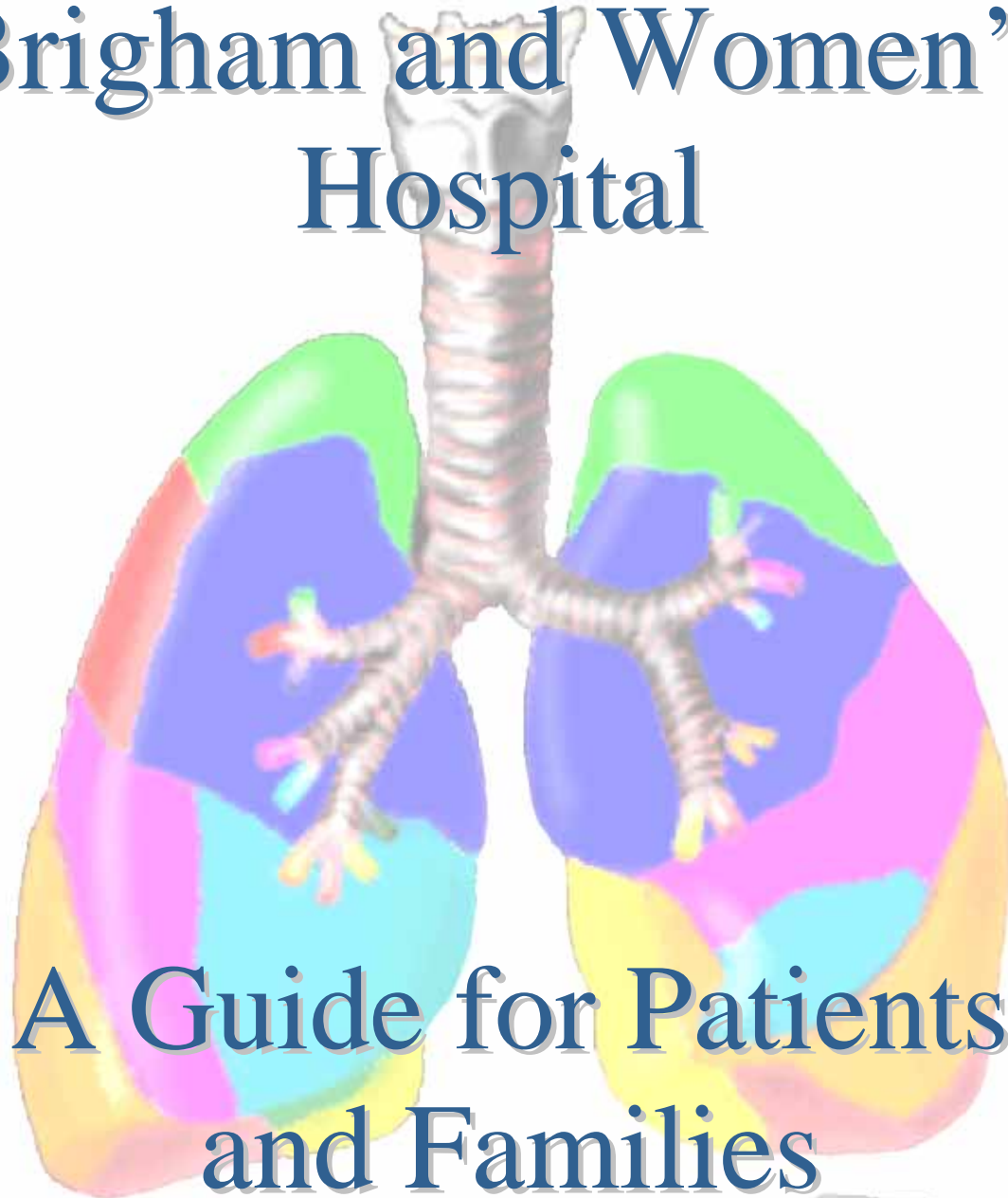


Lung Transplantation at Brigham and Women's Hospital



A Guide for Patients
and Families



BRIGHAM AND
WOMEN'S HOSPITAL



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

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***Beginning the Process of Lung Transplantation –
What You Need to Know***

Who's Who on the BWH Lung Transplant Team

Administrative Coordinators:

Pre-Transplant Administrative Transplant Coordinator:

Mariel Muir

Brigham and Women's Hospital

75 Francis St.

Boston, MA 02115

617-278-0502

(f) 617-264-6892

Mariel is your first point of communication during the consultation and evaluation process, and will assist with scheduling, testing, and clinic appointments. She can also point you in the right direction for other questions related to the evaluation process. You can feel free to contact Mariel 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 Transplant Coordinator:

Patrick Townsend

Brigham and Women's Hospital

75 Francis St.

Boston, MA 02115

617-732-7269

(f) 617-264-6868

Patrick is your primary contact regarding scheduling, testing, and clinic appointments after your transplant. He can also help connect you to the appropriate person to assist with questions that he cannot answer. You can feel free to contact him 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.

Nurse Coordinators:

Pre-Transplant Nurse Coordinator:

Caitlin McKane, RN

Brigham and Women's Hospital

75 Francis St.

Boston, MA 02115

617-525-9851

(f) 617-264-6892

Caitlin is our pre-transplant nurse coordinator, and she will facilitate all of your care during the evaluation process. She will meet patients 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. Caitlin will also communicate with you and your referring physicians regarding testing that is required for completing the evaluation process.

Inpatient Nurse Coordinator:

Shirley Dujour, RN
Brigham and
Women's Hospital
75 Francis St.
Boston, MA 02115
617-525-9471
(f) 617-264-5170

Post-Transplant Outpatient Nurse Coordinators:

Linda Cronin, RN
Brigham and
Women's Hospital
75 Francis St.
Boston, MA 02115
617-732-7299
(f) 617-264-5170

Betsy Bernazzani, RN
Brigham and
Women's Hospital
75 Francis St.
Boston, MA 02115
617-732-5971
(f) 617-264-6892

Shirley, Linda, and Betsy 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. Shirley will focus on coordinating your inpatient care when you are hospitalized, providing education related to the management of your transplant, and communicating with Linda and Betsy when you are ready to be discharged. The outpatient 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. Linda is available between 8 AM and 4:30 PM every business day except Thursday, when she is in from 7:30 AM to 4 PM. Betsy is available between 7 AM and 3 PM on working business days. You can also feel free to leave a message for them regarding non-urgent clinical issues during off hours, and this call will be returned on the next business day.

Lung Transplant Nurse Practitioner:

Valerie Durney, NP, CCTC
Brigham and Women's Hospital
75 Francis St.
Boston, MA 02115
617-732-8084
(f) 617-264-5170

Valerie Durney is a licensed nurse practitioner, with many years of experience as a care coordinator on our team. Val's current focus is in the transplant clinic, where she will evaluate and help manage our patients in both the pre and post transplant settings. Valerie will also focus on implementation of practice guidelines and protocols. You will likely meet with her during one of your clinic visits with our team.

Transplant Surgeon:

Phillip Camp, MD
Director, Lung Transplant Program
Division of Thoracic Surgery
Brigham and Woman's Hospital
75 Francis Street
Boston, MA 02115
617-732-7696
617-732-7269
(f) 617-730-2853
pcamp@partners.org

Dr. Camp is the Director of the Lung Transplantation Program at Brigham and Women's Hospital and a member of the Division of Thoracic Surgery in the Department of Surgery. He also participates as a member of the critical care staff for the Thoracic ICU. You will meet with Dr. Camp at the time of your initial consultation with the BWH Lung Transplant Team, and during the course of your inpatient stay for evaluation, should this occur. Dr. Camp will discuss the overall medical and technical aspects of lung transplantation with you, and will be performing your lung transplant procedure (unless out of town, during which time other members of the Thoracic Surgical Service, all well versed in transplantation, will perform your surgery.) Dr. Camp will also continue to be intimately involved with your care post-transplantation. Dr. Camp also participates in the development of the policies and procedures of the Lung Transplant Service.

Transplant Pulmonologists:

Please note: The Pulmonary involvement of the BWH Lung Transplant Program works via a team approach to care. The pulmonologists rotate coverage of lung transplant clinic, the inpatient lung transplant service, and other clinical services related to the care of our patients. The BWH team feels strongly that this approach to care allows all participants to be familiar with each transplant patient and his/her particular concerns and medical problems. Therefore, you will not be assigned one transplant pulmonologist, but will meet all or most at various stages of your care. While this approach may lead to some confusion for you at the start of your involvement with our team, we hope that over the short and long term you will get to know all of us and be reassured that a team of providers is participating in your management at all times.

The on-call pulmonologist can be reached during working and non-working hours (24 hours per day, 7 days per week) by calling the BWH page operator at 617-732-5656 and requesting that the 1-LUNG (15864) beeper be paged. You should contact the on-call pulmonologist at this number for any urgent concerns during off-hours or if you cannot reach the transplant coordinators during business hours. In the event of an emergency, please first call 911 to summon local emergency medical services, then contact the on-call pulmonologist to let him/her know of the emergent issue occurring.

When contacting the on-call transplant pulmonologist, please do not hold on until the physician responds, but ask the page operator to leave a call-back number where you can be reached.

Hilary Goldberg, MD, MPH
Medical Director, Lung Transplant Program
Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115
617-732-7420
(f) 617-732-7421

Dr. Goldberg is the Medical Director of the Lung Transplantation Program at BWH and a member of the Division of Pulmonary and Critical Care Medicine in the Department of Medicine. In addition to participating in your inpatient and outpatient clinical care as noted above, Dr. Goldberg may be called upon as the Medical Director to address difficult clinical questions regarding your management. In conjunction with Dr. Camp, she also spearheads the development of the clinical services, policies and procedures of the Lung Transplant Team, and she may speak to your concerns regarding these areas as is necessary during the course of your care.

Anne Fuhlbrigge, MD, MS
Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115
617-732-7420
(f) 617-732-7421

Dr. Fuhlbrigge is the immediate past Medical Director of the Lung Transplantation Program at BWH and the current Clinical Director of the Division of Pulmonary and Critical Care Medicine in the Department of Medicine at BWH. Dr. Fuhlbrigge has extensive experience in dealing with the clinical and administrative issues of the transplant program. She is one of the primary pulmonologists on the inpatient service and in transplant clinic, and continues to provide administrative input into the policies of the transplant program.

Ivan Rosas, MD
Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115
617-732-7420
(f) 617-732-7421

Dr. Rosas joined our team from UPMC. His focus is on research in interstitial lung disease and idiopathic pulmonary fibrosis. He also participates in the ILD Clinic at BWH. Dr. Rosas is well versed in transplant related issues after his time at UPMC. He participates in both the inpatient and outpatient management of our lung transplant recipients.

Miguel Divo, MD
Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115
617-732-7420
(f) 617-732-7421

Dr. Divo joined our team from St. Elizabeth's Hospital in Boston. His areas of interest are obstructive lung disease and pulmonary physiology. He participates in both the inpatient and outpatient management of our lung transplant recipients.

Souheil El-Chemaly, MD, MPH
Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115
617-732-7420
(f) 617-732-7421

Dr. El-Chemaly is a pulmonologist in the Division of Pulmonary and Critical Care Medicine in the Department of Medicine at BWH. He also participates in clinical care and research related to Interstitial Lung Disease and Lymphangiomyomatosis. Dr. El-Chemaly participates in both inpatient and outpatient clinical services for our lung transplant patients.

George Washko, MD, MPH
Charlotte McKee, MD
Raja Abdunour, MD
Patrick Burkett, MD, PhD

Dr's Washko, McKee, Abdunour and Burkett are members of the Division of Pulmonary and Critical Care Medicine in the Department of Medicine at BWH. They are all active in research in various aspects of Pulmonary and Critical Care medicine and have extensive experience in the management of lung transplant patients. They participate in the outpatient clinic for lung transplant recipients, primarily in consultation for patients newly referred to the clinic. You may well meet one of them at your initial visit to the clinic, and sometimes may also see one in follow-up. *Because these physicians see patients only for their new patient visits, questions that arise in follow-up to your visit with them will likely be addressed by one of the nurse coordinators or one of the other transplant pulmonologists.*

Physician Assistants:**Kathy Gauthier, PA-C****Jillian Lynch, PA-C****Kristen Paolucci, PA-C****Brigham and Women's Hospital****75 Francis Street****Boston, MA 02115****617-732-7420****(f) 617-732-7421**

Kathy Gauthier will be responsible for coordination of your care during your stay during evaluation for transplant. She will help to facilitate your testing, and is available for any questions you have during this hospital stay. Jill and Kristen will be the primary providers of your inpatient care for most of your hospitalizations after transplant, in coordination with the pulmonologists and Dr. Camp. 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 are able to 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:**Stacey Salomon, LICSW****Brigham and Women's Hospital****Care Coordination****75 Francis St.****Boston, MA 01225****617-732-5500 x 32748****(f) 617-732-6468****(pager) 617-732-5500 # 15896**

Stacey is the social worker for the Lung Transplant Program. You will meet with her during the evaluation process for an initial assessment and to review your support team. Stacey will also help with support and guidance through the lung transplant process, and can provide information on resources and services available in the local community or on a state or federal level. Stacey also leads the Lung Transplant Support Group at BWH. Stacey is an invaluable resource and can be of tremendous help in navigating the process of transplantation. Stacey is available Monday-Friday from 8-5 PM. You can also leave a message for her regarding non-urgent issues on off-hours which will be returned on the next business day.

Financial Coordinator:

Cassandra Girard
Brigham and Women's Hospital
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617-525-9724
(f) 617-713-3025

Cassandra Girard is the financial coordinator for the lung transplant program. She 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. Cassandra is available to discuss financial concerns by phone or in person depending upon patient needs.

Nutrition:

Hannah Dalpiaz, RD
Brigham and Women's Hospital
Department of Nutrition- PB-153
75 Francis St
Boston, MA 02115
617-732-6054

Hannah is the dietician for the transplant inpatient service. You may meet her during the course of your inpatient evaluation for your nutritional assessment, and she will also be available to address nutritional concerns as they arise post-transplantation.

Pharmacy:

Keri Townsend, Pharm.D
BWH
75 Francis St.
Boston, MA 02115
617-525-8901
(f) 617-732-7507
kroberts11@partners.org

Keri Townsend is a licensed pharmacist who specializes in the management of transplant recipients. She has extensive experience in managing the complex medication regimens of transplant patients. She 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 close to 400 lung transplants.

Successful lung transplantation was achieved in the 1980's as a result 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 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 (pulmonologists), infectious disease (ID) 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 worker, physical and respiratory therapists, nutritionists, an administrative coordinator, a registered nurse coordinator and a nurse practitioner.

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. Included in this manual is information about medications used after transplantation, as well as explanations for the reasons for the various tests and procedures before and after transplantation.

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 of your questions.

The Evaluation Process

Initial Appointment

Your first appointment will be a consultation with one of the Pulmonologists and/or the Thoracic Surgeon of the Lung Transplant Program. During this meeting we will review your medical history and results of tests previously performed by your primary doctor (x-rays, CAT scans, lung function studies), and perform a physical examination. We will also discuss the lung transplantation process with you. This initial evaluation may require a **full day**, so please plan accordingly. Your visit may also include meeting a transplant pulmonologist, a thoracic surgeon and a transplant coordinator. At the conclusion of these meetings, depending on your interest and our assessment of your medical status, we may recommend further testing for lung transplantation. Based on past experience, a decision to go ahead with further testing occurs in about one half of patients who have an initial appointment. Because we will discuss a large amount of complicated information related to your medical care, we strongly suggest that you bring a family member or a friend who can help you ask questions during this first visit.

Should you and your family/supports as well as the transplant team mutually decide to proceed with evaluation for lung transplantation, the **next step** is to complete the testing necessary. The evaluation process to become a candidate for a lung transplant is quite extensive. The majority of testing is completed during a 48-72 hours admission to BWH and the remainder of items can often be completed as an outpatient in coordination with your local providers.

Comprehensive Evaluation (at BWH)

Please note the following testing items should only be completed after a decision is made to move forward with the evaluation.

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 a number of 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 heart beat, 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 (PA pressure). 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 is able to carry to your body tissues. The test is performed by placing a needle into an artery in your wrist. Approximately 3 cc of blood is required. This procedure takes about 5 minutes. Any discomfort at the site where the needle was inserted will go away in a few minutes. This will need to be updated at least every 6 months.

Pulmonary Function Tests (PFT's): a pulmonary function test measures lung volume and the rate of air-flow 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. The oxygen titration part uses a device called an oximeter to measure the amount of oxygen in your blood. Based upon the results of this walk it may be determined that you require supplemental oxygen when you walk. It also helps us assess your functional status. This test will need to be completed every 6 months or more often if clinically indicated.

Radiographic Studies (X-rays): 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, three minute 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. A CXR is required for your evaluation and must be updated at least every year.

A 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. These images are compared to your CXR. Chest CT assists with the detection of problems of the chest not easily found on CXR. Occasionally, the use of an injected contrast material is required. You will require repeat chest CT scans at regular intervals during the transplant waiting period.

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.

Ventilation/Perfusion Scan (Lung 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. **Only a select few** patients will undergo V/Q scanning.

Laboratory Specimens: blood samples are required for both routine and specialized testing. Specimens are sent for blood chemistries including potassium, sodium, cholesterol, triglycerides, liver function tests, kidney function tests, and other 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 infected with a variety of diseases, including herpes simplex virus, HIV, and other viruses. We also will collect sputum, urine and stool 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 takes between 30-60 minutes and 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 take into account 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 are 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 amount 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. The dietician is also available in the clinic on appointment days to monitor your progress and discuss any issues.

Infectious Disease Consultation: patients with Cystic Fibrosis, Bronchiectasis, and other disorders will undergo (at the discretion of the evaluating physician) evaluation with our infectious disease specialists. This physician will interview you regarding your infectious disease history. This will include your usual childhood diseases, such as chicken pox, measles, mumps, and German measles. 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. If sinus surgery is required, a short hospital stay may be scheduled for a later date.

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. Generally speaking, if these items are up-to-date, a repeat test may not be necessary at the time of evaluation. For example, if you had your colonoscopy last year and do not need the test again for 5 years, please do not repeat it unnecessarily!

Enrollment in outpatient pulmonary rehabilitation exercise class

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 60, or as clinically indicated

Bone Density Scan: within last 2 years

Dental Care: routine dental cleaning, exam, and letter of dental clearance

PPD/Mantoux: skin test for tuberculosis

Hepatitis B vaccine series: initiate the 3 shot series

Routine Vaccinations: TdaP, Flu, Pneumonia, varicella

24 hour PH probe with impedance: 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.

As you can see, the workup for lung transplantation is quite extensive. It requires a great deal of coordination, time and effort by the transplant team members but most importantly by you and your family or friends. Our goal is to complete your evaluation as quickly and as comfortably as possible. Your safety, comfort and state of mind are very important to us during this stressful time.

The Decision about Transplant Candidacy

Only after all the interviews, tests, **and** paperwork are completed, can the members of the Transplant Team, including representatives from Pulmonology, Thoracic Surgery, Psychiatry, Social Work, and Transplant Nurse Coordination, review the information and make recommendations concerning the treatment of your lung disease. They may suggest **further testing** or other therapies to try prior to lung transplantation. The team may decide that you should be listed for lung transplantation with the *United Network for Organ Sharing (UNOS)*. It is important to remember that lung transplantation is not an appropriate therapy for all patients with lung disease.

If accepted as a lung transplant candidate, you will join many other patients who are awaiting a lung transplant. You will then be seen on a regular basis to monitor your progress. If you are not accepted initially as a lung transplant candidate, the reasons for the decision and any further testing and therapeutic options available will be discussed with you and your referring physician (if applicable).

As mentioned above, there are occasions when lung transplantation is not in the best interest of the patient. If appropriate, a referral is made for alternative treatment.

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. Each candidate is evaluated individually, and all of the patient's issues are reviewed, in order to determine candidacy.

- 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 chronic infections such as HIV or hepatitis
 - 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 in order 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 in order to be considered for transplant. In addition, patients must be able to walk 500 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 insure 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.

Information About Your Planned Transplant Procedure

Having a single lung transplant involves an operation to remove one of your diseased lungs and replace it with a new lung. Having a double lung transplant involves an operation to remove both of your diseased lungs. The new lung(s) will work to help you breathe by providing your body with oxygen and removing carbon dioxide just as your own lungs did when they were healthy. This new lung or lungs will come from a person who is an organ donor. This person has suffered an irreversible injury leading to death. This person's lungs are normal and not affected by this injury.

The decision regarding single lung versus double lung transplantation depends on your age, lung disease, and other factors. In general double lung transplantation is pursued when feasible. If a single lung transplant is performed, the existing lung disease in the remaining original lung does **not** spread to the transplanted lung. An exception to this is if the lung has a chronic infection. In these instances, which are most common in patients with cystic fibrosis, double lung transplantation is performed so that no site of infection remains in the chest.

The staff at UNOS works to match donors with the people who are awaiting transplants. This matching is based primarily on the size of the donor and the blood type. The lungs from the donor are removed by a surgeon from the Transplant Team, who brings the lungs to Brigham and Women's Hospital. While this is happening, you will be notified to come to the emergency room at Brigham and Women's Hospital. You will then be transferred to the operating room where an anesthesiologist will prepare you for surgery.

If you are having a single lung transplant, the incision will be made on your side. In the case of a double lung transplant, the incision will run across the lower part of your chest.

The lung, whether single or double, is connected to the pulmonary artery, pulmonary veins and the mainstem bronchus (airway). The incision or incisions are closed and a dressing is applied. The incisions will be uncomfortable and will take several weeks to heal. Your pain will initially be treated with epidural anesthesia, infused into the area around your spine, if possible. As you recover, your pain medication will be administered orally. The transplant surgery can take anywhere from 4-10 hours to complete. The length of hospitalization after transplant is very difficult to predict. The length of stay can be as short as one week to 10 days or as long as a number of weeks.

Patients who are listed for lung transplantation are given another manual with important information. The manual also has charts you will fill out after transplant with medications taken, daily measurements of lung function and oxygen levels. By reading and understanding the material presented in your manuals prior to your transplant, you will better understand what to expect. Being informed may shorten your hospital stay, as it is necessary to understand this material prior to discharge. Reading the material ahead of time will also allow you the opportunity to ask any questions you might have during your office visits pre-transplant.

Once your surgery has been completed and you have been discharged from the hospital, successfully living with a transplant becomes the next challenge you will face. Caring for your transplanted lung(s) will require you to return to the hospital very frequently for clinic visits, blood tests, x-rays, and biopsy procedures. This level of follow-up is needed to monitor and treat medical problems that frequently develop in lung transplant patients. Two major problems that you may face are **rejection** of the new lung and **infection**.

Rejection/Infection

“Rejection” describes damage to the new lung caused by your immune system. Normally, your immune system recognizes and destroys foreign material. This process is important for fighting infections.

When a major organ, such as a lung, is transplanted from another person, your immune system recognizes the new lung tissue as foreign and will try to destroy it (i.e., “rejection”). In order to prevent rejection, transplant patients are treated with powerful drugs that suppress the immune system. Taking these drugs must become second nature to you because without these drugs your immune system will attack your new lung tissue, causing major illness or possibly death. These medications require a lifelong commitment from you. You will also take medication to prevent infection.

Although medications can reduce the severity of rejection in many cases, many lung transplant patients may have episodes of rejection that occur most frequently in the first several months after transplant. These are not uncommon. The treatment often includes doses of the anti-rejection medications given intravenously. This may be done in the hospital, or sometimes, as an outpatient. Determining the proper levels of immunosuppressant medication requires frequent blood tests and dose adjustments, as each individual is unique and requires an individualized approach. To assist in this adjustment process and to catch any episodes of rejection or infection early, when they are easier to treat, you will be asked to monitor your lung function at home and to report any significant changes. Our goal is to find the lowest dose that will prevent rejection and therefore minimize the risk of infection and side effects from the medications.

The medications used to suppress rejection have several known side effects that include kidney damage, diabetes, bone thinning, high blood pressure and other problems. The most concerning side effect is susceptibility to infection. Many of these side effects cannot be eliminated but can be managed. This requires frequent, close follow-up.

Now that you have decided to pursue lung transplantation, *you must accept the responsibility to take the anti-rejection medications prescribed by the team for the rest of your life, every day, and some medications multiple times a day. Failure to take these medications will result in the rejection of your new lung. Rejection of the new lung can result in death. YOU are responsible for keeping your appointments with the transplant team to ensure your good health and monitor your blood work and levels of medications.*

REMEMBER: A LUNG TRANSPLANT IS NOT A CURE, BUT A TREATMENT FOR YOUR LUNG DISEASE.

Acceptance into the Program –
Information and Resources for Patients and Supports

What to Do Now That You Are 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 UNOS (United Network for Organ Sharing) and the New England Organ Bank. Your name is placed on a list with the names of many other patients awaiting lung transplants in New England and nationally. Awaiting a transplant is often the most difficult time for a patient and his/her family.

UNOS and the New England Organ Bank have established criteria to determine the distribution of lungs for transplant. In 2005, the lung organ allocation system utilized by UNOS was changed, in order to ensure that organs were allocated with priority to the sickest patients on the transplant list, and those most likely to experience a survival benefit from transplantation. This system is based on the *Lung Allocation Score (LAS)*, a number from 0-100 that is generated by UNOS after analyzing multiple pieces of data provided to them by the transplant center for each recipient listed. The LAS score is not helpful when reviewed in isolation, but only in the context of the current list of recipients awaiting transplant. For this reason, the BWH Lung Transplant Team will not reveal your score to you, and will be unable to accurately predict your waiting time for transplantation. For more information on the LAS system of lung allocation, please refer to the UNOS website at www.unos.org. From the top menu select 'Allocation Calculators', then the link 'Learn more about the LAS System'. Some of the available information from UNOS regarding lung transplantation is also included as a separate insert with this manual.

Once you have been listed you will need to provide the transplant team with all of your available contact information, including home, cell 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. You must have working batteries in your cell phone and have the phone on at all times when you are not at home. In addition, your travel arrangements for getting to the hospital once you are called in should be arranged at the time that you are listed, well in advance of receiving the actual call for transplantation.

If you are to travel outside the range in which we are able to contact you, you will need to make other arrangements during this time. Once again you should always let the coordinator know of any travel/vacation plans while you are listed with us. If your travel distance is beyond the agreed upon range in which you can arrive in appropriate time for transplantation, you will need to be inactivated for the duration of your trip.

Should you need to contact someone from the transplant team during off hours, you can call 617-732-6660 and ask to page the 1-LUNG (15864) medical transplant beeper.

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.**

MOST COMMON POST TRANSPLANT MEDICATIONS:

1. Tacrolimus (also known as Prograf)
2. Cyclosporine modified (also known as Neoral or Gengraf)
3. Mycophenolate mofetil (also known as CellCept)
4. Azathioprine (also known as Imuran)
5. Prednisone
6. Valganciclovir (also known as Valcyte)
7. Acyclovir (Zovirax)
8. Sulfamethoxazole/Trimethoprim DS (also known as Bactrim DS)
9. Nystatin

- **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. **MICRO-SPIROMETER:** a respiratory monitor that measures your FVC and FEV1.

**** Many insurance companies do not cover the full cost of a pulse oximeter and/or microspirometer. Medicare does not cover either. You can find them online at sites such as Amazon.com but their stock and prices will vary.

NON-MEDICAL RELATED TRANSPLANT COSTS:

- Does your policy reimburse for the following costs? (some do)
 - 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)

ALSO:

- 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.
- Provide your insurance company with documentation giving your insurance company permission to speak to family member(s)
- **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 worker. 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 their supports who are awaiting transplantation. Participants often find that other lung transplant candidates and family members have questions and concerns similar to 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 two to three months, the group features a panel of lung transplant recipients and/or their caregivers who are invited to provide first hand information about their various lung transplant experiences. Participants are encouraged to ask questions and share their concerns.

The lung transplant support group meets on the first Wednesday of every month from 2:30-3:30 in Carrie Hall (*because of construction at the 15 Francis St. entrance, the closest entrance is now at 45 Francis St.*). Coffee and snacks are provided during a 30 minute period of informal discussion after each session. While we believe there is significant benefit to attending the group in person, we understand this is not always possible. For this reason, archived videos of past support groups are available to be viewed any time. Instructions on how to access these videos are included on the next page.

Copies of the support group schedule are provided by the transplant social worker and are also available in clinic on transplant coordinators' desk. Suggestions for topics and presenters are always welcome.

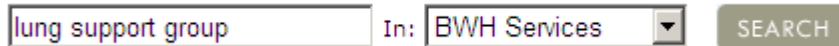
Please note that due to infection control issues, only one patient with *Cystic Fibrosis* is permitted to attend each group session. If you have CF and are interested in attending one of the groups in person, please contact the transplant social worker to make arrangements.

Instructions for Viewing Support Group Videos

You can view any of our prior Support Group videos by browsing to our Support Group page. First, go to the Brigham and Women's Hospital home page www.brighamandwomens.org. From there, you can find the Support Group page in 2 ways:

Method 1. Search the web site:

In the search box at the top right of the home page type **lung support group** then click the search button:



lung support group In: BWH Services SEARCH

In the search results you will see **Lung Transplant | Support Group**. Select this link to go to the Support Group page.

Method 2. Browse to the support group page:

On the BWH home page www.brighamandwomens.org click the menu option: **Departments and Services**.

At the top of the Departments and Services page click on the link: **ALL TREATMENTS AND SERVICES (A-Z LIST) >**.

Scroll down to the T's and select **Transplant Surgery**.

From the left side menu select **Lung Transplant**.

From the left side menu select **For Patients**.

Under the **For Patients** category select **Support Group**. This will take you to the Support Group page.

On the Support Group page, you will find links for all the previous support group videos, from most recent to oldest.

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 at the time of your surgery. Failure to reliably participate in a pulmonary rehabilitation program prior to lung transplantation will result in being inactivated from the list.

Lung transplantation will improve your shortness of breath and oxygen need. A comprehensive rehabilitation program will help improve the other problems. Therefore, you will be introduced to the importance of exercise and activity prior to your transplant.

Before your surgery, you will be followed in an outpatient pulmonary rehabilitation program. There you will be evaluated and placed on an exercise program. This will include training for your respiratory muscles as well as a biking and/or walking program for your general conditioning. You will need to continue this program after your transplant.

IT IS IMPORTANT FOR YOU TO UNDERSTAND THAT FAILURE TO PARTICIPATE RELIABLY IN YOUR REHABILITATION WILL RESULT IN BEING TAKEN OFF THE TRANSPLANT LIST.

The following describes the pulmonary rehab program here at the Brigham and Women's Hospital. You may enroll in a rehabilitation program closer to your home.

The BWH Pulmonary Rehabilitation Program

The Pulmonary Rehabilitation Program is 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. 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.

We have a modern facility located at Faulkner Hospital. The staff, under the direction of a Pulmonary Physician, is composed of dedicated, caring professionals who specialize in Pulmonary Rehabilitation.

We can be reached at (617) 983-7549.

Alternative Pulmonary Rehabilitation Programs

The following is a list of pulmonary rehabilitation programs in the New England Area:

Pulmonary Rehabilitation Centers - Massachusetts

Attleboro:

Sturdy Memorial Hospital
211 Park Street
Attleboro, MA 02703-0963
508-236-7552

St. Elizabeth's Medical Center
736 Cambridge Street
Boston, MA 02135
617-789-2394

Ayer:

Nashoba Valley Medical Center
200 Groton Road
Ayer, MA 01432
978-784-9543

Braintree:

Kindred Hospital Northeast
2001 Washington Street
Braintree, MA 02184
781-952-2455

Beverly:

Beverly Hospital
85 Herrick Street
Beverly, MA 01915
978-922-3000 EXT 2555

Brockton:

Brockton Hospital
680 Centre Street
Brockton, MA 02302
508-941-7558

Boston:

Brigham and Women's Hospital
1153 Centre Street
Boston, MA 02130
617-983-7549

Burlington:

Lahey Clinic Medical Center
41 Mall Road
Burlington, MA 01805
781- 744-2196

Massachusetts (continued)Concord:

Emerson Hospital
133 ORNAC
Concord, MA 01742-4169
978-287-3715

Fall River:

Southcoast Hospital Group- Charlton Site
Mitchell Therapy
363 Highland Avenue
Fall River, MA 02720
508-679-7423

St. Anne's Hospital
795 Middle Street
Fall River, MA 02721-1978
508-235-5310

Falmouth:

Falmouth Hospital
100 Ter Heun Drive
Falmouth, MA 02540
508-457-3687

Gardner:

Heywood Hospital
242 Green Street
Gardner, MA 01440
978-630-6568

Greenfield:

Baystate Franklin Medical Center
164 High Street
Greenfield, MA 01301
413-773-2724

Haverhill:

Whittier Rehab
76 Summer Street
Haverhill, MA 01830
978-372-8000 EXT 225

Holyoke:

Holyoke Hospital
575 Beech Street
Holyoke, MA 01040
413-534-2555

Hyannis:

Cape Cod Hospital
27 Park Street
Hyannis, MA 02601
508-862-5709

Lowell:

Saints Medical Center
1 Hospital Drive
Lowell, MA 01852-0030
978-934-8238

Medford:

Hallmark Health -
Lawrence Memorial Hospital
170 Governor's Avenue
Medford, MA 02155
781-306-6840

Milford:

Milford Regional Medical Center
14 Prospect Street
Milford, MA 01757
508-422-2290

New Bedford:

St. Luke's Hospital
101 Page Street
New Bedford, MA 02740
508-679-7423

Northampton:

Cooley Dickinson Hospital
30 Locust Street
Northampton, MA 01060
413-582-2404

Massachusetts (continued)Norwood:

Caritas Norwood Hospital
800 Washington Street
Norwood, MA 02062
781-769-4000 EXT 2024

Oak Bluffs:

Martha's Vineyard Hospital
Box 1477 Linton Lane
Oak Bluff's, MA 02557
508-693-0410 EXT 444

Pittsfield:

Berkshire Medical Center
725 North Street
Pittsfield, MA 01201
413-447-3093

Plymouth:

Jordan Hospital
275 Sandwich Road
Plymouth, MA 02360
508-830-2650

Sandwich:

Rehabilitation Hospital of the Cape and
Islands
311 Service Road
East Sandwich, MA 02537
508-833-4065

Springfield:

Baystate Medical Center
3300 Main Street Suite 2A
Springfield, MA 01199
413-794-7026

Stoughton:

New England Sinai Hospital 7
Rehabilitation Center
150 York Street
Stoughton, MA 02072
781-297-1383

Wareham:

Southcoast Hospital Group -
Tobey Hospital
43 High Street
Wareham, MA 02571
508-273-4170

Weymouth:

South Shore Hospital
55 Fogg Road
South Weymouth, MA 02190
781-340-8824

Wilmington:

Winchester Hospital
500 Salem Street Rt 62
Wilmington, MA 01887
978-988-6172

Worcester:

U Mass Memorial Medical Center-
University Campus
55 Lake Avenue North
Worcester, MA 01655
508-856-6962

Pulmonary Rehabilitation Centers - MaineBangor:

Eastern Maine Medical Center
(cardiovascular)
489 State Street
Bangor, ME 04401
207-973-4600 or 207-973-7202

Brunswick:

Mid Coast Medical Center
123 Medical Center Drive
Brunswick, Maine 04011
207-373-6367

Maine (continued)Caribou:

Cary Medical Center
163 Van Buren Road Suite 1
Caribou, ME 04736
207-498-1616

Rockport:

Penobscot Bay Medical Center
6 Glen Cove Drive
Rockport, ME 04856
207-596-8880

Dover-Foxcroft:

Mayo Regional Hospital (cardiovascular)
897 West Main Street
Dover-Foxcroft, ME 04426
207-564-4207

Scarborough: Maine Medical Center
(cardiovascular)

96 Campus Drive Suite G
Scarborough, ME 04074
207-885-8700

Lewiston:

Central Maine Medical Center
Pulmonary Rehab
76 High Street, Suite 300
Lewiston, ME 04240
Phone 207-795-5544
Fax 207-795-5645

Skowhegan:

Redington Fairview General Hospital
46 Fairview Ave
Skowhegan, ME 04976
207-474-5121

Pulmonary Rehabilitation Programs - New HampshireClaremont:

Valley Regional Hospital (cardiovascular)
243 Elm Street
Claremont, NH 03743
603-542-3458

Manchester:

Elliot Hospital
1 Elliot Way
Manchester, NH 03103
603-663-2366

Keene:

Cheshire Medical Center
580 Court Street
Keene, NH 03431
603-354-6730

Nashua:

Southern New Hampshire Medical Center
29 Northwest Blvd
Nashua, NH 03063
603-577-5737

Lebanon:

Dartmouth Hitchcock Medical Center
(cardiovascular)
1 Medical Center Drive
Lebanon, NH 03766
603-650-5861

Peterborough:

Monadnock Community Hospital
458 Old St. Rd.
Peterborough, NH 03458
603-924-4699 EXT 9291

There may be other pulmonary rehabilitation programs in your area. If there is a hospital within your community please contact them to inquire if they provide outpatient pulmonary rehabilitation services.

Pre-Transplant Nutrition

Proper nutrition plays a key role in preparing for lung transplantation. Each individual 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 amount 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.

Calories

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

Tips for Those Who Are Underweight:

- Keep high calorie foods readily available at home and in your car.
- Bring high calorie snacks when away from home.
- Add fruits, ice cream, or peanut butter to milkshakes or blend with commercial nutritional supplements.
- Add calories to vegetables by stir frying in canola or olive oil, or serving with a cheese sauce.
- Add calories to salads by adding salad dressings, seeds, avocados, olives.
- Eat small meals and snacks every couple of hours throughout the day.
- If overwhelmed by your usual dinner plate, use a small plate instead.

- Avoid eating snacks too close to mealtimes to avoid decreasing your appetite for meals.
- Keep fluids to a minimum at mealtimes but don't forget to drink between meals.
- Try higher calorie soups like split pea, tomato bisque, chowders, cream soups, and chili.
- Sip on higher calorie fluids such as juices, whole milk, frappes, and commercial nutritional supplements.
- As a high calorie snack try custards and puddings.
- Stimulate your appetite by relying on your favorite foods.
- Eat well during times when your appetite is better.

Protein

Proteins are the building blocks of cells and are an important part of your diet. Your body needs a certain amount of protein each day for growth of new tissue, maintenance of existing tissue, and repair of damaged tissue. For these reasons you need to pay special attention to getting adequate protein in your diet. Animal products contain the highest quality protein. The best protein choices are meats, fish, poultry, eggs and dairy products like milk, cheese, and yogurt.

Here are some suggestions on how to increase the amount of protein you eat:

- Add skim milk powder to foods or regular milk to increase protein content.
****Enriched milk = one cup skim milk powder to one quart regular milk****
Some examples of foods it can be added to include: hot cereals, soups, scrambled eggs, gravies, ground meats (for meat patties, meatballs, meatloaf) and casserole dishes.
- Use whole or enriched milk (see recipe above), or half and half instead of water when making soups.
- Add ground meat to soups or casseroles.
- Add grated or chunks of cheeses to sauces, vegetable soups or casseroles.
- Add peanut butter to bread, sauces, waffles or crackers.
- Add cooked or cubed tuna, crabmeat or sliced boiled eggs to sauces, rices, noodles, buttered toast or hot biscuits.
- Choose dessert recipes that contain eggs, such as sponge cake, custard or rice pudding.
- Try meat substitutes such as tofu, dried peas or beans.

If you have additional questions and have not seen the dietitian, please ask to set up an outpatient appointment or request to see someone at your next lung transplant clinic visit.

Identifying a Support Person

During the evaluation process it is important to identify a group of support people. Having a lung transplant means making an ongoing commitment to 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 of time after transplant, if you are unable to care for yourself. We will also ask you to complete a form identifying your health care proxy. Completion of a living will is also of particular aid to both your family/support team and providers. This living will clarifies your goals of care in the event of untoward events at the time of transplant or in the future. The forms described above are attached below for your review.

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 discharge, you will be seen as an outpatient in the Center for Chest Diseases clinic just like before transplant. You will be seen WEEKLY for an indefinite period of time 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.

The next pages provide samples of the support team worksheet, living will and healthcare proxy forms that you will be asked to complete as part of the transplant evaluation process.

Patient Name: _____

Date: _____

Brigham and Women's Lung Transplant Program

Planning for Support after Your Transplant

Our experience has been that having strong support from family, friends and/or members of your community is an essential component of a successful outcome after transplant. As a lung transplant candidate, it is important that you work with our team to identify members of your support system who will be available throughout the transplant process. It is our hope that after a transplant, you will be able to regain your independence and return to activities that you love. However, we know that for at least the first few months after transplant you will have to depend on others to support you with different aspects of your day to day routine. Some of the responsibilities of your support team:

- Transportation to BWH at the time of “the call.”
- Providing emotional support for you and your loved ones as you cope with the stress of the surgery and recovery.
- Attending family meetings and educational sessions with members of the transplant team during all hospital admissions.
- Helping to prepare/ clean the home prior to discharge home from hospital.
- All your transportation needs in the first couple months after transplant, including frequent (weekly, bi-weekly) appointments in the BWH Transplant Clinic.
- Ongoing transportation is also needed medical procedures (i.e. bronchoscopy), and both planned and unplanned admissions.
- Twenty-four hour at-home support for the first few weeks following discharge home from the hospital or rehab center. Responsibilities during this period include providing assistance around a complex medicine schedule, and assistance with activities of daily living.
- Taking care of your bills, pets, home while you are in the hospital.

Please complete this form with those who you identify as your supports. Please have each of them print and sign their name on the back of this form. We also encourage you to bring in your supports to clinic appointments and support group meetings.

Primary Support:

Name: _____ Relationship: _____

Address: _____

What is the distance between you and this person? _____

Phone Number: (H) _____ (W) _____ (C) _____

What is this person's availability? _____

Secondary Support Person:

Name: _____ Relationship: _____

Address: _____

What is the distance between you and this person? _____

Phone Number: (H) _____ (W) _____ (C) _____
What is this person's availability? _____

Additional Support Person:

Name: _____ Relationship: _____
Address: _____
What is the distance between you and this person? _____
Phone Number: (H) _____ (W) _____ (C) _____
E-mail address: _____
What is this person's availability? _____

Additional Support Person:

Name: _____ Relationship: _____
Address: _____
What is the distance between you and this person? _____
Phone Number: (H) _____ (W) _____ (C) _____
E-mail address: _____
What is this person's availability? _____

Who will be transporting you at the time of surgery? Who will be your back up person?

Primary Driver

Name: _____ Relationship: _____
Address _____
Phone Number: (C) _____ Additional Numbers : _____

Back-up Driver

Name: _____ Relationship: _____
Address _____
Phone Number: (C) _____ Additional Numbers: _____

Who will transport you to weekly Wednesday clinic appointments, routine bronchoscopies, and unexpected/unscheduled clinic visits or admissions post-transplant?

Primary Driver

Name: _____ Relationship: _____
Address _____
Phone Numbers: (H) _____ Additional Numbers _____

Secondary Driver

Name: _____ Relationship: _____
Address _____
Phone Numbers: (H) _____ Additional Numbers _____

Who will be staying with you or who will you be staying with for at least two weeks following your discharge from the hospital after your surgery?

Name: _____ Relationship _____

Address: _____

Phone Number (H): _____ Additional Numbers: _____

Name: _____ Relationship _____

Address: _____

Phone Number (H): _____ Additional Numbers: _____

Name: _____ Relationship _____

Address: _____

Phone Number (H): _____ Additional Numbers: _____

Name: _____ Relationship _____

Address: _____

Phone Number (H): _____ Additional Numbers: _____

Identified Supports:

Print Name _____ Signature _____ Date: _____

Print Name _____ Signature _____ Date: _____

Print Name _____ Signature _____ Date: _____

Print Name _____ Signature _____ Date: _____

Print Name _____ Signature _____ Date: _____

Please include additional information on an extra page if needed and feel free to contact Stacey Salomon, LICSW with any questions: (617) 732-5500 x 32748

Please return this form to clinic or fax it to: Jenny Hoyer, RN at Fax # 617-264-6892

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
www.chest Surg.org/treatment/lung-transplant/
- Second Wind Lung Transplant Association
www.2ndwind.org
- www.transweb.org
- En Espanol
<http://www.trasplantesyvida.org/>
- MedlinePlus:
<http://www.nlm.nih.gov/medlineplus/lungtransplantation.html#cat59>
- New England Donor Bank:
www.neob.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: Organ Transplant Fund: 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)
(646) 292-7930
www.esiason.org

CAREGIVER AND SUPPORT ORGANIZATIONS

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

Free online services that helps 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 (GREAT RESOURCE!)

- 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

ACCOMODATIONS NEAR BRIGHAM AND WOMEN'S HOSPITAL

Here is a list of several hotels that are most conveniently located to the hospital. Be sure to ask for the hospital rate. If you have any additional questions or concerns, please contact Stacey Salomon, LICSW at 617-732-5500 x 32748.

****Please note that many hotel rates vary per season. All rates are subject to change.

HOTELS WITH HOSPITAL DISCOUNT RATES

Inn at Longwood Medical

Cost: \$169.00 + tax per night
(617) 731-4700
Address: 342 Longwood Avenue,
Boston, MA 02115
Distance from BWH: 0.2 miles
• walking distance from BWH
• Parking: \$20 per day

Howard Johnson's – Fenway

Cost: \$115.00 + tax per night
(617) 267-8300
Address: 1271 Boylston Street,
Boston, MA 02215
Distance from BWH: 1.5 miles
• Free parking and shuttle services to
BWH

Holiday Inn Boston at Brookline

Cost: \$149.00 + tax per night
(617) 277-1200
Address: 1200 Beacon Street,
Brookline, MA 02446
Distance from BWH: 1 mile
• Free Shuttle to BWH 7am–10pm
• Parking: \$19 per day

Best Western Roundhouse Suites

Cost: \$99.00- \$109.00 plus tax
(617) 989-1000
Address: 891 Massachusetts Ave.
Boston, MA 02118
Distance from BWH: 2.5 miles
• Shuttle service

Hampton Inn & Suites

Cost: \$139.00 + tax per night
(617) 445-6400
Address: 811 Massachusetts Avenue,
Boston, MA 02118
Distance from BWH: 3 miles
• Free Shuttle to BWH
• Parking \$10 per day
• Free WiFi, pool, and fitness center
• Complimentary breakfast

Best Western Terrace Inn

Cost \$119.00 + tax per night
(617) 566-6260
Address: 1650 Commonwealth Ave,
Boston MA 02135
Distance from BWH: 2.5 miles
• No shuttle but parking is free

Courtyard by Marriott at Brookline

Cost: \$149.00 – \$179.00 + tax per night
(617)734-1393
Address: 40 Webster Street
Brookline, MA 02446
Distance from BWH: 1.7 miles
• Parking: \$24 per day
• Free Shuttle to BWH

OTHER AREA HOTELS

Please call for the discounted medical rate.

Coolidge Corner Guest House: cost: \$79-189
(medical discount is 20% and weekly and monthly rates available)
(617) 734-4041
1719 Littell Rd, Brookline MA 02446

Residence Inn by Marriott: 617-242-9000; 44 Charles River Ave, Boston, MA 02129
Long term rooms available with fully equipped kitchen

Holiday Inn Boston at Beacon Hill: 617-742-7630; 5 Blossom St, Boston MA 02114
Located 3.6 miles from BWH; convenient to public transportation and adjacent to MGH
(which offers free shuttle busses to BWH). Ask for Brigham and Women's Hospital rate when
booking (rate Code- ILVRN). Rates from \$129-\$189, based on seasonality and availability.

****If your hotel requests a letter for the hospital rate, please contact BWH Patient Family
Relations or the lung transplant social worker.*

OTHER RESOURCES:

*****Hospitality Homes******

(888) 595-4678 or visit www.hosp.org

A non-profit organization dedicated to providing very low cost comfortable, short-long and
long term accommodations in a variety of locations donated by volunteer hosts in the Boston
and Brookline areas. .

LONGER TERM HOUSING

A furnished apartment may be cheaper than daily medical rate of a hotel. Some helpful
resources:

www.craigslist.org

www.homeaway.com

www.furnishedapt.com

www.bostonapartments.com/furnish/htm

<http://boston.sublet.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 \$35 to \$16 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 OR FRIEND PER PATIENT CAN APPLY.**

TYPES OF ASSISTANCE:

1. **Five** \$8 off parking coupons which takes off the two most expensive hours of parking.
OR
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.)

PARKING AT BRIGHAM AND WOMEN'S HOSPITAL

All rates subject to change.

· VALET PARKING – 75 or 45 Francis St entrances

- For patients only. We encourage all families/visitors to park in the Service Center Garage at 80 Francis St.
- Valet tickets are already reduced, NO validation is available.
- Valet DOES NOT have a discounted evening or weekend rate.

HOURS:

0-1	\$8.00
1-2	\$9.00
2-3	\$10.00
3-4	\$12.00
4-5	\$13.00
5-6	\$15.00
6-7	\$17.00
7-24	\$21.00

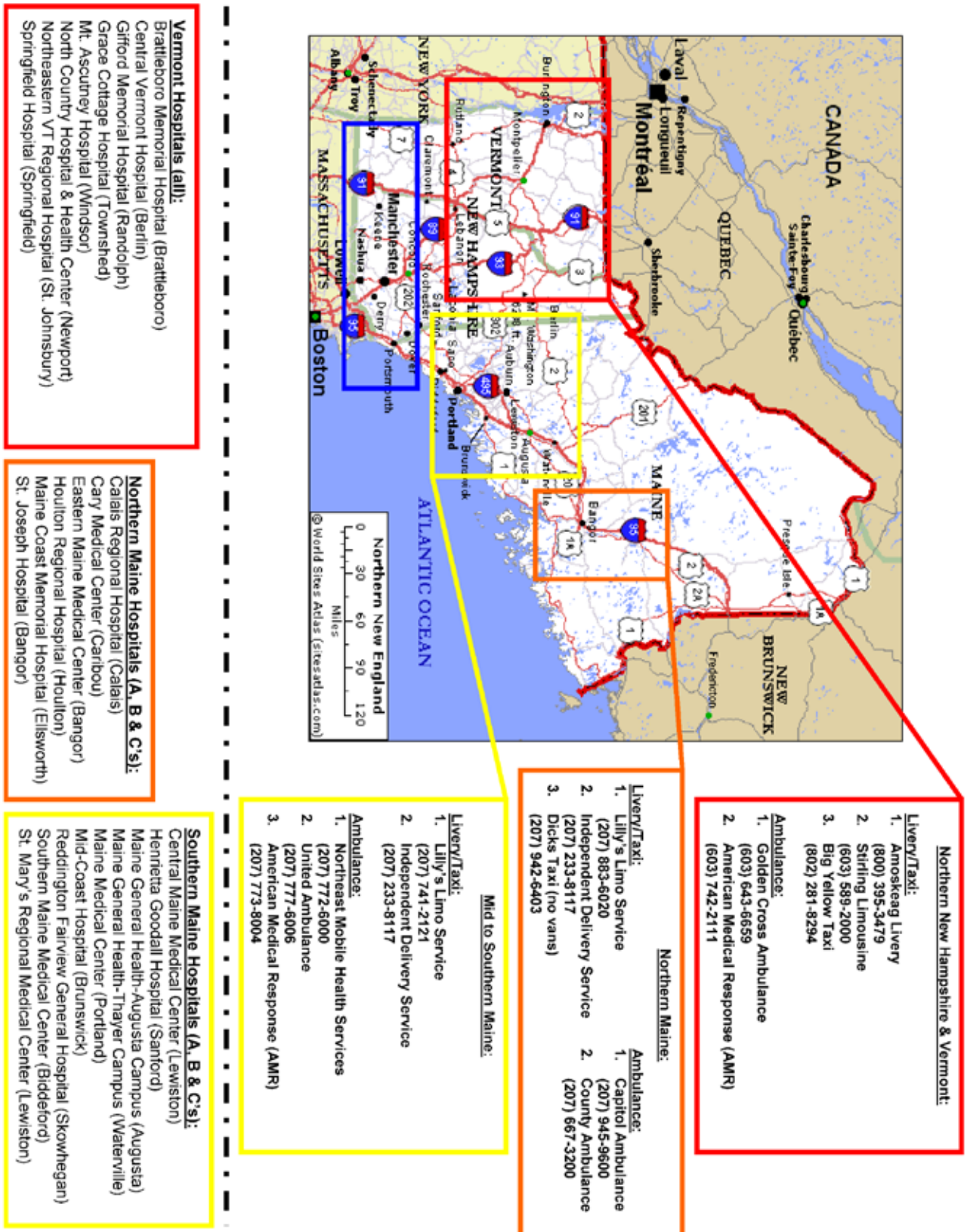
· SERVICE CENTER GARAGE – 80 Francis St.

- Parking validation is needed when patients/visitors are parked 6 hours or longer.
- Patient/Family Relations validates from 7:30 a.m. – 6 p.m.
- Main Information Desk at 75 Francis validates after hours.
- A max rate of \$8.00 for 24 hours will be charged on Saturday, Sunday and Holidays. (No validation needed.)
- If you enter after 5 p.m. and exit before 8 a.m. the next day, the rate is \$8.00.

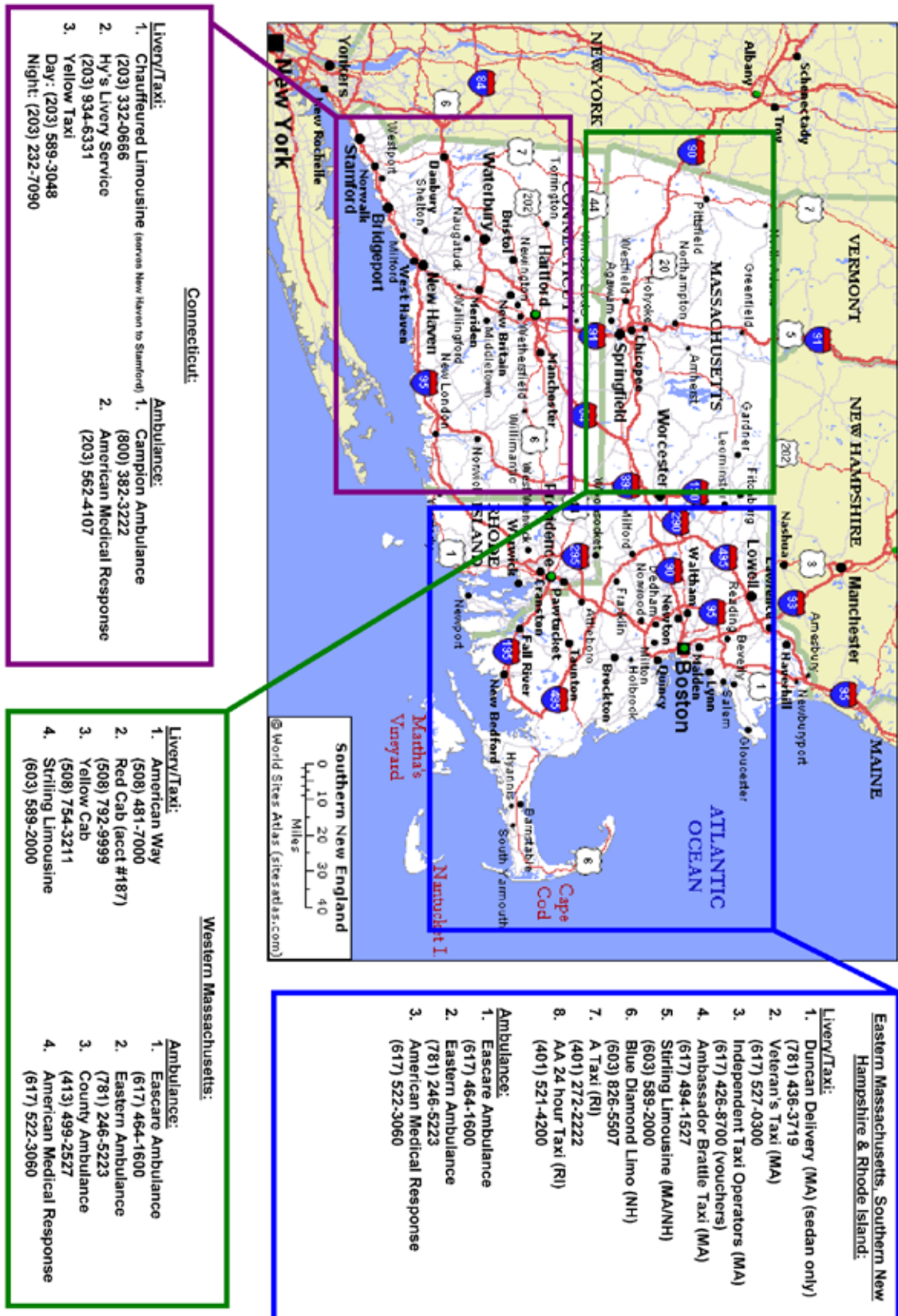
HOURS:

0-1	\$7.00
1-2	\$8.00
3-4	\$10.00
4-5	\$12.00
5-6	\$14.00
6-7	\$35.00 (with validation, reduced to \$16.00)
7-24	\$40.00 (with validation, reduced to \$20.00)

New England Transportation Resource Maps



New England Transportation Resource Maps (continued).



New England Transportation Resource Maps (continued).

Eastern Massachusetts Hospitals (A, B & C's):

Addison Gilbert Hospital (Gloucester)
 Anna Jacques Hospital (Newburyport)
 Beth Israel Deaconess Hospital-Needham Camp (Needham)
 Beth Israel Deaconess Medical Center (Boston)
 Boston Medical Center (Boston)
 Brigham & Women's Hospital (Boston)
 Brockton Hospital (Brockton)
 Cambridge Hospital (Cambridge)
 Cape Cod Hospital (Hyannis)
 Caritas Good Samaritan Medical Center (Brockton)
 Caritas Holy Family Hospital (Methuen)
 Caritas Norwood Hospital (Norwood)
 Carney Hospital (Dorchester)
 Children's Hospital (Boston)
 Emerson Hospital (Concord)
 Falmouth Hospital (Falmouth)
 Faulkner Hospital (Jamaica Plain)
 Lawrence Memorial Hospital (Medford)
 Jordan Hospital (Plymouth)
 Lahey Clinic (Burlington)
 Lawrence General Hospital (Lawrence)
 Leominster Hospital (Leominster)
 Lowell General Hospital (Lowell)
 Marlborough Hospital (Marlborough)
 Massachusetts General Hospital (Boston)
 Melrose-Wakefield Hospital (Melrose)
 Merrimack Valley Hospital (Haverhill)
 MetroWest Medical Center (Framingham)
 Milford-Whitinsville Regional Medical Center (Milford)
 Milton Medical Center (Milton)
 Morton Hospital (Taunton)
 Mount Auburn Hospital (Cambridge)
 New England Baptist Hospital (Boston)
 New England Medical Center (Boston)
 Newton-Wellesley Hospital (Newton)
 North Shore Medical Center-Salem Campus (Salem)
 North Shore Medical Center-Union Campus (Lynn)
 Northeast Health Svc. Beverly Hospital (Beverly)
 Quincy Medical Center (Quincy)
 Saints Anne's Hospital (Fall River)
 Saints Medical Center (Lowell)
 South Shore Hospital (S. Weymouth)
 Southcoast -Charlton Memorial Hospital (Fall River)
 Southcoast-St. Lukes Hospital (New Bedford)
 St. Elizabeth's Medical Center (Brighton)
 Sturdy Memorial Hospital (Attleboro)
 UMMHC-Memorial Campus (Worcester)
 UMMHC-University Campus (Worcester)
 Whidden Memorial Hospital (Everett)
 Winchester Hospital (Winchester)
 Worcester Medical Center/St Vincent Hospital (Worcester)

Western Massachusetts Hospitals (A, B & C's):

Athol Memorial Hospital (Athol)
 Berkshire Medical Center (Pittsfield)
 Clinton Hospital (Clinton)
 Cooley Dickinson Hospital (Northampton)
 Harrington Memorial Hospital (Southbridge)
 Heywood Hospital (Gardner)
 Holyoke Medical Center (Holyoke)
 North Adams Regional Hospital (North Adams)
 Wing Memorial Hospital (Palmer)

Northern New Hampshire Hospitals A, B & C's):

Androscoggin Valley Hospital (Berlin)
 Dartmouth Hitchcock Medical Center (Lebanon)
 Franklin Regional Hospital (Franklin)
 Frisbie Memorial Hospital (Rochester)
 Littleton Hospital (Littleton)
 Memorial Hospital (North Conway)
 Speare Memorial Hospital (Plymouth)

Southern New Hampshire Hospitals A, B & C's):

Catholic Medical Center (Manchester)
 Concord Hospital (Concord)
 Elliot Hospital (Manchester)
 Exeter Hospital (Exeter)
 Portsmouth Regional Hospital (Portsmouth)
 Southern New Hampshire Reg. Med. Ctr. (Nashua)
 St. Joseph Hospital (Nashua)
 Wentworth-Douglas Hospital (Dover)

Rhode Island Hospitals (all):

Kent Hospital (Warwick)
 Landmark Medical Center (Woonsocket)
 Memorial Hospital of Rhode Island (Pawtucket)
 Miriam Hospital (Providence)
 Newport Hospital (Newport)
 Rhode Island Hospital (Providence)
 Roger Williams General Hospital (Providence)
 South County Hospital (Wakefield)
 St. Joseph's Health Services (N. Providence)
 Westerly Hospital (Westerly)
 Women and Infants Hospital (Providence)

Connecticut Hospitals (all):

Bridgeport Hospital (Bridgeport)
 Danbury Hospital (Danbury)
 Greenwich Hospital (Greenwich)
 Griffin Hospital (Derby)
 Milford Hospital (Milford)
 New Milford Hospital (New Milford)
 Norwalk Hospital (Norwalk)
 St. Mary's Hospital (Waterbury)
 St. Vincent's Medical Center (Bridgeport)
 Stamford Hospital (Stamford)
 The Hospital of Saint Raphael (New Haven)
 Waterbury Hospital (Waterbury)
 Yale New Haven Hospital (New Haven)

When Called For Your Transplant

When you are called for the transplant you need to proceed to the Emergency Ward at BWH as soon as possible. **Remember not to eat or drink anything once you are called in for your surgery, even if you are called in as a back-up recipient.**

Prior to the transplant the Social Worker and Coordinator will discuss with you and your family the transportation you will be using and your travel time to BWH. 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 Ward and parking garage.
- Phone calls to family members. We suggest you call one family member who will, in turn, notify other family members.
- Babysitting/child care.
- An alternative transportation plan should the person driving you be unavailable.
- Local accommodations for family/support team members.

REMEMBER

- Bring your blue hospital card with you.
- Give your cell phone to the person driving you to the hospital and keep it turned "on". Keep your cell phone with you at all times during your trip in, as we may need to contact you en route.
- 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 "false alarms" 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, you will undergo a history and physical examination, radiographic testing (Chest x-ray and/or CT scan,) an EKG, and blood work. Further testing may be performed as determined on a case-by-case basis.
- 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.

Discuss any individual concerns with the Coordinator or Social Worker. **TIME IS OF THE ESSENCE IN COORDINATING THE TRANSPLANT OPERATION.** It is critically important that you have a detailed travel plan in place before you are called in for the transplant and that you and the transplant team have an accurate idea of how long it will take you to get to the hospital.

What to Expect at the Time of Transplant

At the Time of Your Transplant

A lung transplant can occur at anytime. There is no way to know in advance when that time will be. At the time that a lung (s) becomes available for you, you will be notified by a member of the lung transplant team that you need to come to the Brigham and Women's Hospital emergency room. At the time you are called you will be told not to have anything to eat or drink, including water. As mentioned earlier, you should already have a plan in place as to how you will be traveling to the hospital. Once you are called, your support person (s) should bring you to the emergency room where the triage nurse will be expecting you.

When you arrive in the emergency room several things will happen: you will have blood work drawn, have a CXR and possibly a chest cat scan (depending when your last one was done) and have an EKG done. You will also meet with the surgeon before the operating room. It is important to remember that you may be called to the emergency room only to find out that the transplant has been cancelled. This may occur at any time up until the beginning of the transplant operation. Please remember that the emergency room is a very busy place and all of your family members may not be able to be with you. During the surgery your family may wait in the waiting room on the 11th floor, where you will be admitted after the transplant, or in the OR patient and family waiting room. The surgeon will contact your family after the transplant is completed.

Once you are brought into the OR you will be met by the anesthesiologist (s) and nurses. You will be give medication to help you to relax and IV lines will be inserted. The surgery takes approximately 4-10 hours.

Once Your Surgery Is Completed

When your surgery is completed, you will be transferred from the operating room (OR) to 11C (Thoracic Surgery ICU). Prior to your arrival, 11C will have limited communication with the OR. The OR will inform 11C of when they can expect your arrival. If your family is in the 11th floor family room, they will be informed of your status. Once you arrive on 11C, you will probably be asleep. It will take your nurses approximately 1-2 hours to get you settled and stable. They will be monitoring your blood pressure, heart rate, respirations, and other vital signs frequently. As you wake up, you will become aware of your tubes, drains and intravenous lines.

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 sometimes Jackson-Pratt or other drains, (small tubes connected to a small plastic bulb), 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 extend across the front of your lower chest, from axilla to axilla (armpit).

In almost all cases, an epidural catheter inserted into the area around your spinal cord in your upper back will control your pain. This catheter in your back 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. 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 physicians, some of whom you will have met prior to your surgery. The 11C Critical Care Team will also follow you. They will be actively involved in your care, along with your surgeon and pulmonologists.

Information About the Thoracic Surgery Intensive Care Unit

Introduction:

This is a brief overview designed to give you a brief description of our 11th floor ICU.

We are a 10-bed unit specializing in the care of patients recovering from thoracic surgery. Typically, these patients require a high degree of medical and nursing care.

They also require specialized equipment to help monitor and support their body systems.

You can expect to see:

- Machines that assist patient's breathing
- Monitors to record vital signs and oxygen
- Various tubes and IV's that deliver fluids and medications

Phone Numbers:

- 11C secretary's desk:
(617) 732-7750
- Nurse Manager- Joyce Thomas-Browning:
(617) 732-7668
- Patient and Family Relations:
(617) 732-6636
- Interpreter Services:
(617) 732-6639
- Chaplaincy Services:
(617) 732-7480

Visiting Information:

- Visitors are welcome at all times but we encourage you to visit between 1:00 pm and 8:00 pm
- We ask that visits be short (about ten minutes)
- Two visitors at time
- Children are discouraged
- No cell phones except at elevators
- Upon arrival to visit, please call from the visitor waiting into the ICU to make sure it is an appropriate time to visit

- The visitor waiting area has a few reclining chairs in the rare event that a family member needs to stay overnight
- Please keep in mind that mental and physical rest are an important part of the recovery process for all patients and their families

To Call from Outside the Hospital:

- Dial (617) 732-7750 and ask to speak to the nurse caring for the patient
- Choose one family spokesperson and have this person call for updates on the patient's condition
- Call from home before visiting as patients may be involved in a test or procedure

Additional Information:

- Restrooms are located near the "A" pod and in the lobby
- Public telephones are located near the visitor elevators and in the visitor waiting area
- Please do not use cell phones except near elevators
- There are no phones in the ICU patient rooms
- Food and beverages are available in the 2nd floor cafeteria and in Au Bon Pan on the 1st floor lobby
- A gift shop is located in the main lobby
- Do not send flowers, plants, balloons or food while the patient is in the ICU

The ICU Team:

Critical Care Physician or "Attending" physician- coordinates your care with your primary surgeon (and the Lung Transplant Medical Team)

Resident Physicians- physicians undergoing advanced training that work closely with the attending physicians to provide your care

ICU Nurses- Nurses with advanced training in the care of the critically ill

Patient Care Assistant (PCA's)- Provide support to the nursing staff

Care Coordinators- Nurses and social workers who provide support and assistance with financial and discharge planning

Unit Coordinators- Provide phone assistance and general information needs

Physical Therapists, Occupational Therapists, Dieticians, Respiratory Therapists and Chaplains- are all involved in patient care

* Communicate with your nurse if you would like to speak with your family member's physician or other team members

The Inpatient Care Team

The Lung Transplant program at Brigham and Women's Hospital utilizes a multidisciplinary approach to your care. The following is a description of the various team members who will participate in your care.

Nursing:

Your nurses will work most closely with you as you recover from your transplant and prepare to go home. Your nurse will be responsible for many components of your care. Initially, his/her priorities relate to the extensive physical and emotional aspects of your recovery. Your nurse will work closely with you, your doctors and therapists to coordinate the treatments and activities in a way that is most beneficial to you. When you are ready to begin the extensive discharge teaching process, you and your nurses will develop a plan to incorporate your teaching needs into your daily activity schedule. As your discharge date approaches your nurses, along with the transplant team, will coordinate a meeting with your support person(s) to have an in-depth discussion of what is expected after you go home. You will also be informed of all home care services that have been set up for you as well as any appointments that have been scheduled for you after discharge. At this meeting you will be encouraged to ask any questions you might have to make the transition home as easy for you as possible. It is helpful to keep a written list of questions that arise during your hospitalization so that these can be addressed by nursing, physicians, or care coordinators during daily rounds or during your discharge family meeting.

Physician Care Team:

Many of the doctors and therapists you met in the Thoracic Surgery Intensive Care Unit will continue to follow you until you are discharged from the hospital. Your Pulmonologist and Surgeon will make early morning rounds with their fellows and residents to discuss any issues that may have occurred overnight and to make goals for your day. This is a good time for you to ask questions about your progress and plans. You should have a good understanding of what your goals are for the day after being seen by the team, so it is important that you ask any questions during morning rounds. The care team will also hold family meetings routinely during your transplant stay to update all involved on your progress and any clinical issues that are being addressed. These meetings will be planned as frequently as necessary, to ensure that all concerned are well informed about your care in the hospital, and what will be required after discharge.

Endocrinology:

The endocrinology team, which deals with glandular function and hormone metabolism, is often involved in the care of the lung transplant patient. They help assist in the management of elevated blood sugar (diabetes), as well as osteoporosis. Immunosuppressant medications may cause an increase in blood sugar often requiring treatment with Insulin. Many patients after transplant will require Insulin injections for an undetermined time. You will receive in-depth instructions about Insulin and diabetes management should you require it. Another side effect of steroids (Prednisone) is that they contribute to the development of osteoporosis,

which results in weakness of the bones due to mineral loss. The endocrinology team will make recommendations concerning dietary intake and medications to help manage this condition. In addition, regular physical activity has also been shown to minimize problems with osteoporosis. This aspect of problem prevention will be addressed in your rehabilitation program.

Physical Therapy:

A physical therapist will work with you once a day. The goal of your physical therapy is for you to achieve complete independence in all your activities. The therapist will prescribe strengthening and mobilizing exercise and will start you on a daily biking program. You will be monitored closely during exercise and goals will be set by you and your therapist to assess your progress.

Dietician:

The lung transplant dietician will visit you periodically and will be closely involved with your care. She will work with you in providing a nutrient filled diet individually designed to meet your needs for healing. She may suggest many different ways of meeting your nutritional needs. As mentioned earlier, specific dietary recommendations may be made in order to increase your calcium intake to reduce the risk of osteoporosis.

Social Work:

The Lung Transplant Social worker will continue to follow you post transplant as she did prior to transplant. She will be available to discuss any of your concerns related to finances, insurance coverage, job training and/or emotional needs. If questions arise and you wish to speak with the social worker please ask your nurse to contact her and arrangements will be made for you to speak with her. The social worker will stop by to visit with you even if you do not have any issues to discuss and will offer support to you as well as your family.

Pharmacy:

The inpatient pharmacy team will be involved in working with the transplant team to ensure that your medication regimen is complete and that medication dosages are appropriate. In addition, prior to your discharge, your medication list will be reviewed by a transplant pharmacist. He/she will make recommendations regarding completeness, dosing, and scheduling of medications, and timing of administration. The transplant pharmacist is also a resource for you and the transplant team after discharge, for discussion of medications that may be recommended for you in the future, and to ensure their compatibility with the remainder of your transplant medications.

Chaplaincy:

Chaplaincy services are available to all patients. Please inform your nurse or social worker if you wish to speak with a Chaplin and arrangements will be made for you to be seen.

As You Progress

As you recover your activity will increase. Prior to your surgery you were required to exercise. This will NOT change and it will be a very important aspect of your postoperative care.

Your morning routine may begin early with a chest x-ray on some days. You will also be weighed on a bed scale until you progress to a stand up scale. 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 will have at least two bronchoscopies performed during your hospitalization to look at your new lung.

When you are allowed to start eating and drinking your fluids may be restricted. This is very important since your new lung is very sensitive to fluids. 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 *very* busy day. Your nurse will try to provide uninterrupted rest time, which may mean restricting visitors. You can discuss this with your nurse. 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 are able to 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.

Transferring out of the ICU

When you are ready to leave the Thoracic Intensive Care unit you will be transferred to a private room on 11A, 11B or 11D. You will continue to receive nursing care from registered nurses who are experienced in caring for patients who have undergone lung transplantation surgery. Nursing care goals will be aimed at continuing to assist you in your recovery from surgery and preparing you for discharge.

Your daily schedule will be planned to include your physical care needs, teaching needs and emotional needs. A sample daily activity schedule is included on the following pages. 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.

A chest x-ray will be taken routinely. This x-ray will be taken in your room while your chest tube is connected to suction. When suction is no longer needed you will have your x-ray taken in the radiology department. When walking outside your room or traveling to any tests you are required to wear a mask. You will have bronchoscopies performed when the pulmonologists decides they are necessary. Discharge teaching is a major part of your discharge preparation and you are expected to be an active participant in your learning. It is **ESSENTIAL** that you become well acquainted with the information in your Lung Transplant Manual **PRIOR TO YOUR TRANSPLANT**. Please spend time reviewing each section in your manual, as this information is vital to your discharge teaching.

Your nurse and coordinator will develop a discharge plan with you. 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. 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. A family member will be asked to bring a new bathroom scale into the hospital for you so you will record your daily weights. Using the same

scale at home will provide a more accurate record of your weight. Discharge planning will also include Visiting Nurses who will come to your home and call the team with any issues.

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.

Information for Family and Friends

The following section addresses specific concerns that family members, friends, and support team members may have related to your transplant hospitalization and subsequent care. The transplant team also recommends that family and friends write down any questions that they may have so that we can address them either directly or through you.

As family members, the operative waiting period can be a very trying time for you. Once we have your loved one settled we will then be able to let you in to see him/her. This can be a very long process and can take up to 1-2 hours. If you arrive on the 11th floor before your family member has arrived from the operating room, please call the nurses from the 11th floor waiting room to let them know you are there and will be waiting to hear from them. The nurses will let you know of any updates from the operating room. Again, communication is limited but you will be informed of any information that is available. Once allowed in to visit you will be required to wear a mask, gown and gloves. This is to protect the patient from any germs and continues for at least 1-week post transplant.

Here is some other information about visiting patients in the Thoracic Intensive Care Unit that you should be aware of:

- Only 2 visitors at one time are allowed and visits are limited to 10 minutes per hour. Depending upon the patient condition this may be changed. You will need to discuss this with the nurse.
- Visitors are restricted to family and or significant others. Children under age 12 years of age are not permitted in the ICU.
- Flowers and fruit baskets are not allowed.
- Visitors are required to first call from the 11th floor visiting room to see if the patient is ready for visitors.
- The phone number to the ICU will be given to you so that you may call from home to check on the patients' condition. It is requested that only one family member be responsible for calling the unit to inquire about the condition of the patient. This person can then let the rest of the family know the patients condition. If the nurse is busy caring for your family member and can't come to the phone you will be asked to call back a little later. Your cooperation is appreciated.

The staff on 11C understand how overwhelming and frightening this experience can be and they encourage you to ask any questions to alleviate your fears. The care team will also hold family meetings routinely during your loved one's transplant stay to update all involved on his/her progress and on any clinical issues that are being addressed. These meetings will be planned as frequently as necessary, to ensure that all concerned are well informed about your loved one's care in the hospital, and what will be required after discharge.

Being the support person for someone who has undergone lung transplantation is a challenging and rewarding experience. It is a role that requires a lifelong commitment. The time that is

expected of you while the recipient is hospitalized and after discharge will lessen as the person improves and begins to resume a normal life.

Your goal as the support person is to help the lung transplant recipient live an independent life and to help that person to develop a health maintenance program.

Your role during the early part of the hospital stay will focus on the obvious need to provide the kind of love and support that only a close family member can give. This time can be an emotional and trying time for the patient and you. Taking care of yourself by getting adequate rest and nutrition will make it much easier for you to be helpful and supportive.

Once the transplant recipient has transferred from the ICU to the Intermediate Care Unit on 11A/B/D, the focus begins to change. The need arises for everyone to begin thinking about regaining independence. Beginning discharge planning and teaching becomes a priority.

The Primary Nurse works closely with the patient to develop a daily schedule and will work with both of you to formulate a list of discharge and teaching needs. Some of your responsibilities include the following considerations:

- Help the Primary Nurse and other staff to get to know the patient and your family by sharing pertinent information.
- Assist the patient in maintaining a daily schedule and offer suggestions for improvement. (Daily schedules help in structuring a routine at home.)
- Encourage the patient to gradually increase what he/she eats and drinks to aid in the healing process.
- Read the Patient Educational Manual and begin to learn about the medications and health maintenance program.
- Participate in teaching/learning sessions arranged with the Primary Nurse.
- Assist the patient with teaching and reinforce what has been learned.

11 A/B/D Sample Patient Activity Schedule

5:00-7:00 AM

Daily weight, vital signs, bath or shower, get dressed, provide samples of urine and sputum.

7:30-8:30 AM

Transplant Team makes rounds, chest x-ray, morning blood samples.

8:00-9:00 AM

Breakfast, medications, medication teaching, walking.

9:00-10:00 AM

Chest therapy, rest.

10:00-11:00 AM

Physical therapy (exercise or walk), vital signs, wound care.

11:00-12:00 PM

Rest, EKG, dietician, medications.

12:00-1:00 PM

Lunch, family visit, Lung Transplant Manual teaching.

1:00-2:00 PM

Walk, chest therapy, visit by social worker, care coordination.

2:00-3:00 PM

Physical Therapy (biking, stair climbing).

3:00-4:00 Rest

4:00-5:00

Medications, vital signs, family visit, teaching.

5:00-6:00 PM Dinner

6:00-7:00 PM

Walk, vital signs, wound care, blood tests.

7:00-8:00 PM

Medications, prepare for sleep.

Precautions

You will receive medications that are necessary to prevent your body from rejecting your new lungs. These drugs decrease your body's ability to fight infections. You will be assigned to a private room while in the hospital. These are specially designed rooms with filters built in to protect you from infections, and to your exposure to other people.

You will be on "precautions." This means that everyone entering your room will wear a mask, gown, and gloves, for at least 7 days after your transplant. Your visitors are limited to immediate family or significant others during this time. Anyone with a cold, flu or any ailment that could put you at risk for infection will not be allowed to go into the room. Flowers and fruit baskets will not be allowed in your room.

Good hand washing is the most effective way to stop the spread of bacteria and prevent infection. This includes family, hospital staff, all visitors, as well as yourself. Your nurse can instruct you and your family on proper hand washing.

When you leave your room for any reason, you must wear a mask.

Respiratory Care

A nurse or respiratory therapist will visit you two to three times a day. He/she listens to your lungs and performs chest physical therapy (CPT). CPT consists of tapping and vibrating your chest while you lay in different positions in bed. CPT also involves teaching you to take deep breaths and cough effectively. You will receive CPT frequently from both the therapists and the nurses taking care of you.

The respiratory therapist and the nurse will help you to walk three to five times every day. As you recover, you will walk independently. The more you walk, the more you increase the blood supply to your new lung, and the stronger you become! This will prove to be the most important aspect of your recovery and will be given the priority it demands.

Monitoring Your Health

Oximetry and Spirometry:

A respiratory therapist will teach you how to monitor two parameters: your oxygen level (oxygen saturation) and your lung volumes (spirometry). Your oxygen saturation is measured with a machine called an oximeter. The oximeter is a small monitor that you place on your finger tip. It reads the percentage of blood saturated with oxygen. Using this monitor enables us to wean you from your oxygen after surgery and allows us to notice problems before they become serious.

You will learn how to measure “forced vital capacity” (FVC) which is the amount of air you can force out of your lungs with one breath. The other important measurement is the “forced expiratory volume in one second” (FEV1). The spirometer records this number as the amount of air exhaled during the first second of your forced exhalation. You will measure the FVC and FEV1 daily and record the values in your notebook.

A decrease in your oximetry and/or spirometry may reflect either infection or rejection. Within a few weeks of discharge, you will receive an oximeter and spirometer for home use. It is important for you to be consistent in taking and recording your measurements to help us detect these problems early.

Physical Therapy

Physical therapy will begin as early as 1-2 days after your surgery. The goal of physical therapy is to improve your movement, increase your functioning and relieve pain. This is essential to your recovery after your transplant. It will assist you in preventing pulmonary complications and the side effects of your medications that can cause muscle weakness.

The therapist will first evaluate your strength, coordination, range of motion, pain, breathing techniques, and mobility. The therapist will carefully monitor your cardiopulmonary status (heart rate, blood pressure, respiratory rate, and oxygen saturation), during activity. Initially you will have many lines (I.V.'s , heart monitor, chest tubes, epidural). The nurse and therapist will assist you in moving with all above mentioned lines. At this time you will be started on an individualized exercise program, which will progress rapidly from in bed to sitting and finally standing. This will assist you in increasing your strength and endurance. Activity will help you in clearing your secretions as well as improving your breathing pattern.

Once you are able to get out of bed and are walking short distances, you may also begin a biking program in your room. You will be closely monitored throughout your individualized biking program. If you have been using a treadmill at home you may be evaluated while using this prior to going home. You will be seen on a daily basis for exercise, biking and walking. It is expected that you participate daily to help prevent pulmonary complications and expedite your discharge to home. Your goals prior to discharge will be to walk and climb stairs independently and to have a well-established exercise program.

By the time of discharge we anticipate you will be independent in all routine activities of daily living, independent in walking to allow you to get to your appointments, and able to climb the stairs. You will have an exercise program designed for you to continue at home every day.

You will be expected to follow up with outpatient rehab to continue with your rehab program once you have recovered from transplant. While in the hospital occupational therapy is also available if needed. An occupational therapist would assist in activities of daily living.

There are several limitations to be aware of, however, to allow complete healing of the incision. These include:

- Do not drive until your doctors gives you permission (at least 6 weeks after transplant)
- Do not lift anything heavier than 8 lbs (the weight of a gallon of milk) including children until you are given permission (at least 6 weeks after transplant)
- Do not push or pull anything heavier than 8 lbs (the weight of a gallon of milk) until you are given permission (at least 6 weeks after transplant)

IT IS ESSENTIAL THAT YOU PARTICIPATE IN YOUR EXERCISE PROGRAM BOTH PRE AND POST SURGERY. KEEPING YOURSELF IN THE BEST PHYSICAL SHAPE POSSIBLE IS THE MOST EFFECTIVE WAY TO AVOID COMPLICATIONS OF SURGERY AND IMPROVE YOUR QUALITY OF LIFE.

Medic Alert Bracelet

You are expected to be an active participant in your health maintenance. You will take medications such as Prograf/Cyclosporine, Prednisone and Imuran/Cellcept for the rest of your life. In case of an emergency or other unplanned situation that requires medical-attention, it is essential to inform your health care providers that you are taking these medications.

The most effective way of alerting others is by wearing a Medic Alert bracelet or necklace. It is your responsibility to obtain this bracelet. The form should be filled out once you have been transferred out of the Intensive Care Unit, and are getting ready for discharge. If you do not have the form to fill out please ask your nurse for one and she/he will assist you in filling it out. You will-need to mail in the form with a check or call in the order with a credit card. Once you have received your Medic Alert jewelry, you must make a commitment to wearing it and report to the company if it becomes lost or broken.

As You Prepare to Go 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. Your transplant team will continue your lung care. This team includes the Pulmonologists you saw prior to transplant in the Center for Chest Diseases Clinic, the Surgeon who performed the transplant, the Lung Transplant social worker, the nurse coordinator and the administrative coordinator as well as the Lung Transplant Nurse Practitioner.

At this point though, 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 healthy 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 of your doctors, your dentists and your pharmacist know about your medications and your current condition.

Patient Discharge Information

Now that your transplant surgery is over and you continue to recover from the operation, it is important that you prepare to care for yourself at home. The details of your care that you and your support people are learning here are an essential part of your life long commitment to maintaining your health. We feel it is very important that you know these details before you are discharged from the hospital. You must know your medications- what they are, what they do, what amount to take and when to take them. You must understand how to use a spirometer, to record your lung volumes and to use an oximeter to monitor your oxygen saturation.

You also must know how to accurately record your weight and your temperature, and for some patients, your blood sugar. We expect you to know the symptoms and problems to report and how to report them. Since you are the person who is responsible for monitoring your health at home we will work with you throughout your stay to make your health maintenance a normal part of your day.

The next section includes information you will need at home to assist you. You will also receive a medical diary for recording information. A list of your health team members with their telephone numbers and other contact information is provided in the first section of this manual. These resources are yours to use as references forever. Please bring your charted information, including weight, temperature, blood sugars, etc, with you to all your appointments.

Communication with the Transplant Team

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

The information contained in this education book describes issues related to the lung transplant process and regaining your health and strength. The road to recovery can be long. Each person has different concerns or issues related to his or her own individual lifestyle. If you have any questions or concerns, please write them down and feel free to address these questions to your nurse coordinator or any member of the transplant team before you go home or at your next follow-up visit.

Please remember:

- When in doubt, call!
- If you are thinking about calling, call!
- The transplant team is always available to answer your questions!

Living With Your Lung Transplant

The Transition to Home

The initial time at home can be quite busy. There will be many scheduled and unscheduled appointments with pulmonologists, visiting nurses, physical therapists, and your primary care doctor. 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.

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 all 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, and you may experience one or all of these feelings at different points after transplant, especially in the early post-transplant period. 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 talk with your nurse, social worker or any transplant team member about any concerns or questions you might have about your hospitalization or discharge. Someone is always available to assist you.

Resources for Managing Your Transplant Health

In preparation for your discharge from the hospital after your transplant, you will be provided with a separate 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. Every patient has special needs that should be dealt with. You will be expected to ask your transplant team lots of questions and to seek guidance on your particular 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. During the evening or on weekends you can reach the physician on call by dialing 1-617-732-5656 and asking for beeper # 15864 (1-L-U-N-G). Please ask the operator not to hold on, but to leave a call-back number for the on-call physician to reach you.

For any medical life threatening emergencies you need to call 911 and go to the nearest emergency room. Have the physician there call the Lung Transplant physician at the above beeper number. For any emergency you should always call 911; do not drive yourself to the hospital.

Wound Care:

Inspect your incision and tube sites every day for signs of infection — these include redness, drainage, increased pain, and/or swelling. Please notify the transplant team if any of these signs of infection occur. The visiting nurse will also be looking for any of these signs of infection. You may continue to wash your incision with soap and water during your daily shower. However, we do not advise sitting in a bath until your incision is completely healed.

Temperature:

You should be checking your temperature twice daily, at the, same time each day in the morning and in the evening. Make sure not to eat or drink anything for 20 minutes before taking your temperature. If your temperature increases more than one degree from your normal you should inform the team. An increase in temperature may indicate infection or rejection. Please be sure to record all results in your diary.

Oximetry and Spirometry:

You will receive an oximeter and spirometer within a few weeks of transplant. Oximetry is a measurement of the saturation of your arterial blood with oxygen. This measurement must also be done daily and recorded in your manual. Rejection can present itself as a decrease in your oximetry or spirometry measurements, so it is *very* important that you are consistent in taking and recording your measurements. Spirometry measures your lung function and is also a very important component in your lung health and must be monitored at home. Any consistent decrease in your spirometry over a few days should be reported to the team even if you are feeling well; it could be a sign of rejection or infection.

Weight:

Weigh your self daily at the same time (usually first thing in the morning after you have urinated and before you eat or drink). A trend of increasing weight or an increase of 6 pounds in one week needs to be reported. This change usually indicates water retention. Please remember to record this information along with your temperature, other vital signs, spirometry and oximetry.

Clinic Visits

Professional support persons such as a visiting nurse will visit you when you go home. Appointments for follow-up in the Center for Chest Diseases along with any other appointments you might need will be made before you are discharged from the hospital.

You will need to be seen every week at the Lung Transplant Clinic, which is held on Wednesdays, for an indefinite period of time until your acute issues are addressed. A Pulmonologist who is in clinic that week will see you. Just as during your pre-transplant clinic visits, the various pulmonologists involved with lung transplantation will rotate in clinic, and you will see different members of the team on different days. This is also true when you schedule a bronchoscopy; the Pulmonologist who is on service on the day your test is scheduled will do your bronchoscopy.

When you return to the clinic after your transplant you should arrive ONE HOUR PRIOR TO YOUR SCHEDULED APPOINTMENT. You should first go to the outpatient clinical laboratory at the 45 Francis St. entrance to have your blood drawn. A lab slip will be waiting for you there. You should then take the Ambulatory Elevators near the laboratory down one floor to the X-ray Department on L1 to have your chest X-ray done. An order will be entered in the computer for this before you arrive. You must allot enough time to do these tests in order to ensure you arrive on time to your clinic appointment. Every effort is made to schedule your appointment in a way that is most convenient for you.

Remember:

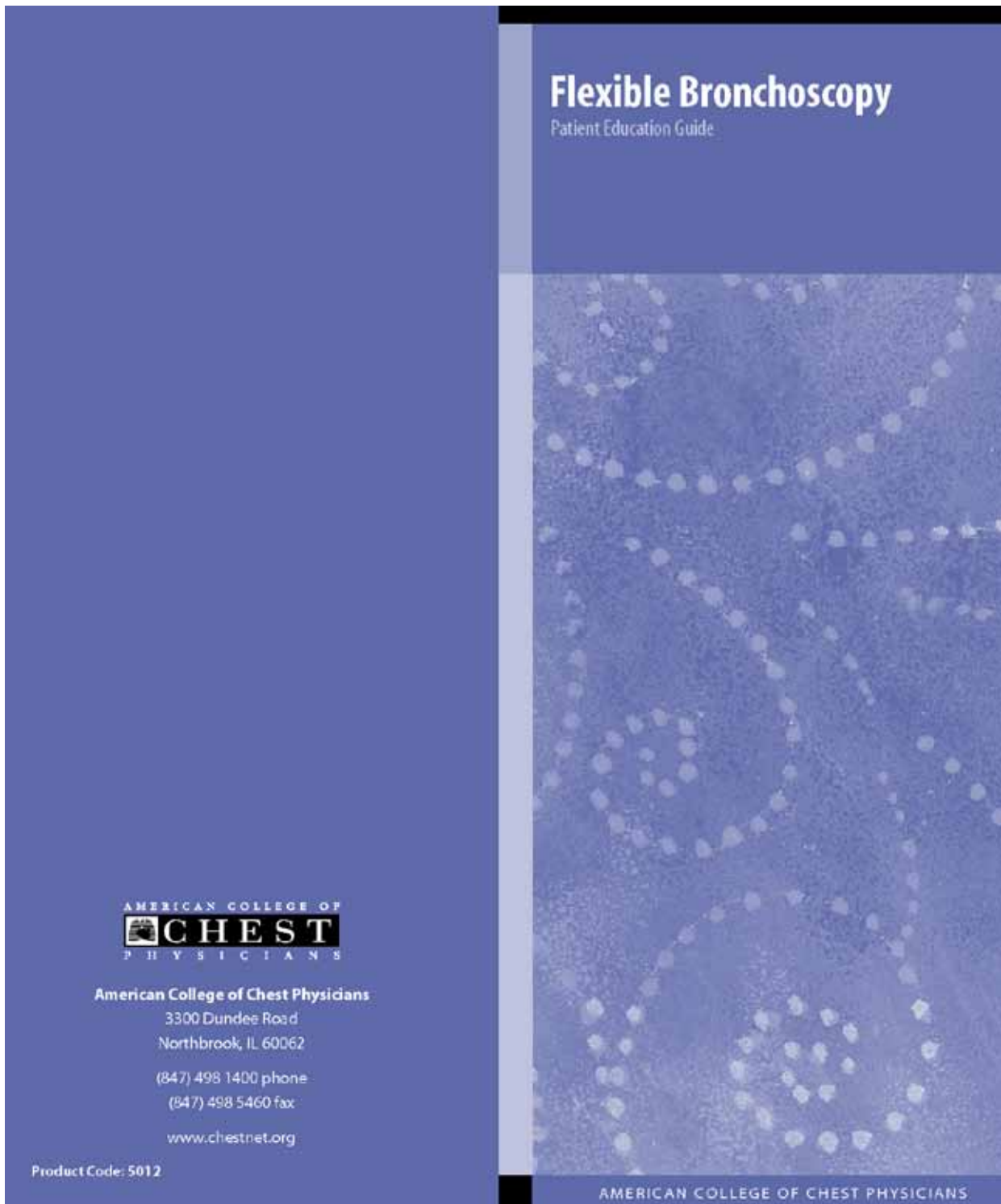
Please remember to bring your FK506 (Prograf) or Cyclosporine with you to the clinic appointment. **DO NOT** take your morning dose of FK506/Cyclosporine before having your blood sample drawn. You need to take the medication AFTER your blood work is drawn. It is also very important that you have your blood drawn 12 hours after you have taken your evening dose of FK506/Cyclosporine. If the time interval is greater than 12 hours it will make your level inaccurate.

On days when you are scheduled for follow-up visits, please make sure to bring your diary with your recorded information with you. You will be told about routine lab work (to keep track of your blood count, kidney and liver function, medication levels, etc) or special tests that you might need.

You will undergo lab tests each time you come in for an office visit. These can include blood, urine and sputum tests. Some of the things the tests look for are:

- Your white blood cell count, which can indicate whether you have an infection or side effects from medication.
- How well your kidneys and liver are working.
- Whether you have enough minerals in your body.
- How much medication is staying in your bloodstream and for how long. How much sugar (glucose) is in your blood.
- How well your blood can clot.

Information About Bronchoscopy



Flexible Bronchoscopy
Patient Education Guide

AMERICAN COLLEGE OF
CHEST
PHYSICIANS

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www.chestnet.org

Product Code: 5012

AMERICAN COLLEGE OF CHEST PHYSICIANS

Flexible bronchoscopy (pronounced bron-kos-ko-pee) is a procedure that enables your physician or surgeon to examine the major air passages of the lungs. This allows your physician to evaluate your lungs and take small samples of tissue or fluid, if necessary. Usually the procedure is performed after you are mildly sedated and your nose or mouth is numbed. Your physician will then insert a bronchoscope, which is a flexible lighted tube about the width of a pencil, through your nose or mouth and into your windpipe. A small channel in the instrument allows tissue and fluid samples to be collected when appropriate.

This brochure is intended for adults undergoing bronchoscopy and parents of children who will have the procedure. Any part of the procedures that is different for children is noted in the appropriate section.

Why Should I Have a Bronchoscopy?

There are many medical reasons for having a bronchoscopy. Common reasons include abnormal findings on a chest x-ray, CT scan findings (like a spot on the lung), or coughing up blood. Diseases of the lung, such as pneumonia, tuberculosis, or lung cancer, can be found by sampling lung fluid or tissue. Samples are sent to a laboratory for testing, and results may assist your doctor in making a diagnosis.

In children, reasons for having a bronchoscopy include noisy breathing or persistent choking that does not respond to therapy. Doctors also may do a bronchoscopy following up babies who are born early, who have had a tracheostomy, or who have abnormal findings on a chest x-ray that do not change over time. If a child gets an object caught in his airway, he may need to go to the operating room for removal of the object by a surgeon using a rigid bronchoscope.

How Do I Prepare for a Bronchoscopy?

1. Your physician will review all the medications you are taking and may have you stop taking certain medications prior to the procedure. Certain medications can complicate the bronchoscopy procedure, so a complete review of your medication by the physician is necessary.
2. If you are diabetic, your medication or insulin dose may need to be adjusted both before and after the procedure.
3. Blood tests sometimes may be necessary prior to the procedure.
4. Do not eat or drink anything (not even water) for 6 hours prior to the procedure. It is important that your stomach is empty well before the bronchoscopy to lessen certain risks, such as vomiting during the procedure. However, you may take your regular medications with a little water.

If your child is to have a bronchoscopy, your doctor may give you special instructions and ask that the child not eat or drink for a longer period of time.

5. Bring someone to drive you home, or arrange for alternate transportation. If you receive sedation during the procedure, you are not allowed to drive or travel by yourself for 12 hours after the procedure.

How Is a Bronchoscopy Performed?

Before the procedure begins, you will receive medication that will numb your mouth, nose, and throat. The medication will help you relax, reduce any cough, and limit throat irritation. A small needle will be inserted into a vein so that additional medications can be given.

Your nurse or physician will connect you to a heart and blood pressure monitor. You will be given extra oxygen through your nose during the exam. If needed, additional sedation may be given through the needle in your vein.

Your physician will then pass the bronchoscope through your mouth and throat (in children, the tubes pass through the nose), through your vocal cords to your windpipe, and into your lungs. When the tube passes through your vocal cords, you may feel the urge to cough or feel some minor discomfort. The feeling is not unusual and is temporary. Your physician will stop to let you catch your breath before continuing the examination.

During the procedure, medication will be given through the scope to help relieve any coughing. You can help by taking slow, shallow breaths through your mouth.

Do not talk during the procedure. Talking can make you hoarse or give you a sore throat after the procedure.

Occasionally, the examination is done with the aid of x-ray equipment to help your physician locate the exact area from which to take a sample. Pain is unlikely to occur during the procedure. A nurse or another health-care professional will be present during the exam to assist you and the physician.

Bronchoscopy is a safe test that carries little risk. Complications are rare, but if they occur, they may include collapsed lung, bleeding from the sample site, an allergic reaction to medicines, hoarseness, and slight

fever. Only rarely do patients experience other, more serious complications. If problems occur, the doctor and health-care professional can easily take care of them.

What Happens After a Bronchoscopy?

When the procedure is finished, you will be observed until you are awake enough to leave. Tell the nurse if you have any chest pain, difficulty breathing, or notice more than flecks of blood in your phlegm. It is normal to cough up a small amount of blood for 1 to 2 days after the procedure.

Your blood pressure, pulse, and breathing rate will be checked prior to your discharge. The needle in your vein will be removed, and a chest x-ray may be taken.

You cannot eat or drink anything for 2 hours after the procedure because your throat may still be numb. For a child, however, the doctor may want to see that the child can drink liquid before going home.

Your physician will be happy to discuss any questions you may have regarding the examination and will tell you when to expect a report of the test results. Sometimes it takes a few days to a week for the results to come back from the laboratory.

Your physician may have spoken to you about additional procedures that may be done in conjunction with bronchoscopy to address specific problems in your airways. Please make sure that you understand the specific indications, risks, and benefits of any additional procedures. In adults these may include procedures such as tumor ablation (photodynamic therapy, cryotherapy, cautery, brachytherapy), or tracheobronchial stenting. In children, the doctor may rinse the lungs with a small amount of liquid, or, rarely, take a sample of lung tissue.

If you have any questions or problems after your bronchoscopy, call your health-care professional.



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Immunology

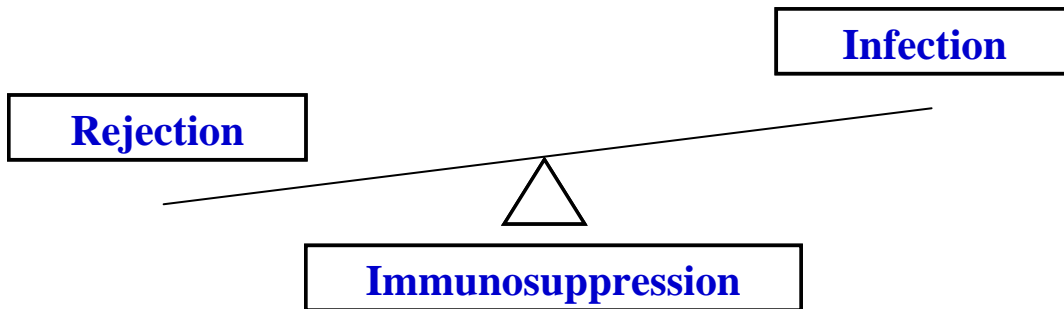
There are two parts of the human immune system- natural immunity and acquire immunity. The natural immune system is the one with which you were born. Some of the elements of the natural immune system are commonly known, such as the skin, the lining of your mouth and stomach, and white blood cells. There are other parts of the body that are also part of the natural immune system but are less familiar to most people. Stomach acids neutralize foreign substances, coughing helps clear the lungs of congestion, and even eyelids function to filter out dust and other particles in the air. All of these parts help protect the body from infection by providing a barrier to germs.

There are several types of germs (you may hear us refer to them as organisms). The most common ones are bacteria, fungi, and viruses. The two most important things to remember about organisms are that (1) they are present everywhere and (2) given the proper environment they cause infection such as pneumonia.

If organisms get by the protective guards, the white blood cells flood or invade the area of infection to destroy the organisms. There are different types of white blood cells and each of them acts in a specific way to fight infection. The type of white blood cell that is particularly important after a lung transplant is called a lymphocyte.

Lymphocytes are also part of the acquired immune system. This system develops over time and is why you may become sensitive or allergic to something later in life. After repeated exposures, the lymphocytes recognize a foreign object as not part of the body and attempt to destroy it. In the case of an organ transplant, the lymphocytes recognize the transplanted organ as foreign and attempt to destroy or “reject” it.

The lymphocytes will always try to protect you from foreign bodies. For this reason a person that has an organ transplant will take medications every day for the rest of his or her life to suppress the lymphocytes in their attempt to protect the body. Although there are occasional stories in the press concerning a patient being able to stop all medication after a transplant, this occurrence is very rare. In most instances, stopping immunosuppressant medications results in rejection of the organ and can lead to death. It is absolutely essential that you discuss any changes in your medications with a member of the lung transplant team before making the change.



The risk of taking these medications is that you will be more vulnerable to infection. As stated earlier, the purpose of the immune system is to protect you from infection. It follows that an immune system that is suppressed is less able to protect you from infection. The balance between adequate immune suppression and prevention of infection is a difficult one after transplant. Achieving the right balance for you will take time, perhaps as long as a few months. For this reason, it is critical that you work with us to help adjust your medications properly and to report any new symptoms to us promptly. We have found that often the signs of infection are very similar to the signs of rejection. These signs may be subtle, and changes that might have been normal for you before transplant may now signify a pending problem. Please let us know about any changes in symptoms or measurements that you experience as soon as they occur, even if they might not have concerned you before your transplant.

Common Infections

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. Initially you will be on it twice a day and then down to 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 on Monday-Wednesday-Friday, 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.

You need to call the transplant office if you have any of the signs of infection or rejection that are listed above. The physicians will review your medications and blood tests and if necessary alter the doses in an effort to balance the risk of rejection against the risk of infection.

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 of your lung transplant team’s instructions for taking medications

- If you have any questions about medications, please ask your lung transplant providers. They’ll be happy to answer.

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:
 - ü Before preparing food to eat
 - ü After touching raw meat like chicken or steak
 - ü Before eating
 - ü After using the restroom
 - ü After changing a baby’s diaper
 - ü After touching animals such as dogs and cats
 - ü After going outdoors or to a public place
 - ü 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.
 - ü If you develop blisters or sores in your mouth, let your lung transplant team know.
 - ü 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.

Addressing Your General Healthcare Needs

Diabetes:

Some of the anti-rejection medications that you take may cause diabetes. Diabetes is an increased level of sugar in the blood. Signs of diabetes may include excessive thirst, increased urination, blurred vision, and confusion. Call your transplant team if you have any of these signs. Early detection can result in reversal or reduction of high blood sugar.

In some cases, blood sugar can be reduced by weight loss, careful diet, and exercise. You may need an oral diabetes drug or insulin injections. If you get diabetes, you will be given special teaching about how to deal with this problem.

Osteoporosis:

Osteoporosis is a bone disease that can be thought of as a “thinning of the bones.” Prednisone therapy increases the chances of developing this condition.

Bones are made of calcium, phosphorus, and several other minerals. Calcium gives bones their strength and stiffness. If there is a calcium deficiency, bones become fragile and thin. Most people are not aware they have osteoporosis until they have pain or break a bone.

To prevent osteoporosis, maintain a diet rich in calcium, found in milk, dairy products, and dark green leafy vegetables. After transplant, you will take supplemental calcium and vitamin D, unless contra-indicated. We will also start an additional medication for bone health in most patients after transplant. Regular weight bearing exercise, such as walking, promotes bone growth. We will perform bone density assessments every 1-2 years after transplant.

Health Maintenance:

You should continue to see your primary care physician (PCP) yearly for routine physical examinations. You should also contact your PCP and local pulmonologist at or about 3 months after your transplant for follow-up and updating of your medical information. Your PCP and local pulmonologist are important resources for you and your transplant team, and we will rely on them to help us take care of you after your transplant. Prior to starting you on any new medication, your local physician should contact the transplant team to make sure the new medication will not interact with anything you are already taking.

Women should undergo routine pelvic examinations with PAP smears with your local physician as recommended. You should perform breast self-examination monthly. You should also undergo yearly mammograms if age appropriate as recommended by your PCP.

Men should perform monthly testicular self-exams. Prostate cancer screening if age appropriate should be performed as recommended by your PCP.

Both men and women should undergo colon cancer screening if age appropriate as recommended by your PCP.

Skin Care:

Transplant patients are at an increased risk for developing skin cancer as a result of sun exposure. Skin cancers are caused by the ultraviolet rays from the sun. These rays are present even when it is cloudy. Patients are instructed on the following steps to protect against harmful ultraviolet rays: Always wear sun block and lip block with a SPF of 30 or higher. Wear clothing that is protective, such as hats and long sleeved shirts. Wear sunglasses when outside during the day. Report any changes in your skin, such as a change in a mole or a wart, or appearance of any new growth. You should have a full body skin check performed annually by a dermatologist.

Generally, you should shower or bathe as often as necessary to keep your skin clean. Most soaps are safe for use.

Prednisone can cause acne on your face, chest, shoulders or back. Cyclosporine can make your skin oily. If acne develops, wash the area three times a day with mild soap, scrubbing gently with a clean, wet washcloth. Rinse the soap completely from your skin to leave it clean. Any benzoyl peroxide solution may be used. To prevent infection, do not pick at or touch the pimples. Report any acne that may be infected. The acne should clear as your prednisone dose is decreased. You may require treatment from a dermatologist if the acne is severe.

To avoid acne:

- Keep your hands away from your face and avoid rubbing the area
- Limit the use of cosmetics
- Do not scrub your skin vigorously
- Avoid soaps that contain creams and oils

Due to spores and molds, patients are advised not to do yard work. If yard work is unavoidable, a mask and gloves should be worn.

Hair Care:

Prednisone will probably change the condition of your hair. Permanent hair dyes, wave lotions and bleach may cause your hair to become brittle and break. It is recommended that you wait until your prednisone dosage is at 20 mg per day or lower before having permanent or coloring to your hair. Tell your hairdresser that you are taking prednisone before any hair treatments.

Unwanted hair growth may result from your medication regimen. Hair removal cream (depilatory) can be used for excessive facial hair. Be sure to follow directions carefully to avoid eye or lip irritation. Excess hair can also be bleached with a 50% peroxide solution.

Waxing and electrolysis are other options. Do not alter your medications due to excess hair growth. Speak with your care team if this becomes a problem for you.

Dental Care:

Continue with your daily routine of dental hygiene by brushing and flossing. You should have regular dental check-ups every six months. Antibiotic coverage is necessary for cleaning or any invasive dental procedures. Notify the team if you have any dental work planned, and you will be provided with a prescription for a single dose of antibiotic to be taken one hour prior to the procedure. This is done in case your mouth or gums are injured during the procedure, since you are more prone to contract an infection in this case. Dental surgery should be postponed until at least 3 months after your transplant if at all possible.

Sexual Activity:

Sexual activity may be resumed, as able, approximately 6 weeks following surgery. Your recovery process will impact how soon you feel ready for sexual activity. You should discuss this with your providers during your clinic visit.

Your transplant may affect your sexual functioning. Certain medications can also interfere with sexual functioning. Some people avoid sexual activity because they are afraid of hurting their new lungs, or of infection. If you have any of these concerns, please discuss them with your transplant team. Since you are immunosuppressed, it is ESSENTIAL that you practice safe sex, because of an increased risk of acquiring a sexually transmitted disease. You **MUST** use contraception to prevent unplanned pregnancy as well. Please feel free to address questions/concerns to the transplant team.

Pregnancy:

The immune suppressing medications that you take after transplant are teratogenic, meaning that they can injure a fetus before the fetus is born. As highlighted in previous sections of this book, in order to preserve your lung function, it is imperative that you not stop these medications for any period of time, even for the purpose of pregnancy. Moreover, the impact of pregnancy on your lung function remains unclear. Pregnancy has the potential to worsen your lung function, a decline that may not be reversible. For this reason, the BWH Lung Transplant Program discourages pregnancy for women after lung transplantation in the strongest terms. The impact of immune suppressing medications on male fertility and fetuses born of men on these medications is also unclear.

We strongly encourage the use of proven contraception methods for patients who have undergone lung transplantation. If you have further questions about pregnancy and childbearing after lung transplantation, please discuss them with the lung transplant team in advance of listing for transplant. The pursuit of in-vitro fertilization (IVF) or other assisted methods of child-bearing should also be discussed with the team at the start of your evaluation for transplant. These techniques can impact upon your lung health and also upon your ability

to be active on the transplant list, and should be discussed at the earliest appropriate time in the transplant process.

Alcoholic Beverages:

The consumption of alcoholic beverages should be infrequent due to possible interactions with medications.

Medications

Lung Transplant Medications

Important information about medications

Important Things to Know About Your Transplant Medications:

- ❖ **Noncompliance (not taking your medications) is the most common reason for transplant rejection.** Try never to miss even one dose of your transplant medications. If you miss a dose of your medicine, take it as soon as possible.
- ❖ If it is almost time for your next dose, skip the missed dose, notify a member of your transplant team and return to your regular schedule.
- ❖ Never “double-up” on your medications.
- ❖ It is very important to note that doses of your medications may change very often. This is especially true right after the transplant. You need to be dedicated to keeping a list of your current medications and doses and bring it with you to all clinic visits.
- ❖ Because doses change so often, sometimes the doses listed on the prescription bottle may be incorrect.
- ❖ If you are ever confused about the dose of your medications, call a member of the transplant team for clarification.
- ❖ Try to establish a schedule, meaning, try to take the medications the same time everyday. This will help maintain a consistent level of the medications in your body and could help prevent rejection.
- ❖ All medications prescribed by your transplant team play an important role in keeping you healthy.
- ❖ However, along with their benefits, many of these medications can have several side effects and drug interactions.
- ❖ The side effects can be managed, but it is important that you notify the transplant team about any troubling side effects as soon as possible.
- ❖ Do not make changes in your own transplant medications to help prevent side effects; this can lead to rejection or toxicities.

- ❖ Many of the transplant medications have several drug interactions. Please check with a member of your transplant team when starting a new prescription or over-the-counter medication, as these drugs may impact your transplant medications.

Lung Transplant Medications

Immunosuppression – Meds you need to know

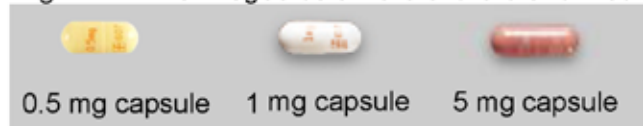
Maintenance Medications – Prograf (tacrolimus, FK506, FK)



Tacrolimus (we often call this medication FK506 or just FK)



Prograf - is currently available as a generic but we prefer brand if the cost difference is manageable. Please contact us for options if the cost difference is not manageable. *The images below are of the brand medication.*



What is Prograf?

- ❖ FK506 suppresses the immune system.
- ❖ This is necessary in transplant patients to prevent organ rejection by the normal immune function of the body.



How long will I need to take Prograf?

- ❖ FK506 is a life-long medication.



How much Prograf do I take?

- ❖ Doses are different for each patient.
- ❖ We generally start this medication at a low dose in the hospital after the transplant procedure and then titrate the dose of the medication up so that we can achieve an adequate level of drug in your blood.
- ❖ You will be required to take blood tests so that we can adjust the dose according to how much of the drug is in your blood.
- ❖ Doses of this medication change often, especially right after the transplant. It is important that you know how much of this medication you are taking at all times.



How do I take Prograf?

- ❖ Follow your transplant team's instructions carefully.
- ❖ This medication is generally given twice a day (the best way to take it is every 12 hours).
- ❖ You will be asked to take this medication with food to help prevent stomach upset.



Tell me about the special blood test that I will need while I am taking Prograf?

❖ In order to make sure that you get the appropriate dose of FK506, it is necessary for the transplant team to check how much of this drug is in your blood.

❖ We will check your FK506 blood level every time you come to the outpatient transplant clinic for labs.

❖ To successfully check the FK506 level in your blood you must follow several steps:

1. Take all morning medications, except for the FK506, prior to coming to the clinic.
2. After you have given the blood sample, take your morning dose of FK506.
3. It takes 4 – 6 hours for us to get results back, so, if we need to change your FK506 dose, we will call you at home to change your evening dose.



Are there interactions between Prograf and other drugs?

❖ An interaction generally means that one drug may increase or decrease the effect of FK506.

❖ Also, the more medications a person takes, the more likely there will be a drug interaction.

❖ FK506 interacts with many prescription and non-prescription medications, as well as some dietary supplements.

❖ Please consult with your transplant nurses before starting any new medications because of the potential for drug interactions.



Are there interactions between Prograf and foods or beverages?

❖ It has been shown that grapefruit, grapefruit juice and other foods and beverages that contain grapefruit (for example, the soda Fresca has natural grapefruit juice in it) can increase the blood level of FK506.

It is recommended that you avoid grapefruit, grapefruit juice and other foods and beverages that contain grapefruit while taking FK



What are some of the more common side effects of Prograf?

❖ Increased creatinine(a measure of kidney function): FK506, especially at high levels, may increase your creatinine. If this occurs, it may be necessary for one of the transplant team members to decrease your dosage. This is one of the major reasons why we will check your FK506 levels so much.

❖ Increased blood sugar: some patients who are not diabetic before the

transplant may develop difficulties controlling their blood sugars after the transplant. We sometimes have to administer insulin to help control these high blood sugars. This side effect is one that may go away with time.

❖ Increased potassium: elevations in potassium levels can be seen in patients who are receiving FK506. Potassium levels are monitored every time labs are drawn. We can manage high potassium levels by lowering the FK506 dose (if possible) or administering a medication that acts to lower the potassium levels.

❖ High blood pressure: high blood pressure is very common after transplantation. FK506 can contribute to this. Several medications are available for use in transplant patients with high blood pressure.

❖ High cholesterol: high cholesterol is very common after transplantation. FK506 can contribute to this. Several medications are available for use in transplant patients with high cholesterol.

❖ Stomach upset and/or diarrhea: stomach upset and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take FK506 with food.

❖ Hand tremor: FK506 can cause a fine hand tremor in several transplant patients and usually occurs in patients with a high blood level. This tremor may go away with time, but if it occurs please let one of the transplant team members know and, if possible, we can lower the FK506 dose.

❖ Hair loss: hair loss occurs in about 20% of patients receiving FK506. This side effect is generally seen within the 3 months post-transplant, and generally resolves on its own after approximately 6 months.

NOTES:

Lung Transplant Medications

Immunosuppression – Meds you need to know

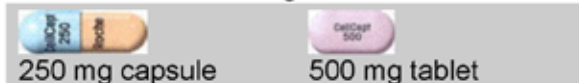
Maintenance Medications – CellCept (mycophenolate mofetil, MMF)



Mycophenolate mofetil



Cellcept - is currently available as a generic and it is OK to take the generic version of this medication. *The images below are of the brand medication.*



What is CellCept?

❖ CellCept suppresses the immune system, but works differently compared to FK506.



How long will I need to take CellCept?

❖ CellCept is a life-long medication.



How much CellCept do I take?

❖ Most patients take 1000 mg twice per day.

❖ We generally start this medication 5-7 days after transplant

❖ Doses may be decreased if you experience some side effects.



How do I take CellCept?

❖ Follow your transplant team's instructions carefully.

❖ This medication is generally given twice a day (the best way to take it is every 12 hours).

❖ Even though, the manufacturer of this medication recommends taking it on an empty stomach, you will be asked to take this medication with food to help prevent stomach upset.



Are there interactions between CellCept and other drugs?

❖ CellCept does not have as many drug interactions as FK506; however, there are still some medications that may interact with CellCept.

❖ In particular, you will most likely be taking calcium carbonate as a calcium supplement after the transplant. **CellCept and calcium cannot be taken at the same time, because there is an interaction in the stomach that decreases the absorption of CellCept.** Because of this interaction, you will be instructed to take calcium supplements 1 hour before or 2 hours after taking the CellCept.

❖ Please consult with your transplant nurses before starting any new medications because of the potential for drug interactions.



Are there interactions between CellCept and foods or beverages?

❖ There are no known food or beverage interactions with CellCept.



What are some of the more common side effects of CellCept?

❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection. Decreased white blood cell counts are common in patients taking CellCept. If this side effect occurs, it may require that we reduce your CellCept dosage.

❖ Stomach upset and/or diarrhea: stomach upset and diarrhea are the most common side effects with CellCept. In order to help prevent this, we may ask you to take CellCept with food. If this side effect occurs despite taking the CellCept with food, it may require that we split up the way we administer this medication (instead of two times a day, we may have you take smaller doses three or four times a day) or lower the total daily dose. Some patients who cannot tolerate the stomach upset or diarrhea from CellCept may be changed to another transplant medication called Imuran (azathioprine) that may cause less gut irritation.

❖ Increased risk during pregnancy: miscarriage and birth defects have been reported in patients who became pregnant while receiving CellCept. Pregnancy testing and dual contraception are recommended while taking CellCept and at least 6 weeks after discontinuing the use of CellCept. If you are a female of child bearing age, you will be asked to sign a form acknowledging this risk with CellCept.

Lung Transplant Medications

Immunosuppression – Meds you need to know

Maintenance Medications – Prednisone



generic name **Prednisone**



❖ This drug is available as a generic and is no longer available as a trade name product.

❖ Many pharmaceutical companies make a generic version of this medication; therefore, the pills are available in several different shapes and colors.

❖ In general, prednisone is available in 2.5, 5, 10 and 20 mg tablets.



What is Prednisone?

❖ Prednisone suppresses the immune system, but works differently compared to both FK506 and CellCept.

❖ Prednisone is known as a steroid. You may be familiar with this medication, as it can also be used to treat inflammation and pain.



How long will I need to take Prednisone?

❖ Prednisone is a life-long medication.



How much Prednisone do I take?

❖ You will receive high doses of steroids initially after transplant. Then you will wean your dose over the first few months after transplant.



How do I take Prednisone?

❖ Follow your transplant team's instructions carefully.

❖ This medication is generally given once a day.

❖ You will be asked to take this medication with food to help prevent stomach upset.



Are there interactions between Prednisone and other drugs?

❖ Prednisone can interact with many prescription and non-prescription medications, as well as some dietary supplements.

❖ Please consult with your transplant nurses before starting any new medications because of the potential for drug interactions.



Are there interactions between Prednisone and foods or beverages?

❖ There are no known interactions with any foods or beverages. However, prednisone may cause retention of sodium (salt), so try to keep your salt intake to a minimum.



What are some of the more common side effects of Prednisone?

- ❖ Increased blood sugar: some patients who are not diabetic before the transplant may develop difficulties controlling their blood sugars after the transplant. We sometimes have to administer insulin to help control these high blood sugars. This side effect is one that may go away with time.
- ❖ High blood pressure: high blood pressure is very common after transplantation. Prednisone can contribute to this. Several medications are available for use in transplant patients with high blood pressure.
- ❖ High cholesterol: high cholesterol is very common after transplantation. Prednisone can contribute to this. Several medications are available for use in transplant patients with high cholesterol.
- ❖ Stomach upset and/or diarrhea: stomach upset and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take prednisone with food.
- ❖ Weight gain: prednisone can cause patients to gain weight by two mechanisms. First, it makes people hold onto water; therefore, the more water they hold onto, the heavier they get. Second, this medication can cause an increased appetite in approximately 3% of patients.
- ❖ Bone loss: osteoporosis is a rare, yet serious side effect of prednisone. Even as little as one dose of prednisone can cause bone loss. If you are maintained on prednisone, we will periodically check your bone mineral density to check to see if prednisone is affecting your bones. Also, you will be asked to take a calcium and vitamin D supplement after the transplant to help prevent osteoporosis. Patients will be asked to receive a bone-mineral density test (also known as a DEXA scan) to determine the strength of their bones. This test is usually performed every two to three years in patients who remain on prednisone after the transplant.
- ❖ Night sweats: Some patients may experience night sweats while receiving prednisone. This side effect usually takes place with higher doses and goes away with time.
- ❖ Mood changes: We make a similar drug to prednisone in our bodies every night when we sleep called cortisol. Cortisol helps us deal with stress and our emotions. When prednisone is prescribed after the transplant, it is not uncommon to see patients develop rapid mood swings (i.e. happy to sad, laughing to crying). This side effect generally disappears after about 5 days of being on the prednisone.

❖ Cataracts: we recommend yearly visits to your eye doctor to make sure that this side effect is diagnosed and managed appropriately.

❖ Acne: a small percentage of patients may develop acne after the administration of prednisone. Good skin hygiene is the best prevention for this, and over-the-counter acne medications may be helpful, but please consult with a transplant team member before starting any medications for acne.

NOTES:

Lung Transplant Medications

Anti-infectives

Anti-infectives

- ❖ Anytime a person's immune system is suppressed they are at increased risks for infections.
- ❖ Proper hygiene, especially hand-washing, is essential to prevent infections.
- ❖ It is important to make sure that you have been adequately vaccinated prior to the transplant (i.e. pneumococcal vaccine, flu-vaccine, etc.).
- ❖ In order to help prevent you from getting an infection after the transplant we will be putting you on two different types of antibiotics.
- ❖ You will receive one medication that is active against a type of pneumonia.
- ❖ Lung transplant patients are at high-risk for developing a pneumonia called *Pneumocystis jiroveci* (formerly known as *Pneumocystis carinii* or PCP).
- ❖ This germ is spread in the air and is common all over the world. Since you can't help being exposed to this germ, you will receive a medication to prevent this infection.
- ❖ The most common medication used to prevent this pneumonia is called Bactrim, which is a sulfa-drug.
- ❖ Some patients have an allergy to sulfa-drugs. If you are allergic to Bactrim, you will receive another medication called Mepron or be desensitized to bactrim.
- ❖ You will receive a second medication that is active against viral infections.
- ❖ Cytomegalovirus or CMV, is a virus that is common in about 70% of Americans.
- ❖ People are usually infected by the time they are 2 years old or during their teenage years.
- ❖ Many people are infected with CMV and don't even know it because CMV usually does not cause long-term problems.
- ❖ CMV is spread through contact with an infected person's body fluids (such as saliva, blood, urine, semen or breast milk). It can be sexually transmitted or transmitted through an organ transplant.
- ❖ Both you and your donor will be tested to see if you have ever been exposed to this virus.
- ❖ If either you or your donor have been exposed to the CMV virus, then you will receive the medication Valcyte. If neither you nor the donor have never been exposed, you will receive Valtrex.

Lung Transplant Medications

Anti-infectives

Antibiotic – Bactrim (Sulfamethoxazole / Trimethoprim, SMZ / TMP)

- ❖ As mentioned above, the most common antibiotic used to prevent *Pneumocystis* pneumonia is called Bactrim, which is a sulfa-drug.



generic name

Sulfamethoxazole / Trimethoprim (also known as SMZ / TMP)



Trade Name

Bactrim or **Sepra** - this drug is available as a generic medication.



How do I take Bactrim?

- ❖ The dose is different for every patient. It is dependent on blood tests at the time of transplant.



How long will I need to take Bactrim?

- ❖ Bactrim is a life-long medication.



What are some of the more common side effects from Bactrim?

- ❖ Stomach upset and/or diarrhea: stomach upset and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take this drug with food.

- ❖ Increased potassium: elevations in potassium levels can be seen in patients who are receiving Bactrim. Potassium levels are monitored every time labs are drawn.

- ❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

- ❖ Sensitivity to the sun: this medication can make your skin more sensitive to the sun and more likely to develop sunburn, even in the winter. Please wear sunscreen when you go out into the sun to help prevent sunburns.

- ❖ Rash: rarely, patients receiving Bactrim can develop a rash. If this happens to you please call your one of the transplant team member. You may need to be switched to another antibiotic.

NOTES:

Lung Transplant Medications

Anti-infectives

Antibiotic – Mepron (Atovaquone)

❖ For those patients that are allergic to sulfa-drugs, we may use Mepron to prevent *Pneumocystis pneumonia*, which is just as effective, but does not cause the allergic reactions that are seen in some patients who take sulfa-drugs.



generic name

Atovaquone



Trade Name

Mepron - this drug is not currently available as a generic.



How do I take Mepron?

❖ You will take 1500 mg (10 mL or 2 teaspoons) everyday.



How long will I need to take Mepron?

❖ Mepron is a life-long medication.



What are some of the more common side effects from Mepron?

❖ Stomach upset and/or diarrhea: stomach upset and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take Mepron with food.

NOTES:

Lung Transplant Medications

Anti-infectives

Antiviral – Valcyte (Valganciclovir)

- ❖ If either you or your donor have been exposed to the CMV virus, then you will receive a medication called Valcyte (valganciclovir), which is very effective at preventing the CMV virus from causing an infection.



generic name

Valganciclovir



Trade Name

Valcyte - this drug is not currently available as a generic.



450 mg tablet



How long will I need to take Valcyte?

- ❖ You will need to take Valcyte for 6-12 months after transplant.



How do I take Valcyte?

- ❖ You will take 450 mg (2 tablets=900mg) once daily.



What are some of the more common side effects from Valcyte?

- ❖ Stomach upset and/or diarrhea: stomach upset and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take this drug with food.

- ❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

NOTES:

Lung Transplant Medications

Anti-infectives

Antiviral – Valtrex (Valacyclovir)

- ❖ If neither you nor the donor have ever been exposed to the CMV virus, then you will receive a medication called Valtrex (valacyclovir), which is used to prevent an infection from Herpes Virus.



generic name

Valacyclovir



Trade Name

Valtrex - this drug is not currently available as a generic.



500 mg tablet



How long will I need to take Valtrex?

- ❖ You will need to take Valtrex for 6-12 months.



How do I take Valtrex?

- ❖ Doses will be different for patients based on blood tests at the time of transplant.



What are some of the more common side effects from Valtrex?

- ❖ Stomach upset and/or diarrhea: stomach upset and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take this drug with food.

- ❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

NOTES:

Lung Transplant Medications

Vaccinations

Vaccinations

- ❖ It is important to make sure that you have been adequately vaccinated prior to the transplant (i.e. pneumococcal vaccine, flu-vaccine, etc.).
- ❖ However, after the transplant, some vaccines should not be administered to patients on drugs that suppress the immune system.
- ❖ See below for a list of vaccines that are appropriate for patients before and after the transplant procedure.
- ❖ Please discuss the use of vaccines with a member of the transplant team before receiving any vaccinations.
- ❖ You will be given the flu (influenza) vaccine every year and the pneumococcal vaccine every five years.

Vaccine	Safe for transplant candidates	Recommended for transplant recipients
Influenza (Flu)	Yes	Yes
Hepatitis B	Yes	Yes
Hepatitis A	Yes	Yes
Tetanus	Yes	Yes
Polio, inactivated	Yes	Yes
<i>S. pneumonia</i>	Yes	Yes
<i>N. meningitides</i>	Yes	Yes
Rabies	Yes	Yes
Varicella	Yes	No
Zostavax	Yes	No
Smallpox	No	No
Anthrax	No	No

Lung Transplant Medications

Other Commonly Used Meds

High Blood Pressure and High Cholesterol Medications

- ❖ Heart disease is a very serious problem in lung transplant patients.
- ❖ High blood pressure occurs in nearly 54% of patients within the first year after the transplant.
- ❖ High cholesterol occurs in nearly 26% of patients within the first year after the transplant.
- ❖ Your blood pressures and cholesterol levels will be monitored very closely after the transplant operation.
- ❖ It is very important for transplant patients to try to stick to a heart-friendly diet and to exercise (walking, biking, swimming, etc.).
- ❖ Proper management of your blood sugars (in patients who have diabetes) can all help improve your health.

High Blood Pressure	High Cholesterol
<ul style="list-style-type: none"> ❖ The goal blood pressure after the transplant will be less than 130/80. However, if you are a diabetic, the recommended goal blood pressure is at or less than 125/75. ❖ Many patients require more than one medication to control their blood pressure. ❖ Your transplant team will choose the blood pressure medication(s) that is/are right for you. 	<ul style="list-style-type: none"> ❖ The important transplant medication FK506 is known to increase cholesterol, and so is prednisone. ❖ The goal "bad cholesterol" (LDL cholesterol) is less than 100. ❖ Diet is the first step to try to reduce your cholesterol. ❖ Many patients will require medication to lower their cholesterol level. ❖ Your transplant team will choose the cholesterol lowering medication that is right for you. ❖ When you are on a cholesterol medication, a muscle enzyme test known as "CK" and your liver enzymes will be checked every 3 months, because cholesterol-lowering medications may rarely affect the levels of these lab tests.

Lung Transplant Medications

Over the Counter Medications

- ❖ It is important for you to know that many over-the-counter medications contain several different drug combinations. For example, Tylenol Allergy Sinus contains acetaminophen, chlorpheniramine and pseudoephedrine. Because this product contains pseudoephedrine, transplant patients should not use it.
- ❖ Please read over-the-counter medication boxes very carefully, looking specifically for the active ingredients.
- ❖ Call one of your transplant team members if you are confused about what over-the-counter products you can or cannot take.
- ❖ The Food and Drug Administration (FDA) doesn't approve dietary supplements for use in the United States; therefore, we cannot safely advise our patients to take them.
- ❖ Several dietary supplements have been shown to have severe interactions with transplant medications. For example, St John's Wort has been shown to decrease the blood levels of FK506, which may cause rejection.
- ❖ **Please avoid the use of any dietary supplements, unless it is specifically discussed with one of the transplant team members.**

NOTES:

Lung Transplant Medications

Important Drug Interactions

The following medications might interact with your transplant medications and cause you to become ill.

Because medications can go by different names, before you start ANY new medication you should check with your Transplant Pharmacist or Doctor.

<i>Antibiotics;</i>	<i>Antifungals:</i>	<i>Anti-hypertensives:</i>	<i>Pain meds:</i>	<i>Others:</i>
Erythromycin Clarithromycin Rifampin Isoniazid	Ketoconazole Fluconazole Itraconazole Amphoterecin B	Verapamil Diltiazem Nicardipine	Ibuprofen Indomethacin Naproxen Other NSAIDs	Danazol Amiodarone Phenytoin Pheno- barbital Carba- mazepine
Gentamicin Tobramycin				

Diet and Exercise After Transplant

Nutrition After Lung 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. This handout will cover the general guidelines that accompany a lung transplant. Your dietitian and/or doctor will discuss any specific individual nutrition needs with you. Your dietitian will also assist you in planning your individual meal plan.

Calories:

Maintaining your body weight is a good way to be fairly certain that you are getting enough calories every day. You should weigh yourself weekly. If you are underweight please refer to the pre-transplant handout for tips to increase calories that follows this section. Avoid overeating if you have a tendency to gain weight. If you are overweight, please refer to the section addressing your nutritional needs that follows the section on being underweight. Talk to your dietitian about weight setting goals.

Protein:

The medications you are taking as well as the healing process increase your body's need for protein. For these reasons, you need to pay special attention to getting adequate protein in your diet. Animal products contain the highest quality protein. The best protein choices are lean meats, fish, poultry, eggs (limit 2-3 per week or choose egg substitutes to limit your cholesterol) and dairy products like milk, cheese, and yogurt (choose low fat varieties). Your dietitian will discuss with you just how much protein you need each day. For further suggestions to increase protein please refer to the pre-transplant handout.

Salt:

Since many individuals on steroids and/or immunosuppressant medications have a problem with fluid retention, a no added salt (NAS) diet is recommended. This is because salt contains the mineral sodium which can act like a sponge in the body, holding on to fluid and raising the pressure in your blood vessels.

If you have cystic fibrosis, talk to your physicians regarding the appropriate amount of sodium for your diet. Severe limitations on sodium intake can affect the manifestations of CF in your other organs.

General Guidelines for a low sodium diet:

1. Do not add salt at the table.

2. Avoid using salt when cooking. If you do cook with salt, no more than ½ teaspoon should be used per day.

3. Avoid packaged and processed foods which contain large amounts of salt and sodium. These include:

A. Smoked, Cured, or Dried Meats and Cheeses

Bacon	Sardines
Ham	Smoke Salmon
Sausage	Hot Dogs
Cold Cuts	Canned Meats
Corned Beef	Cheese, processed (American or spreads)

B. Canned foods/boxed mixes with added sodium

(choose low sodium varieties when available)

Canned vegetables, Soups, Pasta dishes
Boxed pasta, Rice and Potato mixes with sauces

C. Snacks and Miscellaneous items

Saltines	Cheese Curls
Potato Chips	Salted Popcorn
Pretzels	Salted Nuts

D. Seasonings, Sauces and Dressings

Salt	Seasoned Salt
Garlic Salt	Onion Salt
Pickles	Meat Tenderizers
Olives	Relish
Ketchup	Soy Sauce

Fat and Cholesterol:

One of the side effects of the medications which you are now taking is that they have the tendency to raise your blood cholesterol level to higher than normal levels. To help control your blood cholesterol, it is important to limit the amount of cholesterol, trans fat and saturated fat in your diet. Fat is also a concentrated source of calories, so cutting back on your fat intake can help you control your weight (if weight control is an issue).

Suggestions to Limit Saturated Fat and Cholesterol:

*Limit red meat to 2-3 times a week in 3 to 4 ounce portions. Red meat is beef, lamb, pork and veal.

*Choose white meats such as chicken, turkey and fish as protein sources more often than red meat.

*Trim visible fats from meats. Remove poultry skin before eating.

*Limit egg yolks to 3 per week. Use egg whites or egg substitutes instead of whole eggs whenever possible.

- *Choose non fat and low fat dairy products such as skim or 1% milk, non fat yogurt and frozen yogurt, low fat or non fat ice cream or ice milk, and low fat or non fat cheeses.
- *Avoid organ meats such as kidneys, liver, and brain.
- *Limit your use of butter and stick margarine. Choose light tub or liquid margarine.
- *Avoid frying foods. Prepare by baking, broiling, roasting, or steaming.
- * For stir-frying, use a non-stick pan and Pam spray, or use Canola or Olive oil.
- *Avoid commercially prepared cookies, cakes, crackers, chips and dips, ice cream, pastries and salad dressings. Use canola oil rather than butter, lard, or vegetable shortening when making bread products at home.
- *Read all labels carefully for the type and amounts of fats they contain.

Calcium:

Osteoporosis is a risk factor after transplant as a result of medications. It is very important to have adequate calcium intake, 1200 mg per day, either by diet or supplements to help maintain strong bones.

Some of the best sources of calcium are dairy products. For example, one cup of milk can give you 300 mg of calcium. This is 25% of your Daily Value. If dietary fat is a concern, there are many low fat dairy products from which you can choose.

Other non-dairy dietary sources of calcium include soy products, broccoli, turnip, collard and mustard greens. If high calcium foods are difficult for you to eat regularly please ask your doctor or dietitian which calcium supplements are right for you to take. Additional vitamin D supplements are also recommended to help you absorb adequate amounts of calcium.

Additional dietary modifications such as triglyceride, blood glucose control, low potassium and high magnesium guidelines may be necessary due to the effects of medications and will be individualized for you by the dietitian.

For Cystic Fibrosis patients after transplants: All your life you have been encouraged to gain weight and eat whatever foods appealed to you. Now after lung transplantation caution needs to be taken with weight gain efforts as some of your medications may cause high triglyceride and cholesterol levels. Please see the dietitian for heart healthy ways to increase calories while decreasing saturated fat intake. You may have also consumed foods with high sodium content and at this time it is still allowed, but avoid using extra salt at the table and while cooking. For additional questions and suggestions ask the dietitian at clinic or by appointment.

The following documents are guidelines prepared by the Brigham and Women's Hospital Department of Nutrition. The first pertains to all lung transplant patients and the second to patients who are underweight. The next section makes suggestions for those trying to lose weight.

DEPARTMENT OF NUTRITION**Lung Transplant Nutrition Care Plan**

The information provided on the following pages is intended as a guideline to promote sound nutrition for a long and healthy life. More detailed information is available from your inpatient dietitian. As you are further out from your transplant your special nutrition needs may change. It is important for you to know that you can always have access to a dietitian at Brigham and Women's Hospital. If you live far away, the physician following you in your area can provide you with a referral to a dietitian that is closer to you. Nutrition plays a very important role after transplant and can have a significant impact on your quality of life as well as the success of your transplant.

Maintain a healthy weight

Keeping your weight within a healthy range will ease stress on your lungs, decrease high blood sugars associated with steroids, and decrease blood pressure. Talk to your doctor or dietitian about a desirable weight for your height after transplant.

A side effect of the Prednisone that you will be taking is increased appetite. It will be important to keep healthy snacks on hand, and to avoid turning to "junk food" to curb your cravings.

Healthy Snack Ideas:

- § Whole Grain (like Wasa, Kavli, or Ak Mak) crackers with "natural" peanut or almond butter. (Natural butters have oil on top and need to be mixed before eating).
- § Carrots, cherry tomatoes, cucumber, and/or celery sticks with a vinaigrette salad dressing.
- § Nonfat yogurt
- § Fresh fruit or vegetables with low-fat cottage cheese
- § Baked corn chips with fresh salsa or guacamole.
- § ½ whole-wheat tortilla with a few slices of turkey, tomato, avocado
- § Low salt soup with whole grain crackers
- § English muffin pizza: ½ whole grain English muffin + tomato sauce + light shredded mozzarella cheese
- § 1 cup of Whole grain cereal with skim/1% milk
- § Bean dips or Hummus with baked pita chips
- § Whole grain rice cakes or soy cakes.

Meet your body's need for vitamins and minerals:

Take a multiple vitamin with minerals for at least the first two months after transplant unless instructed not to do so by your transplant doctor or nurse practitioner.

A well balanced diet can usually meet your body's needs for vitamins and minerals in times of good health. Try to consume foods from each of the food groups every day, especially *vegetables, fruits, whole grains, and low fat dairy products*. If you eat at least five servings of fruit and vegetables per day, you may discontinue your multivitamin two months after transplant. Although, to ensure you are meeting your body's needs for all vitamins and minerals, you may also continue a daily multivitamin on a regular basis.

Avoid herbal supplements and any other types of over-the-counter nutritional products not approved by the transplant team.

Take in adequate calcium

Everyone young and old needs calcium in his/her diet to help keep their bones and body healthy. If you don't get enough calcium from the foods and beverages you consume, your body takes calcium from your bones to meet its needs. The Prednisone you are taking causes your body to lose calcium, and over time this can make your bones weak and brittle.

It is recommended that you take in 1,200 mg of Calcium per day. Below you will find the calcium content of food items:

Dairy Foods

Yogurt, nonfat plain (1 cup)	452 mg
Skim milk (1 cup)	302 mg
Cheddar cheese (1 oz.)	204 mg
Ricotta cheese, part skim (1/4 cup)	169 mg
Cottage cheese (1 cup)	150 mg

Collards, frozen (1/2 cup cooked)	179 mg
Broccoli (1 cup, cooked)	150 mg
Black beans (1 cup)	103 mg
Almonds (1 tbsp.)	50 mg

Nondairy Foods

Tropicana Season's Best Orange Juice plus Calcium (1 cup)	333 mg
Whole Grain Total Cereal (1cup)	250 mg
Pink salmon with bones, sardines (3 oz. cooked)	181 mg

Soy Products

Soy yogurt with calcium (3/4 cup)	300 mg
Soy milk, enriched (1 cup)	300 mg
Tofu, firm or extra firm (1/4 cup)	250 mg
Soy nuts, roasted/salted (1/2 cup)	103 mg

If these foods are not part of your regular diet, you may need to take a calcium supplement to make sure your body is getting the calcium it needs. To enhance absorption, choose a supplement with at least 400IU of Vitamin D per day. If you are at high risk for bone disease, you may also be put on other medications to protect your bone health.

Practice Good Food Safety

Since you are taking immunosuppressing drugs, you will be more susceptible to infections and food-borne illnesses. The following recommendations should help to decrease your risk of this potential complication.

- § Check expiration dates on all food packaging, and consume the product before expiration.
- § Wash tops of cans prior to opening.
- § Follow package directions for storing items.
- § Wash hands with warm soapy water before and after handling any raw foods.
- § Thaw frozen foods in the microwave or in the refrigerator. Never thaw or marinate foods on the counter or in the sink.
- § Sanitize cutting boards and counters with bleach (1 tablespoon per gallon water). Always clean cutting board after cutting raw meats.
- § Never eat raw meat, poultry, seafood, or eggs. Cook eggs until whites are cooked and the yolk thickens
- § Cook meats and poultry thoroughly. Use a meat thermometer inserted in the thickest part of the meat to make sure the internal temperature is at least 165 degrees.
- § All juices and dairy products should be pasteurized. Avoid fresh squeezed juice, fresh apple cider, and homemade eggnog.
- § Avoid sprouts, such as alfalfa, bean, and broccoli sprouts.
- § Thoroughly rinse raw fruits and vegetables before eating or using in cooking.
- § Avoid eating from street vendors, buffets and salad bars, and food samples at grocery stores. Use caution when eating out at restaurants.
- § Use airtight containers to store leftovers. Refrigerate promptly. Do not let food sit at room temperature for more than 2 hours. Discard leftovers after two days in the refrigerator.
- § Do not eat hot dogs, luncheon meats, or deli meats, unless they are reheated until steaming hot.

- § Avoid getting fluid from hot dog packages on other foods, utensils, and food preparation surfaces, and wash hands after handling hot dogs, luncheon meats, and deli meats.
- § Do not eat soft cheeses such as feta, Brie, and Camembert, blue-veined cheeses, or Mexican-style cheeses such as queso blanco, queso fresco, and Panela, unless they have labels that clearly state they are made from pasteurized milk.
- § Do not eat refrigerated pâtés or meat spreads. Canned or shelf-stable pâtés and meat spreads may be eaten.
- § Do not eat refrigerated smoked seafood, unless it is contained in a cooked dish, such as a casserole. Refrigerated smoked seafood, such as salmon, trout, whitefish, cod, tuna or mackerel, is most often labeled as "nova-style," "lox," "kippered," "smoked," or "jerky." The fish is found in the refrigerator section or sold at deli counters of grocery stores and delicatessens. Canned or shelf-stable smoked seafood may be eaten.

Remember, it is always better to err on the side of caution. "When in doubt, throw it out!"

Limit sodium intake

Some of your transplant medications cause sodium and fluid retention. One way to prevent some of this extra fluid accumulation is by restricting your sodium intake. You may find that you need to adjust your sodium intake depending on how well your body is maintaining your fluid status. If you are taking moderate to high doses of diuretics, are experiencing ankle or leg swelling, or have any other symptoms of too much fluid in your body you may need to be more restrictive with your sodium intake.

- Avoid using salt at the table or in cooking.
- Limit your use of processed foods such as canned goods, convenience foods, fast foods, and foods with more than 300-400 mg of sodium per serving.
- Try alternate flavoring aids such as pepper, spices, lemon and lime juices, fresh herbs, garlic, onion, and other sodium free flavorings.

Limit Alcohol

It is the general recommendation of the transplant team that alcohol consumption be limited to special occasions only. Talk to your doctor before drinking any alcoholic beverages.

Questions?

- § Ask your Nurse Practitioner or Physician during your clinic visit.
- § **Make an appointment with a dietitian at the Brigham and Women's Nutrition Consultation Service: (617) 732-6054**

10/07

Department of Nutrition

Cramming in the Calories – Guidelines for Underweight Patients

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

Nausea, vomiting, bowel irregularities, taste changes, and a decreased appetite can all pose stumbling blocks to eating well. **Getting enough calories is important** to prevent weight loss and to spare the protein in your muscles from being broken down for energy.

Calorie Boosters:

	<u>Portion size</u>	<u>Calories</u>	
Nuts/Seeds	1/8 cup	100	Eat as a snack. Add chopped ground nuts to pancakes, muffins, cereals, fruitcups, ice creams, puddings, yogurts, grains, chicken, tuna, or vegetable salads, casseroles, or baked goods.
Trail Mix/Granola Bar	1/4 cup/1 bar	120	Eat as a snack. Top yogurts, ice creams, puddings, cereals, pancakes, or fruitcups.
Dried fruit	1/4 cup	100	Add to pancakes, grains, cereals, yogurts, chicken or vegetable salads. Cook in muffins, chicken or pork entrees.
Nut butters	1 Tbsp.	100	Spread on whole grain bread, crackers or bagels. Mix in cookies, brownies, and shakes.
Bean dips/Hummus	1/4 cup	100	Top nachos, baked potatoes, pita bread, tortillas. (Don't forget the cheese!)

	<u>Portion size</u>	<u>Calories</u>	
Cheese & cheese sauces	1 oz/1/8 cup	100	Top cooked vegetables, pasta, crackers, bagels, breads, nachos. Melt in soups, sandwiches, & eggs.
Oils (canola, olive)	1 Tbsp.	120	Use to stir fry vegetables, chicken, fish, eggs. Drizzle over breads. Toss with pasta or salads. . Add to frappes.
Pesto sauce	2 tbsp.		Toss with pasta. Spread on bread. Use as a marinade. Brush on grilled items. Use as a condiment to season soups & sauces.
Cream cheese	2 Tbsp.	100	Spread on bagels, toast, crackers, fresh vegetables.
Sour cream	1/4 cup	100	Top baked potatoes, beans, chili; Add to avocado dip. Add salsa and sour cream to scrambled eggs and roll up in a tortilla fried in olive oil.
Avocado	1/3 of a medium	100	Slice and add to sandwiches, salads, or crackers. Use to make guacamole dip.
Flax seed oil	1 Tbsp.	120	Add to flavored yogurts and frappes. Mix into your favorite salad dressing.

TIPS:

- † Keep high calorie foods readily available at home and in your car.
- † Bring high calorie snacks when away from home (especially doctor's appointments).
- † Add calories to fruits by layering with granola and baking, dipping in nut butters, or baking in pies and turnovers. You can also add to milkshakes or commercial nutritional supplements.
- † Add calories to vegetables by stir frying in canola or olive oil, or serving with a cheese sauce.
- † Add calories to salads by adding salad dressings, seeds, avocados, olives.
- † Eat small meals and snacks every couple of hours throughout the day.
- † If overwhelmed by your usual dinner plate, use a small plate instead.
- † Avoid eating snacks too close to mealtimes to avoid decreasing your appetite for meals.
- † Keep fluids to a minimum at mealtimes but don't forget to drink between meals.
- † Try higher calorie soups like split pea, tomato bisque, chowders, cream soups, and chili.
- † Sip on higher calorie fluids such as juices (try cranberry, grape, & nectars), milk, frappes, and commercial nutritional supplements.
- † As a high calorie snack try custards and puddings.
- † Stimulate your appetite by relying on favorite foods.
- † Eat well during times when your appetite is better.

References:

Pennington JA; *Bowe=s and Church=s Food Values of Portions Commonly Used*. Seventeenth Edition. Philadelphia, PA J.M. Lippincott Company, 1998.

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Recipes

California Guacamole

makes 12 servings

serving size:

(Adapted from the California Avocado Commission)

2 avocados	3 tablespoons chopped tomato
3 tablespoons lemon juice	1/2 teaspoon salt
1/2 cup diced onion	2 tablespoons minced cilantro
1 clove minced garlic	1 tablespoon sour cream

- 1) Cut avocados in half and remove seeds
- 2) Scoop out pulp and place in bowl
- 3) Drizzle pulp with lemon juice and mash
- 4) Add remaining ingredients, mix well and serve

Nutrition Facts: *Calories: 61, Protein: .8g, Fiber: 2g, Fat: 5.5g, CHO: 4g, β -Carotene: 123mg, Vit C: 5.5mg, Vit E: .5mg α TE, Selenium: .15mcg, Mg: 14.5mg, Ca: 7.5mg, Folic acid: 23mg*

Rice-Nut Loaf

Makes 6 servings

serving size: 1 slice

(Adapted from USA Rice Council pamphlet "Veg-able Rice")

3 cups cooked brown rice	1/4 cup chopped walnuts
2 cups (8 oz) shredded sharp cheddar cheese	1/4 cup chopped sunflower kernels
4 eggs, lightly beaten	1/4 cup sesame seeds
1 medium onion, chopped	1/2 teaspoon salt
1 cup shredded carrots	1/4 teaspoon ground black pepper
1/2 cup Italian-style bread crumbs	1 (16 oz) jar spaghetti sauce (optional)

- 1) Combine rice, cheese, eggs, onion, carrots, breadcrumbs, walnuts, sunflower kernels, sesame seeds, salt, and pepper
- 2) Pack into greased 9-inch loaf pan
- 3) Bake at 350° F for 50-60 minutes, until firm
- 4) Let cool in pan 10 minutes
- 5) Unmold and slice; serve with heated spaghetti sauce

Nutrition Facts: *Calories: 467, Protein: 24g, Fiber: 7.5g, Fat: 21g, CHO: 48g, β -Carotene: 3000mg, Vit C: 16 mg, Vit E: 5mg α TE, Selenium: 25mcg, Mg: 89mg, Ca: 368mg, Folic acid: 49mcg*

Cheese Sauce

Makes 1 quart

serving size: 1/8 cup (32 servings)

6 tablespoons butter or margarine
6 tablespoons flour
1/4 cup chopped onion
salt, pepper

4 cups whole milk
1 1/4 cups grated cheese (cheddar, Fontina, or
Swiss)

- 1) Melt butter; add onions and flour; mix well
- 2) Add milk and whisk until smooth
- 3) Simmer 30 minutes; strain if desired.
- 4) Gradually whisk in cheese. Season with salt & pepper

*Nutrition Facts: Calories: 68, Protein: 2.5g, Fiber: .1g, Fat: 5g, CHO: 4g, β -Carotene: 0mg,
Vit C: .4mg, Vit E: .1mg, Selenium: 1.5mcg, Mg: 5.5mg, Ca: 66mg, Folic acid: 3mcg*

HummusMakes 2 cups
(8 servings)

serving size: 1/4 cup

1 14-oz. can chick peas
1/2 cup sesame tahini paste
6 garlic cloves minced
1 1/2 teaspoons paprika
1 teaspoon fresh chopped parsley

juice of 3 lemons
1/4 cup olive oil
3/4 teaspoon cayenne pepper (optional)
1/4 teaspoon cumin

- 1) Puree all ingredients in a food processor or blender
- 2) Adjust consistency with more olive oil or water
- 3) Season to taste with salt and pepper

*Nutrition Facts: Calories: 206, Protein: 5g, Fiber: 4g, Fat: 16g, CHO: 13g, β -Carotene: 212mg,
Vit C: 8mg, Vit E: 1mg, Selenium: .6mg, Mg: 56mg, Ca: 44mg, Folic acid: 18mcg*

Rice Pilaf with Dates and Almonds

Makes 3 cups

serving size: 1/4 cup

(12 servings)

1 tablespoon butter

1 tablespoon olive oil

1 medium onion, chopped (about 1 cup)

1 large garlic clove, minced or pressed

 1 red, green, or yellow bell pepper,
chopped fine

1 teaspoon turmeric

1/2 teaspoon ground allspice or nutmeg

1/2 teaspoon cinnamon

3 cups cooked brown, white, or basmati rice

2 tablespoons chopped fresh parsley

1/4 cup hot water

1/2 cup chopped toasted almonds

salt and ground black pepper to taste

- 1) In a large, heavy skillet, heat the butter and oil
- 2) Add the onions and garlic and saute over medium heat until tender
- 3) Add the bell pepper, turmeric, cinnamon, allspice or nutmeg, and dates
- 4) Stir in the rice and parsley, sprinkle on the water, and heat, uncovered, for a few minutes
- 5) When the rice is hot, stir in the almonds, add salt and pepper to taste, and serve

Nutrition Facts: Calories: 137, Protein: 3g, Fiber: 3g, Fat: 5.5g, CHO: 20g, β -Carotene: 406mg, Vit C: 25.5mg, Vit E: .75mg, Selenium: 8mcg, Mg: 44.5mg, Ca: 31mg, Folic acid: 13mcg

Cheese Beans

Makes 6 cups

serving size: 1/4 cup

(24 servings)

6 cups cooked pinto or kidney beans*

2 teaspoon butter or margarine, melted

2 cups chopped onion

2 large cooking apples, cut in chunks

 2 cups grated muenster or monterey jack
cheese

4 medium tomatoes, chopped

2 teaspoons chili powder

6 tablespoons dry white wine

1 1/2 teaspoons salt

1 teaspoon dry mustard

1/8 teaspoon pepper

- 1) Saute onions in butter until soft & clear
- 2) Add chili powder & mustard.
- 3) Add remaining ingredients
- 4) Pour into large buttered casserole dish.
- 5) Cover & bake at 350° for 35-40 minutes

* If using raw beans: soak 3 cups raw beans in a large bowl of water for 1 1/2 hrs. Place beans in a pan, cover with plenty of water, and cook for an additional 1 1/2 hrs or until desired tenderness.

Nutrition Facts: Calories: 142, Protein: 8g, Fiber: 7g, Fat: 3.5g, CHO: 20g, β -Carotene: 102mg, Vit C: 6.5mg, Vit E: .3mg, Selenium: 6mcg, Mg: 45.5mg, Ca: 105mg, Folic acid: 129mg

Basil Pesto

Makes 1/2 cup

serving size: 3 Tablespoons

(2 2/3 servings)

1 cup fresh basil leaves

1/2 cup parsley

3 garlic cloves

1 tablespoon pine nuts

2 tablespoons olive oil

1/2 tablespoon parmesan cheese

- 1) Puree all ingredients in a blender or food processor
- 2) Add more olive oil to adjust consistency if necessary
- 3) Season with salt & pepper

Can be tossed with pasta or used as a marinade, a barbeque sauce, a seasoning for soups & sauces, or as a spread on bread.

***Nutrition Facts:** Calories: 126, Protein: 2g, Fiber: 1g, Fat: 12g, CHO: 3g, β -Carotene: 720mg, Vit C: 19mg, Vit E: 1.5mg, Selenium: 1mcg, Mg: 27mg, Ca: 63mg, Folic acid: 29mcg*

Bean Dip

Makes approx: 7 cups

serving size: 1/4 cup

(28 servings)

1 Tablespoon olive oil

1 can Guiltless Gourmet Black Bean Dip

1 can fat-free refried beans -16oz.

3/4 cup sour cream

1/4 cup mayonnaise

1 pkg. taco seasoning mix

1 cup mild salsa

1 cup shredded cheddar cheese

1 cup shredded lettuce

tortilla chips

optional garnish: chopped tomato, scallions, fresh cilantro

- 1) Combine olive oil, bean dip, and refried beans
- 2) spread in square or round pan.
- 3) Mix sour cream & mayonnaise; season with taco mix to desired taste
- 4) Spread over bean mixture
- 5) Next spread salsa, then cheese, then lettuce
- 6) If desired, garnish with chopped tomato, scallions, and/or cilantro. Serve with tortilla chips.

***Nutrition Facts:** Calories: 74, Protein: 3g, Fiber: 1g, Fat: 5g, CHO: 5g, β -Carotene: 12mg, Vit C: 4g, Vit E: .15mg, Selenium: 1mcg, Mg: 3mg, Ca: 44.5mg, Folic acid: 6mcg*

Granola

Makes ~ 12 cups
(48 servings)

serving size: 1/4 cup

4 cups rolled oats	1 cup wheat germ
1 cup sesame seeds	1 cup sunflower seeds
1 1/2 cups almonds	3/4 cup powdered milk
1 cup olive or canola oil	1/3 cup honey
1 1/2 cups raisins	1 cup chopped dates

- 1) Spray or lightly grease 1 or 2 shallow cake pans.
- 2) Mix oats, wheat germ, seeds, almonds, powdered milk
- 3) Mix oil & honey together and pour over mixture and bake at 325° for 15-20 minutes
- 4) Add the dried fruit about 5 minutes before the granola is done cooking. Stir once or twice during cooking for uniform doneness

Nutrition Facts: Calories: 170, Protein: 4.5g, Fiber: 3g, Fat: 10.5g, CHO: 16g, β -Carotene: 2mg, Vit C: .5mcg, Vit E: 4mg, Selenium: 6.5mg, Mg: 43mg, Ca: 67mg, Folic acid: 23mcg

Pumpkin Bars

Makes 20 bars
(40 servings)

serving size: 1/2 bar

4 eggs	1 large (29-oz) can pumpkin
1 1/2 cups sugar	1 teaspoon salt
1 teaspoon cinnamon	1 teaspoon ginger
1/2 teaspoon cloves	1 can (12 fl oz) evaporated milk
1 package yellow cake mix	1 cup walnuts chopped
1 cup Smart Balance margarine	

- 1) Preheat oven to 325°
- 2) Beat eggs slightly. Add pumpkin, sugar, seasonings, and evaporated milk and mix well
- 3) Pour into greased 9 x 13-inch pan
- 4) Sprinkle with dry cake mix and nuts. Melt margarine and drizzle over mixture
- 5) Bake 1 1/2 hours until pumpkin mixture is set and topping is golden.
- 6) Cool and cut into 20 squares

Nutrition Facts: Calories: 166, Protein: 3g, Fiber: 1g, Fat: 8g, CHO: 21g, β -Carotene: 2683mg, Vit C: 1mg, Vit E: 1mg, Selenium: 3mcg, Mg: 15mg, Ca: 52mg, Folic acid: 9mcg

Indian Pudding

Makes 4 cups

(16 servings)

4 cups whole milk

2 tablespoons canola oil

1 teaspoon salt

1/2 teaspoon ginger

1 cup evaporated milk

serving size: 1/4 cup

5 tablespoons yellow corn meal

1 cup molasses

3/4 teaspoon cinnamon

2 eggs, well beaten

- 1) Preheat oven to 350°
- 2) Heat milk in the top of a double boiler almost to boiling. Remove from heat and allow to cool for 5 minutes
- 3) Add corn meal slowly, stirring constantly. Cook over medium heat, stirring constantly, for 15 minutes, then add the oil, molasses, seasonings, and beaten eggs
- 4) Turn into shallow buttered baking dish and bake for one hour
- 5) After the first 15 minutes of baking, pour evaporated milk over the mixture, but do not stir in. Bake remaining 45 minutes. Remove from oven and cool.

Tips: Serve with vanilla ice cream, vanilla frozen yogurt, or whipped topping

Nutrition Facts: *Calories: 145, Protein: 4g, Fiber: .25g, Fat: 5.5g, CHO: 20.5g, β -Carotene: .2mg, Vit C: .6mg, Vit E: .5mg, Selenium: 16mcg, Mg: 62mg, Ca: 159mg, Folic acid: 6.5mcg*

Super Pudding

Makes 3 cups

(6 servings)

2 cups whole milk

2 tablespoons canola oil

serving size: 1/2 cup

3/4 cup dry milk powder

1 package (4 1/2 oz) instant pudding (your favorite flavor)

- 1) Stir together milk, milk powder, and oil
- 2) Add instant pudding and mix well
- 3) Pour into dishes and refrigerate

Tips: Serve with vanilla ice cream or vanilla frozen yogurt

Nutrition Facts: *Calories: 143, Protein: 6g, Fiber: .2g, CHO: 12g, β -Carotene: 0mg, Vit C: 1.5mg, Vit E: 1mg, Selenium: 4mcg, Mg: 24.5mg, Ca: 222mg, Folic acid: 9mcg*

MILK SHAKES

Makes: 1 beverage

Orange Julius

1/2 cup orange juice
1/2 cup whole milk
1/2 cup vanilla ice cream
1/4 cup pasteurized liquid egg
1 teaspoon vanilla extract

Nutrition Facts: Cals: 330, Pro: 15g,
Fiber: .25g, Fat: 14g, CHO: 35g,
 β -Carotene: 46mg, Vit C:63.5mg, Vit E: .5mg
Sel: 7mcg, Mg:45mg, Ca:277mg, Fol:56mcg

Orange Kooler

1/3 cup orange juice concentrate (undiluted)
3/4 cup powdered milk
1 cup ice water (or whole milk)
1/2 cup vanilla ice cream

Nutrition Facts: Cals: 758, Pro: 30g, Fiber: .75g
Fat: 33g, CHO: .88g, β -Carotene: 49mg, Vit C:138mg
Vit E: 1mg, Sel: 15mcg, Mg: 122g, Ca: 990mg,
Fol: 184mcg

Pineapple Soda

1/4 cup crushed pineapple, drained
1/2 cup whole milk
1/2 cup vanilla ice cream
1/2 cup pear nectar

Nutrition Facts: Cals: 302, Pro: 6.7g, Fiber:1g
Fat: 11.5g, CHO:46g, β -Carotene: 8mg, CHO: 64g, β -Carotene: 0mg, Vit C:2mg, Vit E:5mg,
Vit C:8mg, Vit E: .3mg, Sel: 6.5mg, Mg:40mg Sel:11,cg, Mg:138mg, Ca:256mg, Fol: 47mcg
Ca: 245mg, Fol: 14mcg

Peanut Butter Drink

1/2 cup whole milk
3 tablespoons smooth peanut butter
3 tablespoons chocolate syrup
1/2 cup vanilla ice cream

Nutrition Facts: Cals:615, Pro: 20g, Fiber: 4g, Fat:36g
Sel:11,cg, Mg:138mg, Ca:256mg, Fol: 47mcg

- 1) Place all ingredients in blender and blend well
- 2) Pour into tall, frosted glasses
- 3) Use your favorite garnish: maraschino cherry, sprig of mint, or whipping cream

NOGS

Makes: 1 beverage

Eggnog

1/2 cup whole milk
1/2 cup pasteurized liquid egg
1 teaspoon vanilla extract
Dash of nutmeg
1 tablespoon sugar

Nutrition Facts: Cals: 461, Pro:22g, Fib: .3g
Fat:8.5g, CHO:20g, β -Carotene: .4mg,
Vit C: 1mg, Vit E: .75mg, Sel: 2mcg,
Mg: 29mg, Ca: 213mg, Fol: 25mcg

Yogurt Nog

1/3 cup yogurt (your favorite flavor)
3 tablespoons pasteurized liquid egg
1/3 cup orange juice
3 tablespoons powdered milk
1/3 banana
2 teaspoons honey

Nutrition Facts: Cals: 305, Pro: 16g, Fiber: 1g, Fat: 8g
CHO: 44g, β -Carotene: 46mg, Vit C: 43.5mg, Vit E: .7mg
Sel: 4mcg, Mg: 54mg, Ca: 408mg, Fol: 48mcg

Strawberry Nog

3/4 cup whole milk
3 tablespoons powdered milk
3 tablespoons pasteurized liquid egg
3/4 cup strawberry ice cream

Nutrition Facts: Cals: 461, Pro: 22g, Fiber: .3g Fat: 22g, CHO: 45g, β-Carotene: 0, Vit C:11mg, Vit E: 1mg, Sel: 6.5mcg, Mg:63mg, Ca: 580mg, Fol: 37mcg.

High-Protein Nog

1 cup whole milk
3 tablespoons powdered milk
1/2 cup pasteurized liquid egg
1 tablespoon granulated sugar
1 teaspoon vanilla extract
Dash of nutmeg

Nutrition Facts: Cals: 315, Pro: 22g, Fiber: 0, Fat: 10.5g CHO: 21g, β-Carotene: 0, Vit C: 1mg, Vit E: .7mg, Sel: 2mcg, Mg:17mg, Ca:226mg, Fol: 6mcg

- 1) Place all ingredients in blender and blend well
- 2) Pour into tall, frosted glasses
- 3) Use your favorite garnish: maraschino cherry, sprig of mint, whipping cream, or dash of nutmeg

SHERBET SHAKES

Apricot Raspberry Shake

1/2 cup apricot nectar
4 apricot halves, chopped
1/2 cup raspberry sherbet
*Cals: 314 Pro: 2g Fiber 3g
Fat: 2g CHO: 76g β-Carot: 1934mg,
Vit C: 9mg, Vit E: 1mg, Sel: 3mcg
Mg: 23 mg Ca: 74mg Fol: 8mcg*

Banana Orange Shake
1/2 cup orange juice
1/2 cup orange sherbet
1/2 banana
*Cals: 247 Pro: 2.5g, Fiber: 2g
Fat: 2.5g CHO: 57g β-Carot:74mg
Vit C: 72 mg Vit E: .3mg Sel: 3 mcg
Mg: 39mg, Ca: 71mg, Fol: 53mcg*

Cranberry Lemon Shake

1/2 cup cranberry juice
1/2 cup lemon sherbet
1/2 banana
*Cals:263 Pro: 2g Fiber: 2g
Fat: 2.5g CHO: 62g β-Carot: 31 mg
Vit C: 54 mg, Vit E: .2 mg Sel: 3 mcg
Mg: 28mg, Ca: 61mg, Fol: 15mcg*

Orange Shake

1/2 cup orange juice
1/2 cup mandarin orange sections, drained
1/2 cup orange sherbet
*Cals: 235, PRO: 2.5g, Fiber: 3g
Fat: 2.5g CHO: 54g, β-Carot: 584mg
Vit C: 96mg Vit E: .4mg Sel: 3mcg
Mg: 33mg Ca: 81mg Fol: 61mcg*

Pineapple Lemon Shake

1/2 cup pineapple juice
1/2 cup lemon sherbet
2 pineapple slices, chopped, drained
*Cals: 268 Pro: 2g, Fiber: 2g
Fat: 2g CHO: 64.5g β-Carot:51mg
Vit C: 25mg Vit E: .3mg Sel: 3.5mcg
Mg: 39mg Ca: 84mg Fol: 14mcg*

Sunshine Sipper

1/4 cup grapefruit juice
1/4 cup pineapple juice
1/2 cup orange juice
1/2 tablespoon sugar
1/2 cup lime sherbet
*Cals: 280 Pro: 2.5g Fiber: 1g
Fat: 2g CHO: 65g β-Carot:50mg
Vit C: 96mg VitE: .2mg Sel: 3mcg
Mg: 37mg Ca: 83mg Fol: 62mcg*

Banana Grape Shake

1/3 cup grape juice
1/3 cup whole milk
1/2 banana
1/2 cup lemon sherbet

Berry Freeze

1/3 cup whole milk
3/4 cup raspberry sherbet
6 to 8 strawberries
*Cals: 298 Pro: 5g Fiber: 4g
Fat: 6g CHO:59g β-Carot:23mg
Vit C: 89mg Vit E: .4mg Sel: 6mcg
Mg: 37mg Ca: 196mg Fol: 35mcg*

Strawberry Banana Shake

1/2 cup whole milk
1/2 banana
6 strawberries
3/4 cup lemon sherbet
*Cals: 356 Pro: 7g Fib: 4g
Fat: 7.5mg CHO: 70g β-Carot:40mg
Vit C: 54mg Vit E: .5mg Sel: 6mcg
Mg: 52.5mg Ca: 239mg Fol: 36 mcg*

Pineapple Berry Freeze

1/3 cup whole milk
1/2 cup fresh pineapple
3/4 cup raspberry sherbet
*Cals: 292 Pro: 5g Fiber: 2g
Fat: 6g CHO: 58.5g β-Carot: 9mg
Vit C: 19mg Vit E: .25mg Sel: 5mcg
Mg: 33.5mg Ca: 181mg Fol: 18mcg*

1. Place all ingredients in blender and blend well
2. Pour into tall, frosted glass
3. Use your favorite garnish: maraschino cherry, sprig of mint, or whipping cream

Recommendations for Overweight Patients

Excess weight can be detrimental to your overall health as well as to your lung function after transplant. As you likely have concluded from the previous sections of this book, your lung transplant team strongly encourages you to follow a balanced diet and incorporate an exercise routine into your daily life after transplant.

Should weight loss be recommended for you before or after transplant, we would suggest no more than 1-2 lbs of weight lost per week, focusing on a balanced diet. The general guidelines provided in this manual regarding a balanced diet are a good starting place for your nutrition regimen. We are also happy to provide you with a referral to our nutritionist for consultation. In addition, you can ask one of the transplant coordinators to provide you with the information packet entitled “Guide to Healthy Eating” that has been prepared by our Nutrition Department.

Please also remember that exercise is a key component to any weight loss regimen and to a healthy lifestyle post-transplant. Participation in a pulmonary rehabilitation program is another good place to start, but keep in mind that these programs provide a guideline for proper exercises that should also be pursued on days when you are not at rehab. We recommend an exercise program that incorporates low impact aerobic exercise such as walking or swimming as well as strength training. We recommend some form of physical activity be performed at least 5 days per week. Also keep in mind the focus on building endurance and strengthening your lungs, muscles, heart, and quality of life through a healthy lifestyle.

Exercise and Recreation

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. If you choose to incorporate routine exercise into your life, you will improve how you feel, how active you are, and how well your lungs work after transplant.

All patients have received nutrition education by a transplant dietitian. Maintaining ideal body weight decreases the risk of complications such as atherosclerosis and osteoporosis. Regular exercise is a necessary weapon against obesity, osteoporosis and hyperlipidemia. Walking is the most economical and beneficial activity. You control your diet and exercise plan, two of the most important factors in your post-transplant outcome!

Conclusion

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.

Appendix

Appendix 1

National and Transplant Center Outcomes- Scientific Registry of Transplant Recipients (SRTR) Jun 2014

1-Year Graft Survival

For patients transplanted between 01/01/2011 and 06/30/2013

	This Center	United States
Number of transplants	67	4409
Percent of grafts surviving at end of period		
Observed	79.50%	85.52%
Expected, based on national experience	85.51%	
How does this center's survival compare to what is expected for similar patients?	Not significantly different (a)	
Do these outcomes meet the Centers for Medicare and Medicaid Services guidelines?	Yes	

1-Year Patient Survival

For patients receiving their 1st transplant of this type between 01/01/2011 and 06/30/2013

	This Center	United States
Number of transplants	67	4204
Percent of grafts surviving at end of period		
Observed	79.50%	86.37%
Expected, based on national experience	86.05%	
How does this center's survival compare to what is expected for similar patients?	Not Significantly Different (a)	
Do these outcomes meet the Centers for Medicare and Medicaid Services guidelines?	Yes	

(a) This difference could plausibly be just a chance occurrence.

Source: www.srtr.org

(Select the menu options Program and Hospital Data, Find a Transplant Center, Lung)

National and Transplant Center-Specific Outcomes (previous page)

Recent statistics from the Scientific Registry of Transplant Recipients (SRTR) (www.srtr.org) are shown on the previous page. The results at Brigham and Women's Hospital indicate that we meet the expected survival for our patients. For additional information we encourage you to consult with the public data available at www.srtr.org or ask us for a copy.

Organ Donor Risk Factors

Organ donor risk factors that could affect the success of the transplant or your health include; the donor's history, condition or age of the organs used, or your potential risk of contracting other infectious diseases including HIV, hepatitis B virus (HBV), hepatitis C virus (HCV), or cancer if the donor is infected, but the infection is not detectable at the time of donation.

Recipient Follow up in Transplant Clinic

Medical and Surgical follow-up recommendations after your transplant will be given to you upon discharge. It is your responsibility to follow those recommendations to assure your ongoing future health.

Right to Refuse

You have the right to refuse transplant at any time during the process. You should not feel pressured or obligated to undergo such a serious procedure and should discuss any concerns with your team so they can further assist you.

Concerns or Grievances

The United Network for Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients, living donors, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll free services line number is 1-888-894-6361.

Notification of Medicare Outcome Requirements Not Being Met By Center

Specific outcome requirements need to be met by transplant centers and we are required to notify you if we do not meet those requirements. Brigham and Women's Hospital Transplant Center currently meets all of the requirements as a transplant center under CMS (Medicare).

Transplantation by a Transplant Center Not Approved by CMS (Medicare)

If a transplant is not provided in a Medicare-approved transplant center, it could affect your ability to have immunosuppressive drugs paid for under Medicare Part B.

Insurance Coverage Disclaimer

- Future health problems related to the transplantation may not be covered by your insurance carrier; referral to social work and financial counseling will be made as needed.
- Attempts to obtain medical, disability, and life insurance could be jeopardized and coverage denied.

(Revised 4-16-12)

Notes

Slide Show