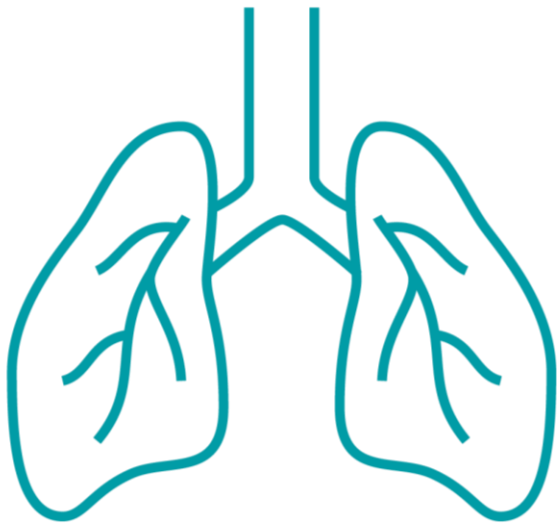


# Lung Transplant Waitlist Handbook



**HARVARD MEDICAL SCHOOL**  
**TEACHING HOSPITAL**

Lung Transplant Program  
Brigham and Women's Hospital  
75 Francis Street  
Boston, MA 02115

## Table of Contents

	Page
Welcome.....	2
A. Contact information.....	3
B. When to call.....	4
C. Patient Gateway information.....	5
D. Clinic appointments.....	6
E. Testing requirements.....	7-10
F. Diet and Exercise tracking.....	11-12
G. Preparing for the call.....	13-14
H. Support group instructions.....	15

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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.

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## Contact Information

Pre-transplant Administrative Coordinator

☎ 617-278-0502

Please contact for scheduling clinic appointments and testing.

Kathleen Boyle, RN

Lung Transplant Nurse Coordinator, last names A-K

☎ 617-525-9851

Fax 617-525-0428

Gina Damp, RN

Lung Transplant Nurse Coordinator, last names L-Z

☎ 617-525-9723

Fax 617-525-0428

If you need to contact us during “off hours” or weekends and it is an emergency, please have your local physician call the main hospital operator at 617-732-5500 and page beeper number 1-Lung (#15864).

Carmel Owens

Financial Coordinator

☎ 617-525-9724

Please contact for insurance and financial related questions.

Samantha Pearlstein, LICSW

Social Worker

☎ 857-307-2840

Angela Lombardo, LICSW

Social Worker

☎ 617-525-1376

Please contact for social support and other related questions.

Mailing address [for imaging CDs]:

BWH

1620 Tremont Street

OBC 2<sup>nd</sup> Floor, Transplant Administration

Attn: [nurse coordinator]

Boston, MA 02120-1613

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## 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 (example: 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 20 mg per day
- If received a blood transfusion
- New need for narcotic pain medication
- General questions related to transplant

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## 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](http://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 the Pre-transplant Administrative Coordinator at 617-278-0502.

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## **Clinic Appointments**

At least every 2 months you will be seen in pre-lung transplant clinic in The Lung Center C at 15 Francis Street. Please allow extra time when traveling to Boston as traffic/construction can be unpredictable.

*If you are late to your clinic appointment, it is possible that we will be unable to complete your clinic visit, and you may be rescheduled.*

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
- Wait List Handbook

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## **Testing Requirements**

An important piece of maintaining active listing is to ensure all testing is up to date. Most testing must be updated every 2, 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 can have multiple things completed in one trip to Boston.

If you are unsure of a test date or time, please ask your nurse coordinator during your clinic visit or call the pre transplant administrative coordinator.

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



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## Testing Requirements

### **Every 2 months:**

Clinic appointment  
Blood work  
ABG  
6-minute walk test (on resting oxygen level)  
Spirometry

### **Every 4 months:**

Chest x-ray

### **Every 6 months:**

Chest CT  
Echo  
Formal 6-minute walk test (minimum distance 650 ft)

### **Every year:**

Full set of transplant blood work  
EKG  
Full pulmonary function test

### **Every other year:**

Abdominal ultrasound  
Consults with psychiatry, social work (including all three members of your support team) and nutrition

Testing may require more frequent updating depending on a patient's clinical status and changes in condition. We will do our best to coordinate your testing with your appointments at BWH.

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## Testing Requirements

Patient Information:	NAME:
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	2M F/U			6M F/U		Yearly F/U			Every 2 year F/U			
	ABG	6MW	Spiro	CCT	ECHO	EKG	PFTs	Labs	SW	Psych	Nutrition	Abd u/s
Date Performed												
Date Updated												
Date Updated												
Date Updated												
Date Updated												
Date Updated												
Date Updated												
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Date Updated												
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\*Please note, at every clinic visit you will have routine lab work drawn\*

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## Outpatient Testing

This testing is completed with the assistance of your primary care provider. It is the patient's responsibility to ensure all routine health maintenance tests remain up to date. 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. T Spot or PPD/Mantoux (skin test for tuberculosis) [every 2 years]
6. Letter of Dental Clearance [annually]
7. Immunizations (Influenza, Pneumonia, Tdap, COVID, Shingrix) as indicated

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## **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 (please check with your insurance company for eligibility). The goal for all patients is to be exercising for at least 30 minutes 5 days 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. Please discuss this with your primary pulmonologist.



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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 happens. You may spend several 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
- 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 your away
- The doctor calling will ask how you've been feeling and if you've 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

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- 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 and Women's can be found at <https://www.brighamandwomens.org/patients-and-families/patient-resources>

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## Support Group Instructions

You can view any of our prior Support Group videos by visiting our Support Group page. First, navigate to our home page at [www.brighamandwomens.org](http://www.brighamandwomens.org). From there, you can find the Support Group page by either of the methods below:

Method 1. Search the web site:

- From the home page [www.brighamandwomens.org](http://www.brighamandwomens.org) click the magnifying glass at the top right of the page.
- In the search box type **support group** then click the search button.
- You will see at/near the top of the search results the link **Lung Transplant Support Group**. Select this link to go to the Support Group Video page.

Method 2. Navigate through the Lung Transplant web pages to the support group page:

- From the home page [www.brighamandwomens.org](http://www.brighamandwomens.org) in the left panel select **Services**.
- In the Centers of Excellence section select **The Lung Center**.
- In the left panel select **About Us**.
- Under this section select **The Lung Center A-Z**.
- Scroll down to the L's and select **Lung Transplant Program**.
- From the left menu select **For Patients and Families** then **Patient Resources and Support**. *Please note there are several links on this page to important lung transplant information.*
- In the first paragraph select the **Support Group page** link to go to the Support Group Video page.

### 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 user name is your email address

The password is BWHLung (password is case-sensitive)

### 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 2:00 to 3:00pm  
virtually.