Lung Transplant for the Pulmonary Fibrosis Patient: The Real Story

DISCLAIMER: Please note I am not a medical professional. I spent 6 years as caregiver for my mom, until her passing in 2009. I have since been a PF Advocate for Patients & Families, as well as moderator & owner of the Breathe Support Network of Groups. Information provided is from personal experience, combined with years of learning through interaction with patients, other caregivers, & medical professionals in the field of PF/IPF.

Many have questions about the lung transplant process.

Sometimes they're not given much information by their healthcare team. Some may even be told "*it comes with too many risks to be worth it*" or "*it's not very risky at all*." Both of which are horribly incorrect.

While some transplant teams are becoming more and more forthcoming with the "reality" of transplant, many still hold back. I'm not sure why this is the practice.

> Maybe they don't want to scare patients and loved ones.
> Maybe they don't want to be accused later of not saying enough.

Whatever, the reason, in my humble opinion (and being an information junkie myself), I feel it's important that anyone thinking about going down this road (and their loved ones) know the realities of what the lung transplant process might entail.

Below is something I wrote up to send to a concerned caregiver and their loved one who is living with pulmonary fibrosis and grappling with the decision about lung transplant. I am sharing it with you in hopes that you'll have these conversations with your loved ones and with the healthcare team.

Please note this is not all inclusive. Not every detail of lung transplant is in here. This is a guide to help you get started on learning more from the healthcare professionals in your life. A guide to get you thinking about more questions you want to (and should be) asking.

I don't want you to be afraid of the lung transplant process. I want you to be armed with information so you can make an "informed decision."

Is lung transplant a cure?

Lung transplant is not a cure. Lung transplant is trading one terminal illness for another. It comes with many life changes and ongoing medical needs: medications, more clinic/hospital visits, restrictions surrounding activities and personal interactions, and more.

The recipient's body will ALWAYS try to reject the donor lungs because those lungs are foreign to the body and the body knows that. Those donor lungs have a different DNA than the recipient's body and the body knows that. The attempt at rejection will never stop.

While some patients live a very short time after lung transplant, a lot of people live a very long time. The reality is that in most who are post-transplant, eventually those donor lungs will be rejected and the person will succumb to that rejection. That might be in weeks, months or years. There have been stories of people who lived 20+ years after lung transplant. I know people personally who are into their double digits on years after lung transplant and doing very well. Never lose HOPE.

What medications might I expect after lung transplant?

The most important medication someone post-transplant may take are the many anti-rejection medications. These medications suppress the immune system, helping to reduce rejection problems.

Another very important group of medications are the antibiotics they take. They need to be as close to free of infection as possible because infection increases the risk of rejection. Those post-transplant may take these medication to help their body fight off infections that may crop up.

There are medications for other things as well. Sometimes they have an antibody that is problematic and need to take medication for that. (I admit, the antibody issues are something I don't know a lot about, I just know that some people have or don't have certain antibodies and so additional medications are needed. This is definitely a question you should be asking the doctor – especially if you're told that antibodies are a problem.)

There are also medications to treat side effects of the other necessary medications.

Sometimes the medications are oral. Sometimes they are IV and given via a permanent port, surgically implanted, so the medications can be given at home by oneself or their caregiver.

These medications MUST be taken ON SCHEDULE. When the prescription says "every 12 hours" they really mean "every 12 hours". NOT every 11 hours or every 13 hours. **Every 12 hours.** The expectation is the same if the medications are prescribed every 8 hours or every 6 hours, etc. Wavering from this schedule can put someone who is post-transplant at serious risk of a complication. Keeping a regimented schedule is EXTREMELY important.

The medications (as I've been told) are also where most of the post-transplant out of pocket costs reside. At least in countries like the United States, where we don't have socialized medicine and paying for things are up to us or our insurance. In countries where the government provides medical care, patients tend to pay less out of pocket for these medications.

Will I need to avoid other people?

Someone who is post-transplant needs to stay away from those who are sick or even symptomatic. Because of a suppressed immune system, even a common cold can

become critical for those who are post-transplant, especially if they are newly post-transplant.

This means their caregiver/s also needs/need to be careful with who they interact with, especially early on after their loved one has been transplanted.

How long do these restrictions last?

For a while after transplant (usually the first 6 months to a year) the requirements or recommendations on these things are more strict than later on. After a time, dosages of some of the medications (like anti-rejection medications) may be decreased, which does help with resuming a more normal life. I have known and know many who have been transplanted that resumed a fairly normal life a year or two after transplant and the longer they lived, the more normal their life became. That first 6 months to a year is the critical point.

However, it is important to note that if someone who is post-transplant is having ongoing problems (especially with rejection), they may find their restrictions are stricter than, say, someone who is more stable post-transplant.

Will I be free of clinics and hospitals after lung transplant?

Medical attention is super important after transplant.

Aside from the ongoing tests those post-transplant will undergo to check for rejection, any new symptom, even as simple as a slight cough or congestion, is a cause for concern and the healthcare team should be contacted right away. The simplest thing that would normally seem benign can be an early warning of bigger processes going on.

Some who are post-transplant may also have post-operative problems requiring medical attention. An example might be excess scar tissue building up in the esophagus due to intubation during and after surgery.

Those who are post-transplant need to be willing and ready to seek quick medical care - potentially often. As with the rest of the transplant process, this is usually more often in the earlier weeks and months post-transplant. As things get more settled, it may not be as often. Someone who is post-transplant really can't "let their guard down."

Additionally, some will have more problems than others. It’s important to remember that each person is different post-transplant, just as they were different prior to the transplant.

What other changes might I expect after lung transplant?

There are a lot of other life changes after transplant. Dietary changes are fairly significant for many. Usually nothing "undercooked or raw" is allowed in the diet. No sushi or undercooked meats, possibly not even raw produce for a while. Eggs must be fully cooked, so if one prefers their eggs with a runny yolk, that is not recommended.

Everything should be fully cooked to reduce the risk of infection from food borne bacteria.

Swimming in public waters might be a no-no due to the risk of contaminants in the water. For people who are avid swimmers, this is something they may find they have to give up, at least temporarily. This does seem to be one restriction that transplant facilities differ on. MOST people I talked to said they did not have this restriction. I have talked to a few who did.

Public travel may also be off limits for a while, at least. Many do eventually resume things like traveling by plane, but it’s after quite a while. Again, this is due to the risk of infection from so many in close proximity sharing germs. When they do travel, most wear a mask.

Mask wearing becomes common place. It's not just during something like COVID. It becomes a more frequent occurrence. Especially in settings with a lot of people. I do know many who didn't wear masks once they were years post-transplant. I think this is due to lower immunosuppression and good stability at this point.

Early on post-transplant, visitors are discouraged. Those who are post-transplant are at their highest level of immunosuppression at this point and are at much more increased risk of infection.

Will I be able to predict how my lung transplant process will go?

Just as the progression of pulmonary fibrosis is impossible to predict, the post-transplant process is also impossible to predict.

Someone who is sick with PF but otherwise, young, healthy and strong - with a positive great attitude - might have a really rough time of it, not live very long, or maybe not even make it out of the operating room. Whereas someone who has both PF and other comorbidities, isn't in the best physical shape, may be much older - and has a somewhat negative attitude - might do great, get out of the hospital quickly, not have many problems at all, and live a very long time.

Then there is the person who does great, heals quickly, lives for years, has a sudden rejection problem and passes away suddenly. Or the person who does poorly, has a lot of ongoing problems, is constantly in and out of the clinic or hospital, and lives for many years.

There are also those who struggle with skin cancer from all the medications and have to have cancerous skin lesions removed or deal with kidney disease or may even need a kidney transplant because their kidneys failed. Or the person who has chronic rejection and has a 2nd lung transplant. That 2nd transplant may go poorly or it may go well.

The outcome - both short term and long term - is completely unpredictable.

What if I change my mind after I've been listed for lung transplant?

At least in the United States, you can always say "NO", but you can't always say "YES – I want a transplant." Other countries around the world may do things differently.

What I tell everyone – or rather "suggest" to everyone – is that they go through the discussions with the healthcare team, get the transplant evaluation done (as soon as possible), get listed and then… make that final decision when they get the phone call that donor lungs are available.

Why do I tell them this?

I have known too many over the years who said early on "*I don't want to have a lung transplant*." Then, when their PF progressed to a critical point, especially those who progressed faster than they had "planned," they changed their mind and wanted to undergo evaluation and get listed. There are so many problems with this.

It takes time to get evaluated. It can take days or weeks, or even months. Sometimes the patient needs a surgical procedure prior to being listed in order to qualify. For example: They might have serious GERD (acid reflux) and may need a Nissan Fundoplication to correct a physiological problem in the digestive tract. It takes time to have this done and to fully heal.

They may progress to the point where they pass away during evaluation.

Or they may just be too sick to evaluate. There is such a thing as "too well to transplant" and "too sick to transplant." And that line between the two is very thin. If a patient crosses that line, they may not even be eligible for evaluation.

They may have other comorbidities or be at an age limit that their local transplant facility disallows. Whereas had they started this process earlier, they may have found a facility somewhere else that would take them as a transplant candidate even with their comorbidities and advancing age. Each transplant facility in the United States has their own rules. Some do higher risk transplants than others. Some transplant patients much older than others. Some have no limit on age at all. They focus on the patient's overall physical health and fitness.

Many people relocate temporarily to get to a transplant facility that will take them.

Remember… when it comes to PF, even someone early in the disease progression who is very stable and not yet needing oxygen can have an exacerbation (with or without a cause) and progress rapidly in a very short period of time.

I have personally known those who had this experience but said no early on and then changed their mind. Sadly, it was too late for them.

This is why I suggest people not make that final decision right away. I suggest they keep their options open.

Is the lung transplant decision a group decision between the patient and loved ones?

The short answer is NO. This is a decision that ONLY the patient can make.

This is not a decision to be made by their loved ones because the PATIENT is the one that has to go through all of this.

We, as loved ones, can only be there to help them along this journey. To do whatever we can to make it easier for them. But the patient is the one that physically and emotionally goes through this. So it is their decision and theirs alone.

That is not to be said that this process should not be discussed with loved ones. It should. The primary caregiver/s and those close to the patient, should know what this entails. The primary caregiver/s especially need to know what THEY are signing up for by agreeing to be the primary caregiver/s. But in the end, this is not their decision to make.

I don't want to discount the caregiver/s and other loved ones here.

Caregiver/s and loved ones also go through this process both physically and emotionally. Being a caregiver is a very physical and emotional thing. But not nearly as much as being that person who has to undergo yet another test or procedure, take yet one more medication when they are already taking 60 pills a day, or give up the foods or activities they enjoy doing.

We caregivers and loved ones don't live with the pain, the scars on our body, and everything that goes with undergoing a lung transplant.

We caregivers and loved ones also don't live with "survivor guilt."

We don't live knowing that someone else gave us life. That we are now breathing from the lung/s of someone's loved one: their parent or sibling, their grandparent or aunt or uncle, or heaven forbid - their child. I have heard from a few over the years who are post-transplant that knowing this can be pretty complicated to rationalize in their head. Some seek therapy in working through these emotions as well as the life they have had to put behind them for the new life they now have.

The transplant process is a very personal journey. We as their caregiver/s and loved ones need to be as supportive as we can.

Are there regrets?

What I can tell you is this... I have known a LOT of people over the years who have undergone lung transplant. Not one of them has said to me they regret it. Even the ones who had a lot of difficulty and didn't survive very long after transplant. I have also not yet heard from a caregiver that they regretted their loved one’s transplant.

Transplant is not a cure.

Transplant is not a guarantee.

Transplant is HOPE for more TIME.

Transplant is something that gives someone TIME with their loved ones. TIME to spend watching their kids or grandkids grow up. TIME to walk their daughter down the aisle at her wedding or dance with their son at his wedding. TIME to meet their grandkids. TIME to just be with the people they care about. Many have also taken the TIME to travel and have new life experiences. Travelling to places they have wanted to see but have never been. Some have gone sky diving, climbed mountains, etc.

TIME is precious and once it's gone, we can't get it back.

Most people want as much as they can get. Transplant for them is a true GIFT OF LIFE.

A GIFT OF TIME.

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Breathe Support Network
Advocating to provide support for pulmonary fibrosis patients & families

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