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INTRODUCTION

This handbook is used to provide education to pre and post heart transplant patients and their families. It is yours to keep. The handbook has instructions on diet, medications and activity after your child leaves the hospital. It also gives you blank forms to keep track of your child’s temperature, blood pressure, weight, and medicines that your child will be taking. These records are **very important** in helping us know how to best take care of your child according to his or her needs. **Please read this notebook regularly and carefully, and be sure to bring this information with you when you come to all clinic visits. You will be tested on the information that is in this book. We have organized this book to have key points at the beginning of each section to help point out what you need to learn.**

Although heart transplant doctors and transplant coordinators will be in charge of much of the care for your child, you also have a *very* important part to play. You have already done a great job of caring for your child’s medical needs. Now, we will help you learn how to take care of your child after a heart transplant.

Always feel free to ask *any* questions that you have. No question is too small or unnecessary. Doctors, Transplant Coordinators, Dietitians, Psychologists, Social Workers, and Child Life Specialists are here to help you in the care of your child. It is okay to feel nervous about going home. Your transplant team is always here to help you.

Important Phone Numbers

Children’s Medical Center Dallas Main Number.....	214-456-7000
Heart Transplant Clinic.....	214-456-8600
Heart Transplant Office FAX.....	214-456-7758
Toll Free Number.....	800-846-6768

Transplant Clinic Location:

Solid Organ Transplant (SOT) B2300

Children's Medical Center of Dallas
1935 Medical District Drive
Dallas, Texas 75235
Phone 800-846-6768 or 214-456-8600
Main Fax 214-456-8405

Office Hours:

****Monday through Friday 8:30 a.m. until 5:00 p.m. ****

After hours, weekends, and holidays, dial 214-456-7000 and ask for the Heart Coordinator on-call.

IMPORTANT TIMES TO CONTACT THE HEART COORDINATOR

It is very important to contact the Heart Transplant Coordinator if your child becomes *ill* with any of the following:

- Temperature greater than 100.5 by mouth or under the arm.
- Vomiting or diarrhea.
- Heartbeat when at rest is not normal, less than _____ or greater than _____.
- Systolic blood pressure (top number) greater than ___ and diastolic blood pressure (bottom number) greater than ___ which does get better after one hour of taking the blood pressure medicine.
- Trouble breathing or breathing faster than normal.
- Dizziness
- Decreased appetite
- Decreased energy
- Increased puffiness of the face, hands, feet or body
- Need to urinate with more frequency or burning with urination.
- Signs of respiratory infection (cough, sore throat, green or yellow sputum)
- Signs of wound infection (redness, swelling, warm to touch, tender to touch)

The One for Children.....The One for Transplant

One of the largest comprehensive pediatric transplant centers in the country, working **to make life better for children.**

The *Solid Organ Transplant Center* at Children’s Medical Center provides complete care for pediatric patients needing heart, kidney, liver, and intestinal transplantation. Focused on patient family-centered care, the dedicated team of transplant specialist will support, guide, educate, and care for you and your child through the stages of transplant.

As the pediatric teaching hospital for The University of Texas Southwestern Medical Center, Children’s is committed to clinical excellence and advancing research. Children’s offers more than 50 subspecialty programs across two campuses and satellite outpatient centers across North Texas. This allows for nearby, continuous, and complete care of your child within the Children’s system. Our mission is going beyond expectations of treatment and care for children needing organ transplant. The Solid Organ Transplant Program strives to advance the medical, social, and scientific aspects of pediatric transplantation....to make life better for children.

Our program has performed more than 1000 transplants. This is a rare accomplishment in the field of pediatric transplant. Listed below are accomplishments of the transplant program at Children’s.

Kidney Transplant

More than 400 pediatric kidney transplants have been completed at Children’s since the program started in 1979. Children’s has constantly been a leader in the number of pediatric kidney transplants performed in Texas.

Liver Transplant

More than 450 pediatric liver transplants have been completed at Children’s since its first liver transplant in 1984. Children’s has the highest number of pediatric liver transplanted in Texas. In 2006, the state’s first pediatric liver-heart transplant was performed at Children’s.

Intestinal Transplant

The first pediatric intestine transplant in North Texas was performed by Children’s in 2006. Since the program’s start, Children’s has performed the most pediatric intestinal transplants in the state. The Intestinal Transplant Program is managed jointly with the Intestinal Failure Program.

Heart Transplant

Children’s has performed more than 160 heart transplants since completing Dallas’ first pediatric heart transplant in 1988. Children’s has the highest number of pediatric hearts transplanted in Texas, with the most organs transplanted for patients younger than age 5. In 2006, Children’s performed the state’s first pediatric heart-liver transplant. In 2008, Children’s also transplanted the state’s smallest transplant recipient.

The Transplant Team

Heart transplantation is a procedure that requires the knowledge of many specialists trained in medicine, surgery, and immunosuppressive management. For this reason, we use a team approach to coordinate your child’s care. In addition, all of the heart team members are pediatric experts.

The professional members of this team include: doctors (MD), advanced practice nurses, transplant coordinators, nurses, social workers, psychologists, dietitians, pharmacists, child life specialists, chaplains and others who have been trained to meet the special needs of pediatric heart transplant patients and their families. The transplant coordinators and doctors are always available to answer your questions about transplant. A brief description of some of the transplant team members follows.

Transplant Cardiologists (Heart Doctors)

The transplant cardiologists are pediatric heart specialists with expert knowledge in heart transplant. They will work with your child’s primary pediatrician(s). After heart transplant, the transplant cardiologists will become your child’s heart doctors. They will manage your child’s heart care, and will work closely with you and with your child’s pediatrician to be sure all your child’s medical needs are met.

Transplant Surgeons

The transplant surgeons are the doctors who will transplant the new heart into your child's body. The transplant surgeons are specialists in cardiothoracic surgery. The transplant surgeons will also care for your child on a daily basis during the first few days following transplant. The surgeon will make rounds to check on your child and review lab test results and other procedures.

Transplant Nurse Practitioners and Assistants

Transplant Nurse Practitioners are nurses with a higher degree of education and practice experience. Physician Assistants have a Master’s degree and work under a doctor. They help the family understand their child’s specific needs. They collect patient history, do physical exams, diagnose acute (short term) and chronic (long term) illnesses, and order or perform diagnostic tests for the pre (before) and post (after) transplant patient.

Transplant Coordinators

The transplant coordinators are experienced registered nurses who are responsible for organizing all parts of the transplant process, from referral by the local doctors, to evaluation, and on through post-transplant, discharge and follow up care. The transplant coordinator works with the cardiologist, your local doctor, transplant doctor and surgeons to coordinate or organize your child’s care. The coordinator is always available to answer any questions you may have about transplant, and the transplant process.

Financial Coordinators

A Financial Coordinator is available to help families with financial concerns throughout the transplant process. The financial coordinator will call your insurance company to get a benefit summary and find

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out if approval is required for evaluation and transplant. At the time of evaluation, a financial coordinator will review the details of your benefits and identify other financial resources. The financial coordinator will help you when applying for state/federal programs (ie. Medicaid, Supplemental Security Income). Should you have any questions about your health insurance, we encourage you to call your financial coordinator.

Social Workers

A social worker will help you deal with the many stresses that come with the transplant and hospitalization of your child so you won't have to face the difficult times alone. A social worker can help you find the resources you need before transplant surgery like transportation, lodging, and financial assistance. A social worker can also give counseling and emotional support to help lessen any emotional distress you feel. The social worker will also help arrange your child's discharge from the hospital and make the right appointments to outside community resources if needed.

Psychologists

As part of the evaluation process, all children and families will see one of the transplant team psychologists. The psychologists are experts in child development and behavior and in helping children and their families deal with the stresses from heart transplant. Your child will get a complete developmental exam before the transplant. This will provide the baseline for future yearly exams after the transplant.

Many children with long lasting illnesses show small developmental (age-related) delays, and if these are found, more help will be needed. The psychologist will ask about any concerns you have about your child's emotional status and behavior. Many parents find it helpful to talk about their concerns with an expert who may be able to make some suggestions that can make a difference to them and their child's adjustment to the transplant.

The team psychologist is also there to help other members of the family. A transplant is not just surgery; it is a special experience that affects every family member. The psychologist has worked with many transplant patients and is qualified to help you and your loved ones get the most from the new opportunities that transplant offers.

Dietitians

A registered, clinical dietitian will help evaluate your child's nutritional status before the transplant and follow him or her throughout the transplant period and after surgery. The dietitian will keep detailed records of your child's height, weight, and muscle growth. The dietitian will also work closely with you to develop the best diet for your child. For younger children, the dietitian will tell you how to mix formulas, which may need to be changed from time to time as your child's nutritional status changes. Like the other members of the transplant team, the dietitian is experienced in developing special diets for children with heart disease. The dietitian provides expert nutritional advice for your child's needs.

Transplant Pharmacist

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The transplant pharmacist is responsible for identifying, preventing and fixing possible and actual medication problems. He or she is a resource to the medical team while your child is in the hospital. The transplant pharmacist’s role is to also teach your child and family about the medications.

Care Teams

Your child will have a care team during his or her inpatient stay at Children's. The care team will be responsible for creating the plan of care for your child. You will be asked to help with this plan so that we can best meet your child's needs. The care team will also be responsible for checking vital signs; giving medications; monitoring I.V. lines, dressings, and drainage tubes; tracking daily intake, output, and weights, ordering lab tests, and performing procedures. Your care team will always be available to answer questions, explain treatments and procedures, and offer help to make your stay as comfortable as possible.

Child Life/ Child Development Specialists

You child will need help to emotionally prepare for the transplant surgery and the hospital stay. A child life specialist is someone that will explain all the pieces of medical equipment and procedures to a child in words he or she can understand. This process includes "medical play", a time when the child can see and touch different pieces of medical equipment, under the child life specialist's supervision, and pretend to be a doctor or nurse for a stuffed animal. This allows the child to express his or her fears and worries about the hospital and the child life specialist can address those worries with the child. Other activities with the child life specialist may include a tour of the surgery area and the intensive care unit (ICU) and viewing children's videos about what to expect during a hospital stay. During your child's hospital stay, a child life specialist will be available to direct supervised play time in the hospital's playroom and organize special events for the children at the hospital.

Chaplains

Hospital chaplains are available to help patients and families with the faith and spiritual questions that may come up during the course of the transplant experience. At Children's Medical Center, pastoral care provides daily chapel services, regular pastoral visits, supportive counseling and parent support groups.

The pastoral care department helps persons from all faith traditions. Their goal is to help you find the spiritual support you need during a hospital stay. The chaplains can also help you by contacting your minister or other clergy from home or a clergy person from your faith tradition.

Other Staff Members

Many other specialists trained in pediatrics will help care for your child. These specialists include pathologists (microscope doctor), radiologists (x-ray doctor), infectious disease doctors (germ doctor), renal doctors (kidney doctor), cardiologists (heart doctor), respiratory therapists (breathing specialist), and physical and occupational therapists (body movement specialist).

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Other staff members, such as interns and residents (doctors in school), often are with your doctor on rounds. These are graduate, licensed doctors who are getting more training in specialized medical or surgical skills under the supervision and direction of the transplant team.

Your transplant team wants you to be involved in the care of your child. It is important for you to ask the team questions you may have and tell them about any changes in how you feel. The best way to remember your questions or concerns is to write them down in a journal or on a notepad when you think of them. When the doctors make rounds, you can discuss each item on your list with the transplant team.

Heart Transplant Explained

Key Points:

- ***What is a Heart Transplant?***
- ***Where do hearts come from?***
- ***How long have heart transplants been performed***
- ***The Good and Bad of getting a Heart Transplant***
- ***Who pays for a transplant?***

What is a Heart Transplant?

A heart transplant is surgery to remove a person’s diseased heart and replace it with a healthy heart from a deceased donor.

Where do hearts for transplant come from?

A deceased donor is a person who has recently died, and the family has agreed to donate the organs for transplant.

How long have heart transplants been performed?

The first human heart transplant was performed in December of 1967 in Cape Town, South Africa.

What are the advantages of heart transplant?

Although close supervision is still needed, after a successful transplant, your child will resume a more normal life, including the following:

- Likely to have freedom from mechanical valves, pacemakers, etc.
- Corrected symptoms of heart disease
- Improved quality of life
- Fewer diet and fluid limitations
- Improved growth (when on low dose steroids)

What are the disadvantages of heart transplant?

- Medicine needed to prevent or stop the body from rejecting the new heart have unwanted side effects
- Complex medical follow-up

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- Rejection may happen even though your child takes medicine to prevent or stop rejection
- Increased risk of infection (special care must be taken to avoid contact to other people who are sick)
- Increased risk of cancer
- Cataracts (cloudy spots in the eye)
- Joint and bone disease
- Weight gain
- Diabetes may be caused by steroids (medication taken to prevent rejection)

Who pays for a transplant?

- ◆ The Financial Coordinator will discuss your insurance coverage with you during the evaluation

Each child is different. In general, Medicare, Medicaid, or most insurance plans cover the cost of transplant for the recipient. The coverage for the cost of a heart from a deceased donor depends on the individual insurance policy. A Financial Counselor or your Social Worker is available to help you through this involved process.

The Transplant Evaluation

Key Points:

- *There are many tests that are needed before transplant*
- *A committee reviews the test results to see if transplant will be an option for your child*

Heart transplant is offered not only to extend a child’s life, but also to offer a better quality of life. Someone who is being considered for a heart transplant has no other medical or surgical options available. A child may need a heart transplant because he/she was born with a heart defect that cannot be fixed with surgery, or his/her heart muscle is not working. In rare cases, heart transplant may be an option when a child has a serious, abnormal heart rhythm that cannot be controlled by any other way.

What are the steps of the transplant evaluation?

Once financial coverage has been verified from your medical payment source (private insurance, Medicare, Medicaid, etc.), the transplant evaluation can begin.

1. *Medical Evaluation:* The patient has a complete medical evaluation including medical history, physical exam and a series of tests to help decide if your child is healthy enough to receive a heart transplant.
2. *Tissue Typing / ABO Blood Type:*
 - ◆ *Tissue Typing* is a *blood* test, (not a sample of tissue.) These special blood tests are used to determine HLA antigens (your child’s genetic make-up.) Blood is taken from the patient (your child) and any possible donors. This is how we find the best match between donor and recipient.
 - ◆ *ABO Blood Type* controls blood group compatibility. The donor and recipient must have *compatible* blood groups.
3. *Psychosocial Team Evaluation:* The patient and family will meet with members of our psychosocial team. This part of the evaluation measures parents’ understanding of transplant and the effects transplant may have on your family. Other areas that may be assessed include: outside support systems, i.e., church, school, neighbors, friends, and other family, relationships with brothers and sisters, home setting, financial resources/work history, how you handle stress, medical and mental health history, and the parent’s relationship with the patient.

The psychosocial team has members with different educational backgrounds and expertise. The team includes a Pediatric Transplant Psychologist, Clinical Social Worker, and a Child Life Specialist. The discussion with your child’s psychosocial team is important, as everyone in the family will likely be affected during the transplant process. The transplant team requires that (2) adults be present, at least one of the adults being the primary caregiver, during evaluation meetings with social work and psychology.

4. *Financial Team:* It is important to know the benefits and limits of your insurance policy, along with the possible out-of-pocket costs for items not covered by the insurance. The transplant financial coordinators are here to help you understand extra costs and help you make choices about financial coverage. During the transplant evaluation, you will meet with a financial coordinator who will help explain transplant related insurance benefits and answer any questions you may have.

5. *Presentation to the Transplant Selection Committee:* After your child’s evaluation is done, the patient will be presented to the Transplant Selection Committee for final approval. Once approved by the Transplant Selection Committee and financial clearance for transplant has been received, the patient will be registered with the United Network for Organ Sharing (UNOS) - the national wait list for patients waiting for an organ transplant.

PRE-TRANSPLANT TESTING

Before the transplant team can decide if your child will benefit from heart transplant, many tests must be done. The two main goals of the evaluation before transplant are: 1) to be certain a heart transplant is needed (i.e. that no other medicines or surgeries will cure the illness), and 2) to be certain that your child’s other body systems are healthy enough to survive a transplant and the side effects of all the medicine after transplant. Many of the standard, pre-transplant tests are listed below. A member of the transplant team can tell you which tests will be needed for your child.

Cardiac catheterization

This test checks the pressure inside the heart and lungs. Small tubes called catheters are put into blood vessels in the groin or neck. The small tubes are passed through the blood vessels into the chambers of the heart and out to the lungs to measure pressure and oxygen levels. If the blood pressure in the lungs is high (also known as pulmonary hypertension), one or more medicines will be given during the test to lower the pressure. If the blood pressure in the lungs cannot be lowered, then the heart transplant would not be successful. The donor heart would not work because it would not be able to pump against the high pressure in the lung vessels. This test takes about two to four hours. Your child will be sedated for this test.

Electrocardiogram (EKG)

This test measures the electrical conduction pattern through the heart. Several “stickers” (also known as leads) will be placed on your child’s chest and connected to a machine that receives the electrical impulses from your child’s heart and records them on paper. When the test is over, the stickers will be removed. This test only takes a few minutes. It is not painful. No medicine is needed to help the patient sleep.

Echocardiogram (Echo)

This is an ultrasound of the heart. This test uses sound waves to draw a picture of the heart that can be seen on a TV screen and recorded on videotape. The echocardiogram gives doctors another way of looking at how well the heart muscle and valves are working, and measures the size of the heart. Your child will lie on a bed and lubricating jelly will be placed on his/her chest. The technician will slide a transducer (which is like a microphone) over the chest to obtain the pictures. This test uses no needles and does not hurt, but it does take about 20 to 40 minutes. During the test your child will need to lay still. For this reason, most babies and toddlers are given medicine to help them sleep for this test. Older children will be able to watch a video during the test; we have several from which to choose.

Radiology Studies

A chest x-ray (CXR) allows us to look at the size of the heart and the condition of the lungs. Spinal x-rays and hand x-rays will be done to measure bone age, and help to assess bone structure before transplant. A child’s “bone age” may be different from his/her actual age in years and these x-rays help

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us to measure your child’s potential for future growth. Each x-ray takes only a few minutes and it is not painful.

Pulmonary Function Tests (PFTs)

These tests show how well a child’s lungs can expand and how well oxygen is carried to the blood. If your child is tall enough (about 40 inches) and old enough to cooperate, he or she will be asked to breathe into a tube connected to a machine. The test takes about 20 minutes.

Head Magnetic Resonance Imaging (MRI)

This test takes special pictures of the brain to see if any defects are present. Because some of the immunosuppressant medications may have neurological side effects, these pictures can also be compared to those taken after transplant if any neurological changes occur. The MRI camera looks like a short tunnel. Your child will lie on an exam table that will move slowly through the “tunnel” while the pictures are taken. Your child should be aware that the camera is noisy, but it will not touch his/her body and it will not hurt. He/she will need to be still for this test to get the best picture, so babies and very young children are usually given medicine to help them sleep. This test can take 25 minutes to one hour. Children with pacemakers or other metal implants will not be able to have an MRI, but will have a head CT (computed tomography) scan instead. The CT scanner is like the MRI camera, except that it looks like a large donut rather than a tunnel. A head CT takes less time than an MRI, 10 to 30 minutes.

Kidney Testing

The transplant team needs to assess your child’s kidney function. Kidney function may not be normal before transplant, but can become normal after transplant. However, if the kidneys are permanently damaged, a heart transplant will not repair kidney function. Some of the medications after transplant can cause damage to the kidneys. While this damage is usually small, we must be certain that your child’s kidneys will be able to handle the medicines. The kidney function will be measured by testing the urine, blood, and collection of urine over a 24 hour period.

Blood Testing

Blood samples will be taken to measure kidney function, liver function, immune system response, blood type, and prior exposure to certain viruses, including HIV, which is the virus that causes AIDS.

Consultations

Several specialists will examine and work with your child. These will include any or all of the following: a cardiologist (heart doctor), transplant surgeon, neurologist (brain doctor), pulmonologist (lung doctor), nephrologist (kidney doctor), psychologist, psychiatrist, dietician, social worker, child life specialist, and a financial counselor (insurance specialist). These specialists form the transplant team and they work together to help your child and your family.

Financial Agreement

Key Points

- *You must notify your coordinator if you lose your insurance coverage immediately*
- *Transplant is expensive and a big commitment for life*
- *Transplant requires insurance coverage*
- *Medications for the first month after transplant can cost up to \$15,000*

Transplants are life changing. It is a serious lifetime commitment and is expensive. The decision for transplant is a partnership between you, your doctors, and the transplant team.

It is important to keep insurance coverage to support the cost of the transplant and required for on-going care and medications.

It is important that you understand the rules and requirements of your current insurance plan.

If your insurance changes or is cancelled, please call your transplant financial coordinator, **immediately**. If you know it will be cancelled call the financial coordinator **before** it is cancelled. Your failure to do so can result in an insurance denial. You will be responsible to pay all charges for the transplant and test(s).

Not notifying your transplant team of insurance changes can also change listing status.

Please be aware that Children’s Medical Center at Dallas is unable to pay for your medications. Your Transplant Financial Coordinator can help you in reviewing the other options to insurance plans.

WAITING FOR TRANSPLANT

Key Points:

- *Timeframes and how the waitlist works*
- *Defining the waitlist*
- *Getting support during the waiting time*
- *The matching of the donor and the recipient*

The Wait

Depending on your child’s medical illness, his or her status may change while waiting for a donor heart. The waiting time for a heart to become available can range from a few days to several months. During this time, you will be asked to bring your child to the Transplant Clinic for follow-up visits. Also, you will need to call the transplant coordinator anytime your child has a fever or any other signs of illness such as runny nose, cough, vomiting or diarrhea. If your child develops an infection while waiting for a donor heart, he/she will not be able to have the transplant until the infection is cured. This is due to high doses of immunosuppressant medications that are given at the time of transplant which can allow infection to overwhelm your child’s body.

Living Arrangements

The family must be within a two-hour drive of Children’s Medical Center at all times while waiting for a donor heart. This will allow enough time to get to the hospital when a heart becomes available. If your home is outside this two-hour limit, your child and one parent may be required to live in the Dallas area while waiting. Our social worker can help with housing during this time.

Multiple Listing

A patient can be registered at more than one transplant center. However, each center decides who it accepts as candidates and has the right to decline patients who are listed at other centers. Caregivers should inform the centers they contact of their multiple listing plans. The waiting time starts after each center evaluates a patient and places him/her on the organ transplant waiting list.

Transfer of Waiting Time

Your child’s transplant center can be changed by moving his/her primary waiting time to the new center upon registering at that center.

The caregiver should then tell the original center to remove them from their list.

How does the waiting list work?

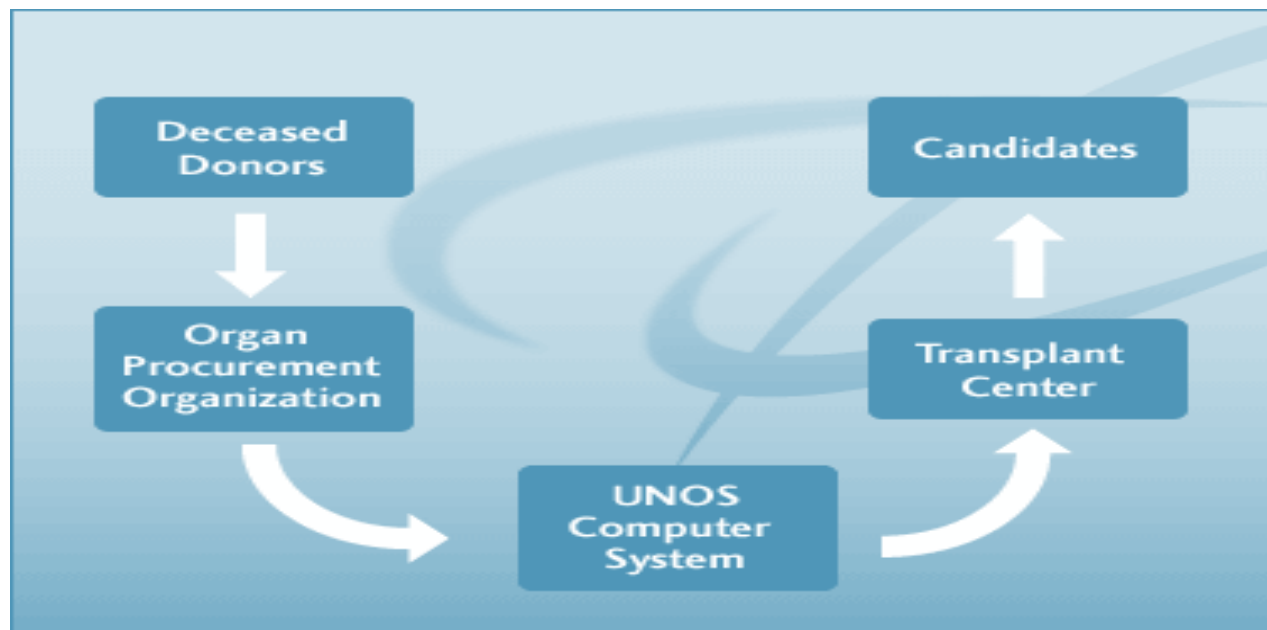
The U.S. Department of Health and Human Services' Health Services & Resources Administration (HRSA), United Network for Organ Sharing (UNOS) keeps a central computer system called UNetSM. Transplant centers can access this computer network 24 hours a day, seven days a week.

UNet connects all transplant centers and organ procurement groups in a safe, real-time setting. Because UNet uses the Internet, it gives access to many transplant professionals. However, in order to protect private medical records, all users must use have a secure password.

Matching Donor Organs with Transplant Candidates

When a deceased organ donor is identified, a transplant coordinator from an organ procurement group accesses the UNet system and enters medical information about the donor. The system uses this information to match the medical information of the candidates waiting, against those of the donor. The system then creates a ranked list of patients who are fit to receive each organ. This list is called a "match run." Factors affecting ranking may include:

- tissue match
- blood type
- weight range
- length of time on the waiting list
- immune status
- distance between the possible recipient and the donor
- degree of medical urgency (for heart, liver, lung and intestines)



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The organ is offered to the transplant team of the first person on the list. Sometimes, the top transplant candidate will not get the organ for one of many reasons. When a patient gets an organ offer, he or she must be available, healthy enough to have a major surgery and agree to be transplanted immediately. Also, a laboratory test to measure the match between the donor and potential recipient may be needed. If the organ is refused for any reason, the transplant hospital of the next patient on the list is contacted. The process continues until a match is made. Once a patient is selected, contacted, and all testing is complete, the surgery is scheduled and the transplant occurs.

The Five Steps of the Matching Process

1. **An organ is donated.** When the organ becomes available, the Organ Procurement Organization (OPO) working with the donor sends the donor’s information to UNet. They report medical and genetic information, including organ size and condition, blood type, and tissue type.
2. **UNet generates a list of possible recipients.** The UNet computer creates a list of possible transplant candidates who have medical and biologic profiles that match the donor. The computer ranks candidates by this biologic information, as well as clinical characteristics and time spent on the waiting list.
3. **The transplant center is notified of an available organ.** Organ placement specialists at the OPO or the UNOS Organ Center contact the centers whose patients appear on the local list.
4. **The transplant team considers the organ for the patient.** When the team is offered an organ, it decides its acceptance or refusal of the organ based upon established medical criteria, organ condition, candidate condition, patient availability and organ transportation. By policy, the transplant team has only one hour to make its decision.
5. **The organ is accepted or refused.** If the organ is not accepted, the OPO continues to offer it to patients at other centers until it is placed.

Blood Group Matching

- If your child has type A blood, he or she may receive a heart from a donor with type A or type O blood.
- If your child has type B blood, he or she may receive a heart from a donor with type B or type O blood.
- If your child has type O blood, he or she will receive a heart from a donor with type O blood.
- If your child has type AB blood, he or she may receive a heart from a donor with type AB, type A, type B blood or type O).

***The exception to this is infants who can accept a heart from a donor with any blood type**.*

Pediatric Candidate Status

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Each candidate waiting for a heart transplant is given a status code which corresponds to how quickly the candidate needs to receive a transplant. The status criteria are:

Status 1A: Children who are critically ill are listed as status 1A. These children may be on a ventilator (machine to help breathing) and/or one or more drip medications given by constant IV infusion) to help circulation. Children at home on certain IV medicines may also be listed as Status 1A.

Status 1B: Children who are a little more stable than status 1A patients are listed as status 1B. These children may be in the intensive care unit on a single low-dose drip medication, or on the regular cardiac unit, or out of the hospital. They must meet certain medical criteria, such as poor growth. Many children will be in this category.

Status 2: Children who do not meet criteria for status 1A or 1B listing are listed as status 2. In general, these children will be more stable and out of the hospital.

Status 7: A child listed as Status 7 is temporarily unsuitable to receive an organ transplant. This can be due to illness, patient availability, or other factors that make the *child* unsuitable for transplant. The child may also be listed as a Status 7 if his or her condition improves.

Size of the Donor Heart

The donor heart can be from a person who is up to two or three times the size of your child. If the new heart is large, it will accommodate to your child’s size. The new heart is living tissue and will grow along with your child.

THE TRANSPLANT SURGERY

Pre-Transplant Events

When a heart for your child becomes available, the heart transplant coordinator will call and give you instructions about what needs to be done.

Once you are told that a heart is available, do NOT give your child anything to eat or drink. You will need to bring him/her to the hospital right away. Once you are at the hospital your child will have blood work, a urine test, and a chest x-ray before surgery. He/she will also be given some immune suppression medication before going to surgery. You will be able to stay with your child until he/she goes to surgery, and will be shown where to wait during the surgery to receive updates. The heart transplant coordinator will give you updates from the operating room. For your use, there is a phone in the waiting room.

If your child is sick (cold or flu virus, pneumonia, or another infection) at the time a heart becomes available, or the tests before surgery show that your child has an infection, then the transplant may be cancelled. If this happens, the donor heart will be given to the next person on the waiting list. After your child is better from his/her infection, he/she will wait for another heart to become available.

The Surgery

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Heart transplant surgery usually takes from six to eight hours. A team of doctors and surgeons is with your child every moment. First, the chest will be opened and your child will be connected to a heart/lung machine. After the donor heart arrives in the operating room, your child’s own heart will be taken out and the donor heart will be stitched into place. Once the donor heart is in place and starts beating, your child will be disconnected from the heart/lung machine. He/she may be started on one or more IV medications to “help” the new heart and may have a temporary pacemaker. Once your child is stabilized and his/her chest is closed, he/she will be taken to the CVICU.

Immediately After Transplant

Your child will be taken from the operating room to the CVICU. You will be able to see your child for a moment as he/she is being taken to the CVICU. He/she will be connected to many tubes and monitors, which can be an overwhelming sight if you have never seen anyone after heart surgery before. All of the tubes, monitors, and IVs will be explained to you when there is more time to visit. When your child goes to the CVICU after surgery, he/she will need a period of “settling in,” which takes at least one to two hours. You will not be able to visit during this time. You will be able to call from the CVICU waiting room to check on your child. As soon as your child is “settled,” you will be able to visit.

Your child will be on a ventilator (breathing machine) until he/she is ready to breathe on his/her own. This can take a day or two for older children and teenagers, but sometimes takes longer for babies. If the blood pressure was high before the transplant, he/she may need to stay asleep and on the ventilator (breathing machine) for a few extra days. Your child’s nurse and doctors will tell you what to expect from day to day.

Most children come back from the surgery with a temporary pacemaker in place. This is because the donor heart often beats at a slower rate than is desired, and pacing is needed for a few days. The pacemaker wires will be attached to your child’s heart and come out through the skin. They are very thin. The generator (power source) looks like a little box. It will be connected to the wires outside your child’s body.

The ventilator and other monitors in the room will be used to check heart rhythm, blood pressure and oxygen level in the blood. Your child’s nurse will be able to explain the monitors to you. You should feel free to ask questions..

A bladder catheter (small tube) will be in place to drain urine. This soft plastic tube is put in during surgery. A nasogastric tube will also be in place. This tube will be put in through the nose; the tip will be in the stomach to drain fluids. Chest tubes will be in place to drain fluids which collect in the body during surgery. These tubes will come out through the skin just underneath the ribs. Several intravenous lines will also be in place.

Possible Post-Operative Complications

Soon after surgery, while your child is still in the CVICU, the most common problems include infection, rejection, and graft failure. Infection and rejection are talked about several times in this handbook, because of the possible negative effects caused by these two problems after surgery

Infection

. Infection can happen when your child’s immune system is not working well. The largest doses of immunosuppressant medicines are given during and right after surgery. For this reason, infections which are usually minor can be life-threatening to someone who has received a heart transplant. Therefore, strict hygiene rules are in place right after surgery to help reduce the risk of infection.

Rejection

Rejection happens when the body identifies the heart as “not part of me; an invader” and tries to get rid of it. The body “rejects” the heart. Rejection can occur at any time after transplant, but is most common in the first several weeks. Monitoring for rejection will actually require lifelong follow-up visits. (See “Wellness” section). In the ICU the patient will need a physical exam and EKG every day, as well as regular blood tests, chest x-rays, and at least one echocardiogram. Your child may also have a cardiac catheterization with biopsy to look for rejection before he/she is sent home from the hospital. During this test, a catheter with a tiny device on its tip is put in through a vein in the groin or the neck and a few small pieces of the heart muscle are taken out to look at under a microscope. Rejection is treated with very high doses of immune suppression medicine for a short time.

Graft failure

Graft failure means the heart cannot work like it is supposed to. This happens for a few reasons, and most of the time it is treatable. One reason for failure of the new heart is that it may not be able to pump against the higher blood pressure in the lungs. Several medicines can be given to lower the lung blood pressure, but sometimes these do not work. In this event, your child may need to be put on a heart-lung machine for several days. This is like the one used in the transplant surgery. This machine helps the new heart while it gets used to the higher pressures.

Other problems, such as irregular heart rhythms, bleeding, and stroke can happen after any open heart surgery. These problems are not specific to only transplant surgery.

Long-term Complications

Problems that can happen after a heart transplant include rejection, infection, post-transplant lymphoproliferative disease (a type of cancer), other types of cancer, and transplant coronary artery disease. The medicines that your child will need may have several side effects too. The medicines and their side effects are talked about in more detail in the last part of this booklet.

Rejection and Infection

Rejection and infection can occur at any time after transplant surgery but it is more common in the early months. This happens when the body is “getting used to” the new heart and the medicines are at high dosages.

The risk for both of these problems does decrease with time, but late rejections do occur, sometimes years after transplant. For that reason, watching for rejection is a life-long process. Your child will need

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to stay on immunosuppressant medicines for the rest of his/her life. The exact rejection monitoring schedule is in the “Wellness” section of this handbook.

Post-transplant Lymphoproliferative Disease (PTLD or LPD)

PTLD is a type of cancer of the lymph nodes which can happen in people who have had an organ transplant (heart, lung, kidney, liver, or bone marrow.) This is usually seen in patients who have a viral infection for a long time because their immune system does not work well. . Lowering the immunosuppressant medicine makes rejection more likely. PTLD occurs in about 10% of patients who had a heart transplant. In some cases, PTLD must be treated with chemotherapy and/or radiation therapy.

Transplant Coronary Artery Disease (TCAD)

Transplant coronary artery disease (TCAD) is a problem that usually happens years after transplant. The true risk of TCAD is not known, because it can be such a late event that it never gets reported. TCAD is the narrowing of the arteries that carry blood to the heart muscle. The arteries get narrower because the artery walls become thicker. This can cause a heart attack or even death. TCAD is still being studied, but some things are known. TCAD is related to long-term and short-term rejection, and may also be related to high cholesterol levels and some viral infections. TCAD may happen without any warning signs, so constant monitoring is needed. All heart transplant patients have a cardiac catheterization every year with angiography (moving x-ray pictures) of the arteries to look for TCAD. Once a coronary artery problem is found, we may do other tests and/or start one or more different medicines to try and keep it from getting worse. Sadly, once TCAD becomes severe, the only way to get rid of it may be repeat heart transplant..

FAMILY COMMITMENT

The choice to allow your child to have the evaluation for transplant and actual listing for transplant is a very tough decision. We know this is a stressful time and will do our best to help you in any way we can. However, the demands of a heart transplant do not stop at the hospital door. This is a major event that will affect every person involved with your child, especially every family member. Care of the transplanted heart is a lifelong commitment. In fact, the hardest work starts *after* your child goes home from the hospital. Your child will have to come to many follow-up visits, have follow-up tests on schedule, and take many medicines on a strict schedule. You will also need to check his/her heart rate, temperature, and blood pressure twice a day. You will need to watch his/her diet very closely, and may need to change the whole family’s eating habits. *No one* should ever smoke around someone who had a heart transplant, so you may need to make rules with friends and relatives. Certain animals, mainly birds, can carry diseases, so the choice for family pets will be limited. The overall success of a transplant depends much more on long-term care and follow-up than on the transplant surgery itself.

The support of family and friends is very important to the success of the heart transplant. Knowing when and how to ask for help can make life easier for you, your child, and your family.

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It is important to keep siblings aware of the situation. Some children imagine things as being worse than they really are. You may have to talk to them and help them to understand what is going on. Brothers and sisters need to know they are part of the “family team” and they are loved and valued, even though the sick child may need the most attention. Children require different amounts and types of information based on their age. The child life specialist can help with discussions geared toward brothers and sisters.

Your child must live close to the hospital while waiting for a heart and in the first three months after transplant. This living arrangement your family may not be able to live together during this time. Our social worker can help you make housing arrangements while you are in the Dallas area. Make plans to have your other children taken care of and your home is maintained while you are away from home. Relatives, friends, and members of your church, temple, or mosque may be willing to help.

Life-Long Follow Up

It is very important to watch for problems after surgery and is required of all transplant recipients. The first year after transplant is hard and you will need to make many visits to the transplant clinic. If you live more than 2 hours away, you and your child will need to move closer for the first three months after transplant. There are apartments at the Ronald McDonald house or hotel apartments nearby for this reason.

Your child will be seen in the transplant clinic often for the first 6 months after transplant surgery. The visits will begin twice a week for the first 2 months, and then it will spread out depending on how well your child is doing after transplant. Watching for rejection is important in the first year following transplant.

A schedule will be provided to help with this process.

If your child is older than one, the visits will include heart catheterizations and myocardial (heart muscle) biopsies. Along with regular tests, a biopsy will be done any time there is a feeling of rejection, and again after treatment of any rejection episodes. If your child is under one year old, then an echocardiogram will be done to check for rejection. The first six to eight weeks after transplant, your child will need to be seen in the transplant follow-up clinic twice a week. The visits will then space out over several months if your child is doing well. At the end of one year your child will come to the clinic every two to three months. Your child will need follow up transplant visits every three months for his/her lifetime. These visits will include a chest x-ray, an EKG, blood tests, and a visit with the doctor. On the “in between” months your child will need to have blood tests and an EKG. Every year your child will have a cardiac catheterization with angiography to look at the coronary arteries and evaluate for possible TCAD development.

Limitations

Restrictions of the heart transplant recipient are very few. It will take about three months for the chest stitch to completely heal. After that your child should be able to return to all normal activities, and it is likely that he/she will be much more active after transplant than before.

THE TRANSPLANTED HEART

The blood flow of the transplanted heart follows the same path of the normal heart. However, the new heart will respond differently. This difference is because the transplanted heart is denervated, which means “without nerves”. Normally nerves send messages straight to the heart to beat faster or beat slower. These nerve fibers are cut during transplant and do not grow back.

The denervated heart must now get its signal to beat faster or beat slower from chemical agents that travel in the body called catecholamines. The chemical agents are released by the adrenal glands located on the top of the kidneys when the body needs more oxygen. When the chemical agents reach the heart, it pumps faster and stronger. This chemical method takes a longer time to excite the heart compared to the direct nerve fiber method.

How does this affect your child? Every person is different both before and after a heart transplant. Learning to pace activities will be an individualized process. Your child can enjoy all kinds of physical activity after recovery from heart transplant. It is important to know how the transplanted heart responds:

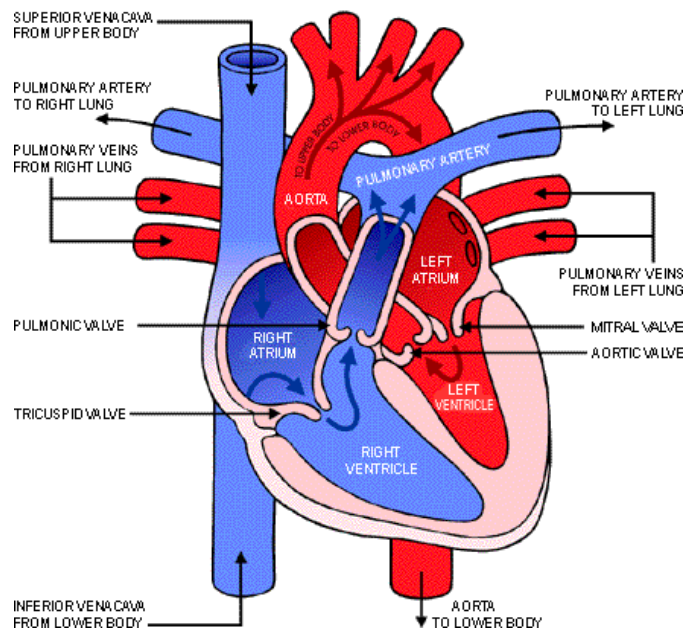
- the new heart might beat a little faster than the old heart when at rest

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- when your child begins exercising, the new heart will take longer to start beating faster
- when your child stops exercising, the new heart will take longer to slow down

The new heart cannot feel chest pain because there are no nerves. Chest pain which is felt is connected with lung or chest muscle tension.

This diagram shows the normal heart and how blood flows through a normal healthy heart.



Left Side of the Heart

The blood coming from the lungs to the heart collects in the Left Atrium, filling it up. This causes a contraction of the walls of the Left Atrium forcing the Mitral Valve to open as the blood flows into the Left Ventricle.

Right Side of the Heart

The blood coming from the body to the heart collects in the Right Atrium, filling it up. This causes a tightening of the walls of the Right Atrium forcing the Tricuspid Valve to open as the blood flows to the Right Ventricle.

The Left Ventricle fills with blood which forces the Mitral Valve to close and causes the muscle of the Left Ventricle to contract, open the Aortic Valve, and squeeze the blood through the Aortic Valve and on to the body.

The blood coming out of the Left Ventricle to the Aorta is under high pressure. This pressure is enough to send it to the different parts of the body at high speed and give its oxygen and nutrients to the body tissues. The blood comes back from the body to the right side of the heart.

The Right Ventricle fills with blood which forces the Tricuspid Valve to close and causes the muscle of the Right Ventricle to contract, open the Pulmonic Valve and squeeze the blood through the Pulmonic Valve and on to the lungs.

This blood will refill itself with more oxygen and get rid of the carbon dioxide and return to the left side of the heart to begin another cycle.

WHEN TO CALL THE TRANSPLANT OFFICE DAY OR NIGHT

To contact a transplant coordinator after hours, call 214-456-2333 or 214-456-7000 and ask that she page the heart transplant coordinator on call.

Please call the transplant coordinator for the following:

1. Temperature greater than 100.5 by mouth or under the arm.
2. Vomiting or diarrhea.
3. Heartbeat when at rest is not normal, less than _____ or greater than _____.
4. Systolic blood pressure (top number) greater than ___ and diastolic blood pressure (bottom number) greater than ___ which does get better after one hour of taking the blood pressure medicine.
5. Trouble breathing or breathing faster than normal.
6. Dizziness
7. Decreased appetite
8. Decreased energy
9. Increased puffiness of the face, hands, feet or body
10. Need to urinate with more frequency or burning with urination.
11. Signs of respiratory infection (cough, sore throat, green or yellow sputum)
12. Signs of wound infection (redness, swelling, warm to touch, tender to touch)

Do **NOT** skip any doses of medicine. Notify the transplant coordinator if a dose is missed for any reason.

Do **NOT** give any medicines that have not been approved by the transplant team without checking with the transplant coordinator first.

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Do **NOT** give the morning dose of Immunosuppression (Prograf, Neoral, and Cellcept) on days which are scheduled for lab draws. In order to make dosing changes in the Immunosuppression, we need labs to be drawn 11-12 hours after the previous dose.

Bring all medicines to the hospital with you. After the lab draw, you may give the medicines which are due. Each time you come to transplant clinic, please bring your medication schedule and your vital signs record sheet.

Transplant clinic hours of operation are 8 am to 4:30 pm Monday through Friday. Cardiac transplant patients are normally seen on Monday and Thursday, but other days may be necessary. Appointments can be made with the transplant scheduling coordinator. She can be reached at 214-456-2970 or 214-456-8600.

If a lab draw or a clinic visit is missed, please let the transplant coordinators know as soon as possible, so we can reschedule your appointment.

MEDICATIONS

Key Points:

- ***Know what medications your child takes for rejection***
- ***Learn what your child’s medications are treating***
- ***Know the main side effects of your child’s meds***
- ***Know what time to give the medications***
- ***Learn how to give the medications to your child***
- ***Learn how to store the medications***
- ***Know which meds cannot be given together***

Medicines are important to the success of your child’s heart transplant. Without these medicines, the body will reject the new heart. The body’s reaction to the new heart is to fight it off as it would a cold or virus. Medicines are given to your child’s specific needs to stop the body from fighting or rejecting the new heart. The medicines must be taken as directed; do not change or stop giving your child’s medicines unless told by a member of the transplant team. We expect you and your child, to understand the actions of each medication over time; make sure to ask questions to help understand any information given to you. Understanding the medicines helps you to recognize the side effects when they happen.

A few days after transplant, you will begin to give medicine to your child, with the help of your nurse. You will be given a schedule for the medicines that you may change each time an adjustment in medications is made.

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Before going home from the hospital, we will teach you:

1. The generic and brand names of each medicine
2. What each medicine looks like
3. The purpose and action of each medicine
4. How to determine the correct dose of each medicine
5. safety measures required for each medicine
6. How and when to take the medicine
7. The common and uncommon side effects of each medicine

The medication schedule should be updated with each change to dose or administration time. Any changes that are made to the schedule should be done using a pencil. If a change is made during hospital stay the nurse will inform you, and you can mark the change on the schedule. The nurse will verify that the entries are correct. Should you have any questions, please verify the change with your nurse. This process will help you feel comfortable making changes at home.

Once you are at home, medications should be given by your schedule, not according to the instructions written on the medication bottle.

Be sure to keep all the medicines in their original containers. This will be helpful in keeping up with the expiration dates, who prescribed each drug, etc. Keep all medicines away from heat, direct light and moisture, each of which can cause the medicine to go bad. Always give the medicine at the same time every day. Each of the regular medicines needs to reach a stable level in the blood. Watching these blood levels at certain times and the test results will help make changes in medication dosages. Therefore, it is important that medicines are given at the same time every day.

Your child must take all their medicines as they are ordered. If your child has nausea, vomiting or diarrhea and cannot take the medicines, please call the Transplant Coordinator immediately for instructions. If a dose is not given at the ordered time, please give the dose as soon as possible. Do not give the missed dose close to the next dose, instead space the dose apart and go back to the schedule the next day

Many medicines will affect the absorption of the immunosuppressive drugs or may react with them in a bad way. Therefore, do not give your child any store bought medicines or medications ordered by a doctor who does not know your child’s medical history without first talking to the transplant team.

Always bring your child’s medicine schedule to the clinic so that changes can be made if needed. You may also want to give your child a copy of medicines to keep with them. Should your child need hospital admission, please bring all your medicines with you along with your medication schedule to make the admission process easier..

Should you have any questions or problems, contact the transplant office immediately. There is a transplant coordinator available 24 hours a day to answer questions.

General Medication Information

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- Prescription Refills are done during normal business hours, Monday through Friday. Please get refills done early before you run out. Please notify the pharmacy 7 days before a refill is due to make sure you receive it on time.
- Generic formulations of Brand name Immunosuppressants such as: Prograf, Neoral and Cellcept are available. It is important to stay on the brand name unless your doctor tells you it is ok to take the generic version.
- Always take medicines as ordered. Follow the dosage instructions given by your transplant doctor, not what is printed on the label of the medicine. Since, the dose may be changed before your next refill from the pharmacy.
- Do not stop taking any drug without being told to do so.
- Do not add any over-the-counter (store bought) medicines or supplements, including herbal remedies, unless your transplant doctor is aware of it.
- Contact your transplant doctor if you notice any physical or mental changes in your child.
- Take medicines at the same time every day to avoid missing doses.
- If your child vomits within thirty minutes of taking their immunosuppressive medicine give the dose again. If your child vomits after thirty minutes of taking their medicine do not give a second dose, and call the transplant coordinator for more instructions. Please contact the transplant coordinator if vomiting continues.
- Store medicines away from heat, light and moisture (such as the bathroom cabinet or kitchen cabinets).
- Contact your pharmacy if any medicine doesn't look "right" for any reason.
- Do not try to make up for missed doses unless told to do so by your transplant doctor.
- 1 cc is the same as 1 ml
- Check expiration dates on all medicines. Throw away and replace medicines that have expired.

Immunosuppressive Drugs

Some commonly used medicines in transplantation are Prograf (Tacrolimus), CellCept (Mycophenolate Mofetil), Neoral (Cyclosporine), Prednisone and Imuran (Azathioprine). They all work to suppress the immune system and prevent rejection. Your child will need to take immunosuppressant medicines after

transplant for as long as they have their transplanted organ. These are powerful drugs, with many side effects, and they must be taken exactly as ordered.

If your child's immune system is not suppressed enough by the medicines, it will be able to destroy (reject) the transplanted organ. If your child's immune system is suppressed too much by the medicines, it will not be able to protect him or her from infection. It can also cause unwanted and dangerous side effects. Therefore, you must follow the medication schedule exactly as directed. **Under no circumstances** should you change the dosage of these medicines without instructions from your doctor or the transplant office.

The following is a list of medicines which are commonly given to patients after transplant. The medicines prescribed for your child will be personalized to meet his or her needs. This list is for informational purposes only. Your transplant doctors and transplant coordinators will help educate and ensure that you understand the medicines ordered.

Prograf (Tacrolimus)

Purpose

Prograf is an immunosuppressive drug. Prograf helps prevent rejection by suppressing the immune system.

Description

Prograf currently comes in 0.5mg yellow and 1 mg white capsules and 5 mg grayish/red capsules. Prograf is also available as a 0.5mg/1 ml compounded suspension, prepared by the pharmacy.

When to Give

Prograf must be given as ordered. Most children will be given two doses each day; the first at a set time in the morning with the second dose given 12 hours later. It is important that you follow the dosage schedule as directed

How to Give

If your child can swallow pills/capsules, he/she will swallow the correct number of capsules as directed. (Examples: 3 mg dose = three 1 mg capsules; 6 mg dose = one 5 mg capsule and one 1 mg capsule). If your child is taking the suspension, you will be instructed to measure the correct amount using a syringe. Be sure to **shake** the bottle well before taking out the dose. (Example: 2 mg dose = 4 ml of Prograf suspension).

Side Effects

The following side effects have been associated with Prograf. As with Neoral (Cyclosporine), many of these side effects will be more noticeable when the level of the drug is high; they will likely decrease when the drug dose is reduced. **Do not ever** change the dose on your own; you will be putting your child’s transplanted organ at risk.

- Increase in blood sugar. In some cases, insulin may need to be given or medication/dosage changed.
- Low magnesium level in the blood.
- High potassium level in the blood.
- Not able to sleep.
- Shaking of the hands. This is a common side effect that will decrease over time as the Prograf dose is reduced.
- Diarrhea; sometimes with nausea and vomiting
- High blood pressure. Your child may be on medicines to lower blood pressure. If he or she has constant headaches or dizziness, you should tell your transplant doctor because these may be signs of high blood pressure.
- Increased risk of infection. Any fever, cough, rash or mouth lesions should be told to the transplant provider. You must tell your transplant provider immediately if your child has been exposed to chickenpox and he or she has never had chickenpox.
- Possible damage to the liver or kidneys. There will not be any specific symptoms you will notice. Your child may have increases in certain blood work results, such as BUN, creatinine, potassium and liver function tests.
- Possibility of post transplant lymphoproliferative disease (cancer)

Storage

- Store at room temperature.

Precautions:

- Do not eat/drink grapefruit and grapefruit juice.
- If using the liquid form, do not give after the expiration date on the bottle.
- If using the liquid form, carry an extra bottle when traveling.
- Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your check-on luggage is lost.
- Some drugs interfere with Prograf blood levels. Your doctor will have information about how certain drugs affect Prograf. You should not add any over-the-counter medicines or change any other medicines unless told by your doctor or the transplant team.

- If your child vomits within 30 minutes of taking their immunosuppressive medications, give the dose again. If your child vomits after thirty minutes of taking their medications, do not give a second dose and call the transplant coordinator for further instructions. Please contact the transplant coordinator if vomiting continues.
- If your child has diarrhea that lasts more than 24 hours, you must tell your transplant coordinator. **Constant diarrhea can increase the blood level of Prograf, which may increase the risk of harmful side effects.**

Neoral (Cyclosporine)

Purpose

There are two forms of Cyclosporine: Sandimmune and Neoral. These are not the same. **Neoral** is a more equally absorbed form of Cyclosporine and is given to suppress the immune system and to prevent rejection. It should **not** be given with Sandimmune. It is similar to Sandimmune, but they are **not the same**.

Description

Neoral comes in 25mg and 100mg soft gelatin capsules. Neoral is also available as a 100mg/ml microemulsion oral solution.

When to Give

Neoral must be given as ordered. Most children will be given two doses each day; the first at a set time in the morning with the second dose given 12 hours later. It is essential that you follow the dosage schedule as directed

How to Give

If your child can swallow pills/capsules, he/she will swallow the correct number of capsules as directed. If your child is taking the suspension, you will be instructed to draw up the correct amount using a syringe. Be sure to **shake** the bottle well before taking out the dose.

The suspension could be given using an oral syringe or the dosage syringe provided with Neoral. To make the solution tastier, it may be mixed with orange juice, or apple juice in a glass container (not a

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plastic or Styrofoam cup) at room temperature. After drinking the mixture, rinse the container with a little extra juice and drink the rinse. This will ensure that the entire dose of Neoral was given.

Side Effects

-
- Increased Hair Growth
- High Blood Pressure: Your child may be on medicines to lower blood pressure. If he or she has constant headaches or dizziness, you should tell your transplant doctor because these may be signs of high blood pressure
- Tremors, shaking of the hands may happen while on this medicine and/or right after taking the medicine. If it worsens and/or interferes with your daily activities, contact the transplant office
- Gum Swelling/ Sensitivity to Hot and Cold
- Decreased Ability to Fight Infection
- Possibility of post transplant lymphoproliferative disease (cancer)

Storage

- Store at room temperature.

Precautions:

- Do not drink grapefruit juice.
- Drink immediately after mixing. Do not mix **in advance** or it will form clumps.
- If using the liquid form, do not give after the expiration date on the bottle.
- If using the liquid form, carry an extra bottle when traveling.
- Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your check-on luggage is lost.
- Some drugs interfere with Neoral blood levels. Your doctor will have information regarding how certain drugs affect Neoral. You should not add any over-the-counter medications or change any other medications unless approved by your doctor or the transplant team.
- If your child vomits within 30 minutes of taking their immunosuppressive medication, give the dose again. If your child vomits after thirty minutes of taking their medicine, do not give a second dose and call the transplant coordinator for more instructions. Please contact the transplant coordinator if vomiting persists.

- If you have diarrhea that lasts more than 24 hours you must tell your transplant coordinator. **Persistent diarrhea can affect the blood level of Neoral, which may increase the risk of harmful side effects.**
- Do not rinse the dosage syringe provided by neoral as this will cloud the syringe. If the syringe becomes wet or requires cleaning, it must be completely dry before using it again.

Steroids

(Methylprednisolone, Prednisone, Prednisolone)

Purpose

Steroids are hormones similar to hormones our bodies make normally. Steroids help to stop and treat rejection by suppressing the immune system.

Description

Methylprednisolone will be dispensed in 4 mg tablets.

Prednisone will be dispensed in 20 mg, 10 mg, 5 mg, 2.5 mg, or 1 mg tablets. In smaller children, a liquid preparation containing 1 mg/ml or 5mg/ml will be used.

Prednisolone will be dispensed in 3mg/ml solution.

How to Give

The total ordered dose of steroids should be given once each morning. The tablets may need to be cut in half to get the proper dose. For example, if 5 mg tablets are dispensed and your child's dose is 7.5 mg, you would give 1 1/2 tablet. It may upset the stomach and should not be given on an empty stomach. After breakfast is the best time to give the Prednisone.

Side Effects

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Steroids can cause a number of side effects. Some of the side effects include:

- Fluid/salt retention. This may cause the body to keep fluids and cause swelling of the hands or ankles (edema) and increase blood pressure.
- Increased appetite. This can lead to harmful weight gain.
- Increased fat deposits. This condition can occur in the face (called "moon face"), over the upper back and abdomen.
- Increased stomach acid. This may cause or worsen ulcers. An acid reducer is given while your child is on higher doses. Do not give Prednisone on an empty stomach.
- May slow the healing process.
- Decreases the body's ability to fight infections.
- Muscle weakness and weakened connective tissue. This may cause "stretch marks."
- Acne.
- In large doses, Prednisone can affect bone growth.
- Eye changes. Prednisone may cause cataracts or glaucoma. Routine eye exams should be done as instructed by your ophthalmologist (eye doctor). Your child should be seen by an ophthalmologist if any problems occur such as blurred or decreased vision.
- Increased blood sugar. This can happen with higher doses of medicine. In some cases, insulin may need to be given until the blood sugar returns to normal as the steroid dose is decreased.
- Increased sensitivity to the sun. Always apply a sunscreen to exposed skin when in direct sunlight for a prolonged period of time (see "Skin Care" section).
- Mood swings-includes crying easily, happy moods, irritable, etc.
- Insomnia or having trouble sleeping.

Storage

Keep away from heat and light.

Do not store the medicine in the bathroom, near the kitchen sink or refrigerator because moisture will cause the medicine to go bad.

Do not freeze the liquid medicine.

Precautions

Be sure to let any doctors or dentists scheduled to treat your child know that he or she is taking steroids, especially before any invasive procedures or skin tests.

CELLCEPT (Mycophenolate Mofetil capsules)

Purpose

CellCept is another immunosuppressant drug that helps to prevent rejection. It is used with other immunosuppressant medications such as Neoral or Prograf and Prednisone.

Description

CellCept comes in 250 mg, blue and brown, gelatin capsules, 500mg, purple tablets or 200mg/ml suspension.

When to Give

CellCept must be given as ordered. Most children will be given two doses each day. The first dose is given at a set time in the morning with the second dose given 12 hours later.

How to Give

Make sure to separate Cellcept from magnesium by 2 hours before or after.

If your child can swallow pills/capsules, they will swallow the correct number of pills/capsules as instructed, followed by a moderate amount of liquid.

If the child is not able to swallow the capsules, and not able to get the liquid we suggest the following:

- Open capsules and place in a very small amount of pudding, chocolate syrup, applesauce or ice cream. Make sure the child eats all of the medicine mixed with food.
- Open capsule and place in a small amount of juice (apple, orange or grape). Do not use grapefruit juice.

Note: For each capsule there should be 2 cc (2ml) of liquid, followed by a moderate amount liquid.

If you are having trouble giving the medicines, please contact the transplant office.

Side Effects

The most common side effects of CellCept are:

- Diarrhea
- Nausea/ Vomiting
- A decrease in the white blood cell (WBC) count. The greater the immune system is suppressed the higher the risk of infection

Imuran (Azathioprine)

Purpose

Imuran is another immunosuppressant drug that helps to prevent rejection. It is used in combination with other immunosuppressants such as Neoral or Prograf and Prednisone.

Description

Imuran comes in 50mg, 75mg and 100mg tablets. Imuran is also available as a suspension compounded by pharmacy.

When to Give

Imuran should be taken once-a-day, at the same time every day.

How to Give

If your child can swallow pills/capsules, they will swallow the correct number of pills/capsules as directed.

Side Effects

-
- Decreased ability to fight infection due to lowered white blood cell count.

- Decreased platelet count which interferes with the body’s ability to clot.
- Nausea/vomiting
- Mild rash
- Fatigue or weakness

Rapamune (Sirolimus)

Purpose

Rapamune prevents rejection by suppressing the body’s immune system.

Description

Rapamune comes in a 1mg tablet or 1mg/ml solution.

When to Give

Rapamune should be taken once-a-day, at the same time every day.

How to Give

- You may take Rapamune with or without food; but **take it the same way every day**.
- If you are taking Cyclosporine, you must take Rapamune (**Sirolimus**) **four hours after** your dose of Cyclosporine. Unless you have been told differently by your transplant team.
- Oral Solution: **The oral liquid medicine must only be mixed with water or orange juice.**

Side Effects

- Mouth ulcers

- Rash/acne
- Increase cholesterol/triglycerides
- Increase blood pressure
- Decreased ability to heal wounds
- Edema

Storage

- Tablets: Store tablets at room temperature in a closed container, away from heat, moisture, and direct light.
- Oral Solution: Store in the refrigerator. Do not freeze.

Nystatin (Mycostatin)

Purpose

Nystatin is an antifungal used to help prevent thrush, an oral fungal infection. It will be ordered until your child's immunosuppression medications are reduced. Thrush appears as a white coating on the tongue or inside the cheeks.

Description

Nystatin may be given as a liquid, pastille (like a lozenge) or tablet. Each 1 cc (1 ml) of liquid contains 100,000 units of Nystatin; each pastille contains 200,000 units; and each tablet contains 500,000 units.

How to Give

Always shake the liquid well before giving. The solution should be swished around in the mouth before swallowed. The pastille or tablet should be sucked on so they slowly melt in the mouth. The pastille should not be chewed or swallowed because it will not be as effective. For difficult cases, it may be necessary to dip a soft bristled toothbrush in the liquid Nystatin and brush the tongue.

Side Effects

Nystatin is nearly harmless and is tolerated well by all age groups. Large doses have occasionally produced diarrhea, nausea and vomiting.

Storage

The liquid should be stored at room temperature. The pastilles should be refrigerated.

Precautions

- If other medicines are due to be given at the same time, Nystatin should be given last.
- Your child should not eat or drink anything for 30 minutes after taking Nystatin.

Diflucan (Fluconazole)

Purpose

Fluconazole is an antifungal medication used to prevent or treat fungal infection.

Description

Fluconazole may be given as a liquid or tablet.

How to Give

Give as directed

Side Effects

Fluconazole **increases** the absorption of Prograf and Neoral to the body. As a result, levels of prograf and neoral will be checked and doses adjusted.

Storage

- Store tablets in dry place, protected from light
- Store suspension away from light

**Trimethoprim and Sulfamethoxazole
(Bactrim, Cotrim, Septra, TMP-SMX)**

Purpose

Trimethoprim and sulfamethoxazole is an antibacterial combination drug. It is used to prevent serious lung infections in immunocompromised patients. It is given to treat and/or prevent other types of infections, such as urinary tract infections.

Description

Trimethoprim and sulfamethoxazole is ordered by the amount of trimethoprim. It comes in regular strength tablets (400mg/80mg), double-strength tablets (800mg/160mg) and as a suspension (200mg/40mg/5ml).

How to Give

Give as directed. Shake suspension well.

Side Effects

Some of the side effects from trimethoprim and sulfamethoxazole include:

- Nausea, vomiting, anorexia
- Allergic skin reactions (rash or hives)
- Decreased WBC, Anemia & low platelet count

- Increase in BUN and creatinine
- Sun sensitivity

Storage

- Store tablets in dry place, protected from light
- Store suspension away from light

Precautions

- Keep child well hydrated (drink plenty of fluids)
- Stop medicine and notify local doctor at the first sign of skin rash or any sign of adverse reaction such as bloody urine, difficulty breathing, fever, chills or severe fatigue.
- Do not stop taking the medicine unless told to do so by the transplant team.

Ganciclovir and Valganciclovir (Valcyte)

Purpose

Ganciclovir is an anti-viral drug used to prevent and/or treat infections from common viruses like Cytomegalovirus (CMV) and Epstein Barr Virus (EBV).

Description

Ganciclovir is usually given in an intravenous (IV) preparation. Valganciclovir is the preferred oral formulation of ganciclovir and comes both as a 50mg/ml suspension and a 450mg tablet.

How to Give

Give as directed.

Side Effects

Some of the reported side effects include the following:

- Low white blood cell count
- Birth defect (contraception needed for at least 30days after therapy for women and 90 days after therapy for men)

Storage

Protect suspension and tablets from light and moisture.

Precautions

There are no special precautions with the oral preparation.

Acyclovir/Valacyclovir (Zovirax)

Purpose

Acyclovir is an anti-viral drug used to prevent and/or treat infections from common herpes viruses including herpes simplex & varicella-zoster (chicken pox). Valacyclovir is a special tablet of acyclovir that allows for greater absorption of the medication.

Description

Acyclovir comes in 200mg, 400mg and 800mg tablets or 200mg/5ml suspension. It is also available in an ointment for herpes skin lesions and as an intravenous (IV) preparation.

Valacyclovir comes in a 500mg and 1000mg tablet.

How to Give

Give as directed. Administration of intravenous (IV) Acyclovir, when necessary, will be arranged.

Side Effects

Based on clinical practice experience with patients in the U.S. reported adverse side effects are uncommon. Some of the reported side effects include the following:

- Fever
- Headache

- Confusion, dizziness
- Diarrhea, nausea
- Low white blood cell count
- Hair loss (alopecia)
- Itchiness (pruritus), rash

Storage

Keep capsules and tablets from light and moisture.

Precautions

There are no special precautions with the oral preparation.

- An elevation of BUN and creatinine can occur with IV preparation. These will be watched if your child needs to receive IV Acyclovir.

Acid Reducing Agent (Prevacid, Nexium, Prilosec & Protonix)

Purpose

Immunosuppressive medicines can increase stomach acid which can cause ulcers to form or make them worse. An acid reducing agent will neutralize this stomach acid. The acid reducing agent may be stopped when the risk of ulcer formation is decreased.

Description

They come in capsules, oral melting tablets and suspensions.

How to Give

Give as directed.

Side Effects

When taken as ordered, they normally do not cause any side effects.

Storage

Keep away from heat, light and moisture.

Phosphorous Supplement

(Phos-NaK packet, K-phos Neutral, K-phos Original, Sodium Phosphate and Potassium Phosphate)

Purpose

Phosphorous is an important mineral for the body and important for many function of the body. A phosphorous supplement is used to treat low phosphorous.

Description

They come in powder packet, dissolvable tablet, suspension and regular tablet.

How to Give

Give as directed. Mix 1 Phos-NaK packet with 75ml (75cc) of water before administration and administer tablet with a full glass of water.

Side Effects

Monitor for diarrhea

Storage

Keep away from heat, light and moisture.

Precautions

Do not give magnesium by at least 1 hour due to decreased absorption.

Magnesium Supplement

(Magnesium Oxide, Magnesium Hydroxide, Magnesium Gluconate, Magnesium sulfate)

Purpose

Magnesium is an important mineral for the body and important for many function of the body. A magnesium supplement is used to treat low magnesium.

Description

They come in tablet, suspensions and intravenous (IV) formulations.

How to Give

Give as directed.

Side Effects

Monitor for diarrhea

Storage

Keep away from heat, light and moisture.

Precautions

Separate magnesium by at least **2 HOURS** before and after Cellcept.

Pravastatin (Pravachol)

Purpose

Pravastatin is used to lower bad cholesterol and increase your good cholesterol. In heart transplant patients, they are used to protect blood vessels in the heart.

Description

Pravastatin comes in 10mg, 20mg, 40mg and 80mg tablet.

How to Give

Give as directed.

Side Effects

- GI side effects
- Muscle cramps

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

Vitamin C & E

Purpose

Vitamin C & E are antioxidant. In heart transplant patient, they are used to protect the blood vessels in the heart.

Description

They come in both liquid and capsule.

How to Give

Give as directed.

Side Effects

Based on clinical practice experience with patients in the U.S. reported adverse side effects are uncommon.

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

Aspirin (81mg Baby Aspirin)

Purpose

Aspirin is used to prevent blood clots. In heart transplant patients, Aspirin is used to protect the blood vessels in the heart.

Description

Aspirin comes in many different formulations and the 81mg baby aspirin is the preferred formulation.

How to Give

Give as directed.

Side Effects

Based on clinical practice experience with patients in the U.S. reported adverse side effects are uncommon.

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

Dipyridamole (Persantine)

Purpose

Dipyridamole is used to prevent blood clots.

Description

Dipyridamole comes in 10mg/ml solution and 25mg, 50mg and 75mg tablet.

How to Give

Give as directed.

Side Effects

- Bleeding Gums
- Bruising

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

“Wellness”

Vital Signs

By learning certain skills, you will be able to watch your child’s health. Visits to the transplant clinic become less often as your ability to care for your child increases. The record of vital signs is important to help identify early signs of rejection, infection, or the need for medication or diet changes.

The sections below cover the vital signs done at home. Please write down the results and bring this with you to each clinic visit.

Temperature:

The ability to measure body temperature by using a thermometer will be watched while in the hospital. Oral temperature readings are ideal, but axillary readings (under the arm) will be accepted. **RECTAL TEMPERATURES SHOULD NOT BE DONE.** The end of the thermometer should be in direct contact with the inside of the mouth or under your child’s arm for as long as it takes the thermometer to beep. Normal temperatures range from 97.6 to 99.4, depending on the time of day, month, etc.

- Check temperature every morning and evening, or when sick. The frequency will change in time depending on your child’s condition, but you must always check temperature if your child is ill.

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- Body chills are a sign of increasing temperature. The body is trying to decrease this temperature. Try not to put any extra clothing or blankets on your child because this will continue to keep your child warm.
- Never take Tylenol for an increased temperature unless told to do so by a member of the transplant team or other authorized medical personnel. An increased temperature (fever) is a sign of infection. By taking medicines that reduce fever, early signs of infection may be covered up cause a delay in getting the right medical attention.
- Unless otherwise told by your transplant doctor, do not take medicines containing ibuprofen which includes Motrin or Advil.
- If temperatures are below normal for a specific period of time you need to call the transplant office, this can be an early sign of rejection.

During the first three months, always report increased temperatures of 100.6 or more to the transplant office directly. Due to increased risks, treatment will be watched closely by the transplant doctors. After three months, temperatures of 100.6 or more can be told to your local doctor. The doctor must do a physical exam and get the right lab tests; results can then be sent to the transplant office.

Pulse/Heart Rate:

The pulse/heart rate refers to the beats of the heart. Pulse rate is measured by counting the number of times the heart beats in one minute. You will be taught how to measure the pulse rate before leaving the hospital. There are different ways for learning this: the radial method (at the wrist) and the carotid method (alongside the throat). An irregular pulse should be reported if it is a change from previous pulses.

Check your child’s pulse before giving any medicines that may change it, before, during, and 30-60 minutes after exercise, and anytime symptoms such as dizziness, fatigue, shortness of breath, or pounding in the chest.

The normal heart rate is different based on the age of the child. Always call the transplant office if the pulse is less than 60 beats per minute, or if any of the above described symptoms are experienced. If this occurs, do not take those medicines which affect pulse rate until you have checked with the transplant office.

Call the transplant office for:

- Pulse less than 60 beats per minute
- Pulse greater than 140 beats per minute or as instructed by the transplant team
- Irregular pulse

Blood Pressure:

Blood pressure is the amount of pressure applied against the arteries during the pumping and resting phases of the heart.

The top number is called the **systolic** pressure and it is the pressure in the heart when blood is pumped out of it.

The bottom number is the **diastolic** pressure. This number is the pressure inside your heart at rest.

It is very important to keep the blood pressure under control. High blood pressure medicine, regular exercise, a low salt diet, and keeping weight under control all help to keep normal blood pressure.

Normal blood pressure varies and is based on the age of the child. You will be given specific systolic and diastolic blood pressure limits for your child.

Please call the transplant office for continued, or greater than three, blood pressures above those limits. If blood pressure readings remain high, medicines will be ordered to decrease it. Uncontrolled high blood pressures can cause strokes, heart attacks, and damage to kidney function.

Weight

Immunosuppressant medicines doses are closely changed according to specific limits including weight. Helping your child maintain or achieve that weight is important to their health and overall success. Too much weight puts stress on the heart, bones, and joints. However, if weight gain is needed to improve nutritional health, it should be done at an ordered rate per week.

Illness

Avoiding contact with sick persons is one of the most important preventive actions that can be taken. However, by the time someone in the family becomes sick, the transplant patient has probably been exposed. Common sense precautions should be taken. Do not eat or drink from other peoples utensils. Make sure others cover their mouths when coughing or sneezing. Always use clean washcloths and towels. Always wash hands after going to the bathroom, before meals, and anytime hands are soiled. Tell the Transplant Office immediately if exposed to infectious diseases such as chicken pox, measles, or mumps.

When sick, call the Transplant Office. With any cold, and other respiratory symptoms such as a cough or shortness of breath, your child may need to have a chest x-ray. Respiratory infections can be serious and symptoms need to be closely watched.

Symptoms cannot usually be diagnosed over the telephone so your child must be seen in the Transplant Office. This will take place for the first three months after transplant or by the pediatrician after the first

three months. Before any treatment is started by the pediatrician, be sure to call the Transplant Office. This will keep us aware of the treatment and allow us to recommend any changes for the care of the heart. In an emergency situation, notification to the Transplant office can be made after patient is cared for.

Some specific infections are common with immunosuppression. (See complications/infection).

Headaches are a common side effect of some medicines. There may be other causes such as high blood pressure, stress, vascular or neurological problems, and some viral syndromes. If headaches become constant, your child will need to see a neurologist for further evaluation.

Remember, all illnesses must be reported. Any sign or symptom is important to us to and helps with proper follow up. If your child isn’t in perfect health, we want to hear about it!

Infection

Infection is a serious problem in transplants. The drugs taken to prevent rejection all act by suppressing the immune system. The immune system protects the body against the unknown substances it comes in contact with daily. When the immune system is suppressed, this protective function is reduced and allows infection to occur.

Infections can happen at any time after transplant, though the most common time is the first three to six months. They can range from mild to very serious, and can be caused by a number of organisms. There are three types of organisms: bacteria, fungi, and viruses.

Several medicines are ordered to prevent most of these infections. Bactrim prevents the most common bacterial infections of the lungs and urine. Nystatin Swish and Swallow prevents a yeast infection of the mouth called thrush.

Viral infections are not easily prevented and, are the most common type of infection seen.

The symptoms of infection are based on which part of the body is affected. Urinary tract infections may cause burning with urination, the need to urinate, and flank or back pain. Lung infections may cause coughing, making of sputum (often of a yellow, green, or grey color), chest pain, and shortness of breath. Infected wounds are generally red, swollen, warm or hot to touch, and very tender. Drainage from the wound is often present. Infections of all types generally cause fever, malaise or fatigue, decreased appetite, and an increased white blood cell count.

Treatment of infections is aimed at the specific organism involved. Many infections can be treated while at home. However, hospitalization may be needed in serious infections.

The risk of infection may be decreased by following several protective measures:

1. Good hand washing is the most important way to prevent infections of any kind. Always wash hands after going to the bathroom, before meals, and any time hands are soiled.

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2. Avoid contact with persons who are sick or who may be becoming sick.
3. Keep small cuts and scratches clean and dry by washing them with soap and water.
4. Always report signs and symptoms of illness or infection and get medical help.. Call the Transplant Office if: a fever of 100.6° or more develops, diarrhea or vomiting occurs which lasts more than 24 hours, and whenever exposure to any infection occurs.
5. During the first three months after your child’s transplant, or during treatment for rejection episodes, he/she must wear a mask in crowds (i.e., church, hospital waiting areas, and sporting events). If your child is involved in activities that create a lot of dust or dirt into the air, such as heavy cleaning, mowing the grass and gardening, wear a mask to protect from many fungal spores.
6. Do not use other individual’s eating or drinking utensils and always use clean wash cloths and towels.
7. Special cleaning measures for the house and laundry are not needed, but a clean environment is encouraged.
8. Pets do not normally require health hazards except for birds, cats and reptiles. It is best to not own a bird because the waste contains a fungus called cryptococcus. When birds flap their wings, they cause the fungal spores in the waste to be carried into the air where they are easily inhaled. Non-immunosuppressed persons can easily fight these fungal spores. However, after a transplant, cryptococcal spores can cause serious lung infections and meningitis. Although owning a cat is not a problem, we recommend your child not change the litter box. Certain fungal spores found in cat waste may be inhaled during this task and may cause toxoplasmosis (infection). Reptiles carry salmonella which may be passed on to humans. Treatment of these infections can be very difficult and long process.

The following pages explain some of the more common viral infections. These infections are not easily prevented, and are treated after they appear. Two medications, Acyclovir and Valganciclovir, are commonly used to treat these infections and are available in three forms: pills, liquids and intravenous (IV) solution. Be sure to contact the Transplant Office if you have any of the problems with viral infections.

Herpes Simplex Virus

Herpes Simplex infections are the main viral infection in transplant patients. The Herpes Simplex Virus may cause frequent cold sores, and/or genital lesions. The sores begin as blisters which then turn into a shallow ulceration and are often quite painful. As part of the healing process, the ulcer crusts and eventually heals underneath. The lesions are thought to be infections until completely healed.

The Herpes Simplex Virus can be passed on through any direct contact of an infected area, including sexual contact. The virus enters through a tear in the skin, or through mucous membranes (e.g., mouth, nose). The virus is not airborne, and cannot survive on non-living objects, including toilet seats,

swimming pools, and hot tubs. Herpes viruses can remain inactive in the body causing frequent infections.

Varicella-Zoster Virus

The Varicella-Zoster Virus causes both chicken pox and shingles. Chicken pox appears as blisters (small bumps filled with fluid) over the whole body and causes pain and itching. Your child is contagious during the first week that the blisters come out. If your child has never had chicken pox and comes in contact with it, call the Transplant Office immediately. The medicine to stop chicken pox must be given within 72 hours of getting it to be helpful. Chicken pox which happens in the transplant patient can be dangerous. Although it is not common, chicken pox can come back in a transplant patient who has had the disease before. The chicken pox virus will more commonly come back in the form of shingles.

In shingles, blisters normally open up along nerve tracts on the back, chest, and hips, although they may happen in other areas. Often the blisters will be painful. Hospitalization for intravenous acyclovir and pain control may be needed. People who are not protected against chicken pox can develop this after contact with someone who has the virus.

Ebstein Barr Virus

The Ebstein Barr Virus causes infectious mononucleosis. Mono is mainly a disease of young adults and may last from several days to several weeks. Symptoms may include tiredness, severe sore throat, high fever, and headache. The Ebstein Barr Virus has also been linked with a certain type of cancer called lymphoma. (See “Complications, Cancer”).

Cytomegalovirus

Much of the US population has had a Cytomegalovirus (CMV) infection at one time or another. In Texas, it is expected that 80% of the population has been infected. Often these infections do not cause any symptoms. CMV infection in a transplant patient is serious. Symptoms can vary from tiredness, fever and cough to pneumonia, or a deadly infection.

Rejection

Rejection is the process where the body sees the new heart as coming from someone else and views it as an unknown intruder - an enemy. This response causes the immune system to send special cells and chemicals to the transplant heart to try and destroy “the enemy”. Tacrolimus (Prograf), Cyclosporine (Neoral), CellCept and Prednisone are taken to suppress the immune system in order to stop rejection. There are two kinds of rejection which may occur. These are acute rejection and chronic vascular rejection.

Acute Rejection

Acute rejection is an inflammatory reaction involving the heart muscle. Symptoms of a mild rejection are often not clear or absent. They may include tiredness, swelling, weight gain, and fever. These

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problems can be present during an infection or as a side effect of certain medications, this can make it harder to diagnose. During a severe acute rejection the symptoms involved are abnormal heartbeat, changes in blood pressure, dizziness and trouble breathing. Please call the Transplant Office if your child is having any of these problems so it can be taken care of immediately.

The symptoms of early acute rejection are often not clear and not always present, so regular tests are done. EKGs, chest x-rays, blood tests, and heart biopsies and/or echocardiograms are done regularly right after transplant and decrease in frequency with time. Of these tests, the heart biopsy or echocardiogram is the only correct way to check for rejection (see “Heart Biopsy”). Sometimes an EKG or chest x-ray can help find rejection, but a heart biopsy or echocardiogram is the best way to check for rejection at this time.

Although acute rejection can happen anytime after transplant, it normally happens in the first three to six months. During this time, doses of immunosuppressive medications are high. As the body gets used to the new heart, the doses will decrease. One year after the transplant, your child will be taking stable doses of these medicines. Acute rejection after this time is not normal but it can happen. To decrease the risk of acute rejection, **all** medications **must** be taken as ordered. If medication is not taken regularly after transplant, whether it is one week or ten years later, the body **WILL** reject the heart.

If moderate or severe acute rejection occurs, your child will be admitted to the hospital. Treatment is with intravenous (IV) steroids (Prednisone). Biopsies/echocardiograms are done regularly until the rejection is gone. If the steroids do not treat the rejection, other medicines will be given. Rejection is **very serious** and **MUST** be treated as soon as possible.

Chronic vascular rejection

Chronic vascular rejection is different from the acute type in that it involves the coronary arteries (blood vessels of the heart). You may hear chronic rejection referred to as “accelerated graft atherosclerosis.” This means that the coronary arteries become smaller due to cholesterol, platelets, and blood clots. As a result, the arteries have little oxygen to send to the heart which can increase the chance of a heart attack. Symptoms may include swelling and trouble breathing with activity, exercising may become more difficult to handle.

The transplant patient will not experience the most common symptom of heart attack - angina or pain. The lack of pain makes it important to regularly check for chronic vascular rejection.

Chronic vascular rejection can be found by doing an angiogram. Chronic vascular rejection does not usually appear before six months after transplant and is more common after two to three years.

To decrease the chance of chronic vascular rejection, it is important to follow a low fat, low cholesterol diet. Following this diet may decrease the level of cholesterol and triglycerides in the bloodstream, reducing the amount that builds up in the coronary arteries. Persantine or aspirin, both mild blood thinners, are also ordered to help blood flow smoothly through the coronary arteries.

Heart Biopsy

At first, a heart biopsy will be done every two weeks for the first twelve weeks, then monthly for the following three months at nine months and one year post transplant to check for rejection. The procedure is done as an outpatient and takes about an hour.

Your child will be taken to the cardiac catheterization lab and given medicine to help sleep. A catheter, or tube, is inserted through a large vein in the neck or groin into the right chamber of the heart. Through this tube, a wire with a pincher on the end is inserted into the heart where it takes six to eight pieces of heart muscle; each one is no bigger than a pin point. The removal of these pieces will not hurt the heart. During the procedure the heart may have some abnormal heart beats but this will go away after the procedure. After the heart pieces are collected, the tube is removed, pressure is held over the area for 20 minutes to control any possible bleeding and a Band-Aid is placed to the insertion spot. The 6 to 8 pieces are sent to a pathologist who looks at them under a microscope and decides if the heart transplant is in rejection.

The heart or endomyocardial biopsy (EMB) is the best way for finding rejection in the heart transplant patient and for treatment after rejection.-.

The EMB technique has helped with the current success of cardiac transplants. This is important for clinical management. EMB’s are regularly done during the early transplant time, when acute rejection is most often seen, and then at less often but regular times thereafter.

Heart Biopsy Grading Scale

Grade O (No Acute Rejection)

Grade 0 is used when there is no evidence of acute rejection or cell damage on the biopsy specimens. No change in medicines is needed.

Grade 1R (Focal, Mild Acute Rejection)

Grade 1R represents a greater immune system response with no cell damage. One or more pieces of the biopsy tissue may be affected. No change in medicines is needed.

Grade 2R (Moderate Acute Rejection)

Grade 2 an even greater immune system response with possible cell damage. One or more pieces of biopsy tissue may be affected. At least a three day hospital stay and IV steroids will be used to treat this rejection.

Grade 3R (Diffuse, Borderline Severe Acute Rejection)

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Grade 3R represents a greater immune system response and an inflammatory process within several pieces of biopsy tissue. Cell damage is present, which can cause swelling, blood loss, and inflammation of blood vessels. The treatment is hospital stay and IV steroid medicines. Other anti-rejection agents are used if the rejection is resistant to the steroids.

If the rejection is severe, it is treated with IV steroid therapy, using Solumedrol, and then using oral steroids to effectively decrease the medicine.

Once a grade 2 or 3 rejection is found, your child will need to have another biopsy in 2 weeks to make sure rejection has gone. Most children are put on an oral prednisone that will end soon before their next biopsy.

Personal Hygiene

Personal cleanliness is important to stay healthy. Careful attention to skin, mouth, and hair care is needed on a constant basis.

Skin Care

Bathing is needed as often as possible to keep the skin clean. Showers are allowed as soon as all tubes and external pacemaker wires are removed. Water is allowed to run across the incision line. Do not soak in the tub for a long time because it can cause an infection through the incision.

Do not use soaps with creams that can block skin pores. Always use a clean washcloth and softly wash skin areas. Be sure to rinse all soap from the skin. If skin becomes dry, use a moisturizing lotion after bathing.

The use of steroids can cause problems with acne and these areas need complete care. Gently wash the affected areas for several minutes at least three times each day. Do not scrub hard, which will lead to irritation. The goal is to keep these areas dry, but if it is overly dry try washing the area less. Do not put on oils or lotions to these areas. If washing with a mild soap does not control the acne, you may use a non prescription acne medicine such as benzoyl peroxide. Do not use products that contain Retin A, because it can be irritated by the sun. Do not rub, touch, or pick at the acne which could lead to infection.

Be sure to keep hair away from these areas and do not use makeup. If acne continues or becomes severe or infected, call the transplant office.

If your skin is hurt, you need to look carefully at the injury. Wash all small cuts or scratches with soap and water, and then keep those areas clean and dry. An antiseptic such as Betadine solution may be used on these areas. Seek medical attention immediately for large cuts or wounds such as dog bites, and then call the transplant office.

Carefully watch all incisions, cuts, scratches, or other injuries for signs of infection. These signs and symptoms include: areas of redness, swelling, and warmth, presence of drainage, and/or fever. See your primary care doctor as soon as possible if any of these happen and notify the transplant office.

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Immunosuppressant medicines increase the chance of developing skin and lip cancers, no matter how dark your skin is. These cancers are ten times more common in transplant patients than in the general public. Exposure to the ultraviolet rays of the sun on a constant basis may create permanent skin changes. Recommended ways to decrease sun exposure include:

- Never go outside without lip gloss and sunscreen, even on cloudy days or when in shady areas.
- Use a sunscreen that has a minimum sun protective factor (SPF) of 15.
- Avoid the mid-day sun when the ultraviolet rays are the strongest.
- Wear wide edge hats, long sleeves, and pants when outdoors.
- Travel with the car windows rolled up, because glass helps to stop most harmful rays from reaching the skin.

Changes in the skin could be as slight as the development of a dry, patchy area or areas of darker color. If any changes are noticed, call the transplant office.

Hair Care

Hair normally contains many organisms, so keeping hair clean is important in preventing infection.

The use of immunosuppressant drugs can change hair growth, color, and/or texture. Prednisone can cause the hair to break easily, so you should wait until the dose is less than 20mg per day before applying a permanent, hair color, or bleach to avoid excessive damage. Use a good hair conditioner every day to help prevent damage to the hair.

Increased hair growth on the arms, back, and face is seen with Cyclosporine (Neoral). A 50% peroxide solution can be used to bleach this extra hair if desired. A store bought hair cream may be used on the face, please use one that is specifically designed for that area. Follow directions for doing a skin test before using it and avoid contact with eyes, mucous membranes, and lips. Electrolysis for permanent hair removal may be considered, but talk with the transplant office before doing this treatment. Waxing is another choice for hair removal.

Oral and Dental Care

Thorough, consistent oral and dental care will help in the prevention of infection. Regular oral cleanliness should include brushing and flossing the teeth at least two times per day with a soft toothbrush or as directed by your dentist. Carefully use floss avoiding injury to gums. Possible injury can also be caused by the use of toothpicks so these should be avoided.

If your child is an infant, you should start brushing his/her teeth as soon as the first tooth comes through the gum. You can begin teaching him/her how to brush his/her teeth when he/she is about 18 months old.

Your child should be taken to the dentist for check –up 6 months after transplant.

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Mouthwashes may be used, but extreme use may change the normal amounts of germs in the mouth creating a prime environment for fungal infections. Nystatin oral suspension (fungal medicine) must be taken for the first 6 months after transplant, or as ordered by your transplant doctor.

Your child should have dental checkups every 6 months. However, avoid dental work the first six months after transplant because of the increased risk for infection.

One of the side effects of Cyclosporin is gum hyperplasia. Gum hyperplasia is the overgrowth of the gum tissue that surrounds the teeth. A dentist can help control this problem.

Always follow the rules for all dental visits:

- Make an appointment
- Before each appointment, get a prescription for prophylactic antibiotics from your local doctor. If your doctor has questions, please have them look at the American Heart Association for guidance.
- Antibiotics must be taken for each and every dental appointment where cleaning, polishing, or restorative work will be done. Antibiotics are not needed if only x-rays or an oral exam is done.
- If more than one follow-up appointment is expected, schedule them close together.
- Have the dentist call the transplant office for any questions, or if an infection is found.

Bowel Function

Constipation is the main bowel problem experienced after transplant. This problem could become serious and should not be ignored. Each person’s bowel habit varies and some children may go more than once a day while others may go once every 2-3 days.

Many things may cause constipation. Poor fluid or diet intake and lack of exercise are the most common. However, other causes are low potassium levels, muscle weakness from prolonged prednisone use and/or diabetic neuropathy. Prevention and treatment are aimed at the causes. Some suggestions are:

- Increase activity. Encourage your child to be as active as possible. Do not let him/her spend a lot of time in bed.
- Encourage your child to drink plenty of water and other fluids as allowed in the diet plan.
- Include sources of fiber in your child’s diet. Increase the amounts of fresh fruits and vegetables that are eaten.
- Older children may take stool softeners and/or laxatives as needed. Many are available without a prescription. Call the transplant office before taking any of them. **DO NOT** give such medicines to infants or young children. Call your child’s pediatrician for instructions.

Call the transplant office your child needs more laxatives or stool softeners. It is easy to become dependent on these medicines for daily bowel movements and other options may need to be reviewed.

Never try to take out stool yourself. If this is needed, a trained person should do this to avoid injury.

NEVER give your child an enema without first checking with your doctor. Enemas often upset the delicate balance of electrolytes within the body.

Diarrhea can take away important electrolytes and fluids from your child’s body. If diarrhea occurs and continues for longer than one day, call the transplant office.

High Blood Pressure (Hypertension)

Blood pressure is the amount of pressure pushed against the arteries during the time when the heart pumps blood (systolic measurement) and during the time it rests and fills with blood (diastolic measurement). It is measured in millimeters of mercury, and is written:

Systolic pressure

Diastolic pressure

A normal blood pressure can be within a range of numbers, especially in children. Remember that what may be normal for one person may be abnormal for another. Should your child have blood pressures higher than his or her normal blood pressure, let the transplant office know.

High blood pressure is a very common problem after transplant. It can be due to many factors: medicines, kidney problems, increased sodium intake, and obesity.

Many medicines including the immunosuppressant medicines can cause the blood pressure to go up. Immediately after transplant, the blood pressure changes a great deal. As the immunosuppressive drug dosages become stable, so should the blood pressure. We may need to prescribe medicine to keep the blood pressure under control.

Another cause of high blood pressure is kidney not working properly. Kidney problems may occur because of medicines, kidney disease, kidney infections, dehydration, poor heart function, and many other reasons.

Fluid retention, or too much water in the blood, can also lead to high blood pressure. Eating too much salt or sodium does the same. The best way to treat this is by reducing salt intake. If watching the salt intake closely does not sufficiently reduce the blood pressure, a diuretic (water pill) can be given. Furosemide (Lasix) is often the diuretic chosen although there are several others to choose from.

Obesity is another factor which causes high blood pressure. Although Prednisone will increase hunger, it is important to help your child eat right and maintain a good weight.

The symptoms of high blood pressure may include headaches, changes in vision, and too much water in the blood. If any of these symptoms are experienced, take the blood pressure and call the doctor. High blood pressure which is not well controlled can lead to strokes, heart attacks, and kidney failure.

To help keep blood pressure under control, watch it as ordered, reporting abnormal values, adhering to the low salt diet, and making sure too much weight is not gained after transplant.

Kidney Dysfunction

Kidney dysfunction in a heart transplant patient can occur for several different reasons. Prior to transplant, the heart may not have been pumping enough blood to the kidneys, which may have caused them to not work well. There may have been some minor, permanent damage during that time. After transplant, you will be taking medicines which have the potential to be harmful to the kidneys. Together, these two factors are often enough to cause some level of kidney dysfunction.

Indications that the kidneys are not working properly include water retention (abdominal bloating, swelling of the legs, and increase in weight), high blood pressure, increase in laboratory levels (BUN/creatinine), and less urine output. We will monitor kidney function with regular blood tests. It is important to look out for kidney dysfunction. Kidney dysfunction that is not watched closely can worsen and result in severe, long term kidney damage or failure.

Liver Dysfunction

The liver is an organ located in the right upper portion of the abdomen. It has many functions involved in the process of digestion, and development of red blood cells. The liver makes bile and helps to detoxify toxic substances in the blood, while storing food for the cells of your body.

Liver dysfunction is not common, but is a serious problem that may happen after transplant. In most cases, the dysfunction is reversible and it happens because of either an immunosuppressant drug, alcohol, or an infection.

Liver function is regularly measured by blood tests after transplant. Your transplant doctors decide if it is necessary to lower medication doses to prevent or treat liver toxicity.

If the liver dysfunction is because of an infection, the treatment may include antibiotics, antifungal, or antiviral medicines. A liver biopsy may be needed to find the cause of the dysfunction.

Symptoms are usually not noticed until liver dysfunction is significant. They may include jaundice (yellowing of the skin), itching, and delayed ability to clot blood. In most cases, once the cause of dysfunction is known and treated, liver dysfunction can be reversed.

Cancer

There are two types of cancer to which transplant patients are the most likely to get: lymphoma and skin cancer. Immunosuppressive medicine changes the immune system in such a way as to make the body more prone to these cancers. They occur up to ten times more often in transplant patients than in the general population.

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Lymphoma, cancer of the lymph node system, is not common. It may start as a solid mass in the lungs, abdomen, jaw, or lymph nodes. Fever, malaise, and weight loss may also be present. If lymphoma is suspected, several tests will need to be done. Treatment of lymphoma may include chemotherapy, surgery, and/or radiation.

There are two main types of skin cancer seen in transplant patients: basal cell and squamous cell carcinoma. The incidence of both of these cancers has been linked to sun exposure. As these cancers are readily seen on the skin, they can be easily detected and treated. The potential for cure is well over 90%, but if left untreated, can become life-threatening. Treatment is by the removal of the cancer through minor surgery.

You can reduce the risk to skin cancer by daily wearing a sunscreen with a protective factor of 15 or more, and limiting exposure to the sun. Any unusual changes in skin texture or color should be reported to the transplant office.

Preparing for Discharge

Before your child can be discharged from the hospital, you will need to learn many aspects of home care. We recognize it is easier to learn by doing. Because of this, we will ask you to participate in the health care of your child while in the hospital. We will ask you to recite side effects of the medicines and how often we will see your child for outpatient visits. We will ask you to show us how you take vital signs, set up feeds, and give medicines. We will ask you to explain what you should do if your child gets sick or if you have questions.

For the first several weeks after your child goes home, your child will have to return for many outpatient visits. To reduce the stress from long traveling trips and because of the need to quickly treat any complications, your family will have to stay in the Dallas area for at least three months after transplant. A social worker is available to help you with housing arrangements as needed. As soon as is reasonably possible, you will be allowed to return home.

Be sure to keep the transplant office informed of your family’s correct address and telephone number, as well as any changes in doctor names, addresses, and telephone numbers.

Immunizations/Vaccines

Vaccines developed to prevent certain illnesses contain either live or killed organisms. Because your body has been purposefully immunosuppressed to prevent rejection, you are at a high risk for infection. The introduction of live organisms through immunizations/vaccines would result in your developing the disease, which the vaccine was designed to prevent. If immunizations are recommended, **always** check with the Transplant Office before receiving them. For the first several months after transplant, even if vaccines with killed organisms are given, the inflammation of the skin may not be desirable.

Generally, vaccines with live viruses should always be avoided; however, vaccines which contain dead viruses may be given. Remember; **always** check with the transplant office before receiving an immunization.

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If you are planning a trip out of the country, more immunizations may be needed. After the Transplant Office approves your leaving the area, they can inform the Passport Bureau of your ineligibility to take certain vaccines by writing a letter on your behalf.

DO NOT GET THESE VACCINES

Mumps, Measles, Rubella (MMR)
Polio (oral)
Varicella (Chickenpox)
Yellow Fever
Typhoid (oral)
BCG
Rotovirus
Flumist

MAY GET THESE VACCINES

Tetanus
Diphtheria, Pertussis, Tetanus (DPT)
Polio (injectable)
Hemophilus influenza B (HIB)
Hepatitis B (Hep B-series of three)
Flu vaccine
Typhoid (injectable)
HPV
Meningitis

While not a vaccine, your child may receive the Mantoux Tuberculin skin test.

NUTRITION

Nutrition plays an important role in keeping good health and is very important for the transplant patient.

The dietician will work with your family to put together a nutritional care plan especially for your child.

The Basic Principles of the Post-Transplant Diet are:

1. Achieve and/or maintain normal body weight for age.
 - If your child is underweight, it is important to achieve the preferred body weight. Normal body weight provides fat and protein reserves for protection during periods of stress or infection.
 - Excess weight places an added workload on the heart. If your child needs to lose weight, the dietician will tell you the daily calorie limit for your child, so they can lose weight.
 - Long term use of immunosuppression medicine may make your child gain weight. Therefore, weight will be monitored during follow-up visits and changes in diet will be made by the dietician who will be available to help you if needed.

2. Change the cholesterol and fat content of the diet.
 - High blood cholesterol levels have been linked to coronary artery disease in the transplanted heart.
 - Lowering cholesterol and saturated fat content in the diet is recommended.
 - Polyunsaturated fats are substituted since these will help to lower blood cholesterol levels.
 - Your child should follow a modified fat and cholesterol diet even if blood cholesterol is within normal range since Prednisone can raise cholesterol levels.
 - Your dietician will help modify the diet.

3. Restrict sodium intake
 - The use of prednisone causes sodium retention.
 - High amounts of sodium may make your child have fluid retention.
 - A diet with medium-low sodium helps to avoid fluid retention and control high blood pressure.
 - Salt substitutes which have the mineral potassium should not be used since some immunosuppression medicines can cause potassium retention. Other salt alternatives will be recommended by your dietician.
 - The dietician will talk to you about what foods should be avoided and ways of using herbs and spices for seasoning.

4. Limit sugar and concentrated sweets
 - Prednisone may cause an increase in blood glucose and triglyceride levels.
 - It is recommended that intake of sugar and concentrated sweets are limited.
 - The dietician will advise the recommended amount of sugar.

5. Drink plenty of fluids, especially water
 - It is recommended that the transplanted patient stay well hydrated, especially in hot weather. Drinking plenty of fluid during the day will also decrease kidney toxicity caused by the medicines.

CONTACTING THE ORGAN DONOR FAMILY

The decision to write to your donor family is a very personal one.

Donor families are always thanked on the recipient’s behalf by the Organ Procurement Organizations, but any recipient who wishes to write a thank you note or letter to the donor family may do so as long as the letter is completely anonymous (e.g. contains no names, addresses, or other identifying information)

The letter can be sent to the Southwest Transplant Alliance at

5489 Blair Road
Dallas, Texas 75231
214-522-0255

Southwest Transplant Alliance will then contact the donor family to see if they want to receive communication from the recipient. If so, the letter will be forwarded to the donor family. If not, it will be returned to the recipient.

If mutually agreed upon by donor family and recipient, a face-to-face meeting can be arranged by Southwest Transplant Alliance – the local Organ Procurement Organization (OPO).

VISITS TO YOUR CHILD’S SCHOOL

The Transplant Coordinator and Transplant Child Life representatives are always willing to go to your child’s school to discuss with your child’s classmates as well as school personnel about the transplant event.

Children often have many questions about their friend who has received a new heart and we talk with them about the normalcy of their friend.

School personnel often need reassurance about the transplanted child and the expectations for that child. Again, we will be happy to talk to them about your child.

Pediatric to Adult Health Care Transition (PACT)

At some point in the future, our young adult patients will reach a point in which they would be best cared for at an adult medical center by providers who are best trained to care for adults who have had a transplant. This transition typically occurs between the ages of 18 and 21, at a time in which patients may be undergoing several other life transitions as well. These may include graduating high school, moving out of the family home, beginning college, or starting a new job. We want our patients to be well-prepared to manage their health care needs in these new environments, as well as to begin working effectively with adult health care providers. We also realize that transitioning to a new medical center can be a scary and emotional time for patients and their families. Thus, we have developed a program to ensure that we meet all of the educational and emotional needs of transplant families as they transition to adult health care.

The Solid Organ Transplant Program utilizes the PACT (Pediatric to Adult Care Transition) program to assist patients and families with preparing for independent management of one’s health care needs. This program was developed at CMCD and is utilized throughout the hospital, but was tailored by SOTP staff to meet the specific needs of transplant patients. Beginning between ages 14-15, your transplant team will start talking about the transition process during your regular clinic visits. They will discuss with your family issues related to adult health care, how to learn to manage your own health care needs, finding and using support resources, and what you need to know about your health to stay healthy in the future. At some point, you will meet with the following staff:

- Psychologist
- Child Life Specialist
- Dietitian
- Social Worker
- Doctor/Nurse Practitioner
- Financial Counselor

Each year, you will be asked to focus on learning specific information and skills to take care of your health, with the help of your family. If you need additional help with this process, SOTP staff will always be available. We may also suggest additional visits to help with the transition process. Around the time of your senior year of high school (or equivalent) you will be invited to participate in a PACT group day, where we will review these skills with patients and parents (separately) and allow teens/young adults to support each other as you plan your future.

For those patients with specific needs related to their independence (for example, patients with cognitive or developmental concerns), we will create a specific and appropriate transition plan with you and your family.

If you have questions about the PACT Program or would just like more information, feel free to contact Jami N. Gross-Toalson, PhD (214-456-5849) or Melanie Sweat, CCLS (214-456-6447).