



**THE
EARTH**

Transplant Education Book



**Texas Children's
Hospital®**

Disclaimer

The purpose of this education book is to give guidelines for pre- and post-transplant care at Texas Children's Hospital. It does not provide specific medical advice and does not replace medical consultation with a qualified health or medical professional.

Our education book is updated frequently, but with the rapidly changing healthcare system, this information could be out of date and/or contain inaccuracies or typographical errors. Please consult with the transplant team for questions.

Acknowledgments

Transplant Services would like to thank everyone who contributed their time to the development of this patient and family education notebook, both past and present.

In addition to the core team who completed the extensive revisions, this book was made possible by an endowment from the John L. Hern (JLH) Foundation. The mission of the JLH Foundation is to support the financial needs of transplant patients and their families, to promote the need for organ donation and offer support to transplant programs. It is the hope of the transplant team at Texas Children's Hospital that the information outlined in this book will help you make the best possible decision for your entire family.

Welcome from Texas Children's Hospital!

Welcome from Transplant Services at Texas Children's Hospital! You are an essential part of the care team, and we have designed this education book to guide you throughout the transplant process. This book is a resource to assist you, but it will not answer all your questions. You will continue to learn from all the members of the care team throughout the transplant process. Please remember, the medical opinions, techniques, and procedures discussed throughout this book are general statements and recommendations that may vary for each patient. If you have specific questions or concerns related to diagnosis and/or treatment, please speak directly with one of our physicians or transplant coordinators.

Please carry this book to your appointments and bring it to the hospital at the time of your transplant.

This book is yours to keep and to refer to at any time. Please write notes in it as you read and learn.

The decision to move forward with transplantation can be difficult. Even though transplant is not a cure, it can give recipients a chance for a near normal life with lifelong medical care. This includes a lifelong need for medication and regular medical follow-up. Choosing transplant requires a long-term commitment from both the patient and family. Transplant recipients require life-long follow-up care by a transplant team and will take medications for the rest of their lives. We recognize that there will be numerous demands placed on your family before and after transplant. All of these new responsibilities can be overwhelming and take an emotional toll on every member of the family. The transplant team at Texas Children's is committed to working closely with your family in the face of those demands. We want you to feel comfortable with our team as we move forward with the process of transplantation. You are not alone in this process. We are a team!

The gift of a new organ gives our patients a second chance at life and hope for a better quality of life. We look forward to moving through this journey with your family. Our goal is to make the pre-transplant evaluation and transplantation process a positive experience for your family. We have high standards of care for our patients and families. If there is anything additional that we can do to make this a positive experience, please let us know.

Sincerely,

The Texas Children's Hospital Transplant Team

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Team Contact Information

TRANSPLANT COORDINATOR OFFICE PHONE NUMBERS:

Clinical Coordinator/Scheduling _____	832-826-6349
Referral Specialist _____	1-866-683-8032
Transplant Coordinator _____	832-826-5912
Transplant Coordinator _____	832-826-5920
Transplant Coordinator _____	832-826-5707
Transplant Coordinator _____	832-826-1787
Fax Number _____	832-825-2220

MONDAY-FRIDAY, 8:00AM-4:30PM:

Non-urgent Issues: Contact your transplant coordinator by phone or email.

Urgent Issues: Call **832-824-2099** and request to have your *transplant coordinator* paged (Toll-free number is 1-800-364-5437). Calls should be returned within 30 minutes. If you do not receive a return call, please try again as technical difficulties do sometimes occur.

AFTER HOURS, WEEKENDS, OR HOLIDAYS:

Urgent Issues: Call **832-824-2099** and request to have the *transplant physician* on call paged (Toll-free number is 1-800-364-5437). Calls should be returned within 30 minutes. If you do not receive a return call, please try again as technical difficulties do sometimes occur.

For a true medical emergency, such as difficulty breathing or change in responsiveness, please call 911.

OTHER MULTI-DISCIPLINARY TEAM MEMBER PHONE NUMBERS:

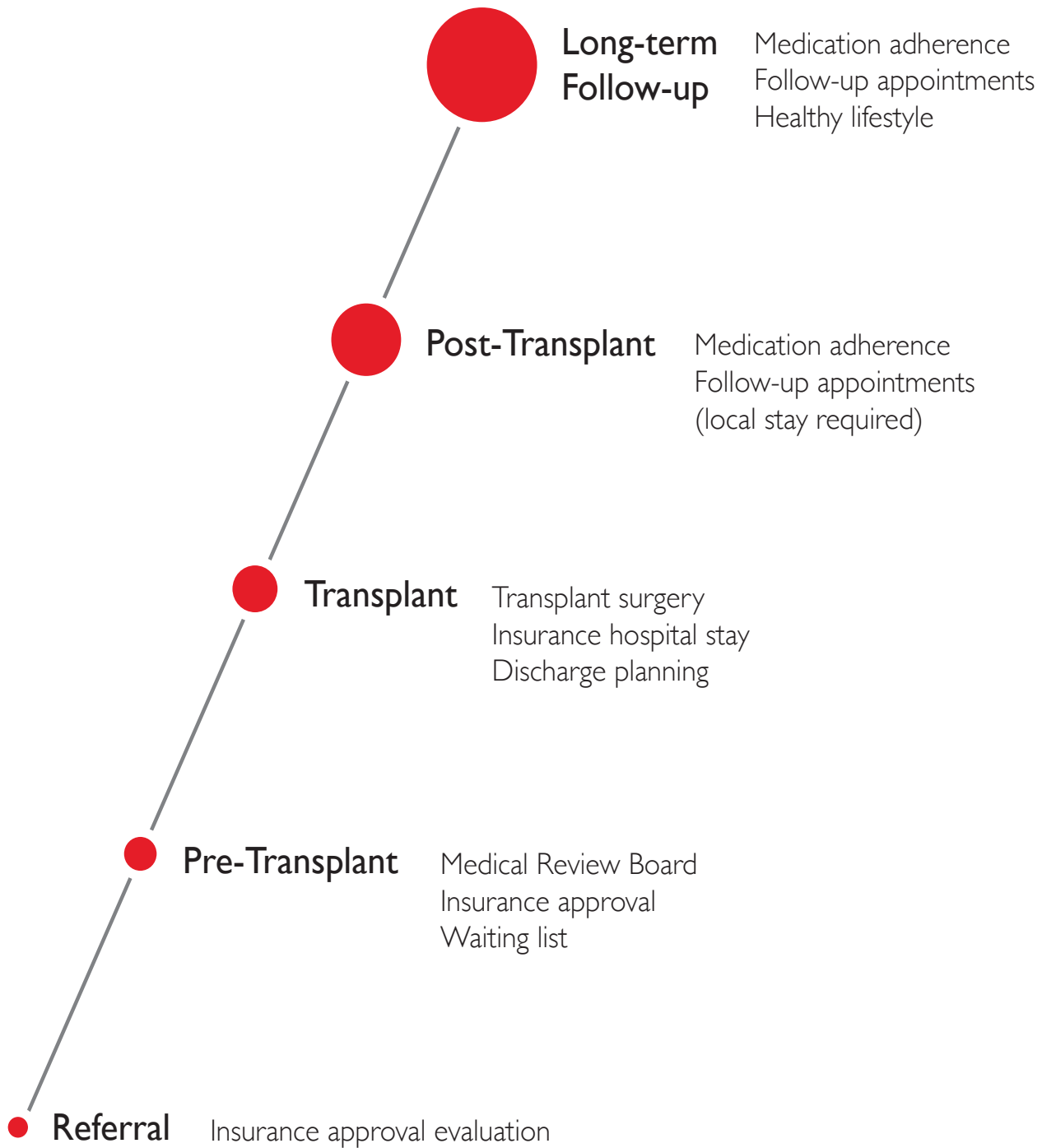
Social Worker _____	832-824-2932
Child Life Specialist _____	832-826-1651
Dietitian _____	832-824-5087
Financial Counselor _____	832-822-5529
Transplant Pharmacist _____	832-824-6553

OTHER IMPORTANT PHONE NUMBERS:

Cardiology Clinic – 20th Floor	832-826-2060
Cardiovascular ICU – 18th Floor	832-826-1860
Family Waiting Room – 17th Floor	832-826-1750
Heart Failure/Transplant Intensive Care Unit (ICU) – 15th Floor	832-826-1550
Cardiac Stepdown/Telemetry – 15th Floor	832-826-1570
Page Operator (to page a team member for urgent issues)	832-824-2099
Toll Free Number to reach a TCH Operator	1-800-364-5437

Chaplain Services are available for inpatients. Please ask your bedside nurse to page them if needed.

Overview of the Transplant Process





Section 1

Heart

The Heart

The heart is one of our most important organs. It is located in the center of your chest, behind your breastbone.

How the Heart Works

The heart is a muscle that pumps blood all through the body.

The heart has 4 chambers:

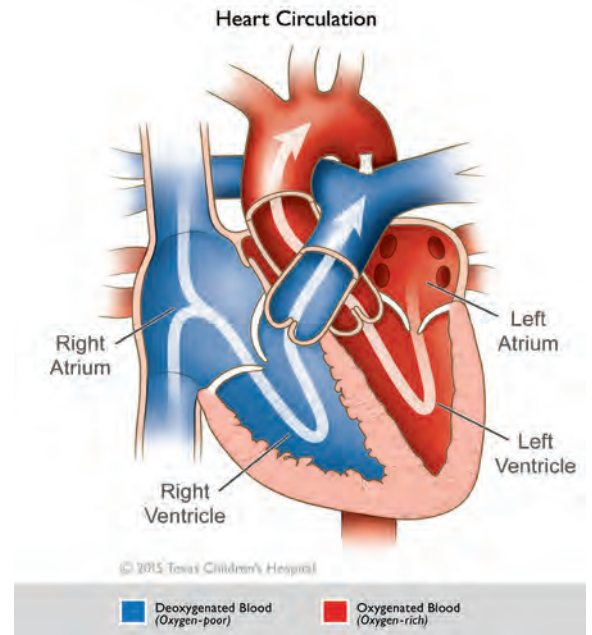
- Right Atrium: Deoxygenated blood enters the heart through the right atrium, then into the right ventricle.
- Right Ventricle: The right ventricle pumps blood to the lungs to absorb oxygen.
- Left Atrium: Oxygenated blood flows from the lungs into the left atrium where it is pumped to the left ventricle.
- Left Ventricle: The left ventricle pumps the oxygenated blood to the whole body.

Reasons a Transplant May Be Needed

A heart transplant may be needed if heart failure cannot be improved by medical therapy or surgery.

Common Reasons for Heart Transplantation

- Congenital Heart Defects
- Cardiomyopathy (Restrictive, Hypertrophic, Dilated, Left Ventricular Noncompaction)
- Lethal Arrhythmias
- Transplant Coronary Artery Disease (TCAD)





Section 2

Before Transplant (Pre-Transplant)

Why Could a Transplant Be Necessary?

If a medical condition has caused one or more vital organs to fail, transplantation may be an option. A transplant is surgery where an organ that is failing (or has stopped working) is replaced by a healthy donor organ.

What Are the Steps in the Transplant Evaluation Process?

1. When a transplant may be needed, a referral request is sent to our transplant center by a patient family or physician.
2. After your family's insurance approves the evaluation, a member of the transplant team will make contact to schedule the evaluation.
3. An evaluation of the patient will be completed at Texas Children's Hospital.
 - Can be completed inpatient or outpatient.
4. Information from the evaluation will be presented to the transplant center's medical review board where transplant candidacy will be determined.



What Happens During a Transplant Evaluation?

MEET THE TEAM

During the transplant evaluation you will meet the members of the transplant team. The following is a list of people you are likely to meet during the evaluation and their role in the transplant process:

Transplant Physician: Provides medical management of the disease including consideration for transplantation. The transplant physician may have a team member called an Advanced Practice Provider (APP) who is a Nurse Practitioner (NP) or Physician Assistant (PA) who may help with the transplant care. The transplant physician or APP will:

- Discuss treatment options and risks/benefits of transplantation
- Review lab work
- Prescribe medications
- Lead the transplant team
- Review the surgical process
- Answer your questions related to transplantation and the transplant surgery

Transplant Surgeon: Performs the actual transplant surgery and leads the surgical management both pre- and post-transplant. The transplant surgeon will:

- Review the surgical process
- Answer your questions related to transplantation and the transplant surgery

Transplant Infectious Disease (ID) Physician: Reviews medical history and performs a physical examination. The ID physician will:

- Review previous infection history.
- Review immunization records and provide recommendations.
- Provide education on preventing infections.
- Provide guidance on travel safety precautions.
- Develop an antimicrobial medication plan (if needed).

Transplant Coordinator: Is a Registered Nurse (RN) who serves as your initial point of contact for questions related to all phases of transplantation. The transplant coordinator will:

- Coordinate the evaluation
- Educate you and your family about all aspects of transplant care
- Provide support throughout pre- and post-transplant

Transplant Pharmacist: Collaborates with the transplant team in the selection and administration of medication therapy. The pharmacist will review medications with you pre- and post-transplant.

Transplant Dietitian: Performs a complete nutritional assessment of the transplant candidate and works with the physician to develop an appropriate nutritional program pre- and post-transplant.

Transplant Social Worker: Reviews your social situation to ensure there is a good support system for needs pre- and post-transplant. They can assist you in finding resources, programs, and other forms of support as needed.

Transplant Child Life Specialist: Helps you and your family to understand medical procedures pre- and post-transplant using age-appropriate tools and resources.

Transplant Financial Counselor: Verifies your insurance (or other source of payment) includes coverage for a transplant and to assist you and your family in making a plan to cover costs both pre- and post-transplant. The financial counselor will:

- Provide an ongoing review of your insurance benefits.
- Answer financial questions related to insurance coverage or transplant benefits.
- Work with you and the social worker to locate additional resources as necessary.



MEDICAL TESTS AND PROCEDURES

The transplant evaluation helps to determine the most appropriate treatment option. The transplant office will schedule the evaluation and will contact you with the date and time for each test, procedure, and appointment. Tests that may be included in the evaluation for transplant are listed below. Your team will advise you if additional tests may be needed.

Name of Test	Explanation of Test
24-hour Holter monitor	Records heart rhythm for 24 hours
Blood tests	Measures the current level of organ function; Identifies blood and tissue types; Screens for other diseases, such as hepatitis, HIV, and some infections
Cardiac catheterization ("cath")	Checks blood flow and pressures in the chambers of the heart
Echocardiogram ("echo")	Evaluates the size and function of the heart
EKG	Checks the heart rhythm and heart rate
Physical exam	Process by which a medical professional investigates the body of a patient for signs of disease
Stress test	Checks the body's response to activity and activity tolerance on a treadmill
Stool sample	Checks for infection or other common problems
Ultrasound	Measures the size and shape of the organs and evaluate the blood vessels using soundwaves
Urine tests	Tests urine by urinalysis, urine culture and/or a 24-hour urine collection
X-ray	A picture of bones or other parts inside the body

COMPLIANCE AGREEMENT

A compliance agreement will be discussed with you and your family during the evaluation to ensure that you understand the transplant team's expectations. Good medical adherence and good communication with your transplant team are an important part of the transplant's success. For this reason, you and/or your family will be asked to sign a compliance agreement which outlines your responsibilities pre- and post-transplant. Please carefully review this agreement to ensure you understand all of the requirements. The compliance agreement signed during the transplant evaluation covers all phases of the transplant.

Transplant recipients directly contribute to the success of their transplant. Failure to comply with the medical regimen is the number one cause of organ failure. Close follow-up with your transplant team and primary-care physician can improve the chances of a good outcome. Careful attention to medication schedules, lifestyle changes, infection-avoidance techniques are all important ways to prolong one's life after transplantation.

What Happens After the Evaluation?

MEDICAL REVIEW BOARD

When the evaluation process is completed, a committee, called the Medical Review Board (MRB), will discuss the information obtained during evaluation. The MRB will determine eligibility for transplant. The MRB consists of team members that you met during the transplant evaluation and other health professionals involved in transplant. There are three possible outcomes:

1. **Accepted/Approved:** the candidate's name will be placed on the United Network for Organ Sharing (UNOS) waitlist for transplant.
2. **Denied:** the candidate will not be placed on the UNOS waitlist for transplant.
3. **Tabled/Deferred:** the committee is unable to make a determination to place the candidate on the UNOS waitlist for transplant at this time.

PLACEMENT ON THE TRANSPLANT WAITING LIST

If approved at MRB, the transplant candidate will be listed on the national transplant waiting list when insurance approval is obtained for listing. The timeframe for insurance approval may vary depending on your type of insurance.

NOT PLACED ON THE TRANSPLANT WAITING LIST

These are common scenarios:

- **Tabled:** More tests or procedures are needed before being represented to the MRB. The transplant candidate will not be listed at the present time because he or she does not meet the listing criteria as determined by the MRB.
- **Denied:** The transplant candidate will not be placed on the UNOS transplant waitlist.
 - If the transplant candidate is denied for transplantation, you will be notified why he or she does not meet criteria. If denied, the transplant candidate may be followed by your primary team or may continue to be followed by the transplant team. At a later date, he or she may be referred back to the Medical Review Board to be considered for transplant again.
 - Occasionally, children cannot be accepted for transplant due to other medical problems. Examples of these problems include children deemed too sick for transplant, those with a recent history of cancer, certain blood disorders, etc.

YOUR FAMILY'S PART IN THE DECISION

The decision to move forward with transplantation can be difficult. Even though transplant is not a cure, it can give recipients a chance for a near normal life with lifelong medical care. This includes a lifelong need for medication and regular medical follow-up. Choosing transplant requires a long-term commitment from transplant candidates and their families. Recipients will require life-long follow up care by a transplant team and will have to take medications for the rest of their lives. There are numerous demands placed on transplant families before and after transplant. While transplant centers approve or deny a candidate for listing, families also have a decision to make. If a candidate is approved, the family will need to decide if transplant is the best option for them.



What is the Organ Donation Process?

For more information, visit: www.unos.org

UNITED NETWORK FOR ORGAN SHARING (UNOS)

The nation's organ procurement and transplantation network (OPTN) managed by UNOS – a private, non-profit organization. It oversees the different parts of the transplant system. This includes all of the Organ Procurement Organizations (OPOs), transplant hospitals, and histocompatibility labs in the United States.

ORGAN PROCUREMENT ORGANIZATION (OPO) / LIFE GIFT

OPOs coordinate the donation process when a donor is available. Each OPO has a specific area. The OPOs also work to increase the number of registered donors. LifeGift is the local agency responsible for organ donation in this area. We receive organ offers through LifeGift and other OPOs through the national computer system.



PROCESS FOR THE DONATION AND ORGAN DISTRIBUTION

1. **OPO Screens the Donor:** Once a donor family decides to donate the organs of their loved one, the OPO begins the process of evaluating the donor. The OPO reviews:
 - Medical history of the donor
 - Donor blood tests to evaluate organ function and the presence of disease
 - Blood type, tissue type, organ size and condition
2. **OPO Contacts UNOS:** The OPO managing the donor sends this information to UNOS.
3. **UNOS Ranks Recipients:** UNOS generates a list of potential recipients that match the donor. Depending on the organ type, the UNOS computer system ranks transplant candidates by some or all of these factors:
 - Clinical information (age, blood, and tissue type)
 - Waiting time
 - Severity of illness
 - Geographic distance between donor and recipient
 - Size of the donor organ in relation to the recipient
4. **OPO Contacts Transplant Centers:** Organ placement specialists at the OPO or the UNOS Organ Center contact the transplant centers whose patients appear on the local list.
5. **Transplant Center Reviews the Organ Offer:** The results of the donor evaluation are reviewed, and the suitability of this donor for the recipient is determined by a transplant physician and surgeon. To protect the privacy of the donor family, you will be given minimal information about the donor. By policy, the transplant center only has 1 hour to respond.

Note: The candidate may be offered an organ from a donor who meets the Center for Disease Control's (CDC) high-risk donor criteria. The transplant team will notify you if the organ offered is classified as CDC high-risk and explain risks/benefits of accepting the organ. A special consent accepting the high-risk donor organ will need to be signed by prior to transplant.
6. **Transplant Center Accepts or Denies the Organ:** If the organ is not accepted, the OPO continues to offer it for patients at other centers until it is placed.
7. **Transplant Center Contacts Recipient if the Organ is Accepted.**



What Should You Do While Waiting for a Transplant?

YOUR RESPONSIBILITIES WHILE WAITING FOR A TRANSPLANT

You and your family are important members of the transplant team. The transplant team depends on your family to assist in giving you the best health care possible. The transplant coordinator must know about changes in the transplant candidate's medical condition. It is your responsibility to call the transplant team. Specific responsibilities are as follows:

Importance of Communication

Communication with the transplant team is very important pre- and post-transplant.

Contact the transplant team immediately:

- If your health insurance changes.
 - Not telling us promptly can delay evaluation, transplantation, or cause the transplant procedure not to be covered (paid for) by insurance.
- If your address or phone numbers change. This includes:
 - Home phone
 - Work phone
 - Cell phone
 - Other family member's phone
- **If on the transplant waitlist**, you must notify your transplant coordinator **immediately** of any change in contact numbers to **avoid missing an organ offer**.
- **Do not rely** on the registration staff to make the changes to your transplant records. **Contact your transplant coordinator directly with any information changes.**
- Make sure you can call us at any time by always:
 - Keeping the transplant center's number with you
 - Having access to a phone
 - Making sure your phone can accept calls from an unknown or blocked phone number (TCH calls may show up unknown)
- If you are leaving town, notify your coordinator (BEFORE you leave) of any plans to leave town while the patient is listed, so necessary arrangements may be made in advance. This also holds true after transplant, as we may need to contact you with lab values and medication changes.
- Changes in medical condition, especially if a hospitalization occurs.
- Changes to medications, including over the counter medications, should be discussed with your transplant coordinator; **prior** to making the change (even if ordered by another physician).

Transportation

You can receive the call for transplant at any time – day or night! You must be able to arrive to the hospital within the timeframe indicated by the transplant coordinator. If a problem with transportation arises at any time while on the transplant waiting list, please contact your transplant coordinator immediately.

Financial Information and Insurance	Each transplant candidate's financial and insurance situation is different based on his or her insurance plan. Please review your insurance plan/co-pay information to ensure medication coverage after transplant. Transplant expenses will last a lifetime and can be expensive. It is the understanding that you will keep insurance and pay for medications. Immediately notify the transplant team of any insurance changes, as this could effect waitlist status.
Compliance	The transplant team will work with you to create a plan for any health needs. It is extremely important for you to follow this plan of care. If you cannot follow the instructions for any reason, you MUST notify the transplant team immediately. A compliance agreement will be discussed with you prior to listing or during any phase of the transplant process if compliance becomes a concern.
Follow-Up	The transplant team will determine how often the transplant candidate needs to be seen in the clinic. These visits are important to assess his or her medical condition.
Emotional Well-Being	Waiting for transplant can be stressful for you and your family. The transplant team believes in speaking honestly about transplantation and the concerns that you and your family may have. Many sources of support are available (community, on-line) to help you and your family address questions and concerns. It can be comforting and informative to talk with people in a similar situation. Some families are better suited for private counseling, especially when they must deal with very difficult or more personal issues. Please ask your social worker or child life specialist about emotional support options and how to increase coping strategies for your family throughout the transplant process.

Average Waiting Time

The waiting period is hard to predict and could take several days, weeks, months, or even years. If your family lives out-of-town, you may be expected to relocate to the Houston area. The wait time depends on his or her listing status, age, size, and blood type. During this time, the transplant team will maintain close contact with you and see the transplant candidate on a regular basis. You can look online at <http://optn.transplant.hrsa.gov/> to view the most up-to-date waitlist information.

Listing Status

There are three active waitlist status levels (1A, 1B, and 2) and one inactive level (7). Each status has specific guidelines. The listing status may change at any time depending on health status.

STATUS 1A

A child meets at least one of the following conditions:

- Needs help breathing with a ventilator and is admitted to the hospital.
- Needs support with a mechanical device such as ECMO or ventricular assist device (VAD)
- Requires support with an intra-aortic balloon pump and is admitted to the hospital.
- Has ductal dependent pulmonary or systemic circulation requiring continuous prostaglandins (PGE).
- Needs certain IV medications, known as inotropes, at a high dose or more than one and has a diagnosis of congenital heart disease.

STATUS 1B

A child meets at least one of the following conditions:

- Needs certain IV medications, known as inotropes but does not have a diagnosis of congenital heart disease.
- Is less than one year old at the time of listing and has a diagnosis of hypertrophic or restrictive cardiomyopathy.

STATUS 2

- A child needs a heart transplant, but does not meet the criteria for Status 1A or 1B.

STATUS 7 (INACTIVE)

- Temporarily inactive on the transplant list (they are too sick or too well). The patient is on the list, but will not accumulate waitlist time or receive any offers.

Reasons for Removal from the Waiting List

If the transplant candidate is removed from the waiting list for any reason other than transplant or death, the transplant center must notify your family in writing within 10 days.

Child's Health Improves: The transplant candidate may be considered "too well for transplant" if health and function improve. He or she can be placed on hold or removed from the list and referred again if health or function declines.

Child's Health Declines: The transplant candidate may be considered "too sick for transplant." Transplant shouldn't be done if he or she may not survive the surgery, due to the severity of illness. If health and function improve, he or she may be placed back on the transplant waiting list with team approval.

On Hold: For safety, the transplant candidate may be placed "on hold" for medical concerns such as recent live virus immunizations or signs of a new infection. Another reason someone may be placed "on hold" is due to an insurance lapse or non-adherence to current medical plan.



Living in Houston and/or at the Hospital While on the Waiting List

Housing

If you are not from Houston, you may have questions about where to stay in the area.

HOTELS/MOTELS:

Many local hotels and motels offer discounts to families of patients in the medical center.

Your social worker has lists available of nearby hotels/motels, the services offered, and estimated rates. You will also want to find out if cooking and laundry facilities are available.

If your family members wish to stay in the area after the transplant, they should make plans to stay in a local hotel, apartment, or guesthouse.

AT THE HOSPITAL:

If the transplant candidate is admitted to the general care unit, a family member will be allowed and encouraged to stay in the room. These rooms have a day bed.

Intensive care areas have a waiting room for a family member to sleep (see specific unit info for more detail).

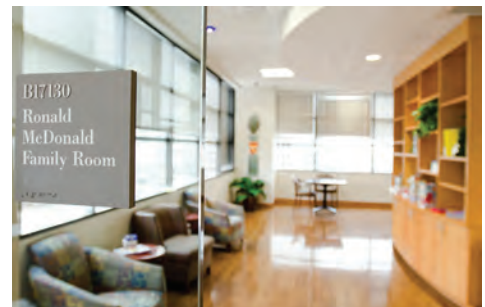
PLANNING FOR POST-TRANSPLANT:

After being released from the hospital post-transplant, your physician will request that you stay nearby for a time period so that the recipient can be closely monitored by the transplant team.

The transplant social worker is available to assist you in making arrangements for housing in the Houston area.

If your family members wish to stay

in the area after the transplant, they should make plans to stay in a local hotel, apartment, or guesthouse.



MEDICAID:

If you are on Medicaid, the social worker may be of assistance in arranging alternative housing as well.

Many area hotels and the Ronald McDonald House participate in Texas Medicaid's housing program.

Medicaid may help cover the cost if you need a hotel room while the transplant candidate is in the intensive care unit, after release from the hospital, if it is medically necessary for you to stay in the area.

Meals

IN THE HOSPITAL:

Patient meals are served at approximately 8:00am, 12:00pm, and 5:00pm.

Meals are not provided to family members.

Sandwiches may be available on request for a parent/caregiver staying at bedside. Your social worker can assist you in accessing this service if needed.

Meals for visitors can be purchased in the Bertner Café (Abercrombie), Texas Children's Hospital food court (Clinical Care Tower), or Fresh Bistro (the Pavilion for Women).

If on Medicaid, speak with your social worker regarding the meal reimbursement program.

LOCALLY:

Numerous grocery stores and restaurants are in the medical center area.

Many local hotels have cooking facilities in the rooms.

If it is approved by a transplant physician and dietitian, you may bring in food from outside the hospital (including restaurant food).

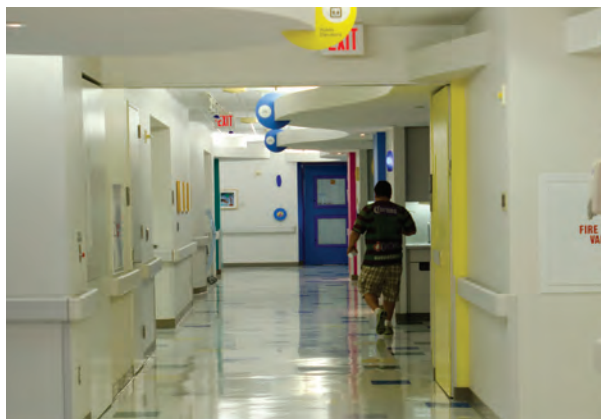
Ask your dietitian any questions you have concerning nutrition or restrictions.

Parking

Parking is available in several Texas Medical Center garages near the hospital or within walking distance. For information on lower cost parking options, please speak with your social worker. Many hotels around the medical center have shuttles available to assist you in coming to and from the hospital.

Laundry

If the transplant candidate is hospitalized, there are coin-operated washers and dryers available on the 16th floor of West Tower. Many hotels have coin-operated laundry facilities on the premises. There are also free-standing laundromats in the area. Ask your social worker if you need additional information.



Infection Control

Before transplant, it is very important to keep the transplant candidate as healthy as possible. That includes limiting exposure to people who are sick. If the candidate develops an infection or cold during the wait for a donor organ, they may be made inactive on the waiting list (will not receive organ offers during the time period they are sick).

We give high doses of immune-suppressing medications at the time of transplant that could allow even a mild infection to become deadly.

Not telling the transplant team about an illness at the time of transplant can be life-threatening.

It is extremely important that you notify the transplant center right away if the candidate develops a fever or any other symptoms of sickness like a runny nose, cough, vomiting, or diarrhea. He or she can be reactivated on the waiting list as soon as the transplant center deems that it is safe for transplant.



WAYS TO LIMIT EXPOSURE TO ILLNESS BEFORE AND AFTER TRANSPLANT

Guidelines for Home

- Do not eat or drink after other people.
- Wash hands frequently with soap and water.
- Keep hands away from your eyes, nose, and mouth unless freshly washed with soap and water (candidate and family members).
- Keep sick visitors away from your home and the transplant candidate.
- If anyone at home becomes sick, have them cover their mouth when sneezing and coughing and wash their hands frequently.
- Keep immunizations up-to-date.
- Please discuss any live virus vaccines with your transplant team, (common live virus vaccines are Varicella, MMR, nasal flu vaccine, etc.), as the candidate may need to be inactivated on the list for a short time after receiving them pre-transplant. See the *table of Allowed Immunizations in Section 5* for more details.
 - It is recommended for family members to receive their flu shot annually and stay up-to-date on their immunizations. Check with your transplant team before anyone in your household receives a live vaccine.

Guidelines for the Hospital

- Wash hands and always use hand sanitizer on the way in and out of the hospital room (candidate and family members).
- Keep hands away from your eyes, nose, and mouth unless freshly washed with soap and water (candidate and family members).
- Make sure the transplant candidate wears a mask when out of their room (if applicable).
- Keep sick visitors away from the hospital and the transplant candidate.
- Items that fall on the floor must be cleaned prior to patient use.
- Transplant candidates should wear socks or shoes when they are out of the bed.
- Personal items that are washable are preferred. The number and size of stuffed animals should be minimized.
- Potted plants and fresh flowers are not allowed in the Intensive Care Unit or Progressive Care Unit.

What Do You Need to Know About Medications After Transplant?

MEDICATION ADHERENCE

Medications are essential to the success of the transplanted organ. Without these medications, the body will reject the new organ. The body's response to the new organ is to fight it as it would fight a cold or virus. Medications are given to prevent the body from fighting (rejecting) the new organ. **The medications must be taken as directed, at the same time every day.**

We expect parents/caregivers and the transplant recipient (when age appropriate) to know the medication dose and reason it's being used. Please be sure to ask questions to better understand any information given to you. Understanding the medications enables you to recognize side effects when they occur. Do not change or stop giving medications unless told to do so by a member of the transplant team.



MEDICATION SCHEDULE

While in the hospital after transplant, a nurse will teach you how to take/give medications. You will be given a schedule for the medications before he or she is ready to go home. Practice keeping the schedule updated and make sure to bring it with you to all appointments.

TYPES OF MEDICATIONS POST-TRANSPLANT

Some of these medications can cause side effects which may require additional medications.

- **Anti-Rejection (Immunosuppressant) Medications:** Anti-rejection medications protect the transplanted organ from rejection by lowering immune response. The transplant recipient will take anti-rejection medications as long as the transplanted organ is functioning. The most commonly used anti-rejection drugs are Prograf® (tacrolimus), Cellcept® (or mycophenolate mofetil), Prednisone, and Sandimmune® (cyclosporine).
- **Medications to Prevent and Treat Infections (Anti-Viral/Anti-Fungal) Medications:** People who take anti-rejection medications will be more susceptible to infection. We use anti-viral or anti-fungal medications to help prevent some of the most common infections.
- **Blood Pressure Medications:** High blood pressure may be a side effect of Prograf®, Sandimmune®, and steroids. It will be important to monitor blood pressure frequently after transplant because there may not be any symptoms of high blood pressure.
- **Vitamins and Supplements/Other Medications:** Medications such as Prograf® can cause abnormal electrolyte levels. Blood tests can be done to check these levels. If low, supplements may be needed.

UNDERSTANDING TRANSPLANT MEDICATIONS

There are a few things you must know about the transplant medications:

- Which medications are anti-rejection medications.
- Which medications need to wait until after labs are drawn.
- What time to give the medications.
- How to give the medications.
- The generic and brand name of each medication.
- Why it is important to use the same brand of medication every month.
- Why each medication is being given.
- The main side effects of the medications.
- Why it is important to take medications as prescribed.
 - You are responsible for giving medications as prescribed.

- You must discuss any medications changes with your transplant physician.
- Use of medications prescribed by outside physicians or obtained over-the-counter must be discussed with and approved by the transplant coordinator/physician.
- No new medications (including over-the-counter medications or herbals) should be started (even if prescribed by another physician) without approval from the transplant team.
 - Do not take or use herbal supplements unless approved by your transplant team.
 - Herbal supplements can adversely interact with transplant medications.
 - Herbal remedies include herbal drugs, herbal teas, essential oils, etc.
- Know to keep at least a two-week supply of medications.
- Know how to get medication refills:
 - When you have **refills remaining, contact your pharmacy directly at least 5 days before you run out of medication.** If you are having difficulty obtaining medications, you must notify your coordinator well before you run out.
 - When you are out of refills for medications, contact your transplant coordinator at least 5 days before you run out of medication.
 - Coordinators may only refill medications during office hours, Monday through Friday, 8:00am – 4:30pm.
 - No refills will be done after hours, on weekends or on holidays.



GENERAL MEDICATION GUIDELINES

- Take medications at the same time every day.
- Give the **exact amount** of medication as taught by the transplant team. **Do not** follow the bottle instructions as changes occur frequently.
 - 1 cc = 1 ml
 - Note: mg does not equal ml.
- Check the expiration date on all medication bottle labels.
- Keep each medication in its own easy-to-read, labeled container. You may organize the medication into a daily/weekly pill box.
- Keep an updated list of current medications with you at all times.
- Know what each medication is used for and the common side effects.
- If you forget a medication dose, follow these general guidelines, and let your transplant coordinator know about the missed or late dose:
 - **Never** double up on doses to make up for a missed dose.
 - For medications given once per day, give the dose as soon as you remember.
 - For medications taken two or more times per day:
 - ù If you remember **within 4 hours**, give the dose and resume your normal schedule when the next dose is due.
 - ù If you remember **after 4 hours**, do not give the dose and resume your normal schedule when the next dose is due.
 - ù If you are not sure what to do, call the transplant coordinator or physician on call.
 - ù If you forget any doses of your anti-rejection medications, call your transplant coordinator ASAP. Lab tests may be needed.
- Vomiting around medication time:
 - Vomiting **within 30 minutes** after medication, repeat the medication dose.

- Vomiting **more than 30 minutes** after medication, **do not** repeat the medication dose **unless** you can actually see tablets/capsules or the color of the liquid medication in the vomit.
- Call the transplant coordinator if vomiting persists.
- When you are out of refills for medications, contact your transplant coordinator at least **5 days before** you run out of medication.
- Coordinators may only refill medications during office hours, Monday – Friday, 8:00am – 4:30pm
- No refills will be done after hours, on weekends or on holidays.
- When you have refills remaining, contact your pharmacy directly at least five days before you run out of medication.
- Do not give over-the-counter medications, herbal remedies or food supplements without approval by transplant team. These include aspirin, antacids, cough medications, cold pills, laxatives or herbal remedies (herbal drugs, herbal teas, essential oils, etc).
 - You may give Tylenol® (acetaminophen) per manufacturer dosing instructions for fever or pain.
 - **Never** give medications known as NSAIDs (non-steroidal anti-inflammatory drugs) like Motrin® or Advil® (ibuprofen).
 - Many over-the-counter cold and cough medications are not safe to take with transplant medications.

Why Is Good Nutrition Important Before the Transplant?

Good nutrition is important for everyone, but especially before transplant. It can enhance overall health, promote healing and decreases the probability of post-surgical complications. If the transplant candidate cannot meet his or her nutritional needs through diet alone, nutritional supplements may be prescribed. It may take some time to regain a good appetite after transplant.

A dietitian is available to provide nutrition counseling. He or she can make recommendations to help improve and maintain the transplant candidate's nutritional status throughout the transplant process. The dietitian will offer recommendations appropriate for his or her age, developmental level, and medical status. The dietitian can also give tube feeding and TPN (nutrition given through the veins) recommendations.

The medications taken to prevent rejection after transplant increase risk for diseases such as diabetes, high blood pressure, heart disease and excessive weight gain or weight loss. A dietitian can provide education and written information to help decrease the chance of these complications.

The transplant team recommends a sensible and healthy diet to reduce the risk of damaging the new organ:

- Drink plenty of water
- Eat a variety of foods from the basic food groups: milk, meats, vegetables, fruits, and breads
- Eat foods with adequate starch and fiber
- Monitor the amount of fat, salt, and sweets, as directed by your physician:
 - Please read the ingredient labels of the products you purchase at the grocery store

If you have any questions or concerns, please contact the transplant team's dietitian or let your healthcare provider know you would like to speak to a dietitian.



How Active Can a Transplant Candidate Be?

Although heavy exercise may not be possible (due to condition), it is important to try to maintain or improve current physical condition and stamina. A regular exercise routine is important to overall well-being and should be done under the supervision of the transplant physician.

Transplant candidates may be referred to a physical therapist (PT) or occupational therapist (OT) to help with body conditioning in preparation for transplant. PTs and OTs can help transplant candidates maintain or achieve a healthy and active lifestyle. This will help them be as strong as possible to get ready for transplant.

Some ways PT and OT can help are:



Physical Therapy

- Assess strength and endurance
- Provide education on importance of maintaining mobility and an active lifestyle
- If outpatient: follow up with home exercise program of therapy services as needed
- If inpatient: provide inpatient therapy services as appropriate

Occupational Therapy

- Feeding
- Fine motor skills
- Mental developmental
- Strength
- Endurance
- Senses
- Community reintegration
- Activities of daily living
- Showering
- Dressing
- Brushing teeth

Can Your Family Go on Vacation While on the Transplant Waiting List?

If your family intends to travel while on the transplant waiting list, always consult with the transplant team before planning to travel. Depending on the area your family will be traveling to, the transplant candidate's listing status may be placed "on hold" during the trip. Please let the transplant center know if you will be in an area with limited cell phone service prior to travel.



What Should You Know About Research Studies?

Texas Children's Hospital participates in many research projects in our center and across the nation. Clinical research is the reason that there has been improvement in patient and graft/transplanted organ survivals. Participation in research is voluntary. Parents/Caregivers can participate in a research study. You can choose whether or not to participate in a research study without worry that saying "no" will affect the medical or nursing care the patient receives.

How Long Can a Transplanted Organ Last?

While transplanting a healthy organ to replace a diseased or failed organ can prolong life, transplants do have limits. Please visit <http://www.srtr.org/> for current patient and graft (transplanted organ) survival statistics post-transplant and/or ask the transplant team about the specific graft and patient survival rates at your transplant center.

RE-TRANSPLANT: IS IT AN OPTION?

Transplants in children may not last for a lifetime, which might lead to conversation about re-transplantation. Re-transplantation is discussed on a case-by-case basis and due to organ shortage, transplant centers must be thoughtful in their selection for re-transplantation. If re-transplantation is pursued, an entire evaluation must be completed again with thorough investigation into cause of graft (transplanted organ) failure.

Pre-Transplant: Section Quiz Review

1. Who are the members of the Multidisciplinary Team?
 - a. Transplant Physician
 - b. Transplant Surgeon, Pharmacist, Dietitian
 - c. Social Worker, Child Life Specialist, Transplant Coordinator
 - d. All of the above
2. The transplant evaluation helps to determine if transplant is a treatment option.
 - a. True
 - b. False
3. Will you need to sign a compliance agreement?
 - a. Yes
 - b. No
4. Which of the following must be reported to the transplant coordinator when changes occur?
 - a. Insurance
 - b. Address
 - c. Patient's condition
 - d. All of the above
5. The transplant candidate will be placed on the waitlist if they are approved by the Medical Review Board (pending insurance approval):
 - a. True
 - b. False
6. Which of the following are ways to limit exposure to illness before transplant?
 - a. Wash hands frequently with soap and water or hand sanitizer
 - b. Keep sick visitors away
 - c. Check with your transplant team regarding immunizations
 - d. All of the above
7. Who should you call after hours for any urgent need?
 - a. Transplant Coordinator
 - b. Page operator for physician
 - c. Transplant assistant
 - d. Pharmacist
8. I can reach someone from the transplant team 24 hours a day, 7 days a week.
 - a. True
 - b. False

9. Throughout the pre-transplant process, it is common for patients and families to experience a variety of emotions.
- a. True
 - b. False
10. In regards to medications, which of the following is FALSE?
- a. It is important to take medications at the same time every day.
 - b. It is important to keep an updated medication list with you at all times
 - c. Medication timing is not important, just take them whenever you remember.
 - d. You should call for refills at least 5 days before running out.

Common Questions in the Pre-Transplant Period

- 1. Will the transplant candidate need to be admitted to the hospital for the transplant evaluation?**
Not necessarily, evaluations can be done on an inpatient or outpatient basis, depending on health status.
- 2. Will accommodations be set up for your family during the evaluation?**
No, if assistance is needed, the transplant social worker can assist you with making those arrangements prior to arriving.
- 3. How will you know where to go for the evaluation?**
Once the evaluation is approved by your insurance company, the transplant coordinator assistant will schedule the appointments. A secure email and Fed Ex shipment will be sent to you with a detailed itinerary that will include appointment times and a map of the hospital.
- 4. Will the transplant candidate be placed on the waiting list right away?**
No, a formal evaluation must be completed. Then, the transplant candidate's evaluation information will be presented to the Medical Review Board for voting. If approved by the MRB, the transplant center submits financial approval for listing to your insurance. Once insurance approves a candidate to be listed, he or she will be placed on the waiting list.
- 5. Can you stay in your hometown while waiting for transplant?**
When listed for heart transplant, you are required to relocate within one hour of Texas Children's Hospital.
- 6. How often will the transplant candidate be seen in clinic while on the waiting list?**
Transplant candidates will be seen once monthly while listed for heart transplant. If health status changes, candidates may need to be seen more frequently.
- 7. If the transplant candidate is fearful of the surgery, what resources are available to help?**
Child life is available to assist transplant candidates and their families to aid in decreasing fears through written materials, videos, and/or hospital tours. A psychologist is available as needed.
- 8. Will the transplant candidate be cured once they receive a transplant?**
Transplant is not a cure, but it can be a treatment option.
- 9. How long will the transplant candidate be on the waitlist?**
Wait times can vary from weeks to years depending on the candidate's listing status.
- 10. Will meals be provided by the hospital while a candidate is on the waiting list?**
No, talk with your social worker if you need assistance with resources for meals.

Reasons to Call the Transplant Team While on the Waiting List

Transplant candidates may experience acute medical problems while waiting for transplant. In addition, their general medical condition may get worse during the waiting period. Please contact the transplant team about any changes in behavior, appetite, breathing, activity level, any signs of illness, or with questions about your care. This is a list of the most common and most urgent reasons to call the transplant team. **For a true medical emergency, such as difficulty breathing or change in responsiveness, please call 911.**

Vital Signs

- Changes in vital signs (blood pressure or heart rate decreases or elevations)
- Heart rate becomes rapid at rest, is irregular, or is pounding
- Difficulty breathing (abdominal breathing, making grunting noises)
- Increased cyanosis (blueness)
- Decreased oxygen saturation level

Gastrointestinal/Genitourinary Problems

- Increased abdominal size, abdominal pain, or swelling
- Persistent vomiting, diarrhea, or severe abdominal pain
- Vomiting blood
- Blood present in vomit or bowel movement (coffee ground-like or red vomit; dark tarry or bright red bowel movement)
- Bloody urine
- Decrease in urine output (decreased frequency or amount)
- Difficulty or pain when emptying bladder

Activity

- Decrease in activity level (not keeping up like normal)
- Decreased exercise tolerance
- Sleeping more than usual
- Decrease in appetite
- Irritability

Miscellaneous

- Sweating more than usual
- Jaundice (yellowing of the eyes/skin)
- Persistent or severe headaches
- Bloody sputum (mucus)
- Swelling/retaining fluid (if their feet, legs, hands, or eyelids swell)
- If you must leave town for an emergency

Illness

- Fever of 101° or higher (or extremely low temperatures less than 96°)
- Cough, congestion, or runny nose
- Exposure to chicken pox, shingles, measles, mumps, TB, or hepatitis
- Medication changes, illnesses, or hospitalizations

Contact Information

MONDAY-FRIDAY, 8:00AM-4:30PM:

Non-urgent Issues: Contact your transplant coordinator by phone or email.

Urgent Issues: Call **832-824-2099** and request to have your *transplant coordinator* paged (Toll-free number is 1-800-364-5437). If you do not receive a return call within 30 minutes, please try again as technical difficulties do sometimes occur.

AFTER HOURS, WEEKENDS, OR HOLIDAYS:

Non-urgent Issues: Email your transplant coordinator.

Urgent Issues: Call **832-824-2099** and request to have the *transplant physician* on call paged (Toll-free number is 1-800-364-5437). If you do not receive a return call within 30 minutes, please try again as technical difficulties do sometimes occur.

For a true medical emergency, such as difficulty breathing or change in responsiveness, please call 911.



Section 3

Transplant (Transplant Phase)

What Happens When You Receive the Call for Transplant?

IF YOU ARE WAITING AT HOME

When a donor organ has been accepted, you will be notified by a member of the transplant team, via phone or pager. **This is urgent**, and you should respond immediately (within 5 minutes). This call may come at **any time, day or night**. Please be sure that your pager and/or cell phone are in working order at all times while the candidate is on the waiting list. If you are required to carry a pager, you should test it weekly to verify that it is working and has fresh batteries. It is extremely important to keep the transplant coordinator updated with current contact numbers.

Have a bag packed with the following:

- Clothing
- Medication
- Medical supplies
- Cash
- **Education book**



When you receive the call, you will be told exactly what to do.

You may be told to be on standby at home, or you may be told to come into the hospital immediately depending on your location and timing of the transplant. The transplant candidate will be admitted through the emergency room or the admitting office, depending on the time of day. Don't forget your packed bag!

Remember: Ask the transplant team member what time the transplant candidate should stop eating and drinking.

After hospital admission for the transplant, you will be very busy. A physician will ask about the candidate's medical history and perform a physical exam. You or your parent/caregiver will be asked to sign a consent form for the surgery. A physician from the anesthesia department will explain how he or she will give medications to help the patient sleep during surgery. An X-ray, blood and urine tests may be obtained. An IV (a small tube placed in a vein) is placed to allow the patient to receive medications and fluids in preparation for transplant.

IF YOU ARE WAITING IN THE HOSPITAL

If the candidate is already in the hospital when we find out that there is an organ available, we will begin the process of preparing for transplant as if you came in from home. You will be very busy. A physician will ask about the candidate's medical history and perform a physical exam. You or your parent/caregiver will be asked to sign a consent form for the surgery. A physician from the anesthesia department will explain how he or she will give medications to help the patient sleep during surgery. An X-ray, blood and urine tests may be obtained. An IV (a small tube placed in a vein) is placed to allow the patient to receive medications and fluids in preparation for transplant.

Dry Run Please be aware that the transplant may be cancelled at any time prior to the new organ being placed. This can happen for many reasons such as a change in donor suitability, problems with the donor organ, or weather conditions. This is called a **“dry run.”**

What Happens Once the Candidate is Ready for Surgery?

A parent/caregiver may go from the acute care floor to the operating room (O.R.) holding area with the patient, but they cannot go past the holding area. The candidate will be escorted to the O.R. by the anesthesiologist. A mask that can give oxygen or anesthesia medications will be placed on the patient's face once in the O.R. Anesthesia medication may also be given through the IV.



Once asleep, a tube (endotracheal tube) will be placed in the windpipe to control breathing during the surgery. An additional tube (central venous catheter or central line) will be placed in a large vein in the neck or shoulder area to help the anesthesiologist give medications and fluids during the transplant. Small plastic tubes (catheters) are placed in the arteries in the wrist to monitor blood pressure continuously. Another tube (Foley catheter) will be placed in the bladder to drain urine.

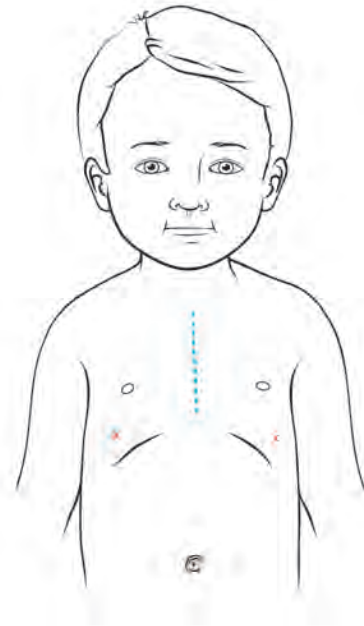
For patients in the Cardiovascular Operating Room (CVOR), a blue "buzzer" may be issued to you on admission until the patient is out of surgery. You will be assigned a private consultation room when paged on the blue "buzzer" where you and your family will receive updates from the medical/surgery team.



What Happens During the Transplant Surgery?

Our procuring surgeon will examine the donor heart.

- If the heart is appropriate for transplant, he or she will notify the transplanting surgeon.
- After confirming that heart is "good" on visualization, the transplanting surgeon will begin the surgery.
- Type of incision:
 - Sternotomy: Vertical incision in the center of chest
- Patient is placed on a heart-lung bypass machine during the surgery. This machine does the work of your heart and lungs while your heart and lungs are stopped for the surgery.
- The old heart is removed.
- The donor heart is placed in the chest and surgeons will begin the delicate process of connecting all the heart, veins, and arteries.
- The patient could be in surgery for 8 to 16 hours.
- Communication to parent/guardian during surgery:
 - Parents should be given updates approximately every 2 hours by the O.R. team



What Should You Expect After Transplant Surgery?

CARDIOVASCULAR INTENSIVE CARE UNIT (CVICU)

The Cardiovascular Intensive Care Unit (CVICU) is divided on 2 separate floors, the 18th floor and the 15th floor. The 15th floor ICU is dedicated to patients with heart failure or post heart transplant and is called the Heart Failure Intensive Care Unit (HFICU). Heart transplant patients may be admitted directly to the 18th floor CVICU if space is limited in the HFICU. The medical and nursing teams cover both floors. The length of time the patient will stay in ICU varies. It is determined by the level of care needed, the level of illness before transplant, and the how well the patient progresses after transplant. They will stay in the ICU until they are ready to transfer to the progressive care unit or acute care unit.



Recipients will be on **sternal precautions** for 6-8 weeks after heart transplant. This will help the chest incision heal completely and help prevent injury. Recipients will need help remembering not to pull themselves up with their arms. Your team can help you learn what sternal precautions mean. They can teach patients how to do activities without pushing and pulling with their arms. Recipients will be encouraged to walk as soon as they are able, usually within the first 24 hours.

The goal of the CVICU is to provide a safe, secure and clean environment. The unit guidelines are set forth in order for us to identify family and visitors entering the CVICU and maintain a safe, pleasant and quiet area for families and patients. *Please refer to the CVICU welcome handout for the most up-to-date visitor restrictions and waiting area guidelines.*

On admission, the receptionist will give the two primary caregivers a card with the "patient code." This code must be given to the staff when calling for information about the patient. NO information will be given by phone to anyone other than the primary caregivers.

WAITING AREA GUIDELINES

- Immediate family members, including mothers, fathers, and siblings and/or primary caregivers, should be the only individuals visiting in the ICU immediately after transplant.
- Please limit the number of visitors to no more than 6 people in waiting area, including caregivers. If the waiting area is full, you may be asked to use other waiting areas in the hospital. The limit on family members may change.
- All visitors over the age of 18 must have a valid picture ID to visit.
- Siblings under the age of 18 are permitted in waiting area or patient rooms and must be supervised by an adult at all times. No other children under age of 18 are permitted.
- Do NOT reserve seats for family members that are not present in the waiting area. All belongings should be removed when leaving the 17th floor.
- Consultation rooms are for family updates only. Please limit the number of family members when receiving an update.
- Please be mindful of voices and do not play music in the CVICU nor in the waiting room.
- Food and drinks are not permitted in the waiting room. Eating is limited to the Ronald McDonald Family Room,



Food Courts, and Public Waiting Areas. Lights are always on in the Ronald McDonald Family Room, be courteous and refrain from sleeping or lying down in this area.

- After 9PM the waiting room is available for two primary caregivers. Additional family members must exit the hospital.
- Caregivers may sleep in the lounge chairs in the waiting area on the 17th floor.
- Blankets and pillows can be obtained from the receptionist starting at 7:30pm and are to be returned in the morning at 8:00am.
 - No personal pillows or blankets for sanitary reasons.
 - If not returned by the designated hour it will be picked up by staff.
- Lights are turned off from 11pm-7am in the waiting area.
- The Family Restroom has lockers. Lockers can be purchased in the gift shop. Lockers are first come first serve and are limited to one per family. Please do not place valuable items in the cabinets found in the waiting area.
- Please clean up after yourself & notify the secretary if attention is needed in the waiting room, as we are NOT responsible for your items.
- Waiting room will be closed every Monday for cleaning between 10am – 12pm. Ronald McDonald Family Room will remain open to visitors.



VISITATION GUIDELINES

- For security purposes the CVICU is “locked down” to visitor access. However, you may visit your child 24 hours a day with the following guidelines:
- ALL visitors including the families of patients on 15 CVICU must check in with the receptionist on the 17th floor before entering the unit daily. Only 2 visitors are allowed to visit the patient at a time.
- Visitor Stickers: Prior to entering the unit, all visitors will be screened daily for signs and symptoms of infection on the 17th floor. After screening a visitor sticker will be issued which must be worn at all times in the hospital.
- The primary caregiver may designate additional people who can visit in their absence between the hours of 9am-9pm.
- After 9pm, an access card is needed to operate the patient elevators between the 18th and 15th floor. Primary care-givers of patients on 15 CVICU are given an access card during the duration of their stay and must be returned when the patient is transferred to a different unit. Primary care-givers of patients on 18 CVICU must return the access card upon daily check-in.
- At any time, the unit may close for emergencies and surgical procedures.



SIBLING VISITATION GUIDELINES

- The bedside nurse must be notified of each sibling visit.
- Siblings under the age of 12 are required to have a scheduled sibling preparation visit with the Child Life Specialist prior to entering the CVICU.
- After the initial preparation, if it is determined that no further Child Life presence is required, documentation will be communicated to the staff.
- Visits should be limited to 30 minutes.
- Siblings may visit 2 times per day between 9am-9pm.
- Additional sibling visits may be discussed on a case by case basis with Nursing Leadership.
- At any time, if needed, the siblings may be asked to leave by the medical staff.

We hope these guidelines will ensure your comfort while you are here and help us in providing a waiting area that will meet the needs of all families and visitors as we care for the patients. We recognize it is a stressful and difficult time. Please let us know if you have other needs or concerns. The receptionist is available to help you with any questions you may have. If we can assist you at any time, please do not hesitate to contact the receptionist. If you need further assistance, have the receptionist contact the nurse manager.

While in the CVICU Transplant recipients are still quite ill and very at risk for infection. The number of visitors must be minimized to keep infection risk as low as possible. In addition, all visitors must wash their hands thoroughly. Patients need rest and will have plenty of time after going home from the hospital to visit with family and friends. It sometimes works best to assign a family member the job of updating everyone. If you are having difficulty controlling the number of visitors, please ask your bedside nurse for assistance with crowd control.

Visitation guidelines are subject to change for all hospital units based on current infection control needs/rules. Please contact the unit prior to bringing siblings into the hospital to verify that they will be able to visit.



ACUTE CARE UNIT (15T OR 15 TOWER)

15 West Tower is the floor designated as the acute care unit for heart transplant at Texas Children's Hospital. It is located on the 15th floor of the West Tower. The nurses have additional training regarding care of the pre and post-transplant child. In addition to the transplant team, residents and medical students will be involved in patient care.

Your Daily Routine

Throughout the day there will be many activities. The nurses will check vital signs every 4 hours. The respiratory therapist will provide treatments that will encourage deep breathing and coughing. This helps prevent pneumonia. If the patient is unable to get out of bed, they must turn from side to side every 2 hours. Sitting up and walking can help prevent pneumonia and speeds recovery from surgery.

Recipients will be on **sternal precautions** for 6-8 weeks after heart transplant. This will help the chest incision heal completely and help prevent injury. Recipients will need help remembering not to pull themselves up with their arms. Your team can help you learn what sternal precautions mean. They can teach patients how to do activities without pushing and pulling with their arms.



Check with the transplant team to see if the patient is able to visit the playroom or other activity areas during the post-transplant stay. If they are unable to go to the playroom, Child Life Specialists can bring activities to their room. Requests for activities should be made before 3:00pm.

Occupational therapists and physical therapists will work with patients to improve strength and activity levels.

While on the 15th floor Transplant recipients are still quite ill and very at risk for infection. The number of visitors must be minimized to keep infection risk as low as possible. In addition, all visitors must wash their hands thoroughly. Patients need rest and will have plenty of time after going home from the hospital to visit with family and friends. It sometimes works best to assign a family member the job of updating everyone. If you are having difficulty controlling the number of visitors, please ask your bedside nurse for assistance with crowd control.

Visitation guidelines are subject to change for all hospital units based on current infection control needs/rules. Please contact the unit prior to bringing siblings into the hospital to verify that they will be able to visit.

RETURNING TO A NORMAL LIFESTYLE WHILE IN THE HOSPITAL

A note for parents/caregivers: While your child is in the hospital, you should begin the process of returning to a more normal lifestyle. You will be able to stay all day and night. You will be expected to be involved in your child's care. As discharge from the hospital gets closer, the nurses will teach you the skills you need to prepare you to care for your child.

What Should You Do for Infection Control After Transplant?

The transplant recipient will receive some very strong anti-rejection medications at the time of transplant that lower the body's ability to fight off infections. Special care must be taken to avoid contact with other people who are sick. Only immediate family members should visit during this time.

Remember, the transplant recipient is **highly** immunosuppressed after transplant and is at **high risk** for infection. An infection during this time could be considered life-threatening. Everyone who visits post-transplant **must** practice good hand washing techniques. Limiting visitors is important, especially in the first 6 months post-transplant.

Any fever, cough, vomiting, rash or mouth lesions should be reported to the transplant physician.



WAYS TO LIMIT EXPOSURE TO ILLNESS POST-TRANSPLANT, WHILE IN THE HOSPITAL:

For parents/caregivers and patients:

- Wash your hands and always use hand sanitizer on the way in and out of the hospital room.
- Keep your hands away from your eyes, nose, and mouth unless freshly washed with soap and water.
- Keep sick visitors away from the hospital.
- Items that "fall" on the floor must be cleaned prior to patient use.
- Personal items that are washable are preferred. The number and size of stuffed animals should be minimized.
- Potted plants and fresh flowers are not allowed in the ICU or PCU

For the patient:

- Wear a mask when out of your room.
- Wear socks or shoes when out of bed.



What Are the Activity Restrictions After a Recent Transplant Surgery?

Transplant recipients:

- Should not lift anything greater than 5 pounds for 6 weeks after surgery.
- Should not perform strenuous activity for 6 weeks after surgery.
- Should avoid pulling or positioning themselves using their arms for 6-8 weeks after surgery.
 - When moving from a lying position, have someone support you behind your back to move to an upright position. **Do not** pull or push yourself up using your arms.
 - When moving from a sitting position, the patient should use their legs to support their weight.

- Parent/caregivers should avoid lifting the transplant recipient by picking him or her up under the arms. “Scoop” the patient for at least 6 weeks after surgery.
- Should not drive for 8 weeks after surgery (if applicable).
- Should check the incision daily. If there is any unusual redness, swelling, pus, drainage, or pain, contact your transplant coordinator.
- Follow the surgery team’s instructions for incision care.
 - Keep the incision clean and dry. Do not apply ointments, lotions, or creams (unless prescribed).
 - May shower and wash the incision only briefly with mild soap and water after the sutures are removed.
 - Should not soak the incision area for at least 4-6 weeks after the surgery when bathing.
 - Should not enter lakes, swimming pools, hot tubs, etc. until complete healing of the wound occurs and there are no more scabs.

Will You Need Physical or Occupational Therapy After Transplant?

PTs and OTs will be involved early after transplant to help get the recipient up and moving. They will assist in achieving independence with normal everyday activities.

Some ways PT and OT can help are:

Physical Therapy	Occupational Therapy
<ul style="list-style-type: none"> • Post-op mobility • Getting patients up and walking • Parent/caregiver/child education • Reinforce sternal precautions • Importance of mobility • Home exercise program • Facilitate independence with mobility • Balance • Stairs 	<ul style="list-style-type: none"> • Feeding • Fine motor skills • Developmental skills • Strengthening • Endurance • Sensory • Community reintegration • Activities of daily living <ul style="list-style-type: none"> - Showering - Dressing - Brushing teeth

REHABILITATION

Occupational and Physical Therapy work closely together and often overlap when addressing rehabilitation needs. The major goal of therapy for transplant recipients is to help them reach their highest level of functioning and independence after transplant surgery.

This involves helping recipients regain strength, range of motion of joints, age appropriate fine and gross motor skills, perceptual skills, and ability to participate in everyday activities. Home programs, caregiver instruction, and referral to community programs are made when needed. Rehabilitation and therapy programs are created based on each patient’s needs.



What Are Your Responsibilities After Transplant?

PARENT/CAREGIVER RESPONSIBILITIES

- You will be able to resume routine care first - bathing, feeding, teeth brushing, and diaper changes (if applicable). Good hygiene is important following transplant to prevent infection.
- Give a sponge bath every day until the incision is completely healed.
- Do not allow the recipient not to scratch or pick at the incision. Keep nails short to prevent skin abrasions from scratching.
- Brush teeth after meals and at bedtime for good dental hygiene.
- Good nutrition helps wound healing and promotes growth. Patients can usually have regular foods or formula after transplant, but the recipient should follow the prescribed diet (if applicable).
- Please ask your nurse if they need to weigh diapers or record the amount of urine before disposal. Monitoring urine amounts is needed for the transplant team to track their fluid balance. You can help by changing the diapers frequently. Children who are toilet trained will need to urinate in a special container for the urine to be measured.

PATIENT RESPONSIBILITIES

There will be several tasks patients will learn and perform in the hospital. Many of these will continue at home. The following tasks would be joint responsibility of the recipient and the parent/caregiver based on recipient age and ability. Some of these tasks are outlined below:

- **Medication Administration** – Take medications as directed. The recipient and the parent/caregiver can work together with the transplant team to learn about the new medications.
 - Learn the name of each new medication and why it's being used.
 - Learn how the medications should be taken (when, how much to give, and how to give).
 - Practice giving the medications while still in the hospital. Always check the medications with the nurses before you give them while in the hospital.
 - Learn a good routine while in the hospital, because you will be expected to give all medications as prescribed once you go home.
 - Your home medication schedule may be different than the hospital schedule. It will be very important to use the printed medication schedule you were given, every time you give medications.
 - Medication doses may change frequently. Use your printed medication schedule, not the prescription bottles for knowing how much medication to give.
 - Carry the medication schedule with you at all times, and bring it to clinic visits.
- **Intake** – Keep a record of what the recipient eats and drinks. This allows the transplant team to monitor fluid balance and calorie intake.
- **Vital Signs**
 - **Blood Pressure and Heart Rate**- Keep a blood pressure (BP) and heart rate (HR) record. If you don't know how to take a BP and HR, someone can teach you. You will go home from the hospital with a correctly sized BP monitor.
 - ù The blood pressure monitor will also give you a HR when you check BP.
 - ù Check and record BP and HR twice daily unless the team changes the frequency.
 - ù If BP or HR are out of range, call your transplant coordinator!
 - ù Always check BP/HR BEFORE giving any medications that can affect BP or HR.
 - ù If BP or HR are out of range, call your transplant coordinator BEFORE giving the BP or HR medications (do not hold anti-rejection medications).
 - ù If he or she was upset or agitated during the BP check, attempt to recheck once calm.
 - ù Always bring the BP/HR record to transplant clinic.



What Should You Know About Transplant Medications?

UNDERSTANDING TRANSPLANT MEDICATIONS

- You should know a few things about transplant medications:
 - Which medications are anti-rejection medications.
 - Which medications need to wait until after labs are drawn.
 - What time to give the medications.
 - How to give the medications.
 - The generic and brand name of each medication.
 - What each medicine is used for and the common side effects.
 - Why it is important to use the same brand of medicine every month.

ABC PHARMACY 1234 Anywhere Rd Houston, TX 12345 832-824-1000	
JANE SMITH Written: 9/1/2016	
Strength	PROGRAF PO Tab 1 mg
Medication Name	Give 2 tab by mouth every 12 hours.
Dose	Rx#: 12345678 Qty: 30 tabs
Frequency	Filled: 9/1/2016 Use by: 9/1/2017
Expiration Date	3 Refills Remaining before 12/31/2016
How many refills are left?	Prescriber: TCH Doctor, MD
Is this the same manufacturer as previous bottle?	NDC (or MFR): 123456789 ASTELLAS

- Why each medication is being given.
- The main side effects of the medications.
- Why it is important to take medications as prescribed.
- You are responsible for giving medications as prescribed.
 - You must discuss any medications changes with your transplant physician.
 - You must discuss and get approval from the transplant coordinator/physician before using medication prescribed by a physician who is not part of the transplant team or using over-the-counter medicine.
- Know that no new medications (including over-the-counter medicines or herbals) should be started (even if prescribed by another physician) without approval from the transplant team.
 - Do not take or use herbal supplements unless approved by your transplant team.
 - Herbal supplements can adversely interact with transplant medications.
 - Herbal remedies include herbal drugs, herbal teas, essential oils, etc.
- Know to keep at least a 2-week supply of medications.
- Know how to get medication refills:
 - When you have refills remaining, contact your pharmacy directly at least 5 days before you run out of medication. If you are having difficulty obtaining medications, you must notify your coordinator well before you run out.

- When you are out of refills for medicines, contact your transplant coordinator at least 5 days before you run out of medicine.
- Coordinators may only refill medications during office hours, Monday – Friday, 8:00am – 4:30pm
- No refills will be done after hours, on weekends or on holidays.

GENERAL MEDICATION GUIDELINES

- Take medicines at the same time every day.
- Give the EXACT AMOUNT of medication as taught by the transplant team. Do not follow the bottle instructions as changes occur frequently.
 - 1 cc = 1 ml
 - Note: **mg** does not equal **ml**.
- Check the expiration date on all medicine bottle labels.
- Keep each medicine in its own easy-to-read, labeled container. You may organize the medication into a daily/ weekly pill box.
- Keep an updated list of current medications with you at all times.
- If you forget a medication dose, follow these general guidelines, and let your transplant coordinator know about the missed or late dose:
 - **Never** double up on doses to make up for a missed dose.
 - For medications given once per day: give the dose as soon as you remember.
 - For medications taken two or more times per day:
 - ù If you remember within 4 hours, give the dose and resume your normal schedule when the next dose is due.
 - ù If you remember after 4 hours, do not give the dose and resume your normal schedule when the next dose is due.
 - ù If you are not sure what to do, call the transplant coordinator or physician on call.
 - ù If you forget any doses of your anti-rejection medications, call your transplant coordinator ASAP. Lab tests may be needed.
 - Vomiting around medication time:
 - ù Vomiting **within** 30 minutes after medicine: repeat the medication dose.
 - ù Vomiting **more** than 30 minutes after medicine: **Do not** repeat the medication dose **unless** you can actually see tablets/capsules or the color of the liquid medication in the vomit.
 - ù Call the transplant coordinator if vomiting persists.
- When you are out of refills for medicines, contact your transplant coordinator **at least 5 days** before you run out of medicine.
 - Coordinators may only refill medications during office hours, Monday – Friday, 8:00am – 4:30pm.
 - No refills will be done after hours, on weekends or on holidays.
- When you have refills remaining, contact your pharmacy directly at least five days before you run out of medication.
- Do not give over-the-counter medications, herbal remedies or food supplements without approval by transplant team. These include aspirin, antacids, cough medicines, cold pills, laxatives or herbal remedies (herbal drugs, herbal teas, essential oils, etc.).
 - You may give Tylenol® (acetaminophen) per manufacturer dosing instructions for fever or pain.
 - **Never** give the transplant patient medications known as NSAIDs (non-steroidal anti-inflammatory drugs) like Motrin® or Advil® (ibuprofen).
 - Many over the counter cold and cough medications are not safe to take with transplant medications.



What are the Different Types of Transplant Medications?

There are 4 types of transplant medications: anti-rejection (immunosuppressant) medications; medications to prevent and treat infections (anti-viral/anti-fungal) medications; blood pressure medications; and other medications including vitamins and supplements.

ANTI-REJECTION (IMMUNOSUPPRESSANT) MEDICATIONS

Anti-rejection medications protect the transplanted organ from rejection by lowering the transplant recipient's immune response. The most commonly used anti-rejection drugs are: Prograf® (tacrolimus), Cellcept® (mycophenolate mofetil), and Orapred® (prednisolone) or prednisone. The transplant recipient will take anti-rejection medications for life. The transplant recipient may experience some side effects with some of these medications. The dose may be decreased over time after surgery, depending on his or her condition, which may help decrease the side effects. All of the following drugs are associated with an increased risk of infection and an increased incidence of cancer. Other common side effects of each drug are listed below.

Prograf® (Tacrolimus)

Available formulations: capsule, compounded liquid

Purpose

Tacrolimus is an immunosuppressive medication. It helps prevent rejection by suppressing the immune system.

When to Give

Tacrolimus must be taken at the same times every day to help keep a constant level of medication in the blood. The transplant recipient will be given 2 doses each day; the first dose in the morning (9:00am) and the second dose 12 hours later (9:00pm).

How to Give

The transplant recipient should take consistently, either with or without food, to minimize variability of the medication in the blood.

If the transplant recipient can swallow pills, he or she will swallow the appropriate number of capsules as directed by the transplant team. If the transplant recipient is taking the compounded liquid, you will be taught by the transplant pharmacist to draw up the correct amount using a syringe. Shake the bottle well before drawing up the dose.

It is ideal to stick with just one brand or manufacturer of this medicine. If your pharmacy dispenses tacrolimus from a different manufacturer from the one you were using previously, please contact your transplant coordinator to discuss need for more frequent follow-up labs.

What to do on Lab Draw Days

The transplant recipient will be having blood drawn regularly to check the level of tacrolimus in their blood.

Tacrolimus levels need to be drawn 30 minutes before the next dose. If the dose is due at 9:00am, a tacrolimus trough should ideally be drawn at 8:30am.

Please arrive at the lab 30 minutes before the lab draw (or 8:00am in this example) in case there is a line at the lab. On days of lab work, bring medications with you to the lab so you can give the tacrolimus dose **after** the blood has been drawn.

When to Call the Transplant Team

If the transplant recipient has vomiting and/or has diarrhea, notify the transplant team. When the recipient has diarrhea, the body will either not absorb enough or absorb too much of the tacrolimus. If not enough medicine is absorbed, rejection can occur. If too much of the medicine is absorbed it can lead to high blood pressure and kidney damage.

Food and Drinks to Avoid

Transplant recipient should not have grapefruit, pomegranate, starfruit, Seville oranges (used to make marmalade), Noni fruit or juice. Remember that juices/sodas that contain any of these foods as they can interfere with the levels of tacrolimus. These foods can interfere with the absorption or the breakdown of tacrolimus and may cause high levels that can lead to toxic side effects.

Medications to Avoid

Any antibiotics should only be given after interactions have been checked by the transplant team. Some of these medications can interfere with the absorption or the breakdown of tacrolimus and may cause high levels that can lead to toxic side effects. Do not give the recipient any over-the-counter medicines not approved by the transplant team or transplant pharmacist, unless they are on an approved over-the-counter medication list.

Common Side Effects

- High blood pressure
- Tremors
- Decrease in kidney function
- Abdominal discomfort/nausea
- Headaches
- Elevated blood sugar
- Decreased magnesium level in blood
- Seizures



Neoral[®], Gengraf[®] (Cyclosporine Modified); Sandimmune (Cyclosporine Non-modified)

Available formulations: capsule, liquid

Purpose

Cyclosporine is an immunosuppressive medication. It helps prevent rejection by suppressing the immune system.

Cyclosporine is available as two forms: a modified form (Neoral[®] or Gengraf[®]) or non-modified (Sandimmune[®]). Modified forms (Neoral or Gengraf) are not interchangeable with non-modified forms (Sandimmune[®]).

When to Give

Cyclosporine must be taken at the same times every day to help keep a constant level of medication in the blood. The transplant recipient will be given 2 doses each day; the first dose in the morning (9:00am) and the second dose 12 hours later (9:00pm).

How to Give

The transplant recipient should take consistently, either with or without food, to minimize variability of the medication in the blood.

If the transplant recipient can swallow pills, they will swallow the appropriate number of capsules as directed by the transplant team. If the transplant recipient is taking the compounded liquid, they will be taught by the transplant pharmacist to draw up the correct amount using a syringe. Shake the bottle well before drawing up the dose.

The liquid suspension should be given using the oral syringe provided. **Do not** administer the liquid in a plastic or Styrofoam cup. The liquid can be mixed with a small amount of orange or apple juice in a glass container. Rinse the container with extra juice and have the transplant recipient drink the rinse to ensure the entire dose was given.



What to Do on Lab Draw Days

The transplant recipient will be having blood drawn regularly to check the level of cyclosporine in their blood. Cyclosporine levels need to be drawn 30 minutes before the next dose. If the transplant recipient dose is due at 9:00am, a trough should ideally be drawn at 8:30am.

Please arrive at the lab 30 minutes before the lab draw (or 8:00am in this example) in case there is a line at the lab. On days of lab work, bring medications with you to the lab so you can give the cyclosporine dose **after** the blood has been drawn.



When to Notify the Transplant Team

If the transplant recipient has vomiting and/or has diarrhea, notify the transplant team. When the transplant recipient has diarrhea, the body will either not absorb enough or absorb too much of the cyclosporine. If not enough medicine is absorbed, rejection can occur. If too much of the medicine is absorbed it can lead to side effects.

Food and Drinks to Avoid

Transplant recipient should not have grapefruit, pomegranate, starfruit, Seville oranges (used to make marmalade), Noni fruit or juice. Remember that juices/sodas that contain any of these foods as they can interfere with the levels of cyclosporine. These foods can interfere with the absorption or the breakdown of cyclosporine and may cause high levels that can lead to toxic side effects.

Medications to Avoid

Any antibiotics should only be given after interactions have been checked by the transplant team. Some of these medications can interfere with the absorption or the breakdown of cyclosporine and may cause high levels that can lead to toxic side effects. Do not give any over-the-counter medicines not approved by the transplant team or transplant pharmacist, unless they are on an approved over-the-counter medication list.

Common Side Effects

- High blood pressure
- Tremors/shaking of hands and/or feet
- Decrease in kidney function
- Abdominal discomfort/nausea
- Headaches
- Elevated blood sugar
- Decreased magnesium level in blood
- Seizures
- Increased body hair
- Increased growth of gum tissue

Rapamune® (Sirolimus)

Available formulations: tablet, liquid

Purpose

Sirolimus an immunosuppressive medication. It helps prevent rejection by suppressing the immune system. This medication is used in special circumstances. It is not the first drug of choice to help prevent rejection.

When to Give

Sirolimus must be taken at the same time every day to help keep a constant level of medication in the blood. It is typically taken once daily. The timing of this dose will be determined by the transplant team and Transplant Pharmacist.

If the transplant recipient is also taking cyclosporine, sirolimus must be taken at least 4 hours after the cyclosporine dose.

How to Give

The transplant recipient should take consistently, either with or without food, to minimize variability of the medication in the blood.

If the transplant recipient can swallow pills, they will swallow the appropriate number of capsules as directed by the transplant team. If the transplant recipient is taking the compounded liquid, they will be taught by the transplant pharmacist to draw up the correct amount using a syringe. Shake the bottle well before drawing up the dose. The liquid can be mixed with a small amount of **only** water or orange juice.

What to Do on Lab Draw Days

The transplant recipient will be having blood drawn regularly to check the level of sirolimus in their blood. Sirolimus levels can be drawn anywhere from 30 minutes to 4 hours prior to administration.

On days of lab work, bring medications with you to the lab so you can give the sirolimus dose **after** the blood has been drawn.

When to Notify the Transplant Team

If the transplant recipient has vomiting and/or has diarrhea, notify the transplant team. When the transplant recipient has diarrhea, the body will either not absorb enough or absorb too much of the sirolimus. If not enough medicine is absorbed, rejection can occur. If too much of the medicine is absorbed it can lead to side effects.

Food and Drinks to Avoid

Transplant recipient should not have grapefruit, pomegranate, starfruit, Seville oranges (used to make marmalade), Noni fruit or juice. Remember that juices/sodas that contain any of these foods as they can interfere with the levels of sirolimus. These foods can interfere with the absorption or the breakdown of sirolimus and may cause high levels that can lead to toxic side effects.

Medications to Avoid

Any antibiotics should only be given after interactions have been checked by the transplant team. Some of these medications can interfere with the absorption or the breakdown of sirolimus and may cause high levels that can lead to toxic side effects. Do not give the transplant recipient any over-the-counter medicines not approved by the Transplant Team or Transplant Pharmacist, unless they are on an approved over-the-counter medication list.

Common Side Effects

- High blood pressure
- Mouth ulcers
- Swelling of the arms, leg, and/or face
- Increased cholesterol & triglyceride levels
- Low red blood cell count
- Impaired wound healing

Cellcept®, Myfortic® (Mycophenolate)

Available formulations: tablet, liquid

Purpose

Mycophenolate is an immunosuppressive medication. It helps prevent rejection by suppressing the immune system.

When to Give

Mycophenolate must be taken at the same times every day to help keep a constant level of medication in the blood. If the transplant recipient is taking this medication, he or she will be given two doses each day; the first dose in the morning (9:00am) and the second dose 12 hours later (9:00pm).

How to Give

It may be taken with food to decrease stomach upset.

What to Do on Lab Draw Days

The transplant recipient may have blood drawn regularly to check the level of mycophenolate in their blood.



Mycophenolate levels need to be drawn 30 minutes before the next dose. If the dose is due at 9:00am, a trough should ideally be drawn at 8:30am.

Please arrive at the lab 30 minutes before the lab draw (or 8:00am in this example) in case there is a line at the lab. On days of lab work, bring medications with you to the lab so you can give the mycophenolate dose **after** the blood has been drawn.

Common Side Effects

- Nausea/vomiting/diarrhea
- Stomach pain
- Low white blood cell count



Precautions

Mycophenolate may cause **severe birth defects or pregnancy loss.**

Males/Females who are sexually active must use **2** effective birth control methods (e.g. birth control pills and condoms) before starting therapy, during therapy and for a time period after the medication has been stopped. It is very important to discuss the most effective birth control methods with your physician.

Females: should use **2** contraceptive precautions (such as birth control pills **and** condoms) before, during, and for **6 weeks** after the medication has been stopped.

Males: sexually active men are recommended to use condoms before treatment, during treatment, and for at least **90 days** after the medication has been stopped. Female partners of male patients are also recommended to use highly effective contraception before, during treatment, and for **90 days** after the last dose.

Pregnant caregivers: should avoid inhalation or direct contact with the powder inside the capsule or suspension (it should not be administered by pregnant women if possible).

CORTICOSTEROIDS

Orapred® (Prednisolone); Deltasone® (Prednisone)

Available formulations: tablet, liquid

Purpose

Prednisone or prednisolone are corticosteroids and at certain dosages they help prevent the transplant recipient from rejecting the new organ. In addition, they affect the salt and water balance of the body, and the breakdown of fat, protein, and glucose in the body.

When to Give

Corticosteroids should be given once daily in the morning unless otherwise directed by the transplant team or transplant pharmacist.

How to Give

Giving a corticosteroid with food or milk makes it less irritating to the stomach.

Common Side Effects

- Round face
- Stomach upset
- Weight gain
- Fluid and salt retention (swelling)
- Mood swings
- Acne
- Increased appetite
- Bone loss (loss of calcium from bones)
- Easy bruising
- Blurry vision
- Cataract formation
- Elevated blood sugar
- Poor height/growth

MEDICATIONS TO PREVENT AND TREAT INFECTIONS (ANTI-INFECTION MEDICATIONS)

Anti-rejection medications make transplant recipients more susceptible to infection. These infections are usually caused by overgrowth of organisms that normally live in the transplant recipient's body. We use anti-viral, anti-bacterial, and anti-fungal medications to prevent some of the most common infections. Anti-infection medications are typically needed for at least 6-12 months after transplant, some patients may need to take these medications for a lifetime.

Bactrim®, Sulfatrim® (Sulfamethoxazole-Trimethoprim)

Available formulations: tablet, liquid

Purpose

Bactrim is a sulfa-containing antibiotic. It is used to prevent a type of pneumonia (lung infection) known as pneumocystis pneumonia (PJP).

Common Side Effects

- Sensitivity to sunlight (wear full-coverage clothing and sunscreen)
- Decrease in kidney function
- Low white blood cell count
- Rash
- Nausea/Vomiting

If a decrease in white blood cells or allergy occurs, the medication may be decreased or discontinued. Encourage the transplant recipient to take with a glass of water.

NebuPent® (Pentamidine)

Available formulations: inhaled solution

Purpose

Pentamidine is an alternative medication for Bactrim®. It is given as an inhaled treatment every month in the Pulmonary Clinic.

Common Side Effects

- Allergic reaction
- Blurred vision
- Chest pain or irregular heart beat
- Difficulty breathing
- Dizziness, confusion, fainting spells, or excessive tiredness



Valcyte® (Valganciclovir)

Available formulations: tablet, liquid

Purpose

Valganciclovir is an antiviral drug that may be used to prevent or treat a virus called Cytomegalovirus (CMV).

Common Side Effects

- Headache
- Stomach upset
- Sensitivity to sunlight (wear full-coverage clothing and sunscreen)
- Kidney stones
- Decrease in kidney function
- Low white blood cell count

Precautions Valganciclovir may cause **severe birth defects or pregnancy loss**. Males/
Females who are sexually active must use **2** effective birth control methods (e.g. birth control pills and condoms) before starting therapy, during therapy and for a time period after the medication has been stopped. It is very important to discuss the most effective birth control methods with your physician.

Females: should use **2** contraceptive precautions (such as birth control pills **and** condoms) before, during, and for **30 days** after the medication has been stopped.

Males: sexually active men are recommended to use condoms before treatment, during treatment, and for at least **90 days** after the medication has been stopped. Female partners of male patients are also recommended to use highly effective contraception before, during treatment, and for **90 days** after the last dose.

Pregnant caregivers: should avoid inhalation or direct contact with the powder inside the capsule or suspension (it should not be administered by pregnant women if possible).

Cytogam® (Cytomegalovirus Immune Globulin)

Available formulations: intravenous

Purpose

This medication can be used in the prevention of CMV by giving anti-CMV antibodies. It is given within the first 72 hours of transplant. The remaining infusions will occur in a specific sequence post-transplant. The infusion takes approximately 4 hours and the transplant recipient will be monitored during each infusion.

Most patients will be pre-medicated with Benadryl® (diphenhydramine) and Tylenol® (acetaminophen) to reduce the risk of side effects.

Common Side Effects

- Fever and chills
- Muscle cramps
- Back pain
- Nausea and vomiting
- Wheezing
- Drop in blood pressure

Mycostatin® (Nystatin)

Available formulations: liquid

Purpose

Nystatin prevents and treats thrush, which is a fungal infection of the mouth.

How to give

Nystatin should be taken after meals and before bedtime. It should be swished and swallowed, or brushed inside the mouth with a soft toothbrush. For best results, the medication should be held in the mouth as long as possible. Do not let the transplant patient eat or drink anything for 15-30 minutes after taking it. The medicine needs to coat the inside of the mouth to be effective – do not give through Nasogastric Tube (NGT) or G-tube. Remember that good oral hygiene is important in preventing mouth infections.



Vfend® (Voriconazole)

Available formulations: tablet, liquid

Purpose

Voriconazole is used to treat or prevent fungal infections. This medication may affect the way that tacrolimus is metabolized. Therefore, tacrolimus (or other transplant medications) will be adjusted to compensate for this when voriconazole is started or stopped.

How to Give

Voriconazole should be taken with food to increase absorption.

Common Side Effects

- Vision changes
- Rash
- Decrease in kidney function
- Photosensitivity (rash, sunburn caused by sun exposure)
 - Recipients taking voriconazole should wear full coverage clothing and sunscreen if in the sun.



- Recipients who are on voriconazole for longer than 1 year should see a dermatologist annually for an exam.

Precautions Voriconazole has a major impact on blood levels of immunosuppressant medications (ex: tacrolimus). It should **never** be **started** or **stopped** without clear instructions from the transplant team.

BLOOD PRESSURE MEDICATIONS

High blood pressure may be a side effect of Prograf®, Sandimmune®, and corticosteroids. Listed below are the names and side effects of medications used in the treatment of high blood pressure. The transplant recipient may not have any symptoms of high or low blood pressure or may not complain of dizziness or headache. Therefore, it is essential that you check their blood pressure twice daily prior to giving any medications that may treat high blood pressure or as directed by your coordinator. When necessary, you will be provided with a digital blood pressure cuff upon discharge and given guidelines as to when the blood pressure reading is considered high. If the transplant recipient's blood pressure falls outside of the provided range, you will need to contact your coordinator. A daily log of the transplant recipient's blood pressure readings should be kept and brought to clinic appointments.

Norvasc® (Amlodipine)

Available Formulations: tablet, compounded liquid

Purpose

Amlodipine is a medication used to treat high blood pressure.

Food and Drinks to Avoid

Do not give the transplant recipient grapefruit, pomegranate, starfruit, Seville oranges (used to make marmalade), Noni fruit or juice. Remember that juices/sodas that contain any of these foods as they can interfere with amlodipine.

Common Side Effects

- Decreased blood pressure
- Dizziness
- Swelling

Vasotec® (Enalapril)

Available Formulations: tablet, liquid

Purpose

Enalapril lowers blood pressure and protects kidney function in patients who have protein loss.

Common Side Effects

- Dizziness
- Headache
- Chest pain
- Abnormal taste
- Cough
- Unusual tiredness
- Nausea/vomiting
- Heartburn

Procardia[®], Adalat[®], Afeditab[®], Nifediac[®] (Nifedipine)

Available Formulations: capsule, tablet, compounded liquid

Purpose

Nifedipine is a medication used to treat high blood pressure.

Common Side Effects

- Rapid heartbeat
- Flushing
- Swelling
- Dizziness

STOMACH ACID REDUCERS

Zantac[®] (Ranitidine), Prevacid[®] (Lansoprazole), Nexium[®] (Esomeprazole)

Available formulations: tablet, liquid

Purpose

These medications reduce stomach acid and are often used in patients with acid reflux disease. It is important that the patient is taking a stomach acid reducer while they are prescribed corticosteroids (i.e. prednisone, prednisolone) in order to protect their stomach from damage and to prevent abdominal pain.

When to Give

These medications should be given before meals.

Common Side Effects

- Headache
- Diarrhea
- Nausea
- Stomach pain



STATIN

Lipitor[®] (Atorvastatin), Pravachol (Pravastatin)

Available formulations: tablet

Purpose

These medications are used to lower bad cholesterol and increase your good cholesterol. In transplant patients, it is used to protect blood vessels in the organ and prevent a special type of rejection (for heart and lung transplant patients).

Common Side Effects

- Stomach upset
- Muscle cramps

VITAMINS AND SUPPLEMENTS

Electrolyte, vitamin, and mineral levels may be checked after transplant, and if levels are low the transplant recipient may need to take additional supplements.

Magnesium Supplements: Magnesium Gluconate, Magnesium Oxide

Available formulations: tablet, capsule, liquid

Purpose

Magnesium is important for many functions of the body. A magnesium supplement may be needed to treat low magnesium levels due to wasting of magnesium found with Prograf® (tacrolimus) administration.

How to Give

If possible, separate magnesium by at least 2 hours from Cellcept® (mycophenolate) and 1 hour from phosphorous supplements.

Common Side Effects

- Diarrhea
- Facial flushing

Potassium Supplements: Potassium Chloride

Available formulations: tablet, capsule, liquid

Purpose

Potassium is needed to help cells grow and for your muscles to function properly. Potassium supplements come in various forms.

Common Side Effects

- Diarrhea

DIURETICS

Lasix® (Furosemide)

Available formulations: tablet, liquid

Purpose

Furosemide will help remove excessive fluid in the body by causing increased urination, which may help reduce blood pressure. Follow a low salt diet to prevent fluid retention.

Common Side Effects

- Muscle cramps
- Headache
- Low potassium level
- Sensitivity to sunlight (wear full-coverage clothing and sunscreen)

Bumex® (Bumetanide)

Available Formulations: tablet, liquid

Purpose

It will help remove excessive fluid in the body by causing increased urination, which may help reduce blood pressure. Follow a low salt diet when directed to prevent fluid retention.

Common Side Effects

- Muscle cramps
- Headache
- Low potassium level
- Sensitivity to sunlight (wear full coverage clothing and sunscreen)

Diuril® (Chlorothiazide)

Available Formulations: tablet, liquid

Purpose

Often combined with other diuretics like Bumex® (Bumetanide) or Lasix® (Furosemide) to enhance urination

Common Side Effects

- Muscle cramps
- Headache
- Low potassium level
- Sensitivity to sunlight (wear full coverage clothing and sunscreen)

Aldactone® (Spironolactone)

Available Formulations: tablet, liquid

Purpose

Often combined with other diuretics like Bumex® (Bumetanide) or Lasix® (Furosemide) to prevent low potassium levels and enhance urination

Common Side Effects

- High potassium level

OTHER MISCELLANEOUS MEDICINES:

Aloprim®; Zyloprim® (Allopurinol)

Available formulations: tablet, chewable tablet

Purpose

Allopurinol is used to lower uric acid in the blood. High uric acid can lead to gout, which can be painful.

Common Side Effects

- Stomach upset
- Diarrhea

Aspirin

Available formulations: tablet, chewable tablet

Purpose

Aspirin thins the blood, assisting in blood flow through the veins and arteries to the new organ

Common Side Effects

- Bruising
- Bleeding
- Stomach upset

Please notify your transplant coordinator if you notice that the transplant recipient is bruising more easily.

OVER-THE-COUNTER MEDICATIONS

Do not give over-the-counter medications, or food supplements without speaking to the transplant team, unless they are on an approved over-the-counter medication list. These include aspirin, antacids, cough medicines, cold medicines, laxatives or herbal drugs. Many medicines contain drugs that cause high blood pressure. Do not take any of these medicines without first checking with the transplant coordinator or transplant pharmacist. Herbal supplements can adversely interact with transplant medications. **Do not take herbal supplements unless first discussed with your transplant coordinator or transplant pharmacist.** Herbal remedies include herbal drugs, herbal teas, essential oils, etc.



What Should You Learn About Food and Nutrition?

Food Safety Guidelines

After transplant, recipients will be immunosuppressed. Children who have a transplant are at risk for foodborne infections, just like they are at risk for other infections. Foodborne illness or infections are often called food poisoning. Food poisoning can occur after eating raw or undercooked food. After transplant it is very important to practice good hand hygiene when cooking or eating food and to avoid food that is raw or undercooked. Your transplant dietitian will be able to provide more education on specific foods to avoid to prevent foodborne illness and safe cooking practices.

See food & water safety guidelines in the post-transplant section.

Food/Drug Interactions

Do not give grapefruit, pomegranate (or juices that contain either one), starfruit, Seville oranges (usually found in marmalade) or Noni juice as these foods can interfere with the levels of Prograf® (tacrolimus) and cyclosporine. Additionally, any antibiotics should only be given after interactions have been checked by the transplant team. These foods and medications can interfere with the absorption or the breakdown of Prograf® (tacrolimus) and cyclosporine and may cause high levels that can lead to side effects.

Vitamins and Supplements

Sometimes electrolyte levels may be altered after transplant. Electrolytes may need to be replaced with medication. Vitamin and mineral levels may also be checked after transplant, and if levels are low, recipients may need to take additional supplements. Your transplant team will tell you which supplements to take if needed. Herbal supplements can adversely interact with transplant medications. Do not take herbal supplements unless first discussed with your transplant coordinator or physician. Herbal remedies include herbal drugs, herbal teas, essential oils, etc.

Is the Compliance Agreement Still in Effect?

Good medical adherence and good communication with your transplant team are an important part of the transplant's success. The compliance agreement you signed during transplant evaluation is for all phases of transplant (pre-transplant, during the transplant hospitalization, and post-transplant).

What Should You Know About Research Studies?

Texas Children's Hospital participates in many research projects in our center and across the nation. Clinical research is one of the main reasons that there has been improvement in patient and graft/transplanted organ survivals. Participation in research is voluntary. Parents/caregivers can participate in a research study. You can choose whether or not to participate in a research study without worry that saying no will affect the medical or nursing care the patient receives.

Transplant Phase: Section Quiz Review

1. How can you make sure you are ready to get the call for transplant?
 - a. Be prepared for the call at any time, day or night
 - b. Keep your cell phone and/or pager charged and in working order at all times
 - c. If you have a pager, you should test it weekly to make sure it's functioning properly
 - d. Have a bag packed with clothing, medication, medical supplies, and cash for miscellaneous items
 - e. All of the above
2. What should you do when you receive the call that an organ is available?
 - a. Panic
 - b. Follow the instructions the transplant coordinator gives you
 - c. Go eat a big meal
 - d. Take a nap
3. Can the transplant be cancelled once the transplant candidate is called in to the hospital?
 - a. Yes, the transplant could be cancelled at any time prior to the new organ being placed.
 - b. No, once the candidate is called in to the hospital, it's a sure thing.
4. To prepare for transplant, the team will do the following: Obtain the candidate's height and weight; order an X-ray and lab tests; start an IV (if one isn't already in place); and the surgeon and anesthesiologist will come and ask you to sign a consent for the surgery.
 - a. True
 - b. False
5. While the patient is in the Intensive Care Unit (ICU), there is a limit of 2 visitors at a time. It is important that you limit visitors as much as possible to reduce the patient's risk for getting an infection.
 - a. True
 - b. False
6. You should review unit visitation policies before allowing any children to come to the hospital, to make sure they are allowed to visit that unit.
 - a. True
 - b. False
7. Once the patient is transferred to an acute care floor, how often are vital signs checked?
 - a. Twice a day
 - b. Every 4 hours
 - c. Once a day
 - d. Never

8. Which of the following are ways to limit exposure to illness after transplant?
 - a. Wash hands frequently with soap and water or hand sanitizer
 - b. Keep sick visitors away
 - c. Keep your hands away from your eyes, nose, and mouth unless freshly washed with soap and water.
 - d. All of the above
9. What are some common activity restrictions after transplant?
 - a. The recipient should not enter lakes, swimming pools, hot tubs, etc. until incisions have completely healed and there are no remaining scabs.
 - b. No driving for 6-8 weeks following surgery (if applicable)
 - c. No lifting anything heavier than 5-6 pounds for 6-8 weeks following surgery
 - d. All of the above
10. All family members should receive the flu vaccine annually.
 - a. True
 - b. False
11. You will be taught how to check vital signs and record them on a log sheet.
 - a. True
 - b. False
12. In regards to transplant medications, which of the following is FALSE?
 - a. Medication timing is not important, just take them whenever you remember
 - b. It is important to take medications at the same time every day
 - c. It is important to keep an updated medication list with you at all times
 - d. You should call for refills at least 5 days before running out
13. Should any medications be started or stopped without talking to a transplant team member (whether prescribed by another provider or bought over the counter)?
 - a. No. Contact the transplant team prior to starting or stopping any medications
 - b. Yes. I can do whatever I want
14. The following are types of medications the transplant recipient may be on:
 - a. Anti-rejection medications
 - b. Anti-infection medications
 - c. Blood pressure medications
 - d. All of the above

15. Due to interactions with medications, some fruits and their juices to avoid are:

- a. Grapefruit, Pomegranate
- b. Grapefruit, Pomegranate, Starfruit, Seville Oranges (Marmalade), or Noni juice
- c. Seville Oranges (Marmalade), Bananas, Grapefruit, Pomegranate, Oranges
- d. Starfruit, Grapefruit

Answer Key: 1) e 2) b 3) a 4) a 5) a 6) a 7) b 8) d 9) d 10) a 11) a 12) a 13) a 14) d 15) b

Common Questions in the Transplant Period

- 1. How long can parents/caregivers stay with the transplant candidate before surgery?**

Parents/caregivers can stay with the candidate until they leave the operating room holding area.
- 2. If the transplant candidate is fearful of the surgery, what resources are available to help?**

Child life is available to assist transplant candidates and their families in decreasing fears through written materials, videos, and/or hospital tours. A psychologist is available as needed.
- 3. What do transplant recipients look like after the surgery?**

They will have an incision (that may be covered by a dressing) where their transplant surgery occurred. They will be attached to several machines after the surgery. They will have multiple wires/cables that help the care team monitor vital signs. They will have several types of tubes that were placed in the O.R.
- 4. When can you see the patient after the surgery?**

After surgery, the patient will be moved to the recovery room or be moved straight to the ICU. Once the team has transferred the patient to the new area, they will let you know when it's ok to visit.
- 5. How long will the patient be in the hospital after transplant?**

Average length of stay is 14 days, but can vary depending on complications and severity of illness prior to transplant.
- 6. How long will the transplant recipient be on medications after transplant?**

Almost all transplant recipients remain on medications for the rest of their lives. Some patients are able to be placed on fewer medications over time.
- 7. How will you know what medications to give once out of the hospital?**

The transplant team will create a medication schedule for you to follow. You will be taught about each medication and how to give it.
- 8. What if a transplant recipient vomits after taking his or her medications?**

WITHIN 30 minutes after medication: repeat the medication dose.

MORE THAN 30 minutes after medication: DO NOT repeat the medication dose UNLESS you can actually see tablets/capsules or the color of the liquid medication in the vomit.

Call the transplant coordinator if vomiting persists.
- 9. Will the patient be cured after receiving a transplant?**

Transplant is not a cure, but it can be a treatment option.
- 10. When will follow-up be needed after leaving the hospital?**

You are required to live in the Houston area for 3 months post-transplant. Follow-up visits will be very frequent once discharged from the hospital. Appointments will be spaced out gradually over time as your comfort level increases, and you heal from the surgery.

When Should You Contact the Transplant Team After Transplant?

Vital Signs

- Changes in vital signs (blood pressure or heart rate decreases or elevations)
- Heart rate becomes rapid at rest, is irregular, or is pounding
- Difficulty breathing (abdominal breathing, making grunting noises)
- Increased cyanosis (blueness)
- Decreased oxygen saturation level

Gastrointestinal/Genitourinary Problems

- Increased abdominal size, abdominal pain, or swelling
- Persistent vomiting, diarrhea, or severe abdominal pain
- Vomiting blood
- Blood present in vomit or bowel movement (coffee ground-like or red vomit; dark tarry or bright red bowel movement)
- Bloody urine
- Decrease in urine output (decreased frequency or amount)
- Difficulty or pain when emptying bladder

Activity

- Decrease in activity level (not keeping up like normal)
- Decreased exercise tolerance
- Sleeping more than usual
- Decrease in appetite
- Irritability

Miscellaneous

- Sweating more than usual
- Jaundice (yellowing of the eyes/skin)
- Persistent or severe headaches
- Bloody sputum (mucus)
- Swelling/retaining fluid (if feet, legs, hands, or eyelids swell)
- If you must leave town for an emergency
- Prior to having any dental work done, including routine cleaning (antibiotics may be needed)

Illness and Medication

- Fever of 101° or higher (or extremely low temperatures less than 96°)
- Cough, congestion, or runny nose
- Exposure to chicken pox, shingles, measles, mumps, TB, or hepatitis
- Redness or drainage in or around incision or any open wound
- If a dose of medication is missed
- Difficulty obtaining medications (notify team BEFORE supply will run out)
- Before starting any new medications (including over the counter medications)
- If a doctor tells you to change or stop a medication (ask the transplant team before making the changes)
- Medication changes, illnesses, or hospitalizations

Contact Information

MONDAY-FRIDAY, 8:00AM-4:30PM:

Non-urgent Issues: Contact your transplant coordinator by phone or email.

Urgent Issues: Call **832-824-2099** and request to have your *transplant coordinator* paged (Toll-free number is 1-800-364-5437). If you do not receive a return call within 30 minutes, please try again as technical difficulties do sometimes occur.

AFTER HOURS, WEEKENDS, OR HOLIDAYS:

Non-urgent Issues: Email your transplant coordinator.

Urgent Issues: Call **832-824-2099** and request to have the *transplant physician* on call paged (Toll-free number is 1-800-364-5437). If you do not receive a return call within 30 minutes, please try again as technical difficulties do sometimes occur.

For a true medical emergency, such as difficulty breathing or change in responsiveness, please call 911.

TRANSPLANT



SURVIVOR

Section 4

Possible Complications

This section will help you understand some possible complications that could occur after transplant. Our goal is for transplant recipients to have a full life, including the opportunity to go to school and enjoy recreation. To accomplish these goals, we suggest some reasonable measures that will control exposure to infectious agents without severely limiting their lifestyle. Please call the transplant office if the recipient gets sick. The team will determine if the recipient needs to come in or have tests.

Things to Avoid

- Hay
- Compost piles
- Bat caves
- Duck or bird stools
- No cleaning of a litter box or after any animal
- Construction sites
- Certain animals like reptiles, birds, etc. See *pets recommendations in Section 5 Post Transplant*
- Discuss swimming activities and locations with the transplant team



Childhood Diseases/Common Infections

VIRAL RESPIRATORY INFECTION:

- We may recommend testing for certain viruses.
- Viral testing is not typically done in a non-transplant setting!
- Most of these viruses will NOT cause significant problems and many are not treatable.
- Some are potentially dangerous but are treatable like influenza, RSV and adenovirus.
- Antiviral therapies work best when they are started early in the course of an infection.
- If fever, nasal congestion and cough begin over the weekend, notify the transplant center right away!
Do not wait until Monday.
- Flu (influenza)
 - General information
 - ù Caused by a virus
 - ù Recipients should obtain flu vaccine every year
 - Signs and symptoms
 - ù Fever
 - ù Cough
 - ù Sore throat
 - ù Runny nose
 - ù General muscle aches
 - Treatment
 - ù A medicine can be started to help lessen flu symptoms if started in the first 48 hours of illness



CHICKENPOX (VARICELLA)

- General information:
 - Common childhood disease.
 - Can develop at any age, but occurs more frequently from ages 5 to 10 years.
 - Can be a serious illness for the immunosuppressed transplant recipient that can cause complications or death in severe cases.
- How it is spread:
 - Spread through the air or by close contact with someone who has the virus.
 - Contagious for 2 days before the rash occurs and until all the pox have developed a scab (usually 6 days after the rash appears).
 - If exposed, he or she could develop chickenpox anywhere from 14 to 21 days following exposure (the incubation period).
- Signs and symptoms:
 - Often begins with a fever and dry cough.
 - Splotchy rash may begin on the head and spread downward, or on the trunk and spread outward.
 - Rash consists of small, watery blisters with red rings around them.
 - A person with chickenpox feels very ill for a few days.
 - The rash may be altered in appearance because of the Varicella-Zoster Immune Globulin (V-ZIG) injection or immunosuppressant drugs.
- Prevention:
 - Please tell your friends and family, classmates, and teachers about the danger of chickenpox.
 - Ask them to call you if any child is exposed or gets chickenpox. We have found that most people are sympathetic to your situation and are willing to cooperate. Even with precautions, your child may be exposed.
- What to do if a transplant recipient is exposed:
 - If you come into contact with someone who breaks out with chickenpox within 24-48 hours, call your transplant coordinator immediately.
 - You will need to have a V-ZIG injection within 3 days of exposure. The injection may not prevent chickenpox, but may lessen the severity of it.
 - If the recipient still gets chickenpox even after the V-ZIG:
 - ù He or she may need to be hospitalized and started on Acyclovir.
 - ù Usually a 10-14 day hospital stay until all lesions are crusted over.

SHINGLES (VARICELLA)

- General Information
 - Caused by a reactivation of the same virus that causes chickenpox (Varicella)
 - When the virus is reactivated, it will cause an outbreak of shingles. You can get chicken pox when exposed to the drainage from these lesions.
- Signs and Symptoms
 - One to three days before rash appears symptoms may include: pain, tingling, and burning on the side of the chest, neck, forehead, back, hip, or leg.
 - Rash and sores appear in clusters of blisters
 - You will no longer be contagious when all lesions are scabbed over
- Treatment
 - Contact the transplant team immediately – see “chicken pox” for treatment

CYTOMEGALOVIRUS (CMV)

- General information:
 - CMV is a member of the herpes virus group.
 - Can cause serious illness in organ transplant recipients.
 - Viral levels can be checked by blood test and are ordered routinely before transplant and as needed as part of transplant follow-up.
- How it is spread:
 - Virus can come from an infection you had before transplant that comes back due to immunosuppression.
 - Virus can come from your donor.
 - Virus can come from an outside source.
- Signs and symptoms:
 - Headaches
 - Fatigue
 - Aching
 - Fever
 - Swollen glands
 - Diarrhea
 - Pneumonia
- Prevention:
 - Practice good hand washing.
 - Do not share drinks.
 - Once CMV is in your body, you have it for life.
 - It can reoccur.
 - We can give medicines to help prevent CMV infection.
 - Younger children are more likely to spread the virus. Keep this in mind in daycare settings and for recipients with younger siblings.
 - If the transplanted heart is CMV (+), or the recipient is already CMV (+) they will receive prophylactic treatment in the first 3 months to 1 year post-transplant.
 - There are 2 types of treatment/prevention medications
 - ù Ganciclovir (IV) /Valcyte (oral): This medication is used for the treatment and prevention of CMV. You will take this medication for the first 3-months if you receive a CMV (+) organ or if blood tests are CMV (+) prior to transplant.
 - ù Cytogam (IV only): This medication is used in the prevention of CMV by giving anti-CMV antibodies. It is given within the first 72 hours of transplant. Six more doses will be given at scheduled intervals over approximately 12 weeks. It will be given at a separate appointment in the infusion center. The infusion takes approximately 4 hours and the recipient will be monitored during each infusion. Recipients will only receive this medication if they receive a CMV (+) organ or if blood tests are CMV (+) prior to transplant. Your coordinator will remind you each time a dose is due.



EPSTEIN-BARR VIRUS (EBV)

- General information:
 - EBV is a member of the herpes virus group.
 - Can cause serious illness in organ transplant recipients.
 - EBV is common in the community and causes mononucleosis; also known as "the kissing disease."
 - Viral levels can be checked by blood test and are ordered routinely before transplant and as needed as part of transplant follow-up.
- How it is spread:
 - Virus can come from an infection the patient had before transplant that comes back due to immunosuppression
 - Virus can come from the donor
 - Virus can come from an outside source with intimate contact.
- Signs and symptoms:
 - Extreme fatigue
 - Fever
 - Sore throat
 - Swollen glands (lymph nodes)
- Prevention:
 - Practice good hand washing.
 - Do not share drinks.
 - Once EBV is in your body, you have it for life.
 - It can reoccur.
- Treatment:
 - Medications can be given as a precaution/preventative or for confirmed infection.
 - Medications are available in IV and oral form depending on severity of illness.
 - Immunosuppression doses may need to adjusted with guidance of the transplant team.
- Complication of EBV: Post-Transplant Lymphoproliferative Disease (PTLD):EBV has been linked to a rare complication called PTLTLD
 - PTLTLD can be serious or fatal
 - Complication of chronic immunosuppression in organ transplant patients
 - It is a cancer of the lymphocytes that is caused by the EBV virus in patients on anti-rejection medications
 - Treated by decreasing anti-rejection medications, antiviral medications, surgical removal, or chemotherapy/ radiation if necessary.



Types of Rejection

Rejection is the body's normal reaction to something it thinks does not belong there. The immune system keeps you healthy. It works by protecting the body from attack by foreign things like germs (bacteria or viruses) and cancer cells. The transplant recipient's immune system will try to reject the new organ because it recognizes that the new organ is different from the rest of the body. Transplant recipients take immunosuppressant medications for the rest of their lives to prevent rejection of the transplanted organ. Rejection is more likely in recipients who miss medication doses. Taking medication as prescribed consistently will help prolong the life of the transplanted organ. There are different types of rejection. With acute rejection, it is possible for heart function to improve. When chronic rejection is diagnosed, the heart function will usually not improve.

ACUTE CELLULAR REJECTION (ACR)

ACR is caused by the white blood cells in your body

Grades and Treatment:

- **Grade 0 (No Acute Rejection):** No rejection or cell damage on the biopsy tissue (heart tissue samples). The transplant team will not typically make any medication changes.
- **Grade 1R (focal, Mild Acute Rejection):** Mild immune response against the organ is detected, but it is not causing harm to the organ. This is often described to families as the body recognizing that the heart is not the original organ, but it is not trying to fight it off. There is usually no need to change your child's medications.
- **Grade 2R (Moderate Acute Rejection):** A greater immune system response is detected and there is noticeable cell damage. This score typically requires a 24-48 hour hospital admission for IV steroids and an increase in the current doses of immune suppression medications. We typically repeat the biopsy about two weeks after treatment to make sure that the rejection is gone.
- **Grade 3R (Diffuse, Borderline Severe Acute Rejection):** An even greater immune system response is detected and the cells have been damaged. This result requires your child be admitted to hospital, where they will receive IV steroids. He or she may also receive other anti-rejection medications if the rejection does not respond to the steroids. After treatment for the rejection, we will repeat the biopsy in about two weeks to make sure that the rejection is gone.

ANTIBODY MEDIATED REJECTION

Caused by proteins called antibodies that recognize foreign things in your body.

- Testing for antibody mediated rejection is done by pathologist from biopsy tissue.
- Results are either positive or negative.
 - Positive = Antibody Mediated Rejection
 - Negative = No Antibody Mediated Rejection

CHRONIC REJECTION

Transplant Coronary Artery Disease (TCAD): the most prevalent long-term complication associated with heart transplant. Currently, the only treatment for this disease is re-transplantation.

Signs and Symptoms of Rejection

- Fever
- Fatigue
- Shortness of breath
- Stomach upset
- Irritability
- Palpitations (faster heart beat)
- Dizziness
- Swelling or significant weight gain
- Changes in your child's usual heart rate or blood pressure

Possible Treatment for Rejection

There are several treatment options for rejection. Treatment will be based on the type and severity of the rejection and will be individualized for each patient. If any of these treatments are necessary, we will discuss them with you.

Possible treatment options:

- “Pulse” steroids: large increase in steroids over a short time period.
- Addition of another immunosuppressant.
- High dose IVIG.
- Use of stronger medicines like rituximab or bortezomib.
- A procedure called plasmapheresis to remove the antibodies from the blood.

Other Possible Complications

KIDNEY DYSFUNCTION

HIGH BLOOD PRESSURE

GINGIVAL HYPERPLASIA: Overgrowth of gum tissue in the mouth

HIRSUTISM: Excessive hair growth

OSTEOPOROSIS: Weakening of the bones

OBESITY

HYPERLIPIDEMIA: High cholesterol and/or triglycerides

DIABETES MELLITUS: High blood sugar

WHAT YOU CAN DO

Transplant recipients directly contribute to the success of their transplant. Failure to comply with the medical regimen is the number one cause of organ failure. Close follow up with your transplant team and primary-care physician can improve the chances of a good outcome. Careful attention to medication schedules, lifestyle changes, infection-avoidance techniques are all important ways to prolong one's life after transplantation.





Section 5

After Transplant (Post-Transplant Phase)

How Long Will You Need To Stay in Houston After Transplant Surgery?

All heart transplant patients are required to remain within 1 hour of Texas Children's Hospital for 3 months post-transplant.

How Often Will the Transplant Recipient Need to Come to Texas Children's After Transplant?

FOR ROUTINE CLINIC VISITS

The transplant team will determine how often each recipient needs to be seen for follow up in the transplant clinic.

Standard (approximate) clinic follow-up is as follows:

Initially, clinic visits are once a week or once every two weeks, either in the outpatient clinic or for a heart biopsy. Over time, the frequency of outpatient visits will spread out. It will be important for you to remember that the first three months after transplant is the time the recipient is at the most risk for infection and rejection. Visits will decrease in frequency the longer the time post-transplant.

After the first year of transplant, transplant patients are typically seen once every four months. This generally consists of two clinic visits and one biopsy per year.

Outpatient appointments will take place on the 20th floor of West Tower. These appointments will always require testing to be done. Once all of the testing is complete, you will be seen by the physician. Adjustments to medications may need to be made. These are the tests that may be ordered:

- Blood tests – to check for infection, rejection, kidney and liver function and the levels of antirejection medications in the blood
- Chest x-ray – to check for pneumonia or fluid collection in the chest cavity
- EKG – to check the heart rhythm
- Echocardiogram – to check the heart function
- Vital signs – to check the heart rate and blood pressure
- Physical exam – to listen to heart sounds and lung sounds
- 24 hour holter monitor – to record the heart rhythm for 24 hours
- Stress test – done on a treadmill to check the body's response to activity and to check activity tolerance

FOR ROUTINE LAB DRAWS

On days of lab work, do not give the immunosuppressant medications until the blood has been drawn. However, you should give all the other medications. You must bring the immunosuppressant medications with you, so you can give them after the blood is drawn. Immunosuppressant medications levels need to be drawn 30-60 minutes before



the next dose. If the dose is due at 9:00am and 9:00pm, a pre-medication level (called a trough) should be drawn between 8:00am and 9:00am.

Labs are usually checked weekly to twice weekly in the outpatient lab. Over time, the frequency of lab draws will decrease.

PROCEDURES AND BIOPSIES

A biopsy of the heart muscle is the most accurate way to diagnose rejection. This procedure is normally completed on an outpatient basis. The transplant team will determine how often a biopsy is needed to assess organ function.

The normal protocol for biopsies during the first three months after transplant is at 2, 4, 8, and 12 weeks. At the 12 week biopsy, coronary angiography will be performed to establish a baseline. There will be another biopsy six months post-transplant and again near the one year anniversary. This schedule will be followed as long as there is no rejection present. If rejection is found, the schedule will be altered as needed.

Coming to the hospital and before the biopsy

- The recipient may not have any food or liquids after midnight on the night before the biopsy.
- Hold all morning meds unless otherwise instructed. Bring all medications with you on the day of the biopsy.
- Labs will be drawn before the procedure.
- An IV will be placed before the procedure. Medication is given through the IV to make the recipient sleepy and relaxed before the test is performed.
- A Child Life Specialist will explain the procedure in advance and will be present during the procedure to provide coping support.

During the biopsy

- The biopsy will be performed in the cardiac catheterization lab (cath lab) on the 18th floor of West Tower.
- The procedure will take 2-3 hours
- The patient will be sedated for this procedure.
- Once sedated, a tube is inserted either in the neck or groin.
- The physician will measure the pressures on the right side of the heart. These measurements indicate how well the heart is working.
- Once the pressure measurements are complete, an instrument called a bioptome is used to take small pieces of heart tissue.
- This tissue is then sent to the pathology lab, processed and evaluated by a pathologist to determine if there is rejection.

After the biopsy

- The recipient will need to recover from the sedation in the recovery area.
- There will also be a pressure bandage present at the insertion site of the catheter used during the procedure. This bandage has to stay in place for 4-6 hours depending on which vessel was used for the procedure.
- You are required to stay in the recovery area until the results from the biopsy score are available. It can take until 5:00-6:00 pm to get the results back. Please be prepared to spend the day at the hospital when you come for a biopsy.

Compliance/Adherence

Good medical adherence and good communication with your transplant team are an important part of the transplant's success. The compliance agreement you signed during transplant evaluation is for all phases of transplant (pre-transplant, during the transplant hospitalization, and post-transplant). It is expected that you will give medications as prescribed, return for follow-up clinic visits and go for routine lab work.

Transplant recipients directly contribute to the success of their transplant. Failure to comply with the medical regimen is the number one cause of organ failure. Close follow up with your transplant team and primary-care physician can improve the chances of a good outcome. Careful attention to medication schedules, lifestyle changes, infection avoidance techniques are all important ways to prolong one's life after transplantation.

How Can You Get Transplant Medications?

- You will be discharged home with the necessary medications. Your transplant coordinator and physician will order the medications from a specialty pharmacy based on your insurance requirements. It is your responsibility to request medication refills once discharged from the hospital.
- When you have refills remaining, contact your pharmacy directly at least 5 days before you run out of medication.
- When you are out of refills for medications, contact your transplant coordinator at least 5 days before you run out of medication. Coordinators may only refill medications during office hours, Monday – Friday, 8:00am – 4:30pm. No refills will be done after hours, on weekends or, on holidays.

How Can You Get Transplant Supplies?

- Hospital staff will order needed supplies for discharge from a supply company based on your insurance requirements. It is your responsibility to request needed supplies after discharged from the hospital.

What Are the Activity Restrictions After a Recent Transplant Surgery?

Transplant recipients:

- Should not lift anything greater than 5 pounds for 6 weeks after surgery.
- Should not perform strenuous activity for 6 weeks after surgery.
- Should avoid pulling or positioning themselves using their arms for 6-8 weeks after surgery.
 - When moving from a lying position, have someone support you behind your back to move to an upright position. **Do not pull or push yourself up using your arms.**
 - When moving from a sitting position, the patient should use their legs to support their weight.
 - Parent/caregivers should avoid lifting the transplant recipient by picking him or her up under the arms. "Scoop" the patient for at least 6 weeks after surgery.
- Should not drive for 8 weeks after surgery (if applicable).
- Should check the incision daily. If there is any unusual redness, swelling, pus, drainage, or pain, contact your transplant coordinator.
 - Follow the surgery team's instructions for incision care.
- Should keep the incision clean and dry. Do not apply ointments, lotions, or creams (unless prescribed).
- May shower and wash the incision only briefly with mild soap and water after the sutures are removed.
- Should not soak the incision area for at least 4-6 weeks after the surgery when bathing.
- Should not enter lakes, swimming pools, hot tubs, etc. until complete healing of the wound occurs and there are no more scabs.

Will You Need Physical or Occupational Therapy After Transplant?

PTs and OTs will be involved early after transplant to help get the recipient up and moving. They will assist with achieving independence with normal everyday activities.

Some ways PT and OT can help are:

Physical Therapy

- Post-op mobility
- Getting patients up and walking
- Parent/caregiver/child education
- Reinforce sternal precautions
- Importance of mobility
- Home exercise program
- Facilitate independence with mobility
- Balance
- Stairs

Occupational Therapy

- Feeding
- Fine motor skills
- Developmental
- Strengthening
- Endurance
- Sensory
- Community reintegration
- Activities of daily living
 - Showering
 - Dressing
 - Brushing teeth

REHABILITATION

Occupational and Physical therapy work closely together and often overlap when addressing rehabilitation needs. The major goal of therapy for transplant recipients is to help them reach their highest level of functioning and independence after transplant surgery.

This involves helping recipients regain strength, range of motion of joints, age appropriate fine and gross motor skills, perceptual skills, and ability to participate in everyday activities. Home programs, caregiver instruction and referral to community programs are made when needed. Rehabilitation and therapy programs are created based on each patient's needs.

What Should You Do for Infection Control Post-Transplant?

The transplant recipient will receive very strong anti-rejection medications at the time of transplant that lower the body's ability to fight off infections. Special care must be taken to avoid contact with other people who are sick. Only immediate family members should visit during this time.

Remember, the transplant recipient is **highly immunosuppressed** after transplant and is at **high risk for infection**. An infection during this time might be considered **life-threatening**. Everyone who visits post-transplant **MUST** practice good hand washing techniques. Limiting visitors is important, especially in the **first 6 months post-transplant**.



Any fever, cough, vomiting, diarrhea, rash, or mouth lesions should be reported to the transplant physician.

WAYS TO LIMIT EXPOSURE TO ILLNESS POST-TRANSPLANT

For the patient:

- Wear a mask when at the hospital for clinic visits (if applicable).
- Avoid crowds for the first 3 months after transplant, if possible.

For parents/caregivers and recipients:

- Wash your hands, and use hand sanitizer.
- Keep hands away from your eyes, nose, and mouth unless freshly washed with soap and water.
- Keep sick visitors away.
- Take off shoes and outerwear before entering the home.
- Wash your hands as soon as you get home.
- Wash hands frequently with soap and water.
- Always use separate drinking glasses and eating utensils.
- If someone at home becomes sick:
 - Try to limit the ill person's time around the recipient (keep them apart if possible).
 - Have the ill person cover his or her mouth when sneezing and coughing.
 - Wash hands frequently.
- Keep immunizations up-to-date. **No live virus vaccines for the recipient, ever.** Always check with your transplant team before anyone in your household receives a live vaccine.

How Can You Balance Your Family's Needs After Transplant?

Caring for a transplant recipient can change the family's daily routines. Everyone will need some time to get used to the transplant recipient being home from the hospital. As time passes, your family will gain confidence in caring for the recipient.

Before transplant, a lot of the focus was on the sick child. The family may have found it difficult to participate in certain activities. After transplant, improvement in the transplant recipient's health can improve quality of life for the recipient and his or her family. You may find that your family is able to plan and do more activities together.

Below are some of the common issues families can face after a transplant. Talking openly with your transplant team about these issues can help you find solutions for all family members. The transplant team can help you locate resources as needed.

PARENTS/CAREGIVERS

Some parents/caregivers may struggle with establishing good behavioral limits for their child after transplant. Saying no can be hard because of all that their child has been through. Most children feel safer with consistent discipline, rules to guide them, and normal routines. Other parents/caregivers may struggle with being overprotective, but as time passes, parents/caregivers usually become less overprotective and find it easier to allow their child some freedom.

RECIPIENT

In addition to the feelings that come from having a new organ, being away from home for the operation and hospital stay can be hard on the recipient. Recovering emotionally after a transplant will take time and patience.

It is normal for there to be some behavioral changes with a life event as big as transplant. Recipients can become withdrawn, more outgoing, and/or more attached to family. Younger children may regress in meeting their developmental goals. This usually gets better with time.

BROTHERS AND SISTERS (SIBLINGS)

Siblings may go through a period of adjustment following transplant because of long periods of separation. This can contribute to feelings of anxiety. Siblings might compete for attention and/or become jealous of the transplant recipient, which can create tension in the family unit. Siblings may become more attached, more demanding, more temperamental, or may struggle with following rules.

To help siblings cope with these changes, parents/caregivers can set time to spend just with them. Parents/caregivers should allow siblings to express their feelings about transplantation and how they've been affected. Promote feelings of family togetherness by participating in activities your family can do together.

FAMILY MEMBERS/FRIENDS

Extended family members and friends may have the same types of feelings and struggles after transplant. They will want to visit once you return home, but please remember the importance of limiting visitors, especially in the first 6 months post-transplant.

Do Transplant Recipients Return to School?

The goal of transplant is to return to as near a normal life as possible. Returning to school can be a source of anxiety for many parents/caregivers and children, but it is an important part of childhood. Our expectation is for the transplant recipient to return to school once medically cleared.



How Can Transplant Recipients Have a Healthy Lifestyle?

Routine health care, good nutrition, drinking plenty of water, and regular exercise can enhance overall health. These are an essential part of staying healthy after transplant.

ROUTINE HEALTH CARE

Immunizations

- Routine vaccinations, EXCEPT for live virus vaccines, are important to protect patients with compromised immune systems after transplant. It is recommended that transplant patients and their family members stay up to date on their regular immunization schedule.
- Most recipients resume their regular immunization schedule (except for live virus vaccines like varicella and MMR, see *the table on the next page* for more detail) at 6 months after transplant.
 - Exception: the flu shot can be given 2 months after transplant, or can even be given as early as 2 weeks after transplant during peak flu season.
 - ù When a sibling or family member receives a live virus vaccine (which transplant recipients **cannot** receive), caution should be used to avoid contact with body fluids from the person who received a live virus vaccine for at least 2 weeks (no drink sharing, good hand washing, etc.).
- It is recommended that family members receive their flu shot annually.



- If you or your local physician have a question about an immunization that is not on the list at the next page please feel free to contact the recipient's transplant coordinator directly.

Allowed

- DTaP, Tdap: diphtheria, tetanus toxoid, acellular pertussis
- Td: diphtheria, tetanus toxoid
- Haemophilus influenzae type B (Hib)
- Poliovirus (IPV) (Injectable)
- Hepatitis A (HAV)
- Hepatitis B (HBV)
- Typhoid (injectable)
- Pneumococcal (PCV13, Pneumovax 23)
- Rabies
- Meningococcal vaccine (MCV4)
- HPV (papillomavirus) (Gardasil®)
- Influenza (flu) (injectable)

The following are not immunizations, but they are allowed:

- Mantoux (TB) tests (PPD): test for tuberculosis
- Immune globulin (gamma globulin): infusion

Not Allowed

- MMR: measles, mumps, rubella (German measles)
- Varicella virus (Varivax®)
- Poliovirus (OPV) (Oral)
- Yellow fever
- BCG (for TB)
- Cholera
- Smallpox
- Typhoid (oral)
- Rotavirus (oral)
- FluMist (nasal spray influenza) (flu)
- Shingles (Herpes Zoster)

Dental Care

- All children should receive regular preventative dental care once the primary teeth are in place (as early as 18 months for some children).
- Topical applications of fluoride to the teeth may be necessary if the water supply in your home community does not contain fluoride. Fluoride is an excellent preventative against tooth decay.
- **Routine dental work (filling a cavity or cleaning of teeth) may require pre-treatment with antibiotics to prevent infection. Please consult with your transplant coordinator prior to dental procedures.** Your dentist can consult with the transplant physician regarding the protocol.
- You will also need to communicate to your dentist if the recipient is taking steroids daily. Dental procedures do not usually require extra doses of steroids for patients who take a daily dose of steroids.

Skin Care

- Patients may be more at risk for developing certain types of skin conditions, including skin cancer after transplant.
- Dermatology screening visits may be recommended. Please discuss with the transplant team.

Well-Woman Visits (for females >13 years old)

- Standard recommendations for well-woman visits recommend an initial educational visit to a gynecologist between the ages of 13 and 15 years old.
 - Generally does not include pelvic examination and focuses on patient education.
 - ù Establish the clinician-patient relationship.
 - ù Discussion of body development, body image, self-confidence, weight management, immunizations (including the human papillomavirus vaccine), contraception, and prevention of sexually transmitted infections (STIs).
 - ù Patients who are sexually active, regardless of age, should see a gynecologist for check ups and education.
- Pap smears (screening for cervical cancer):
 - ù Recommended to begin at age 21 (regardless of sexual activity) and then every 3 years.
 - ù Women who have a weakened immune system may need to be screened more frequently.

ù Please talk to the transplant team and/or gynecologist to discuss needs on an individualized basis.

- Resource: <http://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Gynecologic-Practice/Well-Woman-Visit>

FOOD AND NUTRITION

Food Safety Guidelines

The recipient will be immunosuppressed after transplant. Transplant recipients are at risk for food-borne infections, just like they are at risk for other infections. Food-borne illness or infections are often called food poisoning. Food poisoning can occur after eating raw or undercooked food. After transplant, it is very important to practice good hand hygiene when cooking or eating food and to avoid food that is raw or undercooked. Your transplant dietitian will be able to provide more education on specific foods to avoid to prevent food borne illness and safe cooking practices. The U.S. Department of Agriculture and Food and Drug Administration have provided guidance to decrease the risk.

Food safety guidelines are for:

- Cleaning: washing hands, surfaces, and fruits/vegetables.
- Separating: preventing cross contamination by preparing raw food away from cooked food
- Cooking: ensure foods are cooked to a safe temperature
- Chilling: make sure food is chilled promptly
- Online resource for transplant food safety: <http://www.fda.gov/downloads/Food/FoodborneIllnessContaminants/UCM312793.pdf>

Water Safety Guidelines

Because of the transplant recipient's lowered immune system after transplant, they can become ill from exposure to contaminated water. Water consumed after transplant needs to be safe and free from bacteria.

Water safety guidelines are for:

- Cooking and drinking
- Washing dishes and utensils
- Brushing teeth

Safe Water Sources:

- City Water: If your home faucet water comes from a city water supply or a municipal well, it is safe.
- Bottled Water:
 - Is considered safe if it has been processed in one of these ways:
 - ù Reverse osmosis
 - ù Distillation
 - ù Filtration with an absolute 1 micron or smaller filter
 - Not all bottled water is considered free from bacteria. Bottled water labeled as well water, spring water, or mineral water does not mean it is safe. Read the label to find out if the water has been treated by osmosis, distillation, or filtration (see above).
 - ù For more information: www.bottledwater.org



- Distilled Water
 - ↳ A steam distillation system can distill water. After processing, place water in a clean bottle or pitcher with a lid and refrigerate. Discard within 3 days.
- Boiled Water
 - Heat water to a rolling boil for at least 1 minute. Allow water to cool prior to placing water in a clean bottle or pitcher with a lid and refrigerate. Discard within 3 days.

Possibly Unsafe Water Sources:

- Private Well
 - Water from private or small community wells may not be safe.
 - Testing is needed and should be repeated annually or as recommended by your water laboratory.
 - For more information: www.wellowner.org
 - Center for Disease Control and Prevention – Private Drinking Water:

<http://www.cdc.gov/healthywater/drinking/private/index.html>

Other Water Tips:

- When traveling to an outside country (such as Mexico or South America), please use bottled water. Keep in mind that ice and drinks with ice may be contaminated as well.
- Avoid accidental water intake when you shower or brush your teeth, swim (especially in lakes), use a hot tub or go boating.
- If you are unsure where tap water is from, you should avoid drinking it (example: water from a refrigerator and drinks made at a fountain).
- Be careful when using ice machines that may not be cleaned regularly.

Food-Drug Interactions

Transplant recipients should not eat grapefruit, pomegranate (or juices that contain either one), Starfruit, Seville oranges (usually found in marmalade) or Noni juice. These can interfere with the blood levels of medications used to suppress the immune system. Additionally, any antibiotics should only be given after interactions have been checked by the transplant team. These foods and medications can interfere with the absorption or the breakdown of Prograf® (tacrolimus) and cyclosporine and may cause high or low levels that can lead to side effects and/or increase the risk of transplant rejection.



Vitamins and Supplements

Sometimes electrolyte levels may be altered after transplant. Electrolytes may need to be replaced with medication. Vitamin and mineral levels may also be checked after transplant, and if levels are low, recipients may need to take additional supplements. Your transplant team will teach you about which supplements to take if needed. Herbal supplements can adversely interact with transplant medications. Do not take herbal supplements unless first discussed with your transplant coordinator or physician. Herbal remedies include herbal drugs, herbal teas, essential oils, etc.



OUTDOOR SAFETY

Sun Safety

Some transplant medications can cause sensitivity to sunlight. Transplant recipients need to wear sunscreen and protective clothing/hat/eyewear when outdoors. Limit outdoor activities from 10am to 4pm, during the hours of greatest sun exposure. Regular dermatology screening visits may be recommended. Please discuss this with the transplant team.



Exercise

Outdoor activities are good for recipients. Use common sense about safety for all outdoor exercise activities. It is ok to return to safe sports, such as P.E. (class, track, etc.) **once medically cleared**. If you have questions about which sports are safe, check with the transplant team.

Please ask your team about any activities that might be an infection risk, like hunting, fishing or scuba diving, **before** participating. Make sure to stay well hydrated during any physical activity.



Bug Safety

Take precautions to avoid infections that can be caused by bug bites. Avoid going out during peak mosquito feeding periods and use insect repellents that contain DEET. These precautions can help prevent illnesses spread by mosquitoes such as Zika, West Nile, Dengue, and others. Make sure to use bug spray if you will be out during a time when mosquitos and other bugs are out.

How Should You Plan for Travel and Vacations?

Your family can travel after transplant, but traveling is not recommended for at least the first 6 months, because that is the time the recipient is most at risk for infections. It is important to over-prepare for travel by remembering the following things:

- Contact your transplant center **before** travel to let them know what area you are traveling to, especially if outside the United States. Extra immunizations or special precautions may be needed.
- If possible, refill your medications before you travel, and take what you will need plus an extra 10-day supply. Many other countries may not have the same type or quality of medications as those regulated in the United States. Even if traveling inside the U.S., certain medications may not be available everywhere.
- Make a plan before you travel, locating the hospitals and physicians closest to where you will be staying in case the recipient needs medical care while traveling. The American Embassy or consulate can also be contacted if you need help finding a hospital or physician.
- Air Travel:
 - Carry medications/supplies on the plane with you. Do not check them with your bags because they may be lost or exposed to extreme temperatures in the plane's cargo area.
 - Request a letter from your transplant office with permission to travel with needed medications and medical supplies to make the airport security process easier. These letters can be dated for 1 year and replaced annually if needed.

- Only drink bottled or canned drinks, unless it is a beverage like tea or coffee that is made with boiled water. Avoid iced beverages if traveling in an area where there may be poor water quality. If there are no bottled or canned drinks available, you will need to boil water for cooking and drinking and allow it to cool before use.
- Monitor the food the recipient eats and make sure it is well cooked. In areas where sanitation is poor, avoid unpasteurized milk and other dairy products like cheese or fresh milk. Fruit must be peeled or cooked. Do not eat raw fruits or vegetables in an area where water quality or sanitation are poor.
- Swimming in contaminated water increases risk for infections, especially ear or stomach infections if you submerge (jump) in the water. Correctly chlorinated pools are the safest places to swim. After swimming, it is best to rinse off or shower right after getting out of the water.
- Ponds and lakes are the riskiest areas to swim, due to stagnant water and build-up of bacteria and other infectious agents (parasites). Avoid these if possible. If you make the decision to swim in a pond or lake, the recipient shouldn't place his or her head underwater. Do not swim if you have any open, unhealed wounds. Try to keep the recipient from swallowing any water when swimming.



How Can Transplant Recipients Be Around Pets Safely?

Studies have shown that the bond between people and their pets can increase fitness, lower stress, and bring happiness to their owners. Pets sometimes carry germs that can make people sick! Transplant recipients are even more at risk for getting sick from animals, so special precautions need to be taken.

It is hard to know which animals could be carrying diseases, especially since pets carrying these germs often look healthy and normal. Here are some tips:

- Keeping your pet healthy
 - Take your pet to the veterinarian regularly.
 - Keep pets immunizations up to date.
 - Feed pets healthy food and don't let them drink from toilets or eat from the trash.
 - Keep your pets clean by bathing them frequently.
 - Regular flea & tick prevention is needed, especially for cats and dogs.
- Keeping yourself healthy
 - Practice good hygiene around your pets so they don't pass germs to you.
 - ù Wash your hands thoroughly with running water and soap after handling animals.
 - ù Adults should supervise children during hand washing.
 - ù Do not place litter boxes or pet cages in kitchens, dining rooms, or other areas where food is prepared and eaten.
 - Learn about diseases different types of pets can spread - just in case.
 - Use caution if you come into contact with farm animals, including animals at petting zoos and fairs. Wash hands thoroughly.



- Transplant recipients should:
 - Avoid contact with animal feces.
 - Avoid cleaning cages, tanks, litter boxes, aquariums, etc...
 - If you must come into contact with one of these items, wear gloves and wash hands thoroughly with soap and running water.
 - Toxoplasmosis (a type of parasite infection) can be acquired many ways-through infected animals, from playing in infected sand boxes or from playing with contaminated dirt. Avoid these things if possible.
 - Avoid sharing a bed with a pet (due to increased risk for infection).
 - Avoid an animal licking their face or hands. If this occurs, wash with soap and water as soon as possible.
 - Avoid any direct contact with petting zoos, farm animals and their enclosures if possible.
 - ù Avoid having food near or eating by the animals or their enclosures.
 - ù Direct contact with animals is not necessary to contract most diseases spread by animals. Indirect contact with contaminated surfaces can cause infection.
 - ù Exposure to farm animals causes risk for E. coli bacterial infection.
 - ù Children are at the greatest risk for serious complications caused by E. coli infection.
 - ù Young children are less likely to follow hand hygiene rules.
 - ù Young children constantly place their hands to their eyes and mouth, which increases infection risk.



RECOMMENDATIONS FOR PETS

- Dogs
 - Any cat or dog that has diarrhea should be checked by a veterinarian for infection with Cryptosporidium, Giardia, Salmonella, and Campylobacter.
- Cats
 - Keep pet cats indoors. Do not pet stray cats. Litter box should be kept away from food preparation areas. Litter boxes should be cleaned frequently by someone other than the transplant recipient.
- Fish
 - Aquarium should be cleaned by someone other than the transplant recipient.

PETS TO AVOID

- Reptiles, including lizards, snakes, and turtles (can carry salmonella in their stool).
- Birds, including chicks and ducklings.
 - If you must have a bird, bird cage linings should be cleaned daily, by someone other than the transplant recipient.
 - We recommend against birds as pets because of potential airborne infectious agents in their stool.
- Hamsters and gerbils (or other animals that may bite).
- Exotic pets, including monkeys.
- Wild animals
 - Do not adopt wild animals as pets or bring them into your home (Animal bites/scratches can cause infections and fever).



More information can be found at: <http://www.cdc.gov/healthypets/specific-groups/organ-transplant-patients.html>

How Can You Get CPR (Cardiopulmonary Resuscitation) Training?

You and your family may attend a CPR training course which can be taken at Texas Children's Hospital or a facility of your choice.

How Can You Get a Medic Alert Bracelet?

You may purchase a medic alert bracelet, necklace or anklet to identify the transplant recipient. It can give life-saving information in an emergency. There are many options available online for you to choose from. Talk to the your transplant team to see if the recipient needs one.

What Should You Communicate to the Transplant Team?

Contact the transplant team if there are any changes in insurance coverage, address, or phone numbers. We will need to contact you with lab values and medication changes. Please keep the transplant center's number with you, and always have access to a phone.

Any changes in medical condition, such as medications or other issues must be communicated to your transplant coordinator, prior to making the change. This includes, but is not limited to, over-the-counter medications and visits to physicians other than ones on the transplant team.

How Does Your Referring Physician Stay Updated?

Once you are home, you will be in regular contact with your transplant coordinator, and you are expected to return to Texas Children's for follow-up transplant care. Through the transplant process, the transplant team will communicate with your referring physician. Routine care will be gradually transitioned to your referring/primary care physician.

How Can You Write to the Donor Family?

To protect the privacy for your donor family, you will only be told minimal information about your donor at the time of transplant (usually age and gender). The donor family receives the same information about the person who receives the organs from their loved one. You or a member of your family have the opportunity to write to the donor family to say "thank you." Here are a few things to include:

- Include the **recipient's first name only**.
- Acknowledge the donor family's loss and thank them for their gift.
- Include what kind of transplant the recipient had and how long he or she waited for a transplant.
- Tell them a little about your family's interests and hobbies.
- Explain how the transplant has improved the recipient's health and changed your lives.

If you would like to write to your donor family, consider sending a hand-written or typed letter or a greeting card. Please give the letter to your transplant coordinator or social worker to ensure it is sent to the donor family. You may or may not receive a letter from your donor family. Some



donor families have said that writing about their loved one and their decision to donate helps them in their grieving process. Other donor families, even though they are comfortable with their decision to donate, may prefer privacy and choose not to write.

We strongly encourage you to write a letter for your donor family. Your transplant coordinator can give you a handout called "Writing to Donor Families" if you need additional help.

How Can We Help Adolescents Transition into Adult Care?

We encourage recipients to begin learning about their condition, medications, and how to advocate for themselves beginning from an early age (usually 12). Along with the guidance of parents/caregivers, we are slowly able to teach adolescents how to assume responsibility of their care. The gradual increase in responsibility needs to be monitored by parents/caregivers to ensure the recipient is taking the correct medications and obtaining follow up when needed.

Allowing adolescents to gradually learn how to navigate the medical system prepares them for transition into adult care. When providers, parents/caregivers, family members, and recipients work together, a smooth transfer to adult transplant care is achievable.

Is the Compliance Agreement Still in Effect?

Good medical adherence and good communication with your transplant team are an important part of the transplant's success. The compliance agreement you signed during transplant evaluation is for all phases of transplant (pre-transplant, during the transplant hospitalization, and post-transplant).

What Should You Know About Research Studies?

Texas Children's Hospital participates in many research projects in our center and across the nation. Clinical research is one of the reasons that there has been improvement in patient and graft/transplanted organ survivals. Participation in research is voluntary. Parents/caregivers can participate in a research study. You can choose whether or not to participate in a research study without worry that saying no will affect the medical or nursing care the patient receives.



Post-Transplant Phase: Section Quiz Review

1. Transplant recipients need to come back to Texas Children's for transplant follow-up care.
 - a. True
 - b. False
2. All of the following are true in regards to finding balance for your family after transplant, **except**:
 - a. Parents/caregivers may struggle with being overprotective.
 - b. Some transplant recipients may struggle with behavior challenges, they may become more withdrawn, more outgoing, or more attached to their parent/caregiver as they adjust to life after transplant.
 - c. Siblings might compete for attention and/or become jealous of the transplant child, which can create tension in the family unit.
 - d. All family members will behave normally and no one will have to cope with the emotional changes that may come with transplant.
3. Can transplant recipients go back to school after transplant?
 - a. Yes, they can go back to school the day they go home from the hospital after transplant.
 - b. Yes, they can go back to school once they are medically cleared.
 - c. Yes, they can go back to school whenever they want.
 - d. No, they can never go back to school.
4. Which of the following are correct in regards to transplant patients and their families receiving vaccines post-transplant?
 - a. Routine vaccinations are important to protect patients with compromised immune systems after transplant. It is recommended that transplant patients and their siblings/family members stay up to date on their immunizations on their regular immunization schedule.
 - b. Transplant patients CANNOT receive LIVE virus vaccines.
 - c. When a sibling or family member receives a live virus vaccine (which transplant patients CANNOT receive), caution should be used to avoid contact with body fluids for at least two weeks (no drink sharing, good hand washing, etc).
 - d. All of the above
5. Dental care is not important after transplant.
 - a. True
 - b. False
6. Should you contact the transplant team before any dental procedures are done?
 - a. Yes, you should contact the transplant team prior to dental appointments because dental procedures, including routine dental work (filling a cavity or cleaning of teeth) may require pre-treatment with antibiotics to prevent infection.
 - b. No, your transplant center doesn't mention dental care at all.

7. Some foods (fruits and their juices), transplant recipients should AVOID are:
 - a. Grapefruit, Pomegranate
 - b. Grapefruit, Pomegranate, Starfruit, Seville Oranges (Marmalade), or Noni juice
 - c. Seville Oranges (Marmalade), Bananas, Grapefruit, Pomegranate, Oranges
 - d. Starfruit, Grapefruit

8. Which of the following are ways to limit exposure to illness after transplant?
 - a. Wash hands frequently with soap and water or hand sanitizer.
 - b. Keep sick visitors away.
 - c. Keep your hands away from your eyes, nose, and mouth unless freshly washed with soap and water.
 - d. All of the above.

9. In regards to safety for outdoor activities, which of the following is **false**?
 - a. Limit exposure to sunlight, because some medications can cause sun sensitivity. Transplant recipients should wear protective clothing/hat/eyewear when outdoors.
 - b. Transplant recipients are not allowed to play or be outside.
 - c. It is ok to return to safe sports once medically cleared by the transplant team.
 - d. Use bug spray if you will be out during a time mosquitos and other bugs are out.

10. Some things to remember when traveling with a transplant recipient are:
 - a. For air travel, do not check medications with your baggage. Carry them in your carry on bag, so they won't be accidentally lost.
 - b. If possible, refill your medications before you travel, and take what you will need plus an extra 10-day supply.
 - c. Make a plan before you travel, locating the hospitals and physicians closest to where you will be staying in case the transplant recipient needs medical care while traveling.
 - d. All of the above are correct.

11. Wash your hands thoroughly with running water and soap after handling animals and their feces (stool). If possible, transplant recipients should avoid direct contact with animal feces. Adults should supervise the hand washing of children.
 - a. True
 - b. False

Answer Key: 1) a 2) d 3) b 4) d 5) b 6) a 7) b 8) d 9) c 10) d 11) a

Common Questions in the Post-Transplant Period

1. On lab work days, should the recipient take medications before labs?

No, please do not give the immunosuppressant medications until the blood has been drawn. The labs should be scheduled to be drawn just before (usually 30 minutes to 1 hour) the medications are due to be given.

2. When medication refills are needed, what do you do?

When there are refills remaining, contact your pharmacy directly at least 5 days before you run out of medication. When you are out of refills for medications, contact your transplant coordinator at least 5 days before you run out of medication.

3. How do you monitor the surgical incision?

Check the incision daily. If there is any unusual redness, swelling, pus, drainage, or pain, contact your transplant coordinator. Follow the transplant team's instructions for incision care.

4. Will transplant recipients always be more at risk for infection after transplant?

Yes, they are HIGHLY immunosuppressed and at a HIGH risk for infection, especially during the first 6 months post-transplant. Any infection during that time period could be life-threatening. Even if medication doses are able to be lowered they will still be at risk for infection.

5. How long will transplant recipients be on medications after transplant?

While some of the medications they are on in the hospital may be decreased or stopped, they will remain on immunosuppressant medications for the rest of their lives.

6. How will I know what medications to give once we go home from the hospital?

Your transplant coordinator or transplant pharmacist will create a medication schedule for you to follow. You will be taught what each medication is for and how to give it.

7. What if we are struggling emotionally after transplant?

Recovering emotionally after a transplant will take time and patience for your family. The transplant team can help you locate resources and provide counseling as needed.

8. One of our family members got a live virus vaccine today. Do I need to take any special precautions?

When a family member receives a live virus vaccine (which transplant patients **cannot** receive), caution should be used to avoid contact with body fluids for at least 2 weeks (no drink sharing, good hand washing, etc).

9. Is it ok to have a pet?

Yes, but precautions should be taken to keep recipients from catching any illness that a pet may be carrying. Transplant recipients should not handle animal urine/feces, including cleaning bird cages, litter boxes, fish tanks, etc. There are certain types of animals you should avoid having which include reptiles (lizards, snakes, turtles); birds (including baby chicks or ducklings); and exotic pets (including monkeys).

When Should You Contact the Transplant Team After Transplant?

Vital Signs

- Changes in vital signs (blood pressure or heart rate decreases or elevations)
- Heart rate becomes rapid at rest, is irregular, or is pounding
- Difficulty breathing (abdominal breathing, making grunting noises)
- Increased cyanosis (blueness)
- Decreased oxygen saturation level

Gastrointestinal/Genitourinary Problems

- Increased abdominal size, abdominal pain, or swelling
- Persistent vomiting, diarrhea, or severe abdominal pain
- Vomiting blood
- Blood present in vomit or bowel movement (coffee ground-like or red vomit; dark tarry or bright red bowel movement)
- Bloody urine
- Decrease in urine output (decreased frequency or amount)
- Difficulty or pain when emptying bladder

Activity

- Decrease in activity level (not keeping up like normal)
- Decreased exercise tolerance
- Sleeping more than usual
- Decrease in appetite
- Irritability

Miscellaneous

- Sweating more than usual
- Jaundice (yellowing of the eyes/skin)
- Persistent or severe headaches
- Bloody sputum (mucus)
- Swelling/retaining fluid (if feet, legs, hands, or eyelids swell)
- If you must leave town for an emergency
- Prior to having any dental work done, including routine cleaning (antibiotics may be needed)

Illness and Medication

- Fever of 101° or higher (or extremely low temperatures less than 96°)
- Cough, congestion, or runny nose
- Exposure to chicken pox, shingles, measles, mumps, TB, or hepatitis
- Redness or drainage in or around incision or any open wound
- If a dose of medication is missed
- Difficulty obtaining medications (notify team BEFORE supply will run out)
- Before starting any new medications (including over the counter medications)
- If a doctor tells you to change or stop a medication (ask the transplant team before making the changes)
- Medication changes, illnesses, or hospitalizations

Contact Information

MONDAY-FRIDAY, 8:00AM-4:30PM:

Non-urgent Issues: Contact your transplant coordinator by phone or email.

Urgent Issues: Call **832-824-2099** and request to have your *transplant coordinator* paged (Toll-free number is 1-800-364-5437). If you do not receive a return call within 30 minutes, please try again as technical difficulties do sometimes occur.

AFTER HOURS, WEEKENDS, OR HOLIDAYS:

Non-urgent Issues: Email your transplant coordinator.

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For a true medical emergency, such as difficulty breathing or change in responsiveness, please call 911.



Section 6

Frequently Asked Questions

1. Is it normal for transplant recipients to have trouble sleeping?

It is common for patients to have trouble sleeping after surgery. Medication or behavioral therapies can be used to help with this. Please talk to your transplant team if you are having trouble falling asleep or staying asleep.



2. Is it common for recipients to lose some hair after transplant?

Hair loss can happen after a stressful event like surgery. Certain medications may cause hair loss too. Talk to your transplant team if you notice hair loss happening.

3. Is bedwetting common after transplant? What could be the reason?

While not common, it can happen as a result of the transplantation process. Bedwetting can cause low self-esteem and can be socially limiting. The transplant recipient should not be blamed for the bedwetting. Please talk to your transplant team if you have concerns about this.

4. What is the recommendation on piercings and tattoos?

Getting tattoos or piercings are not encouraged due to infection risk. For ear piercings, we recommend waiting until 6 months after transplant. Please contact your coordinator for ear piercing safety instructions.

5. Should transplant recipients be around people who smoke?

Recipients should stay away from all forms of tobacco smoke that includes cigars, cigarettes, hookah, electronic/vapor (e-cigarettes). If friends or family members have to smoke, then they should do so outside and not in the home or car with the recipient.

6. Can transplant recipients smoke?

Since transplant patients are more at risk for cancers, avoiding all tobacco products is important. This includes dip, chew tobacco, cigars, hookah, and cigarettes, including electronic/vapor (e-cigarettes). Smoking is harmful to everyone, but it is more harmful for transplant recipients. Exposure to cigarette smoke could cause serious complications. Recipients should avoid smoke-filled areas as much as possible. We can provide personal counseling to adolescents about their own smoking choices.

7. How can illegal drugs affect someone with a transplant?

Only use medications as instructed by your physician(s). Illegal drugs that are inhaled, ingested or intravenous place a transplant patient at risk for infection, viruses or can even cause death. Some drugs can cause dangerously high blood pressures, stroke (bleeding in the brain), confusion, mood swings and changes in behavior.

8. Can a transplant recipient drink alcohol?

A transplant patient should not drink alcohol because it can cause organ damage/failure. It can cause reactions while on certain medications. Alcohol can cause confusion, mood swings and changes in behavior, or irritate the stomach and cause ulcers.



9. What are the risk factors of participating in sexual activity after transplant?

Sexual activity of adolescents is a sensitive topic. Our doctors are comfortable talking with recipients and their parents/caregivers about sexual issues and concerns. Sexual activity puts recipients at risk for unplanned pregnancy and sexually transmitted diseases (STDs). Some STDs cannot be cured. Abstinence (not having sex) is the best way to avoid STDs or unplanned pregnancies. If a transplant recipient chooses to be sexually active, 2 methods of birth control are recommended. Using condoms may reduce the risk of STDs and accidental pregnancy. Pregnancy prevention is the responsibility of both participants. See *Section 5 How Can Transplant Recipients Have a Healthy Lifestyle, Routine Health Care, Well-Woman Visits for more details on women's health recommendations.*

10. Will my child be able to have children of their own in the future?

If pregnancy is desired, the recipient should be transitioned to an adult transplant center. Whether male or female, recipients should talk to their transplant team before planning to start a family. A healthy pregnancy may be achieved in a post-transplant patient with proper planning and medication changes made by your physician.

Female recipients: If sexually active, it is possible to become pregnant even before having their first menstrual period. Pregnancy after transplant may be risky for both the transplant recipient and the baby. Many immunosuppression medications (such as mycophenolate) can cause birth defects or miscarriages. If a recipient gets pregnant, she will likely be transitioned to an adult transplant center. **Call the transplant office immediately if pregnancy is suspected.**



Section 7

Resources

Transplant-Related Websites & Organizations

<http://www.transplantliving.org/>

Purpose: Patient Education

<http://www.organtransplants.org/understanding/interactivebody/index.html>

Purpose: Patient Education; Click "interactive body"- patients can click on different organs and parts of the body. Many additional education resources on the www.organtransplants.org home page.

<http://www.organtransplants.org/>

Purpose: Patient Education

<http://www.americantransplantfoundation.org/>

Purpose: Organ donation awareness

<http://www.trioweb.org/>

Purpose: Information and resources for transplant recipients, families, and donor families

<https://donatelife.net/>

Purpose: Information and resources for transplant recipients, families, and donor families

<http://wish.org/refer-a-child>

Purpose: Grant the wish of every child diagnosed with a life-threatening medical condition

Transplant Fundraising Organizations

HELP HOPE LIVE

<http://www.helophopelive.org>

Phone #: 1-800-642-8399

Assists with fundraising for people facing transplant or catastrophic injury. They provide consultation and tools to help you launch a fundraising campaign. They hold the funds and distribute to patients for approved medically related expenses. The funds are not taxable income and do not jeopardize participation in assistance programs. Due to them being a nonprofit organization they provide fiscal accountability and tax deductibility for donors. They charge 4% of funds raised. They provide challenge grants

CHILDREN'S ORGAN TRANSPLANT ASSOCIATION (COTA)

<http://www.cota.org>

Phone #: 1-800-366-2682

COTA helps families facing organ transplant fundraise by organizing and training your volunteers, planning events and activities, working with local media, and using online and web-based resources for communication and fundraising. They hold the funds and distribute for approved medically related expenses. The funds are not taxable income and do not jeopardize participating in assistance programs. There is no fee for their services. They are a nonprofit organization and offer tax deductibility for donors. They offer challenge grants as well.

GIVE FORWARD

<http://www.giveforward.com>

Phone #: 312-488-9861

Give Forward helps you create an online page that describe your fundraising efforts. They then promote the pages via e-mail and Facebook. People can donate to your Give Forward Page using credit or debit cards or PayPal accounts. When your fundraiser reaches it's end date, Give Forward will send your funds via PayPal transfer or personal check. Families should work closely with a banker to ensure that funds do not jeopardize eligibility for state and federal programs. Give Forward takes a 7% processing fee.

Books

Organ Transplants: What Every Kid Needs to Know, by UNOS- information to make the transplant process easier to understand for elementary-age children in need of an organ transplant.

Now Caitlin Can: A donated organ helps a child get well, by Ramona Wood

How Will They Get That Heart Down Your Throat?: A Child's View of Transplants, by Karen Walton, Allison Patrice Peterson (Illustrator)

Precious Gifts: Katie Coolican's Story. Barklay and Eve Explain Organ and Tissue Donation, by Karen L. Carney

Organ Transplants: A Survival Guide for the Entire Family (It Happened to Me) (Hardcover), by Tina P. Schwartz

Housing Resources

RONALD MCDONALD HOUSE

Address: 1907 Holcombe Blvd. Houston, TX 77030

Phone #: 713-795-3500

<http://www.rmhhouston.org>

Holcombe House is a home away from home for families whose seriously ill children are being treated at a Texas Medical Center member institution. The House has 50 private bedrooms equipped with two queen size beds and a full bath. Dedicated volunteers provide frequent meals and family activities for residents of the House. The House also has a Houston Independent School District school room for patients and school bus transportation for siblings to area public schools. Additionally, families staying at Holcombe House are provided scheduled weekday van service to Texas Medical Center hospitals and a near-by grocery store.

Eligibility Criteria for staying at the Ronald McDonald House:

- Immediate family members of children age 21 or younger who are hospitalized and/or receiving treatment for serious illnesses at a Texas Medical Center member institution are eligible to stay at the Holcombe House.
- Each family is allowed one room with a maximum of four guests (including the patient).
- There are no income or mileage restrictions for admittance.
- If the parent/caregiver of the patient is under the age of 21, he/she must be accompanied 24/7 by an adult over the age of 21.
- During their stay at RMH Houston all families are provided lodging, many meals, laundry facilities, transportation to and from hospitals, and other services. In order to help cover some of these costs, we request a contribution of \$25 per night per room. However, if this presents a hardship for a family, arrangements can be made with the Manager on Duty. No one has ever been turned away from Ronald McDonald House Houston because they couldn't afford to pay. A family may be admitted to the Holcombe House for a maximum of 45 days during their child's hospital stay or treatment. After 45 days families are asked to 'step out' for a period of 7 days and then are eligible for re-admission.

NORA'S HOME

Address: 8300 El Rio Street. Houston, TX 77054

Phone #: 832-831-3720

<http://www.norashome.org>

Nora's Home offers affordable lodging for pre-transplant and post-transplant patients who travel to any of the Texas Medical Center transplant centers.

Eligibility Criteria for staying at Nora's Home:

- Patients receiving treatment in the Texas Medical Center for solid organ transplant and their families. There are no age restrictions for the transplant patient.
- Each family is allowed one room with two queen size beds, a bathroom, with a walk-in shower, TV, dresser, bed side table, and a recliner. There can be a maximum of four guests (including the patient) per room.
- All family members, caregivers, or friends must be over the age of 10 years old that are staying in the room with the patient.
- The cost of a room is \$75 per night. Lodging costs can be submitted to any participating insurance providers for reimbursement.

Texas Children's Heart Center – Transplant Center

Compliance Contract for _____

In order to take the best care possible of _____ while on the transplant list, we want to make you aware of the Heart Transplant Team's expectations for pre- and post-transplant medical care. Schedules for follow-up visits, lab work intervals, as well as specific medication dosing information will be given to you and the primary caregiver. A copy will also be kept in _____ chart.

1. You are responsible for ensuring that the Transplant Team has your family's most up-to-date demographic information, including home address and phone numbers. It is important that the Transplant Team is able to get in touch with you at any time to discuss aspects of _____ medical care.
2. You are responsible for making _____ appointments for clinic visits and lab draws on a schedule directed by your physicians both before and after transplant. You are responsible for getting to and from your appointments. If you must miss an appointment, you must notify us 24 hours in advance to reschedule. You are responsible for maintaining necessary contact with the Transplant Team to keep them informed of essential information about your child's health. You are responsible for bringing necessary referral papers with you. Rearranging clinic visits due to any event must begin two weeks before the scheduled visits. No more than two rescheduled visits per year will be accommodated. Missed appointments without notification will not be tolerated.
3. You are responsible for giving _____ his/her medications as prescribed by his/her physicians. You must discuss any changes in _____ medications with his/her physicians. Use of medications prescribed by outside physicians or obtained over-the-counter must be discussed with and approved by the transplant coordinator and/or physician. _____ should always have at least a two-week supply of medications on hand. Refills are handled Monday through Friday, 9:00 am—4:00 pm. If you are having difficulty obtaining _____ medications, you must notify your coordinator before your minimum supply runs out. Not giving _____ his/her medications will not be tolerated.
4. You are responsible for keeping the heart transplant team aware of any changes in _____ condition, for example, fever (over 101), diarrhea (more than four times a day), vomiting, difficulty breathing, cough, not acting himself/herself, decreased appetite, weight loss, and decreased activity both before and after transplant. Each of these events must be reported to the transplant coordinator and/or physician by phone the day of occurrence. Expect that the medical team will contact you within four hours to further assess and instruct you.
5. Contact the transplant coordinator by phone or the cardiology fellow on-call, at 832-824-2099 the day of occurrence, if you have any questions or concerns related to _____ medical care. Contact the social worker by phone at 832-824-2932, if you have any questions or concerns related to the above expectations.
6. As a transplant candidate, you MUST be able to be at the hospital within one hour after being called. Not arriving within one hour will result in loss of the organ for the patient named above. If you go out of town, you must contact the transplant coordinator and/or physician so that an organ will not be accepted while you are out of town. The first three months post-transplant _____ must stay in Houston, Texas.

7. You are responsible for being available by phone in the event that a donor organ becomes available. Failure to make contact with the Transplant Team within one hour to accept/decline a donor offer will result in the organ being declined.
8. Failure to comply with the above expectations may result in CPS referral.

In order to have my child's name placed on the transplant list, I understand that I need to demonstrate compliance with the contract outlined above. Very few organs are available for transplant; for this reason, I must take very good care of my son/daughter, _____, to prove that he/she is an appropriate candidate. I am aware that _____ may not receive an organ transplant if I do not show the heart transplant team I am capable of taking care of him/her. I will work closely with the transplant team in a coordinated effort to make sure this contract is fulfilled, both pre- and post-transplant.

Primary Caregiver #1

Primary Caregiver #2

Transplant Coordinator

Social Worker

Physician/Nurse Practitioner

Patient

Date

Campus Map



Building Level Guide

Clinical Care Tower	Tower E	Pavilion for Women	West Tower	Abercrombie Building	Feigin Tower
5-17	5	5-15	5-21	5-7	5-20
4	4	4	4	4	4
← 3rd Floor Bridge →					
2	2	2	2	2	2
1	1	1	1	1	1
B1	B1		B1		B1
B2-B4	B2-B4		B2		B2-B3

Abercrombie Building Directory

Red Elevators - Levels B1 - 7

Level B1

- CHI St. Luke's
- Bertner Cafe
- Texas Children's Hospital Auditorium

Level 1

- ATM
- CHI St. Luke's
- Gift Shop
- Health Information Management (HIM) (Medical Records)
- International Services
- McDonald's
- Model Train Exhibit (Choo-Choo Hut)
- Security Service Center
- Valet / Drop Off
- Volunteer Services
- Welcome / Information desk

Level 2

- CHI St. Luke's
- Gastrointestinal Procedure Suite (GIPS)

Level 3

- CHI St. Luke's
- Bridge to Texas Children's Hospital West Tower

Level 4

- CHI St. Luke's
- Ronald McDonald® House
- The Children's Garden

Level 5

- 5 North Inpatient Unit
- Employee Health and Wellness

Level 6

- 6 North Inpatient Unit

Level 7

- Clinical Research Center (CRC)
- 7 North Inpatient Unit
- 7 South Inpatient Unit

From 9pm to 6am, all visitors must check in with Security on Level 1 of West Tower Main Lobby. Please use the Bellow Dr./ valet line crosswalk on Level 1 to access.

De 9pm a 6am, todos los visitantes deben registrarse con el Servicio de Seguridad en el primer nivel de West Tower Lobby (entrada principal).

Por favor, ingrese a través del pasillo de la Calle "Bellows", frente a la línea para servicio valet en el nivel 1.

Clinical Care Tower Directory

Public Elevators - Levels 1 - 17

Level 1

- Garage Elevators - Levels B4-3
- Information Station
- Public Elevators - Levels 1-17
- Valet / Drop Off
- Welcome/ Information Desk

Level 3

- ATM
- Beanstalk Coffee Shop
- Bridge to West Tower and Pavilion for Women
- Conference Center
- Food Court
- Garage Elevators - Levels B4-3
- Gift Shop
- Information Station
- Infusion Center
- Outpatient Laboratory
- Outpatient Pharmacy
- Public Elevators - Levels 1-17
- Welcome/ Information Desk

Level 4

- Pediatric Radiology

Level 5

- Audiology
- Ophthalmology
- Otolaryngology (ENT)
- Pediatric Dentistry Clinic
- Speech, Language and Learning

Level 7

- Ambulatory Surgery

Level 8

- Dermatology
- Orthodontics
- Pediatric Orthopedics & Scoliosis
- Pediatric Radiology
- Pediatric Surgery
- Pediatric Urologic Surgery
- Plastic Surgery

Level 9

- Allergy and Immunology
- Asthma Center
- Blue Bird Circle Clinic for Pediatric Neurology
- Pediatric Neurosurgery
- Pulmonary Diagnostic Clinic
- Pulmonary Medicine

Level 11

- Adolescent Gynecology
- Adolescent Medicine
- Diabetes
- Endocrinology
- Gastroenterology, Hepatology, Nutrition
- Physical Therapy Gym
- Renal
- Rheumatology
- Sports Medicine Clinic
- Young Women's Clinic

Level 14

- Cancer and Hematology Centers

Level 16

- Bariatric Surgery Clinic
- Genetics
- Infectious Disease
- Pain Management Clinic
- Physical Medicine and Rehabilitation
- Psychology Service
- Spina Bifida Clinic

Level 17

- Child Protective Health Clinic
- Feeding Disorders
- International Adoption
- Junior League Children's Health Care Clinic
- Program For Healthy Bodies
- Psychiatry Services
- Residents' Primary Care Group
- Retrovirology
- Special Needs Primary Care
- Travel Medicine
- Weigh of Life

Go to Level 1 or 3 to access elevators to **P** Parking Garage 16, Levels B1-B4

West Tower Directory

Express Elevators - Levels 1, 3, 16-21

Level 1

- Emergency Center (EC)
- Pediatric Radiology
- Valet / Drop Off
- Welcome/Information Desk

Level 3

- Admissions
- Ambulatory Surgery/
Surgery Admissions & Waiting
- Bridge to Clinical Care Tower
and Pavilion for Women
- Children's Chapel
- Gift Shop
- Language Services
- Pediatric Intensive Care Unit
(PICU)
- Post-Anesthesia Care Unit (PACU)

Level 16

- Beauty Salon
- Family Laundry
- Family Resource Center
- HISD Classrooms
- Phi Beta Pi Library
- Radio Lollipop/Kids' Own Studio
- The Child Life Zone

Level 17

- Cardiovascular Intensive Care Unit
(CVICU)
- Cardiovascular Surgery
- Ronald McDonald® Family Room
- Waiting Room (CVICU)

Level 18

- Cardiac Catheterization Lab
- Cardiovascular Intensive Care Unit
(CVICU)
- Cardiovascular Surgery

Level 20

- Heart Center Clinic

Level 21

- Neurophysiology
- Physical Medicine and
Rehabilitation
- Sleep Lab

Go to Levels 1, 3 or 16 to access the Public Elevators to Levels B2-16

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West Tower Directory

Public Elevators - Levels B2 -16

Level B2 <ul style="list-style-type: none">• P Parking Garage 12	Level 4 <ul style="list-style-type: none">• Milk Bank• Newborn Center (NICU)	Level 12 <ul style="list-style-type: none">• Inpatient Rehabilitation Unit (IRU)• Transplant Services Inpatient Unit
Level B1 <ul style="list-style-type: none">• Pathology Lab• Respiratory Care	Level 7 <ul style="list-style-type: none">• Progressive Care Unit (PCU)	Level 14 <ul style="list-style-type: none">• Adolescent Medicine Inpatient Unit• Pulmonary Medicine Inpatient Unit
Level 1 <ul style="list-style-type: none">• Emergency Center (EC)• Pediatric Radiology• Valet / Drop Off• Welcome/Information Desk	Level 8 <ul style="list-style-type: none">• Bone Marrow Transplant Clinic• Bone Marrow Transplant Unit• Renal Dialysis	Level 15 <ul style="list-style-type: none">• Cardiovascular Intensive Care Unit (CVICU)• Heart Center Inpatient Unit
Level 3 <ul style="list-style-type: none">• Admissions• Ambulatory Surgery/ Surgery Admissions & Waiting• Bridge to Clinical Care Tower and Pavilion for Women• Children's Chapel• Gift Shop• Language Services• Pediatric Intensive Care Unit (PICU)• Post-Anesthesia Care Unit (PACU)	Level 9 <ul style="list-style-type: none">• Cancer and Hematology Centers• Ronald McDonald® House	Level 16 <ul style="list-style-type: none">• Beauty Salon• Family Laundry• Family Resource Center• HISD Classrooms• Phi Beta Pi Library• Radio Lollipop/ Kids' Own Studio• The Child Life Zone
	Level 10 <ul style="list-style-type: none">• Epilepsy Monitoring Unit• Neurology/Neurosurgery Inpatient Unit	
	Level 11 <ul style="list-style-type: none">• General Surgery Inpatient Unit• Orthopedic Surgery Inpatient Unit	

Go to Levels 1, 3 or 16 to access the Express Elevators to Levels 16-21

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Non-urgent Issues: Email your transplant coordinator.

Urgent Issues: Call **832-824-2099** and request to have the *transplant physician* on call paged (Toll-free number is 1-800-364-5437). If you do not receive a return call within 30 minutes, please try again as technical difficulties do sometimes occur.

For a true medical emergency, such as difficulty breathing or change in responsiveness, please call 911.