Soon your child will be discharged from the hospital. Since she is still unable to eat or digest enough food to nourish her body and give her energy, the doctor may order Total Parenteral Nutrition (TPN) for your child to receive at home. A few days before discharge, you will be taught how to give the TPN to your child. It is hospital policy that you start the TPN for your child twice before her discharge. Your child’s clinical nurse specialist (CNS) and a nurse from the IV infusion company will be your teachers. The teaching sessions last from 1–2 hours each.

Who should be taught to give TPN?

We ask that only 2 primary caregivers learn how to set up and give the TPN to your child. This will keep your child’s care as much the same as possible. The caregivers who will be with your child at night for “hooking up” and in the morning for “disconnecting” need to be taught how to give your child’s TPN. We prefer that the 2 caregivers attend the teaching sessions together. If it is too hard to get both of you at the same teaching sessions, the staff can arrange separate sessions. The clinical nurse specialist will help you decide who will be taught, how many sessions will be needed, and when the teaching sessions will be held.

Checking your child’s urine for sugar

You will be taught how to check your child’s urine for glucose (sugar). The clinical nurse specialist will also give you a sheet called “Do you know…How to check urine for glucose and ketones.”

If your child is on “cycled” TPN, you will check her urine 2 hours after the TPN starts and one (1) hour after her TPN is complete. If your child is on “continuous” (non-stop) TPN over 24 hours, you will check your child’s urine one (1) time each day.

Urine checks are important because they show how your child’s body is using the sugar in the TPN. Sometimes when a patient has an infection or is taking a medicine like a steroid she will have trouble handling the sugar in the TPN. If there is too much sugar in the blood, it will “spill into the urine.” If the urine test result is high, you should report it to the St. Jude staff right away, even after hours. The “Do you know” sheet tells you when you should call and who you should call.

Adding multivitamins to the TPN

You will receive multivitamins (a mixture of several vitamins and minerals) to add to your child’s TPN. The types of vitamins and minerals ordered are based on your child’s needs. You need to know the following information about adding multivitamins to TPN:
TPN at home

- You will add the multivitamins to the TPN bag right before you “hook up” your child’s TPN. Please do not add the multivitamins to the bag ahead of time, since they are only stable for a certain period of time.
- When you receive your child’s TPN, the liquid in the bag is clear like water. When you add the multivitamins, the TPN liquid turns yellow.
- Sometimes your child may be able to take the multivitamins by mouth. At these times, you will not add the vitamins to the TPN bag. If your child is having nausea and vomiting you will continue to add the multivitamins to the TPN bag.
- Multivitamins come in two forms, pediatric and adult. One way they differ is the amount of liquid in the bottle or vial.
- Multivitamins are packaged in many different ways. During your teaching session with the clinical nurse specialist and the IV infusion company nurse, you will learn what type of vitamins your child will receive and how to draw up the vitamins into the syringe.

Showing what you have learned

After the teaching session(s), you will be asked to show what you have learned. You will perform the following steps with a nurse standing by to answer your questions.

- Add the multi-vitamins to the TPN
- Spike the TPN bag
- Prime (fill) the tubing by running TPN through it
- Program the ambulatory pump (the machine used for giving TPN)
- Connect the TPN to your child’s central line

You will be asked to do this for at least 2 nights in the hospital before your child is discharged as an outpatient. While in the hospital, your child’s TPN is prepared by the pharmacy and sent to the floor.

Giving TPN is not a test of your memory. Feel free to look at the printed information you have received. Your child’s nurse will bring in the TPN solution, multivitamins, and all of the supplies that you will need right before 10 p.m. Please ask the nurse if you have questions about the process.

Remember that TPN can be given “continuous” or “cycled”, depending on your child’s needs. Your clinical nurse specialist will give you a “Do you know” sheet that offers step by step guidelines for giving your child’s type of TPN.

Use the “Do you know… TPN steps for home use” sheet to help you set up, connect, and disconnect your child’s TPN. Since there are many kinds of pumps, you will receive a specific guide on how to program your child’s pump. The clinical nurse specialist or IV infusion company nurse will give you this information during your teaching session.
TPN at home

Keeping everything clean

If germs enter your child’s central line or the site where the line enters your child’s body, a blood infection could occur, making your child very ill. The following guidelines will help you keep everything as clean as possible.

- It is important to wash your hands well with an anti-bacterial soap before touching the supplies or your child’s central line. See “Do you know… Clean hands” in this packet.
- Wash your hands before and after cleaning your work area. Then do not touch anything except the TPN and supplies. If you touch anything such as the telephone or furniture, wash your hands again.
- Try not to cough or sneeze over the TPN and supplies.

Preparing your work area to set up TPN

- Choose a space that is away from household traffic and other things that could distract you.
- The work area should be clean and dry.
- The work area should be a hard surface that is washable, such as a bedside table or countertop. Do not prepare the TPN on your child’s bed.
- Remember that the tables and hard surfaces around your home may have dust and germs on them. This is normal. You should clean off the work area with alcohol or an anti-bacterial soap or spray such as Clorox or Lysol. Dry it with a clean cloth or paper towel.
- If the work area is not washable, such as a wooden tabletop, wipe it free of dust and spread a clean cloth or paper towel over the surface.
- Try not to cough or sneeze over the clean surface.
- Keep all pets out of the room while setting up your child’s home TPN.

Keeping TPN and supplies clean

Keeping the TPN mixture and supplies sterile (clean) is very important. Sometimes the TPN or supplies can become contaminated (dirty). TPN has sugar in it, and bacteria (germs) love sugar. TPN can become dirty with germs if it is not kept clean. Contamination of the TPN mixture or supplies does not happen often, but it can happen. The following tips will help prevent germs from entering your child’s central line.

- Keep the TPN supplies in their packages until you are ready to use them.
- Store the TPN, multivitamins, and batteries in the refrigerator. Place them either on a clean shelf or in a clean drawer. Do not store any food items on the same shelf or in the same drawer as the TPN.
- Store supplies in a clean dry place, away from children and pets.
- Check the TPN bag for leaks. Give the bag a gentle squeeze. If the bag has a hole, you will see the TPN leak out.
- While you are adding the multivitamins, the needle could pierce the plastic bag. This would contaminate the bag (make the contents dirty with germs). Do not use a bag that has a hole.
- Anytime you have a question or concern, call your IV infusion company.

This document is not intended to take the place of the care and attention of your personal physician or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your physician.
**TPN at home**

### What to do if the TPN becomes contaminated

- Do not use the bag. If you have an extra TPN bag in the refrigerator, use it. After you have connected your child to the TPN, call the IV infusion company. Tell the company about the leak or contamination. You will receive a new TPN bag the next day.

- If you do not have an extra bag, call the IV infusion company and report the problem. The company will make a new bag and bring it to you.

Accidents do happen. Sometimes the clean end of the TPN tubing may fall on the floor. If this happens, it is considered dirty. Do not use it. Use new tubing instead. This rule applies to all supplies that have a sterile tip or end, such as needles and syringes. Anytime you are not sure that something was kept clean, such as your vials or clave, start over. Re-clean items that can be cleaned with alcohol.

### Discharge day and beyond

The nursing staff along with the clinical nurse specialist will help you order the supplies you will need outside the hospital. A day or two before discharge, start writing down a list of supplies you will need. Give your nurse a list of supplies, so they will be ready by the time you leave the hospital.

The IV infusion company nurse will contact you in the hospital and again when your child is discharged as an outpatient. This nurse will talk to you about what time of day you want to connect your child’s TPN. The infusion company nurse will come to you on your first night out of the hospital to watch you set up and connect your child to the TPN. This nurse will be there to answer your questions and to make sure you feel comfortable with these tasks. But the nurse will not connect your child to the TPN. Remember to use the “Do you know” sheets during your first night at home and whenever you need them.

It is important that you connect your child to her TPN at about the same time each night. TPN is routinely connected in the hospital at 10 p.m. We know that outpatient life is different. You can change the times you hook up and disconnect TPN to fit your life. For example, if your child gets TPN for 12 hours, then you might want to connect her to TPN around 8 p.m. so that the TPN will be complete at 8 a.m. By disconnecting your child from TPN in the early morning, you will not have to bring it to the clinic with you. Choose a time to start your child’s TPN, and stick with it. Every night try to stay within 30 minutes of the time you have chosen to start your child’s TPN.

### Outpatient TPN

Several members of the Metabolic and Infusion Support Service (MISS) team will be overseeing your child’s TPN while she is an outpatient. In the Ambulatory Care Unit, a clinical pharmacist and a clinical nutritionist will closely watch your child’s blood work results and your child’s weight. You will also be asked to keep a Urine Glucose Diary. You will be checking your child’s urine glucose twice a day for “cycled” TPN and one (1) time each day for “continuous” TPN. Bring this diary with you to each clinic visit.
TPN at home

Please remember to call the IV infusion company:

- If you change hotels or living facilities;
- If your child is admitted to the hospital; or
- If there is a change in your child’s program (pump numbers), such as a change in the amount of fluid or a change in the number of hours it should run. Your infusion company nurse will talk to you by phone or will leave a message for you to call before you hook up your child’s TPN that night. By telephone, the nurse will help you re-program the pump to be sure it has the correct numbers. If you cannot get the new numbers into your child’s pump, this nurse will come to help you.

Other things that will help you with outpatient TPN

- Equipment and supplies can be ordered by the nursing staff in the Ambulatory Care Unit. Give them a list of supplies that you need.
- You will use a urinal (sometimes called a “hat”) to collect your child’s urine for the glucose checks. Make sure that you change your child’s urinal every 2-3 days. Dispose of the old one in the regular trash.

If your child is admitted or re-admitted to the hospital

- Bring your child’s TPN pump with you.
- Depending on the protocol that your child is on, the pharmacist may stop the TPN for a while, and then restart it. It will all depend on your child’s treatment plan.
- Also, your child’s TPN is good for 14 days as long as it is kept cold the entire time.

When will my child’s TPN be stopped?

Your child’s clinical team will stop ordering TPN when she is eating enough calories to maintain her weight and when nausea and vomiting has ended. Patients receiving TPN are reviewed often by the MISS team. Team members watch for TPN benefits, side effects and clinical changes that may help or hinder your child’s nutrition. They will look at how much your child is eating and drinking, her blood work, her urine glucose results, and her weight changes.

Questions?

If you have more questions about TPN, please talk to your child’s doctor, clinical nurse specialist, nurse, pharmacist, or nutritionist.