

After the Surgery

After the transplant surgery, your child will recover in the pediatric intensive care unit (PICU) at CMH. He/She will require frequent laboratory tests as well as intense monitoring of vital signs, urine and stool output, and fluid hydration. Your child will be placed on intravenous nutrition, TPN and intralipids providing the stomach, intestine, and liver with time to recover. Additionally, he or she will have several IV's, a catheter in the bladder, a tube through the nose into the stomach, and a breathing tube in the mouth attached to a ventilator. The nurses will explain the purpose of all the monitors and tubes during your first visit.

Your child will receive pain medications and strong sedatives to keep him or her comfortable.

The breathing tube will stay in place until your child is strong enough to breathe without help and will be removed as soon as it's safe.

The length of stay in the PICU will vary depending on your child's recovery after transplantation. When the transplant team determines your child is ready, he or she will be transferred out of the intensive care unit. Many of your child's tubes will be removed prior to the transfer.

The Post Operative Period

Ileostomy

Your child will return from surgery with an ileostomy in place. An ileostomy is an artificial surgical opening to bring the intestine to the surface of the abdomen. This opening is called a stoma. Stool comes out of this opening rather than traveling through the intestines and out the rectum. A bag (pouch) covering the stoma prevents the stool output from getting on your child's skin and clothes. This is called an ileostomy bag.

An ileostomy is created to access the transplanted intestine and check for rejection and ensure the intestine looks healthy. The "ostomy" also allows the stool to be measured. Increased stool output can be a sign of rejection and needs to be closely monitored. The ileostomy can usually be removed or "reversed" approximately 6-12 months after surgery.

Caring for a child with an ostomy takes both practice and patience. The bedside nurse will teach you how to care for your child. Once your child has recovered from surgery, you will need to:

- Take care of your child's skin around the stoma
- Empty and measure the ostomy bag
- Change the ileostomy bag
- Monitor the stoma for problems, including bleeding and color changes

Gastrostomy Tube

After transplant surgery, your child will have a gastrostomy feeding tube, or G-Tube in place. This feeding tube is placed from outside the abdomen to the inside of the stomach. Your child's feedings will be delivered through the tube and into the stomach slowly. This helps your child better tolerate his/her feedings.

The nurse will teach you how to care for the gastrostomy tube. Before you leave the hospital, you will be comfortable with the following:

- Cleaning around the gastrostomy tube
- Taking care of your child's skin around the tube
- Inserting/ changing the gastrostomy tube
- Connecting the feedings to the gastrostomy tube
- Programming and managing the feeding pump

Ileoscopy with Biopsy

After transplantation, your child's intestine will be examined thoroughly using a procedure called an ileoscopy. During this procedure, a scope is inserted through the ostomy, the intestine is visualized, and small pieces of the intestine will be taken to look for rejection. Since there is not a specific blood test, the only way to detect rejection is evaluating the intestinal cells under a microscope. This procedure will be done weekly for the first month after surgery. Additional ileoscopies will be performed for the following indications:

- Increased stool output
- Fever or infection
- Changes in stoma or tissue color
- Bloody ostomy output

Central Line Management

Your child may already have a central venous catheter called a PICC line or a central line. If not, she/he will have this after surgery. The purpose of this line is to:

- Draw blood labs to ensure your child is receiving the proper nutritional support she/he needs
- Draw blood labs to ensure your child is receiving the proper immunosuppressive therapy to avoid rejection
- Provide intravenous nutrition as well as additional intravenous fluids, if necessary
- Administer intravenous antibiotics if a blood infection is present

How will I know how to care for my child's central line?

The nurse will teach you how to care for the central line. The dressing covering this line will need to be changed at least once a week. In addition, this line will need to be flushed at least once a day with a heparin solution to prevent the line from clotting. Central lines need to be cared for and cleaned very

carefully each time used to prevent infections. Your child's central line is his/her lifeline for growth and development, but an infection in this line can be life-threatening. Therefore, signs and symptoms of infection should be monitored closely, and the CMH team should be notified immediately.

When will my child not need this line?

Once your child is tolerating his/her goal enteral feedings, off TPN, gaining healthy weight, and maintaining adequate immunosuppressant levels, the line will be removed. The central line will remain in place for a minimum of a few months after surgery.

Laboratory Schedule

Your child's labs will be checked on a daily basis for the first few weeks after transplantation. Once stable, labs will be checked on a biweekly/weekly basis. After discharge, a nurse from the home health company will come to your house to draw these labs from the central line or they will be drawn at your child's clinic appointment. The laboratory tests are monitored frequently to ensure your child is receiving the most effective intravenous nutrition, hydration, as well as the proper amount of immunosuppressive therapy. The laboratory tests monitored on a weekly basis include:

- Chemistry panel (Chem 14)
- Complete blood count (CBC)
- Liver function tests (LFTs)
- Magnesium
- Phosphorus
- Ionized Calcium
- Prograf level
- Rapamycin level

As a result of the immunosuppressant medications, including prograf and rapamycin, your child is at increased risk for infections. For the first few months after surgery, additional viral studies from the blood and stool will be sent weekly to ensure your child does not have certain viral infections, including Epstein-Barr virus (EBV), Cytomegalovirus (CMV), or Adenovirus.

Stool Replacements

After an intestinal transplant, you will be asked to measure and record stool output. Your child will be placed on a stool replacement regimen with intravenous fluids to ensure that your child stays well-hydrated. You will be taught how to measure your child's stool output. If your child's stool output is greater than a given amount per day, you will be instructed to call the transplant team and perhaps replace the stool output with an intravenous solution (Lactated Ringers) or with an oral solution (Pedialyte). The replacement supplies will come from your infusion company and extra supplies should be kept in your home at all times.