



Levine
Children's
Hospital

Pediatric Blood & Marrow
Transplantation Program

Discharge Handbook

FOR: _____

Rev September 2008

Allogeneic BMT

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DISCHARGE CHECKLIST



Make sure that you understand the information in this checklist before going home.

Whom and When to call

- Review general guidelines.
- Know when a doctor must be called.
- Review important phone numbers.
- Understand the importance of compliance (every drug has a reason for being given).
Never stop any drug without first talking with your Bone Marrow Transplant doctor! Call immediately if your child cannot take a medication or if you have run out of a medication.

Monitoring for Infection

- Have a thermometer at home.
- Know how to correctly read and use a thermometer.

Special Precautions

- Understand the goal and general principles of the special precautions.
- Read and review with BMT nurse coordinator the special precautions regarding masks, screening visitors, handwashing, pets, housekeeping and laundry, etc.

Central Line Care

- Perform dressing change.
- Perform heparinization of central venous catheter.
- Perform cap change.

Diet/Food Preparation

- Understand Low Microbial Diet and food preparation.

School

- Arrange home tutor if applicable.

Medications

- Review purpose, dose frequency, side effects with BMT Pharmacist.
- Know all medications prior to discharge.
- Have discharge medications/prescriptions.

Follow-up After Discharge

- Review outpatient plan with BMT nurse coordinator.
- Have appointment for BMT outpatient visit.
- Have all discharge equipment and supplies or plan for home delivery.

Miscellaneous

- Review form to apply for Medic Alert bracelet.
- Review skin precautions (sunscreen).
- Discuss immunizations.

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 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 discuss in detail what you need to know to care for your child after a stem cell transplant. The following information will be reviewed with you and your family by the various members of the Blood and Marrow Transplant team prior to discharge from the hospital. Be sure to ask questions and take notes as needed. *Remember...once you're home we're only a phone call away.*

1. WHOM TO CALL

- Call Pediatric BMT Clinic between 8:30 am and 4:30 pm with questions or concerns (704) 381-9900 or toll-free 800-275-6302)
- After hours, call the page operator (704) 381-9900 and have the Pediatric Bone Marrow Transplant Doctor paged

2. WHEN TO CALL

Call the Pediatric Bone Marrow Transplant Doctor ***IMMEDIATELY*** if any of the following occurs:

- Your child develops **fever**. We define a fever as a temperature higher than 38°C (100.5F) under the arm or by mouth. Also, if your child has shaking chills after flushing his/her central line, take your child directly to the nearest emergency room in addition to calling.
- Possible signs of graft-versus-host disease (rash, diarrhea, vomiting, yellow eyes)
- Redness, swelling, pus or drainage from any wound or central line site
- Severe headache or pain
- Exposure to chicken pox

It is also important to call the Pediatric Bone Marrow Transplant Doctor for the following:

- Rash
- Red or swollen areas on body
- Runny nose or nasal congestion
- Cough
- Loose bowel movements (diarrhea)
- Blood in urine or stool
- Nausea and/or vomiting
- Loss of appetite
- ***Inability to take any prescribed medications.***
- If a family member is exposed to or gets chicken pox, TB (tuberculosis), fever blisters or cold sores, or hepatitis.

In case of an emergency, call 911 IMMEDIATELY.

EXAMPLES OF EMERGENCIES:

- Unable to breathe
- Convulsions (seizures)

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

3. TEMPERATURE TAKING

Take your child's temperature if you feel your child feels warm or is listless, irritable, chilled or not acting like himself/herself. **DO NOT TAKE A RECTAL TEMPERATURE.**

4. SPECIAL PRECAUTIONS

The first major milestone towards bone marrow engraftment occurs when your child's ANC (absolute neutrophil count) is greater than 500. Along with this increase in neutrophil count comes your child's ability to fight bacterial and fungal infections and his/her being allowed to leave the bone marrow transplant room.

Until your child's new immune system completely recovers, infection remains a major concern. 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.

Blood will be drawn every three months after transplant to check your child's immune 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 may include medications like Septra and acyclovir. Immunoglobulin infusions (IVIG) can provide antibody to replace the function of B-cells if necessary.

The precautions that follow help decrease the risk of potentially fatal infections. In spite of all these precautions, infections may develop or exposures 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 graft-versus-host- disease prevention/treatment is stopped, he/she can stop special precautions, stop taking the medications to prevent infections, and resume a normal life.

There are several general precautions you should take to decrease your child's risk of being exposed to infections. Here are some general guidelines:

Avoid contact with visitors and friends who are or have recently been ill.

Screen all visitors (especially children) for:

- Runny nose.
- Cough.
- Cold sores.
- Sore throat.
- Diarrhea.
- Vomiting.
- Fever.
- Rash.
- Pink eye (conjunctivitis).
- Chicken pox exposure
- Rash within 3 weeks of chicken pox vaccine.
- ***Any other symptoms*** that lead you to believe the visitor may be ill.



The goal of these precautions is to prevent getting contagious viral infections!

In situations where you cannot screen others, your child should wear a mask.

MASKS:

Your child will not be required to wear a mask at home or around screened visitors. We recommend avoiding crowds. Examples are:

- School
- Shopping malls
- Church and temple
- Movie theaters
- Parties
- Airplanes

When you must be in public places (hospital, clinic, grocery store, restaurants), we recommend that your child wear a surgical mask and that you go at a less busy time of the day to avoid exposure to many people. It is a good idea to have a mask available at all times.

Masks (N-95 masks) are also useful to decrease risk of inhaling fungal spores. These spores can cause fungal infections in the sinuses and lungs. Fungus lives on plants, grass, fruits, vegetables, in dirt, and walls of buildings. Your child should **avoid the following**:

- Sandboxes and gardens (dirt)
- Woodchips/bark/mulch
- Construction sites (wear a mask when near the Hospital!!)
- Home or building renovation or destruction (Remodeling)
- Exposure to freshly plowed fields and recently harvested crops
- Grass mowing or freshly mowed grass

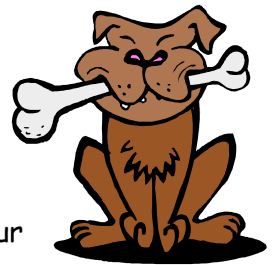
Your child does not need to wear a mask while traveling in a vehicle. However, your child should wear a mask when the car is close to sources of fungal spores listed above. This includes within a block or two of the hospital (where there is often construction). We recommend that you keep the car windows up and use the air conditioner if possible.

HAND WASHING: Good hand washing 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 and before eating. Hand washing should be performed with an antimicrobial soap and water. If this is not available, use of hygienic hand rubs is an acceptable means of maintaining hand hygiene. Encourage your child to avoid touching their mouth, lips, eyes, or nose unless they have washed their hands first.



It is a good idea to have your child, family and friends follow these hand washing guidelines:

- before eating or preparing food
- after handling diapers
- after gardening or touching plants or dirt
- after touching pets or animals
- after touching secretions, urine, or stool or items that might have had contact with human or animal urine or stool (for example clothing, bedding, toilets)
- before and after touching wounds



PETS:

Animals presently in the house are allowed to stay.

- Attempt to prevent your pet from licking your child's face and teach your child not to kiss the pet.
- Do not allow your pet to sleep with your child.
- Do not allow your child to come in contact with animal waste (for example litter box) or pet food/dish.
- Remember to use good handwashing after handling the pet.
- ANY pet that experiences diarrhea should be checked by a veterinarian as soon as possible for infection with *Campylobacter*.
- Your child should not have any contact with reptiles, its food or anything it has touched.
- Bird cage linings should be cleaned regularly and your child should not have exposure to bird droppings.
- Your child should avoid petting zoos
- Avoid adopting ill or juvenile pets (for example age less than 6 months for cats) and any stray animals

SWIMMING:

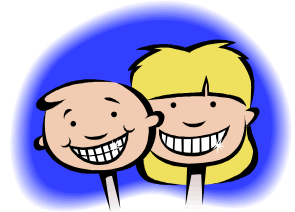
- Your child should not swim in lakes, beaches, oceans, or public swimming pool.
- Your child should not be in hot tubs.

GENERAL CARE

SCHOOL: Your child will not attend school for at least 6 months after transplant. A home tutor should be arranged following discharge from the hospital so that he/she will not fall behind in school. Your child's in-hospital school teacher can help arrange a home tutor.



MOUTH CARE: Good oral hygiene continues to be important for your child's care after the stem cell transplant. Keeping your child's teeth clean is essential to prevent tooth decay and infection.



After discharge from the hospital your child should brush his/her teeth with a soft bristle toothbrush twice daily. Notify your doctor if you notice sores, any white patches or bleeding in your child's mouth or on the lips. If your child's platelet count is very low, your child may have to use toothettes.

IMPORTANT: If your child requires dental work while he/she has a central line (Hickman catheter or infusaport), an oral antibiotic must be given to provide protection against infection. Please discuss this with your doctor and dentist.

SKIN CARE:

- Your child may use regular soap and water to take baths.
- Your child can be outdoors following discharge from the hospital.
- **THE SUN CAN TRIGGER GRAFT-VERSUS-HOST-DISEASE OF THE SKIN AT ANY TIME AFTER TRANSPLANT.** Excessive sun exposure is *NOT good* for anyone and in particular for someone who has received chemotherapy or TBI. It can increase the risk of skin cancer. 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 sunblock (SPF of 30 or above, UVA/UVB coverage with zinc or titanium dioxide) when out in the sun. You must reapply sunblock hourly if in the sun for a long time. You should also reapply sunblock after swimming.
- Your child's skin may be dry after transplant and a good moisturizing lotion can help decrease the dryness.



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

SMOKING: It is important to **AVOID** second hand smoke. No one should be allowed to smoke anywhere inside the house whether or not your child is present.

IMMUNIZATIONS: Your child will not receive any childhood vaccines until approximately one year after transplant (or longer if your child is receiving treatment for graft-versus-host-disease). The BMT team will keep you informed as to when it is safe to resume vaccinations. **No LIVE** vaccines (measles, chicken pox) until at least 2 years after transplant. Get approval from the BMT team before giving these.

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

CENTRAL LINE CARE: If you have not done this previously, you will be taught how to care for your child's central line prior to leaving the hospital.

DIET/FOOD PREPARATION

A restricted diet (Low Microbial Diet) and special precautions must be followed after stem cell transplant until the Transplant team says that it can be stopped (not until your child stops taking all immunosuppressive medications).

- **Avoid** sharing cups, glasses, and eating utensils with others, including family members, to prevent passing infection.
- Encourage your child to drink. This will help your child stay well-hydrated.
- Do not drink well water.
- Fruits and vegetables must be washed under running faucet water and peeled by someone other than the patient.
- 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 and fungal growth and can lead to infection in your child.
 - Fresh berries (for example strawberries, blueberries, raspberries...). Frozen or canned berries are fine.
 - Unpasteurized milk and milk products.
 - Raw or undercooked meats, fish (including shellfish), poultry - no sushi!
 - Raw or undercooked eggs.
 - Unprocessed bran if purchased from bulk stock (for example in bins) and not baked or cooked before consumption.
 - Unprocessed pepper (for example peppercorns)

HELPFUL HINTS:

- "Leftovers" should be refrigerated within 2 hours of being served 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 uncooked 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 dishwashing soap.
- Encourage a variety of different foods in the diet to make it nutritionally balanced.

RESTAURANT FOOD: *Until your child is off special precautions (not taking immunosuppressive medications), it is recommended that your child not eat out in a restaurant.* If you must eat out in a restaurant, please go at low-traffic times. Your child should wear a mask until the food arrives. Take-out food (burgers, fries and pizza) that is freshly made from established franchise restaurants (McDonalds, Burger King, Dominos, Pizza Hut, etc.) is permitted. No "Mom and Pop" type of restaurant food, buffets/cafeterias, or pot-lucks. 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. Avoid ordering **soft-serve** ice cream, shakes/malts made with soft serve ice cream, and frozen yogurt. The temperature of soft-serve machines is not constantly monitored.

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 permitted if purchased in cartons from a major grocery store chain.

HOUSEKEEPING

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 contains fungal spores 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. Don't forget to vacuum under beds and furniture.
- Dust all surfaces, including baseboards, ceiling fans, blinds and lamp shades (do not use a feather duster).
- Clean tubs, toilets and sinks with disinfectants. Make sure that mold is not present.
- Clean the refrigerator.
- Clean or purchase new filters for forced air heating and cooling units (as recommended by manufacturer).
- Wood stoves should be avoided.



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 vacuuming and remain out of the room for at least 30 minutes.

Bathtubs and/or showers should be cleaned often to prevent mold and mildew. We recommend that you keep cleaning simple and use a Shower to Shower® or Lysol® spray product (not necessary to wipe down). Turn on the shower for 30 seconds before having your child get into the shower to decrease the risk of infection from the showerhead.

Bed linens should be changed at least 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.

FOLLOW-UP/OUTPATIENT APPOINTMENTS

Following discharge from the hospital, your child will be seen frequently by the BMT team and/or your referring doctor for several months. The frequency of these visits depends on a variety of factors, including need for transfusions, infections, type of transplant, graft-versus-host-disease, and other problems.

Your child will be seen by the BMT team on the following schedule. This schedule may vary depending on how far you live from Levine Children's Hospital and how well your child is doing. This is a *general* idea of how often clinic visits will be required:

First 3 months following transplant	1-2 times per week
Three months to one year following transplant	Once every 1-4 weeks
Greater than one year following transplant: ➤ If GvHD is present ➤ If GvHD is not present	At least once a month Every 3 - 6 months

During the visit you will be asked questions about your child's health since his/her last appointment. You will be asked about concerns you may have. If you have a lot of questions, sometimes it is helpful to write them down in advance. Blood work is usually drawn at these appointments.

We will do studies to look for recurrence of your child's disease every 3 months. A comprehensive evaluation will occur yearly (around the anniversary of the transplant). Several tests will be performed including an echocardiogram and lung function tests (depending on your child's age).

IF YOUR CHILD'S DONOR IS AN UNRELATED ADULT DONOR FROM THE NATIONAL MARROW DONOR PROGRAM (NMDP):

You can exchange personal information with your child's donor (if desired) usually starting one year after his/her transplant. Contact your BMT Nurse Coordinator who will complete the necessary paperwork. Your child's donor will need to give consent also.

Prior to one year, you can still communicate in writing to the donor as long as you do not use your child's name or any identifying information that could be used to determine your location. All written correspondence is read by your BMT Nurse Coordinator, the NMDP and the local Donor Center Coordinator before it is delivered to your child's donor.

COMMONLY ASKED QUESTIONS DURING THE FIRST MONTH FOLLOWING DISCHARGE FROM THE HOSPITAL

When will my child feel hungry?

Taste buds have been damaged by the chemotherapy and/or radiation. Your child may complain that some foods "don't taste the same." This usually improves about one month after the transplant. Your child's stomach may not be used to eating after transplant so it may take time to build up his/her appetite. It may take several months for your child's appetite to return to normal.

When can my child stop taking these medications?

Many of the medications decrease the risk of infections. Once your child has regained enough immune function to fight infections (usually at least six months after a bone marrow or stem cell transplant) your child may be able to stop these medications. **Please do not stop taking any medicine without discussing this with your Transplant doctor first.**

When can my child's friends visit?

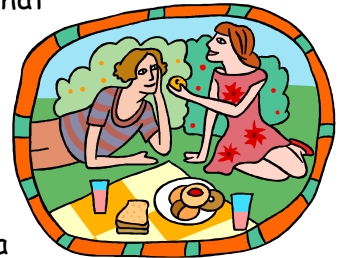
It is preferred that only a couple of friends, whom you have screened for symptoms of infection, visit at one time.

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 who have not been screened for infection. If there is harvesting of crops or construction that may make dirt go into the air nearby, we recommend that your child not go out. If your child does, make sure that he/she wears a N-95 mask.

Can my child go to the movies?

Unfortunately no. You cannot screen people in a movie theater for colds and other contagious infections. Try renting a video/DVD and inviting a couple of screened friends over for a movie night.



When will my child's hair grow back?

It usually takes 3-6 months for your child's hair to grow 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 if no one has been home.

Can we go to others' houses?

Yes - if no one at the house is ill and if the house is reasonably clean.

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 (for example Dannon, Yoplait, etc.).

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. Children who have had a stem cell transplant are at risk for lung disease, and second-hand smoke probably increases this risk.



When can my child go back to school?

When they are taken off "special precautions" (when their ability to fight infection recovers).

Should family members get flu vaccines?

Yes, all family members should get the flu vaccine. Patients may get the flu vaccine after six months from transplant. NO FLU-MIST (intra-nasal flu vaccine) for ANYONE in the family because it can be passed to the transplant patient!

There will always be questions - please do not hesitate to call your Bone Marrow Transplant Doctor or nurse coordinator!

