After Your Child’s Liver Transplant
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Dear transplant recipient and family,

Congratulations! Your child has had a liver transplant. This booklet tells you and your family what you need to know to take care of the transplant. You and your family are the only ones that can do this.

While you are in the hospital you will have many questions about your transplant. Your transplant team will help you answer those questions. This transplant booklet is yours to keep. It includes information about staying healthy, food to eat, medicines, signs of problems and what to do about them, and getting ready to go home. There is room in this booklet for you to write notes and questions. The information here will guide you when you get home. However, you may also call us if you need to speak with someone.

Sincerely,

Your Liver Transplant Team
Learn what you need to know before you go home

The Journey Board is a tool we use to make sure you understand everything that is important to care for your child. Every box on the Journey Board is something you may need to know about, such as, “I can tell you about my child’s medicines.” We will talk to you about your child’s care every day. Then we will ask you to teach back to us the items on the Journey Board. This is not a test. This is to make sure we explained everything you need to know in ways you understand. If we were not clear, we will find another way to explain it. We want to make sure you know what to do, and how to do it.

If you don’t understand something about your child’s care, ask us. If English is not your first language, and you would understand us better if you heard it in another language, ask for an interpreter.
After the transplant

It would be great if a child who gets a liver transplant does not have any problems. However, most people who get liver transplants have at least one complication. Since we know this, the Transplant Team closely watches your child for problems. Some of the problems we may see include:

— Rejection
— Infection
— Blood clot (thrombosis) of a major vein or artery going to or coming out of the liver
— Biliary tract obstruction
— Liver disease returns

These problems can be serious and need to be treated quickly. A child who gets one of these complications may have to go into the hospital for treatment.

I can tell you what rejection is.

The body keeps you healthy with a defense system that destroys foreign proteins, like viruses and bacteria. This system would attack the new liver like it was an invader. Rejection happens when your child's immune system tries to destroy the new liver. If we notice liver rejection when it first begins, we can treat it right away. Children rarely lose liver function and need another transplant.

The results of blood tests will tell us if your child is starting to reject the liver.

How will the doctor know if my child is rejecting the liver?

When the body attacks the liver, it is called a rejection episode. Rejection can occur at any time after transplant, but it is very common in the first three months after transplant.

Your child will have blood tests to check liver function. If the tests results become abnormal, we will give your child an abdominal ultrasound. This will let us see if the blood is flowing well to and from the liver, and if the bile ducts are working well.

If the ultrasound shows no problems, but the liver function blood tests are still not normal, your child will need a liver biopsy. If the biopsy shows your child is
rejecting the liver, treatment will be needed.

At first, rejection is treated with higher doses of steroids. Blood will be tested every day. If the liver tests do not improve, the child may need another liver biopsy and stronger medicine. This will usually treat the problem, but sometimes, not often, the child may need another liver transplant.

What can we do to help prevent rejection of the liver?

The medicines your child takes after transplant help prevent rejection. Your child needs to take these medicines every day to keep his or her body from rejecting the transplanted liver. If your child stops taking these medicines, the new liver can fail.

These are called immunosuppressive or anti-rejection medicines. These medicines keep your child's immune system working at a low level. This is good for the liver, but when the immune system is not as strong, your child has a greater chance of getting an infection.

If your child has any signs or symptoms of rejection, call the Transplant Team right away.

I can tell you what infection is and what the symptoms are.

Infections can be caused by viruses, bacteria, or fungus. The signs and symptoms of infection include:
— Fever greater than 101.4 F or 38 C
— Chills
— Irritability
— Tired or fatigued
— Loss of appetite
— Sick to the stomach or throwing up
— Loose stools
— Stomach pain
— Cough
— Sore throat
— Stuffy or runny nose
— Shortness of breath
— Dizziness or light-headedness
— The transplant incision is swollen, tender, open, or draining
— Headache
— Painful urination

Infections are more likely when your child is taking medicine that keeps the body from rejecting the liver. Germs which do not bother people with normal immune systems can infect people taking these medicines. They take the opportunity when it is presented to them, so they are called opportunistic infections.

Here are some of the germs that are seen in children who have transplants.

**Viruses**

**CMV or Cytomegalovirus**

The risk of getting a CMV infection is highest in the first 3 months after transplant. CMV can affect the eyes, lungs, stomach, and esophagus.

**Treatment for CMV**

The child is treated with an IV medicine called ganciclovir (or Cytovene) or valcyte (Valganciclovir), a medicine given by mouth.

**EBV or Epstein-Barr Virus**

EBV can cause a disease known as PTLD or post transplant lymphoproliferative disease. Symptoms may start with feeling tired, weight loss, and fever. Another sign is swollen lymph nodes. EBV can also infect the intestines, causing belly pain, changes in bowels, or bloody stools.

To be sure it is PTLD, a child with the symptoms may also have a:
— CT scan to look at swollen lymph node or a mass.
— Biopsy of the swollen node or mass
— Endoscopy
— Bone marrow aspiration

**Treatment for EBV**

The child is sometimes admitted into the hospital, given an IV, and treated with a medicine called ganciclovir (or Cytovene). The child’s doses of immunosuppressive
medicines may be lowered. Hematology doctors may be consulted, and other medicines may be given. The child will need to see the Transplant Team often while being treated.

Herpes

Herpes viruses usually infect the skin as cold sores (herpes simplex) or shingles (herpes zoster). Herpes cannot be cured, but it can be treated. Depending on the infection, treatment may be applied to the skin, by mouth, or by IV.

Fungal Infections happen less often, because we give the medicine fluconazole to prevent them after liver transplant.

PCP or Pneumocystis carinii Pneumonia

PCP is a yeast-like fungal infection. Since immunosuppressive medicines can put children at greater risk for PCP, they are given an antibiotic (usually Bactrim or Sulfamethoxazole/Trimethoprim) that helps to prevent it.

Candida

Candida is yeast that can cause infections. When it infects the mouth or throat it is called thrush. Thrush causes white, raw areas, tenderness or pain in the mouth or throat, a white film on the tongue, and trouble swallowing. Candida can also infect the tube that goes from the throat to the stomach (the esophagus). It is treated with medicine by mouth or IV.

If your child has any signs or symptoms of infection, call the Transplant Team right away.

I can tell you what is done to prevent infection.

Your child will get medicine to prevent infections. In addition, here are some other things you and your family can do:

— Germs enter the body when hands touch the nose, mouth, or eyes. Your child should keep hands away from the face and mouth.
— Your child and everyone in contact with your child should wash hands often for
15 seconds with soap and water, or use hand sanitizer.
— Wash hands after coughing or sneezing, and throw tissues into the trash right away.
— For the first 6 weeks after the transplant, your child should stay away from crowded places, such as malls, movie theaters, and classrooms.
— Stay away from people who are sick. Ask friends and family to stay away when they are sick.
— Keep your child’s body clean. Wash any cuts or scrapes with soap and water.
   See a doctor to treat more serious wounds. Your child should wear shoes (not flip flops or sandals) to avoid cuts on the feet.
— Brush and floss your child’s teeth two times each day.
— If someone you live with gets sick, your child has already been exposed to his or her germs. Do not share dishes, cups, glasses, forks, or spoons at the same time. Your child should wash his or her hands often. If your child shows the same symptoms as the sick family member, call the Transplant Team right away.
— If your child has had close contact with someone who gets or has been near someone who gets chicken pox, measles, or mumps, call the Transplant Team right away.
— Immunizations also help prevent infections. 3 months after the transplant your child may be able to have a flu shot. After transplant, your child should not receive any live vaccinations, such as MMR, Varicella, or Nasal Flumist. The live virus can cause serious infections. Your child will need to get a flu shot every year.

I can tell you why hand washing is important.

One of the best things everyone can do to prevent infection is to wash hands well and often. This keeps germs on your hands from infecting you and others.

• Wash your hands:
  — before and after cooking, or preparing food, snacks, or bottles
  — before eating meals and snacks
  — after using the toilet or helping a child use the toilet
  — after diapering a child
  — after you touch things that have body fluids or wastes on them (like blood, urine, stool, saliva, or fluids that come from the nose, eyes, or sores)
  — before and after giving medicine, changing bandages, or doing another medical procedure
— after playing with animals
— after cleaning up after animals
— after caring for a sick child or animal
— after coughing, sneezing, or wiping your nose
— whenever your hands are dirty

• Teach your child how to wash his or her hands. Remind young children to wash their hands.

• Check your child’s hands before meals to make sure they have been washed well.

**Medicine**

I can tell you what medicines our child will need to take.
I can tell you why our child has to take the medicines.
I can tell you what medicine side effects to look for.
I can tell you where we will get the medicines.
I can tell you where to store the medicines at home.

After the transplant, your child will need to take medicine every day for the rest of his or her life. This can be hard to do at times, but it is very important. Your child needs to take medicines every day to keep the body from rejecting the new liver. These medicines are called immunosuppressive medications. Your child also needs to take medicine every day to fight off germs to prevent infections. Some children need other medicines, too, to stay healthy.

Members of your Transplant Team will teach you about your child’s medicines, and you will get a written list. Before you leave the hospital, you will be able to tell a team member the names and reasons for each medicine, how much to give, what side effects to look for, and what to do if they occur. Medicine doses may be changed over time, based on results of lab tests.

You must keep your child’s current medicine list with you and the child at all times.

Every medicine has some possible side effects. Your child will not get every side effect, but we want you to know what to look for and what to do if you see one. If you want to give your child any medicine not on this list, check with the Transplant Team first. Mixing drugs that don’t work well together can cause serious problems.
Here is information about some of the medicines your child may be given.

**Prograf**

*Other name:* Tacrolimus

**Why is it given?**
This medicine keeps your child’s body from rejecting the new liver. Another word for this is immunosuppressant.

**What to do**
- Give this medicine at the same time every day.
- If you give this medicine twice a day, give it every 12 hours (such as 8 am and 8 pm)
- You may give this medicine with or without food.
- If you give this medicine with food, always give it with food.
- Do not let your child eat grapefruit or drink grapefruit juice.

**Things to know about this medicine**
When your child is having blood drawn, do not give the morning prograf (Tacrolimus) dose until after blood is drawn.

**What should I do if my child misses a dose of this medicine?**
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

**Possible side effects**
- headaches
- shaking that the child can’t stop (tremors)
- loose stool (diarrhea)
- sick to the stomach (nausea)
- throwing up (vomiting)
- loss of appetite
- hair loss
- trouble sleeping
- numb or tingling hands and feet
- kidney damage
- high blood sugar (diabetes)
- high potassium levels
- low magnesium levels
- seizures
- increased chance of getting an infection
- wounds take longer to heal than usual
Neoral

Other name: Cyclosporine

Why is it given?
This medicine keeps your child’s body from rejecting the new liver. Another word for this is immunosuppressant.

What to do
• Give this medicine at the same time every day.
• Do not let your child eat grapefruit or drink grapefruit juice.

If your child take the liquid form of Neoral:
• Use a glass or hard plastic cup to mix the medication with milk or orange juice.
• Do not use grapefruit juice
• Stir the medicine with a metal spoon.

Things to know about this medicine
Make sure the medicine you get when you refill looks like the medicine you’ve gotten before. This medicine comes in different strengths, and you want to get the right one every time.

When your child is having blood drawn, do not give the morning cyclosporine dose until after blood is drawn.

Possible side effects
• more hair grows on face
• gums grow bigger
• high blood pressure
• trouble sleeping
• headaches
• shaking that the child can’t stop (tremors)
• numb or tingling hands and feet
• loose stool (diarrhea)
• sick to the stomach (nausea)
• high potassium levels
Sirolimus

Other names: Rapamune or Rapamycin

Why is it given?
This medicine keeps your child’s body from rejecting the new liver. Another word for this is immunosuppressant.

Things to know about this medicine
When your child is having blood drawn, do not give the morning sirolimus dose until after blood is drawn.

Possible side effects
• triglyceride and cholesterol levels go up
• wounds take longer to heal than usual
• pimples on the face
• platelet count goes down
**Cellcept**

**Other name:** Mycophenolate Mofetil

**Why is it given?**
This medicine keeps your child’s body from rejecting the new liver. Another word for this is immunosuppressant.

**What to do:**
- Can be taken with food.
- Do not take this medicine within 2 hours of a magnesium supplement.

**Possible side effects**
- headache
- loose stool (diarrhea)
- sick to the stomach (nausea)
- throwing up (vomiting)
- not hungry (loss of appetite)
- low white cell count
- low platelet count
- increased chance of getting an infection

**Call your doctor right away if your child:**
- has any unusual bruising or bleeding
- This medicine is not safe for pregnant women. It can harm the developing baby.
  Call the transplant center if you think your child is pregnant.

**What should I do if my child misses a dose of this medicine?**
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the Transplant Team.
**Prednisone**

**Other names:** Prednisolone, Prelone or Orapred

**Why is it given?**
Prednisone is given to help keep your body from rejecting your new liver. It is a steroid and an immunosuppressant.

**What to do:**
- Give prednisone with food. If given without food it could upset the stomach.

**What should I do if my child misses a dose of this medicine?**
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

**Possible side effects**
- hungry
- trouble sleeping
- sweating
- muscle weakness
- mood changes
- trouble healing
- pimples
- swelling; holds fluids
- face looks fatter
- stomach ulcers
- high blood sugar
- high blood pressure
- changes in eye sight
- hair gets thinner
- sensitive to the sun
- weak bones if high doses are taken for a long time

**Call your doctor right away if your child:**
- throws up blood
- has bloody stool
Bactrim

Other names: Septra, sulfamethoxazole with trimethoprim

Why is it given?
Bactrim is given to treat or prevent certain lung infections (pneumonia).

Things to know about this medicine
• Children allergic to sulfa should not take Bactrim. Tell your child’s doctor if your child is allergic to sulfa. If your child has allergies to sulfa another medicine will be prescribed.
• This medicine makes the skin more sensitive to the sun. Always wear sunscreen when taking this medicine.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• sick to the stomach (nausea)
• throwing up (vomiting)
• not hungry (loss of appetite)
• headache
• upset stomach
• rash
• itching
• sensitive to the sun
• low white blood cell count

Call your doctor right away if your child gets a bad rash, especially around the eyes or mouth.
Cytovene or Valcyte

Other names: ganciclovir or valganciclovir

Why is it given?
Ganciclovir is used to prevent CMV (cytomegalovirus) or EBV (Epstein Barr Virus) disease. Ganciclovir may keep your child from getting CMV or make the illness milder. Valganciclovir is the liquid form of ganciclovir.

Things to know about this medicine
• It is best to take this medicine with food.
• This medicine will be given for 3 months after the transplant.
• If you child gets a CMV or EBV infection, this medicine will be given again.
• If your child is treated for rejection, this medicine will be given again.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• fever
• rash
• shaking that the child can’t stop (tremors)
• confusion
• low white cell count
• kidney damage
• upset stomach (if given by mouth)
Diflucan

Other name: fluconazole

Why is it given?
This medicine is given to treat or prevent an infection caused by a fungus, such as yeast and Valley Fever. Another word for this is antifungal.

Things to know about this medicine
• Do not change this medicine unless your transplant doctor tells you to.
• This medicine affects the way your child’s body handles the medicine Prograf.
• This medicine may make birth control pills (oral contraceptives) not work well. A person taking this medicine should not take birth control pills.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• loose stool (diarrhea)
• sick to the stomach (nausea)
• throwing up (vomiting)
• rash
• headache
• not hungry (loss of appetite)
• dizzy
• food may taste different
You may ask your nurse or doctor for the handout, Taste Changes, #950
Baby Aspirin

Why is it given?
This medicine is given to prevent blood clots from forming in the blood vessels that supply the liver with blood.

Possible side effects
• upset stomach
• bleeding
• bruising
• body rash

Actigall

Other name: Ursodiol

Why is it given?
This medicine improves the flow of bile through the liver. It will help to prevent gallstones.

Possible side effects:
• loose stool (diarrhea)
• metallic taste in mouth.

You may ask your nurse or doctor for the handout, Taste Changes, #950

Prevacid

Other name: Lansoprazole

Why is it given?
This medicine helps prevent stomach ulcers caused by steroids.

Possible side effects:
• headache
• loose stool (diarrhea)
• sick to the stomach (nausea)
• throwing up (vomiting)
What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• hard dry stool (constipation)
• loose stool (diarrhea)
• sick to the stomach (nausea)
• throwing up (vomiting)

Call your doctor if your child has stomach aches or heartburn. Your child may need a different antacid.

If your child has other medical problems or develops other medical problems, other medicines will be given in addition to the liver transplant medicines. For example, some children have diabetes or high blood pressure.

Your child may need antibiotics before having some types of dental work. At least one week before your child’s dental appointment, tell the Clinical Transplant Coordinator. If a prescription for an antibiotic is needed, the transplant coordinator will call your pharmacy with the prescription.
Side effects of medicines

It is not easy to get used to the new medicines your child needs to take to prevent rejection and infection. Your child needs to take several medicines every day, and they have side effects. Some of these side effects change the way your child looks and the way your child feels about his or her body.

- Will my child get every side effect listed?
Your child will not get every side effect of every medicine. However, every child gets some side effects. If you know what to expect, you will know what is happening. Talk to your child’s transplant team to learn how deal with these side effects.

Changes you might see

- **Skin Changes**
Your child may get pimples on the face (acne). Wash this area twice a day. Deodorant soap (like Dial) will clean and help dry the extra oils on the skin. Do not use soap with oil or cream. These can make acne worse. If acne is a problem for your child, talk to the transplant team.

Your child may have dry skin. Use a mild soap, like Ivory. Use a bath oil, like Keri. After a bath or shower, put lotion on the skin. Skin problems usually get better when the doses of medicines after transplant are lowered.

- **Hair Changes**
Your child’s hair may get weaker and break more easily. After starting medicine after the transplant, wait a few months before you dye or perm your child’s hair.

- **Mouth Changes**
Your child’s gums may bleed and teeth may become more sensitive to hot and cold foods and drinks. Your child must brush and floss twice a day to prevent infection. Take your child to the dentist twice a year.

- **Mood changes**
Your child may be more emotional. Your child may cry or get upset easily. Tell family and friends this may be caused by the new medicine. Help your child talk about feelings to family, friends and the transplant team. Discipline your child the same way all the time, so he or she knows what to expect.
• **Trouble Sleeping**

Your child may have problems falling asleep or staying asleep. Your child will be more tired at night if he or she does not nap during the day. If you are concerned about your child’s trouble sleeping, talk to the transplant team.

**How will I get my child’s medicines?**

Your transplant coordinator and social worker will help you find a drug store (pharmacy) that works with your insurance company. Before your child leaves the hospital, your child’s home medicines will be brought to the hospital room. The transplant pharmacist and the transplant coordinator will talk to you about each of the medicines before you go home.

**Medications in tablet or capsule form that should not be split or crushed**

- Sirolimus (Rapamune)
- Mycophenolate (Cellcept/Myfortic)
- Valganciclovir (Valcyte)

**Where do I keep my child’s medicines at home?**

Keep medicine in a dry place, out of reach of children.

**How to store liquid medicine**

<table>
<thead>
<tr>
<th>Medicine</th>
<th>How to Store</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tacrolimus (Prograf liquid)</td>
<td>Room temperature</td>
</tr>
<tr>
<td>Mycophenolate (Cellcept liquid)</td>
<td>Room temperature</td>
</tr>
<tr>
<td>Sirolimus (Rapamune liquid)</td>
<td>Refrigerator</td>
</tr>
<tr>
<td>Cyclosporine (Neoral)</td>
<td>Room temperature</td>
</tr>
<tr>
<td>Prednisolone (Orapred)</td>
<td>Refrigerator or Room temperature Check with pharmacy</td>
</tr>
<tr>
<td>Valganciclovir (Valcyte)</td>
<td>Refrigerator</td>
</tr>
<tr>
<td>Sulfamethoxazole/Trimethoprim (Bactrim liquid)</td>
<td>Room temperature</td>
</tr>
<tr>
<td>Fluconazole (Diflucan liquid)</td>
<td>Room temperature</td>
</tr>
<tr>
<td>Amlodipine (Norvasc liquid)</td>
<td>Refrigerator</td>
</tr>
<tr>
<td>Ursodiol (Actigal liquid)</td>
<td>Refrigerator</td>
</tr>
<tr>
<td>Lansoprazole (Prevacid liquid)</td>
<td>Refrigerator</td>
</tr>
</tbody>
</table>
I can tell you what to do if we miss a dose of medicine.

• **What do I do if my child misses a dose of medication?**

If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

• **What happens if my child doesn’t take these medications every day?**

Taking too little medicine may let your child’s body reject the transplanted liver. Too much medicine may hurt the liver and make it hard for your child’s body to fight infection.

Do not stop, start, or change your child’s medication unless your doctor or transplant coordinator tells you to.

• **What happens if my child is sick and cannot take his or her medicine?**

If your child is sick to the stomach or is throwing up and cannot take medicine, call your doctor or transplant coordinator.

If your child has more than 4 loose stools in 24 hours, call your doctor or transplant coordinator.

• **Can my child take medicine not prescribed by the transplant doctor?**

Your child’s medicine needs change after transplant.
• Do not give your child any medicine, supplement, or herb until the transplant doctor or coordinator says it is all right. They may interfere with your child’s transplant medicine.
• If any other doctor prescribes medicine for your child, tell your transplant doctor or coordinator before you give it.
• Do not give your child any of these medicines unless your transplant doctor or coordinator says it is all right:
  — medicine to treat loose stools or diarrhea
  — cold medicine, like nose sprays or decongestants (like Sudafed)
Some medicines or grapefruit can cause dangerous drug interactions when taken with the immunosuppressive medications. If your child’s pediatrician or other doctor prescribes any new medicines for your child, call the transplant team or transplant pharmacist to discuss any new medications before giving them to your child.

**If your child has fever or pain,** you can give regular strength acetaminophen (Tylenol) in the right dose for your child’s age and weight.
Ask your nurse or doctor for the handout, *How Much Acetaminophen to Give* #1038

If you give the acetaminophen for more than 48 hours and your child still has symptoms, call
— your Clinical Transplant Coordinator at (602) 933-5134 if the clinic is open
— Or call the on-call GI provider through the hospital operator at (602) 933-1000 if it is after 4:30 pm, or a weekend or holiday.

**Do not give Advil, Motrin, ibuprofen, ketoprofen, naproxen, Aleve or aspirin for fever or pain.** These can affect kidney function.

The clinical transplant coordinator will call you with your child’s lab results and to let you know if the doctors want to make any changes to your child’s medication.

**What do I do if we run out of medicine when we are home?**

Missing a dose of immunosuppressant may affect your child’s liver and increase risk of rejection. Make sure you have enough medication to last at least 1 week. Call drug store for refills as soon as you see you are running low, because it takes the pharmacy time to make some of these medicines.
If there are no refills left, ask them to call the Transplant Center at 602-933-5134.
At your next appointment, you can ask your doctor or Transplant Coordinator for new prescriptions.

If you run out of medicine, call transplant team right away. You may have to go to the Emergency Department of the hospital for medication.

For more information, ask for the handout, *Always Have Medicine* #909
What do I do if I cannot pay for my child’s medicine?

Your child must always have his or her medicine. If you do not have money to pay for refills, before you run out of medicine call your social worker at the transplant center for help.

**Over-the-Counter Medicines**

If a medicine is not listed here as safe, ask your Transplant Team before you give it to your child.

Your child should not take anything with pseudoephedrine, phenylephrine, phenylpropanolamine, ibuprofen, naproxen, or ketoprofen. Avoid combination or multi-symptom cold, sinus, and flu products (Triaminic multi symptom products, Dayquil, Nyquil).

### OVER THE COUNTER MEDICATIONS

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Safe</th>
<th>Not Safe</th>
</tr>
</thead>
</table>
| Sneezing, Itching and Runny Nose | ▪ Loratadine (Claritin)  
▪ Fexofenadine (Allegra)  
▪ Cetirizine (Zyrtec)  
▪ Cromolyn (Nasacrom)  
▪ Diphenhydramine (Benadryl)  
▪ Chlorpheniramine (Chlor-trimeton) | ▪ Loratadine + Pseudoephedrine (Claritin-D)  
▪ Fexofenadine + Pseudoephedrine (Allegra-D) |
| Nasal and Sinus Congestion     | ▪ Oxymetolazone nasal spray/drops (Afrin or Allerest 12 hour Nasal Spray)  
▪ Little noses saline spray/drops  
▪ Sodium Chloride nasal spray (Ocean spray) | ▪ Pseudoephedrine (Sudafed, Afrin tablets)  
▪ Phenylephrine (Sudafed PE)  
▪ |
| Cough                          | ▪ Dextromethorphan (Delsym,)  
▪ Dextromethorphan/Guaifenesin (Robitussin DM)  
▪ Guaifenesin (Robitussin) | ▪ Dextromethorphan + Guaifenesin +Phenylephrine (Robitussin CF)  
▪ Acetaminophen + Diphenhydramine + Phenylephrine (Robitussin Nighttime Multi Symptom Cold Relief) |
I can tell you our child’s fluid and diet plan.

The Registered Dietitian on your Transplant Team will teach you about your child’s fluid and diet plan and answer all your questions.

Your child will be on a low microbial diet.
— Drink bottled water.
— Do not eat raw fish or rare meat.
— All fruits and vegetables must be washed, dried, and peeled.
— Do not eat grapefruit or drink grapefruit juice. It interacts with tacrolimus.

To learn more, ask your Transplant Team for the handout, Low-Microbial Nutrition Therapy.

Will my child have any diet restrictions after transplant?
Most children will be able to eat more foods than they could before transplant.

What can my child eat after the liver transplant?
Transplant medicines may increase your child’s appetite. Food may taste better than it used to. Give your child a lot of different foods to try.
Your child can now enjoy many fruits, vegetables, whole grains, and low fat dairy products. Eating a lot of different foods will help your child get all the vitamins, minerals, and protein needed for wound healing, recovery from surgery, and to help fight infections. Children may like foods they did not like before the transplant.

What foods should my child stay away from?
If your child has high blood pressure, he or she should stay away from food high in salt or sodium.

I can tell you our child’s fluid goal

How much water does my child need to drink?
It is important that your child has enough fluids. The best fluids have no caffeine or sugar, such as water and skim milk, or flavored waters without sugar, such as Crystal Light.
Nutrition after a liver transplant

In the first months after a liver transplant, you or your child will be recovering from the stress of surgery. It is important to take in enough protein, calories, vitamins and minerals to help wounds heal and prevent muscle loss.

If your child feels full after eating part of a meal, offer smaller meals 6 times a day instead of 3 full meals.

Talk to the Transplant Team if your child does not want to eat, feels sick to the stomach, or has bowel problems.

Calories

You or your child should eat enough calories to slowly gain back weight and build muscle. Choose foods that are dense with nutrients, like milk, cheese, whole grains, fruits, and vegetables. Keep away from foods that have few nutrients, like soda and candy. If your child has a poor appetite, tell the Transplant Team.

Protein

Protein is important for healing and muscle gain. High doses of prednisone given after transplant breaks down muscle, so extra protein is important.

Every day you should eat some foods that are high in protein.

Animal-based proteins

Fish
Poultry, like chicken or turkey
Egg whites or egg substitute
Eggs — Your child should not eat more than 4 yolks each week
Dairy products, like milk, cheese, or yogurt
Red meat, like beef, pork, or veal

Plant-based proteins

Unsalted nuts
Peanut butter or other nut butters
Beans, lentils, and split peas, including kidney, black, pinto, navy beans
Soy products like tofu, soy milk, tempeh
Seitan, which is wheat gluten
Choose protein lower in fat more often and cook them in ways that use less fat, such as grilling or baking.

**Sugar**

Prednisone can make your body take less sugar into the body’s cells, so there is more sugar left in the blood. This may cause you or your child’s blood sugar (glucose) level to rise. This condition is called high blood sugar, hyperglycemia, or steroid-induced diabetes. We can treat this side effect of prednisone by limiting simple carbohydrates and sugars.

Your child should get only small amounts of these simple sugars:
— Sugar
— Molasses
— Doughnuts, pastries, sweet rolls
— Pies, cakes, cookies
— Candy, chocolate candy
— Ice cream, frozen yogurt, sherbet
— Honey
— Syrups, such as corn syrup or maple syrup
— Jam, jelly, marmalade
— Soft drinks
— Other sweetened beverages, like fruit juice or sweet tea
— Jell-O

Your child may use diet soda, and unsweetened or artificially sweetened jams, jellies, and marmalade. The best fluids have no caffeine or sugar, such as water, skim milk, flavored water or Crystal Light.

**If your child has high blood sugars:**
— Feed your child at least three meals each day at regular, evenly spaced times. Avoid skipping meals. Every meal and snack should include a high quality protein. For example, a meal can be a turkey sandwich on whole grain bread with a salad. A snack could be ½ cup of 1% cottage cheese with fresh fruit or berries.
— Foods with carbohydrates should be high in fiber. Choose to eat whole grain products, lentils, peas, beans, and vegetables. Avoid white breads. Choose cereals with at least 5 grams of fiber per serving.
— Limit fruit to one serving per meal. One serving is the same as ½ cup or one
medium sized piece of fruit.
— Read food labels. Avoid foods with added sugars list in the ingredients.
   Different names for sugars include fructose, maltose, dextrose, corn syrup,
   high fructose corn syrup, honey, raw sugar, and brown sugar.

If you want to learn more, ask your child’s dietitian questions or ask for the
handout, **Using the Nutrition Facts on the Food Label.**

**Sodium or salt**

Sodium is salt. Surgery and medicine such as prednisone can cause the body to
hold on to (retain) sodium and water. Too much fluid in the body can increase
blood pressure.

One way to avoid holding on to sodium and water is to eat less salt. The easiest
way to do this is to not add salt and not eat foods which are made with added salt.
This is called the **No Added Salt diet**, which keeps the sodium down to less than
3000 mg each day.

**No Added Salt Diet**

• Do not add salt to food.
• Do not cook with salt. Use herbs and spices for flavor.
• Read the label on all the foods you use. Even foods that don’t taste salty may
  have lots of salt. Look at foods that say, “no salt added.”
• **Avoid or limit these foods:**
  — High salt soup. Most canned, dehydrated, and bullion soups are high in salt.
    Consider soup that says it is low in sodium.
  — Processed meats like ham, bacon, sausage, frankfurters, cold cuts (like bologna,
    salami, pastrami), corned beef, smoked or dried meat or fish, canned meat,
    salt pork.
  — Processed or canned foods. Cheese, packaged meals, most canned foods, frozen
    vegetables with sauce, pickles, sauerkraut, vegetable juice.
  — Food in restaurants. One meal often has more than 3000 mg of sodium.
  — Salted snacks. Crackers, pretzels, potato chips, corn chips, tortilla chips,
    popcorn, nuts, seeds.
  — Condiments and seasonings. Ketchup, mustards, horseradish, sauces (like
    barbecue, chili, steak, Worcestershire), MSG (monosodium glutamate), soy
    sauce, meat tenderizers, pickle relish, olives, garlic salt, onion salt, salad
    dressing.
Potassium

Some medicine, like Cyclosporine and Tacrolimus, can make blood potassium levels go up. Other medicines, like furosemide, can make blood potassium levels go down. Potassium blood levels that are not right can cause problems with muscle and the heart. Your child’s health care team may manage your child’s blood potassium levels with medicine or diet.

Here are some foods **high in potassium**. Eating more of these foods would raise blood potassium levels. Eating fewer of the foods would lower blood potassium levels. If your child’s diet needs to control potassium carefully, your child’s dietitian will give you a longer list.

**Fruits**
- Apricots
- Avocados
- Bananas
- Dried fruit
- Melons
- Nectarines
- Oranges
- Peaches

**Vegetables**
- Leafy greens
- Pumpkins
- Potatoes
- Split peas
- Dried beans
- Lentils
- Tomatoes

**Juices**
- Orange juice
- Prune juice
- Tomato juice
- V-8 juice

**Other food**
- Milk and dairy
- Peanut Butter
- Nuts
- Chocolate
Magnesium

Some medicine, like Tacrolimus and diuretics, can make blood magnesium levels go down. Magnesium blood levels that are too low can cause changes in heart rhythm, muscle cramps and weakness, tremors, confusion, depression, and high blood pressure. Your child’s health care team may manage your child’s blood magnesium levels with medicine or diet.

Here are some foods **high in magnesium**. Eating more of these foods would raise blood magnesium levels. Eating fewer of the foods would lower blood magnesium levels. If your child’s diet needs to control magnesium carefully, your child’s dietitian will give you a longer list.

**Whole grains**
- Quinoa
- Millet
- Buckwheat
- Brown Rice
- Bran (rice, wheat, and oat)
- Rye
- Whole wheat bread

**Vegetables**
- Dark leafy greens, like spinach or chard

**Beans**
- Black beans
- Soy beans
- Navy beans
- Pinto beans
- Kidney beans
- Lima beans
- Lentils

**Nuts and seeds**
- Pumpkin seeds
- Sesame seeds
- Sunflower seeds
- Flax seeds
- Brazil nuts
- Almonds
- Cashews
- Peanuts
Fish
- Salmon
- Halibut

Fruit
- Dates
- Bananas
- Raisins
- Avocados

Dairy
- Yogurt
- Milk

Other foods
- Dark chocolate
- Molasses

Calcium

After transplant, children and teens should take in enough calcium every day. How much calcium depends on his or her age.

<table>
<thead>
<tr>
<th>Age</th>
<th>Calcium requirement (mg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 3 years</td>
<td>700 mg/day</td>
</tr>
<tr>
<td>4 – 8 years</td>
<td>1000 mg/day</td>
</tr>
<tr>
<td>9 – 18 years</td>
<td>1300 mg/day</td>
</tr>
</tbody>
</table>

Dairy products are a good source of calcium. Each 8 ounce glass of milk has about 300 mg of calcium. If your child does not get enough calcium from food, talk to the dietitian about calcium supplements.

If your child needs to be tube fed at home, we will teach you how to do this. You will be able to practice this in the hospital and have time to ask questions.

Immunizations

Your child should not have any immunizations until 3 months after transplant. The high dose of medicine that suppresses your child’s immune system could keep the immunization from working.

After transplant, your child should not receive any live vaccinations, such as MMR,
Varicella, and Nasal Flumist. The live virus can cause serious infections.

Your child and everyone in the family should get flu vaccines every year in the fall, at the beginning of flu season.

If you have a question about immunizations, ask your Transplant Coordinator.

**I can tell you what activities our child can participate in.**

Right after surgery your child may not have a lot of strength and energy for activities. Over time, this will improve.

**What activities are good for my child?**

After leaving the hospital, your child should bathe, get dressed, eat and walk every day. Walking every day will help your child get stronger. When your child is tired, he or she should take a nap.

**What activities should my child not do?**

For the first 6 weeks after the transplant, your child should not lift anything weighing more than 10 pounds. Your child should not do a lot of bending, stretching, or straining. Your child should not do things that bounce the body, like horseback riding, aerobics, motorcycle riding, or jogging.

**When can my child participate in sports?**

It can take 3 to 4 months for your child to fully heal from transplant surgery. After healing, if your child wants to start football, martial arts, wrestling, boxing, hockey, or lacrosse, ask your child’s Transplant Team.

**Can my child go swimming? Can my child go in a hot tub or Jacuzzi?**

Children with IV lines or catheters that come out of the body cannot safely go into the water to swim or soak. Children with incisions that are still healing cannot do this, either. When the tubes are out and the incision is healed, ask your child’s transplant team if it is safe for your child to swim, go into a hot tub, or use a Jacuzzi.

**Can my child drive?**

If your child is legally able to drive, ask the transplant team if he or she is allowed to drive. Your child should never drive when taking medicine to treat pain. Your child must always wear a seatbelt when in a vehicle.
Can my child travel?
It is much easier to travel after a transplant.
• Always pack enough medicine.
• Always carry the medicine. Do not check it with baggage.
• Carry the name and number of your child’s doctor and transplant team, and your child’s medicine list and emergency card.
• If you plan to go to a country that requires immunizations, talk to the transplant team. Your child cannot get any live immunizations, such as varicella, measles, mumps, rubella, oral polio, yellow fever, or rotavirus.

Life after Liver Transplant

We expect your child to be able to enjoy a full and normal life after transplant.

Doctor visits

The Transplant Team and your child’s doctor share information about your child. Take your child to the doctor for a check up every year, so the doctor can see how your child is doing. Your child will continue to see the Transplant Team often in the first year, and then twice a year for follow-up and changes in medicines and doses.

Returning to school

Your child’s immune system is weakest for the first 3 months after transplant, when the doses of immunosuppression medicines are highest. This puts your child at greater risk for infections. Your child should not return to school until the doses of these medicines are lowered, 3 months after the transplant.

Once your child is back in school, ask the school to let you know right away when there is an infection, like chicken pox or measles, going around. When this happens, take your child home right away and keep your child out of school until the infections have stopped spreading.

Sports

For the first 3 months after transplant your child should not lift anything heavy or play contact sports. Ask the Transplant Team if it is safe for your child to begin an activity or sport before starting.
Housekeeping

— Keep your home clean.
— Give your child chores that do not increase risk of infection.

Public places

In the first 3 months after transplant, your child should wear a mask in public places. Avoid all contact with sick people. Sick friends and family should not visit.

Medical Alert Identification Tags

In case of emergency, your child should wear a Medical Alert Identification Tag. This is usually worn on the neck or wrist. This tag tells emergency workers that your child has received a liver transplant. It also lists:
— Medical conditions your child has
— Allergies your child has
— The telephone number to the Transplant Center.

Ask your Transplant Coordinator how you can order these tags.

Pets

Here is how you can keep your child safe around pets:

Keep clean
— Your child should not have any contact with an animal’s body fluids, like saliva or urine.
— Don’t let an animal lick your child’s wound or face.

Litter box care
— After transplant, your child should never clean the litter box.
— Keep the box away from kitchen and places where people eat.
— Clean the litter box at least once each month with bleach.

Animal bites
— If your child is bit by an animal, rinse the wound in cold water right away and
put on Neosporin or Bacitracin. Then call your child’s doctor or the Transplant Team to find out what to do next.

Pets to avoid
Some types of pets carry germs that can spread to humans, which could cause serious illness or death to someone who has had a transplant. Your child should keep away from stray animals, reptiles like turtles and snakes, birds, monkeys, and other wild animals.

Travel
Your child’s immune system is weakest for the first 3 months after transplant, when the doses of immunosuppression medicines are highest. This puts your child at greater risk for infections. Your child should not travel during this time. Complications are more likely to occur in these first three months, so your child should be close to home.

Tell your Transplant Team if you are planning a trip. Travel outside of the United States may require extra precautions and vaccinations. When away from home, make sure you have enough medicine for your child for the whole trip. You may not be able to get medicine from a pharmacy when traveling. Your Transplant Coordinator can help you plan for a safe trip.

Skin care
Some of the medicines your child takes after transplant can make your child’s skin more likely to burn in the sun and get skin cancer. Your child needs to wear sunscreen and a hat when outside. If you notice a new growth on your child’s skin, ask your child’s doctor to check it.

Moving away
If you move away from here, we can tell you what pediatric liver transplant center is near your new home. We can send them your child’s records and work with them so your child will continue to get care. As soon as you know you are moving, tell the Transplant Team.
Becoming an adult

After the age of 18, your child is an adult. He or she can then be followed by an adult liver transplant team. Your child may move away. We will help your child learn to care for him or herself, and transfer medical records to the new team.

Public Education

Some family members may want to volunteer to teach others about transplants and the value of donating organs. Activities include:
— Handing out information at health fairs.
— Speaking to community groups and schools.
— Being interviewed for television, radio, newspaper, and magazines.

If you would like to learn more about this, contact the Donor Network of Arizona at 602-222-2200 or 1-800-943-6667

Reaching out

Your family may choose to write a letter to the donor family for the gift of life that your child received. If you decide to write a letter, it should be anonymous. You can give this letter to your Transplant Coordinator or social worker, who will send it to the procurement organization who will then forward it to the donor family.

Sometimes a donor family may want to send you a message. Before we send this to you, we will ask if you want it. If you do not want to hear from the donor family, let us know.
I can tell you who to call with questions or concerns.

I can tell you who and when to call.

**Call 911 or emergency services if your child:**
- is throwing up blood
- has chest pain
- has trouble breathing
- having black or red stools
- has severe belly pain (abdominal pains)

When your child is getting treatment, call the Transplant Coordinator to tell us what has happened.

**Put these telephone numbers in the memory of your cell phone now:**

The 24 hour telephone number for the Transplant Program is (602) 933-0940. Please do not call this number between the hours of 5 pm and 8 am to schedule a regular clinic visit.

After 5 pm and on weekends and holidays, if you have an urgent question or issue, please contact the on-call GI provider through the hospital operator at (602) 933-1000.

If you need to schedule an appointment please call the GI clinic at (602) 933-0940 during routine clinic hours or leave a message on the voicemail.

**Call the Transplant Coordinator or the on-call physician right away if your child:**
- has a temperature of 101.4°F (38.5°C) or higher
- is throwing up for a long time. Your child may need to get fluids or medicine by IV.
- the incision looks infected: red, warm, swollen, painful, draining fluid, pus or large amounts of blood
- has large amounts of watery stools (diarrhea), or blood in the stool.
- yellowing of the skin and eyes (jaundice)
- belly gets big (abdominal distention or ascites)
Call the Transplant Coordinator if:
— your child’s medical condition changes
— you have questions about the plan of care
— you have questions or concerns about your child’s medicine
— call with any new medications before starting them
— inform us of any visits to the Emergency Department or Hospital Admission

Call the team Social Worker if:
— you have a problem with transportation
— you have a problem or concern with emotions, coping, or relationships
— you need help dealing with an issue at home

Call the team Administrative Assistant if:
— you need to schedule an appointment
— you need a copy of your child’s medical records sent to a doctor
— you need copies of test results
— you need orders for blood lab tests
— you need to get insurance authorization for a procedure or appointment

Call the team Financial Coordinator if:
— you plan to change your health insurance policy
— you change your health insurance policy
— you receive a bill you don’t understand
Problems some children have after liver transplant

Blood clots (thrombosis)

The blood vessels going in and out of the liver are small. Sometimes after a liver transplant small blood clots form in there and keep the blood from flowing well. Sometimes a doctor in the Radiology Department can put a wire into the blood vessel and pull out the blood clot. Other times, the clot may have to be removed by surgery.

Blockages of the bile ducts

Sometimes after transplant, bile ducts may narrow and may get blocked. Surgery may be needed to help the bile flow again.

The liver has another problem

Some problems that can occur after liver transplant include:
— Hepatitis B
— Hepatitis C
— Primary Sclerosing Cholangitis
— Autoimmune Hepatitis

The transplant team will watch your child’s liver function closely to look for signs of the problem coming back. Treatment may be available.

Skin Cancer

Some of the medicines your child takes after transplant can make your child’s skin more likely to burn in the sun and get skin cancer. Your child needs to wear sunscreen and a hat when outside. If you notice a new growth on your child’s skin, ask your child’s doctor to check it.
Diabetes and High Blood Pressure

The medicine your child takes may cause diabetes or high blood pressure. These may be treated with diet changes. Few children need insulin, but some may need to take medicine to lower the blood pressure, and measure blood pressure at home.

I can tell you when our first clinic appointment is.

After the transplant, we will see your child often. We will watch your child for signs and symptoms of infection or rejection.

At most of these visits we will draw blood from your child to do lab tests. Do not give your child immunosuppressive medicine before the blood is drawn, because it changes the results.

Our clinic is in the Main Hospital, 2nd Floor, Clinic C

Come 15 minutes before your appointment time to fill out forms. Sign in at the desk, and sit in the waiting room until you are called. When your child is doing well, these visits usually last about 30 minutes. If you cannot make the appointment, please call us at (602) 933-0940 to cancel. If your child is sick, and needs to be seen right away call the Transplant Team.

Clinic Appointments

If your child is well, this is how often you will see us. You will see us more often if your child has complications, infection, or rejection.

<table>
<thead>
<tr>
<th>Period</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1 through Week 2:</td>
<td>2 times a week</td>
</tr>
<tr>
<td>Week 3 through Week 8:</td>
<td>1 time a week</td>
</tr>
<tr>
<td>Month 2 through Month 3:</td>
<td>Every 2 weeks</td>
</tr>
<tr>
<td>Month 3 through Month 6:</td>
<td>Monthly</td>
</tr>
<tr>
<td>Month 6 through Month 12:</td>
<td>Every other month</td>
</tr>
<tr>
<td>If stable after 1 year:</td>
<td>Every 4 to 6 months</td>
</tr>
</tbody>
</table>
Lab Tests

If your child is well, this is how often he or she will have lab tests. Tests will be done more often if your child has complications, infection, or rejection or if medication changes are made. At first we will do the tests at Phoenix Children’s Hospital. Later, you may be able to have these lab tests done closer to your home.

Liver function and levels of immunosuppressive drugs

- **Month 1:** 2 times a week
- **Month 1 through Month 3:** 1 time a week
- **Month 3 through Month 6:** 2 times a month
- **Month 6 through Month 12:** 1 time a month
- **If stable after 1 year:** Every other month

Checking for CMV and EBV infection

- **Month 1 through Month 2:** 1 time a week
- **Month 3 through Month 12:** 1 time a month
- **After Month 12:** 1 time every 4 months

Home Care

Some children who get liver transplants may need some nursing help when they go home. Here are some of the reasons:
- If your child needs IV medicine at home, such as IV antibiotics.
- If your child needs wound care and dressing changes.
- If you need more help understanding your child's medicines and how and when to give them safely.

Sometimes, a Home Care Nurse will visit when you first go home just to make sure you are comfortable giving the medicine, doing the dressing changes, and to answer your questions.

Home Care visits depend on need and health insurance coverage. The social worker will schedule home care before your child leaves the hospital.
Are you ready to go home?

We have a medicine schedule.
We know what time to give the medicine.
We have the medicine.
We know the symptoms of rejection.
We know the symptoms of infection.
We have a thermometer.
We have the phone numbers to call the transplant team.
We have a clinic appointment scheduled.
If you want to know more about child health and illness,
visit our library at The Emily Center at Phoenix Children’s Hospital
1919 East Thomas Road
Phoenix, AZ 85016
602-933-1400
866-933-6459
www.phoenixchildrens.com
Facebook: facebook.com/theemilycenter
Twitter: @emilycenter

Disclaimer
The information provided at this site is intended to be general information, and is provided for educational purposes only. It is not intended to take the place of examination, treatment, or consultation with a physician. Phoenix Children’s Hospital urges you to contact your physician with any questions you may have about a medical condition.
Family Review of Handout

Health care providers: Please teach families with this handout.
Families: Please let us know what you think of this handout.

Would you say this handout is hard to read? □ Yes □ No

Easy to read? □ Yes □ No

Please circle the parts of the handout that were hard to understand.

Would you say this handout is interesting to read? □ Yes □ No

Why or why not?

Would you do anything differently after reading this handout? □ Yes □ No

If yes, what?

After reading this handout, do you have any questions about the subject? □ Yes □ No

If yes, what?
Is there anything you don't like about the drawings?  □ Yes  □ No

If yes, what?

What changes would you make in this handout to make it better or easier to understand?

Please return your review of this handout to your nurse or doctor or send it to the address below.

Fran London, MS, RN
Health Education Specialist
The Emily Center
Phoenix Children’s Hospital
1919 East Thomas Road
Phoenix, AZ 85016-7710

602-933-1395
flondon@phoenixchildrens.com

Thank you for helping us!