is the right treatment for you. If the team decides that you are a suitable candidate:

- You will be immediately registered with the United Network for Organ Sharing (UNOS), a not-for-profit organization contracted by the federal government to operate a patient waiting list and organ matching system. It assures equal access for every patient needing an organ for transplantation.
- The transplant physician and coordinator will meet with you and members of your family to discuss the decision. (You will also have this meeting even if you are not selected as a transplant candidate.)
- A letter detailing the team's decision as well as a summary of the testing will be sent to your referring physician.
- You will receive a letter documenting the date of the UNOS listing and the requirements for remaining on the list.
Waiting for a Transplant

In the New York region, most patients wait from 10-14 months for their replacement organ(s) to become available, depending on their blood type. During your wait, it is critical for you to maintain good nutrition and keep up rehabilitation efforts, under the care of your local physician.

Most transplant recipients will tell you that this waiting time was the most difficult part of their entire transplant experience. The transplant coordinator and social worker serve as your advocates during the wait, recommending and facilitating the support services you may require.

Staying Close to the Hospital

The Lung Transplant Program does not require that you relocate to the Manhattan area when you become a candidate; however, you must be able to reach the campus in northern Manhattan within six hours of receiving notice that your new organ is available. Your transplant coordinator will have helped you plan your transportation well in advance of this call.

Staying in Touch

Once you have been registered with UNOS, it is vital that you stay in touch with the lung transplant team. Your transplant coordinator must be notified of any changes in address and phone numbers, including cell phones and beepers. If you travel for any reason, whether business or pleasure, let the transplant team know. Be sure to contact them if you have any serious illnesses or hospitalizations during the waiting period.

Pagers: You will be asked to carry a pager during the waiting period. Be sure that your transplant coordinator has the pager number and that it is functioning correctly. Check the batteries regularly. It is important that you return your pager after receiving your lung, so that others might benefit from this service.

Transportation: When an organ becomes available, a transplant coordinator will contact you immediately and request that you go to the Admitting Office or directly to the operating suite. It is important that you plan ahead and are prepared to travel to the hospital on very short notice. Your social worker can help you plan these arrangements well in advance.

Preparing for Your Operation
Maintaining or even improving your health during this waiting period is vitally important. Some guidelines include:

- Exercise as directed by your physician. Keeping active, if possible, will improve your flexibility and endurance and may shorten recuperation time following your surgery.
- Consult your primary physician and the transplant team for periodic check-ups.
- Counseling is available to help you cope with what is often a stressful and emotional time for patients and their families.
- Follow the diet guidelines and rehabilitation schedule recommended by your physician. This will help you fight fatigue and other health problems that may be associated with lung disease.

Monitoring Your Health While Waiting for Transplantation

Once you are placed on the UNOS waiting list, a nurse practitioner and transplant pulmonary specialist will oversee your care — explaining all stages of the process, expediting tests and consultations, and being available to answer questions you or your family members may have. Also during this period, you will continue to be under the care of your referring physician for your primary pulmonary care. Communication between your physician and the transplant team will be ongoing.

Until the time of your transplant surgery, you will visit the Beverly & Arthur Shorin Comprehensive Outpatient Transplant Center at least every three to four months. During these visits, your basic health will be evaluated — with emphasis on any medical issues that could affect your status on the organ waiting list. Psycho-social issues related to the transplantation will be addressed, if needed, by the social worker and psychiatrist. Additionally, these visits with your transplant team provide you with an opportunity to address any questions or concerns you may have.

Medical Testing

During this waiting period, you will periodically undergo tests to ensure new medical problems are immediately identified and existing ones are regularly monitored. These tests include:

- Six-minute walk test – every three to six months
- Echocardiography – every six months for single lung transplant candidates
- Sputum culture and sensitivity – every three to six months for patients with bronchiectasis, specifically cystic fibrosis
- Cardiac stress test – every year for patients with coronary artery disease. Some patients may require an annual coronary angiography.
- Blood tests and chest x-ray – every year
- Panel reactive antibody (PRA) test to monitor immune system activity – repeated in certain patients every three to six months

Pulmonary Rehabilitation

You will be encouraged to participate in an outpatient pulmonary
Waiting for a Lung Transplant

rehabilitation program or a home exercise program prescribed by your transplant team. You should begin this program as soon as you are notified that you are a candidate for lung transplantation. If you are relatively fit, your recovery from surgery will be easier.

**Immunizations**
Your immunizations must also be updated while you're waiting for transplantation. It is recommended that you have:

- Pneumovax – every five years
- Influenza vaccine – yearly
- Tetanus toxoid – every ten years
- Hepatitis B vaccine
- Varicella vaccine for non-immune patients

**Support Services**
As part of the pre-transplantation care, candidates are required to attend a special two-hour support group meeting led by the social worker that meets the first Monday and second Tuesday of every month. The first hour is educational, the second offers both candidates and post-surgical lung transplant patients an opportunity to share their experiences and concerns with each other (see Support Services).

**Removal from the Organ Donor Waiting List**
It is possible that candidates can be removed from the donor organ waiting list if health issues develop that would prevent them from undergoing the surgery – or if their pulmonary disease shows significant improvement. If it becomes necessary for you to go off the waiting list, you will not lose the amount of time you have so far accumulated. (The longer you have been on the waiting list, the better your chances for receiving a donor lung.). You will be placed on an inactive list and, in the future, you can once again be placed on the waiting list without starting from the bottom of that list.

Smoking or substance abuse will automatically remove candidates from the active waiting list. During a six-month probationary period, they will be required to join a formal abstinence program and demonstrate abstinence throughout that period. They will be placed back on the waiting list when they meet those requirements. However, if a relapse occurs, they will be permanently removed from the waiting list.
When an Organ Becomes Available

When your transplant team is alerted that a compatible donor organ is available for you, your coordinator will immediately contact you. You will go Columbia University Medical Center within two hours of the call for admission to the cardiothoracic surgical service. There you will undergo a physical examination, chest x-ray and an EKG. Blood testing for final tissue typing will also be performed.

While you are at the medical center being prepared for surgery, members of your transplant surgical team will have traveled to the organ donor's hospital to personally ensure that the organ is satisfactory. This is reflective of the program's commitment to strict quality control. (If the team determines that an organ is damaged or infected, the surgery will be canceled.)

Meanwhile, you will be transported to the operating room. Once the organ has been approved for you, you will receive general anesthesia – and the surgery will begin.
Lung Transplant Surgery

The decision to perform a single or double lung transplantation depends mainly on the type of lung disease the patient has. If the disease involves infection (e.g. cystic fibrosis), then both lungs must be transplanted. This is because the anti-rejection medications (immunosuppressants), which are necessary for all transplant patients, suppress the immune system and, therefore, increase risk of infection. However, if the lungs are damaged but not infected (e.g., emphysema), one lung can be left in place. Patients with pulmonary hypertension do better if they have a double lung transplant. Age can also be a factor. Older adults tend to have more problems following a double lung transplant because it is a longer and more complex surgery. Therefore, they do better with a single lung transplant, when possible.

In the case of a single lung transplant, the lung that is most damaged is the one that is transplanted. This is determined by a test called ventilation-perfusion scan, which shows the blood flow to different areas of the lungs. Areas that indicate less blood flow are the ones with the greater damage.

While the patient is under general anesthesia, the surgeon makes an incision in the chest. If it is a single lung transplant, the incision is made on the right or left side, depending on which lung is being replaced. A double (bilateral) transplant requires an incision across the chest beneath the breast area.

The donor organ, which has been chilled to preserve it until transplantation, must be transplanted within six hours after being removed from the donor. As soon as the new lung(s) arrives in the operating room, the recipient's lung is immediately removed and the donor organ is placed in the chest cavity. When it is a double transplant, the organ with the poorest function is removed first and replaced.

Once the new organ is in place, the surgeon connects the pulmonary artery, pulmonary vein and the main airway (bronchus) of the donor organ to the patient's vessels and airway. Drainage tubes are inserted to drain air, fluid, and blood out of the chest for several days to allow the lungs to fully re-expand.

The surgery can take from four to eight hours, depending on whether it is a single or double lung transplantation and if complications occur.
See Video (4 min.)
Double Lung Transplant in child with cystic fibrosis

Please note: this links to video footage from an actual operation. Discretion advised.
Lung Transplantation Patient Care Guide

Post-Transplant Recovery

Immediately After Transplant Surgery

Lung transplant patients spend the first two to four post-surgical days in Columbia University Medical Center's sophisticated Cardiothoracic Intensive Care Unit (CTICU) located in the modern, new Milstein Pavilion. This special intensive care unit is staffed by critical care specialists who have expertise in monitoring patients recovering from lung and heart transplantation surgery. From there, lung transplant patients recuperate in a state-of-the-art transplant unit. The dedicated nurses in this 32-bed unit bring years of specialized training and experience to provide the very specific care required by lung transplant patients.

Most likely you will be placed on a ventilator, but will probably be taken off it within 24 hours post-surgery. Your post-operative pain will be managed by your transplant team in collaboration with the critical care anesthesiologist/pain management specialist.

You will begin your many (often between eight and ten) medications immediately following the surgery. Among them will be three immunosuppressants. Because your body is designed to identify "foreign invaders" and to reject them, these anti-rejection medications are mandatory for suppressing the body's natural immune response to the new lung(s). Unfortunately, the risk of rejection never goes away. For that reason, you will be taking immunosuppressants for the rest of your life.

In addition, you will begin taking antibacterial, antifungal and antiviral medications, which will be altered according to your culture results and clinical course. Vitamin and mineral supplements (e.g., calcium, magnesium, iron) will be prescribed to ensure your recovery from the transplant surgery.

Lying in bed too long can drain your energy. As soon as you are transferred to the transplant unit, you will begin receiving physical and pulmonary therapy every day. While you are in the hospital, new transplant coordinators will begin overseeing your post-transplant follow-up care. As part of the transition to these new coordinators, your pre-transplantation and post-transplantation coordinators will visit you together every day until you are discharged from the hospital. They will answer any questions you may have, review your medications as well as discuss possible side effects and drug interactions, and once again prepare you for necessary lifestyle changes and follow-up regimens. In general, they continue to educate you and your family on the often complex post-transplantation process.

Four Steps to Successful Transplantation

1. The Evaluation Phase
2. The Waiting Period
3. Your Transplant Operation
4. After Your Transplant
Resuming Life After Lung Transplantation

After returning home, you want to resume "normal living." If you want to go to a movie or a social occasion and feel up to it, DO IT! If you'd like have friends visit you at home, that's OK too! Try as much as possible to return to your normal routine.

However, the key is moderation and understanding your limits. Initially, you will probably have less energy than you did before surgery. It takes time for your body to heal and adjust to your new medications. Napping and pacing your activities is recommended to prevent placing a strain on your recovery.

Animals

No birds should be kept in your house, as their droppings may cause lung infection. Cats should be declawed, and you may not change their litter. Please consult your doctor if you have any other pets or exotic animals.

Exercise

Exercise will become an important part of your life, enabling a faster return to your routine activities, and helping you maintain overall improved health. Exercise has been shown to improve muscle tone, as well as the functioning of your heart and lungs. It also helps reduce stress, and achieve and maintain ideal body weight.

When you return home, we recommend that you exercise daily. We suggest walking 15-20 minutes daily, and gradually increase time as tolerated.

Do not resume workouts with heavy weights until you have been cleared to do so by the transplant team.

Returning to School and Work

You should be able to return to school or work within 3-6 months. Your transplant team will help you decide what is best for you. You may wish to discuss career counseling with the transplant team's social worker.

Driving After Lung Transplant Surgery

You will not be able to drive for about 4 weeks after your transplant. The medications we prescribe can cause tremors, weakness, and
blurred vision, and these side effects, often worse in the first few months, make handling a car difficult. Therefore, we recommend that you abstain from driving until you are cleared to do so by the transplant team.

**Routine Self Examination After Lung Transplantation**

Developing certain cancers is more common when people are on immunosuppressive medications. Because of this, we recommend monthly breast and testicular self-examination and routine medical check-ups. PAP smears, breast exams, testicular exams, and skin cancer screening should be done by your physician every year. Your local physician can perform these tests but duplicate reports should be sent to the transplant team to help us in your follow-up care.

**Skin and Hair Care After Lung Transplant Surgery**

**Acne:** Prednisone may cause acne on your face, chest, shoulders, and/or back, plus cyclosporine can make your skin oily in these areas. Wash any acned area(s) thoroughly three times a day, every day. Scrubbing gently with a wet washcloth and mild soap will help remove accumulating oils, dead skin, and bacteria. Vigorous rubbing and scrubbing can irritate your skin. Avoid soaps that contain creams or oils (such as Dove®, Tone®, or Caress®) because they will aggravate the acne. Completely rinse soap from your skin to leave your pores open and clean. Use a clean washcloth each time you wash. If your skin becomes excessively dry, stop washing those areas temporarily to allow the skin to recover its natural moisture.

If washing with bar soap does not improve or control your acne, use a non-prescription acne mediation with benzoyl peroxide (Oxy® 5 or Oxy® 10). Start by applying benzoyl peroxide 5% once a day. If redness and peeling are not excessive after three days, apply twice per day, gradually leaving it on for longer periods of time until it is left on all day. You may need to use a 10% benzoyl peroxide preparation if your acne is not controlled by the 5% preparation.

We recommend that you do not use Retina A, a powerful acid form of vitamin A. It causes increased sun sensitivity, which should be avoided because you are taking Prednisone.

**Other Ways to Control Acne After Lung Transplantation**

- Shampoo you hair and scalp frequently.
- Keep your hands away from your face and avoid rubbing the affected skin.
- Do not use cosmetics. Avoid the use of medicated hypoallergenic cosmetics meant to cover acne. If you wear make-up, your acne will probably not improve.
- Do not pick or touch your acne. This will help prevent infections.
- If acne remains a problem, tell us about it. Severe or infected acne must be treated by a dermatologist.

**Dry Skin:** If you have problems with dry skin, use a mild soap and
apply body lotion after bathing. For severely dry or scaly skin you may need a rich body lotion such as Alpha Keri®. Alpha Keri also offers an excellent bath oil. There are many good moisturizing products available from your local drug store without prescription; try to find those that work best for you.

**Cuts and Scratches:** Keep minor cuts and scratches clean and dry by washing daily with soap and water. If you wish, you may apply an antiseptic such as Betadine® solution. For larger cuts, dog bites, etc. contact your local physician immediately.

**Sun Exposure:** Transplant recipients run added risk for developing skin and lip cancers, and this risk increases over time. Prednisone makes your skin more sensitive to the sun, so you will burn easier, faster, and to a greater degree than you did before the transplant. Prolonged and repeated exposure to the sun's ultraviolet radiation produces permanent and damaging skin changes. The darker your skin, the more natural protection you have against burning and skin damage. But, bear in mind that you can now burn even if you are black because your medications make you more sensitive to the sun.

You will not need any special skin care unless you develop problems with acne or dry skin. You should take a bath or shower as often as necessary (daily or every other day) to keep your skin clean. It is important to be aware that any persistent skin problem will require evaluation by a dermatologist.

**Skin Cancer**

Your risk of developing skin cancer increases with your length of time after transplant. Skin cancers are ten times more common in transplant patients than among the general population. Therefore, it is essential that you limit your exposure to the sun, and that you protect yourself with proper clothing and sunscreens when you are outside.

Warning signs of skin cancer are any sore that bleeds, scabs, grows, or does not heal in a few weeks. Such sores are most likely to appear on the exposed parts of your body like your face, neck, head (especially if you are bald), and your hands and arms. A mole that bleeds or changes color or size must be examined immediately.

The components of the sun's radiation responsible for skin cancers are the ultraviolet (UV) rays, which are present even on cloudy days and in shady areas. We advise you to always protect your skin from exposure to UV radiation. Avoid the midday sun (10:00 am-3:00 pm) when ultraviolet rays are strongest. The window glass in cars prevents most harmful ultraviolet rays from reaching you. For extra protection from the sun, wear sunscreen lotion and lip balm (SPF 15 or above), broad brimmed hats, long sleeves and slacks every day when you are outdoors.

**Hair Care After Lung Transplant Surgery**

Prednisone often weakens the condition of your hair. Permanent wave lotions, tints, dyes, and bleaching may cause your hair to break. We recommend that you check with your physician before you have a permanent or color your hair.

**Increased Hair Growth:** This problem is caused by cyclosporine, and
is especially annoying to women. You can remove hair with a hair removal cream. There are several on the market made especially for the face. There are a number of products you can try, these are just a few – Sally Hansen® facial hair remover, Elizabeth Arden® facial hair remover, or Nair's® Only for Facial Hair remover. Be sure to test your tolerance of the product by following directions on the bottle. Hair removers can cause severe irritation to the eyes, lips, and mucous membranes, so apply carefully. A safer way to diminish the appearance of excessive hair is to bleach the growth with a 50% peroxide solution. Caution: patients should be particularly careful when using these products on infants and children because their skin tends to be more sensitive.

**Dental Care After Lung Transplantation**

You may have received a dental consultation during your pre-transplant workup to be sure that any necessary dental work would be completed before transplantation. If so, it is not necessary to have routine dental work performed for at least six months following transplant. This includes having your teeth cleaned. However, if you have tooth or gum pain, you should see your dentist immediately.

After transplantation, you need to take an antibiotic when you have dental work done, including cleaning and polishing. You can obtain a letter from the Transplant Office for your dentist regarding your antibiotic prescription.

It is extremely important that you practice good oral hygiene after your transplant. Brush your teeth once or twice a day. You should floss your teeth after transplant, but flossing can irritate your gums and cause bleeding, so be gentle.

If you dental work was not completed before transplantation, you must see your dentist for evaluation within the first few months after your return home. Follow the procedure outlined below when you visit the dentist.

- Make an appointment
- Have the dentist examine your mouth and teeth, but do not allow either the dentist nor a hygienist to pick, clean, or polish your teeth.
- If this is necessary, antibiotics must be taken.
- Have the dentist take X-rays if necessary.
- Schedule all needed appointments as closely together as possible when your dentist knows what work needs to be done.

Your prednisone dose should be as low as possible when dental work is done to reduce the possibility of infection and bleeding, and to enhance the healing process. But do not avoid dental checkups just because your prednisone dose is still high.

If you or your dentist has any questions, contact the transplant office for further information.

**Smoking After Lung Transplant Surgery**
We recommend strongly that you do not smoke. Smoking damages your new lungs, putting you at greater risk for lung infections, including bronchitis, emphysema and pneumonia. It also increases your risk of developing cancer.

Cancer is the leading cause of death after transplantation and smoking dramatically increases the risk of developing lung and other cancers after lung transplant. Smoking diminishes your red blood cells' ability to carry oxygen, so less oxygen reaches all of your tissues and this decreases your ability to heal. Smoking narrows your blood vessels, especially those in your legs, arms, and heart. Smoking also increases the acid in your stomach which will delay or prevent the healing of any ulcers you may develop. Plus, all of these problems are more serious in individuals taking immunosuppressive medications.

**Alcohol**

Do NOT drink alcoholic beverages. This includes non-alcoholic beers, which still contain small amounts of alcohol. Alcohol is metabolized (broken down) by the liver and causes damage which can lead to liver failure. Imuran, cyclosporine, and Bactrim are also metabolized in the liver. Combining these medications with alcohol can seriously harm your liver.

**Sexual Activity After Lung Transplantation**

Sexuality is an important part of who you are as a person. It is more than sexual intercourse. Sexuality involves how you feel about yourself as a man or woman, the giving and receiving of sensual (feeling) pleasure, the desire for closeness with another person, and the release of sexual tension.

A person's sexuality is affected when they have lung failure. This is caused for a variety of reasons. Men may experience impotence (problems getting or maintaining an erection) and a decreased sexual drive (libido). Women's menstrual cycles may become irregular or stop completely.

Some patients take blood pressure medications that can interfere with sexual function. These medicines can cause drowsiness and fatigue, in addition to decreased sexual drive, menstrual cycle irregularities, and/or decreased vaginal lubrication. Sometimes, even though the body functions normally, the sexual experience is not enjoyable. Some patients have found talking to a counselor helpful and this can be arranged by the transplant team.

Lung transplantation can improve some aspects of your sexual functioning. Chronic fatigue should diminish and make sexual life more enjoyable. Men will typically have fewer problems in gaining and maintaining an erection. A woman may resume her menstrual cycle and pregnancy is often possible.

After your lung transplant, however, some things may not get better. You may still need blood pressure medicines and these may affect your sexual functioning. Talk with your doctor or nurse if you are concerned about your blood pressure medicines. Your physician may be able to change your medication to enhance your sexual activity and still control your blood pressure.
Sexuality can also be affected by the medicines that you take to prevent rejection if they cause certain side effects. These might include developing a "moon face," acne, bruising, and/or increased body hair. If a person feels less attractive because of these changes, he or she may feel less interested in sex. Talking with your doctor or nurse about how to diminish the side effects can help.

It is common for transplant recipients to resume a more normal lifestyle, including sexual activity, as they recover. Sexual function may not have been an important part of your life before the transplant, but it may now be higher on your agenda. It is not unusual to worry about something that was unfamiliar in your recent past, but is now taking on new importance. You may also be concerned about the safety of your new lung during intercourse.

Doctors usually recommend waiting 4 to 6 weeks after surgery to begin sexual intercourse. This period gives you and your partner time to share your concerns and feelings, and permits the resumption of your sexual relationship in a slow and relaxed manner. The key to resuming a satisfactory sexual relationship is to talk with your partner in a tender, warm, and affectionate manner. If you do not have a steady partner, it is essential to use condoms to reduce the risk of sexually transmitted diseases.

Women using immunosuppressant medications can develop urinary tract infections with intercourse because they are more prone to infection, and because of the proximity of the vagina, urethra, and anus. To avoid infections, it is important to wash well after bowel movements and to wipe from the front to back. Urinating before and after intercourse and drinking a lot of water can help to prevent urinary tract infections. Symptoms of urinary tract infection are burning while you urinate, smelly or cloudy urine, a fever, or frequent urination. Contact your local doctor's office for proper diagnosis and treatment.

Even though you may not be having regular menstrual periods, it is still possible to become pregnant. It is important to use some type of birth control to avoid unwanted pregnancy. The recommended choices are a diaphragm, sponge, and/or condoms. Used correctly, with spermicidal jellies or creams, they are very effective. There is a higher risk for developing a urinary tract infection if a diaphragm is used. If you have questions or concerns about birth control, talk with the transplant team.

Pregnancy After Lung Transplantation

Some people want to start a family once they have had a lung transplant and recovered their health. For many women this is possible, but there can be greater risks to the mother and fetus. If planning a pregnancy it is important to discuss potential risks with transplant team members so that you can make the right decision for you and your family. Medication adjustments may be necessary.

The transplant program does not recommend pregnancy within the first year after transplant.
Follow-Up Care After Lung Transplantation

Your transplant team's involvement with you does not end when you leave the hospital. They are dedicated to providing you with follow-up care indefinitely.

Follow-Up Clinic Visits, Blood Work and Other Testing

Before leaving the hospital, you will receive a schedule of follow-up clinic visits for lab tests and checkups. The purpose of these important visits is to track your recovery progress and detect any potential complications as early as possible.

You will return to the comprehensive outpatient transplantation center once a week for the first two or three months following your surgery. These may be reduced to biweekly visits at the discretion of your transplant team if your recovery is proceeding without any complications. After three months, your visits will be scheduled once a month for the first year and then every other month thereafter, depending on how well you are doing. You will also return to your referring physician for your care that is not related to the lung transplantation.

- On the days you are scheduled to see the transplant team, bring your medications list and your handbook.
- You need to be at the clinic to have your blood drawn one hour before your morning dosage of medication is due.

Afterwards, you will take your medication. This is necessary so we can get an accurate reading of the immunosuppressant levels in your blood. The lab tests we perform monitor your blood counts, lung function, electrolytes, and the medication levels in your blood. Other tests may be ordered as necessary.

Laboratory Testing

During the first six-week post-transplant period, you will have chest x-rays and blood tests every week and then at regular intervals as necessary. The outpatient center has its own laboratory so that results from your blood tests can be available to your transplant team within 24 hours. This enables immediate and appropriate responses to any problems that are identified, prompting any necessary adjustments to your medications.

Tests for Blood Count

WBC tells us if your white blood cells have increased (usually a sign of
Follow-Up Care After Lung Transplantation

Infection (indicating a lower defense against infection).

HCT measures your hematocrit, the percentage of red blood cells present 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.

PLTS measures the level of platelets in your blood. Platelet cells form blood clots when your body is injured. Low platelet levels may cause you to bruise easily and to bleed for a longer time period.

Tests for Lung Function

PFTs: A noninvasive, outpatient test used to measure lung function

CXR: A radiologic examination to assess chest and lung abnormalities

CT Scan of Chest: An outpatient, noninvasive, radiologic test to assess your chest cavity including your heart and lungs.

Bronchoscopy: is an outpatient, minimally invasive procedure during which your pulmonologist looks at your lungs and airways (the bronchial tubes and lungs)

6 Minute Walk: This is a preoperative evaluation where the physical therapist will walk with you to measure your oxygen saturation level over time and distance.

Intravenous Medications

For the first few months following surgery, you will probably also require intravenous (IV) medications. Your transplant team will make all arrangements for your regular IV treatments.

Remaining Compliant and Vigilant

You will be on a relatively high dosage of three immunosuppressants, including prednisone, a steroid medication. These medications are very powerful, particularly prednisone, which is excellent for slowing inflammation that develops when your body recognizes the new organ. However, they can cause side effects, such as high cholesterol and triglycerides; high blood pressure; and kidney and gastrointestinal problems. When that happens, medications will be prescribed to treat the problems. Eventually, the dosage of immunosuppressants will be somewhat reduced as your body adjusts to the transplanted lung, but they will never be totally withdrawn.

Always keep in mind that the two most serious risks are organ rejection and infection. Those immunosuppressants, which are so important in protecting your new organ from being rejected, also make you more vulnerable to infections. For example, a simple cold can quickly turn into bronchitis or pneumonia. Your transplant team is experienced in immediately diagnosing and treating both rejection and/or infections – particularly when caught in the early stages. So, to help protect yourself from either of these medical problems, you must be compliant and vigilant — e.g., keep your follow-up appointments, call with any problems, do not miss a medication dosage.

Preventing Infection
Follow-Up Care After Lung Transplantation

Although lungs are internal organs, they are exposed to a variety of foreign substances that you inhale, such as dust, bacteria, viruses, which make them quite vulnerable to infections. For that reason, avoid people with communicable diseases. During your first three months following surgery, you will wear a mask covering your nose and mouth whenever you're in public places or taking public transportation, when you have company in your home or you're around children, and even while visiting the outpatient transplant center.

Monitoring for Rejection

At the time of your discharge from the hospital and then at regular intervals during the first year (usually six weeks and three months following discharge and then every three months), your transplant physician will perform a bronchoscopy with a biopsy to look for any subtle signs of rejection.

Symptoms of Rejection

Be alert to possible signs of rejection, which include shortness of breath, fever, flu-like aches, chills, pain over the transplanted lung, and/or a cough. Signs of infection can include fever, sore throat, shortness of breath, redness or draining pus at the site of your incision, a sore throat, pain during urination, nausea, vomiting or diarrhea.

If you experience any of signs or symptoms that concern you, immediately alert your transplant physician, surgeon or coordinator. Rest assured that you can reach a transplant physician or surgeon any time during weekends, holidays, or at night. One of them is always on call.

Tooth and Mouth Infections

Teeth and mouth infections can be particularly threatening. So, make sure you have your teeth cleaned twice a year. But before each cleaning, check with your physician in case you may need to take antibiotics right before the cleaning.

Monitoring Vital Signs

After you leave the hospital you will be asked to monitor your temperature, blood pressure, weight, pulmonary function and to keep a record of these measurements and laboratory test results.

Temperature

It is important to take your temperature every day in the morning. An increase in your normal temperature can be a symptom of either organ rejection or infection. Both rejection and infection are easier to treat when recognized early. Someone whose immune system is suppressed does not always get high fevers. Call your transplant team any time your temperature reaches 101° F (39.5° C).
**Blood Pressure**

High blood pressure is a common side effect of both Neoral® and Prograf®. It can also indicate that you are retaining fluids. Once you return home you will need to take your blood pressure twice a day, once in the morning and once in the evening, and keep a record of the results.

You may be discharged on medications that control blood pressure. You can help keep your blood pressure under control by eating a low-salt diet, and by losing extra weight. The team's nutritionist can help you with this.

Your nurse will teach you how to measure your blood pressure. The top number (systolic) is noted at the first sound you hear and the bottom number (diastolic) is noted when the sound changes (not stops). It is important that you know your normal blood pressure, normal fluctuation range, and when you should be concerned. You should notify your transplant team or local physician if your blood pressure measures:

- **Systolic:** more than 160 or less than 100.
- **Diastolic:** more than 90 or less than 60.

Headache can be a symptom of high blood pressure. If you develop a headache, take your blood pressure. If it is above normal for you, call the transplant team. Also check your blood pressure if you are feeling dizzy or light-headed. These symptoms can be caused by low blood pressure. If your pressure is atypically low, call the transplant team.

**Incentive Spirometry:**
Is a measurement of your airflow. You will be instructed on the daily use of this device before you leave the hospital.

**Peak Flow Measurement:**
Measures the force that you can blow air out of your lungs. You will be instructed on the daily use of a peak flow meter in the hospital.

**Weight**

You should weigh yourself on a standard bathroom scale at the same time each morning after going to the toilet. Record your weight. If you gain more than 2 pounds per day, you could be retaining fluid. Report this to your transplant team or local physician.

**Pulmonary Rehabilitation**

For at least three months, you will also be required to continue the pulmonary rehabilitation program begun in the hospital to increase your strength and endurance. If you are unable to attend the program at Columbia University Medical Center, you can participate in a local rehabilitation program recommended by your transplant team.

You may be able to go back to normal non-strenuous activities, including work, in three to six months. Of course, that will depend on whether your overall recovery process is eventful or not. **Remember: Not only are you recovering from a major surgery but also your serious pulmonary disease.** To regain your strength, you will need to begin exercising. But be careful. Start slowly. Begin with walking at a slow...
pace for a short distance. Then gradually increase the pace and
distance as you feel stronger. Also, do not lift anything heavy for at
least two months following your surgery. Eventually you'll be able to
expand your type and level of exercise. Just let your transplant
physician, surgeon or coordinator know if you plan to try a more
strenuous activity.
Patient Guide to Lung Transplantation

Staying in Touch with Your Transplant Team

Once you leave the hospital, you are NOT alone.

The team's social worker will assist you and your family with the discharge preparations. The transplant coordinators will order your medications from the pharmacy of your choice so that all the medications you need will be available when you leave the hospital. The nurses in the hospital will help educate you about how to care for yourself. Inevitably, questions will arise after you have left the hospital. A member of the team is always available to answer your questions. The phone number for the Program is 212.305.7771.

Routine Calls: The office is open from 9am to 5pm for non-emergency issues. These include questions about your care, reporting or inquiring about lab results, scheduling appointments, tests and procedures, and prescription refills.

Emergency Calls: A physician from the team is available 24 hours a day for medical emergencies. If you are ill, and need to speak with us please do not hesitate to call. The answering service will have the physician return your call promptly.

Call 911: If you have any of the following symptoms, call, or have a family member or friend call 911 to summon an ambulance to bring you to the hospital:

- Chest Pain
- Difficulty Breathing
- Bleeding
- Loss of Consciousness

Be sure to keep the Transplant Office informed of your correct address and phone number(s), and any changes in your referring doctor's name, address, or phone number(s). Also, it is important to tell us whom to contact in case of emergency, including their name, address, and phone and beeper numbers.

Contacting Your Lung Transplant Team

By Phone: 212.305.7771

By Fax: 212.305.5382
Where to Find the Lung Transplant Program

Shorin Comprehensive Transplant Center
622 West 168th Street
14th Floor Center
New York, NY 10032
Immunosuppression and Organ Rejection

The purpose of your immune system is to protect your health. It recognizes and attacks anything different from the substances normally present in your body, even those only slightly different, like your newly transplanted lung. The immune system does not discriminate between harmful substances, like bacteria, fungi and viruses, and transplanted organs — so to your immune system your new lung appears as a foreign substance that needs to be eliminated.

To protect your new lung, we prescribe a variety of medications to suppress your body's natural immune response. These medications are called "immunosuppressants," and they trick the immune system into believing that your new organ is not foreign, and thus it is not attacked. After transplantation, you will be taking immunosuppressant medications for the rest of your life.

Understanding Organ Rejection

Even with the use of immunosuppressants, your body can at times recognize your transplanted organ as a foreign object and attempt to protect you by attacking it. Rejection is the term used when your body's immune system is attacking your transplanted organ. Nearly all patients will experience at least one episode of rejection. If and when you suffer an episode rejection, remember:

- it does not mean that you will lose your new lung,
- it does not mean your new lung is failing.

Rejection may occur early or late after transplantation. Early rejection occurs most often in the first six months after transplant, and late rejection typically occurs after six months.

Symptoms of Organ Rejection

The most common symptoms or signs of rejection are:

- Flu-like symptoms
- Fatigue
- Shortness of breath
- Decreased incentive spirometry
- Cough/chest pain
- Fever
- Decreased peak flow
- Decreased oxygen saturation
If you develop any of these symptoms or signs, contact your transplant team at once.

**Monitoring for Rejection**

Rejection can frequently be silent and without symptoms, and detected only by lung function testing. This is why we frequently measure your lung function during your hospitalization and at your follow-up clinic visits. In addition, a lung biopsy may be necessary to determine if rejection is actually occurring.

Pulmonary function tests, a measure of your lung function, will be performed weekly in the 3 months after your transplant, and less frequently thereafter. This test may reveal the first sign of rejection or infection. Your lung function will be followed at home with the measurement of spirometry and peak expiratory flow measurements, which you will record daily at home. Any persistent decrease in these values should be reported to the transplant team.

If rejection is suspected, a bronchoscopy, or lung biopsy, will be performed to rule out rejection or see if it is actually occurring.

**Managing Organ Rejection**

*We manage a mild rejection episode by making adjustments to your medication dosages.* Moderate or severe rejection may require a few days of hospitalization, allowing us to administer alternative immunosuppressants and observe your progress.
Bronchoscopy/ Lung Biopsy: Monitoring for Organ Rejection after Lung Transplantation

What is bronchoscopy/ lung biopsy?

Bronchoscopy is a diagnostic procedure used to obtain a small amount of lung tissue and fluid samples, which are then examined under a microscope to help in diagnosing a change in your lung function. During this procedure, your lung doctor examines your lungs (bronchial tubes) and looks for abnormal conditions, such as infection, tumors, bleeding and abnormal sites.

Bronchoscopy provides important information about the condition of your transplanted lung(s) and for your treatment. You will be asked to sign a consent form prior to the test. Your consent tells that you understand the reason for the bronchoscopy, how it is done, possible alternatives, and possible risks.

What are the risks of a bronchoscopy?

The primary risk with bronchoscopy is bleeding from the site of the biopsy, but this occurs in less than 1% of patients. Other rare complications include lung collapse, hoarseness, sore nose or throat. You will be monitored closely for several hours after the procedure to make sure no complications arise.

Please note: If you have a heart murmur, heart valve problems or artificial joints, remind your doctor. You may need to take an antibiotic before the bronchoscopy as a precaution.

Instructions for patients having a bronchoscopy.

The office staff will set up the appointment for your bronchoscopy and call you with the date and time. Please be sure to follow these instructions:

1. You must abstain from aspirin and ibuprofen-containing medications. This includes but is not limited to Advil, Motrin, Nuprin, and Aleve. These medications can cause increased bleeding. Tylenol is OK. Notify your physician if you are taking blood thinning medication.
2. You will be notified of arrival time and place of the bronchoscopy.
3. Your doctor may order tests such as blood tests, an EKG, or a chest x-ray, to be performed before the procedure. These tests may be done in the physician's office, the hospital, or in an outside laboratory.
4. On the night before the procedure, do not eat or drink anything after midnight, unless your doctor gives you different instructions.
5. If you usually take medications in the morning, ask your doctor whether you should take them as usual or if they should be taken after the test.
6. When you come for the procedure, bring a list of any medications you are taking, along with the dose of each medication.
7. On the day of the test, please arrive 30 minutes before the appointment time.
8. Please dress comfortably and leave valuables at home.
9. Be sure to arrange for someone who will be responsible for taking you home after testing. This person may arrive with you, or up to four hours after your arrival.

How is bronchoscopy performed?

- In the procedure room, your temperature, pulse, and blood pressure will be taken.
- A plastic clip will be placed on your finger to measure the oxygen in your blood during the procedure. This is known as a pulse oximeter.
- Your heart rate will be monitored throughout the test, and you will receive oxygen.
- An IV (an intravenous line, a thin plastic catheter which goes into your vein) will be started. This is used to give you medication as needed.
- Medication may be used to make you drowsy and relaxed.
- Your throat will be sprayed with a local anesthetic to make it numb. This will make you more comfortable when the scope is passed through the throat.
- The bronchoscope is a long soft tube with a magnifying lens and light on the end. The tube is about as wide as a pencil. The scope is gently passed through your nose or mouth, and into your lungs.
- You will be able to breathe easily throughout the procedure. The doctor will be able to see into the airways, and can take samples of tissue for biopsy through the scope. You will be observed closely by the nurse during the test and afterwards, until you are fully awake and able to leave the area for discharge.

How will I feel during bronchoscopy?

- You might feel some discomfort as the scope is passed through your nose and throat. This will be minimal and it will last only about 10-15 seconds.
- Usually there is a small amount of bleeding after the test if a biopsy is taken. You may notice that you cough up some blood tinged mucous. This will decrease after a few hours. If the bleeding increases or if it lasts longer than 24 hours, call your doctor.

When can I eat after bronchoscopy?
Two hours after the test, you will be able to take a few sips of water.

If you can swallow without a problem, you can eat and drink normally at that time. If not, wait another hour and then try sips of water again.

What should I do when I get home?

You may want to take it easy for the rest of the day after the test. If you received sedation you may feel tired or sleepy. Do not drive or operate machinery or sign any legal documents for the next 24 hours after the sedation.

- Do not take aspirin or medications such as ibuprofen in the first 24 hours after the procedure.
- **Check the label of brand name medications to see if they contain ibuprofen or aspirin. These medications can increase bleeding.**
- Check with your doctor about any possible changes in your usual medications and ask when you can begin to take them again.
- You may have a slight fever after the bronchoscopy and your doctor may suggest taking acetaminophen (for example Tylenol®) for fever or discomfort.

What symptoms should I report to the doctor after bronchoscopy?

- Bleeding that lasts longer that 24 hours or if it increases (report amounts greater that blood-streaked mucus).
- Fever (temperature over 100F) that lasts more than 24 hours.
- Shortness of breath or chest pain.

Notes & Numbers

If you have any questions about the test, or about how you feel, call your doctor or the Lung Transplant Program to speak to a nurse coordinator between the hours of 9:15 AM and 5:00 PM.

This resource provides brief, general information about this health care topic. It does not take the place of specific instructions you receive from your health care providers. For answers to other questions consult your physicians or other health care provider.

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Bronchoscopy Lung Transplant office r17 6/01

Call the Lung Transplant office at 212.305.7771 if you experience any of the following signs after your bronchoscopy:

- Shortness of breath
- Chest pain
- High fever beyond the first day
- Coughing-up large amounts of blood
- Lightheadness/Dizziness
Infections after Lung Transplant Surgery

Because the immunosuppressant medications you take to prevent rejection interfere with your natural immunity, you become more susceptible to infections after your transplant. To combat this, we also prescribe antibacterial, antiviral, and antifungal medications to prevent you from contracting the more harmful infections.

Common symptoms of infection include:

- Fever, chills, sweats
- Sore throat
- Productive cough
- Increased fatigue
- Swelling, pain or redness around incision or drains
- New drainage from the incisions
- Headache
- Shortness of breath

If you experience any of these symptoms, contact your transplant team or primary care physician at once.

If You Develop an Infection

When you get colds or the flu, you may take over-the-counter preparations such as Sudafed® or Dimetapp®. Avoid cold remedies that contain aspirin, Tylenol®, or high quantities of alcohol. (You may take aspirin or Tylenol® for headache or to reduce fever.) If you develop a cough, you may take cough syrups such as Robitussin®, but if your cough becomes productive (bringing up phlegm or mucous) and you are running a fever, call your transplant team. If your local doctor prescribes an antibiotic, please call the transplant team to verify that it will not interfere with the medications you routinely take.

If you are caring for a child on immunosuppressant medication, please check with your pediatrician before administering any medications.

How to Protect Yourself from Infection after Lung Transplantation

Preventing infection is mostly common sense. Protect yourself by following these simple guidelines:
Wash your hands with soap and water often to remove bacteria and viruses; keep your hands away from your face and mouth. You should wash your hands when you come in from outdoors, before you prepare food, before you eat, after working with papers, after cleaning, and after using the bathroom.

When you cough or sneeze, use tissues, dispose of them immediately, and wash your hands.

If someone you know has a cold or the flu, avoid close contact. Don’t hesitate to tell your friends about your special situation and ask that they postpone visiting when they are ill.

Shower instead of bathe, and practice good personal hygiene.

Maintain a well-balanced diet. Wash before and after handling food. You can even use a small amount of soap when cleaning fruits and vegetables. Avoid raw eggs, raw shellfish, and raw meats; they can harbor bacteria. Keep hot foods hot, and cold foods cold. Don’t eat foods whose freshness is in question.

It’s fine to live with pets, but you must be able to delegate cleaning the birdcage, changing the cat’s litter, and cleaning up after the dog to someone else.

Avoid stagnant water because it too harbors bacteria. This includes denture cups, flower vases, soap dishes, and fresh water ponds.

Swimming in chlorinated pools is permitted.

No gardening should be done.

Wear a respiratory mask in crowded public areas and hospitals.
Immunosuppressant Medications After Lung Transplantation

The key to maintaining a successful transplant is taking, for the rest of your life, the medications prescribed to you. Initially it may seem a little overwhelming, but in time you will become very comfortable with the routine. It is important to take your medications as you were instructed.

Because you are responsible for taking your own medications, talk with your physician, pharmacist, or nurse until you fully understand:

- When to take each medication
- Name and purpose of each medication
- How to take each medication
- How long to continue taking each medication
- Principal side effects of each medication
- What to do if you forget to take a dose
- How and when to order more medicine so you won’t run out

Guidelines for Taking Medications

- Always take your medications at the same time every day.
- Never skip a dose. If you accidentally miss a dose, call the transplant team.
- Do not stop taking or change the dose of any medication without prior knowledge and approval of the transplant team.
- Call your Transplant Team if you are experiencing side effects from your medications, or are having vomiting or diarrhea.
- Never take medications other than those prescribed by your transplant team, including over-the-counter medications or those prescribed by other physicians without first calling the transplant team.
- Store your medications out of reach of small children.
- Store medications in a cool, dry place.

REMEMBER THAT NOT TAKING MEDICATIONS AS PRESCRIBED
IS ONE OF THE MOST COMMON REASONS FOR TRANSPLANT FAILURE! Therefore be very careful when taking medications. Call your transplant team with any questions or concerns no matter how seemingly small!

The following pages contain a list of common post-transplant medications. Your nurse will check off the medications that you will be taking.

**Medications After Lung Transplant Surgery:**

- Cyclosporines
- Tacrolimus
- Mycophenolate Mofetil
- Prednisone
- Azathioprine
- Sirolimus
- Daclizumab and Basiliximab
- OKT3
- Anti-Fungal medications
- Antiviral Medications
- Diuretics
- Antibiotics
- Anti-Ulcer Medications
Nutritional Management After Lung Transplantation

Good nutrition plays a key role in recovering from lung transplantation. As after any surgery, adequate calories and protein are needed for proper wound healing. Also, possible side effects of the anti-rejection medications can increase nutrient requirements. Because of these special concerns, you may have to change your diet for a time period after your transplant. However, dietary therapy is always adjusted by the transplant team to meet your specific needs and tolerances.

General Dietary Recommendations

- No grapefruits or grapefruit juice as this may interfere with medications.
- No uncooked food such as sushi or meat. Meat should well done.
- Raw vegetables need to be washed and scrubbed by someone else other than you. Raw fruits and vegetables, especially root vegetables, may contain fungus. Fungus may be inhaled and cause lung infection.
- No salads at public salad bars — to avoid infection from the salad and from the other diners.

Short Term Nutritional Management

Protein Intake

In the first month following lung transplantation you will be recovering from the stress of surgery. It is important to consume enough protein, and total calories, to help your wounds heal. You also need added protein to help overcome muscle breakdown caused by high doses of prednisone. To help meet your protein needs, the following foods are recommended:

- Meats (beef, pork, poultry, turkey, seafood)
- Fish
- Dairy products (mild cheese, yogurt)
- Eggs (but no more than 3 to 4 yolks per week)
- Egg substitutes (egg whites)

The following are vegetarian selections high in protein. When taken in adequate amounts as part of a well-balanced diet, these foods meet your protein needs:
Nutritional Management After Lung Transplantation

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**Nutritional Management After Lung Transplantation**

- **Nuts**: Split peas, Soy products
- **Dried beans**: Peanut butter, Tofu

**Sugars**

Steroid medications can decrease the body's ability to use its blood sugar for energy. This can cause increased blood sugar (glucose). This condition is called hyperglycemia or steroid-induced diabetes.

Avoiding concentrated carbohydrates will help decrease the side effects of steroid medications.

These foods are high in simple sugars and should be avoided:

- Sugar
- Honey
- Molasses
- Syrup
- Sugar pies
- Doughnuts and sweet rolls
- Fruited yogurt
- Jams, jellies, marmalades
- Puddings
- Frozen fruit or juice with added sugar or syrup
- Canned fruit or juice with added sugar or syrup
- Chewing gum with sugar
- Soft drinks
- Sweetened mineral water
- Cookies, candy
- Sweetened condensed milk
- Ice Cream
- Sherbet
- Fruit Ice
- Jello

If you develop hyperglycemia, your diet may need to be changed to include the following guidelines:

- Eating three meals per day are recommended, consumed at regular and evenly-spaced times.
- Limiting fruit to one serving per meal, and eating fresh or water-packed canned fruit only (no syrup or added sugar).
- Reading food labels to avoid foods with sugar, honey, sucrose, dextrose, or corn syrup listed as the first or second ingredient.

**Sodium (salt)**

Prednisone can increase sodium and water retention and increase your blood pressure. Therefore, sodium may need to be restricted in your diet. The "no added salt" diet is generally prescribed. Salt contains sodium, so it is best to limit salt when cooking and not add salt at the table. High sodium foods to avoid include:

- **Commercial Soups**: Bullion cubes, dehydrated soup mixes, canned broth and canned soup (unless labeled "low sodium")
Nutritional Management After Lung Transplantation

- **Processed Meats:** Ham, bacon, sausage, frankfurters, cold cuts (bologna, salami, pastrami), corned beef, smoked or dried meat or fish.
- Canned meats and fish (unless labeled "no salt added")
- Salt pork, processed cheese, and frozen packaged dinners.
- **Processed Vegetables:** Pickles, sauerkraut, canned vegetables (unless labeled "no salt added"), frozen vegetables with sauces.
- **Starches:** Salted crackers, pretzels, potato chips, cornchips, salted popcorn, salted nuts or seeds, etc.
- **Beverages:** Buttermilk, tomato juice and vegetable juice (unless labeled "low sodium").
- **Condiments for use in moderation:** catsup, prepared mustard, horseradish, sauces (barbecue, chili, and Worcestershire).
- **Condiments to avoid altogether:** pickle relish, olives, garlic salt, onion salt, monosodium glutamate (MSG) (Accent), soy sauce, meat tenderizers, and salad dressings (unless homemade).
- Salt substitutes are high in potassium and should only be used with your doctor's permission.

**Potassium**

Some drugs (cyclosporine or Prograf) can increase the potassium level in your blood. Other drugs (Lasix) can decrease your potassium level. When potassium is too high or too low problems with muscle and heart function can develop. Your serum potassium level can mandate a change to your medication and/or diet. High potassium foods include:

**Fruits and Juices**

- Apricots
- Avocados
- Bananas
- Dried Fruits

- Melons
- Nectarines
- Oranges
- Orange Juice
- Prune juice
- Tomato Juice
- V-8 juice

**Vegetables**

- Leafy greens
- Tomatoes
- Lentils
- Potatoes
- Pumpkins
- Split peas
- Dried beans

**Other Foods**

- Nuts
- Milk and dairy products

- Chocolate
- Peanut butter
Healthcare for Life

Following lung transplantation, patients can anticipate the return to a normal, more routine lifestyle. One must, however, receive routine, age-appropriate medical check-ups including annual cancer screening. Prevention of illness is the key to a healthy life, and check-ups are vital to preventing illness.

Your Primary Care Doctor's Role after Lung Transplantation

The physician responsible for your care before you came for a transplant, or the doctor who referred you to us, will continue to monitor your health after your transplant. We recommend that you receive primary care for the first three months after your transplant at our center. You should also continue to see any specialists who were involved in your care before you received the transplant. This includes the pulmonologist, cardiologist, gynecologist, and the gastroenterologist.

And remember to inform the transplant office of any changes in your local doctor's name, address, or phone number(s).

Ophthalmology

It is important to have annual vision check-ups with an ophthalmologist. The immunosuppressant prednisone can cause cataract and initiate changes in your vision. You should schedule your first postoperative ophthalmology exam at six months.

Dermatology

Because of your skin's enhanced sensitivity, it is important that you see a dermatologist on an annual basis for skin cancer screening. Any suspicious moles should be biopsied and removed promptly.

Immunizations and Vaccinations

Patients are encouraged to get all appropriate vaccinations prior to transplantation. After transplant, annual flu shots are recommended after 1 year. If additional inoculations are necessary, you should only receive "dead virus" vaccinations. You may not receive "live virus" vaccines such as varicella, or MMR, because of risk of transmission.

Prescriptions
Your transplant team may be able to recommend a pharmacy that will send all your monthly medications directly to your home. The insurance company who issues your drug plan will have to pre-approve the use of such service.

Many medications will interact with your immunosuppressants; for this reason, you must always consult with the transplant team prior to taking any new medications, or altering the dosage of the immunosuppressants and other medicines we have prescribed.

**Emergency Medical Identification**

Following transplant, you should wear a medical identification bracelet or necklace at all times. Your nurse can provide an order form for this essential and life-saving jewelry. Indicate on the form that you have had a lung transplant, are "immunosuppressed," and have our 24-hour number, 212.305.7771, included on the tag. You may want to include your local doctor's phone number also.

**Psychological Health after Lung Transplantation**

Now that you have had your lung transplant, our goal is to help you enjoy a full and satisfying life. A serious illness such as you have experienced can create many personal and family stresses. To help you and your family make any necessary adjustments, we have a social worker and psychiatrist available for consultation. They are available when you are in the hospital, or in the clinic to help you with concerns that arise after your transplant.

Our transplant team can help you with: job planning or rehabilitation; family stresses, such as parent-child conflicts, marital conflict, and changes in sexual functioning; and financial concerns, such as questions about Medicare, disability and insurance.

Your social worker will evaluate your needs, refer you to an agency in your home community, or provide direct counseling if circumstances and distance permit. You may be able to resolve many questions by talking with one of them. If you need specialized counseling, we will help you find appropriate alternatives.
Support Services after Lung Transplantation

From the moment you and your primary pulmonary specialist begin discussing the possibility of lung transplantation, you will have many questions and concerns about this treatment option. There are practical concerns and emotional reactions. And there are certain lifestyle adaptations that will need to occur following the surgery – changes that will affect not only you but also your loved ones. Members of your transplant team will be there to guide you through each stage of your transplantation.

- Your nurse coordinators will oversee your care — expediting tests and consultations and answering your questions.
- Your social worker will determine what emotional and practical support may be needed by you and your family during this period. She can connect you to those services in the community that can be of possible assistance. The medical center's Social Work Department produces a quarterly newsletter, which will be mailed to you, that covers relevant topics for heart and lung transplant patients and their caregivers.
- Your financial counselor will evaluate your medical insurance during the pre-transplantation and work closely with you to ensure that all possible expenses, including immunosuppressants, will be covered, perhaps through new or additional insurance – or sometimes alternative sources.
- A nutritionist will work closely with you to guide your healthy eating habits as you await your surgery and then assist you in adapting to your new and necessary post-surgical food and preparation requirements. A delicious recipe is highlighted in every issue of the heart and lung transplantation newsletter.

Support Groups

The lung transplantation program offers a two-hour support group on the first Monday and second Tuesday of every month. Coordinated by the transplant team social worker, it offers invaluable information, guidance and moral support to patients and their families. All transplant candidates are required to attend these meetings. Postsurgical patients are encouraged to participate, not only because the sessions continue to be helpful but also because they themselves can offer their own unique perspective about the surgery to candidates waiting for a donor organ.

The meeting is divided into two sessions. The first focuses on education and often has one of the nurse coordinators as a speaker. It
Lung Transplantation Support Services updates the participants on organ rejection and infections, medications and many other matters of importance to them. Once in a while, the first hour is reserved for the caregivers – those responsible for seeing to it that the recovering transplant patients are taking their medications, moving about and getting the necessary care they require at home.

The second hour is purely a support session during which the patients share their experiences and concerns. This period is limited to patients only.

Other Transplant Support Resources

The following organizations provide information and support to transplant recipients:

- **TRIO (Transplant Recipients Organization)**
  1000 16th Street, NW
  Washington, DC 20036
  1.800.874.6386
  http://www.trioweb.org

- **American Society of Transplantation**
  http://www.a-s-t.org

- **American Thoracic Society**
  http://www.thoracic.org

- **Coalition on Donation**
  http://www.shareyourlife.org

- **Eurotransplant**
  http://www.transplant.org/default.htm

- **James Redford Institute**
  http://www.jrifilms.org/index2.htm

- **National Transplant Assistance Fund**
  http://www.transplantfund.org

- **New York Organ Donor Network**
  http://www.nyodn.org

- **Society of Thoracic Surgeons**
  http://www.sts.org

- **The American Lung Association**
  http://www.lungusa.org

- **Transplant Health.com** – Interactive web site for transplantation
  http://www.transplanthealth.com

- **TransWeb**
  http://www.transweb.org
United Network for Organ Sharing (UNOS)
http://www.unos.org
Lung Transplantation Patient Care Guide

The Four Steps to Your Successful Transplantation

Typically, patients are referred to our program by a physician for assessment as a lung or heart-lung transplant candidate, but you may contact us directly about your condition. Once you arrive for assessment at Columbia Presbyterian, you become part of an intensely personal, four-phase program designed to guide you and your family through this challenging time.

I - The Evaluation Phase

Members of Columbia Presbyterian's transplant team conduct a careful and comprehensive evaluation of your physical condition. Necessary tests are performed, including pulmonary function testing (PFT), x-rays and blood tests. Your dental health and bone strength are evaluated.

You meet with the team's coordinator, social worker, psychiatrist, and financial counselor to help you understand and find ways to minimize the personal impact transplantation would invariably have on you and your family. Results are generally complete within a few days of the examination. Then, the team analyzes all the test data and consultation results to determine if transplantation is the correct therapy for you. This evaluation phase is typically completed within 60 days. At the end of the evaluation, an individualized action plan is created for you. If you are accepted as a transplant candidate, you are registered on the organ recipient waiting list of the United Network for Organ Sharing. If transplantation is not right for you, alternative therapies are recommended.

II - The Waiting Period

The United Network for Organ Sharing (UNOS) is the national clearinghouse for organ allocation. UNOS was created to maximize the limited supply of organs and give all candidates a fair chance to receive the organ they need, regardless of gender, race, religion, lifestyle, or financial or social status. It manages the national transplant waiting list, matching donors to recipients 24 hours a day, 365 days a year, for every transplant center in the country.

In the New York region, most patients wait from 12 to 18 months for their replacement organ(s) to become available. During your wait, it is critical for you to maintain good nutrition and keep up rehabilitation efforts under the care of your local physician. Most transplant recipients will tell you that this waiting time was the most difficult part of their entire transplant experience. The transplant coordinator and social worker serve as your advocates, recommending and facilitating the support services you may require.
III- Your Transplant Operation

Columbia Presbyterian does not require that you relocate to the Manhattan area when you join its transplant program. However, you must be able to reach the campus in northern Manhattan within six hours of receiving notice that your new organ is available; your transplant coordinator will have helped you plan your transportation well in advance of this call. From the moment you arrive at Columbia Presbyterian, you are under the continuous care of your transplant team.

The operating rooms in the Milstein Hospital Building are staffed by attending surgeons and full-time cardiac anesthesiologists, who jointly lead the team that includes surgical residents, perfusionists, physician assistants, and nurse practitioners. They are further supported by a sophisticated cardiothoracic intensive care unit, where you receive one-on-one nursing care, under the direction of your surgeon and pulmonologist. Following surgery, you recover in this intensive care unit until you are ready to return to your room.

Throughout your stay at Columbia Presbyterian, the transplant team is there to help you achieve the earliest possible medically appropriate return home.

IV- After Your Transplant

Following your surgery, you remain in the hospital or transfer to a recommended rehabilitation facility to optimize recovery and guard against infection and organ rejection. From there, you begin the life-long process of returning to and maintaining pulmonary health.

You continue to work closely with your transplant pulmonologist, your physical therapist, and members of the social services team. Your local physician remains a key member of the care-giving team, playing an active role in your recovery. In the first few months following surgery, you return weekly to Columbia Presbyterian for checkups.

After four months, the frequency of these visits decreases to once a month. During this time, you take a number of medications that are important to maintaining the health of your new organ(s). The transplant team works with you to make sure that you fully understand the purpose of these medications and are comfortable with the related instructions.

At follow-up visits, you participate in a regular schedule of diagnostic and medical care, including physical examination, complete blood and x-ray analysis, review of medications, bronchoscopy, dental care with antibiotic prophylaxis as needed, and annual eye and, for women, gynecologic care.
Referrals & Contact

NewYork-Presbyterian Hospital
212.305.2500

Lung Transplant Office
212.305.7771

Pulmonary Function Office
212.305.3357

Pulmonary Rehabilitation Office
212.305.0483

Lung Failure Office
212.305.1158

Locations

Columbia University Medical Center
Milstein Hospital Building
177 Fort Washington Avenue
New York, NY 10032-3784

Morgan Stanley Children’s Hospital of New York
3959 Broadway
New York, NY 10032-3784

The General Surgery Group
5141 Broadway
(at 220th Street)
New York, NY 10034

Columbia Presbyterian Eastside
16 East 60th Street
at Madison Avenue
New York, NY 10021
Phone: 212.305.8500

Contact Information
Phone: 201.346.7001
Fax: 201.346.7010
E-mail: sjh2127@columbia.edu

Consumer Referrals
800.227.2762

For Physicians
201.346.7001
Cyclosporines After Kidney Transplantation

Neoral®, Gengraf®, Sandimmune®

Purpose: Neoral® is an immunosuppressive medicine that helps prevent organ rejection.

Dosage: The dose we prescribe for you is based on your lab values. The capsules come in 25mg, 50 mg and 100mg sizes; the liquid in 100mg/cc strength.

When: In the morning, take with breakfast after your lab work is completed. Repeat the dose in the pm, 12 hours after your am dose. If you are on cyclosporin twice a day, your blood level must be measured 12 after your last dose.

Precautions: Cyclosporine blood levels may be altered by some medicines. Before you take any new drugs please contact the transplant team. New mothers taking cyclosporine are advised NOT to breast feed.

Common Side Effects: Headache, seizures, nightmares, memory loss, tremors, fluid retention, decreased kidney function, elevated potassium levels, high blood pressure, hot flushes, loss of appetite, diarrhea, nausea/vomiting, hair growth, gum swelling, increased risk of infection, joint discomfort, leg cramping, low magnesium levels.
Antifungal Medications After Lung Transplantation

Mycelex® Troche, Nystatin® Swish and Swallow, and Diflucan®

Purpose: All prevent or treat fungal (candida) infections often found in the mouth or genital area.

Dosage: Dosages vary and will be explained to you by the transplant team.

Mycelex Troche should be held in your mouth until dissolved.

Nystatin should be thoroughly swished around your mouth before swallowing.

A small oral sponge can be used to coat the inside of an infant's mouth.

Diflucan is available in tablet form.

When: Mycelex and Nystatin are taken 3 times each day until your prednisone is at maintenance level.

Diflucan is taken orally once a day.

If you miss a dose of any of these medications, take it as soon as you can. Do not double dose.

Denture wearers should remove their dentures before taking these medications.

Common Side Effects: Diflucan can elevate the level of Neoral or Prograf in your blood.
Tacrolimus After Lung Transplantation

Prograf®, FK506

Purpose: Prograf® is an immunosuppressive medicine that helps prevent organ rejection.

Dosage: The dose we prescribe for you is based on your lab values. The capsules come in .5mg, 1mg, and 5mg and in a solution of 5mg/ml.

When: In the morning, take with breakfast after your lab work is completed. Repeat the dose in the pm, 12 hours after your am dose.

Precautions: Prograf® blood levels can be altered by some medicines. Before you take any new drugs please contact the transplant team. New mothers taking Prograf are advised NOT to breast feed.

Common Side Effects: Headache, tremors, seizures, change in mental status, insomnia/nighmares, high blood sugar, high-blood pressure, anemia, loss of appetite, diarrhea, decreased kidney function, leg cramping, elevated potassium levels, lowered magnesium levels, hair loss.

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Antiviral Medications

Zovirax (acyclovir) and Cytovene (ganciclovir)

Purpose: Used to prevent or treat viral (herpes) infections often found in the mouth or genital area.

Dosage: Ganciclovir (iv) medication will be administered, in certain patients, once daily for CMV infection prophlaxis for the first 3 months, after transplant. Valcyte adult dosage is typically 900mg taken once a day for 3 months to one year following transplantation.

If you miss a dose of any of these medications, take it as soon as you can. Do not double dose.

Common Side Effects: Side effects are rare but can include lowered white blood cell count and kidney problems.
Mycophenolate mofetil After Lung Transplantation

CellCept®

Purpose: CellCept® is an immunosuppressive medicine that helps prevent organ rejection.

Dosage: The dose we prescribe for you is based on your lab values. The capsules come in 250mg and 500mg sizes. Liquid formulation can be made by your pharmacist in a concentration of 100mg/cc.

When: In the morning, take on an empty stomach. Repeat the dose in the pm, 12 hours after your am dose.

Precautions: Antacids such as Maalox and Mylanta decrease your body's absorption of CellCept. You should never take antacids at the same time as CellCept. You will be prescribed other medicines to protect your stomach, such as Prilosec or Prevacid, while on CellCept.

Common Side Effects: Nausea, vomiting, low white blood cell count, loss of appetite, abdominal pain, diarrhea.
Diuretic Medications after Lung Transplantation

Lasix® (furosemide)

Purpose: Lasix removes excess fluids from your body and sometimes helps us manage your blood pressure.

Dosage: Varies according to your body weight, kidney function, potassium levels, urine output, and blood pressure.

When: The transplant team will advise if they prescribe this medication for you.

Prednisone After Lung Transplantation

Prednisone

Purpose: Prednisone is an immunosuppressive medicine that helps prevent organ rejection.

Dosage: BE SURE TO READ LABEL INSTRUCTIONS.

Adults: Use only 5mg tablets unless instructed otherwise by the transplant team.

Children: Prednisone in liquid formulation of 1mg/cc concentration is recommended.

When: In the morning, take on an empty stomach. Repeat the dose in the pm, 12 hours after your am dose.

Common Side Effects: Mood swings, depression, euphoria, irritability, thrush, increased risk of infection, joint discomfort, muscle deterioration, osteoporosis, high blood sugar, "moonface," cataracts, heightened sun sensitivity, acne, high blood pressure, increased appetite, vision changes weight gain, fluid retention.

Immunosuppressant Medications

- Cyclosporines
- Tacrolimus
- Mycophenolate Mofetils
- Prednisone
- Azathioprine
- Sirolimus
- Daclizumab and Basilecmab
- OKT3
- Anti-Fungal Medications
- Antiviral Medications
- Diuretics
- Antibiotics
- Anti-Ulcer Medications
Antibiotic Medications After Renal Transplantation

Bactrim® (septra)

Purpose: Prevents bacterial infections.

Dosage: Bactrim is available in pill form and adults will take one tablet daily, or three times a week. If you miss a dose of any antibiotic medication, take it as soon as you can. Do not double dose.

Precautions: Some patients are unable to tolerate Bactrim and other sulfa-based medications. For those patients, the transplant team may prescribe Dapsone or other medications.

Common Side Effects: Rash, lowered white blood cell count, nausea, vomiting, diarrhea, sun sensitivity.
Imuran® is an immunosuppressive medicine that helps prevent organ rejection.

The dose we prescribe for you is based on your weight and white blood cell count.

Adults: Tablets are available in 50mg size which can easily be broken in half.

At bedtime with your other nighttime medications.

Certain medications, such as allopurinol, can increase the effects of Imuran and further deplete your white blood cell count. Remember to always contact the transplant team before taking any new medication.

Decreased white blood cell count, decreased platelet count, hair loss, anemia, liver problems.
Anti-Ulcer Medications

**Prilosec® (omeprazole), Prevacid® (lansoprazole), Zantac® (ranitidine), Axid® (nizatidine), Carafate® (sucralfate), Pepcid**

**Purpose:** Prevent stomach ulcers or irritation which can develop when prednisone doses are high, and while taking CellCept.

**Dosage:** Type and dose of medication vary based on individual need. If you miss a dose of any of these medications, take it as soon as you can. Do not double dose.

**Common Side Effects:** Side effects are very rare.
Rapamune® (sirolimus)

Purpose: Rapamune is an immunosuppressive medicine that helps prevent organ rejection.

Dosage: Available in liquid formulation at a 5mg/ml concentration and 1mg tablets.

When: In the morning, take consistently either before or after breakfast.

Precautions: Rapamune levels can be altered by certain medications. Remember to always contact the transplant team before taking any new medication. New mothers taking Rapamune are advised NOT to breast feed.

Common Side Effects: Low white blood cell count, low platelet count, leg swelling, joint pain, headache, diarrhea, anemia.

Immunosuppressant Medications

- Cyclosporines
- Tacrolimus
- Mycophenolate Mofetil
- Prednisone
- Azathioprine
- Sirolimus
- Daclizumab and Basilecmab
- OKT3
- Anti-Fungal Medications
- Antiviral Medications
- Diuretics
- Antibiotics
- Anti-Ulcer Medications
Immunosuppressant Medications

Daclizumab and Basiliximab After Lung Transplantation

Zenapax® (daclizumab) and Simulect® (basilecmab)

Purpose: Both are immunosuppressive medicines that help prevent organ rejection.

Dosage: One of these medications, which are administered only by IV, may be given at the time of your operation, and in the first few days to weeks post-operatively.

When: The transplant team orders the medication and it will be administered by the nurse during your hospitalization, or as an outpatient in the Comprehensive Transplant Program.

Common Side Effects: Constipation, nausea, diarrhea, edema, abdominal distention.

Immunosuppressant Medications

- Cyclosporines
- Tacrolimus
- Mycophenolate
- Mofetils
- Prednisone
- Azathioprine
- Sirolimus
- Daclizumab and Basiliximab
- OKT3
- Anti-Fungal Medications
- Antiviral Medications
- Diuretics
- Antibiotics
- Anti-Ulcer Medications
OKT3 After Lung Transplantation

OKT3® (monoclonal antibody)

Purpose: OKT3 is an immunosuppressive medicine that helps prevent organ rejection.

Dosage: Administered intravenously only.

Adults: Usually receive 5 to 10mg per day over 7 to 14 days.

Children: Usually receive 2.5 to 5 mg per day over 7 to 14 days.

When: The transplant team orders the medication and it will be administered by the nurse during your hospitalization.

Common Side Effects: Fever, chills, flu-like symptoms, shortness of breath, headache, low blood pressure, joint pain, diarrhea.