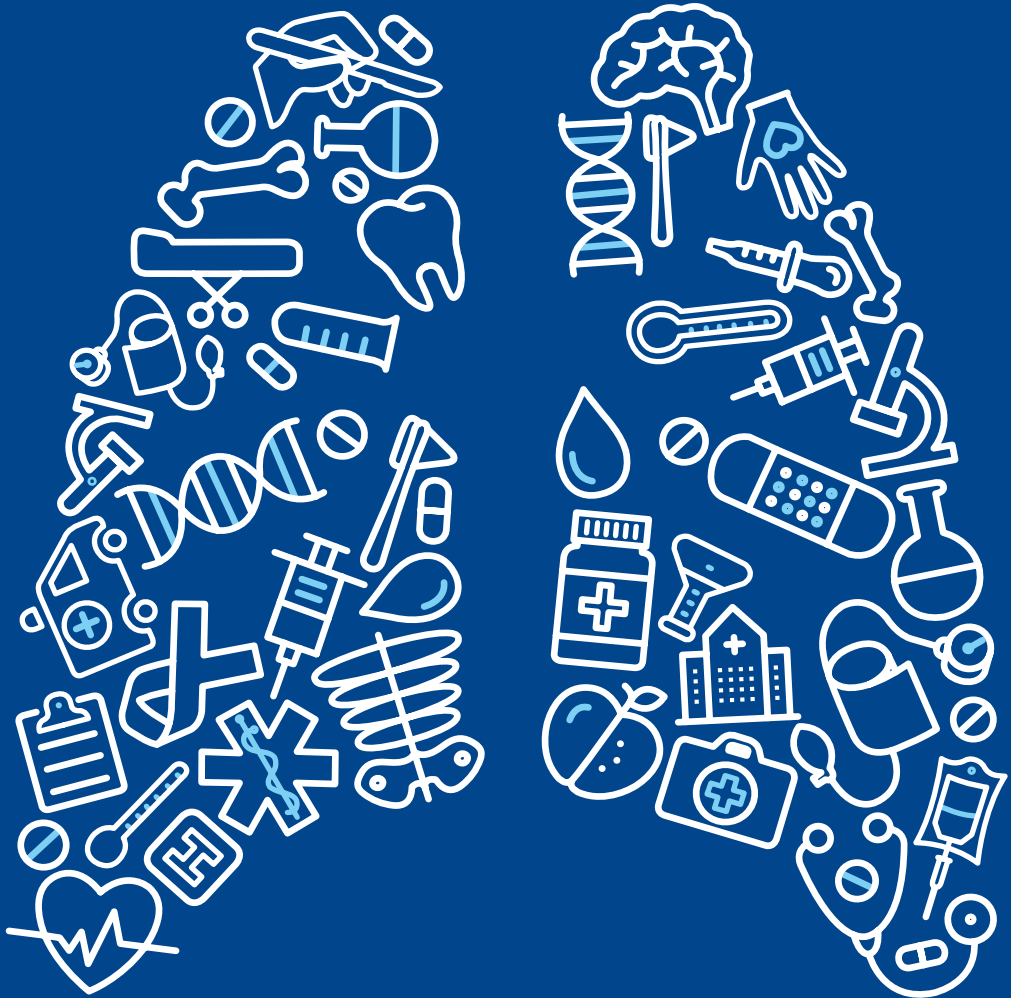


Lung Transplant

What to know before surgery



Boston Children's Hospital
Pediatric Transplant Center

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This booklet is for educational purposes only. For specific medical advice, diagnoses and treatment, talk with your health care provider.

Contact us

For clinic appointments:

9 a.m.–4 p.m.: Call the Lung Transplant Administrative Assistant at 857-218-5097 or call the Lung Transplant Coordinator at 617-355-6681.

For urgent or emergency matters:

8:30 a.m.–4:30 p.m.: Call the Lung Transplant Coordinator at 617-355-6681.

Off-hours, weekends or holidays: Call the Boston Children's Pager operator at 617-355-6369 and ask to speak with the pulmonary fellow on call.

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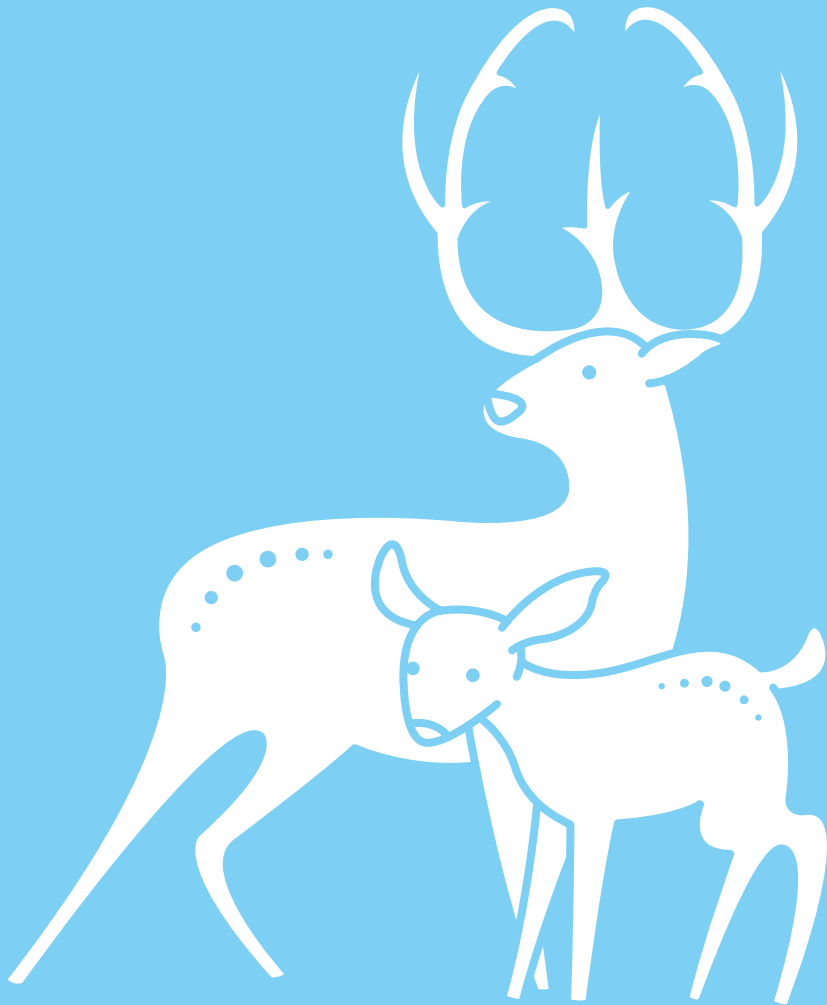
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Overview

Key point: A lung transplant trades life-limiting lung disease for lifelong medications and procedures.

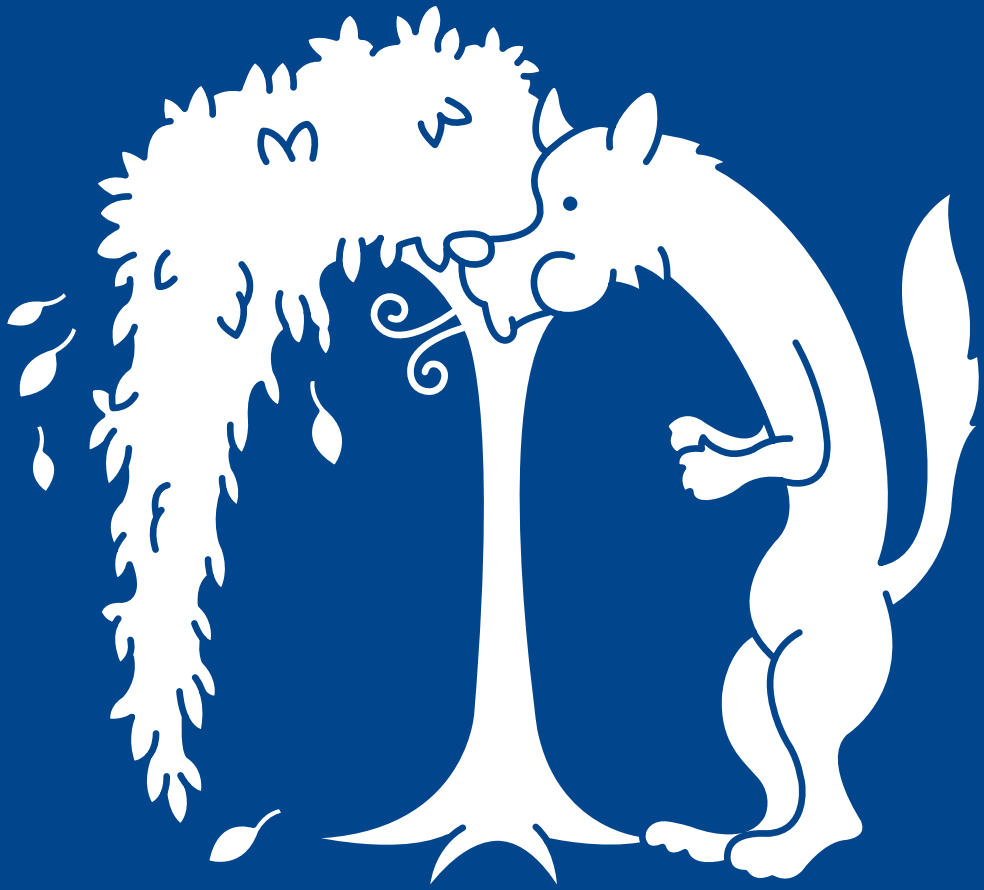
Welcome to the Lung Transplant Program at Boston Children's Hospital. We have successfully been doing lung transplants since our program began in 1990.

A lung transplant should improve your child's quality of life, help them feel better and do activities they enjoy. At the same time, it is important to remember that a transplant is not a cure. A lung transplant means trading a life-limiting lung disease for lifelong medications and their side effects, many doctor's appointments and medical procedures.

Boston Children's lung transplant team is here to offer comprehensive care to you and your family throughout the transplant process. This starts with helping you learn all that you can about qualifying for a transplant, making the decision to have the transplant if your child qualifies, how to prepare and what you can expect.

We understand that there is a lot of information in this guide. Our team will discuss everything with you. When reading this guide, we recommend:

- Reading one section at a time
- Writing down your questions as you go
- Bringing this guide with you to your next clinic visit



How do the lungs work?

Key point: Learn about the location, structure and function of the lungs.

The lungs are part of the respiratory system. This is a group of organs and tissues that make breathing possible.

Healthy lungs are lightweight, spongy and have a cone shape. They lie against the ribs and fill the chest from the bottom of the diaphragm to just above the collarbone (see Figure 1).

The right lung has 3 lobes (sections). Each lobe is like a balloon. Air moves in and out through an opening—a branch of the bronchial tube. The left lung has 2 lobes (see Figure 2).

When you breathe in, the lungs absorb oxygen and the oxygen is added to the blood. The blood leaves the lungs and is carried to the heart, which pumps the oxygen-filled blood to organs, tissue and muscle. Oxygen is exchanged for a gas called carbon dioxide (CO₂) that the body needs to get rid of. The blood carries the CO₂ back to the lungs, where it is breathed out (see Figure 3).

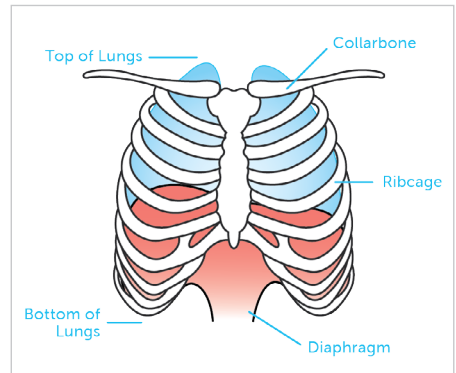


Figure 1

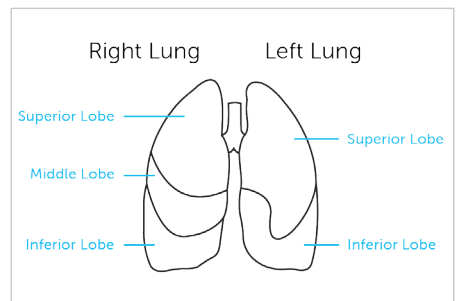


Figure 2

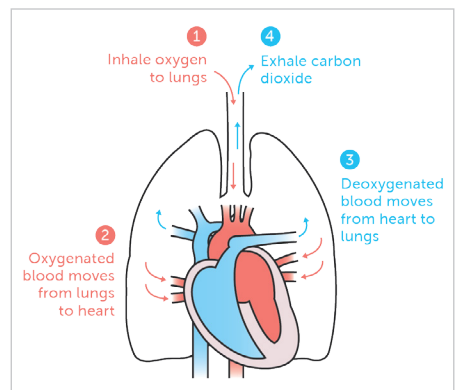
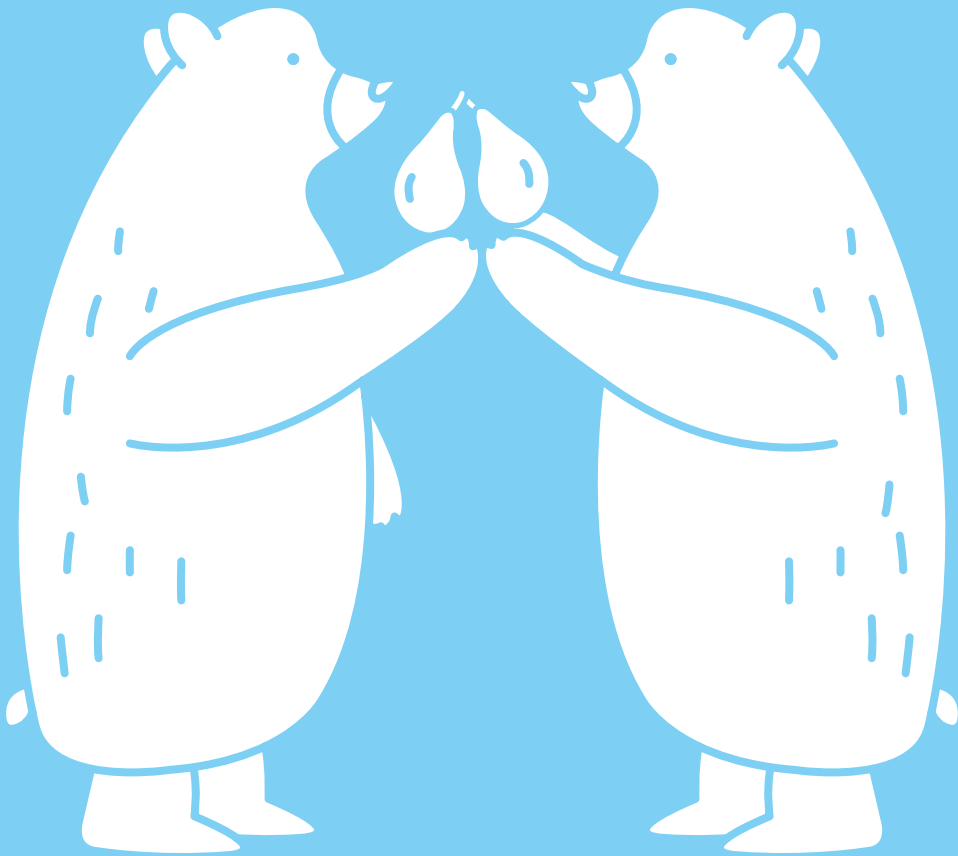


Figure 3

Quick Definition: A lung transplant is when one or both lungs are surgically removed from one person and placed in the body of someone else.



What is a lung transplant?

Key point: Lung transplants come from either cadaveric donors or living-related donors.

During most lung transplantations, the lungs come from a cadaveric donor. Cadaveric donors are people who are declared brain dead. Although the person's brain does not work, their lungs still work.

There is a waiting time for this kind of transplant because there needs to be a suitable match.

Living-related donation is when 2 living people donate 1 lobe each. This kind of transplant is rare, but there is no waiting time since this can be a scheduled procedure.

In children, both lungs are usually transplanted. But this depends on each child's disease and situation.

In a **single lung transplant**, an incision (cut) is often made directly over the sternum, the long flat bone in the center of the chest, in a process known as a sternotomy. It can also be made on either side of the body (see **Figure 4**). The old lung is removed through this incision and the new lung is implanted.

In a **double lung transplant**, the incision goes underneath and across the breast tissue of the chest (see **Figure 5**). Usually, the old lungs are removed and then the new lungs are implanted one at a time.

The new lung(s) gets connected to the pulmonary artery, pulmonary veins and the main stem bronchus (airway) (see **Figure 6**). Then, the surgeon closes the incision with either staples or stitches. It takes several weeks for the incision to heal completely.

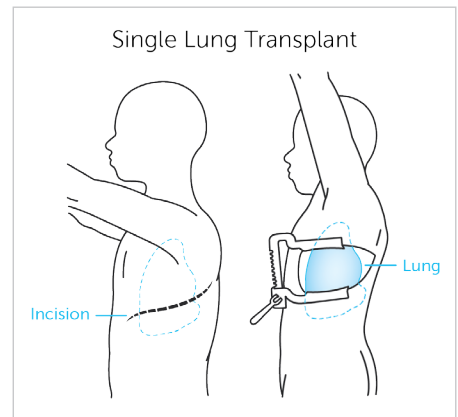


Figure 4

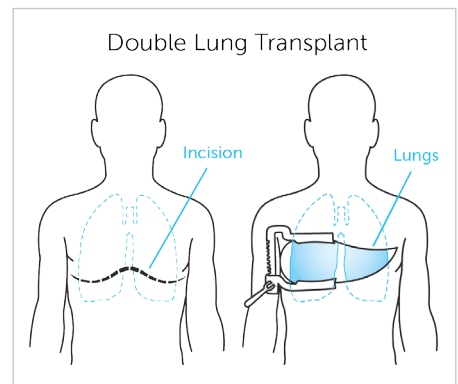


Figure 5

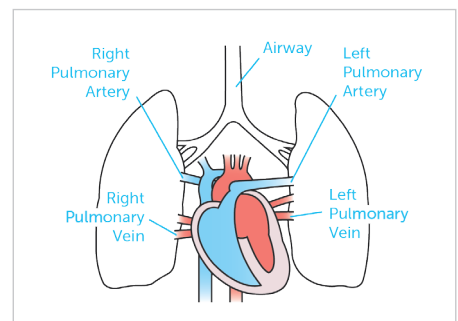


Figure 6

Members of the transplant team

Transplant team members include the transplant surgeons, pulmonologists, physical therapists, social workers, nutritionists, pharmacists and lung transplant coordinators. We work closely with specialists along the way, including doctors and nurses from Anesthesia, Infectious Disease, Cardiology, Otolaryngology and Psychiatry.

The evaluation process

Key point: Your child needs to meet the necessary criteria as well as have several diagnostic tests in order to be considered for a transplant.

The Lung Transplant Program at Boston Children's has an established protocol (system) to evaluate and select patients who might get a lung transplant. The evaluation has many steps.

First, you and your child come in for an informational visit to meet the transplant team and talk about the option of a lung transplant. This is a chance for you to ask questions and share concerns you may have. We encourage you to bring family and close friends to this meeting.

If you and the transplant team agree that a lung transplant could be an option, then **your child will be scheduled for an evaluation**.

After the informational visit, **your child will have to have several medical tests and consultations** with many members of the transplant team.

How do I know if a lung transplant is an option?

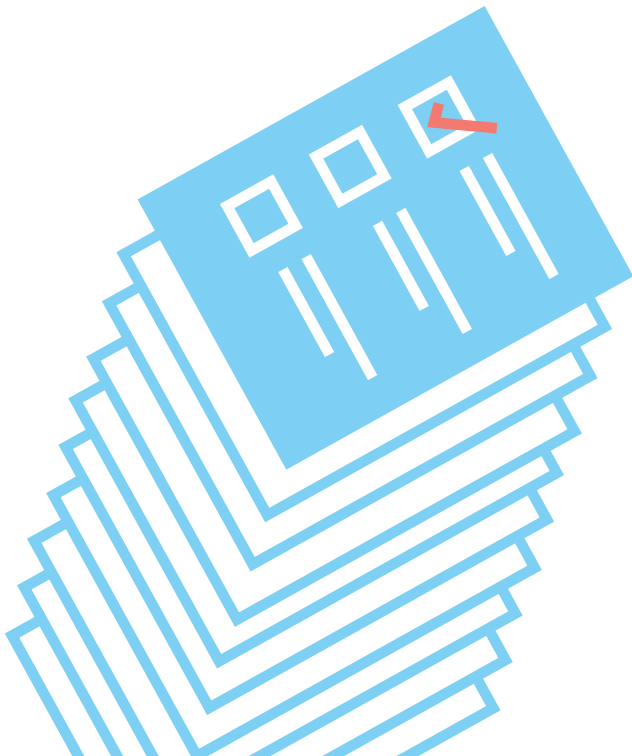
- 1 Your child is diagnosed with irreversible lung injury or disease. This means:
 - Your child has a severe lung disease that cannot be treated in any other way. Some examples of diagnoses that may lead to a lung transplant are cystic fibrosis, pulmonary fibrosis, bronchiolitis obliterans and pulmonary hypertension.
 - Your child could live longer with a lung transplant than without it, assuming the transplant goes well.
- 2 Your child needs to have good heart function and should not need a heart-lung transplant.
- 3 There can be no reason your child should not have a transplant.
- 4 Your child must be able to do everything necessary after the transplant.

The evaluation process

What happens during a lung transplant evaluation?

The evaluation happens over 4–5 days at Boston Children's. We do our best to schedule all the tests and consultations over several days. The evaluation is usually done as an outpatient (you don't stay overnight at the hospital), but it can be done while your child is admitted for another reason. During the evaluation, we will:

- Do a medical evaluation, including some diagnostic tests
- Evaluate your child and family's mental, physical and emotional health
- Educate your family about the lung transplant process
- Do a financial assessment



Diagnostic tests: Your child may need to complete some of these tests.



Blood tests

- Blood type (to match your child's blood type with a donor).
- Liver and kidney function tests.
- Tests for exposures to viruses, including hepatitis A, B and C, HIV, cryptomegalovirus (CMV), Epstein-Barr Virus (EBV), varicella and herpes simplex virus.
- Thyroid tests.
- Complete blood counts to look for infection, anemia or blood-clotting disorders
- Blood chemistries that may include potassium, sodium, cholesterol, triglycerides and other electrolytes.
- Venous blood gas test, to measure the amount of oxygen in the blood. A needle is inserted into a vein in your child's arm. Any discomfort lasts only a few minutes.



Pulmonary function tests (PFTs)

Your child does different breathing exercises and blows into a tube. The tests help measure the extent of lung disease. If your child uses bronchodilators, please bring them with you to the test.



Radiographic studies (X-rays)

Your child will have a chest X-ray to see the lungs, ribs, heart and great vessels.



Computerized tomography (CT scan)

This special X-ray takes detailed pictures of the structures inside your child's chest and sinuses. Your child will have an IV (tube placed in the vein) for this test. It is important to tell us if your child has an allergy to contrast (a special kind of dye).



Electrocardiogram (ECG or EKG)

An EKG records the electrical activity of the

heart. This test can identify abnormal rhythms and cardiac abnormalities. An EKG is a simple and painless procedure.



Echocardiogram (ECHO)

An echocardiogram is an ultrasound of the heart used to see the structure and motion of the heart. It helps us see if there are any structural problems or lesions, and to see how well the heart is working.



Abdominal ultrasound

This test views the structures in the abdominal cavity, including the pancreas, liver, intestines, gallbladder, spleen, stomach and vessels. It is useful in looking for masses, obstructions and structural problems.



Bone densitometry

A bone densitometry test determines the mass or density of your child's bones. This test is useful if your child has osteoporosis or takes corticosteroids (cortisone-like medicine).



Cardiac catheterization

This test measures pressures in the heart and lungs. Your child will be sedated for this test. A catheter (small tube) is passed through a large artery or vein in the groin or neck. The catheter travels into the heart and we measure the pressures. If they are high, your child may take medications to lower the pressures.



Gastric emptying study

This is a 4-hour test. It usually happens first thing in the morning, before your child has eaten. Your child will eat a small amount of eggs (or something similar) that has a tasteless dye in them. Your child rests in Radiology for 4 hours. During this time, we take images of your child's stomach, like an X-ray. We look to see how quickly the eggs are digested.

The evaluation process

Consultations

You and your child will meet with several different specialists during the evaluation. Some of the specialists you will meet are experts in these areas:



Pulmonology

These doctors specialize in lung transplant. They will discuss your child's quality of life, your child's pulmonary (lung) health and treatment options, including a possible transplant. They will order the pulmonary function test to see how well your child's lungs are working. You will also meet with the lung transplant coordinator who will help you through the entire transplant process.



Cardiology

They will review your child's medical history and results of the echocardiogram and electrocardiogram. The cardiologist may recommend your child have a cardiac catheterization.



Infectious disease

They will review your child's infection history and vaccination records. They may recommend treating chronic infections and completing immunization schedules. They will talk to you about preventing infections after the transplant.



Otolaryngology

This is required if your child has cystic fibrosis so we can review your child's sinus health. The specialist may recommend sinus surgery, which would mean an overnight stay in the hospital.



Psychiatry/Psychology

A psychiatrist/psychologist will meet with you to talk about coping strategies, stress management and family life. They will help your family deal with the stress of a chronic disease. The psychiatrist is available to you throughout the waiting period and after the transplant. This specialist can also give you a referral if you need regular counseling to help you during this time.



Social work

The transplant social worker will meet with your family throughout the transplant process to give you practical and emotional support. They may offer help with school planning, resources around community services, places to stay and finances.

**Nutrition**

The nutritionist will go over your child's diet and nutritional needs. It is important for your child to have a healthy lifestyle and good nutrition before the transplant. The nutritionist will talk to you about how to keep your child's weight up before surgery and during recovery.

**Physical therapy**

The physical therapist will evaluate your child's posture, flexibility, strength and endurance. Your child will do a 6-minute walk test. The physical therapist helps you plan an exercise program for your child to follow before the transplant. This may include exercising at home, working with a physical therapist in a local clinic, coming to appointments at a pulmonary rehab program or admission to a rehabilitation hospital.

**Dentist**

Your child must see their own dentist or a dentist at Boston Children's. It is important to treat any cavities, infections or tooth abscesses before the transplant.

**Speech pathology**

A speech pathologist will talk about how your child can communicate while they are in the Intensive Care Unit (ICU) after the transplant. This is to help your child express such things as pain and communicate with your family and medical team.

**Transplant pharmacy**

A transplant pharmacist will go over your child's current medications, allergy history and how well you have followed medication plans. They will talk to you about post-transplant medications and the importance of medication adherence (following the medication plan). Please ask the transplant pharmacist any medication-related questions.

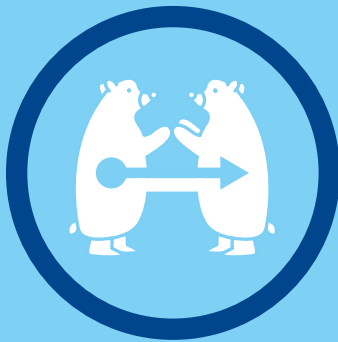
**Surgeon**

You will meet with the lung transplant surgeon to talk about your child's risk factors for transplantation.

**Financial coordinator**

The Pediatric Transplant Center financial coordinator will talk about insurance coverage and financial issues associated with the transplant. Your financial coordinator can help you:

- Understand your financial responsibilities from the evaluation through the transplantation and afterward
- Help you access medical care
- Be aware of procedure costs and approvals that are needed, from the evaluation through after the transplantation
- Identify sources of funding



The care team will make 1 of 3 decisions after evaluation:

- 1 A transplant is an option
- 2 Medication should be considered before a transplant
- 3 A transplant is not an option

Lung allocation score

The United Network for Organ Sharing uses Lung Allocation Scores to rank patients age 12 and older based on their illness and the likelihood of a successful transplant. Patients with the highest scores are placed at the top of the list to get a new organ. Patients younger than 12 are ranked according to how long they have been waiting for a transplant (and sometimes how sick they are).

Transplant decision

Key point: There are 3 general options that the transplant team may choose from for your child's care.

Once the evaluation is over, the transplant team will meet with you to review the information and inform you of the results. Generally, the team makes 1 of these decisions:

- A lung transplant is a treatment option.
- There are other treatments or medications available that should be considered before moving ahead with a lung transplant.
- A lung transplant is not possible.

In all of these situations, the lung transplant team will work with your family to develop a care plan. If a lung transplant is an option, **it is still your decision** whether or not you want to move forward with a lung transplant. Whatever your decision, you will be fully supported by our team.

If you decide to pursue a lung transplant, your child will be listed with the United Network for Organ Sharing (UNOS). UNOS and the New England Organ Bank (NEOB) have certain criteria for matching donors with recipients. UNOS manages the national database and matches the donors to people looking for lungs using a Lung Allocation Score.

Family support

We will do all we can to support your family through the transplant process. But your child's lung transplant can only be successful if your family is 100% committed to making it work before and after.

Preparing for a transplant

Key point: Your family needs to do certain things before the transplant can happen. This includes medical and financial preparations, as well as making arrangements for the day of the transplant.

Medical expectations

If your child has been evaluated and listed for a lung transplant, there are certain things that are very important to do before the transplant happens.

Medication: You already know how important it is for your child to take their medications every day. But this will be even more important after the transplant. If it is hard to have your child take medications now, we will work with you on this before the transplant. If your child does not take the necessary medications, they may need to be taken off the transplant list.

Appointments at our clinic: Your child will have scheduled visits every 2–3 months (or more) while they are on the list. This gives us time to develop a relationship with your family and stay up on any medical changes that may happen. This also gives you a chance to ask questions. It is important to show

us that you are committed to the transplantation by making all of these appointments.

Nutrition: Eating well is very important before and after the transplant. Our goal is for your child to maintain normal growth or catch up, if needed. We understand that it can be hard for your child to keep up their weight. If it is gets too hard, we may recommend surgically placing a feeding tube to give your child added nutrition. The transplant team will help you set specific goals for your child's weight.

Exercise: A physical therapist will work with you to develop an exercise program for your child to follow before the transplant. Exercising will increase your child's endurance and strength—these are key to a successful lung transplant. The physical therapist will also work with you during rehabilitation after the transplant.

Vaccinations checklist

We strongly recommended that your child get as many immunizations as possible before the transplant. The immunosuppressant medications that your child must take after the transplant will cause their immune system to be suppressed (not work at 100%). When the immune system does not work properly, the vaccine may not work.

Vaccinations safe to give after transplant

- Haemophilus influenzae type B (Hib): Usually 3-4 injections (depending on your child's age).
- DTaP (diphtheria, tetanus, acellular pertussis): 5 injections with a tetanus booster later on (depending on your child's age).
- Hepatitis B: 3 injections.
- Hepatitis A: Must be age 2 or older to get these 2 injections.
- Pneumococcal conjugate vaccine (PCV): 4 injections (depending on your child's age). The series usually starts around 2 months of age.
- Pneumococcal polysaccharide vaccine (PPV): Recommended after age 2 and is usually given after the PCV series.
- Meningococcal vaccine: Given to adolescents and for people attending college.
- Influenza vaccine: Can vaccinate yearly after your child is 6 months old. Use caution if your child has egg allergies or had a reaction to the influenza vaccine.
- Tdap (tetanus, diphtheria, acellular pertussis): Recommended for adults age 19 and older to protect against tetanus, diphtheria and pertussis. It is 1 injection.
- HPV (human papillomavirus)/Gardasil vaccine: 3 injections for boys and girls age 9-26 to protect against 2 types of HPV.

Vaccinations NOT safe to give after transplant

- Inactivated polio vaccine (IPV): Usually 4 injections (depending on your child's age).
- MMR (measles, mumps, rubella): 2 injections of the live virus. MMR cannot be given if your child ever had a reaction to gelatin, the antibiotic neomycin or already had a dose of MMR.
- Varicella vaccine (VZV): 1 or 2 injections of the live virus (depending on your child's age). It cannot be given after the transplant.

While you are waiting

There is no question that it is stressful to wait. Parents often feel conflicted about waiting for another child to die so that their child may live. Our team is ready to support you and your child during this stressful time. Our social worker, Child Life specialist and child psychiatrist or psychologist are also available to help.

Preparing for a transplant

Financial planning

The transplant coordinator and social worker will work with you to go over different options to pay for the transplant and medications, before and after the transplant.

Organizing your finances can be very complicated because there are many insurance plans, and all of them have different rules and regulations. If you do not have health insurance, a social worker can provide resources on federal and state funding and charitable organizations that can help.

If your family has health insurance through your employer, you need to find out if transplantation is covered in your policy. If your health insurance only covers a partial cost, a social worker can help you find ways to pay out-of-pocket expenses.

Emotional support

The transplant process is different for everyone, and we always try to meet the needs of each patient family. We hope that you will be open with us and bring up

any concerns. Our transplant doctors, social worker and coordinator have a lot of experience and access to resources that can help your family.

We also have spiritual advisors who are available for you to talk to. Remember that your own religious or spiritual community can be a source of comfort and support, as well.

If you have other children, you are probably concerned about how this illness is affecting them. We offer this advice:

- Tell your other children what is happening. Give them information they can understand. Your social worker can help you with this.
- Keep things as routine as possible. If you can, let them continue after-school activities and spend time with their friends.
- Spend time with your other children. Doing things together like watching TV, reading or simply talking will help them understand that you love them as much as their sick brother or sister.

What plans should I make for the day of transplantation?

Once your child is listed for a transplant, the lung transplant coordinator will contact you to make a plan for what will happen. They will call your cell phone when the donor lung(s) arrive, and will work with you to arrange how to get to Boston Children's (by ambulance or air) when the call happens.

If you are organizing your own transportation for the day of surgery, please consider that you need to get here quickly and plan for the possibility of traffic and bad weather. Other arrangements you should plan in advance include:

- Babysitting/child care for any other children
- Back-up transportation just in case the person scheduled to drive is unavailable
- Calling family members—we suggest you call 1 family member and have them and have them contact other family members
- Packing a bag for the hospital (**see Figure 7**) for you and your child (toiletries, pajamas, pictures, favorite blanket, stuffed animal)

How long should we expect to be on the list?

The waiting time could be months to years.

Sometimes, if patients live very far away, we ask them to move closer to Boston. If this happens, a social worker can work with you to make arrangements and to figure out how to pay for this. We understand that moving closer to Boston for a while can be very hard for your family. We will do everything we can to make the experience easier.

We will work closely with your family during the waiting time to keep your child's lungs working as well as possible and to ensure their best quality of life. Your child will have many visits to the hospital for check-ups, including physical exams, lung tests and blood work.

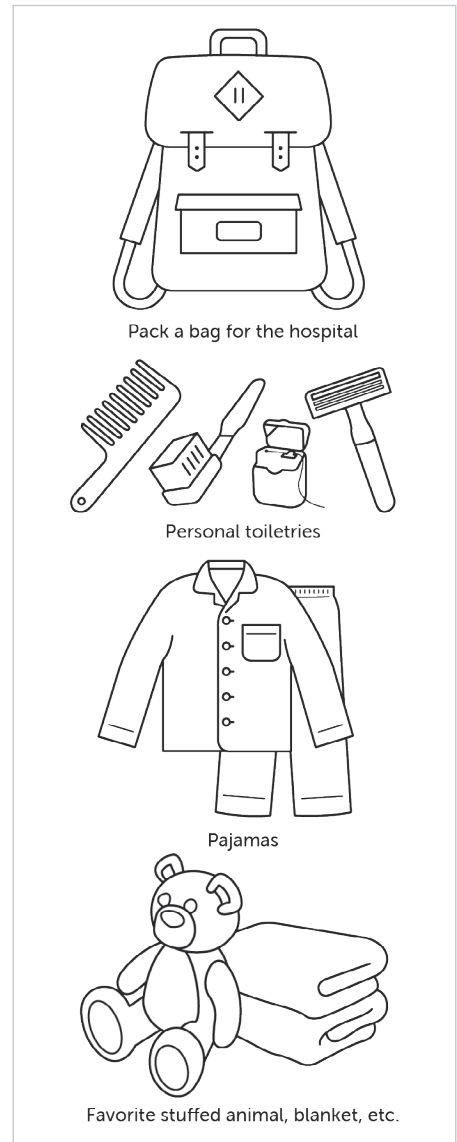


Figure 7

When a lung becomes available

Key point: A lung transplant is a time-sensitive operation. Because of this, you will need to stay within 4 hours of the hospital at all times. After surgery, a team of doctors, nurses and respiratory therapists will monitor your child.

Getting the call

When there is match for your child, you will get a call from the transplant team. It is important that you always leave a phone number—such as a cell number—where you can be reached if you are away from home. It is very important to **be within 4 hours of Boston Children's** so you can get here quickly.

- During the call, ask the transplant team if your child should take any **medications** on your way to the hospital.
- Your child should **not eat or drink** anything after you get the call.

Where to go at Boston Children's

When you arrive at Boston Children's, go directly to 10 South (see map on next page). If you get the call at night, you will need to go through the Emergency Department. Tell them that you have been called for a lung transplant, and they will show you how to get to 10 South.

Most of the time, families are rushing to get ready to come into the hospital, and there is not a lot of time to mentally prepare. These next few sections will help you know what to expect right before and after the surgery.

What happens right before surgery

When you get to 10 South, the doctors and nurses will examine your child and do some tests to make sure your child is ready to go to the operating room. If your child has an upper respiratory infection or a high temperature, the transplant team will decide whether or not it is safe to go ahead with the operation.

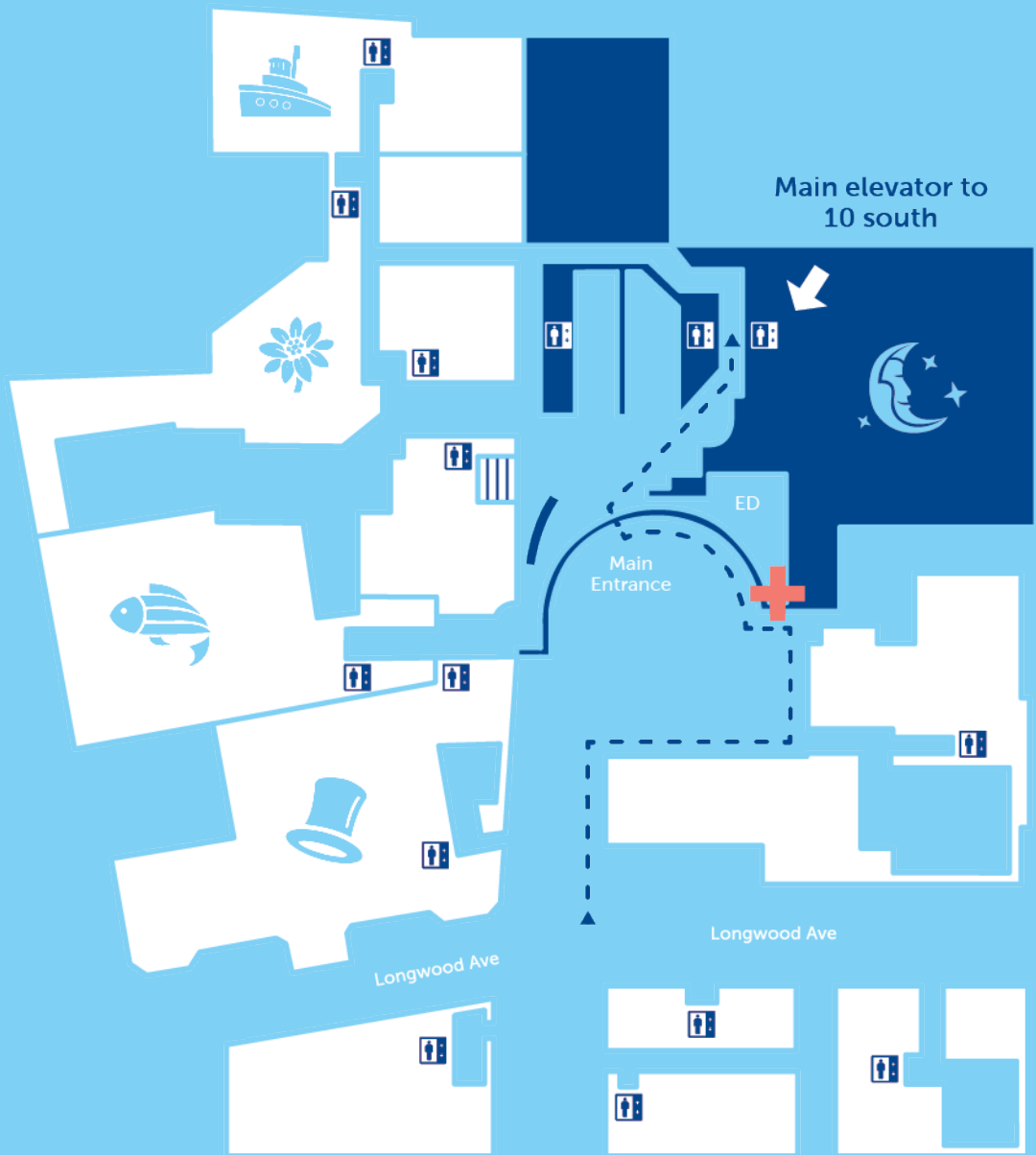
You will meet with the surgeon and anesthesiologist. This is a good chance to go over any questions or concerns you might have about the surgery. You will sign consent (permission) forms.

Surgery

Your child will have anesthesia to help them sleep. They will be prepared for surgery by getting an IV placed in their vein to get medications, blood products and fluid during the surgery.

The time of the operation is planned to match the arrival of the donor lung(s). This is because lungs need to be transplanted within 4–6 hours of being outside of the body. A team from Boston Children's is in charge of bringing the donor lung(s) to the hospital.

The surgery can take **6–12 hours**. While your child is in surgery, your family can either wait in the ICU family waiting room or in the main surgical waiting area (Main Building, 3rd floor). You will be given progress reports every few hours on how your child is doing.



Boat is for Bader



Flower is for Farley



Hat is for Hunnewell



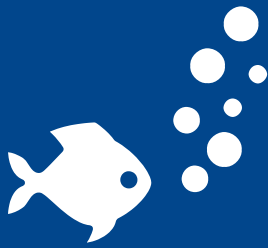
Fish is for Fegan



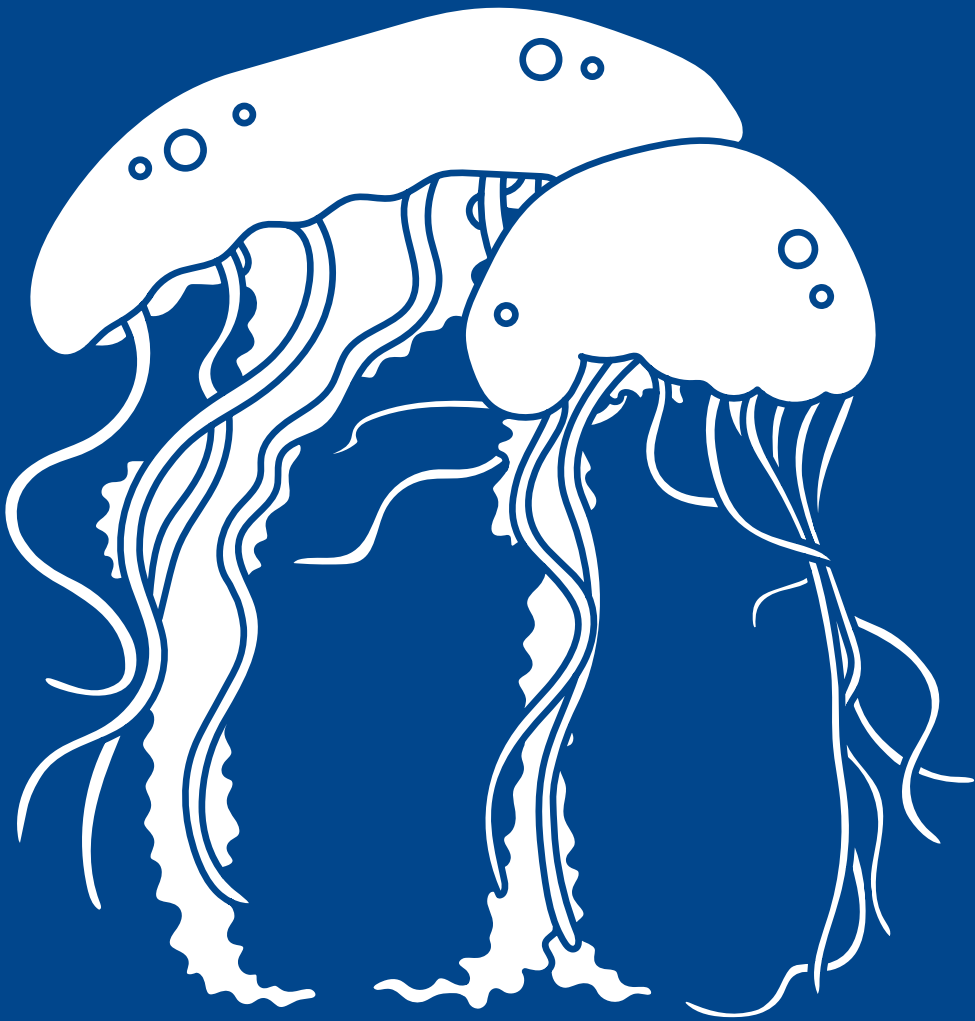
Moon is for Main



Elevator



We know it can be hard to see your child with all those tubes and drains. Don't worry, they are not hurting your child. They are there to help your child heal.



When a lung becomes available

What to expect after surgery

Once the doctors, nurses and respiratory therapists get your child settled in the ICU, you can come in to see your child. As your child wakes up, they will become aware of the tubes, drains and IV lines. Your child will have the following:

Breathing tube: This is attached to a ventilator to help your child breathe. This tube comes out of their mouth, so they will not be able to talk until it comes out. We will have you meet with a speech pathologist before surgery so that you can come up with ways to communicate while your child is in the ICU.

Nasal cannula: After the breathing tube comes out, your child may still need to have oxygen support through a small nose tube (nasal cannula) for a while.

Chest tubes: Your child will still have 4 chest tubes (see **Figure 8**) that were put in during surgery to help drain fluid. Once there is little drainage, the surgeon will make the decision about when to remove the tubes.

Naso-gastric tube: This tube runs from your child's nose down into their stomach (see **Figure 9**). It will keep your child's stomach empty and prevent them from having an upset stomach or throwing up. It may cause a "scratchy" throat after it comes out. If your child has a G-tube (a tube inserted directly into the stomach), they may not need a naso-gastric tube.

Epidural: Your child may also have an epidural catheter placed in their back to get continuous pain medicine after surgery. The ICU nurses are very good at monitoring pain. We will take every measure to keep your child comfortable.

Bladder catheter: A tube will be in your child's bladder to monitor how much they urinate (pee). It is very important for us to keep a close watch on your child's fluid to make sure their new lungs do not get overloaded with fluid.

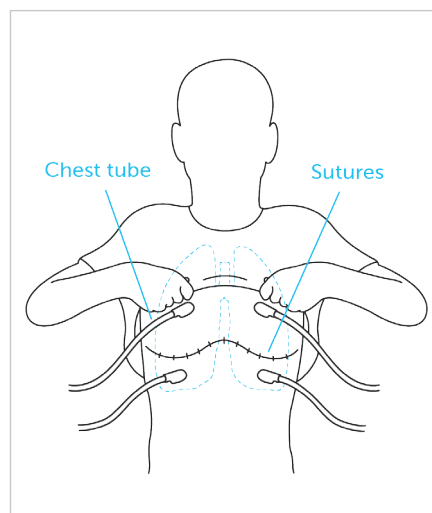


Figure 8

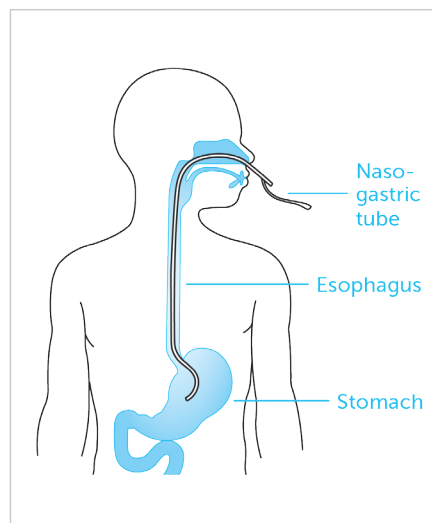


Figure 9

Getting ready to go home

Key point: Your child will take immunosuppressant medications to prevent rejection of the new lungs.

Your child may be in the hospital for up to 3 weeks or more after surgery. During this time, the transplant team and the nurses on the floor will teach your family about your child's medication schedule, and what side effects or complications to watch for at home. We encourage your extended family to be involved in learning about your child's home care. Teaching may take place during working hours. At this point, your role as a member of the transplant team becomes even more important because your child's new lungs need a lot of care, attention and monitoring.

- Once you go home from the hospital, your family will be responsible for looking after your child's health and for calling us if there are any problems.
- Now that your child is on immunosuppressive medication, it can put them at risk for infection and other problems. We ask that you stay mindful of any changes and call us if you are unsure of something.
- A visiting nurse may come to your home to see how your child is doing during the first month.
- If you live more than 2 hours from Boston, we will probably ask you to stay closer to the hospital for a while after you leave the hospital.

Complications after the transplant

Rejection is a normal reaction of the immune system to a foreign object in the body. Because a lung transplant is viewed by the body's immune system as foreign, the

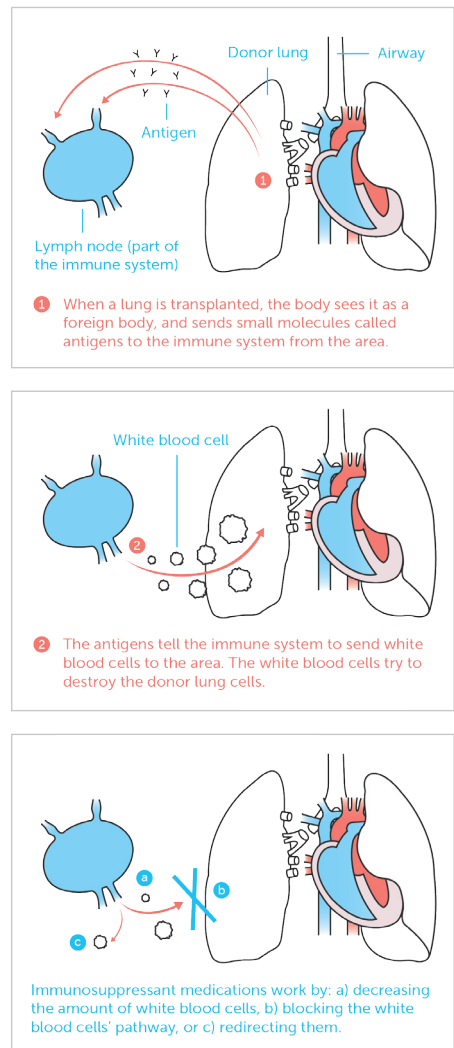


Figure 10

body mounts an attack against the transplanted lungs by sending cells from the immune system to destroy the new lungs (see **Figure 10**). This attack is called rejection.

Your child starts getting immunosuppressive medications during the transplant surgery. These medications work to curb the immune system and prevent rejection of the new lungs. Since these drugs reduce the immune response, it can limit your child's ability to fight off other germs (known as pathogens) that enter the body, and put your child at risk for infections.

Medications to prevent rejection

Our goal is to have your child take the lowest dose of medication that will prevent rejection and minimize side effects. Using drugs in combination allows us to use smaller doses for each drug than if only one drug is used. This is why your child will probably take a combination of drugs to suppress their immune response.

Taking the medications prescribed in the right amount and at the right time **every day** is very important. It is important to follow your transplant team's directions even if they are different from what is written on the bottle. Please call us whenever you have any questions.

- The more common immunosuppressive medications are prednisone, Cellcept and Prograf. The first year after the transplant is often when we are working to figure out the best combination of anti-rejection medications.
- **Expect changes in your child's medication.** You will be given a medication schedule before you leave the hospital. Changes are made to medication doses frequently by the transplant team, so the instructions on your prescription bottle may not be right or up to date.
- Since the process of treating your child's new lungs is ongoing, your child will need to take the medications for the rest of their life.

What happens if there is rejection?

After the transplant, we test for signs of rejection. This is typically done during a bronchoscopy, by taking a very small piece of the new lungs and looking at the cells under a microscope (called a lung biopsy).

If your child has acute rejection: Your child will need to stay in the hospital for 3 days. We treat the rejection with high-dose steroids given through an IV in the vein. About 2 weeks later, your child will have a bronchoscopy to see if the rejection has stopped.

- Steroid-induced **diabetes** is a fairly common complication.
- The high-dosed steroids your child gets during and after the transplant to prevent rejection can cause an increase in blood sugar. When blood sugar increases, the body naturally brings it down by secreting insulin from the pancreas. Signs and symptoms of high blood sugar are being very thirsty, having to pee often, hunger, vision changes and confusion.
- If your child develops diabetes, a nutritionist and an endocrinologist will work closely with you to control it.

If your child has chronic rejection: Your child could have symptoms of chronic rejection within the first year, but it usually happens later than that. It is considered a chronic (ongoing) rejection process and normally happens slowly. There are several treatment options to slow or stop chronic rejection.

Preventing Infection

The following are things you can do to help prevent or lower the chances of an infection:

- Hand washing is your best defense against infection.
- Your child can drink well water from wells that have been tested and are found to be safe. We recommend testing wells once a year. If you are unsure if your well water is safe, it is a good idea to either put a filter on your faucet or use bottled water.
- Try to limit your child's exposure to family or friends who may be ill.
- Your child should not do any gardening or dig in the dirt for 6–8 weeks after the transplant. After the 6–8 weeks, have them wear a mask and gardening gloves.
- Your child should not get any vaccines that are a live virus, like the MMR, polio or smallpox vaccines (see vaccine section on page 15). Talk to the doctor if someone in your household is getting a vaccination with a live virus.
- Please do not expose your child to second-hand cigarette/cigar smoke.
- Wash cuts and scratches with soap and water and use an antiseptic agent.
- Keep fingernails and toenails clean and trimmed.
- Your child should not swim in lakes, reservoirs or ponds. They should only swim in oceans and pools.
- Avoid petting zoos.
- Avoid crowded places 3–6 months after transplant.
- Your child should not return to school or work for 3–6 months after transplant.
- Your child should not get piercings or tattoos. Discuss ear piercing with the transplant team.
- We recommend no new pets for 6 months after the transplant. Please talk about your plan for getting any new pet with your transplant team. Your child should not clean pet cages or litter boxes because of the high risk for infection. Your child should not have birds or reptiles as pets because they carry certain diseases.

Your child's routine

Our goal is for your child to return to as normal a routine as possible at home. Of course, this takes time. These next sections give practical advice about sun exposure, nutrition and physical activity.

Care at home

Key point: Members of your transplant team, including nutritionists and physical therapists, will work with you so that you are comfortable taking care of your child at home after surgery.

Returning to normal activity

Your child will need to slowly build up to being just as active as their peers. Your child may feel great after surgery and want to take part in as many activities as possible. But it is good to go slowly.

Our physical therapist will form an exercise program with you. We may refer your child to a rehabilitation facility near your home to work with a physical therapist during recovery. There is a chance that your child will need more intensive rehabilitation and will be transferred to an inpatient rehabilitation hospital.

While the incision heals:

- Increase your child's walking distance every day but remember to go slowly and take breaks
- No lifting, pulling or pushing over 10 pounds
- Limit over-the-head exercises for 6–8 weeks

We recommend that your child wait **3–6 months** after the transplant before returning to **school or work**. We will talk about specific timing with you.

Travel

Your child is able to travel after the transplant. But since they will need many clinic visits and close follow-up, we ask that you not make any travel plans for the first **3–6 months** after the transplant.

Medical alert ID

It is very important to make sure your child wears their medical alert bracelet or necklace. In an emergency, caregivers will know that your child has transplanted lungs and will know to look for information about their medications and allergies. Please ask the lung transplant coordinator or social worker for details.

Care at home

Nutrition

Good eating habits can make a big difference in your child's long-term health. These recommendations can lead to a healthful diet for the whole family.

The first few weeks: During the first few weeks, your child will need extra nutrition to heal. Your child should have enough calories and protein to help the body heal the incision, fight infection and gain back the weight they may have lost after surgery.

Feeding tubes: Your child may need a feeding tube if they need extra nutrition, or if they are not allowed to take anything by mouth for a while after surgery. A feeding tube feeds your child directly through their small intestine (by NJ tube) or directly into the stomach and then into the intestines (by GJ tube). This reduces the chances of feedings going into the new lungs.

Avoid high-risk foods: Immunosuppression medications can make your child more likely to get an infection. Some foods carry bacteria that can cause food-borne illness and an infection. It is important to avoid these foods right after the transplant (**see Figure 11**) Your transplant team will tell you when it is safe to eat these foods again.

The nutritionist will go over food safety in detail. In general, you should wash all fresh fruits and vegetables well, and heat all deli meats, luncheon meats and hot dogs to steaming (165°F / 73.8°C).

12 weeks post-op: About 12 weeks after the transplant, the healing process is just about done. So your child's calories and protein needs may not be as high. Keep giving healthful foods. Our nutritionist will work with you in the hospital and in the clinic during follow-ups to give ideas, help you plan menus and answer questions.

Avoid alcohol: Your child should not drink alcohol because of potential interactions with some medications.

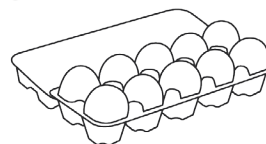
Avoid the following high-risk foods:



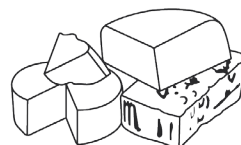
Raw or undercooked meat, poultry and fish



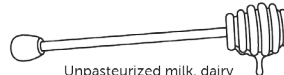
Shellfish and sushi



Raw eggs in any form
(cookie dough, eggnog, tiramisù)



Soft cheeses (feta, Brie, Camembert, bleu, Gorgonzola, queso fresco)



Unpasteurized milk, dairy products, honey or juices



Unwashed fresh fruits and vegetables



Grapefruit and grapefruit juice
(interacts with some medications)

Figure 11

Dental care

We advise that you do not plan any dental work for at least **6 months** after the transplant. Your child will be at risk for an infection after the transplant, and the mouth is a warm, moist area for bacteria to grow.

- It is important for your child to continue to brush and floss their teeth every day.
- Before every dentist appointment, your child will need to take an antibiotic to prevent an infection. Continue regular dentist visits every 6 months.
- Some of the immunosuppressive medications can cause an over-growth of gum tissue, which can be painful. Talk to your child's dentist, who can suggest ways to help with any discomfort.

Sexual activity

About **6 weeks** after the transplant, your child may resume sexual activity (if appropriate). They should avoid positions that could cause strain or pulling across the chest.

Since immunosuppressive medications weaken the immune system, we strongly recommend that they practice safer sex by always using a barrier method of protection with any sexual contact. This includes condoms and oral dams. It is important to prevent sexually transmitted infections, especially when the immune system is suppressed. Please encourage your child to bring any questions or concerns to a member of the transplant team.

Skin care

At the site of the incision: There will be Steri-Strips over the incision to keep it together. It is important that you do not take these off. Let them fall off on their own. Use warm water and soap to gently clean the area. Once the strips fall off, you can apply vitamin E over the incision to help it heal. Call the transplant team right away if your child has redness,

tenderness or drainage at the incision site.

Chest tube sutures: The surgeon will take off the chest tube sutures (stitches) 2–3 weeks after the chest tubes are removed. You may wash the area with soap and water and gently pat it dry. You do not need to keep the sites covered with gauze. You can continue to use vitamin E to help with scarring.

Limit exposure to sunlight: Your child may be sensitive to sunlight due to the immunosuppressive medications. This means that your child's skin can burn more easily and is at greater risk for skin cancer. Here are some tips:

- Take your child to a dermatologist once a year.
- Always apply sunscreen with a 30 SPF or higher when in the sun.
- Avoid spending long periods of time in the sun without sunscreen, hat and sunglasses.
- Since the sun is the strongest between 11 a.m.–2 p.m., try to avoid being outside during this time.
- Call the transplant team if your child's skin becomes discolored or you see moles that change in color, size or shape.

Acne: Some of the medications can cause pimples and dry skin. Prednisone can cause the skin to become thick and oily. If your child gets acne, here are some helpful hints:

- They can gently wash their face twice a day with a mild soap, like Dove or Aveeno.
- They should not scrub, pick, rub or squeeze the pimples since it could cause a skin infection.
- If their skin is dry from washing, stop washing those areas with soap to allow the skin to regain its natural oil.
- Do not use any over-the-counter medications before talking to the transplant team.
- Try to avoid using products that are cream- or oil-based.

Clinic visits

It is important for you to arrive to your clinic visits early so that tests can be done before each appointment. Remember, blood levels need to be drawn before taking Prograf or cyclosporine. It is very important that you have your child's immunosuppressive medication with you so that your child can take them after having blood tests.

Follow-up appointments

Key point: Starting at 1 year post-transplant, your child will have follow-up appointments every 3–4 months.

Your child will come to the lung transplant clinic 1 or 2 times a week at first. At some point, we will begin to space the visits out. By 1 year after the transplant, you will probably come to clinic every 3–4 months.

Before you go home, you will get a notebook to record your child's spirometry results, blood pressure, heart rate, respiratory rate, temperature, weight and oxygen saturations, as well as any new symptoms that occur.

- We recommend that you record weight, oxygen saturation and vital signs every morning.
- You should record spirometry results 2 times a day.
- We ask that you bring this notebook with you to each of your clinic appointments so we can review it with you. We will let you know when to call if a result is abnormal.

Annual physical examination

It is important that you stay in close contact with your child's primary care physician after the transplant. If you do not have a primary care doctor (PCP), we can refer you to someone in your area.

Although we will continue to take care of all of your child's post-transplant-related issues, the primary care doctor should be in charge of your child's routine health issues, like immunizations, physicals, pelvic exams or testicular exams.

Common tests and studies after the transplant



Bronchoscopy

Your child will have many bronchoscopies after the transplant to look for infection and rejection. During a bronchoscopy, a thin instrument, called a bronchoscope, is placed in your child's airway so the throat, larynx, trachea and lower airway can be examined. It is usually done under anesthesia. Your child may have a lung biopsy at the same time to look for signs of rejection under a microscope.

Generally, a bronchoscopy is done right after the transplant in the operating room to look at the airways. It is then done daily while your child has a breathing tube in. Then, your child will have a bronchoscopy at 1 month and then at 3, 6 and 12 months. This allows us to look for signs of infection and rejection. Your child will have the procedure again after this, if needed.



Chest X-rays

These are special pictures taken of the chest. They are done in the Radiology Department. These check for lung infections, fluid build-up and heart size.



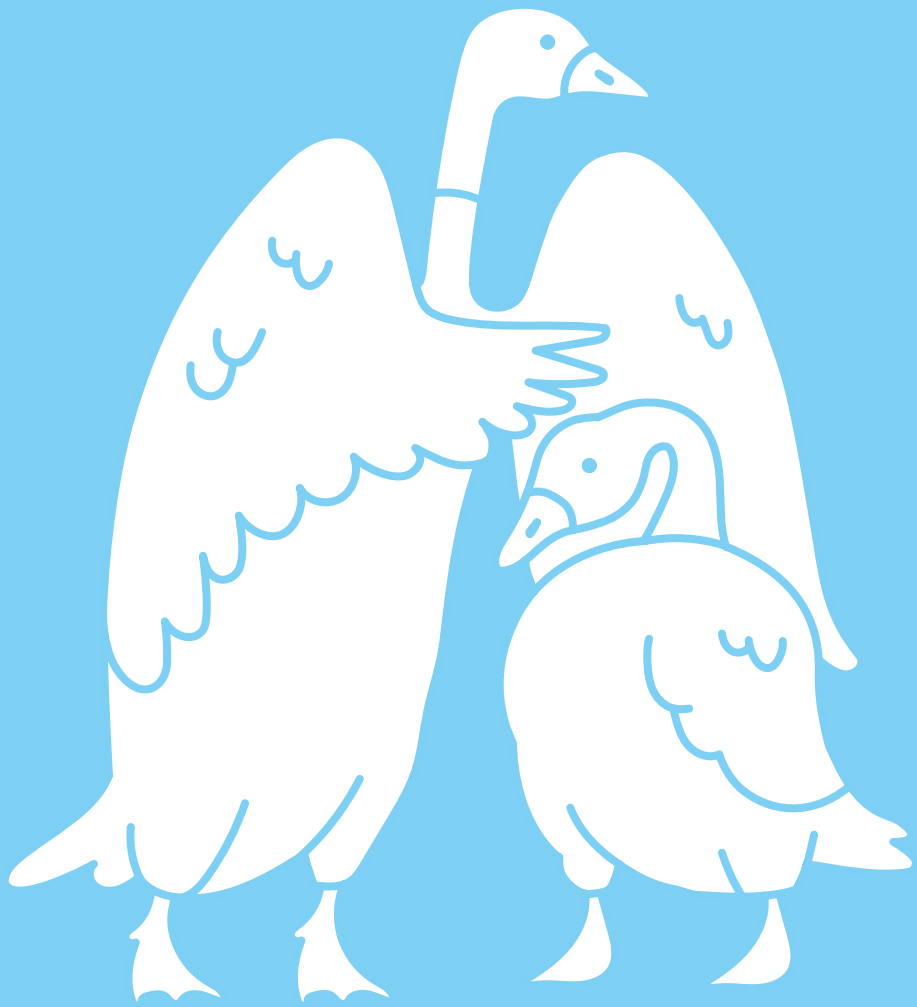
CT Scan

Your child will have a chest CT scan in about 2–3 months. This will give a baseline (starting point) to see how the new lungs are doing.



Impedance probe

Around the time of your child's 3-month bronchoscopy, an impedance probe will be placed while your child is under anesthesia (asleep). This is a small, flexible tube that goes into the nose and down into the stomach. It measures the amount of acid in the stomach and whether or not your child is having reflux. The tube will stay in place for 24 hours, and your child will stay in the hospital during this time.



Talking to the donor family

Key point: You may write an anonymous letter that we will send to the donor family through the New England Organ Bank.

It is our policy to not give information about the donor at the time of your child's transplant. We understand that you are curious to know about the donor, but we are very strict about protecting the privacy of our donor families.

If you are interested in contacting the donor family, you can write an anonymous letter and give it to the lung transplant coordinator or send it directly to the New England Organ Bank (NEOB). The NEOB will forward the letter to the donor family. We ask that you wait before sending your letter, since the family is likely grieving the loss of their loved one. Be sensitive to their feelings and extend your sympathy along with your gratitude.

Please do not add your last name, address, phone number or any other identifying information in your letter. You may include your first name when signing it. Attach a **separate piece of paper** with your full name, address, transplant center, organ that was transplanted and date your child got the transplant. This allows the NEOB to send your letter to the right donor family. Please ask the lung transplant coordinator or social worker for help with this process.

Resources

Many organizations are dedicated to providing information, support and financial help to transplant recipients. We encourage you to use these resources throughout the transplant process. Please feel free to ask the social worker or lung transplant coordinator any questions about these resources.

General information

Massachusetts Rehabilitation Commission

Helps those with disabilities who need help finding a job or want to qualify for federal Supplemental Security Income (SSI) or Social Security Disability Income (SSDI)

Administrative Offices

600 Washington Street

Boston, MA 02111

Phone: 800-245-6543 or 617-204-3600

Web: mass.gov/eohhs/gov/departments/mrc

MediAlert

Health organization that provides 24-hour emergency assistance. You can order medical ID jewelry here.

Phone: 800-432-5378

Web: medicalert.org

National Foundation for Transplants

Offers health care and financial services, and advocates for transplant candidates, recipients and their families

5350 Poplar Ave, Suite 850

Memphis, TN 38119

Phone: 800-489-3863

Email: info@transplants.org

Web: transplants.org

New England Donor Services

Organ procurement organization (OPO) serving New England. It works with UNOS and anonymously connects donor families and transplant recipients

60 First Ave

Waltham, MA 02451

Phone: 800-446-6362

Web: neds.org

Scientific Registry of Transplant Recipients (SRTR)

Provides statistics for solid organ transplant programs throughout the United States

Web: www.srtr.org

UNOS Transplant Living

Provides information and resources on all aspects of transplants

700 N. 4th Street

Richmond, VA 23219

Phone: 804-782-4800

Email: patientservices@unos.org

Web: transplantliving.org

Transplant Recipients International Organization (TRIO)

Helps transplant recipients, their families and donor families with support, education and advocacy

7055 Heritage Hunt DR, #307

Gainesville, VA 20155-3031

Phone: 800-874-6386

Email: info@trioweb.org

Web: trioweb.org

United Network for Organ Sharing (UNOS)

Manages the national wait lists for all organ types and matches donors to appropriate recipients; provides a free transplant information kit

700 North 4th Street
 Richmond, VA 23219
 Phone: 888-894-6361
 Web: unos.org

Financial help

ClaireBear Foundation

Provides financial help for families taking care of sick children far from home
 Web: clairebearfoundation.org

First Hand Foundation

Provides financial assistance for health care expenses to children who need it
 2800 Rockcreek Parkway
 Kansas City, MO 64117
 Phone: 816-201-1569
 Email: myfirsthand@cerner.com
 Web: firsthandfoundation.org

HealthWell Foundation

Provides financial help for health care expenses to those in need
 P.O. Box 220410
 Chantilly, VA 20153-0410
 Phone: 800-675-8416
 Email: grants@healthwellfoundation.org
 Web: healthwellfoundation.org

RxHope

Provides information on financial programs for transplant medications
 Web: rxhope.com

Patient Access Network Foundation

Provides financial help for health care expenses to those who need it
 805 15th Street, NW Suite 500
 Washington, DC 20005
 Phone: 866-316-PANF (7263)
 Email: info@panfoundation.org
 Web: panfoundation.org

Fundraising Information

American Organ Transplant Association

Provides information on fundraising, transportation and other support
 P.O. Box 418
 Stilwell, KS 66085
 Phone: 832-930-2682
 Email: aotaonline@gmail.com
 Web: aotaonline.org

Children's Organ Transplant Association

Provides fundraising help for those needing a transplant
 2501 West COTA Drive
 Bloomington, IN 47403
 Phone: 800-366-2682
 Email: cota@cota.org
 Web: cota.org

YouCaring

Helps you create and promote an online page that describes your fundraising efforts
 Phone: 312-488-9861
 Web: giveforward.com

HelpHopeLive (formerly National Transplant Assistance Fund)

Helps with fundraising for people needing a transplant or after a major injury
 2 Radnor Corporate Center, Suite 100
 100 Matsonford Road
 Radnor, PA 19087
 Phone: 800-642-8399
 Web: helphopelive.org

Transportation

Angel Flight Northeast

Coordinates free flights for medical treatment for patients who need it
 800-549-9980 or 978-794-6868
 Email: angelflight@angelflightne.org
 Web: angelflightne.org

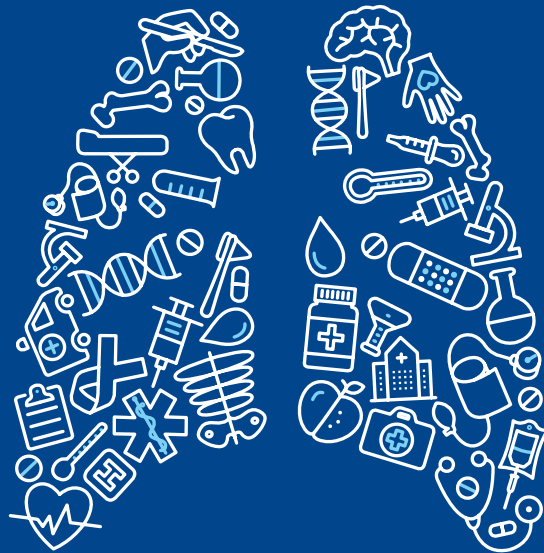
Family Education Guide

Administrative Assistant: 857-218-5097

Coordinator: 617-355-6681

Fax: 617-730-0097

Web: bit.ly/lung-transplant



Boston Children's Hospital
Pediatric Transplant Center