

## POST-TRANSPLANT

### *The Liver Transplant*

In order for a liver to be transplanted from one patient to another, the donor (the person who has died) must be brain-dead. Only then are the donor's organs used. The transplant surgical team will remove the liver from the donor and transport it to the University of Michigan 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 the University of Michigan, 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 the need for a split liver is necessary for your child.

### *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 liver transplant coordinator from the University of Michigan will call you at home, or at the phone numbers you have provided, to tell you that a liver may be available for your child.

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 doing 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 liver transplant coordinator will tell you not to feed your child any more liquids or solids and 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. The longest time you can drive by car is five hours. Any distance longer than a five-hour drive will require you to arrange to fly 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 transplant coordinator will 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 arrive at least two hours before that surgery time.



### *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 at the University of Michigan, your child will be asleep with general anesthesia throughout the surgery. Once asleep, the transplant surgeon will make an incision (cut) shaped like a boomerang or in the shape of an up side down Y 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. The main bile duct (Common Bile Duct) that comes out of the liver is attached to the small intestine (duodenum). This allows the bile that the liver makes to drain into the intestine so food can be digested. Where the bile duct is attached, a small biliary stent (a small plastic tube to help keep the bile duct open) may be placed either within the bile duct (internal) or placed externally with the end attached to a small bag. The use of the biliary stent allows the bile duct surgical site (anastomosis) to heal. If the tube is placed internally, with time this tube will be passed and come out in your child's stool. If the tube is placed externally, the biliary stent will remain in place for six to eight weeks. Before your child's discharge from the hospital, the tube will be clamped off. This will allow all the bile to flow into the intestine instead of the bag. Once liver function has improved, and there are no signs of bile duct complications, the biliary stent will be removed.

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*

There are instances where it may be necessary for your child to return to the operating room the next day after surgery. The most common reasons for returning to surgery include:

- Bleeding
- Problems with the blood vessels going to or from the liver
- Closing the abdominal incision

### *Primary Non-function*

When the liver is removed from the donor, it is placed in ice. 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 the chest area called a Broviac Catheter. The central line is used to monitor your child’s fluid levels during and after surgery. Broviac Catheters are generally used in all small children and will be in place for at least two to three months after surgery. If the IV catheter is in the internal jugular vein, the catheter will be removed within five days after surgery.

- 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 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 in the Mott Hospital. The nurses in the PICU will need several hours to get your child settled in the ICU prior to you seeing them for the first time.

Visitation hours are 11:00 a.m. to 8:00 p.m. 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 is somewhat more restrictive than the general care floor. Visitation is:

- Coordinated through the PICU clerk and your child's nurse.
- There is no visiting during patient rounds and shift change report.
- Limited to one or two visitors at a time.
- 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. Patients receive a large amount of IV fluid during surgery. Most patients will look swollen as they tend to retain these fluids. 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. During the transplant, the Pain Service will be involved in recommending pain control for your child. Initially, the pain medicine will be given through his/her IV and then orally once he/she is on the general care unit. 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 by sponge bathing him/her daily. If there are any signs of new redness, swellings, or drainage, notify the nurse coordinator. Your child cannot take a bath (in a bathtub) or use spas, hot tubs, or swim in a lake or pond until the incisions are completely healed, and the bile tube has been removed. Your child can swim in a chlorinated pool after all of the incisions are completely healed (even if the bile tube remains in place). An exception to this is if your child still has a Broviac catheter in place.

If your child had either sutures or staples to close the incision, you should keep the incision area clean and dry. Usually sutures and staples are removed within two to three weeks after surgery.

### *Bile Tube (T-tube, Biliary Stent, or PTC Tube) Care*

If your child has a bile tube inserted during the transplant, it will usually remain in place for six to 12 weeks. This means that your child will go home with the tube in place. Special instructions for bile tube care are as follows:

- You should bathe your child daily and wash the area around the bile tube with soap and water. Keep the area dry. Swab around the bile tube with hydrogen peroxide on a Q-tip every other day. If the tube is having an excessive amount of drainage, or if the area around the tube is crusty, you should clean around the tube.
- You should check the skin around the tube for redness and/or drainage. If the stitches are loose, secure the bile tube to the skin with tape, and notify the nurse coordinator. It may be necessary for your child to have the bile tube re-sutured. If for some reason the bile tube comes out, notify the nurse coordinator or doctor immediately.

- If your child's bile tube is open to drainage, you need to notify the nurse coordinator if the drainage of the bile should change in color (example: blood in the bile) or the amount of bile drainage changes. This could indicate a possible blockage in the bile tube, or it may have moved out of its proper position. It may become necessary for us to examine the bile tube in radiology.
- If you have any questions or concerns regarding the bile tube, call the transplant coordinator.

### *Internal Biliary Stents*

Internal biliary stents may be inserted into the main bile duct during the transplant surgery. Most of the time, the stent will fall out on its own and pass through the digestive tract. You may notice a small plastic tube in your child's diaper or in the toilet. Most patients will pass the stent within four to six weeks after surgery. An abdominal x-ray may be taken to see if this stent is still in place. If the stent is causing the liver numbers to rise, it may be necessary to remove this stent by using an endoscope (EGD).

### *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 coordinator will have you start to review this education book before leaving the PICU. Before being discharged, the transplant coordinator will meet with you and your family members to discuss the immediate and long-term care needs of having a transplant child at home.



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
- Teach Broviac catheter care and how to order supplies for home
- Arrange Home Care nursing at parents request
- 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 of your difficulties.

Once your child is in the clinic room, the clinic 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/needling refills
- Exposure to chickenpox
- Persistent fever greater than 100° Fahrenheit (37.7° Celsius) 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 the University of Michigan Hospital
- 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

Due to the high volume of telephone calls, you may need to leave a message on the answering machine. Messages are retrieved several times throughout the day. While every effort is made to return all calls on the same day, sometimes this is not possible. Telephone calls are prioritized – with calls from sick patients receiving the highest priority. To ensure the calls are prioritized appropriately, please include the following when leaving a message:

- State clearly your name and child's name
- Provide a telephone number(s) where you can be reached between 8:00 a.m. and 4:30 p.m.
- Briefly state the reasons for the call or concerns
- If your child is sick, give the nature of the sickness
- If you need to reschedule or schedule a clinic appointment this should be discussed with the transplant nurse before any changes in appointments

### *Emergency, Night, and Weekend Calls*

Emergency or urgent calls deal with 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 problem at once.

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

For those emergency phone calls during the weekend or evening hours, you may call the Pediatric GI attending physician for assistance. Telephone the University of Michigan paging operator number at 734-936-6267 and ask for the Pediatric GI attending on call.

Main reasons for contacting the transplant team for emergencies:

- Temperature greater than 101° Fahrenheit (38.3° Celsius) 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.