

Lung Transplantation at Brigham and Women's Hospital

A Guide for Patients and Families

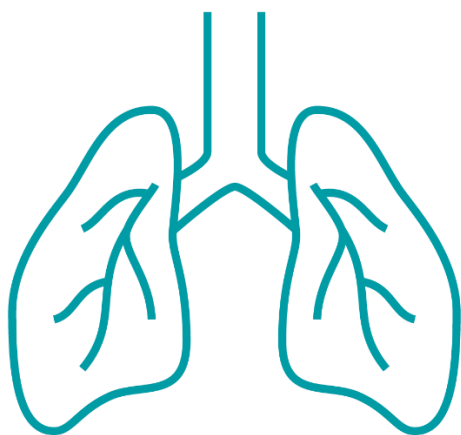


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Part 1: Initial Steps

Members of the Brigham and Women's Lung Transplant Team

Practice Assistant II - Referral Specialist

Jessica Dawn

Phone: 617-525-7614 Fax: 617-525-0429

The Practice Assistant is the primary contact with your Referring Physician and will work with your healthcare and insurance providers to ensure our team has the necessary information for your new patient visit. You have likely already met on the phone when scheduling your new patient visit.

Senior Transplant Administrative Coordinator

Ayanna Stirling-Cornelius

Phone: 617-278-0502 Fax: 617-525-0428

Pre-Transplant Administrative Coordinator

Sonya Gillis

Phone: 617-278-0502 Fax: 617-525-0428

The Pre-Transplant Administrative Coordinators are your first point of communication during the consultation and evaluation process. They will assist with scheduling, testing, and clinic appointments, and can also point you in the right direction for other questions related to the evaluation process. You can feel free to contact your pre-transplant administrative coordinator during normal business hours or leave a message during off hours regarding non-urgent issues. This call will be returned on the next business day.

Post-Transplant Administrative Coordinator

Nireida Fonseca

Phone: 617-732-7269 Fax: 617-394-3216

The Post-Transplant Administrative Coordinators are your primary contact regarding scheduling, testing, and clinic appointments after your transplant. They can also help connect you to the appropriate person to assist with questions that she cannot answer. You can feel free to contact your post-transplant administrative coordinator during normal

business hours or leave a message during off hours regarding non-urgent issues. This call will be returned on the next business day.

Pre-Transplant Nurse Coordinators

Kathy Boyle, RN

Gina Damp, MSN, RN, CCTC

The Pre-Transplant Nurse Coordinators will facilitate all your care during the evaluation process. They will meet you in the new patient clinic, provide education and answer questions regarding lung transplantation, and facilitate communication with the various providers involved in completing the evaluation process. They will also communicate with you and your referring physicians regarding testing that is required for completing the evaluation process.

Post-Transplant Nurse Coordinators

Linda Cronin, RN

Megan Frenette, BSN, RN

Stacia Meadowcroft, BSN, RN

Jessica Mongello, BSN, RN, CCRN

Inpatient Nurse Coordinator

Karen Tsveybel, MSN, RN, CCTC

Per Diem Nurse Coordinators

Ellen Modi, BSN, RN

Deborah Valenza-Glennon, BSN, RN

The Inpatient and Post-transplant Outpatient Nurse Coordinators serve as the heart of clinical care coordination for the lung transplant team, and you will communicate with them frequently. They will help with your initial orientation to the team and will help to adjust and manage your medications after transplantation. The inpatient nurse coordinator will focus on your inpatient care when you are hospitalized, providing education related to the management of your transplant, and communicating with your outpatient coordinator when you are ready to be discharged. The post-transplant outpatient nurse coordinators will address questions related to your symptoms and medical concerns and collate your clinical information for the purpose of post-transplant care. They can also assist you in identifying other providers who might be more helpful in addressing concerns that are not appropriate for the transplant team. You can reach your nurse coordinator during normal

business hours. You can also leave a message regarding non-urgent clinical issues during off hours, and this call will be returned on the next business day.

Nurse Practitioner Team Manager

Valerie Durney, MSN, NP, CCTC

Nurse Practitioners

Jessica Fenty-Scotland, MSN, AGNP-C

Shirley Marshall, MSN, AGPCNP-BC

Our licensed nurse practitioners have many years of combined experience as care providers on our team. Their current focus is transplant clinic, where they evaluate and help manage our patients throughout the transplant process. They also focus on implementation of practice guidelines and protocols. You will likely meet with them during one of your clinic visits with our team.

Transplant Surgeons

Hari Mallidi, MD, FRCSC, Surgical Director

Anthony Coppolino, MD

John Young, MD

Mohamed Keshk, MD, MSc

Transplant surgeon team are members of the Division of Thoracic Surgery in the Department of Surgery. You will meet with one of them during your evaluation. They discuss the overall medical and technical aspects of lung transplantation with you and will be performing your lung transplant procedure and will be closely involved with your care post-transplantation.

Transplant Pulmonologist Team

Nirmal Sharma, MD

Medical Director, Lung Transplant Program

Dr. Sharma is the Medical Director of the Lung Transplantation Program at BWH and member of the Division of Pulmonary and Critical Care Medicine in the Department of Medicine. Dr. Sharma's clinical and research interests are in extracorporeal life support technologies and understanding and treating lung transplant rejection. In addition to participating in your inpatient and outpatient clinical care, Dr. Sharma may be called upon

as Medical Director to address difficult clinical questions regarding your management. In conjunction with Dr. Mallidi, he also leads the development of the clinical services, policies, and procedures of the team, and may speak to your concerns regarding these areas as is necessary during your care.

Hilary Goldberg, MD, MPH

Clinical Director, Pulmonary and Critical Care Medicine

Dr. Goldberg was the prior Medical Director for the Lung Transplant Program and is currently the Clinical Director of the Division of Pulmonary and Critical Care Medicine at Brigham and Women's Hospital. Dr. Goldberg's clinical research is focused on therapies for interstitial lung disease (ILD) and outcomes in lung transplantation. She has authored over 70 peer-reviewed publications and has been involved in the design and implementation of multicenter clinical trials in ILD.

Stefi Lee, MD

Dr. Lee is a pulmonologist in the Division of Pulmonary and Critical Care Medicine and joined our team in 2021. Her interests include research into treatment of flu and pneumonia. Dr. Lee participates in both the inpatient and outpatient care of our lung transplant patients.

Tany Thaniyavarn, MD

Dr. Thaniyavarn is a pulmonologist in the Division of Pulmonary and Critical Care Medicine. He recently joined our team from Duke University Hospital in Durham, NC. His area of interest is antibody-mediated rejection, and he looks forward to conducting more research on this aspect of lung transplantation. He participates in both the inpatient and outpatient management of lung transplant recipients.

Physician Assistants

Will Clippinger, PA-C

Jillian Hamlin, PA-C

Sara Hammer, PA-C

Jillian Lynch, PA-C

Jennifer Lynett, PA-C

Kaitlyn McGowan, PA-C (Chief PA)

Arzoo Patel, PA-C

Hanna Rajabi, PA-C

Katie Ryder, PA-C

Roshni Shah, PA-C

The PA team will be responsible for coordination of your care during your stay during evaluation for transplant. They will help to facilitate your testing and are available for any questions you have during this hospital stay. The inpatient physician assistant will provide your inpatient care for most of your hospitalizations after transplant, in coordination with the pulmonologists and surgical team. You will likely get to know them well. The inpatient physician assistants are the first points of contact for you, the nursing staff, consultants, and other providers during your inpatient stay. They will evaluate you upon admission and for acute changes in your condition in the hospital, will formulate your treatment plan in conjunction with the attendings on service, and will arrange for any inpatient testing and procedures that may be required. You may also see them in transplant clinic in conjunction with one of the transplant pulmonologists. They can get to know you, your problems and concerns very well over the course of your post-transplant care and are able to provide longitudinal inpatient management for these issues. They serve as another invaluable resource to you as you navigate the transplant process.

Social Work

Samantha Pearlstein, LICSW

Angela Lombardo, LICSW

You will meet with one of our Transplant Social Workers during the evaluation process for an initial assessment, and to review your support team with your three supports. They can be of tremendous help in navigating the process of transplantation, including providing information on resources and services available in the local community, or on a state or federal level. The lung transplant process can be stressful- our social workers can help you create strategies for coping with your stress, including helping you find a psychotherapist. They also lead the Lung Transplant Support Group at BWH.

Financial Coordinator

Carmel Owens

Phone: 617-525-9724

The Financial Coordinator can assist with review of available insurance coverage for the transplant procedure and post-transplant care, discuss government programs to supplement coverage, and provide information regarding available resources in the

community. She is available to discuss financial concerns by phone or in person depending on patient needs.

Dietitian/ Nutrition

Caitlin Blakeley, MS, RD, LDN

You may meet the Transplant Dietitian during your inpatient evaluation for your nutritional assessment. Our transplant dietitian will also be available to address nutritional concerns as they arise post-transplantation.

Clinical Pharmacists

Keri Townsend, PharmD, BCPS

Yanmen Yang-Liu, PharmD, BCPS

Our Transplant Pharmacists specialize in the care of transplant recipients and have extensive experience in managing the complex medication regimens of our patients. They will be able to address specific concerns related to the medications we commonly use, their side effects and interactions, as well as help with utilization of other medications that you may receive.

Introduction

The lung transplant program continues a long tradition of excellence in organ transplantation at Brigham and Women's Hospital. The first kidney transplant ever performed was done at BWH. Since then, BWH has been a pioneer in renal, bone marrow, and cardiac transplantation. The initiation and development of a lung transplantation program was a continuation of this tradition and evidence of the hospital's ongoing commitment to providing the most current therapies available for our patients. Since the 1990's the transplant team has completed over 800 lung transplants.

Successful lung transplantation was achieved in the 1980's because of refinement in surgical technique and the development of immunosuppressive medications to prevent organ rejection. Physicians at the Toronto General Hospital did much of the pioneering work in this area and established the first successful lung transplant program. The program at the Brigham and Women's Hospital was developed under the leadership of former Dr. David Sugarbaker, Chief of the Division of Thoracic Surgery, and Dr. Steven Mentzer. Both Dr. Sugarbaker and Dr. Mentzer spent two years at Toronto General Hospital during the development of their program and returned here in 1988 and 1990 to start the BWH Program. In the summer of 1990 as part of the Massachusetts Center for Lung Transplantation, BWH was granted permission by the state of Massachusetts to perform lung transplants for selected adult patients. The BWH Lung Transplant Team performed both the first adult lung transplant in Massachusetts and the first double lung transplant in New England.

Since that time, Brigham and Women's Hospital has assembled a multi-disciplinary team to provide comprehensive care to patients and their families both prior to and after lung transplantation. The team includes thoracic surgeons, specialists in pulmonary medicine, infectious disease specialists, cardiologists, anesthesiologists, pathologists, specially trained members of the nursing staff in the operating room, intensive care units and thoracic intermediate care unit, psychiatrists, social workers, physical and respiratory therapists, nutritionists, administrative coordinators, registered nurses, and nurse practitioners.

This manual is organized into several sections, each relating to a specific aspect of lung transplantation. In this manual we describe the evaluation process, the hospitalization for the transplant and aspects of recovery, the process of transitioning to home, and the long-term aspects of life after transplant.

As outlined in this manual, successful lung transplantation requires a coordinated, multi-disciplinary team effort. An important member of a successful lung transplant team is the patient undergoing transplantation. Becoming educated prior to the transplant and participating actively in pulmonary rehabilitation enhances the chances for a good outcome after transplantation. By reading and understanding the material presented in this manual prior to your transplant, you will better understand what to expect and may shorten your hospital stay, as it is necessary to understand this material prior to discharge. Reading this material ahead of time will also allow you the opportunity to ask any questions you might have during your office visits pre-transplant. Any of the physicians, nursing staff, office staff and team members are happy to answer questions and you should feel free to seek answers to all your questions.

The Evaluation Process

Initial Appointment

Your first appointment will be a consultation with one of the Pulmonologists and/or Thoracic Surgeon of the lung transplant program, and our nursing staff. During this meeting we will review your medical history and results of tests previously performed by your referring provider and perform a physical examination. Based on those we will provide an individualized care plan for you. We will also discuss the general aspects of the lung transplantation process with you. This initial evaluation may require a full day, so please plan accordingly. At the conclusion of these meetings, depending on your interest and our assessment of your medical status, we may recommend further testing for evaluation of lung transplant candidacy. We will discuss a large amount of complicated information related to your medical care; therefore, we request that you bring a family member or a friend who can help you ask questions during this first visit.

Should you and the team mutually decide to proceed with evaluation for lung transplantation, the next step is to complete the evaluation. The evaluation process to become a candidate for a lung transplant is quite extensive. Most of the testing is completed during a two-day, one overnight admission to our hospital. Some other tests need to be completed in the outpatient setting. It is important to finish these in a timely manner for us to determine your eligibility for transplantation.

Comprehensive Evaluation

Please note the following testing items will only be completed after a decision is made to move forward with the evaluation during your clinic visit.

Cardiac Catheterization (Cath): A cardiac catheterization can be divided into a right heart cath and a left heart cath. The right heart cath is designed to evaluate the pressures in the right sided chambers of your heart as well as in the pulmonary arteries. The catheterization is more accurate in measuring these pressures than the echocardiogram. The left heart cath assesses the presence or absence of disease in the coronary arteries, which provide blood flow to the heart itself. During the cardiac catheterization, you will receive light sedation. A site in your neck, groin, or arm will be sterilized and a catheter will be placed through your vessels and into your heart to obtain the described measurements. Depending upon the approach you may be required to lie flat for several hours after this procedure to prevent

bleeding. All patients will undergo a right heart cath, and patients above the age of 40 years or with symptoms of coronary artery disease will also undergo a left heart cath.

Electrocardiogram (EKG): An EKG is a 10-minute procedure which is performed by placing six electrodes on your chest and one electrode on each of your four limbs. A recording of the electrical activity of your heart is obtained which provides information about the rate and rhythm of your heartbeat, how your heart is situated in your chest, and an assessment of any damage to your heart.

Echocardiogram (Echo): An echocardiogram is an ultrasound of the heart. It is performed to evaluate the impact of lung disease on the mechanics of your heart. It examines the chambers, valves, aorta, and the wall motion of your heart. This testing can also provide information concerning the pressure in the pulmonary arteries. This information is important in planning the exact approach during the transplant operation.

Arterial Blood Gas (ABG): An arterial blood gas measures the amount of oxygen that your blood can carry to your body tissues. The test is performed by placing a needle into an artery in your wrist. Approximately 3 ml of blood is required. Any discomfort at the site where the needle was inserted will go away in a few minutes.

Pulmonary Function Tests (PFT): A pulmonary function test measures lung volume and the rate of airflow through your lungs. Pulmonary function tests require that you perform a variety of breathing exercises by blowing into a tube. The results of these exercises measure the progress of your lung disease. Please inform the Physician Assistant or PFT technician before these tests if you are taking bronchodilators or other inhaled medications.

Six Minute Walk Test (6MWT): A six-minute walk test measures how far you can walk at your own pace in 6 minutes. An oximeter is used to measure the amount of oxygen in your blood. Upon the results of this walk it may be determined that you require supplemental oxygen when you walk. This test also helps us assess your functional status.

Radiographic Studies: A radiographic study requires the use of x-rays. The most common is the chest x-ray. A chest x-ray (CXR) is a painless, brief procedure which takes an internal picture of your chest including the lungs, ribs, heart, and the contours of the great vessels of your chest. A CXR can aid in diagnosing infection, collapsed lung, hyperinflation, or tumors.

Chest Computerized Tomography (CT) Scan: A CT scan is a series of pictures of separate horizontal sections of your chest which are combined by a computer system to create highly

detailed images of the structure of your chest. Chest CT assists with the detection of problems of the chest not easily found on CXR.

Abdominal Ultrasound: An ultrasound of your abdomen will be completed to assess your internal organs. This allows us to view their appearance and look for any abnormalities.

Esophageal manometry and 24-hour pH probe with impedance: Esophageal manometry measures the strength at which your esophagus contracts and how well it moves food/liquid to your stomach. A pH probe is a tiny catheter, smaller than a pen, which is placed through your nose into your esophagus. The probe remains in place for 24 hours and is then removed. The readings obtained allow us to assess for acid reflux, which can significantly impair your lungs post-transplant.

Ventilation/Perfusion Scan (V/Q Scan): A V/Q scan is a test that compares right and left lung function. You will need to be injected with a small amount of radioactive material and will then be asked to inhale (through a mask) a radioactive gas which is distributed throughout your lungs. The gas is exhaled normally. We expect your left lung to have a little bit less perfusion and less ventilation than the right lung because the left lung is smaller.

Laboratory Specimens: Blood samples are required for both routine and specialized testing. Specimens are sent for blood chemistries including liver function tests, kidney function tests, cholesterol, and electrolytes. A complete blood count is obtained to determine whether you have an infection or anemia. Blood levels are obtained for information on whether you have been exposed to various infections including herpes simplex virus, HIV, and other viruses. We also will collect sputum and urine samples for culture.

Social Work Assessment: The transplant social worker will meet with you and your support team to review our program in detail and to provide you with educational information you will need prior to transplant. The social worker will also discuss with you your needs, both emotional and physical. We ask that you bring in at least 3 support people to this meeting. As part of this evaluation, you will be asked to complete a support team worksheet highlighting family members and other individuals who are available to help care for you if you are too ill to care for yourself alone. You will also be asked to complete a health care proxy form.

Psychiatric Assessment: The meeting with the transplant psychiatrist serves several purposes. The first is to get a sense of your thoughts and emotions related to the transplant process. As with any important medical decision, it is important that you understand the risks, responsibilities, and treatment options related to your condition as well as to

transplant. The discussion will consider how long you have been considering transplant and explore the personal factors contributing to your choice to pursue evaluation now. A second goal is to identify any psychiatric symptoms you might have that may benefit from further evaluation or treatment. Anxiety, depression, memory problems, and sleep disturbances, for example, are common among individuals with chronic illnesses, including pulmonary disease. While often these symptoms remain mild, or go away on their own, sometimes they can impact day-to-day functioning and happiness. The psychiatrist may have recommendations for psychotherapy or medications that may help your mood, sleep, or appetite. Or there may be suggestions for further testing, such as a sleep study or memory testing. Some of these recommendations may be necessary for transplant candidacy, though most often they are made primarily to improve your wellbeing and overall quality of life. Third, the psychiatrist will ensure that any pre-existing psychiatric illnesses you may have been stable and well treated. In this situation, the psychiatrist may request a more detailed review of your medical records and a conversation with your outpatient psychiatrist or therapist. At various points in the process, you may be asked to obtain additional treatment to ensure your readiness for transplant. Finally, there will be a thorough review of any psychiatric medications you are currently taking, to ensure they are safe and compatible with lung transplant. If necessary, the psychiatrist can help you work with your own mental health provider, primary care doctor, or pulmonologist to make any needed changes in your medications.

Nutritional Assessment: you will also meet with the transplant dietician. During this initial evaluation you will discuss your weight, your weight change history, the foods you typically eat and your appetite. At this time, you will also receive information regarding the number of calories and protein you need to maintain your current nutritional status, as well as your required weight gain or weight loss, whichever is appropriate for you. Patients must have a body mass index (BMI) between 17 and 30 to be listed for transplant. If your BMI is between 30 and 35 and you are consistently losing weight, you can be considered for transplantation. BMI is calculated by dividing your weight in kilograms by your body surface area, which is your height in meters, squared. The dietician will work with each patient to achieve this goal.

Infectious Disease Consultation: patients with Cystic Fibrosis, Bronchiectasis, and other disorders will undergo evaluation with our infectious disease specialists. This physician will interview you regarding your infectious disease history. You will also be asked about any foreign travel, immunizations, or vaccinations you might have had in the past. You will also be asked about any exposure to any occupational or infectious hazards.

Ear, Nose, and Throat Consultation: patients with Cystic Fibrosis, Bronchiectasis, or a history of sinus disease, will be evaluated by an ear, nose, and throat physician. In addition, a CT scan of the sinuses will be performed for these individuals.

Please note that other consultations will be obtained if necessary for specific issues related to your health.

Local Evaluation

We ask you to coordinate the few remaining tests that need to be completed before determining your candidacy through your referring or primary care physician. If these items are up to date, a repeat test may not be necessary at the time of evaluation.

- Enrollment in outpatient pulmonary rehabilitation
- Gynecological exam and Pap Smear: every 3 years if history of negative exams
- Mammogram: women over 40 need this annually
- Colonoscopy: anyone over the age of 45 (Cystic Fibrosis patients over the age of 30), or as clinically indicated
- Bone Density Scan: within last 2 years
- Dental Care: routine dental cleaning, exam, and letter of dental clearance
- Hepatitis B vaccine series
- Routine Vaccinations

Identifying a Support Team

During the evaluation process it is important to identify a group of support people. Having a lung transplant means making an ongoing commitment from you. Your support people, in turn, must make a similar commitment to you. These people must be present in the hospital for teaching and discharge planning and must be readily available to you. We will ask you to outline a list of support team members who will be available to care for you 24 hours per day, seven days per week, for an indefinite period after transplant, if you are unable to care for yourself. We will also ask you to complete a form identifying your health care proxy.

We may require that your family/support team attend clinic visits with you before transplant, so that we can meet the members of your team and for informational purposes. After transplant, you will be seen weekly for an indefinite period after transplant, depending on your post-transplant course. One of your support people must be available to travel with you. This includes driving you to the clinic appointments and other appointments you might need post-transplant. The support person must also be available to bring you in for any emergency and unscheduled visits.

To make your transplant a successful one takes strong support from your family and friends. This support will help ensure you get the health care necessary after your lung transplant.

General Evaluation Criteria

Below is an outline of general criteria that the transplant program uses to evaluate potential candidates. The list below provides a guideline for the team's decision making and is not all-inclusive.

- Recipients should be free of any signs of cancer other than basal or squamous cancer of the skin for at least five years to be considered for transplant.
- Patients with advanced disease of an organ other than lung may be determined unsafe for lung transplantation. Examples include:
 - Coronary artery disease which cannot be corrected
 - Heart failure with limited cardiac function
 - Non-curable active or chronic infections
 - Cirrhosis of the liver
 - Chronic kidney dysfunction
- Diabetes Mellitus, Peptic Ulcer Disease, and other illnesses should be well controlled before consideration of lung transplantation.
- Significant chest wall or spinal deformity may be problematic for transplantation.
- History of inability or unwillingness to comply with medical recommendations will be reviewed.
- Untreatable psychiatric illness, such as depression or anxiety unresponsive to therapy may be obstacles to consideration of lung transplantation.
- Candidates must have a consistent and reliable support team to be considered.
- Addiction to substances such as alcohol, tobacco or narcotics will be reviewed. Patients must be able to wean off narcotic use and abstain from tobacco and alcohol use to be considered for transplant.

- No upper age limit exists for consideration of lung transplantation. Age is considered in combination with other medical problems and conditions in determining if transplant is a safe option.
- Patients must be exercising and enroll in a pulmonary rehabilitation program to be considered for transplant. In addition, patients must be able to walk 650 feet or more on a 6-minute walk test to be considered.
- The transplant team will review each patient's history of prior infections to ensure that an antibiotic regimen exists that will allow for effective treatment after transplant.
- Severe malnutrition or obesity will need to be corrected before listing for transplant. A body mass index (BMI) of 17-30 is considered acceptable. Patients with a BMI between 30-35 who demonstrate persistent weight loss can be considered for listing.
- Degree of osteoporosis and associated symptoms is reviewed in consideration of transplant candidacy.

The Decision about Transplant Candidacy

When your evaluation is complete, the multidisciplinary team reviews all the results and makes recommendations concerning the treatment of your lung disease. The multidisciplinary team meets weekly to review completed evaluations. They may suggest additional testing or consultations to provide additional information regarding candidacy.

If accepted as a lung transplant candidate, you will join many other patients who are awaiting lung transplant. You will then be seen on our clinic on a regular basis for monitoring and ongoing testing.

There are occasions when lung transplantation is not in the best interest of the patient. In these instances, we will discuss referral to alternate programs with you and your referring physician when appropriate.

Part 2: Important Program Information and Resources If Accepted as a Lung Transplant Candidate

Now that all the testing is over and you have been accepted as a lung transplant candidate, you will be listed with United Network for Organ Sharing (UNOS). The organ procurement organization in our area is New England Donor Services (NEDS). Your name is placed on a list with the names of many other patients awaiting lung transplants in New England and nationally.

The Organ Procurement and Transplantation Network (OPTN) have established criteria to determine the distribution of lungs for transplant. In December 2021, the OPTN Board of Directors approved a policy to change the process for matching lung donors and recipients. The new policy, effective March 2023, creates a single, composite allocation score, specific to each match from a lung donor. It will replace a series of matching categories historically used to assess patients' transplant priority.

The new policy is based on a concept known as continuous distribution. Each lung transplant candidate will receive a composite allocation score for each organ offer. This score combines weighted priority for several attributes that reflect the candidate's need for a transplant and how well the candidate matches the organ donor.

Although we can provide this score to you upon request once you are listed, we will not be able to give you a ranking on our waiting list, nor will we be able to accurately predict your waiting time for transplantation. For more information on the CAS system of lung allocation, please refer to the UNOS website at www.unos.org.

Once you have been listed you will need to provide the transplant team with all your available contact information, including home, cellphone, and alternative phone numbers. It will be important that the transplant team be able to reach you at all hours, so that we can quickly inform you if a lung offer becomes available. It is important to always keep your cell phone on. In addition, your travel arrangements for getting to the hospital should be arranged at the time that you are listed, in advance of receiving the actual call for transplantation.

Potential Costs of Transplant

Prior to transplant, we strongly encourage you to check with your insurance companies to ensure that the following medications are covered by your medical insurance. Also inquire about your co-payments and if there are any annual gaps in your prescription coverage. Generic medications are acceptable.

MOST COMMON POST TRANSPLANT MEDICATIONS:

1. Tacrolimus (Prograf)
2. Cyclosporine modified (Neoral/Gengraf)
3. Mycophenolate mofetil (Cellcept/Myfortic)
4. Azathioprine (Imuran)
5. Prednisone
6. Valganciclovir (Valcyte)
7. Valacyclovir (Valtrex)
8. Sulfamethoxazole/Trimethoprim DS (Bactrim DS)
9. Nystatin
10. Atovaquone (Mepron)

All lung transplant patients must have the following two medical devices after transplant:

1. Pulse oximeter: measures the oxygen saturation of a patient's blood.
2. Microspirometer: a respiratory monitor that measures your FVC and FEV1.

Please note many insurance companies do not cover the full cost of a pulse oximeter and/or microspirometer. You can easily find them online at sites such as Amazon.

NON-MEDICAL RELATED TRANSPLANT COSTS:

- Local Hotels: approx. \$120/night
- Meals: approx. \$20/day/person
- Hospital Parking: approx. \$20/day/car (vouchers for one family member may be provided after 1 full week of admission)

Additional Considerations:

- Check with your insurance to see if you can be assigned a transplant coordinator or nurse advocate to assist you with transplant related insurance issues.
- Some insurance companies assist with some non-medical transplant costs
- Please be sure to notify BWH of any changes in your insurance coverage.

Lung Transplant Support Group

The BWH Lung Transplant Program offers a lung transplant support group once a month. This group can be an invaluable source of information and support for those who are at all different stages of the lung transplant process. The group is facilitated by the lung transplant social workers. It is open to patients being evaluated for transplant, listed for transplant and those who are lung transplant recipients. Family members and friends of our patients are also welcome. These groups are intended to provide information that can better prepare patients and supports who are awaiting transplantation. Participants often find that other lung transplant candidates and family members have questions and concerns like their own.

Each month a different member of the transplant community presents on various topics related to transplant. Past presenters include the lung transplant surgeon, transplant pharmacist, thoracic ICU nurse, and consulting transplant psychiatrist. Every few months, the group features a panel of lung transplant recipients and/or their caregivers who are invited to provide firsthand information about their various lung transplant experiences. Participants are encouraged to ask questions and share their concerns.

The lung transplant support group meets virtually on the first Wednesday of every month from 2:00-3:00 PM. Archived videos of past support groups are available to be viewed any time.

Instructions for Viewing Support Group Videos:

You can view any of our prior Support Group videos by visiting our Support Group page. First, navigate to our home page at brighamandwomens.org.

From the home page click the magnifying glass at the top right of the page. In the search box type support group then click the search button. You will see the link Lung Transplant Support Group. Select this link to navigate to the support group video page.

Pre-transplantation Pulmonary Rehabilitation

As a result of your lung condition, you may have developed several associated problems that need to be addressed. These include:

- Shortness of breath and increased oxygen need
- Decreased activity level
- Wasting of your muscle groups including respiratory muscles, postural or trunk muscles, and your arm and leg muscles
- Cardiovascular deconditioning
- Fear or anxiety due to breathlessness

Evaluation and participation in a pulmonary rehabilitation program is essential for all persons considering transplantation. It is important that you be in the best physical shape possible in preparation of your surgery. Participation is required for all candidates.

Pulmonary rehabilitation programs are a multidisciplinary, individually tailored outpatient program for people who are out of breath. It is a sixteen session, eight-week program of education and exercise. The goals of pulmonary rehabilitation are to improve functional status and exercise tolerance along with enhancing the ability to do daily activities.

Participants are carefully monitored during classes. They are instructed in proper breathing techniques and the correct way to use exercise equipment. Exercise on a regular basis will improve the condition of the cardiopulmonary system. Pulmonary rehab uses exercise to increase strength and endurance. While in class an individualized home exercise program is developed and designed to meet each participant's specific needs and lifestyle. Pulmonary rehab provides the tools needed to continue an independent exercise program when discharged.

Education sessions are included in each program. Topics include energy conservation, stress management, and updated information regarding respiratory medications, nutrition, and other topics to help people better understand and manage their conditions.

BWH has a facility located at Faulkner Hospital and can be reached at (617) 983-7549.

Alternative Pulmonary Rehabilitation Programs are available. Discuss locations and referral with your primary pulmonologist.

Pre-Transplant Nutrition

Proper nutrition plays a key role in preparing for lung transplantation. Everyone being evaluated for lung transplantation must meet with a registered dietitian. Your dietitian will help you establish goals for obtaining the best possible nutritional state before transplant surgery. During the initial interview with the dietitian, you will discuss your weight and weight history, the foods you typically eat, and your appetite. At this time, you will receive information about the number of calories, protein, vitamins, and minerals you will need to maintain your current nutritional status, as well as any required weight gain or weight loss, whichever is appropriate for you. Making sure that you are within an acceptable range of body mass index (BMI) helps assure that you will be in good physical condition for your pre-transplant pulmonary rehab and the transplant itself. BMI is calculated by dividing your weight in kilograms by your body surface area, which is your height in meters, squared (kg/m^2). A BMI of between 17 and 30 is considered acceptable at our program, though if your BMI is between 30-35 and you are actively losing weight, the team will proceed with evaluation and listing.

The main goal is to eat as healthily as possible in anticipation of your transplant. Many people with advanced lung disease need high calories and protein to gain weight. Listed below are some tips to increase calories and protein. If you are overweight the dietitian will provide an individual plan for you.

Getting enough calories is important to prevent weight loss and to spare the protein in your muscles from being broken down for energy.

Being well nourished has many benefits:

- Greater energy and endurance
- Maintaining strength
- Better withstanding the effects of medical treatment and stress
- Faster recovery from surgery and illness
- Fewer infections and medical complications

Resources for Patients

BWH Lung Transplant Educational Video

<https://bwhedtech.media.partners.org/programs/lung/orientation/index.htm>

PATIENT EDUCATION

- United Network for Organ Sharing
www.unos.org
- Brigham and Women's Hospital Lung Transplant Program
<https://www.brighamandwomens.org/surgery/transplantation/lung-transplant>
- Second Wind Lung Transplant Association
www.2ndwind.org
- www.transweb.org
- En Español
<http://www.trasplantesyvida.org/>
- MedlinePlus:
<http://www.nlm.nih.gov/medlineplus/lungtransplantation.html#cat59>
- New England Donor Services:
www.neds.org or (800) 446- 6362

ONLINE SUPPORT GROUPS

- Facebook has groups for those at different stages of lung transplant

- <http://groups.msn.com/transplantsupportlungheartlungheart>
- www.healingwell.com
- www.2ndwind.org (great message board for pre and post-transplant patients)
- www.transplantbuddies.org
- www.huff-n-puff.net (Interstitial Lung Disease)
- <http://health.groups.yahoo.com/group/PFF> (IPF)
- www.geocities.com/younglungz (for young adults with chronic lung disease)

DISEASE-SPECIFIC WEB SITES

- Alpha-1 Association
 - <http://www.alpha1.org>
- Coalition for Pulmonary Fibrosis
 - <http://www.coalitionforpf.org/>
- Cystic Fibrosis Foundation
 - <http://www.cff.org/>
- EFFORTS (Emphysema/ COPD Foundation for Our Right to Survive)
 - <http://www.emphysema.net/>
- Pulmonary Hypertension Association
 - <http://www.phassociation.org/>
- Sarcoid Networking Association
 - <http://www.sarcoidosisnetwork.org/>
 - <http://www.sarcoidosisonlinesites.com/>

FINANCIAL GRANTS AND FUNDRAISING

- Help Hope Live Foundation www.helphopelive.org (800) 642-8399
- Children's Organ Transplant Association (also serves adults with CF)
www.cota.org (800) 366-2682
- National Foundation for Transplants www.transplants.org
- National Transplant Assistance Fund www.transplantfund.org (800) 642-8399

RHODE ISLAND RESIDENTS ONLY:

- Rhode Island Organ Transplant Fund (401) 462-6390
<http://www.dhs.ri.gov/Adults/HealthMedicalServices/OrganTransplantFund/tabid/889/Default.aspx>

MASS RESIDENTS ONLY:

- Massachusetts Organ Transplant Fund: Joan Gorga: 617-753-7342
- Dare To Be Alive: www.daretobealive.org (508) 398-1260

FINANCIAL ASSISTANCE FOR CYSTIC FIBROSIS ONLY

- Lungs for Life- (financial grants located under "programs" on web page)
www.lungsforlife.org (585) 436-1385
- Genentech Cystic Fibrosis Endowment (Provides financial assistance for uninsured and underinsured. Also assists with co-pays. Takes family changes into account (marriage, divorce, college, job change). <http://www.genentechcfendowment.org/>)
- Karen's Climb Foundation (advocacy and financial assistance)
www.karensclimb.com (603) 595-8055
- The Joey Fund joeyfriends@joeyfund.org
- Boomer Esiason Foundation (scholarships, transplant grants, resources)

www.esiason.org (646) 292-7930

CAREGIVER AND SUPPORT ORGANIZATIONS

- www.caregiving.com
- www.wellspouse.org
- www.dfci.org/caregiver

Free online services that can help you create a website which allows you to update family and friends via the web about your transplant

- CARINGBRIDGE www.caringbridge.org
- Lotsa Helping Hands www.lotsahelpinghands.com

MISCELLANEOUS INFORMATION

- 2-1-1 Call Center or www.211.org referrals based on state or zip code for assistance with food, housing, employment, health care, counseling, financial grants and more

LITERATURE

- Preparing for Surgery, Peggy Huddleston
- The Lung Transplant Handbook: A Guide for Patients, Karen A. Couture
- After Surgery, Illness or Trauma: 10 Practical Steps to Renewed Energy and Health, Regina Sara Rynan
- Taking Flight: Inspirational Stories of Lung Transplantation, Joanne M. Schum
- Seven Letters that Saved My Life, Dottie Lessard

MOVIE/TELEVISION

- “Boston Med”: <http://bostonmed.abcnews.go.com> (episode 1)
- “The Power of Two” www.ThePowerOfTwoMovie.com

BRIGHAM AND WOMEN'S HOSPITAL PARKING ASSISTANCE PROGRAM

Sponsored by Patient/Family Relations

Located in the Bretholtz Center, behind the Main Information Desk at 75 Francis

Monday-Friday: 7:30 a.m. – 6:00 p.m. Saturday: 11:00 a.m. – 3:00 p.m. (617)-732-6636

VALIDATION:

All visitors are asked to self-park in our Service Center Garage. Valet parking should only be used by patients. If you are here visiting your loved one and you will be parked longer than SIX hours, you can get your ticket validated at Patient/Family Relations. The validation will reduce the rate for 6-7 hours from \$36 to \$17 or 7-24 hours from \$40 to \$20. All patients/visitors MUST get their ticket validated to receive this discount; patients/family members with no validation cannot be reimbursed. There is no time stamp for validation; please stop by Patient/Family Relations anytime during the day, or the please see Security at the Main Lobby Desk at 75 Francis after hours.

ONGOING PARKING ASSISTANCE:

For patients that are inpatient for a minimum of 5 days OR have 3 or more outpatient appointments per week for three consecutive weeks, an application for parking assistance can be requested at Patient Family Relations. Assistance is offered based on the National Poverty Level Guidelines. Once your application is completed a Patient/Relations staff member can determine if you qualify and assistance can begin. Only one family member or friend can apply.

TYPES OF ASSISTANCE:

1. Five, \$8 off parking coupons which takes off the two most expensive hours of parking.
2. Three, all-day parking coupons the first week and the two all-day parking coupons the next week. Your parking ticket must be validated (see above.)

SELF-PARK AND VALET PARKING RATES

Please refer to your New Patient Information booklet, or for additional questions, please contact the Parking Office at (617) 732-5877.

Part 3: What to expect at the time of transplant

When Called for Transplant

When you are called for the transplant, you need to proceed to the Emergency Room at BWH as soon as possible. A lung transplant can occur at any time. There is no way to know in advance when that time will be. It is important to note that you won't be able to eat or drink once you are called in for your surgery.

Prior to the transplant the social worker and nurse coordinator will discuss with you and your family a transportation plan when called in for transplant. Consideration must be given to the possibility of inclement weather and rush hour traffic.

You must plan well in advance for other factors such as:

- Location of the BWH Emergency Room and parking garage.
- Phone calls to family members. We suggest you call one family member who will, in turn, notify other family members.
- Babysitting/childcare/pet care.
- An alternative transportation plan should the person driving you be unavailable.
- Local accommodations for family/support team members.

Additional items to note:

- Bring photo identification with you.

- Keep your cell phone with you at all times during your trip in, as we may need to contact you. You may be contacted by a 3rd party/unknown number. Please answer all incoming calls.
- There is always the possibility that the surgery will be cancelled for a variety of reasons. It is very common for patients to experience one or more "dry runs" that result in a trip to the hospital, only to find out that the transplant is not going to occur. The longer the predicted travel time for a patient, the more likely this is to occur because we call such patients earlier; sometimes before all the information concerning the potential donor is available. Our practices are designed to ensure that no lungs that are suitable for transplant are wasted; this unfortunately results in instances where patients are called into the hospital only to find the transplant has been cancelled.
- Remember that you may be called in as the primary transplant recipient, or as a back-up to another recipient. The practice of calling in "back-up" candidates is used to ensure that no lungs go to waste, in the event of an unexpected medical problem related to the primary recipient. We thank you for your understanding of this practice to give every opportunity to utilize all available lungs.
- Once you arrive at the hospital, all patients will meet with the team and complete a physical examination, vital signs, weight and radiologic tests if necessary.
- There will be a significant period of waiting time, for both primary and "backup" recipients, as we work to ensure that the available lungs are of acceptable quality for transplantation and as we coordinate the timing of lung harvest and of recipient surgery. Remember to bring reading material and other activities with you as will suit your needs during this time. Once again, we thank you for your patience as we work to ensure that the transplant process goes smoothly for all involved.

Once Your Surgery Is Completed

When your surgery is completed, you will be transferred from the operating room to the Thoracic Surgery ICU.

The first tube you will be aware of is your breathing tube. This will be in your mouth and be attached to a ventilator. You will be unable to talk, but when able, you will be asked to write messages. Communication may be frustrating, but the nurses will assist you. The breathing tube will be removed as soon as possible, which may be as early as the first day after your surgery or as late as several days after your surgery. You may need to wear either an oxygen mask or nasal prongs once the breathing tube is removed.

You will have chest tubes and drains inserted during surgery on the side of your new lung (s). These tubes and drains collect fluid and blood. Once the drainage has decreased they will be removed. Sometimes patients will go home with these drains. You will be instructed in the care of the drains if you are to go home with them.

A naso-gastric tube will be inserted through your nose and into your stomach. This tube prevents nausea and vomiting by keeping your stomach empty. This will be removed once your bowel function returns. While this tube is in place, it may cause some discomfort in your throat. If you experience this, you can be given a topical anesthetic that can help relieve this.

You will have a catheter placed in your bladder during the surgery to monitor your urine output hourly. You will have several intravenous lines. Some will be used to monitor your vital signs. Others will be used to administer medications. These will be in your neck as well as your arms; they will be removed at the appropriate time. If you undergo a single lung transplant, you will have a large incision, which will extend from front to back, under your arm on the side of the transplant. If you are having both lungs transplanted your incision will be in the middle of your chest along your sternum or chest bone or below the

In some cases, an epidural catheter inserted into the area around your spinal cord in your upper back or a parasternal catheter in parallel to the surgical incision site will control your pain. These catheters may or may not be inserted in the operating room. If it is not inserted in the OR., it will be inserted once it is safe to do so in the intensive care unit. It is very important that you receive adequate pain relief, so you must let the nurses and doctors know if you are uncomfortable. You will be asked frequently about your level of pain and if you are getting adequate relief.

You will be seen by many of the multidisciplinary team including physicians, nurses, physical therapists, nutritionists, respiratory therapists, social workers, and pharmacists. They will be actively involved in your care during your hospital stay.

During your Hospital Stay

As you recover your activity will increase. Prior to your surgery you were required to exercise and enroll in a pulmonary rehabilitation program if possible. This will be an ongoing expectation and it will be a very important aspect of your postoperative care.

Your morning routine may begin early with a chest x-ray. You will also be weighed daily. This is necessary to monitor your fluid status. You will need to bathe, get out of bed, and have some chest physical therapy each day. Chest physical therapy involves tapping on your back to assist you in coughing up any secretions in your lungs to prevent pneumonia. Physical therapy will also see you every day to assist with exercises initially. Eventually you will ride a stationary bike. You will be monitored continuously throughout your activities. Walking will be encouraged and expected to take place multiple times during the day, beginning very early in your course after surgery, and including in the ICU. In addition to your routine daily activities, you may also have some tests scheduled. You may have bronchoscopies performed during your hospitalization to look at your new lung.

The care team will also assess whether you are able to eat and drink safely. It is possible that based on the testing that you may not be allowed to eat through your mouth. Instead, you may be provided nutrition via a thin tube that is passed from your nose into your stomach. Regular tests will be conducted based on your progress to assess safety and suitability of resuming food through the mouth. Likewise, it is possible based on the testing that you will be allowed to eat through the mouth, but certain fluid or food consistency restrictions would be placed. As you recover, some of these restrictions may be lifted. You may have a very dry mouth, which we realize is quite uncomfortable. Rinsing your mouth and using swabs may help alleviate this feeling. Rest periods will be worked into your day. Your nurse will try to provide uninterrupted rest time, which may mean restricting visitors. As soon as you are able you will need to start learning about your care so your transition to home will go as smoothly as possible. You will be required to learn about your medications. Initially your immunosuppression therapy (drugs used to prevent your body from rejecting your new lung) will be given through an intravenous line. Levels of these medications will be monitored daily. Once you can eat and drink, these medications will be administered by mouth.

The team encourages you to ask questions so that you can be confident and comfortable with your care. When ready, you will be transferred out of the ICU to 11A/B/D where there are

private rooms prepared especially for lung transplant patients

Your daily schedule will be planned to include your physical care needs, teaching needs and emotional needs. Your nurse will work with you to develop an individualized activity schedule that will meet these needs. Your nurse will assist you in moving towards independence in your activities of daily living, including bathing, grooming, and walking. Please arrange for your family to bring in comfortable clothing including sneakers and socks when you have left the ICU. You will continue to participate in physical therapy and chest physical therapy and might feel most comfortable in sweatpants, T-shirts, and shorts. The nursing staff will continue to monitor your vital signs, perform wound care, provide pain relief, and obtain blood, urine and other needed specimens as deemed necessary by your physician. When walking outside your room or traveling to any tests you are required to wear a mask.

The transplant team will develop a discharge plan with you. Discharge teaching is a major part of your discharge preparation, and you are expected to be an active participant in your learning.

Areas of focus will include medications, recognition, and reporting of warning signs to your physician/coordinator and record keeping in your medical diary. Your family or designated support person will be expected to be involved with these teaching activities. Medication teaching will focus on the specific medications you will be taking including the purpose, dosage, time of day to be taken and side effects. As your discharge date gets closer your nurse will assist and supervise you in taking and recording your medications. Having a good understanding of your medication regimen will give you the best success as you transition to home. Your discharge teaching will also include a description of your activity level, specific wound care instructions and warning signs to be reported to the team. Remember that you are encouraged to call the coordinator or physician with any concerns or questions you may have when you have gone home.

Another important area of discharge teaching concerns the accurate record keeping of your diary. Your nurse will demonstrate how to record your daily weight, temperature, spirometry, oxygen saturation level and medications in your diary. Keeping an accurate log will help you to recognize any changes that might occur and will provide important information to the transplant team during your clinic visits. Using the same scale at home will provide a more accurate record of your weight. Discharge planning will also include

visiting nurses and physical therapists who will come to your home and assess your progress and communicate with the team when necessary.

We recognize that this is a very stressful time for you and your family. The 11th floor nursing staff is committed to providing care designed to support your physical and emotional needs.

Transplant Diary

In preparation for your discharge from the hospital after your transplant, you will be provided with a lung transplant diary. This diary will give you a basic overview of your daily healthcare routine, medications, monitoring, and other activities. It also has tips on recognizing problems that may necessitate immediate medical attention. The diary and this manual are invaluable resources for you. You will be expected to ask your transplant team questions and to seek guidance on your routine.

You should use your diary for:

- Recording your spirometry results, daily weight, along with your oxygen saturations, temperature, and blood sugars if necessary.
- Keeping track of medications, dosage changes, time taken, level results, etc.
- Making notes about special instructions.
- Writing down questions you may want to ask.
- Reviewing general health guidelines and precautions.

Warning Signs:

- Any elevation in temperature greater than 1 degree above normal
- A fall in spirometry in either FEV1 or FVC. A drop of more than 10% is significant and you should notify the transplant team.
- A drop in oximetry (oxygen saturations) of more than 2% of normal.
- New or increased difficulty breathing, either at rest or exertion.
- Nausea, vomiting or diarrhea. These can lead to poor absorption of your medications, so you must notify us promptly if they occur.
- Fatigue
- Sore throat
- Increase in sputum production - or change in color or odor.

- Persistent cough
- Inability to clear secretions
- Loss of appetite
- Frequency or burning with urination.
- A cut that does not heal.
- "Just don't feel well"

Should you develop any of these signs or symptoms, or any others that are of concern to you, you should contact the lung transplant team. For any medical life-threatening emergencies, you need to call 911 and go to the nearest emergency room.

Diet and Exercise After Transplant

Now that you have had a lung transplant, you may be wondering if changes will be made in your diet. It is important to your recovery process to maintain a healthy, well-balanced diet. Your dietitian will assess your individual nutritional needs and determine the number of calories and grams of protein you should be receiving every day while you are in the hospital and when you go home. Remember, you have unique nutritional needs based upon your age, weight status, medical condition, and food preferences. Your team will discuss any specific individual nutrition needs with you.

When you are discharged, you will continue to participate in the rehabilitation and exercise program that was developed for you. The goal of your rehabilitation is to maximize your muscular strength and endurance so that you can resume an independent life.

Once you are home you must continue to work on increasing your activity level by trying to do a little more each day. Walking is an excellent way of monitoring your progress and improving your strength. Walk every day and gradually increase the length of your walk. Be sure to pace yourself and provide for adequate rest before and after your walk.

The goal of your lung transplant is to allow you to return to an active lifestyle and improved quality of life. Incorporation of a regular exercise program that emphasizes both aerobic activity and strength training is one of the surest ways to achieve these goals. In addition, performance of aerobic exercise is one of the most important predictors of the lung function that you achieve after transplant.

Diet and exercise are key components of a successful post-transplant outcome. We recommend incorporating them into your daily routine and health maintenance.

Part 4: Life After Transplant Transition to Home

Now that you have had your lung transplant and are preparing to go home, it is important that you understand that having a transplant brings new responsibilities. The initial time at home can be quite busy. There will be many scheduled and unscheduled appointments with visiting nurses, physical therapists, the transplant team, and your local providers. It is also important that you prepare yourself for the likelihood of readmission. Almost every patient is readmitted for medication regulation, intravenous antibiotic therapy for infection or intravenous steroids to treat rejection.

At this point, the most important member of the team is you! Without your active support, the team's best efforts cannot succeed. As the lifetime caretaker of your new lung, you will need to:

- Make sure you have a health daily schedule that includes a good diet and regular exercise.
- Follow your medication schedule.
- Check your weight, temperature, spirometry, and oxygen saturations twice a day initially and eventually once a day.
- Keep all your scheduled clinic appointments.
- Make sure all your doctors, dentists, and your pharmacist know about your medications and transplant status.

Having a lung transplant and taking the medications needed to prevent rejection puts you at risk for several problems. It is important for you to follow the instructions that will help prevent or lessen complications. After discharge, you will be responsible for monitoring your health and calling the transplant team should problems arise.

Readmissions can be a source of frustration and disappointment, especially if they coincide with vacations, holidays, or family gatherings. Please be open with your feelings and concerns so that we can deal with your frustrations, joys and other feelings that accompany an event of this magnitude. It is also natural to experience a range of emotions after transplantation, even in the absence of complications. You have just undergone a major life event and are learning to live with a new and unusual set of circumstances. Joy, guilt, anxiety, depression,

and frustration are all common emotions after transplantation. You may experience one or all these feelings at different points after transplant, especially in the early post-transplant periods. Your transplant team is here to help you through these changes and can provide resources to deal with them. Please let us know if you are uncomfortable in any way and we will work to help you.

These emotions are not only stressful for you, but for your family and friends as well. We recognize this and are ready to assist in any way to help with this stress as it arises.

Please remember:

- When in doubt, call
- If you are thinking about calling, call

Clinic Visits

You will need to be seen every week at the Lung Transplant Clinic until your acute issues are addressed. Appointments are with various providers depending on day and time you're being seen, like when you were seen prior to transplant. This is also true when you are scheduled for a bronchoscopy; the pulmonologist who is on service on that day your test is scheduled will do your bronchoscopy. Please keep in mind that you will need to be flexible with days and times of clinic appointments.

When you return to the clinic after your transplant you will be scheduled for blood work, chest x-ray, and spirometry. This will be required for every visit to clinic. You will need to arrive one hour prior to your scheduled visit to allow time for this to be completed.

Your nurse coordinators will educate you on certain medication changes on the day of clinic visits.

On the days when you are scheduled for follow-up visits, please make sure to bring your diary with your recorded information to review with the team.

Common Infections and Complications

Viral Infections:

Cytomegalovirus (CMV) – CMV is one of the viral infections that occur most often in transplant patients. The risk of CMV is highest in the first months after transplantation. Patients will be started on a medication called valganciclovir in the hospital after the transplant. You will be on it once a day for 6-12 months after the transplant. Signs of CMV include fatigue, high temperature, aching joints, headaches, trouble seeing, pneumonia, and diarrhea.

Herpes-simplex virus type 1 and 2 – These viruses most often infect the skin but can also turn up in other areas like the eye and lungs. Type 1 causes cold sores and blisters around the mouth, and type 2 causes genital sores. Herpes is an infectious disease and can be transmitted sexually. Herpes infections in transplant patients, however, are not necessarily transmitted sexually.

Most herpes infections are mild, but sometimes they can be severe. Although there is no cure for herpes, it can be treated. Depending on the severity of the infection, the treatment is either by mouth, on the skin, or intravenous. Contact your transplant team right away if you think you have herpes.

Symptoms of herpes include feeling weak and having painful, fluid-filled sores in your mouth or genital area. Women should also watch for any unusual vaginal discharge.

Precautions:

1. Keep the sore areas as clean and dry as possible
2. Wash your hands with soap and water after touching the sores.
3. Wear loose-fitting clothing to avoid irritating the sores and spreading the virus.
4. Avoid kissing or having oral sex with someone who has a cold sore.

Herpes zoster (shingles) – Shingles appears as a rash or small water blisters, usually on the chest, back, or hip. The rash may or may not be painful. Call your transplant team if you have this kind of rash.

Varicella zoster (chicken pox) – Chicken pox may appear as a rash or small blister. Call your transplant team immediately if you have been exposed - do not wait to see if you are going to get sick.

Fungal Infections:

Candidia (yeast) – Candidia is a fungus that can cause a variety of infections in transplant patients. It usually starts in the mouth and throat but may also be in the surgical wound, eyes, or respiratory and urinary tracts. Candidia is most severe in the bloodstream. If there is infection in the mouth or throat, it is called thrush. Thrush causes white, patchy lesions (raw areas), pain or tenderness, a white film on the tongue, and difficulty swallowing. Candidia can also infect the tube from the mouth to the stomach (esophagus) or, in women, the vagina. Vaginal infections usually cause an abnormal discharge that may be yellow or white. Call your transplant team if you think you have a yeast infection.

Treatments of fungal infections include nystatin swish and swallow, a liquid medicine for mouth infections. All lung transplant patients will have Amphotericin nebulizers in the hospital to help prevent such infections in their lungs. Treatment of severe fungal infections may require IV medication.

Bacterial Infections:

Wound infections – Bacterial wound infections can occur at the surgical site. If you have a fever or notice redness, swelling, tenderness, or oozing at your incision, call your transplant team. After some tests for bacteria are taken you most likely will be given an antibiotic, and in some instances, you may need to be hospitalized.

Bacteria of many types can cause infection at other sites, such as the lungs, bladder or kidneys, and sinuses.

Other Infections:

Pneumocystis is a germ that is a lot like a fungus, and it is normally found in the lung. In people whose immune systems are suppressed (such as in transplant patients), it may cause a type of pneumonia. You will be on a drug called Bactrim DS after your transplant to prevent this germ. You will take this medicine indefinitely. If you have an allergy to this medication, you may undergo a process called desensitization that will introduce gradually increasing amounts of this medicine into your system until you are able to tolerate it. You will then take this medication every day. Otherwise, another medication will be prescribed for you.

This list does not include all possible infections that you may experience. Should you develop an infection(s) after transplant, your transplant team members will review the type of infection that you have and the best approach to treatment for you.

Common Post-Transplant Complications:

- Renal dysfunction
- Blood clots
- Post-transplant diabetes
- Abnormal heart rhythm (atrial fibrillation)

Preventing Infection Following Lung Transplantation:

Frequently Asked Questions

Why worry about infections?

After a lung transplant, you will need to take medications that prevent your body from rejecting your new lung(s). These medications are very important for you to take, but they can also make it harder for your body to fight off germs that cause infections. There are some things that you can do to help keep from getting sick.

Where do these infections come from?

- Some infections are caused by “reactivation” of viruses that have been in your body for years from past infections. These viruses usually don’t cause problems until your immune system is weakened. Some examples include viruses that cause cold sores (Herpes simplex virus), shingles (Varicella zoster virus), and CMV infections such as pneumonia (cytomegalovirus). These viruses can also sometimes reactivate in the transplanted lung and cause infections. You may receive medications to prevent reactivation of these viruses.
- Some infections are passed along to you by other people (such as influenza).
- Some infections come from germs from other things like food, animals, or dirt.

How can I protect myself from infection?

- Make sure that you follow all your lung transplant team’s instructions for taking medications
- If you have any questions about medications, please ask your lung transplant providers.

It is very important to wash your hands often

- Washing your hands either with an alcohol-based hand sanitizer or with soap and water is very important to prevent infections.
- Wash your hands when they are dirty and at the following times:
 - ✓ Before preparing food to eat
 - ✓ After touching raw meat like chicken or steak
 - ✓ Before eating
 - ✓ After using the restroom
 - ✓ After changing a baby's diaper
 - ✓ After touching animals such as dogs and cats
 - ✓ After going outdoors or to a public place
 - ✓ Before and after touching catheters or wounds

Ask people who touch you to wash their hands

- People can make you sick by bringing in germs from the outside. Don't be afraid to ask them to wash their hands. This includes doctors, nurses, other healthcare professionals, family members (including children), and visitors

Good skin and mouth care is very important

Some medication such as prednisone can increase your chance of getting skin and mouth infections.

- Bathe or shower daily. If your skin becomes dry, use a lotion to soften your skin and prevent cracking.
- Brush your teeth. Use a soft toothbrush. If you are unable to brush your teeth, use an antibacterial mouth rinse such as Peridex.
 - ✓ If you develop blisters or sores in your mouth, let your lung transplant team know.
 - ✓ Check with your doctor before having dental work done.
- Clean cuts and scrapes with soap and water and cover with a bandage.

Keep your living area clean

Before leaving the hospital, make arrangements to clean where you will be staying. We recommend:

- Cleaning heating and air-conditioning vents and changing the filters.
- Removing visible mold and mildew from bathrooms.
- Clean your house weekly, especially your sleeping area. This should include vacuuming carpets. It is best if you're not in the same room while this is going on; if you are, we suggest that you wear a mask during the cleaning.
- If you use a humidifier, clean it daily with a dilute solution of bleach then rinse before refilling the water tank.
- Avoid poorly ventilated spaces such as unfinished basement areas and attics that can be moldy or dusty. If you must spend time in these places, wear a mask.

Stay away from dirt and plants.

- Germs are found in dirt and on plants. These germs can cause serious infections in persons with a weakened immune system that can be difficult to treat.
- No gardening or activities that stir up dirt such as turning soil, mulching, raking, or cutting grass.

- Stay indoors with the windows closed when these activities are going on. It's unknown whether using a mask will protect you against these infections.

Be careful of what you eat and drink

Germs that cause infection can be in the food you eat. You need to be careful about how you prepare food. Here are some steps to keeping food safe:

- **Clean:** Wash hands, utensils, and surfaces with hot soapy water before and after food preparation, and especially after preparing meat, poultry, eggs or seafood.
- **Separate:** Keep raw meat, poultry, eggs, and seafood away from ready-to-eat foods.
 - Do not place cooked food on an unwashed plate where raw meat, poultry, eggs, or seafood has been.
- **Cook:** Cook foods well. Use a food thermometer to check the internal temperature of meat.
 - Cook meat until it is no longer pink, and the juices run clear.
 - Cook eggs until they are firm.
 - Bring sauces, soups, and gravies to a boil when reheating.
 - Avoid eating uncooked deli foods such as cold cuts.
- **Chill:** Keep cold foods cold. Refrigerate or freeze foods that may spoil. Refrigerate leftovers within 2 hours and make sure the refrigerator temperature is no higher than 40°F and the freezer temperature is 0°F. Never thaw food at room temperature, thaw food in the refrigerator.
- Municipal tap water is generally safe. Avoid well water if possible unless the water quality is tested frequently.
 - ✓ Avoid unpasteurized milk or vegetable or fruit juices

Talk to you transplant team about pet safety

Pets are important to many people but can sometimes pass infections to humans. Make sure to talk to your doctor about pet safety.

- Do not handle animal waste. Don't clean litter boxes, animal cages, or fish tanks.

- Do not adopt sick or stray pets or pets less than 6 months old.
- Do not have birds or reptiles as pets during and after the transplantation.

Talk to your transplant team about any travel plans

- Your chance of getting an infection is higher in certain areas of world (including certain parts of the U.S.). Talk to your transplant team before traveling to see whether you need to take any special precautions.
- Avoid travel to areas of the world where you would be unable to receive special medical care for patients with weakened immune systems.
- Talk to your transplant team before receiving travel vaccinations. Some vaccines recommended for travel can't be given to transplant recipients.
- Don't buy food from sidewalk vendors. Depending on where you travel, it may be safest to drink only bottled carbonated beverages and to avoid ice cubes.

Contact your transplant team if you are diagnosed with an infection or new illness or if you experience any of the below symptoms:

- Fever over 101°F
- Cough, stuffy nose, chest pain or shortness of breath
- Diarrhea or vomiting lasting longer than 3 days
- Skin rash
- Mouth or genital sores
- Difficulty or pain with urination
- Dizziness or headache

Part 5: Additional Educational Resources

Lung Transplant Educational Videos

Our staff have developed a variety of video presentations on the following topics that are accessible on our website.

- Evaluation Process
- Waitlist Information
- Postoperative Hospitalization
- Nutrition
- Medications
- Life-style changes after transplant
- Post-Transplant Care

Summary

We as your care providers for lung transplantation hope that the information provided in this educational manual has helped you to better understand the process of lung transplantation. As has been highlighted, you are the most important member of our team. Your understanding of and participation in the process of transplantation at all stages is a key component in our ability to improve your quality of life and avoid complications after transplantation. In conclusion, we would like to highlight the following as you move forward in this endeavor:

- We value your contribution to your care. We encourage you to write down and ask any questions you have, at any stage of the process. We encourage your support team members to do the same.
- The transplant process is exciting, stressful, and uncertain. We would like to provide care for your emotional as well as your physical needs. Please let us know how we can help you through this process.
- As a key team member, you are responsible for the aspects of your management that are in your control. These include ensuring that you understand your responsibilities and how you can participate in your care, that you ask questions when you are uncertain, and that you call your team members for any changes in your condition, no matter how trivial.
- Diet, exercise, and attention to your general medical needs are just as important as any medicine we may give you in enhancing your health and quality of life. We will rely on you and your other providers to work with us towards incorporating these aspects of your care into your routine and working toward our shared goal of making your transplant as successful as it can be.

