

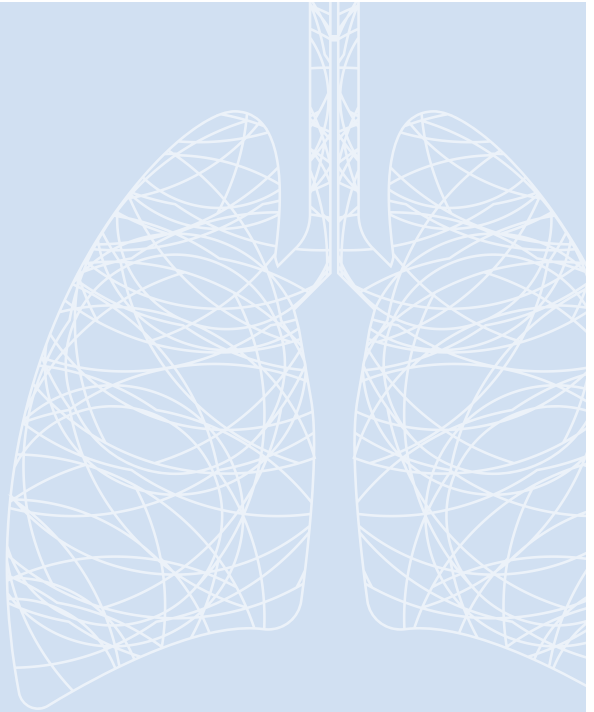
Lung Transplantation



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HEALTH • EDUCATION • RESEARCH

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Introduction

This handout provides an overview of Lung Transplantation at HMC. We'll describe this process as if we are headed straight for transplant, but please know that it may not be that simple. For example, we may find something during the evaluation process that tells us you are not an appropriate candidate for a transplant. If this happens, we will let you know of our findings so that you may follow up as appropriate with your primary pulmonologist.

Lung Transplantation

Evaluation

You have verbally agreed to choose the option of lung transplant in your last appointment with the pulmonary transplant team. We prefer to admit you as inpatient in Hamad General Hospital for your initial evaluation and inpatient pulmonary rehabilitation over 10 to 14 days. Many tests will be conducted to determine:

1. How sick you are.
2. How well you are.
3. You have no current infections or malignancies.

For lung transplants, we are looking for the “transplant window” of being sick enough to need transplant, yet well enough to recover from the large surgery and difficult post-operative period. We will also request testing to determine if you have any infectious or malignant processes going on. The reason for this is that we are looking forward to the transplant process when we will start medications to suppress your immune system. If you currently have a small (and maybe even unknown) infection or malignancy, when we suppress your immune system, we may turn a small problem into a large problem rather quickly. The fourth category of testing involves tests to assess your esophagus and may not be required of all potential recipients.



Types of Testing During Evaluation

Below is a list of the types of testing you can expect during the evaluation process:

- Bone Density Scan.
- Vaccinations.
- Hep A, Hep B, Tetanus, Pneumonia, Flu.
- PAP Smear (women).
- Mammogram (women).
- Colonoscopy (>50 yrs).
- Dental Clearance.
- Infectious Disease Evaluation.
- Cardiology Evaluation.
- Psychiatry Evaluation.
- Other tests depending on medical history or abnormal findings during the first round of testing.

Evaluation Wrap-Up

After the medical tests and rehabilitation is complete, we will schedule you for outpatient visit to assess your candidacy.

Listing

- CT scan.
- Chest X-ray.
- ECG.
- Echocardiogram.
- Cardiac Catheterization.
- Abdominal Ultrasound.
- Urinalysis.
- Blood Tests.
 - Blood Typing (ABO).
 - General Labs.
 - Serologies.
 - Tissue Typing.
- PSA (Men).
- PFTs.
- 6 Minute Walk Test.

Lung Transplantation

Selection Meeting

The lung transplant team has selection meetings on ad hoc basis to discuss patients' cases. Once we have enough information, we will discuss your case and decide if you are a transplant candidate and if now is the right time to list you for transplant.

Consider The Transplant "Window"

Again, we are looking for the window of time when you are sick enough to need transplant, yet well enough to recover from it. There are certainly risks in moving forward with transplant, including risks of the surgery, infection, rejection, and lifelong medications. We do not want to expose you to these risks before it's necessary.

If Decision is to List

If the decision of the team is to list you for transplant, the transplant coordinator will contact you to make sure that you are mentally ready for listing.

Once you are placed on the waiting list

You should know that the time you wait on the list is very unpredictable. We have no way to know when a donor will pass away and if that donor will be compatible with you.

We MUST always be able to reach you, so you will need to keep us up to date with any phone or address changes. If you get sicker or are hospitalized locally, please call us immediately or have a family member or friend call us.

During the waiting period, we encourage you to keep in shape as much as possible, given your breathing issues. Keep your appointments with the pulmonary rehabilitation team.

The transplant team will want to see you periodically in clinic while you are on the wait list to make sure that we are current with your status. If new issues develop, your candidacy will be re-assessed and if you are no longer a candidate, you will be removed from the list. You will be informed of any changes in your candidacy.

The Right Donor

The lungs come from a person who has passed away and their family decides to donate the organs. The donor lungs are never perfect, hence detailed donor evaluation will be done. In order for a donor to be the “right” donor for you, the donor must have a compatible blood type to yours. The lungs must be a compatible size to what your rib cage will hold.

Being Called for Transplant

When we get the call about the “right” lung or lungs for you, we will call and let you know the need to come to the hospital right away. When we call you in, all the information we have indicates that these are the right lungs for you, but at the time we call you, the lungs have not been taken out of the donor yet. The reason we call you in prior to the organ retrieval, is that we want to keep the ischemic time (the time that the lungs are out of the body, either the donor’s or the recipient’s) as short as possible.

If we find a problem with the donor lungs as they are being retrieved, like maybe the anatomy is very complicated and it would be difficult to hook up in you, or that there was a cancer in the lungs, or that they were damaged during the retrieval surgery, we will send you home without transplant. We are looking for the most pristine lungs to start with since there are already enough risks in this process. It may happen as often as 1 out of every 3 or 4 times that we call in a patient who is sent home without transplant. If this should happen to you, nothing is lost in the process.

When we call you in, we will instruct you on where to check in at the hospital and give you any special instructions.

Once checked in, we will get IV’s started, draw some blood, get chest X-ray and ECG and any other pre-operative tests we may need.

Lung Transplantation



Surgery

Single lung, bilateral lung lobar

We can transplant either a single lung or bilateral lungs (meaning both) or lobes of the lungs. You should be prepared to be called in for either one or two lungs, unless we have specifically told you otherwise.

Incision

The most common incision for putting in two lungs is called a clamshell incision. The incision goes from under one arm to under the other arm, across your chest, and comes up about two inches in the middle. The incision is opened top to bottom, not side to side.

If only single lung is being transplanted, the incision will be low over the side of the rib cage on the side of the transplanted lung.

Surgery Length

The average surgery is about 8 to 10 hours long and you are completely asleep for the surgery.

Surgical Risk

The surgical risks of transplant are different from the risks for any general anesthesia surgery as your lungs are weak. During the surgery, the lungs will be removed and hence maintaining your oxygen levels are dependent on your lung function. Therefore, we may maintain your oxygen levels utilizing oxygenation machines. Some risks of procedure, hence also related to low oxygen supply to heart, brain and other organs. Other risks include, infection, blood clots, bleeding, and reaction to the drugs that they give to put you to sleep and there is a small, but real, risk of death. There is a small risk that the transplanted lungs may not work, and this might result in a small, but real, risk of death.

Immunosuppression

During the transplant surgery, we will start you on medication to suppress your immune system. This is due to the nature of the donor genetics and the recipient's immune system.

The normal job of our immune system is to scan the body, recognize "foreign" things, attack them and get rid of them. Unfortunately, the immune system can't tell the difference between "good" foreign (like your new lungs) and "bad" foreign (like a virus). It only sees "foreign" or not "self". This act of the immune system attacking the transplanted organ is known as "REJECTION". Therefore, you need to continue taking lifelong immunosuppression regularly and punctually.

Lung Transplantation

Hospitalization

Once the surgery is over, you will wake up in the Surgical Intensive Care Unit (ICU) in Hamad General Hospital. When you wake up, you will have lots of things attached to you that you didn't have when you went to sleep. You will have a tube in your throat which is connected to the ventilator. Be assured that this tube does not mean that the transplant failed. We need you awake and able to follow some commands to know that the lungs are working well. It's much easier to wait a few hours and make sure that the lungs are working well, then take the tube out, than to take it out too early, and risk having to put it back in again. It's much more traumatic to have to put it back in. Sometimes, if the oxygen supply is low and the lung is not working properly, we may put you on a special oxygenation machine called ECMO machine.

You will have IV's in your neck or shoulder area that you didn't have before you went to sleep. You will have the incision, with the skin closed by stitches across your chest or side. You will have somewhere between two and four "chest tubes". These are tubes about as large around as your finger, and they are connected to containers at the bedside to collect any drainage from the incision. We don't want fluid to collect in your chest or abdomen because of the risk of infection. The chest tubes will come out after the drainage has stopped, typically after several days. You will also have a catheter in your bladder which will be connected to a drainage bag at bedside to collect urine. This will usually be taken out when the epidural catheter for pain management is taken out of your back. You are likely to be on blood thinners to help prevent blood clots from forming while you are bed-bound.

After transplant, you may have a feeding tube for a few days until your bowels start working properly.

Bronchoscopy

There is a procedure you will become very familiar with called a bronchoscopy. A bronchoscopy is a procedure where they use a catheter with a camera attached to it to go down into the main airways and take a look around. While the endotracheal tube (breathing tube) is in your mouth, they will put the camera through this tube. After the breathing tube has come out, the bronchoscope will be inserted through your mouth.

For the first five days after the transplant, they will do this to clean out any secretions or blood that may be present in the lungs and to make sure that the suture (stitching) lines look good. These “clean-out” bronchoscopies must be done when you have an empty stomach to decrease the risk of aspiration into the lungs so you will not be given anything to eat or drink for several hours before the procedure (usually nothing after midnight). You will also not be given anything to eat or drink for a while after the procedure. These early “clean-out” bronchoscopies are rather uncomfortable as we want you to cough up any secretions deep in the lungs so that they can be suctioned out by the catheter. For this reason, the sedation must be kept to a minimum. The doctors may take some secretions to send to the lab for cultures to see if any ‘germs’ are growing that require treatment.



Lung Transplantation

Hospitalization Days After Transplant

Getting Out of Bed

We will get you up and out of bed within one day after surgery, so be prepared to work hard. We want you up for a couple reasons, one is to let those nice new lungs expand fully while you're upright. The second is to try to minimize your risk for blood clots. When you're lying down and the leg muscles aren't moving and helping to pump the blood back to your heart, the stagnant blood may form clots. In your arms and legs, these clots are known as deep venous thrombosis or DVTs. If part of one of these clots break off, it can travel to your head causing a stroke, to your heart causing a heart attack, or to these nice new pretty lungs causing a pulmonary embolism. We don't want any complications that we can prevent, and we certainly don't want any damage to the lungs, your head or your heart.

Physiotherapy Team

The most important component is to get your body used to the new lungs and to get them up and running to attain their full potential. This will require intensive exercise / physiotherapy regime which will require your dedicated efforts. You will be supported by our excellent physiotherapy team.

Pain Management

The first few days will be a bit uncomfortable. We will try to keep you comfortable and will likely use an epidural catheter to help with pain management. Most drugs given for pain control are narcotics.

Unfortunately, narcotics can knock down your drive to breathe and make you too drowsy to get up and out of bed. We can't have you overly sedated since we're trying to minimize your risk for complications.

Emotions

During the first week or so after transplant, your emotions may feel out of control, you may be sleep deprived, and you may experience hallucinations. These are side effects of the medications and the stimulating environment of the hospital equipment

and staff. You may want to let your family know that this is all to be expected and a normal part of the recovery process.

Average Hospitalizations

The average ICU stay is about two to three weeks, barring complications. The total hospital stay is about four to six weeks, barring complications.

Medications

During your hospital stay, we will educate you on the medications you'll be taking and how to care for your new lungs. The list of medications may be up to 20 different meds or more. Most medications will be taken orally, but some are taken by inhaling them, while others require injection. Many of these will be used temporarily, and the list will get shorter over time, but you will ALWAYS have at least the two or three immunosuppressive medications for the rest of your life, to be taken regularly and punctually.



Lung Transplantation

After Hospitalization

Staying in Proximity

For the first six months after you are discharged from the hospital, you will need to stay in Qatar. The reason for the required local stay is two-fold.

Safety. The first is a matter of safety. If you're at home, and have an emergency situation, like shortness of breath or the incision opening up, you can visit the ER at Hamad General Hospital.

Convenience. The second reason we require that you stay locally, is a matter of convenience. Your visits to HGH will be numerous in the first few weeks. For this period of intense follow up, you will be at the hospital or clinic for some part of most working days.

Support Person

During this first six weeks after discharge from the hospital, you will need a support person who can stay with you for 24 hours a day, 7 days a week. The reason for having a support person is that you will have restrictions on lifting and on driving for at least the first 6 weeks. With all that you've been through, it'll also be good to have someone who can assist you as you have been through major surgery, a long recovery, and are on numerous medications and many follow up appointments.

Physiotherapy Post-Surgery

You will continue outpatient physiotherapy on a regular basis so that your lungs will continue to attain their full potential. This will be provided initially by our physiotherapy team and later you will continue in Qatar Rehabilitation Institute.

After Six Weeks

As time goes on, the visits and follow-up testing will become less frequent.

Life with Transplant

Life-long Immunosuppressions

Indeed, the immunosuppressive medications will be needed for the rest of your life. The doses of these drugs will be highest in the beginning. The reason for the larger doses is because we'll need to knock down your immune system to prevent lungs rejection. We will reduce the doses of the drugs down over time, so that, ultimately, you're on a lower maintenance dose. Some immunosuppressive drugs are adjusted based on their level in your blood.

Follow Up Regimen

Though you will be able to leave the hospital in a relatively short period of time (because there are infected people in hospitals and we don't want you catching an infection), you will however need intensive follow up as outpatient. This follow up will become less frequent over time, but you will always come to see us at least once every 3 months, even if everything is going fabulously.



Lung Transplantation

Early Risk after Transplant

There are two early risks after transplant: Infection and Rejection. These are the most prominent over the first six months to a year after transplant. However, these are lifelong risks, which lessen over time.

Infection

The increased risk of infection comes from your immune system being suppressed. Unfortunately, we have not found a way to suppress JUST the part of the immune system that attacks the lungs, so your whole immune system will be suppressed. For this reason, you will be more susceptible to all kinds of infection, not just respiratory ones. We may initially have you on drugs to prevent viral, bacterial and fungal infections during this period while you're most vulnerable.

While you're in the hospital, we'll remind you of a number of ways that you can minimize your risk for infections. The best thing you can do is to WASH YOUR HANDS, wash your hands, wash your hands and gargle with a mouth wash regularly (3 times a day). Other precautions include care in handling foods and avoiding any sick person. We will also recommend that you wear a mask while visiting the hospital and clinic and that you avoid working with soil (like gardening or potting plants), among other things.

Rejection

The other early risk post-transplant is rejection. Rejection is the act of the immune system attacking the transplanted lungs. Left untreated, rejection will eventually lead to enough lung damage that they will fail.

You have two jobs in preventing rejection:

1. Medications. You **MUST** take your medications as prescribed, when prescribed, no 'ifs' and or 'buts'.
2. You **MUST** notify us when you experience any deviations from your "normal". Some of this is very objective. We will have you take your vital signs and your weight once a day. We will give you parameters on when to call us.

3. You MUST call us immediately with deviations from your normal. The worst that can come from this is that you call and we are able to share some information with you about whether this is transplant related or not, and how to monitor it.

Side Effects to Medication

There are numerous side effects of the medications that you'll take after transplant. You may experience a FEW of these or ALL of them. It is important to report any new symptoms you're having so that we can try to help minimize them. Some of the most common side effects that patients report are: hair loss, hand tremors, nausea or upset stomach, puffy face, bruising easily, weight gain or weight loss, headaches, problems sleeping, trouble concentrating and muscle weakness.



Lung Transplantation

Late Risk for Lung Transplant

There are long term risks that may not show up in the first year, or maybe in two years but will show up after a number of years.

Drug Related Issues

Some long-term risks include diabetes (high blood sugars), hypertension (high blood pressure) and osteoporosis (decreased bone strength), which are common side-effects of the immunosuppressive medications, and often require medical treatment.

Malignancies

One of the most common long-term risks is a higher incidence of cancer than the rest of the population, especially skin cancers. This is due to the immunosuppressive medications making your skin more susceptible to sun damage. You will need to protect yourself from the sun by wearing sunscreen daily, and if you know you're going to be out in the sun, wear hats, long sleeves, and long pants.

Current Survival Status

Current survival statistics after lung transplant show that survival rate at one year after transplant, is about 85 to 95% and after 5 years is 50%.

Patient and Family Education



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