POST-TRANSPLANT

The Liver Transplant

When an appropriate donor is identified, the transplant surgical team will remove the liver from the donor and transport it to University of Michigan Health where it is thoroughly inspected.

It is important to remember that there are situations where the potential liver may not be a good match for your child after it has been evaluated by the surgeons. If the surgeons decide the liver is in good condition, they will prepare the liver for your child.

If the transplant surgeons do not feel the liver looks healthy for any reason, the liver will not be used. While this may be very disappointing, it is in your child's best interest. You will have to return home to wait until another organ becomes available. Fortunately, this situation is uncommon.

For most children that are transplanted at University of Michigan Health, the surgeon uses a whole liver. There are times when a child is small in size and a larger liver will be reduced or split to fit your child's body size. The larger section of the liver, if possible, is given to another adult or larger child for transplant. The surgeon will discuss with you if a split liver is needed for your child. Split-liver transplantation is a well-established option with excellent outcomes.

Living Donor Livers

Living donor liver transplant occurs when a healthy adult donates a portion of his/her liver to a family member or close friend. The liver is a very complex organ that does many things necessary to keep us alive. A healthy liver also has an amazing ability to regenerate itself. When a portion of a healthy liver is removed, the liver grows back to its original size within a month. No other organ (except skin) is able to regenerate in this way.

Living donor liver transplants may be advisable for some patients with liver failure. The decision whether a living donor operation is advisable is determined by the surgeons and liver specialists who care for the recipient. Factors considered include the severity of the recipient's illness, the likelihood of getting a deceased donor organ offer, blood vessel structure, and the size of the liver needed. The decision can change as the potential recipient's health changes. If the surgeons and liver specialists determine a patient may benefit from a living donor liver transplant, the option

will be discussed thoroughly with the child's family. Additional printed material will be made available and the risks will be explained in detail to allow the parent to make an informed decision. Other factors considered include the patient's insurance coverage and the availability of a potential living donor.

When the Call Comes

When a liver becomes available for your child, a organ procurement coordinator from University of Michigan Health will call you using the phone numbers you provided.

The coordinator will ask you if your child has had any recent fevers or infections. It is important to tell the coordinator how your child has been feeling. If your child is ill at the time you are called or scheduled for the liver transplant, the surgery may have to be postponed until your child is well. This is because performing a liver transplant when a child is sick (with something like an infectious virus) can lead to death following a liver transplant from an overwhelming infection.

The coordinator will tell you not to feed your child any more liquids or solids, and when to come to the hospital for admission and preparation for the liver transplant.

We generally request that you get to the hospital as soon as you can. Depending on distance, you may need to arrange flying to the Ann Arbor area. Contact your social worker for assistance if you will need flight information. The transplant team requests that you drive safely to the hospital. No speeding is necessary.

At the time of the call, the coordinator might be able to inform you of the approximate time of surgery. If family/friends are planning on coming to the hospital to support you during surgery, have them meet you in the Mott Hospital lobby.

Pediatric Liver Transplant Procedure

When the surgeons feel the organ is ready, they will ask that your child be brought to surgery. You may be sitting with your child in the "holding area" while the surgeons are assessing the liver. While there, you will speak to the anesthesiologist (the person who puts your child to sleep for surgery), and he/she may decide at that time that your child would benefit from a medicine to make them drowsy.

During the liver transplant procedure, your child will be asleep with general anesthesia throughout the surgery. Once asleep, the transplant surgeon will make an incision (cut) on the upper part of the belly. The reason for this type of incision is so that the transplant surgeon can have good exposure to the liver and to the blood vessels going to and from the liver. For this transplant operation, it is very important that the surgeon is able to see all of the vessels going to and from the liver clearly and easily.

The surgical team then removes your child's old liver, leaving portions of major blood vessels in place. The new liver is put in its place, and the team connects the new liver's blood vessels to your child's blood vessels. The last part of the transplant is to connect the bile duct to the intestine. This allows the bile that the liver makes to drain into the intestine so food can be digested.

After all of the blood vessels and bile ducts have been attached, the surgeons check the connections to make sure they are not leaking. The outer layers of the incision will be closed with either invisible sutures (under the skin) or by using staples. If staples are used, they will remain in place for at least three weeks until the incision is well healed. It is not uncommon for drainage or bruising to occur.

Additional Surgery

In approximately one third of patients, it is necessary to return to the operating room. The most common reasons for this include:

- Bleeding
- Problems with the blood vessels going to or from the liver
- Closing the abdominal incision
- Completing the biliary anastomosis (bile duct connections)

Primary Non-function

Despite the care and precautions we take before transplant, there are times when the new liver does not "wake-up" after surgery. This is called primary non-function. If this occurs, your child will need to be re-transplanted immediately.

Communication During the Liver Transplant Procedure

After your child leaves the holding room and goes into the operating room, you and your family will wait in the surgery waiting area. We encourage you to bring books, small games, snacks, or other items that will help you during the waiting time.

The operation can last anywhere from four to 12 hours. The length of the operation can vary depending on if your child had previous abdominal surgery or if excessive bleeding should occur.

After the surgery is completed, the transplant surgeons will come to the surgical waiting area and talk with your family. While the surgery team is meeting with you to update you on the surgery and answer your questions, your child will be taken to the Pediatric Intensive Care Unit (PICU).

Common Tubes Placed During Surgery

- A ventilator or respirator (breathing machine) is used to help your child breathe during and immediately after surgery. The breathing tube is inserted through the mouth into the lungs and is attached to a machine. This allows for optimal anesthesia, relaxation, sedation, and healing occurring during and after surgery. Your child will not be able to talk while the breathing tube is in place. This is because the tube passes through the larynx (voice box). Once the breathing tube is removed, your child's voice will return. The average time that a ventilator is needed is usually two to three days. Smaller children and infants may require longer time on the ventilator due to their size and need for sedation. Sometimes there is a need for restraints to remind the child that they have tubes and lines in place. Restraints are used to avoid pulling any lines or tubes out by mistake.
- A central line or large IV will be placed during surgery into either the large vessel (internal jugular vein) in the neck or in femoral area. The central line is used to monitor your child's fluid levels during and after surgery. If the IV catheter is in the neck or femoral area, the catheter will be removed before transfer to the general care unit.
- A catheter is placed in an artery either at the wrist, elbow, or groin area (arterial line) to constantly monitor blood pressure and to act as a source for future blood draws. This catheter will be removed before being transferred to the general care unit.
- A nasogastric tube (NG tube) is placed through the nasal cavity and into the stomach. It is used to keep the stomach empty of the digestive juices. Once your child is off the ventilator and the large intestines are waking up (passing gas) after surgery, the NG tube will be removed.
- A corpak feeding tube may be placed to provide your child with nutrition if they remain intubated for a longer period post-transplant or if they had a feeding tube before transplant.
- A foley catheter is placed into the bladder to drain and monitor the urine output.

Following Surgery – Pediatric Intensive Care Unit

After surgery, your child will be taken directly to the Pediatric Intensive Care Unit (PICU) in the Mott Hospital. The nurses in the PICU will need some time to get your child settled in the ICU prior to you seeing them for the first time.

Visitation hours are 9:00 a.m. to 9:00 p.m. for non-parents. Visitors are required to check-in at the security badge station for a visitor's pass. Adults will need a photo ID, such as a driver's license, in order to get the visitor pass. No children under the age of 16 are allowed in the patient care areas unless approval is given from the care team.

Visitation for patients in the PICU can be more restrictive than the general care floor. Visitation is:

- Coordinated through your child's nurse.
- Not recommended for individuals who are ill. Sick individuals should not have direct contact with any patient.
- If your child is in need of a procedure while in the PICU, you may be asked to leave and return after the procedure has been completed. The PICU staff's goal is to get you back with your child as soon as possible, but they need to care for your child first.

Most patients begin to "wake up" in one to two hours after arriving in the PICU, but will remain sedated with medications for the next 24 to 48 hours depending on their medical condition.

While your child is in the PICU, he/she will remain connected to many IVs, tubes, and monitoring devices. Most patients will look swollen as they tend to retain the large amount of IV fluids given during surgery. This "fluid weight" will gradually go away, but it may take several days to weeks to do so.

As your child improves, IV lines and tubes will be removed, and he/she will be encouraged to become more active. Patient activity and mobility is important to prevent pneumonia, reduce the potential for blood clots, and to increase strength and conditioning. Increased mobility will depend on the removal of the respirator and lines. Once the respirator has been removed, it will be important to encourage your child to take deep breaths and cough up the secretions that might be present. Blowing bubbles or using an incentive spirometer every hour while he/she is awake are two ways to take deep breaths. When coughing, use either a stuffed animal or pillow to "splint" the incision area and reduce the discomfort. Your child's nurse and care team will help you and your child practice these breathing activities.

For most children after their transplant, they will only need to stay in the PICU for three to five days. Smaller children and infants usually require a longer stay because of their size and special health care monitoring needs. When your child is ready to leave the PICU, he/she will go to the general care unit that specializes in liver transplants until he/she is ready to go home.

Pain Control

All parents are concerned about how much pain or discomfort their child will be in after the transplant or any procedure. Children are very resilient and can tolerate pain and discomfort better than adults. Initially, the pain medicine will be given through his/her IV and then orally once he/she is tolerating an oral diet. The pain medicine will be adjusted according to the amount of pain and discomfort noted. For most children after transplant, by the time they are discharged to home, only Tylenol may be necessary to manage their discomfort.

Incision/Wound Care

Clean your child's incision daily with a clean washcloth and soap. If there are any signs of new redness, swellings or drainage, notify the nurse coordinator. Do not submerge the incision in water (i.e. bathtub) until the incision is completely healed and any tubes and/or drains are removed. Seek clearance from your team if your child would like to use a hot tub, pool, or swim in a lake or pond.

Going Home

Preparing for discharge after a liver transplant really begins the first day after surgery. The nursing staff will start to teach you about your child's care, medications and how to care for him/her after you leave the hospital. The transplant nurse coordinator will provide you with a discharge education packet to review. Before being discharged, the transplant nurse coordinator will meet with you and your family members to review discharge education and medications. On the day of discharge, the transplant nurse coordinator will meet with you bedside to review the final medication plan and confirm you are being sent home with all medications needed.

Most pediatric liver transplant patients are in the hospital only seven to 14 days after transplant. Younger children and infants often require a longer hospital stay due to their nutritional and health requirements. Your child will not be sent home until he/she is physically able to leave the hospital, and you have been taught all of the necessary care needs for your child.

Discharge Planning

Discharge planning is a team approach. You, as the parent, are an important part of this team. Before discharging your child from the hospital, there is much planning and teaching that needs to be completed. As a member of the team, it is your responsibility to actively participate in discharge planning so that you can learn how to maintain a healthy lifestyle for your child and care for the transplanted liver. We are here to support you and answer any questions you have. We want you to feel confident and comfortable managing your child's health care needs when you leave the hospital.

Discharge Education for the Transplant Patient and Family Members

The transplant nurse coordinator will coordinate the following discharge information:

- Frequency of routine clinic visits and lab studies
- Review instructions for transplant medicines, including how to order refills
- Provide a personalized medicine schedule for home
- Teach how to monitor blood pressure and order equipment as indicated
- Review short- and long-term complications after transplant
- Review basic health practices
- Transplant dietitian to review diet, formula and supplement as indicated

Routine Clinic Visits

Just like before your child's liver transplant, on-going clinic visits are extremely important. These clinic visits allow us to ensure that the liver transplant is functioning well. During these visits, we look for any complications that may have developed. Your child's lab studies give us information about any problems. We will review your child's medication and adjust doses if necessary. You will meet with the transplant dietitian, who may recommend nutritional changes after transplant. These clinic visits also allow you and your child to meet with our transplant social worker and transplant psychologist to help with any psychosocial issues.

Clinic visits will be weekly for the first month. As your child recovers from the transplant, the clinic visits will become less frequent. (For example: weekly and then will advance over months to every three to six month visits).

All clinic visits will be in the Pediatric Liver Transplant Clinic. Before each clinic visit, lab studies should be obtained. Once the lab studies have been obtained, check into the clinic area. It is important that you arrive to your child's clinic appointment **ON TIME**. If you are having difficulties in making the appointment on time (such as stuck in traffic), contact the Transplant Office to notify the team.

Once your child is in the clinic room, the visit can range from 30 minutes to two hours, depending on your child's complexity of care and needs. You should bring activities and snacks for your child during the visit and wait time.

Routine Calls

It is expected that you will have to call the liver transplant office. If you have some concerns or issues to discuss with the nurse coordinator, please don't wait until the end of the day to call.

Main reasons for possibly contacting the nurse coordinator during routine business hours:

- Any changes in your child's medical condition
- Persistent diarrhea
- Persistent vomiting. Always call if your child is unable to keep immunosuppressive medicines down.
- Problems with the IV access – Broviac or PICC line
- Problems with abdominal incision or abdominal drains (biliary stent, PTC tube or JP drain)
- Concerns regarding medicines/needing refills
- Exposure to chickenpox
- Persistent fever greater than 100.4˚F (38 .7˚C) under the arm or by mouth
- Bloody or foul-smelling urine
- Painful urination
- Light-colored stools
- Jaundiced (yellow-colored) eyes or skin
- Abdominal pain or swelling
- Rash
- Dentist visit or any dental procedure
- Your child is hospitalized outside of University of Michigan Health
- Another doctor changes your child's medicine or prescribes a new medicine
- Your phone numbers change
- Your child's medical insurance coverage changes
- You need to go out of town
- You are concerned about your child's mood or behavior and you would like to speak to the psychologist
- You are concerned about your child's diet and would like to speak to the dietitian
- You are concerned about school performance, insurance issues, or need to speak to the social worker

Our calls are managed by a call center. During the hours of 8:00 a.m. to 4:30 p.m., your calls will be answered by a call center representative. If you contact the Pediatric Liver Transplant Office outside of normal business hours, you will reach a recording that will notify you our office is closed. You will be given the option to cancel your appointment or remain on the line to connect with the answering service. If you have an emergency or other issue that cannot wait until the next business day, remain on the line and ask to speak to the GI fellow on call. If your question or concern can wait, contact the office the next business day during regular business hours.

Emergency, Night, and Weekend Calls

Emergency or urgent calls are for problems that need to be addressed more quickly. If you believe that your child is having an emergency or urgent problem, you should make the transplant team aware of this immediately.

If you are having a medical emergency, call 911 for assistance or go directly to the nearest emergency room. The emergency room physician may contact the Pediatric GI doctor on call, and if medically necessary, a transfer to University of Michigan Health can be made.

For those emergency phone calls during the weekend or evening hours, you may call the Pediatric GI physician for assistance. Call the University of Michigan Health paging operator at **(734) 936-6267** and ask for the Pediatric GI doctor on call.

Main reasons for contacting the transplant team for emergencies:

- Temperature greater than 100.4˚F (38˚C) under the arm or by mouth
- Systolic or diastolic blood pressure greater than the level your physician told you it should be on two consecutive measurements
- Significant vomiting/diarrhea with signs of dehydration. Signs of dehydration include not making tears while crying, dry or sticky mouth, no urine in over eight hours or decreased number of wet diapers, dizzy or unsteady while standing or walking, less alert than usual, refusing to drink fluids despite encouragement, or sunken “soft spot” (anterior fontanel) on an infant.
- Active chickenpox lesions
- Unusual irritability with sleepiness, shortness of breath, or seizure activity
- Any critical changes in your child’s condition
- Problems with central lines (Broviac catheter/PICC line)

To request a prescription refill, the office will coordinate the request, but will need the following information:

- Your name and child's name
- Your phone number
- Your pharmacy phone number
- The name of the prescription needing to be refilled
- The dose and how frequently the medicine is taken
- The amount of medicine remaining on the current prescription. **NOTE:** It is extremely important not to wait until there are only one or two doses left in the bottle. This is especially important with compounded (liquid) medications. Compounds may take up to several days to make by the pharmacist.

Please allow a minimum of **three days** for prescription refills to be processed.