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**INTRODUCTION**

It is now time to start planning for discharge from the hospital. You have probably already thought about how your lives at home following a bone marrow stem cell transplant may be different. We are sure you have many questions regarding the next several months of your child’s care.

These written instructions outline in detail what you need to know to care for your child after a bone marrow stem cell transplant. The following information will be reviewed with you and your family by the various members of the bone marrow transplant team prior to discharge from the hospital. Be sure to ask questions, take notes as needed. Remember – once you’re home we’re only a phone call away.

**Important Telephone Numbers:**

<table>
<thead>
<tr>
<th>Bone Marrow Transplant Office:</th>
<th>415-476-2188</th>
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<td>24 hour phone service</td>
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**Office Staff:**
- Orla Clifford
- Renee Stafford

**Clinical Nurse Specialist**
- Linda Abramovitz, RN, MSN
  - (415) 476-2188

**Nurse Coordinators**
- Kendra Toomey, RN, BSN
- Marisa Quinn, RN, BSN
  - (415) 353-1063

**Social Worker**
- Amanda Magary, MS
  - (415) 353-2896

**Pediatric Pharmacy Office**
- (415) 353-1265 (Messages)

**The Bone Marrow Transplant Physicians**
- Can be reached through the main office (415) 476-2188
- Dr. Morton J. Cowan; Division Chief
- Dr. Biljana Horn
- Dr. Marion Koerper
- Dr. William Mentzer
- Dr. Kate Matthay
- Dr. Yisheng Lee

**Website:**
- [www.som.ucsf.edu/bmt](http://www.som.ucsf.edu/bmt)
DISCHARGE CHECKLIST

Make sure that all this information is discussed before going home.

Isolation Precautions
- Understand the goal and general principles of the special precautions.
- Read and review with nurse specialist/coordinator special precautions regarding isolation, screening visitors, hand washing, pets, housekeeping and laundry, etc.

Monitoring for Potential Infections
- Have a thermometer at home.
- Know how to correctly read and use a thermometer.
- Know when the temperature is not normal and whom and when to call.

Central Line Care
- Perform dressing change.
- Perform heparinization.
- Perform cap change.
- Understand potential catheter complication; know what to do and whom to call.
- Have central line discharge supplies, including a permanent repair kit.

Diet/Food Preparation
- Review special diet with the Dietician/Nutritionist
- Understand diet and food preparation.

Mouth Care
- Review mouth care routine for home.

School
- Discuss home tutor with social worker.
- Arrange home tutor.

When to call
- Review general guidelines.
- Know when a physician must be called.
- Review important phone numbers.
- Know whom to call first, second, etc.
Medications
- Review purpose, dose frequency, side effects.
- Know administer all medications prior to discharge at least once
- Have discharge medications/prescriptions.

Follow-up/Outpatient
- Review with physician/clinical nurse specialist/coordinator outpatient (follow-up) plan(s).
- Have appointment for BMT outpatient visit (UCSF) (coordinator will schedule).
- Have all discharge equipment and supplies/or plan for home delivery.
- Schedule follow-up appointment with Oncologist/Pediatrician.

Miscellaneous
- Have form to apply for Medic Alert bracelet.
- Review skin precautions (sunscreen).
- Discuss immunizations.
YOUR RECOVERING IMMUNE SYSTEM – SPECIAL PRECAUTIONS

The first major milestone towards bone marrow stem cell engraftment occurs when your child’s ANC (absolute neutrophil count) is greater than 500 for three consecutive days. Along with this increase in neutrophil count comes your child’s ability to fight bacterial and fungal infections and his/her discharge from the bone marrow transplant room.

Until your child’s immune function completely recovers, one of the major concerns after bone marrow stem cell transplant is infection. It takes approximately 6-12 months and sometimes longer for the other types of white blood cells (T and B lymphocytes) to increase in number and fight infections. The time frame varies with the type of transplant performed and from individual to individual.

About every three months from the day of transplant, blood will be drawn to check your child’s immune recovery. T lymphocyte recovery occurs before B-cell recovery. The T-cells help fight fungal and viral infections. The B-cells make antibodies, which also help the body fight infections. Until T-cell recovery occurs, your child will have to take several precautions in order to decrease his/her chance of potential infections. This includes the use of several medications such as Septra and Acyclovir. A monthly immunoglobulin infusion provides functioning antibody until the B-cells can start working correctly.

These precautions help decrease the risk of potentially fatal infections, while maintaining a normal family lifestyle. In spite of all these precautions, infections may develop or exposure may occur which are beyond anyone’s control. Our goal is to minimize their occurrence. In general, once your child’s T-cells grow back and are functioning properly, he/she can stop isolation precautions, return to work/school, stop taking the preventative medications and resume a normal life.

There are several general precautions you should take to decrease your child’s risk of being exposed to potential infections. An important question that you may have is “with whom can my child have contact?” Here are some general guidelines:

Avoid Crowds
- Enclosed shopping centers
- Grocery stores
- School
- Church and other enclosed gatherings
- Movie theaters
- Restaurants
- Parties
- Airplanes
Avoid contact with visitors and friends who are or have recently been ill.

Screen all visitors for:
- Runny nose.
- Cold sores.
- Sore throat.
- Diarrhea.
- Vomiting.
- Fever.
- Rashes.
- Red or runny eyes (conjunctivitis).
- Chicken pox exposure.
- Infants who have had oral polio vaccination (3-4 weeks prior).
- Any other symptoms that lead you to believe the visitor may be ill.

Screen all visitors, especially children
Your child will not be required to wear a mask at home or around screened visitors, however, it is recommended that a mask be worn:
- When visiting the hospital or clinic for follow-up care (crowded halls, elevators).
- Unavoidable crowded situation. (It is a good idea to have a mask available at all times.)

If a family member becomes ill, he/she should limit contact with your child until they recover from the illness. It is not necessary for the ill family member to stay away from the home.
If a family member is exposed to or gets chicken pox, TB (tuberculosis), herpes, hepatitis, please contact your doctor immediately.

GOOD HANDWASHING is the best way to prevent the spread of infections. You should supervise and teach all of your children how to wash their hands after using the toilet, after playing with toys or pets and especially before eating. If you have a baby, you must wash your hands after handling diapers. It is a good idea to have family/friends follow the handwashing guidelines.

TEMPERATURE TAKING: Take your child’s temperature if you feel your child is listless, warm, irritable, chilled or not acting like his/herself. NO RECTAL TEMPERATURE SHOULD BE DONE. Observe for any signs/symptoms of infection (see General Care on page 7)

SCHOOL: Your child will not attend school for approximately 6 months. A home tutor should be arranged following discharge from the hospital so that he/she will not fall behind in school. Our social worker can help to arrange for a home tutor.
**PETS:** Animals presently in the house are allowed to stay. Do not introduce any new pets into the home until your child is off isolation. Attempt to prevent your pet from licking your child’s face and teach your child not to kiss the pet. Do not allow your child to come in contact with animal waste (i.e. litter box) or pet food/dish. Remember to use good hand washing after handling the pet.

Finally, it is important to **AVOID:**
- Lakes, beaches, oceans, and swimming pools (swimming)
- Hot tubs
- Sandboxes and gardens (dirt) (playing)
- Woodchips/bark
- Construction sites
- Remodeling
- Second hand smoke – no one should be allowed to smoke anywhere inside the house whether or not your child is present.
GENERAL CARE

WHOM AND WHEN TO CALL:
Take your child to the nearest Emergency Room IMMEDIATELY if he/she develops shaking chills and/or fever after you flush their central line.

Immediately notify the Bone Marrow Transplant Service (415) 476-2188 and your local physician if any of the following occurs:

- Signs and symptoms of infection;
  - Temperature greater than 38°C (100.4°F) axillary/orally
  - Pus or drainage from any wound or central line site
- Severe headache or pain
- Difficulty breathing
- Bleeding

It is also important to notify the Bone Marrow Transplant Service (415) 476-2188 or your local Doctor for the following:

- Rash.
- Red or swollen areas on body.
- Cough or congestion.
- Exposure to chicken pox or measles (including brother/sister or other family member).
- Change in appearance of the central line exit site.
- Change in the color and/or consistency of your child’s bowel movement.
- Change in the color of your child’s urine.
- Nausea and/or vomiting. Loss of appetite.
- Inability to take any prescribed medications.

We cannot foresee all possible problems with your child. When in doubt:
DO NOT HESITATE TO CALL YOUR PHYSICIAN AT ANY TIME.

After your child has been discharged from the hospital call the Pediatric Bone Marrow Transplant Office at (415) 476-2188 with questions or concerns. If, for some reason, you are not able to reach the BMT attending at that number, call the UCSF Hospital Operator. For life threatening emergencies call 911.

Do not call the Pediatric Bone Marrow Transplant Unit

MOUTH CARE: Good oral hygiene continues to be important for your child’s care after the bone marrow stem cell transplant. Keeping your child’s teeth, mouth and gums clean is essential to protect him/her from tooth decay and infection.

After discharge from the hospital your child should brush his/her teeth with a soft bristle toothbrush after meals and at bedtime. Notify your doctor if you notice sores, reddened areas, any white patches or bleeding in your child’s mouth or on the lips. Every two weeks discard toothbrush and replace with a new one to prevent infection.
IMPORTANT: If your child requires dental work while he/she has a central line, an oral antibiotic must be given to provide protection against infection. Please discuss this with your doctor and dentist.

SKIN: Your child may use regular soap and water to take baths. Your child can be outdoors following discharge from the hospital. Activities can range from taking a walk to riding a bicycle (providing platelets are at a safe level) see below.

Excessive sun exposure is not good for anyone and in particular for someone who has received chemotherapy or TBI. Help your child develop a lifelong habit of minimizing sun exposure. Always make sure that your child covers his/her head with a hat and wears sunscreen when out in the sun. If swimming, you must reapply sunscreen repeatedly.

ACTIVITY: It is important for your child to exercise/play once they are discharged. However, they should avoid contact sports or activities that can cause bleeding until their platelets are greater than 100,000 (football, bike riding).

IMMUNIZATIONS: Your child will not receive any childhood vaccines until his/her immunity comes back. While on IVIG, your child will not be immunized. After your child has been off IVIG for 3 months, their immunity will be checked, it is likely that your child will need to be re-immunized. The bone marrow transplant team will keep you informed as to when it is safe to resume vaccinations. No live vaccines.

MEDIC ALERT INFORMATION: You will be given a Medic Alert form to complete. Please include the following information:

- Bone Marrow Transplant Date
- Irradiate all blood products
- UCSF BMT Service 415/476-2188

EMERGENCY CARDS: You will be given an emergency card to present to health care providers when your child is emergently admitted to an outside facility.

MEDICATIONS
Your child’s discharge medications will include:

- Bactrim (Septra) – Prevents pneumocystis (a type of pneumonia)
- Acyclovir – Prevents herpes infections
- Nystatin/troches – Prevents fungal infection in mouth
- Gammaglobulin – Provides antibodies to prevent and fight infections. Given IV every 4 weeks.
- Heparin – Prevents the central line from clotting
- Sunscreen – Prevents skin from burning. Wear when outdoors in the sun along with a hat. Obtain from local drug store.
- Other

DO NOT STOP ANY MEDICATIONS BEFORE CHECKING WITH YOUR PHYSICIAN.
DO NOT use aspirin or any other products with aspirin in them (salicylate products) or non-steroidal anti-inflammatory drugs (e.g. Ibuprofen, Motrin).

**CENTRAL LINE CARE**: You will be taught how to care for your child’s central line prior to leaving the hospital. You will be given a permanent central line repair kit to take home with you. Bring it with you to the hospital if your child’s line breaks at home and needs to be repaired. Avoid getting the central line or dressing wet.

**DIET/FOOD PREPARATION**
A modified diet and special precautions must be followed post-bone marrow stem cell transplant

- Drink only bottled water or specially prepared tap water. Some good brands of bottled water include Alhambra, Calistoga, Crystal Geyser and Saratoga. Tap water must be boiled for 15 minutes then placed into a covered container. It is good for 48 hours. Bottled water need not be boiled. Avoid all well water, even if boiled.

- Wash all fruits and vegetables well under running faucet water. Use bottled or prepared water for final rinse.

- Use only bottled or specially prepared tap water to prepare foods and beverages that will not be cooked (including ice). Regular tap water may be used to prepare foods that will be cooked thoroughly.

- All foods, meats, fish (including shellfish), poultry and eggs must be cooked well. Do NOT use any of the following food products. These items are high in bacterial growth.
  - Unpasteurized milk and milk products.
  - Raw or undercooked meats, fish (including shellfish), poultry.
  - Raw or undercooked eggs - Raw or undercooked eggs.
  - Unprocessed bran if purchased from bulk stock (i.e. bins) and not baked or cooked before consumption.

- Food served should not stand at room temperature for more than two hours.

- “Leftovers” should be promptly refrigerated and reheated only once before discarding.

- Check dates on all food items purchased and do not keep foods and beverages beyond the recommended shelf-life time.

- Wash hands well before handling and preparing foods. Wash utensils and cutting board well in hot sudsy water between foods (as with chicken and raw vegetables) to prevent spread of germs.
• Wash hands well before eating.

• Use a commercial dishwasher if available to sanitize dishes and utensils. If a dishwasher is not in the household, wash dishes thoroughly with antibacterial soap.

• Do not share eating or drinking utensils.

• Take a daily multi-vitamin with minerals.

• From discharge to the first clinic visit, you may be asked to keep a record of what your child eats and drinks every day. This dietary record will be reviewed by the bone marrow transplant team during an outpatient follow-up appointment. Also during this time, note any problems with nausea, vomiting, and taste changes, etc. The nutritionist can discuss any concerns/issues related to diet by phone or in the clinic when available.

• Encourage a variety of different foods in the diet to make it nutritionally balance.

**RESTAURANT FOOD: Until your child is off isolation your child cannot eat out in a Restaurant.** Take-out (burgers, fries and pizza) is permitted from established franchise restaurants (MacDonalds, Burger King, Dominoes, Pizza Hut etc.). No “Mom and Pop” type of restaurant food. Eat the food while it is hot and well-cooked. Make sure to ask for no fresh vegetables (for example lettuce & tomato). Avoid buffets or salad bars.

**YOGURT:** Commercially available yogurt with *active cultures* is allowed as long as it is made from *pasteurized* milk to which live bacterial cultures have been added. *FROZEN YOGURT* is also permitted if purchased in cartons from a major grocery store chain or from a frozen yogurt or ice cream shop which is part of a large chain (e.g. Baskin-Robbins, Penguin, Double Rainbow).

Once your child’s immunity has returned, your child’s diet will be free of restrictions. However, this usually does not occur until about 6 months after transplant.
HOUSEKEEPING/LAUNDRY

About one week before your child is to return home from the hospital, your house will require a thorough “Spring Cleaning.” The goal of the cleaning is to minimize the amount of dust, which carries fungus and bacteria that are in the environment. Use common sense. It is unnecessary and impossible to create a sterile environment. Please do the following:

- Vacuum all floors, rugs and furniture.
- Wash down all surfaces, including walls, ceilings, windows, appliances, counter tops, floors, etc. with a disinfectant (i.e. Lysol, bleach).
- Dust all surfaces and corners with Endust (this product ensures the removal of dust particles).
- Clean tubs, toilets and sinks with abrasive cleaners and disinfectants.
- Clean or purchase new filters for forced air heaters.
- Wood stoves and Swamp coolers should be avoided.
- Change shower curtain and continue to clean it with disinfectant regularly (every other week). Always clean the tub before your child uses it.

Be sure to keep all cleaning agents out of the reach of young children.

After your child comes home, continue to regularly clean your home at least one to two times per week. Do not allow your child to be present while you dust or vacuum. Have your child in a separate room with the door closed while cleaning.

Your child should have his/her own towels, which should be changed regularly (twice a week). Bed linens should be changed once a week. Clothing may be laundered in the usual fashion with other family member’s clothing. If a family member’s job exposes his/her clothes to an unusual amount of dirt or dust, they must be washed separately.

If you do not own your own washer and dryer and bring your laundry to a Laundromat, Lysol must be added to each load.

ADJUSTING TO LIFE AT HOME

Families often find that they need additional help and information when they return home from the hospital. Many resources are available. Please ask you social worker for more information about:

- Support Groups/Counseling
- Informational Organizations (i.e. Leukemia Society)
- Financial Assistance (i.e. SSI, mileage reimbursement)
- Child/Respire Care
- [www.som.ucsf.edu/bmt](http://www.som.ucsf.edu/bmt)
- Parent handbook
COMMONLY ASKED QUESTIONS DURING THE FIRST MONTH FOLLOWING DISCHARGE FROM THE HOSPITAL

Why do my Child’s legs hurt?
◇ When the muscles in your child’s legs get tired, they hurt. It takes a while to rebuild muscles and strength after not exercising/walking as usual and being in bed. If this problem does not go away, please call.

When will my child feel hungry?
◇ Taste buds have changed from the chemotherapy and/or radiation. Some foods you like “don’t taste the same.” Your child’s stomach is not used to having food, so it takes time to build back his/her appetite. It may take several months for your child’s appetite to return to normal.

When will my child start gaining weight?
◇ It takes awhile. As your child’s appetite returns so will the pounds.

When can my child stop taking these medications?
◇ Most of the medications decrease the risk of infections (Bactrim, Mycostatin, Acyclovir). Once your child has regained sufficient T-cell function (usually six months post bone marrow stem cell transplant) you will be able to stop these medications.

When can my child’s friends visit?
◇ It is preferred that only a couple of friends, whom you have screened, visit at one time. Healthy visitors are welcome once you return home.

Can my child take a walk or go to the park?
◇ Yes. Plan it at a time during the day when few children will be at the park. Avoid other children.

Can my child go to the movies?
◇ Unfortunately no, because you cannot screen people in a movie theatre for colds. Try renting a video/DVD and invite a couple of screened friends over for a movie night. Have lots of popcorn.

When will my child’s hair grow back?
◇ It will take 3-6 months for your child to grow his/her hair back.

How clean should my house really be?
◇ Think of the initial cleaning as a “spring” cleaning. Dust has probably built up during the long hospitalization.

Can we go to others’ houses?
◇ This should be limited to close family homes where a certain amount of cleaning has occurred to reduce the amount of dust. Please discuss further with your physician and clinical nurse specialist.
Can my child eat yogurt?

✧ Yes, yogurt with active cultures may be eaten provided it is made from pasteurized milk. Use only products manufactured by major companies (i.e. Dannon, Yoplait, Lucerne, Lady Lec, etc.) Frozen yogurt, purchased from a major fast-food-type chain (e.g. Penguin, MacDonald’s etc..) may also be eaten.

Can my child be in the same room/house with someone who smokes?

✧ NO, Avoid secondary smoke since it is not healthy for you or your child. This means that no one can smoke in your house even if your child is not present at the time.

When can my child go back to school/work?

✧ When they are taken off “isolation”. (When T-cells recovery occurs).

Should family members get flu vaccines?

✧ Yes, all family members should get the flu vaccine except for the patient. (patients will need the flu vaccine when they are ready to be immunized.)

There will always be questions - please do not hesitate to call the Bone Marrow Transplant Office (415) 476-2188.
**FOLLOW-UP/OUTPATIENT APPOINTMENTS**

Following discharge from the hospital, your child will be seen frequently by the Pediatric Bone Marrow Transplant team at The Children’s Hospital at UCSF and/or your referring physician for several months. The frequency of these visits depends on a variety of factors, including: the type of transplant, medication adjustments, evaluation of graft vs. host disease as well as other current problems.

Your child will be seen at The Children’s Hospital at UCSF by the Bone Marrow transplant team on the following schedule. This schedule may vary depending on how far you live from The Children’s Hospital at UCSF, your private pediatrician and your child.

- Weekly or every 2 weeks for the first 1-3 months, then
- Once a month for six months, then
- Every three months for 18 months, then
- Every six months until 3 years, then
- Yearly. A comprehensive evaluation will occur yearly (around the anniversary of the transplant). Depending on the type of transplant and your child’s underlying disease, several tests will be performed. Examples of these include: an echocardiogram (ECHO) and Pulmonary Function Tests (PFT’s). These tests may also have been performed prior to the transplant.

Your child will be seen in the outpatient pediatric specialty clinic (2\textsuperscript{nd} floor of the Ambulatory Care Center –ACC) for his/her follow-up appointments (on Wednesday mornings.) During the visit you will be asked questions about your child’s health since his/her last appointment. This will include whether they have had an infection, a dietary review as well as other concerns you may have. (if you have a lot of questions, sometimes it is helpful to write them down in advance). Blood work may also be drawn at these appointments.

**MAKE SURE YOU HAVE A RETURN CLINIC APPOINTMENT BEFORE LEAVING THE HOSPITAL.**

**COMMUNICATION:**
Once your child is discharged from the hospital, call your local pediatrician for an initial visit. For any questions/concerns, contact the UCSF Bone Marrow Transplant Program (415) 476-2188. It is very important that the Bone Marrow Transplant Team know about any possible infections, exposure to infections, and other complications. The UCSF Bone Marrow Transplant Team will be coordinating care for your child with your local pediatrician.