LIVER

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Our education book is updated frequently, but with the rapidly changing healthcare system, this information could be out of date and/or contain inaccuracies or typographical errors.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 lifelong 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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Section 1
Overview

Team Contact Information

HOW TO REACH A MEMBER OF THE TRANSPLANT TEAM 832-822-5050

To reach a member of the transplant team, call the main number and select the prompt for the correct person. To reach a member of the transplant team not listed as one of the prompts, select the prompt for "general questions."

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

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

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 *Hepatology 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, bleeding, or a change in responsiveness, please call 911.

OTHER IMPORTANT PHONE NUMBERS

Page Operator (to page a team member for urgent issues)	832-824-2099
Toll Free Number to reach a Texas Children's Hospital Operator	1-800-364-5437
Patient Scheduling	832-822-5050

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

MYCHART

MyChart is a convenient patient portal that gives you online access to your Texas Children's medical records.

How to Sign up for MyChart

1. The next time you are at the clinic or hospital, ask a member of your care team to activate your account.
2. Access your account at mychart.texaschildrens.org or download the app for your mobile device.

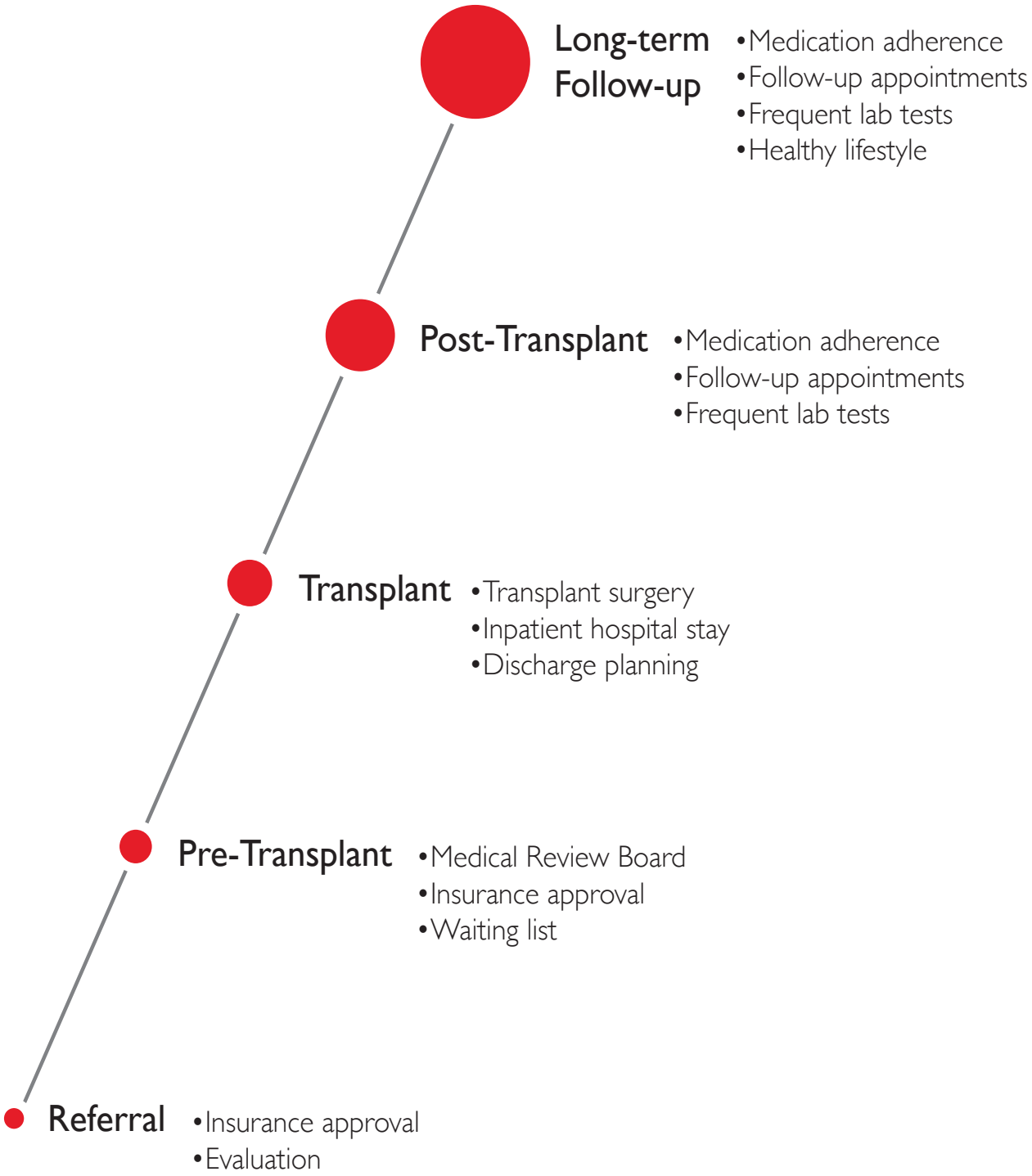
MyChart Helps Patient Families Benefit from Instant Access to

- Scheduling – schedule or request appointments, view upcoming or previous appointments
- Communication – send questions and photos to your providers and care team members
- Billing – pay bills or create payment plans
- Medical Records – view medical history, allergies and medications, immunization records and growth charts, and request record release
- Prescription Refills – send a refill request for any of your refillable medications
- Test Results – automatically receive most test results

Need Help with MyChart?

- Please call 877-361-0111, Monday-Friday, 8am-5pm or email: mychart@texaschildrens.org

Overview of the Transplant Process



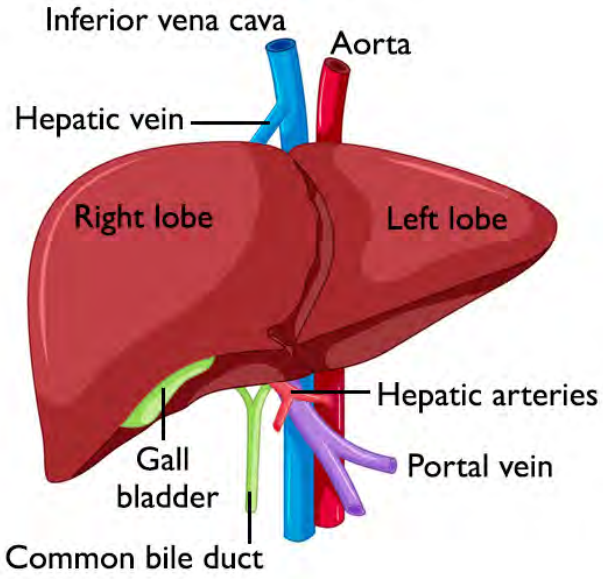
The Liver

The liver is the largest solid organ in the body. It is normally located on the right side of the abdomen, under the rib cage. The liver has two lobes that are divided into sections (lobules). It is connected to the small intestine by bile ducts.

How the Liver Works

Hepatocytes (special cells in the liver) work to:

- Regulate blood sugar levels, hormones, and growth factors
- Make albumin, blood clotting factors, enzymes, and proteins
- Break down food and medications
- Change old blood cells into bilirubin
- Remove wastes and toxins from the blood
- Produce bile, which
  - Aids in absorption of fats and vitamins in the small intestines
  - Contains waste products such as bilirubin
- Bile ducts (small tubes) work to
  - Carry bile and waste out of the liver into the small intestine



Reasons a Transplant May Be Needed

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

Common Reasons for Liver Transplantation

- Biliary atresia
- Metabolic disorders
- Liver cancers
- Fulminant hepatic failure
- Genetic disorders

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 patient, family, or physician makes a referral request to our transplant center.
2. After your family's insurance approves the evaluation, a member of the transplant team will contact the patient/family and tell you more about the process.
3. Patient evaluation will be completed at Texas Children's Hospital. This evaluation can be completed:
   - While the patient is in the hospital
   - As a series of appointments in the clinic and other areas of the hosptial
4. Information from the evaluation will be presented to the transplant center's medical review board. The review board decides if a patient is eligible for a transplant.

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
- Discuss medical management while on transplant waiting list
- Review lab work and diagnostic imaging
- Prescribe medications
- Lead the transplant team
- Review the surgical process
- Complete the informed consent for evaluation
- Answer your questions related to transplantation and the transplant surgery

Transplant Surgeon: Performs the transplant surgery and leads the surgical care before and after transplant. The transplant surgeon will:

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

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

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

Transplant Immunologist: Reviews medical history and performs a physical examination. The transplant immunologist will:

- Review blood type and compatibility for transplant
- Assess the immune system with lab tests and review of infection history
- Develop an immunosuppression medication plan for transplant surgery and post-transplant

Transplant Coordinator: 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 before, during, and after transplant

Liver Intensive Care Unit Team: A specialized team in the ICU who works with the transplant team to care for critically ill liver transplant candidates and recipients. The Liver ICU team will:

- Help to coordinate care for critically ill patients with acute and acute-on-chronic liver disease
- Provide guidance regarding the management of extrahepatic effects of liver failure (e.g. hepatopulmonary syndrome, hepatorenal syndrome, cholecardia, coagulopathy, etc)
- Assist in the initiation and management of life support therapies (e.g. mechanical ventilation, inotropic/ vasoactive support, continuous renal replacement therapy, molecular adsorption recirculation system, extracorporeal membrane oxygenation, plasmapheresis)

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 available to you pre- and post-transplant. They can assist with finding resources to help you with a wide variety of needs and support before and after transplant.

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 that 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

Physical Therapist: performs a strength and exercise exam (or developmental exam determined by age), and works with the transplant team regarding your child's activity tolerance. The physical therapist will:

- Help your child be as strong as possible to get ready for transplant
- Increase your child's active lifestyle with modifications as needed
- Make an individualized home exercise program to help your child prepare for transplant

MEDICAL TESTS AND PROCEDURES

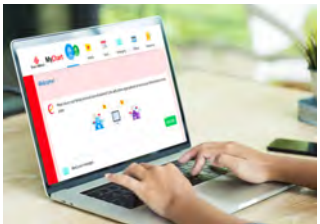
The transplant evaluation helps to determine the most appropriate treatment option. The transplant office will schedule the evaluation and will contact you with the date and time for each test, procedure, and appointment. Tests that may be included in the evaluation for transplant are listed below. Your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

Name of Test	Explanation of Test
Blood tests	Measure organ function, blood counts, chemistry, immune system function; Identifies blood and tissue type and screens for other diseases, such as hepatitis, HIV, and some infections
Bone age	X-ray that evaluates bone age and development
Bone densitometry (DEXA)	A scan to evaluate bone strength
Cardiac catheterization ("cath")	Checks blood flow and pressures in the chambers of the heart
Computed Tomography Scan (CAT or CT)	This scan shows detailed images of your liver and its blood vessels, and other organs and structures such as lymph nodes. A CAT scan also screens for liver cancer
Echocardiogram ("echo")	Evaluates the size and function of the heart
EKG	Measures the heart rhythm and heart rate
Holter monitor	Records heart rhythm for 24 hours
Magnetic Resonance Imaging Scan (MRI)	Uses a powerful magnet, computer and radio waves to provide detailed pictures of the organs and structures inside your body. It may be used as an alternative to or along with a CT scan.
Physical exam	Process by which a medical professional investigates the body of a patient for signs of disease
Pulmonary function tests (PFTs)	Measures how much air the lungs can breathe in and breathe out
Ultrasound	Measures the size and shape of the organs and evaluates the blood vessels using soundwaves
Urine tests	Measures urine chemistry and screens for infection. Can be done as a one-time test or a 24-hour urine collection
X-ray	A picture of bones or other parts inside the body

VIRTUAL VISITS

Texas Children's has made virtual appointments available, in some cases, when coming to the hospital is not an option. These video visits allow patients and families to see and talk to their providers. To participate, the patient's family must have internet access on a phone, tablet or computer. Your transplant team will discuss with you if they think a video visit would be suitable.

If a video visit is appropriate, you will receive a link with the time and information on how to connect. It's important to test the application for the visit before the time of the visit to make sure the connection works. At the time of the visit make sure the transplant patient is available and able to be seen. A room that is brightly lit and quiet works best.



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 treatment, particularly transplant medications, 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, and 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 3 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 (outside of the liver), 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

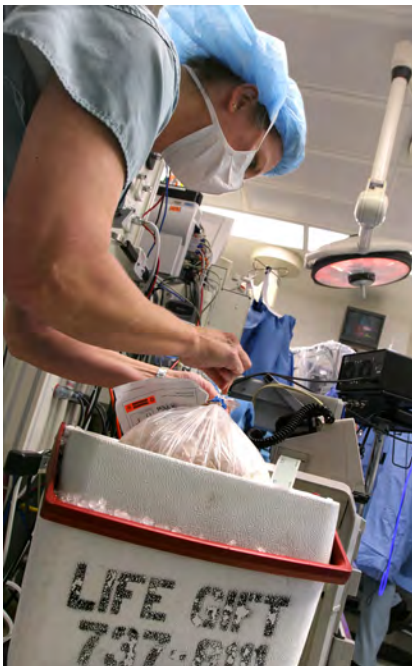
UNITED NETWORK FOR ORGAN SHARING (UNOS)

The nation's organ procurement and transplantation network (OPTN) is 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) / LIFEGIFT

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

PROCESS FOR THE DONATION AND ORGAN DISTRIBUTION: DECEASED DONOR



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.
   Note: The candidate may be offered an organ from a donor who meets the Center for Disease Control's (CDC) increased-risk donor organ criteria. The transplant team will notify you if the organ offered is classified as CDC increased-risk donor organ, and they will explain risks and benefits of accepting the organ. A special consent form accepting the increased risk donor organ will need to be signed by a legal guardian 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.**

Process for Donation: Living Donor Donation

There are two types of possible donors for liver transplant patients: deceased or living. The physician will decide which option is better for the patient. Sometimes, a living donor may not be the best choice for the patient, especially if the patient's disease is hereditary.

Texas Children's currently has an active living donor program for liver transplant. Family or friends who wish to donate will need an evaluation to determine if they meet specific criteria to be considered as a living donor. The evaluation process begins with a simple blood test to determine compatibility with the intended recipient. Once compatibility is determined, the potential living donor may choose to proceed with the evaluation, which consists of a complete medical and psychosocial evaluation, various lab tests, and diagnostic imaging exams. Potential living donors will meet with the living donor team. The team will discuss procedures, answer questions, and make sure the potential donor understands the entire donation and informed consent process. The living donor team is a source of support for the potential donor and his or her family. The transplant team will review options with you during evaluation for transplant.

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

After a patient is evaluated and found to be a suitable transplant candidate, the patient's medical information is sent to UNOS for placement on the national liver transplant waiting list:

MELD (MODEL FOR END-STAGE LIVER DISEASE)

- MELD is used for liver transplant candidates age 12 and older
- Numerical score may change frequently depending on a candidate's health status
- Score reflects how urgently a candidate needs a liver transplant within the next three months
- MELD scores are calculated based on the following:
  - Total bilirubin: measures how effectively the liver excretes bile
  - INR: measures the liver's ability to make blood clotting factors
  - Creatinine: a measure of the kidney function
  - Sodium: level of sodium in the blood

PELD (PEDIATRIC END STAGE LIVER DISEASE)

- PELD is used for liver transplant candidates age 11 and younger
- Score may change frequently depending on a candidate's health status
- Numerical score reflects how urgently a candidate needs a liver transplant within the next three months, based on:
  - Total bilirubin: measures how effectively the liver excretes bile
  - INR: measures the liver's ability to make blood clotting factors
  - Albumin: measures the liver's ability to maintain nutrition
  - Growth failure
  - Age less than 1 year old
  - Sodium: level of sodium in the blood

PRIORITY EXCEPTIONS

- **Status 1A:** Used for candidates with sudden onset liver failure with a life expectancy of hours to days without a transplant
- **Status 1B:** Used for very sick candidates with a long history of liver disease; certain types of cancers or genetic disorders
- **Exceptions by appeal:** Occasionally the MELD/PELD score doesn't truly reflect how sick the candidate is. If the transplant team feels that has happened, they can submit an appeal for an exception on points (rare, and on a case by case basis).

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.

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 (Texas Children's Hospital 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 affect 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.

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:
A family member will be allowed and encouraged to stay in the room. Most patient rooms have a day bed and bathroom for family use.

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.

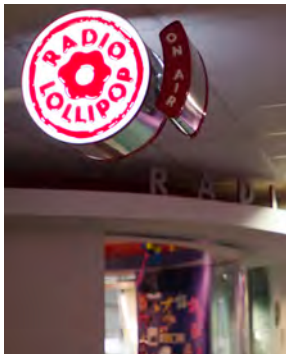
If your family members wish to stay in the area after the transplant, they should make plans to stay in a local hotel, apartment, or guesthouse.

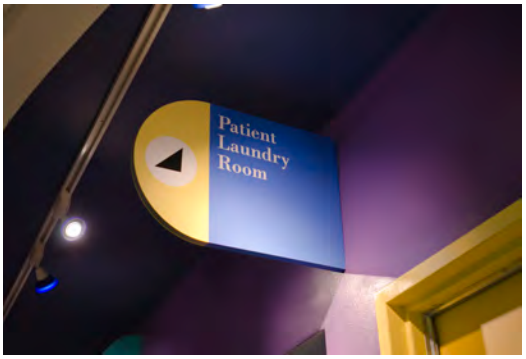
MEDICAID:
If you are on Medicaid, the social worker may be of assistance in arranging alternative housing as well.

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 (Mark Wallace Tower), or Fresh Bistro (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. Legacy Tower has laundry rooms on each floor, which are managed by Guest Services (phone extention x45519). 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 Prevention

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:

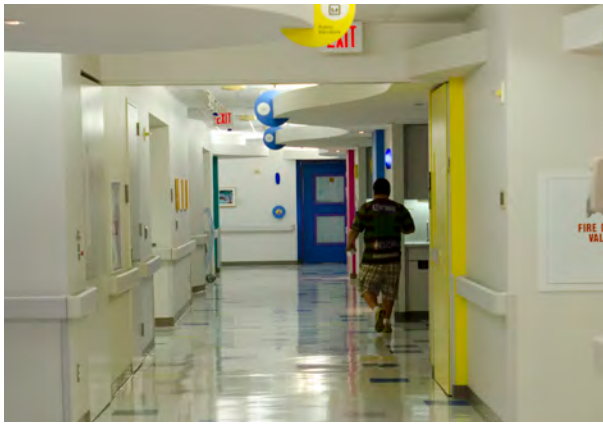
General Guidelines for Transplant Candidates and Family Members

- Do not eat or drink after other people.
- Wash hands with soap and water or use hand sanitizer frequently.
- Wash hands with soap and water before eating or preparing food.
- Wash hands with soap and water before and after using the restroom or diaper changes.
- Keep hands away from your eyes, nose, and mouth unless freshly washed with soap and water or use a fresh tissue to touch those areas.
- Keep sick visitors away from your home and the transplant candidate.
- If anyone at home becomes sick, have them cover their mouth with a tissue or their elbow when sneezing and coughing and wash their hands or use hand sanitizer after.
- Keep immunizations up-to-date.

Please discuss any live virus vaccines with your transplant team, (common live virus vaccines are Varicella [VZV, chickenpox], measles, mumps, rubella [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.



Hospital Guidelines for Transplant Candidates and Family Members

- Wash hands and always use hand sanitizer on the way in and out of the hospital room.
- Keep hands away from your eyes, nose, and mouth unless freshly washed with soap and water or use a fresh tissue to touch those areas.
- 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.

What Do You Need to Know About Medications After Transplant?

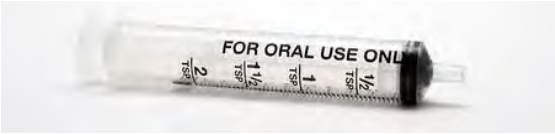
MEDICATION ADHERENCE

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 Neoral®/Gengraf® (cyclosporine).
- **Medications to Prevent and Treat Infections (Anti-Viral/Anti-Fungal):** 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 antirejection medications 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

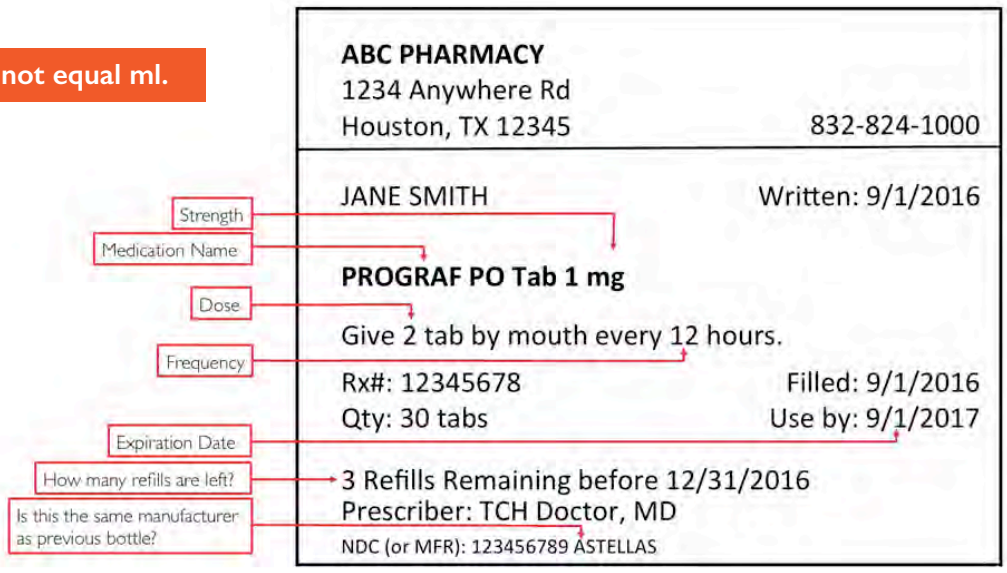
- You should know a few things about transplant medications:
  - Which medications are anti-rejection medications
  - Which medications need to wait until after labs are drawn
  - What time to give the medications
  - How to give the medications
  - The generic and manufacturer's name of each medication
  - What each medicine is used for and the common side effects
  - Why it is important to use the same manufacturer of medicine 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 medication 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 have a negative effect on with transplant medications.
  - Herbal remedies include herbal drugs, herbal teas, essential oils, etc.
- 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 - 4:00pm
  - 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 or 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.
  - If you are not sure what to do, call your coordinator during weekdays. If after hours, call and request to have the transplant physician on call paged. *Missing a dose of medicine is an urgent issue.*

- If you forget any doses of your anti-rejection medications, call your transplant coordinator as soon as you realize. Lab tests may be needed.
- Vomiting around medication time:
  - Vomiting **within** 30 minutes after medicine: repeat the medication dose.
  - 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.
  - 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 – 4:00pm.
  - No refills will be done after hours, on weekends or on holidays.
- When you have refills remaining, contact your pharmacy directly at least 5 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. If you require more than 2 doses within a 24-hour period notify your transplant coordinator.
  - **Never** give the transplant patient medications known as NSAIDs (non-steroidal anti-inflammatory drugs) like Motrin® or Advil® (ibuprofen) or Aleve® (naproxen).
  - 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 chances 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 team.

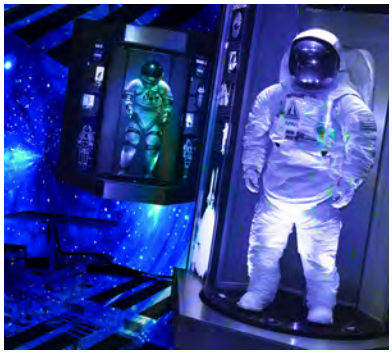
Transplant candidates may be referred to a physical therapist (PT) or occupational therapist (OT) to help with body conditioning in preparation for transplant. PTs and OTs can help transplant candidates maintain or achieve a healthy and active lifestyle. This will help them be as strong as possible to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

Ways PT and OT Can Help

Physical Therapy	Occupational 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	• Feeding • Fine motor skills • Mental developmen • 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.



Disaster and Emergency Preparedness for Transplant Patients

DISASTERS IN YOUR COMMUNITY

While there is no way to truly predict when a natural disaster may occur, you can learn when the risk is higher in your area, such as hurricane or tornado season. Other types of disasters such as earthquakes, wildfires, terroristic attacks, or landslides can happen quickly without warning at any time of the year. Disaster preparedness is the best way for a transplant family to stay ready in any emergency situation.

Houston is particularly susceptible to multiple natural disasters including:

- Flooding
- Hurricanes / Tropical Storms
- Chemical emergencies

During a Houston area emergency, the best way to reach the transplant team is by calling the page operator at 832-824-2099 (for urgent needs) or by sending a MyChart message (for non-urgent needs).

KNOW YOUR RESOURCES:

- Sign up for local warning systems in your area.
- Obtain a weather radio with backup batteries (in case of lost power/no television).
- Utilities: If the patient is electricity dependent due to use of a feeding pump, IV pump, ventilator or mechanical circulatory device, contact your local utility company to see if he or she would qualify for their "critical care" or "chronic condition" list. Check back with them every few months to make sure your status hasn't changed.
- State of Texas Emergency Assistance Registry (STEAR):
  - Texas residents may call 211 to see if you qualify for extra assistance during a disaster event.
  - Please check with your state for local resources.

MEDICATIONS

Try to have 14 days of medications prior to an expected natural disaster. Contact your transplant center and local pharmacy for help if needed.

EVACUATION ASSISTANCE

Wherever you live or travel, natural disasters are always possible. If you live in Texas, you know that we are prone to hurricanes. Hurricane season in Houston is June 1 to November 30. Because your child has special needs, it is important for you to plan ahead in the event of a disaster. If you register with Health and Human Services by calling 211, they will place you on a roster that allows the agency to make arrangements for your child should a disaster occur. Whether you need to be evacuated from your home or need a place to go that has electricity, they can help, if you are registered. If they do not know about your child, they may not be able to send help when you need it. It only takes a few minutes to register. Please make sure you do.

CREATE A DISASTER PLAN

Make a disaster supply kit

- Include enough supplies to last 14 days
- Check often to ensure that supplies have not expired
- Place these items in a waterproof plastic bag:
  - Medications & an updated medication list
  - Printed contact information for your transplant team
  - Insurance information
  - First aid kit (antibacterial ointment, bandages, hand sanitizer)
- Nonperishable food & bottled water
- Flashlight with extra batteries
- Electronic chargers

Make an evacuation plan:

- Plan possible evacuation routes in advance.
- If you have to evacuate, call or send a MyChart message to the transplant team to let them know where you are going and how to reach you.

Remember to communicate with your Transplant Team!

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.

Where Can Information About Transplant Center Survival Outcomes Be Found?

Please visit http://www.srtr.org/ for current patient and graft (transplanted organ) survival rates after transplant. This information is updated every 6 months.

If you have further questions or need help understanding these reports, you can reach out to a member of our transplant team for assistance. We have this same information in an easy-to-understand format, which can be provided upon request.

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.

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 transplant physician on call
   - **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.

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

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, please contact the transplant social worker to 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 detailed itinerary will be sent to you with 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 (MRB) 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?**
   Yes, as long as it is medically acceptable. If an organ becomes available, you will be contacted and travel arrangements will need to be made.

6. **How often will the transplant candidate be seen in clinic while on the waiting list?**
   Clinic appointment frequency is based on the medical needs of each candidate. The frequency will be determined by your transplant physician. Some patients need to be seen more often and other, more stable patients can be seen less often.

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?**
   Average waiting time is 3-6 months. Depending on listing status, it can be hours or years before transplant.

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.

When Should You Contact the Transplant Team?

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, tuberculosis, hepatitis, or influenza
- Medication changes, illnesses, or hospitalizations

Contact Information

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

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

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: Send a MyChart message or call your transplant coordinator.

Urgent Issues: Call **832-824-2099** and request to have the *transplant physcian* 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

What Happens When You Receive the Call for Transplant?

IF YOU HAVE A LIVING DONOR

The transplant surgery is scheduled in advance. The surgeries for both donor and candidate happen on the same day. Talk to your team about the preparation you should expect before coming to and after arriving at the hospital.

Have a bag packed with the following:

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

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.

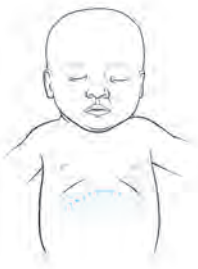
What Happens During the Transplant Surgery?

LIVER TRANSPLANT SURGERY:

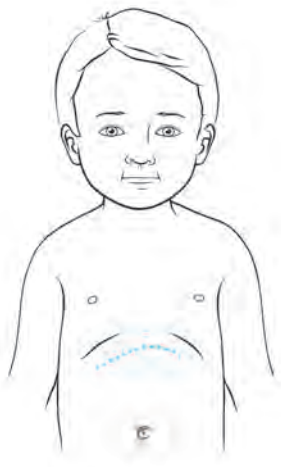
- Living donor transplant is scheduled in advance, and the donor surgery and recipient transplant surgery are done on the same day.
- When a deceased donor liver becomes available, the recipient is called and requested to come to the hospital immediately for preparation for transplant.
- The recipient's old liver is removed and the donated liver is transplanted is placed in the same area in the right upp

TYPE OF INCISION:

Patient will have a chevron or Mercedes incision on the upper of the abdomen



Chevron



Mercedes

SURGICAL PROCEDURE:

- During liver transplantation, the surgeon will connect blood vessels (hepatic veins, hepatic artery, and the portal vein). Occasionally, extra tissue called a graft may be used to connect the blood vessels.
- The biliary ducts can be connected in two different ways:
  - Duct to Duct: the surgeon attaches the donor bile duct to the recipient's bile duct.
  - Roux-en-Y: the surgeon attaches the donor bile duct to the recipient's small bowel.
- Secondary closure: Rarely, the surgeon may need to leave the abdomen open after transplant. The abdomen will be closed at a later time, usually within a few days. Examples of reasons secondary closure may be needed are:
  - To allow time for swelling to decrease
  - To reduce the pressure on the new organ
  - Donor-recipient size mismatch
- Rarely, the recipient may have several bulb-like drains (called Jackson Pratt drains, or JPs) near the incision. These collect blood and fluid from around the liver and will be removed a few days after surgery.

LENGTH OF SURGERY

- In operating room for 4 to 6 hours

COMMUNICATION TO PARENT/GUARDIAN DURING SURGERY

- Parents will be given updates approximately every 2 hours by the Operating Room team

What Should You Expect After Transplant Surgery?

Even though each patient is different, there are many things that all transplant recipients may have after a transplant. It can be overwhelming for transplant recipients and their families to see all the different machines, cables, wires, medical staff, and hear the new sounds and alarms.

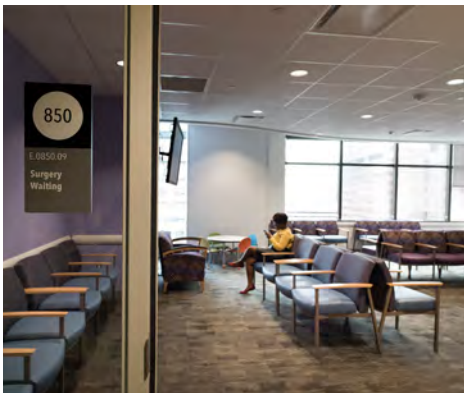
LINES AND TUBES A PATIENT MAY HAVE AFTER TRANSPLANT SURGERY

A team of highly trained medical professionals such as nurses, medical assistants, respiratory therapists, doctors, advanced practice providers, physical therapists, occupational therapists, medical residents, and students who work closely with the transplant team will monitor the recipient. This team will watch over everything connected to the recipient after the surgery. The recipient will have many different types of lines and tubes which will be removed when they are no longer needed. Here are a few common types:

- Breathing tube: during surgery, patients are placed on a machine to help them breathe while they are under anesthesia. This tube can be removed once the medical team is sure the patient is ready to breathe on their own after surgery.
- Intravenous (IV) lines: thin, plastic tubes that are inserted into veins used to give different types of fluids and medications to patients.
- Arterial Line: similar to an IV, but gives a constant reading of the patient's blood pressure and can be used to draw blood without a needle.
- Drain tubes:
  - Urinary catheter: drains urine from the patient's bladder and helps monitor the amount of urine a patient makes
  - Chest tube: drains unwanted fluid and/or air from the chest cavity after surgery
  - Stomach tube: passes through the nose and into the stomach. It drains stomach fluid to help keep patients from throwing up after anesthesia.
  - Cables and wires: connect to a monitor which helps the team check vital signs often. Vital signs include heart rate, breathing rate, blood pressure, and temperature. You will hear beeps and alarms, and the team will be watching the monitors and vital signs closely

Where Will the Recipient Go After Surgery?

Transplant recipients can be in the Operating Room (O.R.) for 4-6 hours. Caregivers will be updated every couple of hours and notified once the recipient can receive visitors. Despite frequent updates, it will still feel like a very long wait. Please bring a book or something to do as time will seem to pass very slowly. A team member will notify you as soon as it is safe to visit your loved one.



After surgery, the transplant recipient will be transferred from the O.R. to the Post-Anesthesia Care Unit (PACU). Once recovered from the effects of the anesthesia, he or she will be transferred from PACU to the Intensive Care Unit (ICU). Once the recipient has improved enough to leave the ICU, he or she will be transferred to an Acute Care Unit. Occasionally, a recipient is too well for the ICU, but too complex for an acute care unit. These patients may temporarily need a higher level of care in our intermediate care unit, called the Transitional ICU (TICU).

AREAS OF THE HOSPITAL AND TYPES OF CARE PROVIDED

Post-Anesthesia Care Unit (PACU): An area that specializes in care after anesthesia, where patients are cared for before they become stable enough to be transfered to a hospital room. The PACU is on the 8th floor of Legacy Tower.

Intensive Care Unit (ICU) and Transitional Intensive Care Unit (TICU): An ICU is an area that specializes in a high level of care for the hospital's most critical patients. The TICU is a special care unit for patients with higher care needs than patients who can go to an acute care unit, but who are too well to stay in the ICU. The ICUs are located in **Legacy Tower** on the following floors: 9 (neurological and surgical), 10 & 11 (medical), 12 (transitional), 16 (heart failure), and 17 (cardiac).

Acute Care Units: Care areas for medically stable patients that help prepare transplant recipients and their families for discharge from the hospital. The general care floors are located in **West Tower** on the following floors: 12 (Transplant Inpatient Unit), 14 (Adolescent Medicine Inpatient Unit), and in **Legacy Tower** on 22 & 23 (Cardiac Patient Care Unit).

VISITATION POLICIES

- Visitation guidelines are subject to change for all hospital units based on current infection control needs/rules
- Contact the unit prior to bringing siblings into the hospital to verify that they will be able to visit.
- Visitors will be limited by number of people, by age limits, and by visiting hours.
- All visitors over 18 must check-in with a valid picture ID.
- Visitor wristbands issued by security are good for 24 hours and must be replaced every day.
- Flowers, plants, and non-washable items are not permitted for infection prevention reasons.

What Will Life Be Like While Staying in the Hospital?

FAMILY AND FRIENDS

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.

DAILY ROUTINE

Medical team members will be in and out throughout the day and night to give medications, check vital signs, and to provide treatments and therapies to improve strength and activity levels.

IT'S NORMAL TO FEEL OVERWHELMED

This process may feel overwhelming, but our transplant team will ensure you are comfortable before sending the transplant recipient home from the hospital. You will learn to develop a routine that works for your family.

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 medical team will teach you the skills you need to care for your child at home.

What Should You Do to Prevent Infections 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, sore throat, runny nose, diarrhea, vomiting, rash or mouth lesions should be reported to the transplant physician.

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

General Guidelines for Transplant Recipients and their Family Members

- Wash your hands with soap & water and always use hand sanitizer on the way in and out of the hospital room.
- Wash hands with soap and water before preparing or eating food. **Soap and water are preferred, but use hand sanitizer if soap and water are unavailable.**
- Wash your hands with soap and water before and after using the bathroom and diaper changes.
- Keep your hands away from your eyes, nose, and mouth unless freshly washed with soap and water or use a tissue to touch that area
- Keep sick visitors away from the hospital and transplant patient.
- 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 hospital room after transplant.
- The transplant recipient **cannot** receive any live virus vaccines (common live virus vaccines are Varicella [VZV, chickenpox], measles, mumps, rubella [MMR], nasal flu vaccine, etc.), but it is important to keep other immunizations up-to-date.
- 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.

See pages 75-76 for more detailed vaccine/immunization safety information.

See page 61 for common things to avoid after transplant

See pages 75-82 for w

What Are the Activity Restrictions After a Recent Transplant Surgery?

Transplant recipients:

- Should not lift anything greater than 5 pounds for 6 to 8 weeks after surgery.
- Should not perform strenuous activity for 6 to 8 weeks after surgery.
- Should not drive for 6 to 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, oceans, 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
• Post-op mobility	• Feeding
• Getting patients up and walking	• Fine motor skills
• Parent/caregiver/child education	• Developmental skills
• Reinforce sternal precautions	• Strengthening
• Importance of mobility	• Endurance
• Home exercise program	• Sensory
• Facilitate independence with mobility	• Community reintegration
• Balance	• Activities of daily living
• Stairs	• 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 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.
  - There are mobile phone applications (apps) that can help you remember when to take medications and call for refills. Please ask your transplant coordinator or pharmacist if you need help setting up a medication app on your phone.
  - 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.

- Vital Signs
  - **Body Temperature** – Keep a temperature record. If you don't know how to take a temperature, someone can teach you. The transplant team can give you a thermometer if needed.
    - Check and record temperature twice daily unless the team changes the frequency.
    - Children under 5 should have their temperature taken in their armpit (axillary).
    - Children older than 5 may have their temperature taken in their mouth (oral).
    - Normal temperature range for all ages is 97° - 99° F.
    - Any time the transplant recipient is ill or feels warm to the touch, check his or her temperature. Check temperature before calling your transplant coordinator.
  - **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.
    - The blood pressure monitor will also give you a HR when you check BP.
    - Check and record BP and HR twice daily unless the team changes the frequency.
    - If BP or HR are out of range, call your transplant coordinator.
    - Always check BP/HR **before** giving any medications that can affect BP or HR.
    - If BP or HR are out of range, call your transplant coordinator **before** giving the BP or HR medications (do not wait to give anti-rejection medications).
    - If he or she was upset or agitated during the BP check, attempt to recheck once calm.
    - Always bring the BP/HR record to transplant clinic appointments.

What Should You Know About Transplant Medications?

UNDERSTANDING TRANSPLANT MEDICATIONS

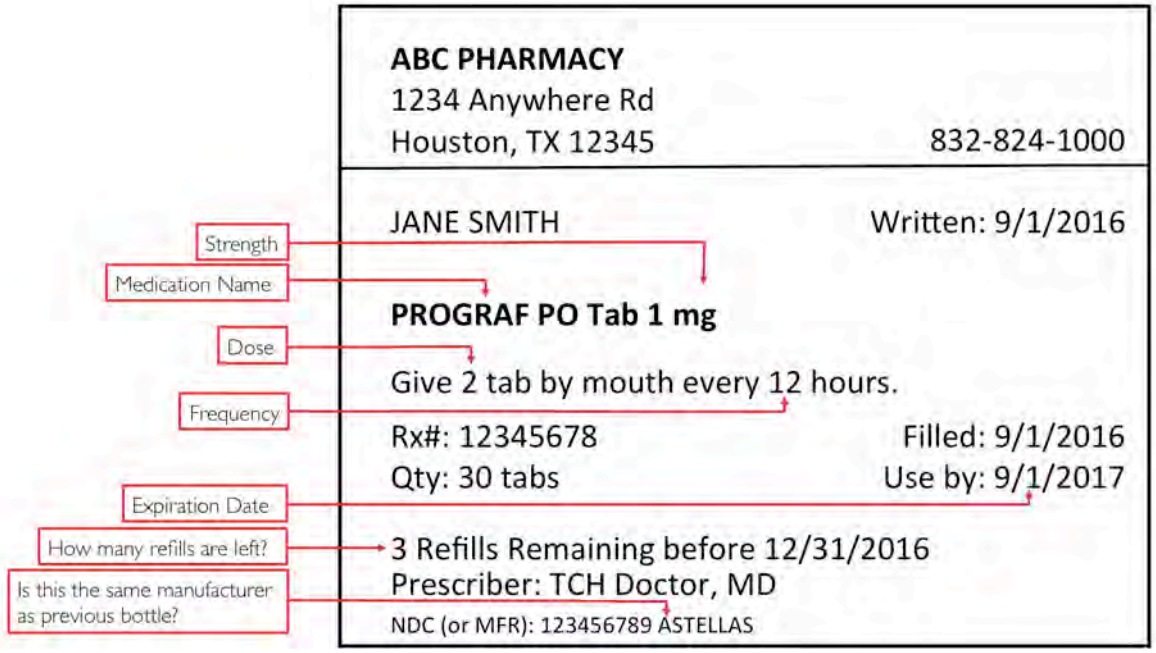
- You should know a few things about transplant medications
  - Which medications are anti-rejection medications
  - Which medications need to wait until after labs are drawn
  - What time to give the medications
  - How to give the medications
  - The generic and manufacturer's name of each medication
  - Why it is important to use the same manufacturer of medicine 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 medication 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 have a negative effect on transplant medications.
  - Herbal remedies include herbal drugs, herbal teas, essential oils, etc.

- 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 – 4:00pm.
  - 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.
  - If you are not sure what to do, call your coordinator during weekdays. If after hours, call and request to have the transplant physician on call paged. *Missing a dose of medicine is an urgent issue.*

- If you forget any doses of your anti-rejection medications, call your transplant coordinator as soon as you realize. Lab tests may be needed.
- Vomiting around medication time:
  - Vomiting **within** 30 minutes after medicine: repeat the medication dose.
  - 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.
  - 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 - 4:00pm.
  - No refills will be done after hours, on weekends or on holidays.
- When you have refills remaining, contact your pharmacy directly at least 5 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. If you require more than 2 doses within a 24- hour period notify your transplant coordinator.
  - **Never** give the transplant patient medications known as NSAIDs (non-steroidal anti-inflammatory drugs) like Motrin® or Advil® (ibuprofen) or Aleve® (naproxen).
  - Many over the counter cold and cough medications are not safe to take with transplant medications.

What are the Different Types of Transplant Medications?

TYPES OF TRANSPLANT MEDICATIONS

- Anti-rejection (immunosuppressant) medications
- Corticosteroids
- Medications to prevent and treat infections (antibiotics, antiviral, antifungal)
- Blood pressure medications
- Stomach acid reducers
- Vitamins and supplements
- Diuretics
- Other miscellaneous medications
- Over the counter medications

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.

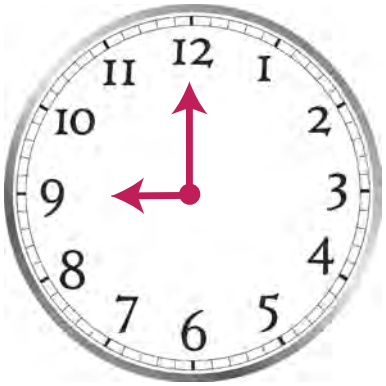
Prograf® (Tacrolimus)

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 have 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

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 recipients 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 should be avoided 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

Cellcept®, Myfortic® (Mycophenolate)

Available formulations: tablet, liquid, capsule **Note:** Mycophenolate comes in 2 different salts, mycophenolate mofetil (Cellcept®) and mycophenolic acid (Myfortic®). They are not interchangeable.

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
- Low red blood cell count
- Increased cholesterol & triglyceride levels
- Low red blood cell count
- Impaired wound healing

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 (ANTIBIOTICS, ANTIVIRAL, ANTIFUNGAL 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 – let transplant team know immediately before taking the next dose
- 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

Mepron® (Atovaquone)

Available formulations: suspension

Purpose

Atovaquone is an alternative medication for Bactrim®. It is given orally once daily.

Common Side Effects

- Nausea
- Vomiting
- Diarrhea
- Low blood cell counts

Note: The suspension will stain clothing.

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 av[redacted]h the powder inside the capsule or suspension (it shou[redacted] women if possible).

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.

BLOOD PRESSURE MEDICATIONS

High blood pressure may be a side effect of Prograf®, Gengraf® or Neoral®, 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

STOMACH ACID REDUCERS

Pepcid® (Famotidine), Prevacid® (Lansoprazole), Nexium® (Esomeprazole)

Available formulations: tablet, liquid, capsules, packets

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

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)

OTHER MISCELLANEOUS MEDICINES:

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.

Ursodiol

Available formulations: tablet, capsule, compounded liquid

Purpose

Ursodiol increases the solubility of bile, allowing it to freely flow through the biliary tree.

Common Side Effects

- GI upset
- Metallic taste

Lovenox (enoxaparin)

Available formulations: Subcutaneous injection, pre-filled syringes

Purpose

Lovenox helps to thin the blood, assisting in blood flow through the veins and arteries to the new organ. It is used to help prevent blood clots from forming or to help treat blood clots if they have already formed.

How to Give

Inject into the abdomen at least 2 inches from the belly button.

Common Side Effects

- Bruising
- Bleeding
- Redness, irritation, or itching where shot is given

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. Medications a transplant patient should not take without approval 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 on pages 77-79.

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 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.

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 canceled 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 on the number of 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, oceans, 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 7-14 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 1 month post-transplant. If complications occur, your stay may be extended until it is safe to transition home. 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?

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, hepatitis, or influenza
- 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-4:00PM

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

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: Send a MyChart message to 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 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, barns, farm animals, chicken coops, bird droppings
- Compost/leaf piles, mulch, gardening, yard work, lawn mowing (plant and soil aerosols)
- Animal stools including litter boxes, cages, fish tanks or mouse droppings
- Uncovered sandboxes
- Construction sites, home renovations, dusty-environments
- Mold, standing water, flood damaged building or vehicles
- Smoke (tobacco, marijuana, camp fires)
- Certain animals like reptiles, birds, rodents, stray animals, etc. *(See pets section on pages 80-82)*
- Going barefoot outside
- Insect or tick bites
- Hot tubs
- Bat caves
- Unimmunized children
- Tuberculous exposure (homeless shelters, prisons)
- Discuss swimming activities and locations with the transplant team
  - Avoid swallowing water while swimming
  - Avoid water that may be contaminated with human or animal waste
  - Avoid cuts or abrasions and wear shoes to protect feet in rocky areas

Common Infections

VIRAL RESPIRATORY INFECTION:

- We may recommend testing for certain viruses.
- Viral testing is often not done in a non-transplant setting.
- Many of these viruses will do not cause significant problems but often are not treatable and must resolve on their own.
- Some respiratory infections are potentially dangerous, but are treatable like influenza.
- Antiviral therapies work best when they are started early in the course of an infection.

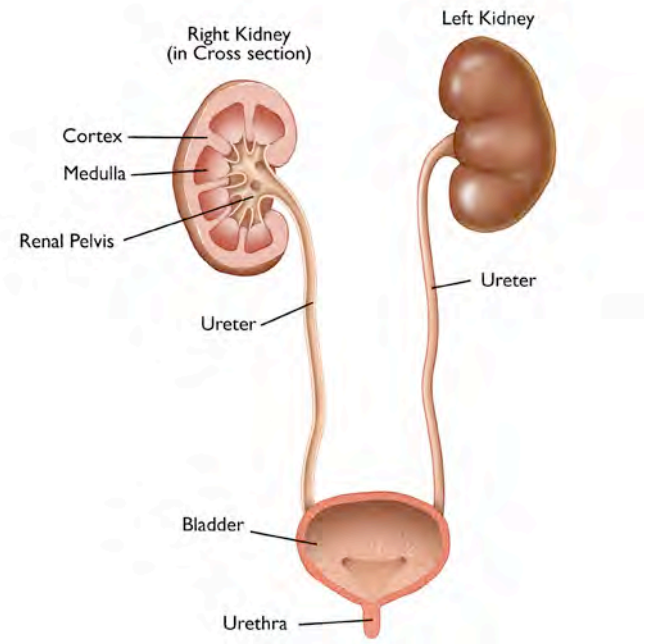
If fever, nasal congestion, cough, or sore throat begin over the weekend, notify the transplant center right away! Do not wait until Monday. Call 832-824-2099 and ask for the on-call transplant provider to be paged.

FLU (INFLUENZA)

- General information
  - Caused by a virus and is most severe in children under 5 years old with a suppressed immune system, lung disease, or chronic illness.
- Prevention
  - Recipients should obtain flu vaccine every year
  - Family, caregivers, and close contacts should obtain flu vaccine every year to decrease recipient's risk of influenzas exposure.
- Signs and symptoms
  - Fever
  - Cough
  - Sore throat
  - Runny nose
  - Muscle aches
- Treatment
  - A medicine can help lessen flu symptoms and reduce complications. It works best if started in the first 48 hours of illness, but it can be started at any time for a transplant recipient.
- What to do if exposed:
  - **If recipient is exposed to influenza,** let the transplant team know right away so a medicine can be given to help prevent influenza infection. This is an urgent issue.
  - **If a recipient tests positive for influenza,** let the transplant team know right away so a medicine can be given to help lesson flu symptoms if started within the first 48 hours of illness. This is an urgent issue.
  - **If household members are exposed to influenza**, they should discuss it with their doctor, since they live with a transplant recipient.

URINARY TRACT INFECTIONS (UTI)

- General information
  - Common with immunosuppressed patients
  - Can involve the urethra, bladder, and/or kidneys
- Signs and symptoms
  - Burning or pain with urination
  - Feeling the need to urinate more frequently and urgentl
  - Foul smelling urine
  - Blood in urine
  - Lower back pain
  - Fever
- Prevention
  - Avoid bubble baths
  - Wear cotton underwear
  - Drink plenty of water
  - After toileting, always wipe front to back
  - Avoid "holding it" when you need to pee



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
    - He or she may need to be hospitalized and started on Acyclovir.
    - Usually a 10-14 day hospital stay until all lesions are crusted over.

SHINGLES (VARICELLA-ZOSTER)

- General Information
  - Caused by a reactivation of the same virus that causes chickenpox (Varicella).
  - When the virus reactivates, it will cause an outbreak of shingles. You can get chicken pox when exposed to the drainage from these lesions.
  - Keeping the lesions covered and avoiding contact with the lesions usually prevents spreading.
- 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 so that the treatment can be started as soon as possible – see "chicken pox" for treatment.

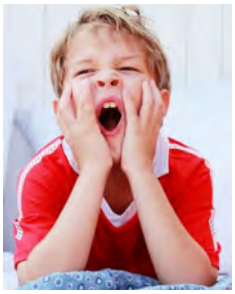
CYTOMEGALOVIRUS (CMV)

- General information
  - CMV is a member of the herpes virus group.
  - CMV remains active in the person's body the rest of his/her life and can reoccur.

- Can cause serious illness in organ transplant recipients.
- About half of the adults in the United States have CMV.
- CMV infection during pregnancy can cause birth defects.
- CMV 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.
- Babies and young children with no symptoms can spread CMV through their saliva and urine for months to years.

• Signs and symptoms
- Headaches
- Fatigue
- Aching
- Fever
- Swollen glands
- Diarrhea
- Pneumonia
- Vision loss



• Prevention
- Practice good hand washing.
- Do not share drinks, eating utensils, or food.
- Avoid contact with saliva and urine.
- Once CMV is in your body, you have it for life, and it can come back (reoccur).
- Younger children are more likely to spread the virus. Keep this in mind when considering daycare settings and for recipients with younger siblings.
- We can give medicines to help prevent CMV infection, but CMV infection can occur after medicine is stopped.
  - Medications such as ganciclovir (IV) and valganciclovir (by mouth) are available to help prevent and treat this virus.

• Treatment:
- Medications can be given as a precaution/preventative or for confirmed infection (such as CMV negative recipients who receive CMV positive organ).
- Medications are available in IV and oral form depending on severity of illness.
- Severe CMV infection is difficult to treat.

EPSTEIN-BARR VIRUS (EBV)

• General information
- EBV is a member of the herpes virus group.
- EBV remains in the person's body the rest of their life and can reoccur.
- Can cause serious illness in organ transplant recipients.
- EBV is common in the community and causes mononucleosis; also known as "the kissing disease."
- EBV 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, usually due to contact with saliva or from intimate contact.
- Signs and symptoms
  - Extreme fatigue
  - Fever
  - Sore throat
  - Swollen glands (lymph nodes)
- Prevention
  - Practice good hand washing.
  - Do not share drinks, eating utensils, or food.
  - Once EBV is in your body, you have it for life.
  - It can reoccur.
- Treatment
  - Medications are sometimes given as a precaution/preventative or for confirmed infection.
  - Medications are available in IV and oral form depending on severity of illness, but they do not work well.
  - Immunosuppression doses may need to adjusted with guidance of the transplant team.

Post-Transplant Lymphoproliferative Disease (PTLD)

- EBV has been linked to a rare complication called PTLD.
- PTLD can be serious or fatal.
- It is a 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, rituximab, or chemotherapy/radiation if necessary.

DIARRHEA

- General information
  - Can be caused by viruses, bacteria, and parasites.
  - Testing is needed to identify the cause, so that it can be treated if possible. Not everything that can be identified can or needs to be treated.
  - Often difficult to treat in transplant recipients and may cause chronic diarrhea or frequent relapses, which is why prevention is so important.
  - Viruses like Norovirus & Rotavirus typically cause vomiting and diarrhea.
  - Parasites like Giardia and Cryptosporidium typically cause non-bloody diarrhea.
  - C. difficile is a bacterial infection that most often occurs after antibiotic treatment, and when severe, can cause bloody stools.
- How it is spread
  - Exposure to infected stool and/or vomit, usually from contaminated hands or food
  - Norovirus and C. difficile spores:
    - Can be spread for a long time after the diarrhea has gone away
    - Are not killed by hand sanitizer, but washing with soap and water can remove the particles from the hands
    - Are not killed by normal disinfectants, so bleach-based cleaners should be used

- Signs and symptoms
  - Diarrhea
  - Vomiting
  - Abdominal pain
  - Fever
  - Bloody bowel movement
  - Dehydration/Decreased urine frequency or amount
  - Weight loss or failure to gain weight
- Prevention
  - Wash hands with soap and water (not hand sanitizer)
    - Before preparing food
    - Before eating (especially after being in or around the hospital)
    - After using the bathroom or changing diapers
    - After being around someone with vomiting or diarrhea
    - When hands are visibility soiled
  - Avoid food at potlucks where many people have served themselves or handled the food. Individually packaged food is safer.
  - Avoid contact with people who have or recently have had diarrhea.
  - Do not eat food prepared by someone who had diarrhea in the past 2 weeks.
  - If anyone at home has vomiting or diarrhea
    - Wash hands with soap and water (not hand sanitizer)
    - Use bleach-based cleaners to disinfect, especially the kitchen and bathrooms
  - Wash fruits and vegetables before eating
  - Avoid getting water in the mouth while swimming in pools or fresh water
- Treatment
  - Depends on the cause of the diarrhea
  - Immunosuppression doses may need to adjusted with guidance of the transplant team

Types of Rejection

The immune system keeps you healthy. It works by protecting the body from attack by dangerous things like germs (bacteria or viruses) and cancer cells. The transplant recipient's immune system will try to reject their new organ because it recognizes that it is different from the rest of the body. Transplant recipients take immunosuppressant medications for the rest of their lives to prevent rejection of their transplanted organ. Even with these medications, rejection may occur at any time after transplant. Recipients who experience an episode of rejection may improve with medication adjustments. Some episodes of rejection require adding another medication. Taking your medication as prescribed consistently will help prolong the life of your transplanted organ.

There are two types of rejection – acute and chronic. It is possible to have acute and chronic rejection at the same time. A transplant recipient may be diagnosed with the following:

- **Acute Rejection:** may occur at any time after transplant, but most often it occurs during the first three months. Usually onset is sudden, and if caught early, it is usually reversible. It may also occur if medicines are missed or not taken correctly.
- **Chronic Rejection:** occurs slowly, and may eventually lead loss of organ function and need for re-transplant. There may not be any symptoms other than a rise in liver enzymes. The process may be slowed with immunosuppression.
- **Medication Toxicity**: the liver can be affected by high medication levels. Decreasing the dose typically reverses this process (not a form of rejection, but also can be diagnosed by biopsy).

SIGNS AND SYMPTOMS OF REJECTION

- Increased organ specific enzymes (usually AST, ALT, and GGT)
- Can be diagnosed by biopsy

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

Other Possible Complications

HEPATIC ARTERY THROMBOSIS

Hepatic artery thrombosis (HAT) can occur in the early post-transplant phase. HAT is a clot that forms in the hepatic artery. This clot prevents oxygenated blood from getting to the liver which results in liver damage.

- Signs/Symptoms: Sharp rise in liver enzymes, bilirubin levels, and causes long blood clotting times
- Diagnosis: By Ultrasound with Doppler
- Treatment: Restore blood flow to liver as soon as possible. This is a medical emergency. If unable to restore blood flow, a re-transplant may be needed.

PORTAL VEIN THROMBOSIS

Portal vein thrombosis (PVT) can occur at any time after transplant. PVT is when a clot forms in the portal vein. This clot prevents blood from the intestines to flow into the liver. This causes increased pressure inside the veins that lead to the liver.

- Signs/Symptoms: increased spleen size, ascites (fluid in the abdomen), decreased blood cell counts
- Diagnosis: By Ultrasound with Doppler
- Possible treatment options depend on the severity of the symptoms:
  - Monitor without intervention.
  - A medicine may be given to thin the blood that may break up the clot.
  - The recipient may need a medical intervention performed in the Interventional Radiology department to clear the clot.

HEPATIC VEIN THROMBOSIS

Hepatic vein thrombosis (HVT) can occur at any time after transplant. HVT is when a clot forms in a hepatic vein. This clot prevents blood from draining out of the liver. This causes increased pressure inside the veins of the liver.

- Signs/Symptoms: enlarged liver and ascites
- Diagnosis: By Ultrasound with Doppler or MRI
- Possible treatment options depend on the severity of the symptoms:
  - Monitor without intervention.
  - A medicine may be given to thin the blood that may break up the clot.
  - The recipient may need a medical intervention performed in the Interventional Radiology department to clear the clot.

BILIARY STRICTURE

Biliary Stricture can occur at any time after transplant. An anastomotic stricture is a biliary stricture that happens where the biliary ducts are connected. If a stricture is in another area, it is called a non-anastomotic stricture.

- Signs/Symptoms: increased bilirubin, jaundice, pain in the right upper part of the abdomen, fever, change in stool color, abnormal liver enzymes
- Diagnosis: By ultrasound or cholangiogram
- Possible treatment options depend on the severity of the symptoms:
  - Monitor without intervention.
  - Endoscopic Retrograde Cholangiopancreatography (ERCP) which is when a scope is used to view the biliary ducts. During the procedure, a stent or dilation of a biliary duct can be done.
  - Percutaneous Transhepatic Cholangiogram (PTC) which is a drain placed by the interventional radiology department. The drain crosses through the area of stricture or drains the biliary system

KIDNEY DYSFUNCTION: A change in the ways the kidnesy clear waste and excess fluids from your blood through urine

HIGH BLOOD PRESSURE: When the force of a person's blood pushing against the walls of the arteries is too high

GINGIVAL HYPERPLASIA: Overgrowth of gum tissue in the mouth

HIRSUTISM: Excessive hair growth

OSTEOPOROSIS: Weakening of the bones

OBESITY: Excessive fat accumulation that results in a higher weight than what is considered a healthy weight for the person's height

HYPERLIPIDEMIA: High cholesterol and/or triglycerides

DIABETES MELLITUS: High blood sugar

NEUROLOGIC PROBLEMS: Headaches, tremor

HEMATOLOGIC COMPLICATIONS: Bleeding, clotting, anemia, low white blood cell count, low platelet count

CARDIOVASCULAR COMPLICATIONS: Cardiomyopathy

RECURRENT DISEASE: Hepatitis B, Hepatitis C, Autoimmune Hepatitis, Primary Sclerosing Cholangitis (PSC) are diseases that may recur in the transplanted liver

DRUG-INDUCED LIVER INJURY: Some of the medications used after transplant may cause toxicity to the liver

DENOVO AUTOIMMUNE HEPATITIS: A condition where the body makes antibodies towards the liver after transplantation, causing elevated liver enzymes.

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.

When Should You Contact the Transplant Team?

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, hepatitis, or influenza
- 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-4:00PM

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

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: Send a MyChart message to 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 5
After Transplant

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

If you live outside of the Houston area, you should plan to stay in Houston at least 30 days after discharge from the hospital. If complications occur, your stay may be extended until it is safe to transition home.

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

FOR ROUTINE CLINIC VISITS

The transplant recipient will be seen weekly in the transplant clinic on either Mondays or Wednesdays. 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.

FOR ROUTINE LAB DRAWS

On days of lab work, do not give the immunosuppressant medications until the blood has been drawn. However, you can 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 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 8:30am and 9:00am.

The transplant team will determine how often each recipient needs to have labs drawn on an individual basis. Plan to have labs drawn at least once or twice a week for the first 4 to 6 weeks. Over time, the frequency of lab draws will spread out.

PROCEDURES AND BIOPSIES

If rejection is suspected, a biopsy will be ordered by the transplant team.

Coming to the hospital and before the liver biopsy

- The recipient may not have any food or liquids after midnight on the night before the biopsy. Medications may be given with water on the morning of the biopsy before leaving home.
- When arriving for the biopsy, the recipient will be admitted to the hospital for an overnight stay. The recipient may need to have blood tests early that morning.
- 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 Interventional Radiology Department.
- An ultrasound of the biopsy is performed first.
- The biopsy area will be numbed after the site is cleaned.
- A special needle is inserted into the liver to take a tiny sample of tissue.
- Pressure is held on the biopsy site and then an adhesive bandage is placed tightly over the biopsy site.

After the biopsy

- The recipient will usually be admitted overnight for the procedure.
- The preliminary results will be available the following day.
- The transplant and pathology teams will discuss the preliminary results and decide on a treatment plan.

LONG-TERM FOLLOW-UP WITH THE TRANSPLANT TEAM:

The transplant recipient will need to be seen by the transplant team routinely for the rest of their lives for examination, tests, procedures and lab work. The frequency of visits may decrease over time, as long as the transplant recipient is doing well. Please keep in close contact with the transplant team, so these routine visits and procedures can be scheduled as appointments can fill up quickly.

VIRTUAL VISITS

Texas Children's has made virtual appointments available, in some cases, when coming to the hospital is not an option. These video visits allow patients and families to see and talk to their providers. To participate, the patient's family must have internet access on a phone, tablet or computer. Your transplant team will discuss with you if they think a video visit would be suitable.

If a video visit is appropriate, you will receive a link with the time and information on how to connect. It's important to test the application for the visit before the time of the visit to make sure the connection works. At the time of the visit make sure the transplant patient is available and able to be seen. A room that is brightly lit and quiet works best.

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.
- 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 - 4:00pm
  - 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 to 8 weeks after surgery.
- Should not perform strenuous activity for 6 to 8 weeks after surgery.
- Should not drive for 6 to 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, oceans, 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	Occupational Therapy
• Post-op mobility	• Feeding
• Getting patients up and walking	• Fine motor skills
• Parent/caregiver/child education	• Developmental
• Reinforce sternal precautions	• Strengthening
• Importance of mobility	• Endurance
• Home exercise program	• Sensory
• Facilitate independence with mobility	• Community reintegration
• Balance	• Activities of daily living
• Stairs	- 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 to Prevent Infection 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 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, sore throat, runny nose, diarrhea, vomiting, rash or mouth lesions should be reported to the transplant physician.

WAYS TO LIMIT EXPOSURE TO ILLNESS POST-TRANSPLANT

General Guidelines for Transplant Recipients and their Family Members

- Wash your hands with soap & water and always use hand sanitizer on the way in and out of the hospital room.
- Wash hands with soap and water before preparing or eating food. **Soap and water are preferred, but use hand sanitizer if soap and water are unavailable.**
- Wash your hands with soap and water before and after using the bathroom and diaper changes.
- Keep your hands away from your eyes, nose, and mouth unless freshly washed with soap and water or use a tissue to touch that area
- Keep sick visitors away from the hospital and transplant patient.
- 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 hospital room after transplant.
- The transplant recipient **cannot** receive any live virus vaccines (common live virus vaccines are Varicella [VZV, chickenpox], measles, mumps, rubella [MMR], nasal flu vaccine, etc.), but it is important to keep other immunizations up-to-date.
- 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.

See pages 75-76 for more detailed vaccine/immunization safety information.

See page 61 for common things to avoid after transplant

See pages 75-79 for ways to stay healthy after transplant

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. The transplant team may ask you to complete surveys that monitor quality of life post-transplant.

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 below* 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.
    - When a sibling or family member receives a live vaccine (which transplant recipients **cannot** receive), caution should be used to avoid contact with body fluids from the person who received a live vaccine for at least 2 weeks (no drink sharing, good hand washing, etc.).
- It is recommended that family members and close contacts receive their flu shot annually.
- If you or your local physician have a question about an immunization that is not on this list please feel free to contact the recipient's transplant coordinator directly.

Allowed	Not Allowed
• Influenza (flu) (injectable) • 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, Men B) • HPV (human papillomavirus) (Gardasil®) • Japanese Encephalitis Virus (Ixiaro) The following are not immunizations, but they are allowed: • Mantoux (TB) tests (PPD): test for tuberculosis • Immune globulin (gamma globulin): infusion	• 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.

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.
    - Establish the clinician-patient relationship.
    - Discussion of body development, body image, self-confidence, weight management, immunizations (including the HPV vaccine), contraception, and prevention of sexually transmitted infections (STIs).
    - Patients who are sexually active, regardless of age, should see a gynecologist for check ups and education.

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.
- Wear broad spectrum (UVA/UVB) or SPF 30 or greater when outside.
- Pap smears (screening for cervical cancer):
  - Recommended to begin at age 21 (regardless of sexual activity) and then every 3 years.
  - Women who have a weakened immune system may need to be screened more frequently.
  - 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 (wash hands with soap and water) 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

Unsafe foods:

- Unpasteurized "raw" milk and cheese/dairy products made from unpasteurized milk
- Unpasteurized juice or cider
- Raw or undercooked eggs (cookie dough, cake batter, some mayonnaise, hollandaise sauce)
- Raw or undercooked meat, poultry, fish or seafood (especially wild game)
- Uncooked seed sprouts (alfalfa sprouts, mung beans)
- Unwashed fruits and vegetables
- Cold cuts/deli meats must be heated until steaming hot to be safe
- Public salad bars/buffets, street vendors, picnics if the food has sat at room temperature for a while, potluck meals
- Food prepared by someone with a recent diarrheal illness

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 produce, 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. Pay attention to city wide notices regarding water quality and follow recommendations.
- Bottled Water:
  - Is considered safe if it has been processed in one of these ways:
    - Reverse osmosis
    - Distillation
    - 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).
    - 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) 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 & 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 and tick bites. Avoid going out during peak mosquito feeding periods and use insect repellents that contain DEET. Wear long pants and long sleeve shirts, socks, closed toes shoes, and a hat. Treated clothing can be considered for longer times outdoors. After being outdoors, check for ticks (especially in hair, under arms, and groin), so that they can be removed quickly, which may prevent infection. 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 mosquitoes 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, which sometimes should be given at least a month before traveling.
- 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 and at the first sign of illness.
  - 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.
    - Tell your veterinarian about the transplant.
    - Wash your hands thoroughly with running water and soap after handling animals.
    - Adults should supervise children during hand washing.
    - Do not place litter boxes or pet cages in kitchens, dining rooms, or other areas where food is prepared and eaten.
    - Do not wash pet cages or litter boxes in the kitchen sink.
    - Avoid new pets in the first 6 to 12 months after the transplant.
  - 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.
  - Avoid being bitten or scratched.

- Transplant recipients should:
  - Avoid contact with animal feces.
  - Avoid cleaning cages, tanks, litter boxes, aquariums.
  - 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.
    - Avoid having food near or eating by the animals or their enclosures.
    - Direct contact with animals is not necessary to contract most diseases spread by animals. Indirect contact with contaminated surfaces can cause infection.
    - Exposure to farm animals causes risk for *E. Coli* bacterial infection.
    - Children are at the greatest risk for serious complications caused by E. coli infection.
    - Young children are less likely to follow hand hygiene rules.
    - Young children constantly place their hands to their eyes and mouth, which increases infection risk.

RECOMMENDATIONS FOR PETS

- Dogs
  - Puppies haver higher risk for infection than older dogs.
  - Any cat or dog that has diarrhea should be checked by a veterinarian for infection with Cryptosporidium, Giardia, Salmonella, and Campylobacter.
  - Avoid contact with a dog's nose or face after kennel cough vaccine since it is a live vaccine.
- 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.
  - Kittens have a higher risk of infection than older cats.
- 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 and skin).
- Birds, including chicks and ducklings.
  - If you must have a bird, the 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, mice, rats, 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 mosquitoes 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) **b** 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?

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, tuberculosis, influenza, 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-4:00PM

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

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: Send a MyChart message to 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 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 or marijuana smoke that includes cigars, cigarettes, hookah, electronic/vapor (e-cigarettes, vaping). If friends or family members have to smoke, then they should do so outside and not in the home or car with the recipient. Recipients should avoid smoke-filled areas as much as possible. We can provide personal counseling to adolescents about their own smoking choices.

6. Can transplant recipients smoke?

Since transplant patients are more at risk for cancers, avoiding all tobacco and marijuana products is important. This includes dip, chew tobacco, cigars, hookah, and cigarettes, including electronic/vapor (e-cigarettes). Smoking tobacco or marijuana is harmful to everyone, but it is more harmful for transplant recipients because of increased risk of infection. Exposure to cigarette smoke could cause serious complications and makes respiratory infections more likely. 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 properly every time reduces 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

https://unos.org/wp-content/uploads/unos/WEPNTK.pdf

Purpose: A downloadable book from UNOS about "What every transplant patient needs to know"

Transplant Fundraising Organizations

HELP HOPE LIVE
http://www.helophopelive.org

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

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

1907 Holcombe Blvd. Houston, TX 77030
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

8300 El Rio Street. Houston, TX 77054
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.

A variety of additional housing resources are available. Please contact your social worker for assistance with housing options.

Texas Children's Liver Center – Transplant Center

Compliance Agreement

In order to take the best care possible of your child, we want to make you aware of the transplant team's expectations for pre- and post-transplant adherence to medical care and ensure you understand the transplant team's expectations for care of your child and communication with the transplant team. Good medical adherence and good communication with your transplant team is an important part of the success of your child's transplant. For this reason, you will be asked to sign an adherence contract which outlines expectations related to your child's care both pre- and post-transplant. Please carefully review this contract to ensure you understand all of the requirements.

You are responsible for making your child's 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. Missed appointments without notification will not be tolerated.

You are responsible for giving your child his/her medications as prescribed by his/her physicians. You must discuss any changes in your child's 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. Your child 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 your child's medications, you must notify your coordinator before your minimum supply runs out. Not giving your child their medications will not be tolerated.

You are responsible for making the liver transplant team aware of any changes in your child's 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.

Contact the transplant coordinator by phone, the day of occurrence, if you have any questions or concerns related to your child's medical care, and contact the clinical social worker by phone if you have any questions or concerns related to the above expectations. As a transplant candidate, you must be able to travel to the hospital after being called. 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 30 days post-transplant your child must stay in Houston, Texas. If complications occur, your stay may be extended until it is safe to transition home.

Failure to comply with the above expectations mandates a 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 my child may not receive an organ transplant if I do not show the liver 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.

Primary Caregiver# 1 _____ Date _____

Primary Caregiver#2 _____ Date _____

Transplant Coordinator _____ Date _____

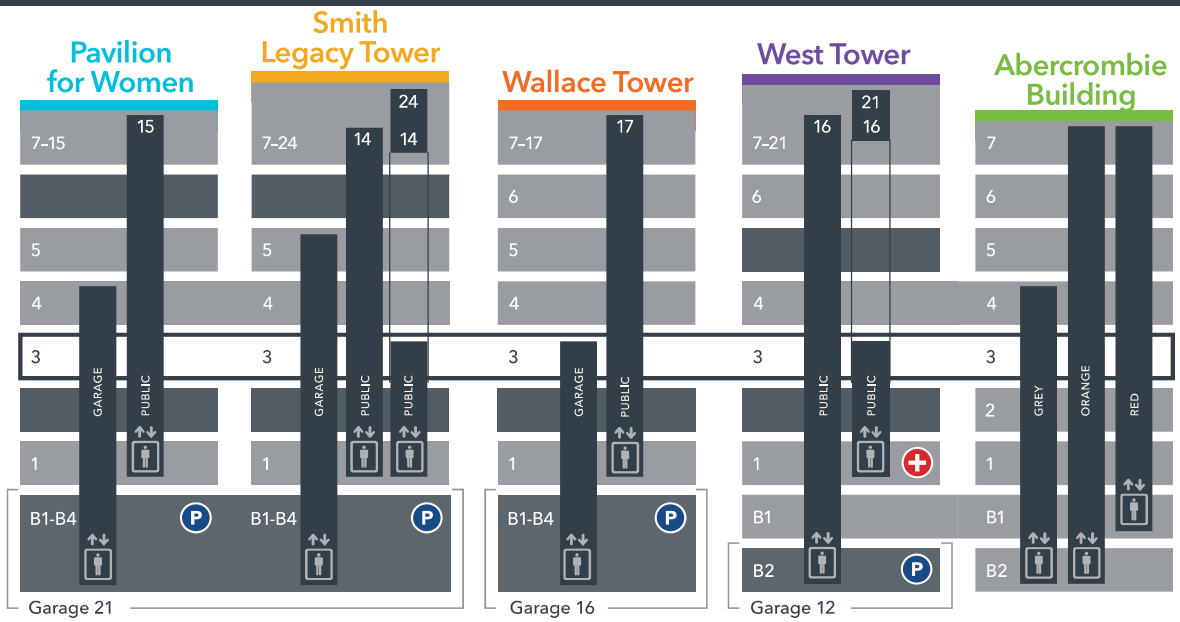
Social Worker _____ Date _____

Physician _____ Date _____

Maps and Elevator Directories

Building Level Guide

Access all buildings via the Level 3 Bridges
Acceder a todos los edificios a través de los Puentes de Nivel 3




Main St.
Fannin St.
Bellows Dr.
Bates St.
P 21
Baylor OB/GYN Clinic
Elevators
Garage Elevators
The Women's Place
Pavilion for Women
Birth Records
Wells Fargo® Bank
Commons
Garage Elevators (Access to Garage 21)
Elevators
Family Fertility Center
Smith Legacy Tower
P 21
LEVEL 3 BRIDGE
LEVEL 3 BRIDGE
LEVEL 3 BRIDGE
LEVEL 3 BRIDGE
P 12
West Tower
Elevators
Elevators (Access to Garage 12)
PACU
Chapel
To Abercrombie Building
Surgery Reception and PASS Clinic
N
Garage Elevators (Access to Garage 16)
Elevators
P 16
Wallace Tower
Infusion Center
Rx
LEVEL 3
BRIDGE & AMENITIES
Texas Children's Hospital®
Admissions | Admisiones
ATM/Bank | Cajero Automático/Banco
Baby Bistro
Coffee | Café
Elevators | Ascensores
Escalator | Escalera Eléctrica
Financial Counseling | Consejería Financiera
Commons Fish Tank | Área de Commons Pecera
Food | Comida
Gift Shop | Tienda De Regalos
Information | Información
Outpatient Lab | Laboratorio
Parking | Estacionamiento
Pharmacy | Farmacia
Restrooms | Baños
Stairs | Escaleras
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Wallace Tower

Elevators Levels 1-17

Level 1
- Garage Elevators
- Information Station
- Valet / Drop-Off
- Welcome/Info Desk

Level 3
- ATM
- Beanstalk Coffee Shop
- Bridge Access
- Conference Center
- Food Court
- Garage Elevators
- Gift Shop
- Information Station
- Infusion Center
- Outpatient Laboratory
- Outpatient Pharmacy

Level 4
- Pediatric Radiology

Level 5
- Audiology
- Dental Clinic
- Ophthalmology
- Oral Maxillofacial Surgery
- Otolaryngology (ENT)
- Speech, Language and Learning

Level 7
- Surgery Reception

Level 8
- After Hours Surgery Clinic
- Bariatric Surgery Clinic
- 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 Lab
- Pulmonary Medicine

Level 11
- Adolescent Gynecology
- Adolescent Medicine
- Diabetes
- Endocrinology

continued on next line
- Gastroenterology, Hepatology, Nutrition
- Physical Therapy Gym
- Renal
- Rheumatology
- Sports Medicine Clinic
- Young Women's Clinic

Level 14
- Cancer Center
- Hematology

Level 16
- Genetics
- Infectious Disease
- Pain Management Clinic
- Physical Medicine and Rehabilitation
- Psychology Service
- Spina Bifida Clinic

Level 17
- Complex Care Clinic
- International Adoption
- Junior League Children's Health Care Clinic
- Retrovirology
- Public Health Ped. Clinic
- Travel Medicine

Go to Level 1 or 3 to access Garage Elevators to (P) Parking Garage 16

Pavilion for Women

Elevators Levels 1-15

Level 1
- Garage Elevators
- Gift Shop
- Information Station
- Patient and Family Services
- Pharmacy
- Valet/ Drop Off
- Welcome/ Info Desk

Level 3
- Admissions
- Baylor Obstetrics and Gynecology
- Bella Luna Boutique/ Baby Bistro
- Birth Records
- Bridge Access
- Coffee Corner
- Family Fertility Center
- Fresh Bistro Cafe
- Garage Elevators
- Information Station
- The Women's Place
- Welcome/ Info Desk
- Wells Fargo Bank & ATM

Level 4
- Conference and Education Center
- Garage Elevators
- Laboratory Services
- Maternal and Fetal Center
- Women's Radiology

Level 5
- Birthing Prep and Recovery
- Post Anesthesia Care Unit (PACU) / Recovery
- Pre-Anesthesia Testing
- Women's Surgery

Level 7
- Partners in OB/GYN Care (POGC)

Level 8
- Neonatal Intensive Care Unit (NICU)
- Ronald McDonald® Family Room

Level 9
- Family Birth Center (Labor and Delivery)
- OB/GYN High Risk Unit

Level 11
- Women's Assessment Center (Triage)
- Women's Specialty Unit (Antepartum)

Level 12
- Mother Baby Unit (Postpartum)

Level 14
- Mother Baby Unit (Postpartum)

Level 15
- Women's Specialists of Houston (WSH)

Go to Level 1 or 3 to access Garage Elevators to P Parking Garage 21

West Tower

Elevators Levels B2 - 16

Level B2
- Parking Garage 12

Level B1
- Pathology Lab

Level 1
- Elevators- Levels 16-21
- Emergency Center
- Information Station
- Pediatric Radiology
- Valet/ Drop Off
- Welcome/Info Desk

Level 3
- Admissions
- Bridge Access
- Children's Chapel
- Elevators- Levels 16-21
- Gift Shop
- Information Station
- Language Services
- Post-Anesthesia Care Unit (PACU)
- Surgery Reception

Level 4
- Milk Bank
- Newborn Center (NICU)
- Ronald McDonald® House

Level 7
- Bone Marrow Transplant
- Hematology/ Oncology Acute Care

Level 8
- Bone Marrow Transplant
- Renal Dialysis

Level 9
- Cancer and Hematology Centers
- Ronald McDonald® Family Room

Level 10
- Epilepsy Monitoring Unit
- Neurology/Neurosurgery Inpatient Unit

Level 11
- General Surgery Inpatient Unit
- Orthopedic Surgery Inpatient Unit

Level 12
- Inpatient Rehabilitation Unit (IRU)
- Transplant Services Inpatient Unit

Level 14
- Adolescent Medicine Inpatient Unit
- Pulmonary Medicine Inpatient Unit

Level 15
- Behavioral Health
- Pediatric Hospital Medicine Inpatient Unit

Level 16
- Beauty Salon
- Elevators- Levels 16-21
- Family Laundry
- Family Resource Center
- HISD Classrooms
- Pi Beta Phi Patient/ Family Library
- Radio Lollipop/ Kids' Own Studio
- The Child Life Zone

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

From 9pm to 6am, all Visitors must Check In with Security on Level 1 of West Tower Main Lobby.

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

West Tower

Elevators Levels 16 - 21

Level 1

- Elevators- Levels B2-16
- Emergency Center
- Information Station
- Pediatric Radiology
- Valet / Drop Off
- Welcome / Information Desk

Level 3

- Admissions
- Bridge Access
- Children's Chapel
- Elevators- Levels B2-16
- Gift Shop
- Information Station
- Language Services
- Post-Anesthesia Care Unit (PACU)
- Surgery Reception

Level 16

- Art Studio
- Beauty Salon
- Elevators- Levels B2-16
- Family Laundry
- Family Resource Center
- HISD Classrooms
- Pi Beta Phi Patient/ Family Library
- Radio Lollipop/ Kids' Own Studio
- The Child Life Zone

Level 21

- Neurophysiology
- Physical Medicine and Rehabilitation
- Sleep Lab

Go to Levels 1, 3 or 16 to access the Elevators to Levels B2-16, including (P) Parking Garage 12

From 9pm to 6am, all Visitors must Check In with Security on Level 1 of West Tower Main Lobby.

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

Abercrombie Building

Red Elevators Levels B1 - 7

Level B1

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

Level 1

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

Level 2

- Emergency Center Surge
- Procedures Suite
- Texas Children's Urgent Care

Level 3

- Bridge Access
- CHI St. Luke's

Level 4

- The Children's Garden
- Milk Bank
- Neonatal Intensive Care Unit (NICU)
- Ronald McDonald® House

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 Bellows 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 linea para servicio valet en el nivel 1.

Abercrombie Building

Orange Elevators Levels B2 - 7

Level B2

- CHI St. Luke's
- Facilities Operations

Level B1

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

Level 1

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

Level 2

- Emergency Center Surge
- Procedures Suite
- Texas Children's Urgent Care

Level 3

- Bridge Access
- CHI St. Luke's

Level 4

- The Children's Garden
- Milk Bank
- Neonatal Intensive Care Unit (NICU)
- Ronald McDonald® House

Level 5

- Employee Health and Wellness

Level 7

- 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 Bellows 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 linea para servicio valet en el nivel 1.

Abercrombie Building

Grey Elevators Levels B2-4

Level B2

- CHI St. Luke's

Level B1

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

Level 1

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

Level 2

- Emergency Center Surge
- Procedures Suite
- Texas Children's Urgent Care

Level 3

- Bridge Access
- CHI St. Luke's

Level 4

- The Children's Garden
- Milk Bank
- Neonatal Intensive Care Unit (NICU)
- Ronald McDonald®House

From 9pm to 6am, all Visitors must Check In with Security on Level 1 of West Tower Main Lobby. Please use the Bellows 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 linea para servicio valet en el nivel 1.

Smith Legacy Tower

Garage Elevators Levels B4 - 5

Levels B1 - B4
- Parking Garage 21

Level 1
- **Elevators**- Levels 1-14
- **Elevators**- Levels 14-23
- Information Station
- Valet/ Drop Off
- Welcome/ Information Desk

Level 3
- Bridge Access
- Coffee Corner
- **Elevators**- Levels 1-14
- **Elevators**- Levels 14-23
- Family Fertility Center
- Fresh Bistro Cafe
- Information Station
- Welcome/ Information Desk

Level 4
- **Elevators**- Levels 1-14
- Women's Radiology

Level 5
- **Elevators**- Levels 1-14
- Nuclear Radiology
- Pediatric Radiology

Go to Level 1 or 3 to access the Elevators to Levels 1-23

From 10:30pm to 7am, all Visitors must Check In with Security in the Lobby on Level 1 or 3.

De 10:30pm a 7am, todos los visitantes deben registrarse con el Servicio de Seguridad en el nivel 1 o 3 de Smith Legacy Tower lobby.

Smith Legacy Tower

Elevators Levels 1-14

Level 1
- Elevators- Levels 14-23
- Garage Elevators
- Information Station
- Valet/ Drop Off
- Welcome/ Information Desk

Level 3
- Bridge Access
- Coffee Corner
- Family Fertility Center
- Fresh Bistro Cafe
- Elevators- Levels 14-23
- Garage Elevators
- Information Station
- Welcome/ Information Desk

Level 4
- Garage Elevators
- Women's Radiology

Level 5
- Garage Elevators
- Nuclear Radiology
- Pediatric Radiology

Level 7
- Pediatric Radiology

Level 8
- Surgery Reception

Level 9
- Neuro Intensive Care Unit
- Surgical Intensive Care Unit

Level 10
- Medical Intensive Care Unit

Level 11
- Medical Intensive Care Unit

Level 12
- Transitional Intensive Care Unit

Go to Level 1 or 3 to access Garage Elevators to (P) Parking Garage 21

From 10:30pm to 7am, all Visitors must Check In with Security in the Lobby on Level 1 or 3.

De 10:30pm a 7am, todos los visitantes deben registrarse con el Servicio de Seguridad en el nivel 1 o 3 de Smith Legacy Tower lobby.

Smith Legacy Tower

Elevators Levels 14-24

Level 1
- Elevators- Levels 1-14
- Garage Elevators
- Information Station
- Valet/ Drop Off
- Welcome/ Information Desk

Level 3
- Bridge Access
- Coffee Corner
- Family Fertility Center
- Fresh Bistro Cafe
- Elevators- Levels 1-14
- Garage Elevators
- Information Station
- Welcome/ Information Desk

Level 16
- Heart Failure Intensive Care Unit
- Conference Center

Level 17
- Cardiac Intensive Care Unit

Level 18
- Neonatal Cardiac Intensive Care Unit
- Cardiovascular Operating Rooms (CVOR)

Level 20
- Cardiac Catheterization Labs

Level 21
- Heart Center Clinics
- Diagnostics

Level 22
- Cardiac Patient Care Unit

Level 23
- Cardiac Patient Care Unit

Level 24
- Adult Congenital Heart Program

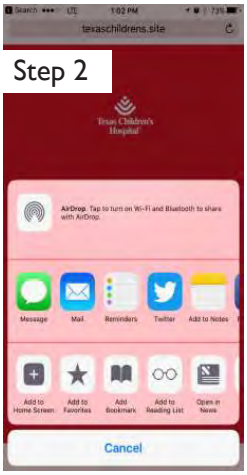
Go to Level 1 or 3 to access Garage Elevators to (P) Parking Garage 21

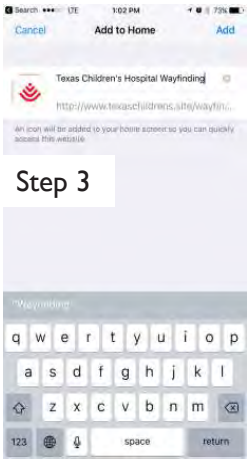
From 10:30pm to 7am, all Visitors must Check In with Security in the Lobby on Level 1 or 3.

De 10:30pm a 7am, todos los visitantes deben registrarse con el Servicio de Seguridad en el nivel 1 o 3 de Smith Legacy Tower lobby.

WAYFINDING APP INSTRUCTIONS – IPHONE

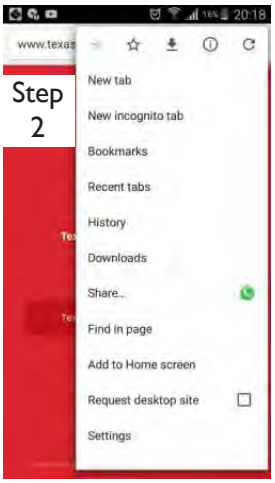
1. With iPhone open Safari
2. Go to **texaschildrens.org/wayfinding**
3. Follow pop-up window prompts, or select ↑
4. Choose "Add to Home Screen"
5. Name the shortcut and save. Icon will appear on your home screen

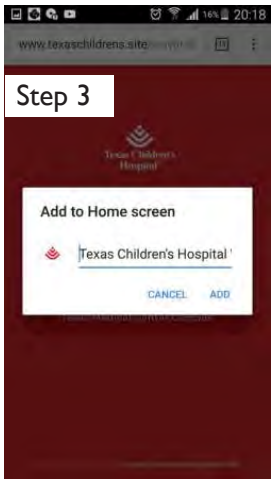




WAYFINDING APP INSTRUCTIONS – ANDROID

1. With Android device, open Chrome or "Internet"
2. Go to **texaschildrens.org/wayfinding**
3. Follow pop-up window prompts, or open browser menu
4. Choose "Add to Home Screen"
5. Name the shortcut and save. Icon will appear on your home screen





When Should You Contact the Transplant Team?

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, tuberculosis, influenza, 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-4:00P:
Non-urgent Issues: Contact your transplant coordinator by phone or MyChart.

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: Send a MyChart message to 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.