



## Hematology/Oncology: Home-Going Instructions

It is important we follow your child's progress and response to chemotherapy (“chemo”). Before going home from the hospital, you should be given discharge instructions with your follow-up appointment in the Hematology Clinic. If you go home on a weekend and do not have follow-up scheduled, be sure to call the clinic Monday morning 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 to receive blood products or chemo. Some children in the waiting area are receiving chemo and may not be able to fight infection. For that reason, it is not a good idea to bring other children with you, or anyone who does not feel well.



**Picture 1** Get prescriptions filled the same day you go home.

### 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. They will provide your supplies and deliver them to your home or to the hospital.
- If you have other home care needs, your case manager or discharge planner will help arrange for a company to provide them. Other supplies can be obtained from pharmacies or medical equipment and supply stores.

- A registered nurse (RN) will provide teaching, either at home or 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 case manager. More supplies will be ordered or you may call your homecare company directly to request more supplies.

## Prescriptions

- Your doctor or nurse will give you prescriptions for any medicines you will need at home. Be sure to ask if you have questions about the dose, schedule or reason for the medicines. The homecare company your insurance requires will give you prescriptions for heparin and GCSF.
- 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 may cause problems for your child. Ask your 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.

### When you call, the doctor will need to know:

- Your child's name, birth date, and diagnosis
- Current problem and how long your child has had it
- Date and type of your child's last chemo
- Your child's last complete blood count results

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.

## **Chemotherapy side effects**

Some side effects of chemo are usual and expected; others should be reported. Please refer to the chemotherapy Helping Hands.

## **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:**

- **Neutropenia (low white blood cells):** Fever (temperature of 100.5°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
- Has blue lips and skin
- Is not able to wake up
- Is having a seizure

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

**Your child shows signs of infection:**

- Fever of 100.5 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 don't 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 persisting for more than one day
- No bowel movement in 1 day or more

**Your child is exposed to chickenpox or shingles.**

**Any time you are in doubt about what to do!**

**Important Phone Numbers**

**Hematology Clinic**, Monday through Friday, 8 a.m. to 4:30 p.m. (614) 722-3250

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