Monitoring Your Child’s Health

One of the tools that you can use to help take care of your child is the diary that your nurse coordinator provided. In it you can record your child’s medicine doses, weight, temperature, blood pressure, etc. When your diary runs out, feel free to ask your nurse coordinator for another.

You will need to monitor the following:

- Check your child’s temperature twice every day, at the same time in the morning and evening. Notify the nurse coordinator if your child’s temperature is greater than 100.5.
- Because your child’s immune system is suppressed, he/she should avoid anyone who is sick with colds, the flu, or other contagious illness.
- Check for signs and symptoms of infection. Notify the nurse coordinator if your child is experiencing any of the following:
  - Fever
  - Sores or rashes in mouth or on skin
  - Redness, swelling, or drainage around the bile tube site or incisions
  - Burning with urination and frequent urination
  - Persistent headaches
  - Sore throat
  - Nausea
  - Vomiting
  - Diarrhea
  - Productive cough
  - Earache
  - Any feelings of being “sick” that you cannot explain
- Check for possible side effects related to the medicines your child is taking.
- Check for signs and symptoms of rejection.
Masks

As you've probably noticed, there is construction going on in and around the University of Michigan Medical Center. Our division has been advised by the hospital’s Infection Control Program to begin preventative measures to protect our patients whose immune systems are compromised from infections carried by airborne dust particles. The yellow mask should be worn when the child enters/leaves the hospital or when the child enters any area of the hospital where there is obvious indoor construction. Masks will be provided for you before discharge from the hospital. Your transplant nurse will inform you when wearing a mask is no longer necessary.

Special Care and Potential Complications

Injuries

Cuts, scrapes, and abrasions should be treated as you ordinarily would. Clean with soap and water and bandage if necessary. If your child has a severe or a non-healing wound, your local doctor should evaluate the wound and treat as necessary.

Bile Duct Problems

Bile duct problems are caused by either a leak or by a stricture (narrowing of the bile duct). Bile ducts are the tube through which bile moves from the liver into the small intestine (bowel). Normally bile that is made is stored in the gall bladder. When you eat, the bile is then moved into the small intestine. However, the gall bladder is removed during the liver transplant. It is important then, that the bile not remain in the liver and that it is transported to the small intestine.

• Bile leak: A bile leak can develop where the two bile ducts are sutured together or at the site where the bile duct is sewn into a loop of bowel (roux-y limb). At times, surgery may be able to repair a leak in the bile duct. However, treatment generally consists of placing a stent or tube across this area until it heals. Stents are placed internally by a procedure performed in the Medical Procedure Unit called an Endoscopic Retrograde Cholangiopancreatography (ERCP). The stent remains in place until it is confirmed that the leak has sealed itself. Internal biliary stents need to be changed every six to eight weeks, but leaks usually heal without further treatment within a few weeks. Internal stents like this can only be used for patients whose bile ducts are sutured duct to duct.
For those that have a roux-y limb type anastomosis, this is not an option. The only option is using a Percutaneous Transhepatic Cholangiography (PTC) tube. The PTC tube is inserted through the skin by interventional radiology. It is considered an internal / external tube since part of it is inside the patient, and part of it remains outside the abdomen. The tube needs to be changed every four to eight weeks.

**Biliary Strictures:** Biliary strictures can develop for several reasons. Bile ducts need a constant blood supply from the hepatic artery. Any interruption of the blood flow will cause damage to the bile ducts. The most common problem in the bile ducts is that they become narrowed (strictured). This narrowing can occur where they are sewn together, or it can occur within the smaller bile ducts within the liver. If the stricture is at the suture site (anastomosis), a PTC tube is placed, and the area is balloononed open. Sometimes, this process is done several times. If it is unsuccessful, surgery may be able to correct the problem.

Strictures that are near the liver or within the liver (intrahepatic) are more of a problem, since they tend to be more permanent and are not usually corrected by surgery. The only treatment option is using a PTC tube or re-transplantation.

If bile accumulates in the liver, it becomes thick like sludge and can form stones. This can cause a condition called Cholangitis which can lead to a serious – perhaps life-threatening infection. Inadequate bile flow can be identified through lab results. If this is suspected, an ultrasound of the liver will be done first to assess and then a diagnostic ERCP or PTC tube will be done next if necessary.

When lab work indicates that the patient has a bile duct problem, the patient is re-started on Actigall or Ursodiol to help thin the bile.

**Blood Flow Problems**

HAT is Hepatic Artery Thrombosis, and PVT is Portal Vein Thrombosis. At times, the hepatic artery or the portal vein (vessels that supply blood to the liver) clot (thrombose) immediately after surgery. A Doppler ultrasound may be performed daily for five days after surgery to check blood flow in these vessels. If the ultrasound detects a clot, your child will return to the operating room to have the clot removed. If the clot is detected quickly, it usually can be removed from the artery or vein. If the clot cannot be removed, your child may need re-transplantation.
Infections

Patients who have had a liver transplant require anti-rejection medicines, usually for their lifetime, to suppress their immune system. Since your child’s immune system is inhibited by these medicines, he/she has an increased risk of getting infections. The risk is highest in the first three to six months after transplant or when higher levels of immunosuppression (anti-rejection medicines) are taken to treat rejection. For the first month after the transplant or after treatment of a rejection episode, avoid large crowds of people. If you want to take your child to a movie or out to the mall for a short shopping trip, go at times of the day when it is less crowded. Avoid people who are obviously sick. If there is an illness in the home, use good hygiene, especially hand washing. Do not share eating utensils, cups/glasses, and toothbrushes with others since many viral illnesses are spread through saliva. More often, you will be the one sick and not your child.

The best advice is to be careful but realistic. Your child cannot enjoy life fully being overprotected.

Chickenpox & Measles

Before the liver transplant, your child’s chickenpox (varicella) titer was checked. Titers are an indication of whether your child has had the chickenpox disease. You can ask the nurse coordinator for results of the titer on your child.

Chickenpox is contagious for 24 hours before the crusts and scabs form. Even though your child may have had the chickenpox, he/she can get it again when using immunosuppressive medications. However, it is more common for the chickenpox virus (varicella) to be reactivated in the transplant recipient in the form of shingles. Therefore, stay away from anyone who is infected with chickenpox or shingles. Notify the nurse coordinator or doctor immediately if you discover that your child has been exposed to either chickenpox or shingles.

It is considered a medical emergency if your child comes down with the chickenpox. Call your child’s transplant medical team immediately. Your child WILL need to be admitted to the hospital for IV medications.

Shingles (Varicella Zoster)

It is estimated that up to 50 percent of immunosuppressed patients develop shingles. Shingles is NOT caused by a new virus. It is caused by the reactivation of the chicken pox virus that remains in the body after the disease appears to have gone away. Even though patients recovered from chicken pox many years ago, the virus remains in the body without the patient being aware of it. The chicken pox virus can become active again, and when it does, it is in the form of shingles.
Shingles starts out as a pain or tingling sensation, followed by blisters. Shingles always follows a nerve pathway (e.g., down the hip and leg). It is treated with anti-viral medication (Acyclovir) and pain medications. Patients are contagious while they have the blisters. This means they can give the chicken pox virus to someone else who does not have adequate immunity for this virus.

_Cytomegalovirus (CMV) and Epstein-Barr (EBV) Virus_

There are two viruses that are of concern and can affect the newly transplanted liver. They are cytomegalovirus (CMV) and Epstein-Barr (EBV).

- **Cytomegalovirus (CMV):** CMV is a common community-acquired virus and is not a serious illness for most people who are healthy. However, CMV may be of more concern to people who are taking immunosuppressive medicines (anti-rejection medicines).

  CMV is a common infection that usually occurs within two to three months after transplant. Some patients are more at risk for CMV than others. The patients who are at the highest risk for getting CMV are those who:
  - Are CMV negative and received a CMV positive liver
  - Receive high levels of immunosuppression
  - Received treatment for rejection

  Because CMV is such a common infection, transplant centers usually have treatments to prevent this infection, particularly in patients who are considered to be at high risk for this infection. Treatment of choice is using Valcyte for 90 days or three months.

**Symptoms of CMV**

- Fever
- Low WBC count
- Flu like symptoms
- GI distress – vomiting, nausea, abdominal pain and/or bloody stools
- Increased liver function tests

CMV is often diagnosed by a blood test. It most commonly occurs within three to 12 weeks after transplant, but can occur at any time. If recognized early, CMV infection often responds well to medicine.
• **Epstein - Barr virus (EBV):** EBV is a virus that causes infectious mononucleosis (“Mono”) in healthy people. Most people have had an EBV infection by the time they become adults. It often presents as a cold. Children who have not had an EBV infection before transplant or received a liver from a donor who has had an EBV infection are monitored particularly closely post-transplant. Patients who develop EBV while on immunosuppression may develop a spectrum of EBV related symptoms. EBV infection can range from:
  - Non-specific viral infection
  - Mononucleosis
  - Post-transplant lymphoproliferative disorder
  - Lymphoma

EBV is diagnosed by a blood test and by clinical examination. If your child develops EBV, he/she may be started on anti-viral medicine (Valcyte), and his/her immunosuppression may be adjusted. If your child develops any of the following, do not hesitate to call the transplant office:
  - Fever
  - Swollen glands
  - Persistent cold symptoms
  - Nausea, vomiting, diarrhea
  - Weight loss
  - Night sweats

When EBV infects children who are taking medicine to prevent organ rejection, the virus can cause certain white blood cells to divide and reproduce very rapidly resulting in a condition which is called post-transplant lymphoproliferative disease (PTLD). PTLD is a serious condition, but is treatable in many cases. We will be monitoring your child frequently during the first year and yearly after transplant for evidence of the EBV virus. If an elevated EBV level is noticed, additional testing may be required to evaluate for PTLD (i.e., CT scan and liver ultrasound). Your doctor will discuss further with you and your child if your child is at risk for an EBV infection or PTLD.
**Human Papilloma Virus (HPV):** Transplant recipients are at an increased risk for contacting the virus that causes warts on the hands and feet. Scratching these warts or lesions can spread the virus to other parts of the body. Your pediatrician or dermatologist can successfully treat them. Current belief is that a transplant patient cannot transmit these warts to other healthy individuals, but they may be capable of transmitting them to people with a compromised immune system.

HPV is also associated with skin cancer, cervical cancer, and genital warts. It is recommended that any female transplant patient between the ages of 12 and 18 obtain the HPV immunization. The immunization is given in three parts, over a period of six months. The immunization can be obtained either from the local pediatrician or health department. Some insurance companies have poor coverage for this immunization. For those patients with poor or no coverage, the immunization should be obtained at the local health department for a low fee (usually around $10 to $15). In addition, adolescent female transplant patients over the age of 18 should be seen yearly by a gynecologist for routine surveillance of the HPV infection.

**Rejection**

“Rejection” is the body’s natural response to fight off foreign objects (e.g., your child’s new liver).

Despite the medicines that your child takes to suppress his/her immune system, it is not uncommon for liver transplant recipients to experience a rejection episode. It most frequently occurs within the first few months after your child’s transplant, but it CAN occur at any time after transplant. Many times your child may feel well but his/her blood tests may indicate a potential rejection episode. Therefore, be mentally prepared for the possibility of being admitted or needing a liver biopsy any time after a blood test or clinic appointment. It is important not to panic if your child has been diagnosed with a rejection episode. We have medicine to treat rejection, so it does not mean that your child will lose his/her liver transplant.

If the nurse coordinator or doctor notes high liver function tests, additional blood tests and procedures will need to be done to evaluate for the possible cause. The most common tests and procedures include a liver ultrasound and liver biopsy. We are usually able to do these tests on an outpatient basis. Many times the tests and procedures will be scheduled within days of the documented abnormalities in the liver blood tests. The earlier the cause of the elevation is found and treatment is started, the easier it is to reverse the probable cause for the high liver function.
The following are signs and symptoms that may indicate a rejection episode (although there are many other possible reasons for them):

- Fever
- Muscle aches (flu-like symptoms)
- Abdominal swelling and/or pain
- Increased tiredness
- Jaundice (yellowing of whites of eyes and/or skin)
- Clay-colored stools
- Tea-colored urine

If your child is experiencing any of these symptoms, you should contact the nurse coordinator.

_Treatment for Rejection_

Rejection is usually treated by increasing the doses of the immunosuppression (anti-rejection medicines) or by adding or combining different anti-rejection medicines. In addition, your child will receive IV prednisone for three doses – one dose per day for three days. Afterwards, the oral prednisone dose will be increased and then slowly tapered (reduced) over time as the liver function improves. If the liver function does not improve after the three days of IV medicine, a repeat liver biopsy may be performed before starting a new form of anti-rejection medicine. Most often, the three day course of medicine improves the liver function.

_Chronic Rejection_

Chronic rejection is a slow process in which the bile ducts dissolve, also known as ductopenic rejection. Chronic rejection usually does not respond well to medicines and with time may result in a need for re-transplantation.

_Renal (Kidney) Insufficiency_

Kidney insufficiency is defined as an increased serum creatinine level and can develop as a result of anti-rejection medicines. It can range in severity from very mild to the point of needing dialysis. The goal is to closely monitor blood work so anti-rejection medicines are given at the lowest possible dose to prevent rejection and have the least harmful effect of the kidneys. To minimize the risk of kidney failure, it is important to maintain good blood pressure and good blood sugar controls.
**Cancer**

The risk of cancer is three to five times greater in a transplant patient than in the general population. This is primarily due to the use of anti-rejection medicines. The most common forms of cancers seen are:

- Skin and lip
- Lymphomas which make up 57 percent of all post-transplant tumors
- Colon cancer
- Breast cancer
- Uterine cancer

As your child progresses in age, the importance of routine cancer screening is recommended. Examples include:

- Self examination (breast and testicular examinations)
- Mammogram
- Gynecology
- Prostate
- Colonoscopy

**Re-transplantation**

Certain liver diseases can re-occur in the liver and cause liver failure again. If this happens, another liver transplant may be considered. The process for re-transplant is similar to the first transplant in that a patient will be evaluated by the Transplant Team after having all the same testing as before. Because re-transplant is more difficult to do and has a higher death rate associated with it, several additional factors are looked at closely:

- How compliant has the patient been since their first transplant?
- How quickly and how severe the disease has returned after surgery?
- How sick the patient is presently – can the patient survive a second transplant surgery?

Patients are **NOT** re-transplanted when they have been non-adherent with medicines and long-term transplant care.
Immunizations

You child should never receive immunizations that contain a live virus. If a live virus immunization is given, there is a potential risk that your child will contract that infection. This has potential for causing liver dysfunction. The following immunizations contain a live virus and should not be taken:

- Small pox vaccine
- Oral polio vaccine
- MMR (measles, mumps and rubella)
- Varicella (chickenpox)
- Influenza (only nose spray type is live)

The following are acceptable immunization for your child to receive, but you should contact your nurse coordinator or doctor first:

- Tetanus
- Typhoid
- Diphtheria
- Pertussis (dT or DPT) (whooping cough)
- Polio (killed virus)
- Haemophilus Influenza Type B (HIB)
- Influenza (injected form only)
- Pneumovax
- Hepatitis B and A series
- Human Papilloma Virus (HPV)

It is necessary that your pediatrician have a copy of the immunizations that your child can receive. If a live virus immunization is given to your child after transplant, your child may get the infection that the immunization is trying to prevent.

Siblings and household contacts should not receive oral polio (Sabin) vaccine. Members of the household can get the MMR immunization, but varicella vaccine may have to be withheld. Please discuss the administration of the varicella vaccine to a household member with the transplant team before it is administered.
**Flu Shots and Pneumonia Shots**

Transplant patients are encouraged to receive a flu shot every year and pneumonia shot every five years. Since high doses of anti-rejection medicines may lessen the effects of these vaccines, transplant patients are recommended to wait approximately three to six months after transplant before getting these or other vaccines.

**Dental Care**

Because many infections start in the mouth, dental care is very important. Here are some points that need to be done to promote good dental hygiene:

- Brush the teeth often – at least twice a day.
- Notify your nurse coordinator before making your child’s first dental appointment after the transplant. Your child will need to take antibiotics before every dental procedure (e.g., cleanings, fillings, and gum surgeries) while on high doses of immunosuppressants. A prescription can be called into your local pharmacy. Antibiotic prophylaxis (pre-medicine) is used until your child is on only one anti-rejection medicine (e.g., only Prograf).
- Your child should see the dentist every six months.
- Inform your dentist of your child’s transplant and the special medicines that your child takes.

**Eye Examination**

It is recommended that your child is seen by an ophthalmologist (eye doctor) on a yearly basis after transplant. This is to monitor for any chronic eye changes that can be noted as a result of the anti-rejection medicines.

**Sunscreen**

Because your child is taking drugs that suppress the immune system, your child has an increased risk of developing skin cancer. We suggest that your child take precautions, including using sunscreen (SPF 15 or greater), hats, and long sleeves (if tolerated). Your child should avoid tanning salons and repeated long unprotected exposure to the sun.
Activity

We encourage your child to resume normal activities as tolerated. However, use moderation in the early post-transplant period. Your child will feel better when participating in normal childhood activities. Exercise will help combat weight gain as well as decrease incidence of bone loss due to prednisone.

Ask your nurse coordinator/doctor about any activities in which your child would like to participate. In general, though, the following activities should be avoided:

- Motorcycles, dirt bikes
- ATVs
- Contact sports such as football
- Anything that would cause direct trauma to your child’s transplanted liver

It is important that your child not lift anything heavier than 10 pounds (e.g., a six pack of pop) for approximately six weeks after surgery. Until that time, your child's abdominal muscles are not completely healed.

If your child is of driving age, he/she may resume driving approximately six weeks after surgery. Check with your nurse coordinator or doctor before driving. Until that time, your child’s reflexes may not be quick enough to drive safely. Your child should always wear a seat belt or be in a car seat.

School

Your child should be able to return to school or work within six to eight weeks after transplant. Check with the nurse coordinator and school before his/her return to school. You should notify your child’s school to make arrangements for home schooling once your child has been discharged from the hospital. Many times there are forms that need to be completed by the nurse coordinator/doctor that you obtain from your child’s school.
Pets

Pets can be an important part of family life. Research has shown that pets help relieve stress and have positive physical and psychosocial benefits as well as possibly improving our quality of life.

Although animals do carry a number of diseases that can be transmitted to humans, few are life threatening. Some guidelines should be followed:

• Wash your hands after handling your pet, especially if you are going to eat, drink, or handle any food.
• Your pet should have regular health visits to the vet and receive the required immunizations.
• Groom your pet on a regular basis. The nails of both the dog and cat should be trimmed on a regular basis to avoid scratches to you. If you do get a scratch, clean the wound with soap and water and apply antibiotic cream. If the scratch should become infected, seek medical treatment.
• All transplant recipients should avoid your pet’s body fluids (urine, stool, or vomit). If possible, have someone else clean up the accident or litter box. If necessary, use some gloves and clean the area with some disinfectant. Wash your hands with some antibacterial soap or hand sanitizer after the cleaning has been done.
• It is not recommended that a transplant recipient clean the litter box if at all possible. The litter and liner should be replaced frequently. The litter box should be cleaned at least every month with disinfectant soap or hot boiling water.
• Seek urgent medical treatment if your child should be bitten by any animal.
• Avoid having the pet lick your child on the face.
• Your child should avoid any stray or sick animal. Transplant recipients should avoid having an exotic animal as a pet (such as reptiles).

Traveling

As soon as your child has recovered from the liver transplant and moved to a more normal routine, you might consider traveling or going on a vacation. Please check with your nurse coordinator before leaving on a vacation to see if it is safe to do so. Most families wait until it has been six to 12 months after transplant.
General traveling tips:

- Notify your nurse coordinator of your destination or vacation site. If possible, give her a phone number where you could be reached if necessary.
- Carry a current list of all transplant medicines.
- Take at least one week of extra medicines with you in case of an unplanned extension of your trip.
- Always carry the medicines with you in a carry-on bag if flying.
- Take a list of important Transplant Center Emergency phone numbers.
- Bring some bottled water and food with you to take medicine.
- If traveling outside of the U.S. is a potential plan, contact your nurse coordinator for instructions regarding possible immunizations that might be necessary for your travel.

Sexual Behavior and Reproduction

Males who have a liver transplant are usually fertile and can father a child. For women, the possibility of conceiving is better than 50 percent.

Adolescent females, who have liver failure before transplant, usually do not have a normal menstrual cycle. This does not mean that they cannot become pregnant during this time. After transplant and the liver has returned to a normal function (usually within two to four months), menstrual cycles should return to normal. We recommend that women over the age of 16 see a gynecologist on an annual basis. Because of the immunosuppressant medicines, there is an increased risk of cancer.

To avoid becoming pregnant, we usually recommend a barrier method (sponge, jelly, and diaphragm) plus a condom as a birth control. Condoms should also be used to protect both the man and the woman against any sexually transmitted infection. The possible side effects of oral contraceptives (the Pill) include increasing blood pressure and increasing the chance of blood clots. Therefore, they are not the first suggestion as a birth control method. Females will be referred to a gynecologist who can suggest suitable methods of birth control according to individual needs.

Each female is different when it comes to the effects of pregnancy and the health of the baby. A woman with a liver transplant has a much higher rate of complications in pregnancy. However, her decision about pregnancy depends on how strongly she and her partner feel about having a family. Many women with stable transplants can have safe pregnancies. Consult with your nurse coordinator/doctor before making this decision.
**Sexually Transmitted Disease (STDs)**

Everyone that is sexually active should be aware of and know about sexually transmitted infections (STIs). STIs can be passed from person to person in the following ways: oral, vaginal, or anal (rectal). STIs can even be passed through kissing and intimate touching, or even by sharing needles, body piercing, or tattoos. The most common forms of STIs are Chlamydia, herpes, HPV (Human Papillomavirus), syphilis, hepatitis B, and HIV. People with STIs often have no symptoms and can pass the infection to another person without being aware of the STI. Most STIs can be treated and cured, but there are some that treatment can only help the symptoms. If the STI is left untreated, it could potentially cause serious health problems.

**How to prevent STIs:** The best way to prevent STIs is to abstain from oral, vaginal, or rectal sex and **NEVER** share needles. If you choose to participate in any form of sex, **ALWAYS** use a latex condom. **Prevention is the BEST practice!**

If you think that you may have an STI, seek medical care at once. Early treatment can prevent long-term complications. If you do have an STI, be sure to tell your partner, so treatment can be given to that individual also.

**Tattoos and Piercings**

Tattoos and body piercing are popular with young adults. The transplant team **ONLY** recommends ear piercing.

There is some information that you should know before getting any tattoos or body piercings.

- Potential risk for a serious infections such as hepatitis B, C, and HIV (the virus that causes AIDS)
- Only use a professional tattooist or piercer. **DO NOT** try to do either a tattoo or body piercing yourself or by a friend
- If a tattooist or piercer is not willing to talk to you regarding the sterilization process, then do not let that person do the tattoo or piercing
- It is **OK** for you to ask to see their sterilizing equipment and how they process their equipment.
- Before getting a tattoo or piercing, you should watch the technician open the sterile instruments
- **NO** tattoo inks should be shared or reused between customers
• Do not get a tattoo or body piercing from a person that has been drinking or using drugs.
• Remember, a tattoo is a big decision and will be with you forever!

The Transplant Center DOES NOT recommend either tattoos or body piercing.

Drugs, Alcohol or Tobacco Products

It is the recommendation of the transplant team that ALL patients should refrain from using all forms of alcohol, street drugs, tobacco products, or other potential harming drugs (such as huffing inhalants). The use of these products can lead to poor health and fatal damage to your body.

Medic-Alert Identification

It is recommended that your child wear a Medic-Alert bracelet or necklace. Your nurse coordinator will provide you with a form. The Medic-Alert Identification is ordered through the Kidney Foundation for a small fee. If your child would like one that is “fancier,” you can order this for him/her at a higher cost. The following information is needed:

• Child’s Name
• University of Michigan
• Liver Transplant
• Name of Transplant Hepatologist
• Phone number (734) 936-6267

You Should Know

Be sure to inform your child’s personal physician of all the medicines that your child is taking, since some drugs cannot be taken with immunosuppressive medicines.

Your Local Doctor

It is a good idea to have a pediatrician, internist, general practitioner, or family doctor see your child for routine medical issues other than your liver transplant. Always make sure you inform us if you change your child’s personal physician, since we will be keeping in touch with him/her every time you come to the Liver Transplant Clinic or are in the hospital.

Your nurse coordinator can provide you and your physician a list of all medicines that interact with the immunosuppressive medicines.