Hematology/Oncology: Homegoing Instructions

It is important for us to follow your child's progress and check to see how the child responds to chemotherapy (“chemo”). Before your child goes home from the hospital, you should be given discharge instructions with a follow-up appointment in the Hematology/Oncology Clinic. If you go home on a weekend and do not have follow-up scheduled, be sure to call the clinic Monday morning at 614-722-3250, option 4 - phone nurse to make an appointment.

At the clinic appointment, blood counts will be checked, and your child may be scheduled for other tests. It is best not to make other plans on the same day as your clinic visit. It takes time to get results from blood counts and to do the tests. Your child may also need time to be given blood products or chemo.

Some children in the waiting area are getting chemo treatments and may not be able to fight infection. For that reason, please do not bring other children with you, or anyone who does not feel well.

Chemotherapy drugs in the home

While a chemo drug may be helpful to the person taking the drug, there are studies that show people who care for patients taking these special medicines can also have changes within their own body’s cells. Chemo drugs are considered hazardous drugs and precautions need to be taken to protect others.

Chemo drugs need to be kept in a secure place so they are not accidentally taken by others. Women who are pregnant or trying to get pregnant may want another family member to give the chemo. Special precautions need to be taken when giving chemo so nothing gets on your skin. If powder or another substance gets
on your skin, wash the skin right away with soap and water. Chemo passes from the body in blood, urine and feces for the first 48 hours after it is given. Cover the toilet with the lid and flush two times after your child uses the toilet for the first 48 hours.

**Supplies**

- If your child has a Broviac or PICC catheter or other homecare needs, your case manager or discharge planner will set you up with a homecare company based on your insurance. This company will provide your supplies and deliver them to your home or to the hospital.

- If you have other home care needs, your discharge planner will help arrange for a company to provide them. You can get other supplies from pharmacies or medical equipment and supply stores.

- A registered nurse (RN) or nurse practitioner will provide teaching in the hospital before your child goes home. Please tell the nurse who does the teaching if you are not comfortable with doing the home care. Often more teaching sessions are needed.

- If you do not have insurance, ask your nurse to contact the Social Service Department to help you find sources of financial help. If you have insurance or other financial help, such as BCMH (Bureau of Children with Medical Handicaps), be sure to call and ask them how supplies are paid for. Phone: (614) 466-1700.

- A letter or prescription from your doctor may be needed. You may need to mail bills to your insurance company or get supplies from a certain store or agency.

- Before you come to clinic visits or scheduled hospital admissions, make a list of the supplies you need and give the list to your provider. More supplies will be ordered or you may call your homecare company directly to request more supplies.

**Prescriptions**

- Your doctor or nurse practitioner will give (or send to you) your child’s prescriptions for any medicines you will need at home. These prescriptions can be sent to our pharmacy or a pharmacy near your home. Your insurance may require some supplies and medicines to be sent through a homecare company. This can be arranged by the doctor, nurse practitioner or discharge planner. Be sure to ask if you have questions about the dose, schedule or reason for the medicines.
• It is important to have the prescriptions filled the same day so your child will not miss a dose (Picture 1, page 1).

• Having immunizations ("baby shots") or taking aspirin or ibuprofen during therapy may cause problems for your child. Ask your child’s doctor or nurse about these medicines before you take your child home.

**Nutrition**

Chemo, radiation therapy and the disease itself may reduce your child’s appetite. Some loss of appetite is expected during treatment and for a few days afterward, but your child needs to stay well-nourished to help rebuild healthy cells, fight infection and withstand chemo treatments.

It may help to offer your child smaller amounts of food more often. Be sure to tell the doctor about your child’s loss of appetite or weight loss if it lasts more than a week after treatment.

**School**

We will help you decide when your child is ready to return to school. Your child’s school should provide a home tutor until the child returns to the classroom.

Some children return for part of the school day and then gradually return full time. The education coordinator can help work out plans with the school or you can arrange this directly with school staff. With your permission we will give packets of information to the school, both at the time of diagnosis and when your child goes back to school.

**Comfort**

Pain is a sign that something is going wrong in the body. Be sure to report any pain your child has so we can try to find the cause. If your child is receiving pain medicine at home and it is not helping, call the hematologist/oncologist or your child’s doctor.

**Low blood counts**

Blood counts start to drop 7 to 10 days after most chemo treatments.
Call the Hematology Clinic if your child has any of these signs:

- **Infection**: Fever (temperature of 100.4 degrees F or higher), chills, rash, burning on urination, drainage from the ear, sore throat, diarrhea, persistent cough, drainage from the central line site, stiff neck, any areas of redness, warmth, or pain. Also, any exposure to a contagious illness, especially chickenpox or shingles.

- **Anemia (low hemoglobin)**: Paleness, dizziness, weakness, tiredness, listlessness, irritability, tendency to feel cold, shortness of breath.

- **Thrombocytopenia (low platelets)**: Bruising, petechiae (purple freckles under the skin), nosebleeds, oozing blood from the mouth or gums, pink or red urine, "coffee-ground" vomit, bright red or blackish bowel movements, headache, trouble waking up.

**Call 911 or Emergency Services RIGHT AWAY if your child:**

- Cannot breathe
- Is not able to wake up
- Has blue lips and skin
- Is having a seizure

**Call the hematologist/oncologist if….**

**Your child shows signs of infection:**

- Fever of 100.4 degrees F or higher
- Cough
- Sores in the buttocks area
- A cut or sore that does not heal well
- Fussiness or not feeling right

**Your child shows signs of bleeding:**

- Nosebleeds that continue after applying pressure for 5 minutes or more.
- Cuts that do not stop bleeding after five minutes of pressure over the area.
- Sudden increase in bruising, purplish red spots on skin, increase in menstrual flow, or blood in urine.
- Severe headaches, sudden vomiting, or change in level of alertness.

**Your child has trouble eating:**

- Mouth sores that interfere with eating
- Difficulty chewing
Your child has digestive tract problems:

- Vomiting and unable to keep down fluids or solids
- Painful bowel movements
- Diarrhea that keeps on for more than one day
- No bowel movement in 1 day or more

Your child is exposed to chickenpox or shingles.
Any time you need to know what to do!

**Important Phone Numbers**

**Hematology Clinic:** Monday through Friday, 8 AM to 4:30 PM (614) 722-3250, option 4, phone nurse.

**Nationwide Children’s Hospital Operator:** Saturdays, Sundays, evenings and holidays (614) 722-2000. Ask for the oncologist on call.