
LUNG TRANSPLANT

Patient Education

 TEMPLE HEALTH

TRANSPLANT PATIENT AND FAMILY EDUCATION

The purpose of this informational session is to educate you about the transplant process including:

- Team members
- Evaluation
- Waiting for the transplant
- Transplant surgery, hospitalization and discharge



TEMPLE UNIVERSITY HOSPITAL TRANSPLANT TEAM

TEMPLE TRANSPLANT TEAM

The transplant team is a multidisciplinary team that cares for you from evaluation for transplant, the transplant surgery and many years thereafter.

THE TEMPLE TRANSPLANT TEAM INCLUDES:

- Transplant Medical Doctors
- Transplant Surgeons
- Transplant Nurse Coordinators
- Nurse Practitioners
- Social Workers
- Pharmacists
- Dietitians
- Financial Coordinators
- Support Coordinators

TRANSPLANT EVALUATION

**WOULD YOU BENEFIT FROM
A TRANSPLANT?**

TRANSPLANT EVALUATION

WHAT DOES A TRANSPLANT EVALUATION INVOLVE?

- Many tests and appointments with doctors, nurses, the social worker and dietitian.
- Patient awareness summary -document reviews the important elements of the entire transplant process. Refer to this as you go through your evaluation.
- This is the time for you to ask questions, read about transplant and decide if this is something you want to undertake if you are approved by the team.

IS TRANSPLANT THE APPROPRIATE TREATMENT FOR YOUR DISEASE?

SUITABILITY OR APPROPRIATENESS FOR TRANSPLANT

- Determined by diagnosis and how sick you are
- Is your lung disease end-stage, meaning there is no other medical or surgical treatment except transplant
- Life expectancy without transplant is less than 50% survival over the next 2 years
- Completing the evaluation not a guarantee that you will be placed on the waitlist

IS TRANSPLANT THE APPROPRIATE TREATMENT FOR YOUR DISEASE?

OTHER QUALIFICATIONS

- Must be strong physically and mentally to undergo surgery
- Must have no other serious medical conditions – no cancer
- Must be committed to being responsible to care for this scarce resource
- Able to follow strict medical schedule
- Must have a stable and adequate support system
- Adequate insurance for transplant surgery and post transplant care
- Must have prescription coverage

TRANSPLANT EVALUATION

TRANSPLANT SURGEON: REVIEWS YOUR EXPECTED SURGICAL PROCEDURE INCLUDING:

- Risks associated with surgery and general anesthesia
- Risks related to blood products
- Donor risk factors
- Risk of organ rejection requiring additional therapy such as
 - ECMO
 - Dialysis
 - Prolong ventilator support
- Additional surgeries
- Expected hospital recovery

TRANSPLANT EVALUATION

- TRANSPLANT PULMONOLOGIST REVIEWS:
- YOUR TEST RESULTS
- YOUR DIAGNOSIS FOR LISTING
- MEDICAL RISKS RELATED TO TRANSPLANT THAT MAY INCLUDE:
 - Wound infection
 - Pneumonia
 - Blood clot formation
 - Afib
 - Post transplant diabetes
 - Organ rejection, failure or re-transplant
 - Need for lifetime anti-rejection medications
 - Other medical risks

TRANSPLANT EVALUATION

- Other information about transplant

THERE ARE POTENTIAL PSYCHOSOCIAL RISKS:

- Depression
- Post traumatic stress disorder (PTSD)
- Generalized anxiety, anxiety regarding dependence on others
- Feelings of guilt

TRANSPLANT EVALUATION DECISION

- The results of your evaluation will be reviewed and discussed by the multidisciplinary team
- You will be notified of one of the following decisions:
 - Approved for transplant
 - Not a candidate (and why)
 - Deferred until a requirement(s) is completed or met
 - You will receive a decision letter and a phone call

LISTED FOR TRANSPLANT

- **Your name and test results are added to the national list**

United Network for Organ Sharing or UNOS administers the only Organ Procurement and Transplant Network (OPTN) in the US

- **Your UNOS identifier is your social security number**
- **In lung transplant there are two categories**
 - **Active** – ready to accept an organ
 - Inactive – not accepting organ

HOW ORGANS ARE ALLOCATED (ASSIGNED)

- In general organs are allocated based on
- Your blood type
- Your height compared to the donor's height
- Your lung allocation score (LAS)
- The LAS number generated is not your place on the list

LUNG ALLOCATION SCORE (LAS)

LAS is used to determine your urgency on the list

- LAS is derived from your test results
- Donor lungs are allocated according to the patient's immediacy of need
- A patient with a high LAS is a sicker patient (0 – 100)

Maintaining your LAS

- Listed patients are seen in the office every 6-10 weeks
- Your score will be adjusted based on your test results
- **Please complete required testing timely**

WHILE YOU WAIT

If you are sick or hospitalized at another hospital, call the transplant office

Educate yourself about transplant

- Attend transplant education series
- Use approved websites to prepare for how to manage after transplant

Insurance: If you expect a change in your insurance, call the financial coordinator to discuss the change

PARTNERING WITH YOUR TEAM WHILE YOU WAIT

- Of course do not smoke; no THC products
- Abstain from alcohol
- Continue to keep your appointments with your PCP
 - Keep your health maintenance testing updated, this is your responsibility
- Continue to keep your appointments with local pulmonologist
 - Keep us informed if your pulmonologist adds an antibiotic or steroids

WAITING IS FOR PLANNING

Here are some strategies to help with the wait

- Remain engaged with your family and friends
- Maintain your hobbies or find a new one
- Review the sample medication list with your insurance company
- Plan for your hospitalization
 - Who will care for the children, elders or pets
 - Is your POA up to date
 - Make plans to pay bills
- Plan for how you are going to pay for co pays
 - **FUNDRAISE**

THE CALL

- **The on-call transplant nurse coordinator (TNC) will call you**
- **Remain close to your phone**
 - Keep cell phones charged
 - Ringers on
- **Answer blocked calls**
 - We may call you from a blocked phone number
- The TNC needs to talk to you directly, you have decisions to make
- **You will be given instructions**
 - Not to eat or drink (okay to use inhalers)
 - What entrance to use

YOU NEED TO COME TO THE HOSPITAL IMMEDIATELY

THE CALL

- You need to arrive at the hospital as soon as possible
 - If greater than four to five hours discuss your travel time with the TNC and SW during the evaluation
- Be prepared
 - You can be called on the same day that you are listed or months later
 - Family members should pack comfort items for the long wait in the ICU waiting room – travel pillow, blanket, snacks, water or sodas
- You most likely will be in the OR waiting for word from the donor hospital that it is a go
- Understand waiting times for you and your family will be long

DONOR INFORMATION

- **The surgeon selects the best organ for you**
- **Donor demographic information will not be shared with you**
 - The donor's privacy is protected
 - Honoring the donor's privacy is a way to demonstrate respect for the gift of organ donation
- **You have a right to refuse the specific donor or the transplant at any time**

HIGH RISK DONOR

- A high risk donor – is someone with behaviors that increase the risk of disease transmission i.e.
 - History of IV drug use
 - History of incarceration
- If the donor is in the high risk category, the TNC will discuss with you and ask if you will accept the organ
- High risk donor organs are equal quality or better than non high risk donor organs
- We have been using high risk donors for many years
- If you accept this type of donor, you will be tested at regular intervals during the first year for HIV and hepatitis

HIGH RISK DONOR FACTS 1:10,000 RISK

- You have a better chance of :
- Being killed by a lightning strike that hit someone else first
- A newly built dam having a total collapse
- Dying from a tree falling on you
- Being in a flood
- Being in a landslide
- Being killed by a grizzly bear
- Being killed by an airplane crashing into you
- Dying from arsenic from planting the garden

PREPARATION FOR TRANSPLANT SURGERY

- You will be prepared for the surgery:
 - Blood work , Chest X ray , EKG
- The transplant surgeon and anesthesia physician will obtain consent
- The nursing staff will provide information to your family about waiting rooms, cafeteria etc.
- The primary focus of the surgical team is you. While the wait may seem very long for your family, communication from the OR to the family maybe sparse.
- Back up cases
- False alarms

MEDICAL TEAM AND FAMILY COMMUNICATION

- We ask that you pick one person as the family spokesperson who will interact with the doctors and nurses about your condition while in the ICU
- The team will automatically select the legal next of kin unless you indicate differently
- Once you are out of the ICU and feeling better, our primary communication will be with you – not your family

AFTER TRANSPLANT

- **Transplant ICU**
 - Ventilator
 - Chest tubes
 - Frequent blood test
 - Frequent vital signs
 - Start immunosuppression medications
- **Transplant Unit**
 - Increasing activities
 - Advancing diet
 - Adjusting the immunosuppression medications

AFTER THE TRANSPLANT

WHEN ARE YOU READY FOR DISCHARGE?

- There is no sign of rejection
- There is no sign of infection
- Walking short distances

DO NOT BEGIN HOME RENOVATIONS!

TRANSPLANT DISCHARGE

DISCHARGE

- Goal is to get you home safely
- You are evaluated everyday for readiness for discharge
- Your support person will need to come in the day of discharge to learn how to help you
 - You may only receive notification of discharge the day prior
- Medications are reviewed and precautions reinforced the day of discharge
- Make a plan in advance for paying for the discharge medications

OUTPATIENT TRANSPLANT

- Education continues with each office visit
- There will be many visits and frequent blood work during the first months after transplant
- You may have lung biopsies, this is an outpatient procedure
- Start preparing to return to you local pulmonologist and PCP
 - Make appointment to be seen by 3 months after discharge

TRANSPLANT OFFICE

- Monday thru Friday
- Business hours 8:00 – 5:00
- Phone number is 215-707-1722
- Fax number – 215-707-4327

PLEASE HANDLE THINGS DURING OFFICE HOURS

- Prescription refills
- Rescheduling appointments
- Questions
- Oxygen equipment
- **We can't handle emergencies on the phone, go to the ER and have them call us**

TRANSPLANT OFFICE

About medications

- Manage your medication refills, do not wait until you have only a week of medication or no medication
- Ask for refills in your office visit
- Many medications require prior authorization, please give us 7 – 10 business days to obtain authorization for refill prescriptions

OFF HOUR CALLS

ON CALL TRANSPLANT NURSE COORDINATOR

- Works with the surgeon to bring patients in for transplant surgery
- Handles illness that arise after business hours
- Examples of transplant issues
 - Fever
 - Shortness of breath
 - GI symptoms

Please do not call the on call nurse for routine questions

TEMPLE LUNG TRANSPLANT PROGRAM

- The Lung Transplant program is a Medicare approved transplant program
- You will be notified if there is a change to this status
- Please note that future health problems related to the transplantation may not be covered by your insurance carrier and you will need to explore alternative financial resources

SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS (SRTR)

- A national database of statistics related to organ transplantation
- Provides data on transplant activity, such as patient survival rates, average time to transplant and many other things
- Reports for all transplant programs are available on the SRTR website.
- ([Http://www.Ustransplant.Org](http://www.Ustransplant.Org))
- The transplant nurse coordinator will review the current SRTR report with you.
- Reports are updated every 6 months
- If you are listed at the time of an update we will provide you with the new report

SRTR REPORT EXAMPLE

What is the SRTR?

The Scientific Registry of Transplant Recipients (SRTR) is a national database of statistics related to solid organ (kidney, liver, pancreas, intestine, heart, and lung) transplantation. The database gathers information on transplant activity, such as patient survival rates to average time on waiting lists.

You may use SRTR to find:

- Reliable transplant information for patients, families and medical professionals
- A complete list of U.S. hospitals with transplant centers
- Waiting time and organ availability
- Patient survival statistics
- Graft survival statistics

Post Transplant Outcomes (Date of Reporting Period) Temple Organ Transplanted Transplant Survival at 1 year

DATA PUBLISHED

	OBSERVED	EXPECTED	NATIONAL
Adult graft survival (based on number of transplants) (%)	xx%	xx%	xx%
Adult patient survival (based on number of transplants)	xx%	xx%	xx%

For complete SRTR data on Temple University Hospital with table discussions,
please visit the SRTR data website (www.srtr.org).

THANK YOUR DONOR

- Donor identification is kept confidential
- Please send a thank you card through our office to the donor
- Honor your donor by being the **BEST TRANSPLANT PATIENT**
 - Follow all directions
 - Take your medications
 - Exercise, rebuild your strength
 - Encourage others to be organ donors

T TEMPLE HEALTH