Lung Transplant Waitlist Handbook
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Welcome

Welcome to the Brigham and Women’s lung transplant waitlist. Our hope for this handbook is to ensure you fully understand testing requirements, clinic follow-up and expectations while you await transplant. Maintaining active listing is a shared endeavor between the transplant team, you and your family. We strive to develop a good working relationship throughout all phases of transplantation.

Please ensure that your support team also reads this handbook.

Included in this handbook is:

- Contact information
- When to call
- Patient Gateway information
- Clinic appointments
- Testing requirements
- Diet & Exercise tracking
- Preparing for the call
- Support group instructions
- Map

When in doubt please don’t hesitate to contact us by phone or Patient Gateway.
Contact Information

Mariel Muir
Pre-transplant Administrative Coordinator
( 617-278-0502
Please contact for scheduling clinic appointments and testing.

Caitlin McKane, RN
Lung Transplant Nurse Coordinator, last names A-K
( 617-525-9851
Fax 617-264-6892

Gail Gerard, RN
Lung Transplant Nurse Coordinator, last names L-Z
( 617-525-9723
Fax 617-264-6892

Contact your nurse coordinator with updates about a new illness, hospitalizations, medication changes and for general questions.

Mitzi Jones
Financial Coordinator
( 617-525-9724
Please contact for insurance and financial related questions.

Andrea James, LICSW
Social Worker
( 617-525-8142
Please contact for social support and other related questions.

Mailing address [for imaging CDs]:
BWH
1620 Tremont Street
OBC 2nd Floor, Transplant Administration
Attn: [nurse coordinator]
Boston, MA 02120-1613
When to Call

Please remember that your primary care provider and pulmonologist will continue to manage your care while you await transplant. They will continue being the first contact for you in terms of your health. If changes occur between your clinic visits please contact your nurse coordinator.

Further examples of when to call the transplant team:

- Changes in condition ie: hospitalization or new treatment plan
- Increase/decrease in supplemental oxygen needs
- Inability to exercise
- New medication or new medical diagnosis
- Changes in support team
- Changes in insurance coverage
- Change in finances
- Travel more than 4 hours from Boston
- Prednisone use of more than 20mg per day
- If received a blood transfusion
- New need for narcotic pain medication
- General questions related to transplant
Patient Gateway

Patient Gateway is a secure and convenient online tool that allows you to reach all members of the Lung Transplant team regarding appointments, medications, testing, etc. This is being used in place of email as it is a more secure and confidential way to communicate with you regarding your healthcare. In addition to the email function you will also have access to see your scheduled appointments and test results. Please keep in mind that not all appointments will be visible in Patient Gateway so please call the office with any questions.

Setting up your personal Patient Gateway account is simple.

Start by going to www.patientgateway.org and clicking Enroll Online.

A request form will ask you to provide basic information: your name, gender, birth date, telephone number, email address, home address, and your Brigham and Women’s health care provider(s). You then can choose to verify your identity online (using an RSA security tool to gather specific questions that only you can answer) or to have an Access Key mailed to you within 7 business days.

If you have any difficulty setting up your Patient Gateway account please call Mariel Muir at 617-278-0502.
Clinic Appointments

At least every 3 months you will be seen in pre-lung transplant clinic in The Schuster Transplant Center at 45 Francis Street. Please allow extra time when traveling to Boston as traffic/construction can be unpredictable.

This visit will include vital signs [including weight], spirometry and blood work in addition to meeting with one of the lung transplant providers (nurse practitioner or pulmonologist). Additional testing may also be scheduled on the same day as clinic visits. You will also meet with your nurse coordinator to ensure all testing is current and to discuss future testing.

Some topics covered at this visit will include respiratory assessment, oxygen requirements, medication/allergy review, exercise routine & weight management goals. This visit is also your chance to make sure you understand the process and that any questions or concerns that you have are addressed.

Please come to clinic with the following:

- Current medication and allergy list
- A support person whenever possible
- A written list of any questions to help guide the visit
Testing Requirements

An important piece of maintaining active listing is to ensure all testing is up to date. Most testing must be updated every 3, 6 and 12 months. Testing must be updated so that we understand your current medical situation and can adjust the plan for your care. Testing must also be updated according to Federal regulations. We will try and coordinate testing to coincide with a clinic visit. Most patients find this helpful as they are able to have multiple things completed in one trip to Boston.

If you are unsure of a test date please ask your nurse coordinator during your clinic visit.

If testing is completed locally you are responsible for obtaining the results and either faxing or providing in person. If a chest CT or chest x-ray is completed locally please mail in the imaging on a CD in addition to providing the report.
Testing Requirements

Every 3 months:
Clinic appointment
Blood work
Chest x-ray

Every 6 months:
ABG
6MW test (6 minute walk)
Spirometry
Chest CT

Every year:
Transplant blood work
EKG
Echo
Full PFT

Every other year:
Abdominal ultrasound
Consults with psychiatry, social work and nutritionist

Testing may require more frequent updating depending on a patient's clinical status.
**Lung Transplant Program**
75 Francis Street
Boston, MA 02115

**Hari Mallidi, M.D., Surgical Director**
**Hilary Goldberg, M.D., Medical Director**

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**Patient Information:**

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**Please note, at every clinic visit you will have routine labs drawn and a chest x-ray completed.**

**Testing Requirements**
Outpatient Testing

This testing is completed with the assistance of your primary care provider. Please have all results faxed to our office or bring in person to your clinic visits.

1. Bone density scan [every 2 years]
2. Colonoscopy [every 2-10 years depending on previous results]
3. Pap smear [every 3-5 years]
4. Mammogram [annually]
5. PPD/Mantoux (skin test for tuberculosis) [every 2 years]
6. Letter of Dental Clearance [annually]
Diet and Exercise

Diet

Maintaining a healthy weight is very important to help in your recovery after surgery. Our BMI [body mass index] criteria is to maintain a BMI between 17 & 30. If patients have a BMI above 30 they risk inactivation if they present to clinic with weight gain. Patients are at a higher complication rate peri-operatively if their BMI is above 30. A nutrition consult was part of the lung transplant evaluation, if you have more nutrition concerns please don’t hesitate to ask as we can schedule another visit. We can also discuss weight loss strategies during your clinic visit.

Exercise

A critical part of your lifestyle while you await transplant is having a diet and exercise plan. We require all patients to participate in a structured exercise program. At least one time prior to transplant all patients are required to complete a course of outpatient pulmonary rehabilitation. Most patients continue with maintenance pulmonary rehabilitation after completing a 12 week formal program. We prefer this option as there is continued monitoring of vital signs and oxygen needs. This is the safest place to exercise. If continuing in a maintenance program isn’t feasible, you must maintain an exercise program independently. This can occur at home or at a local gym. Please keep a log to track your progress [example tracking log included]. An important tool to purchase is a portable pulse oximeter to monitor your heart rate and oxygen saturation during exercise. Oximeters can be ordered online and can often be submitted to insurance for reimbursement. The goal for all patients is to be exercising for at least 30 minutes 5 times per week. Patients often need higher liter flow oxygen during exercise. By monitoring oxygen saturations during exercise this can guide you if adjustments need to be made. Home oxygen supply may need to be increased depending on your needs if exercising at home.
## Exercise Tracking

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Preparing for “The Call”

Awaiting the call for transplant can cause worry in most patients. Learning more about specifics will hopefully alleviate some fears. In addition to the information below please refer to our website: http://www.brighamandwomens.org [then type lung transplant in search field]. The lung transplant manual you received at your first visit and our support group sessions are available on the site.

Most patients are called many hours before a transplant actually happens. You may spend a number of hours in the emergency room after you arrive. Also please note that the procedure may be canceled due to donor issues after you leave home or arrive at BWH. This is an unavoidable and not uncommon occurrence.

- Always keep your cell phone on and with you at all times
- Maintain an accurate medication list and keep it in your purse or wallet
- Have a plan for who will be driving you to Boston once the call comes
- Have a plan for who will be taking care of your children and pets while you're away
- The doctor calling will ask how you’ve been feeling and if you’ve been recently been ill or have any changes in your condition
- The doctor will also ask you to refrain from eating and drinking in preparation for surgery
- Many patients experience a “dry run” which is when you come to the hospital but are sent home without being transplanted-this can occur when a problem develops with the donor
- You may be informed that you are being called in for “back-up” should the first recipient have an issue and not be able to be transplanted
- Patients only need to bring insurance information, O2 and a medication list-you won’t be needing any personal items until a few days to a week after surgery
• Family members should have a bag packed with a change of clothes, toiletries, prescription medications and cell phone chargers
• Keep in touch with the hospital during your trip to Boston should you run into traffic or weather is delaying your arrival
• Unless otherwise instructed report to the Emergency Room and inform them that you were called in for lung transplant
• Once patients leave for the operating room your primary support will provide their cell phone number for communication with the team
• Patients and family members will have access to the Bretholtz Center [75 Francis Street entrance] comprehensive resource center dedicated to the need of our patients and families for support and information while receiving care at our hospital
• Additional information for patients and families receiving care at Brigham & Women’s can be found at http://www.brighamandwomens.org/Patients_Visitors/patientresources/default.aspx
Support Group Instructions

Archived support group videos can be accessed from our web page at www.brighamandwomens.org either by using the search tool or by navigating our web site:

Search our Web Site  (quickest method)
From the BWH home page, in the top right of the page, search for lung support group as shown:

   [Box for search with lung support group]
   [In: BWH Services]

Near the top of the search results you should see the Lung Transplant | Support Group link. Click on this link to go to our Support Group page.

Navigate the Web Site
From the home page select the menu option Departments and Services. Under the Clinical Departments category select Surgery.
On the Surgery page, from the list of departments, select Transplant Surgery.
On the Transplant Surgery page, from the left side menu select Lung Transplant.
From the left side menu select For Patients then, under For Patients select Support Group.

Support Group Page
From the Support Group page, you can select the link to the live webcast or to one of the prior support group videos. You will be first asked to register and then prompted for a user name and password. The password is case sensitive and is listed below:

   The user name is your email address
   The password is BWHLung

First-Time Users
First-time users should connect to the live webcast page in advance of the support group session and run the Audio and Video test to make sure your computer is compatible with the webcast.

Support group schedules are available in clinic.
Meetings occur on the first Wednesday of the month from 2:30 to 3:30pm in the Carrie Hall Conference Room.
Oxygen tanks are available if needed.