



Going Home after Allogeneic Stem Cell Transplant

Information for Patients and families

Emergency Phone Numbers

Monday-Friday, 8:00 am – 5:00 pm:	Oncology Clinic (604) 875-2116
Weekdays, 5:00 pm – 8:00 am,	Oncologist on Call (604) 875-2161
Weekends and Holidays:	ask the operator to page the oncologist on call



STEM CELL TRANSPLANT DISCHARGE INFORMATION

Going home after a haematopoietic stem cell transplant (HSCT) is exciting, but also can seem scary at first. You probably have many questions about how to care for your child outside of the hospital and what you need to do before going home. This booklet will help you plan for this day. We hope this will help answer your questions and give you a guide for caring for your child at home. It is important though, that you realize these are only guidelines. Every child is different, so your child's medical team may ask you to do additional or different things at home. Check with the medical team about any changes. Write these additions or changes in this booklet so you can keep all of this information together.

This resource is for the child who has had an allogeneic stem cell transplant (received someone else's cells).

Discharge Checklist

The following is a list of information and skills that you will need to know or do before going home. You may want to place a check in the box as you complete each skill.

Monitor for Potential Infections

- Have thermometer at home
- Know how to take temperature
- Know how to read thermometer
- Know what to do and who to call if there is a temperature

Prevent and Manage Infections

- Know signs and symptoms of infections
- Understand the special precautions, i.e. isolation, screening of visitors, handwashing, masks, pets, housekeeping and laundry, to try to prevent infections
- Know who to call when you see signs or symptoms of infection

Know Central Line Care

- Know how to change the dressing
- Know how to heparinize the line
- Know how to change the cap
- Know about catheter complications and what to do and who to call
- Have discharge supplies



Diet/Fluids/Food Preparation

- Review your child's diet with the dietician
- Know tips about how to feed your child: understand diet and food preparation
- Know your child's fluid needs
- Review NG tube feeding and have supplies
- Know who to call if you have questions

Mouth Care

- Review mouth care routine

School

- Know the importance of keeping up with school work
- Update the school; discuss the best way to help your child keep up
- Arrange home tutor if needed

When to Call

- Review general guidelines
- Know when to call the physician, nurse or other team members
- Review important phone numbers
- Understand who to call and when

Medications

- Review discharge medications, including dose, frequency, side effects
- Get prescriptions for discharge medications and fill them at the Outpatient Pharmacy in the Ambulatory Care Building

Follow-up/Outpatient

- Review the plan for follow up with physician/nurse
- Make an appointment for outpatient visit
- Discuss what equipment and supplies are needed and make sure you have them before discharge

Miscellaneous

- Review skin care
- Discuss immunizations



Housekeeping/Laundry

Because your child's new immune system is very young, your child's environment is very important. Germs, such as bacteria, can live anywhere. These guidelines will help you to reduce your child's exposure to germs.

One week before discharge, clean and disinfect your home. This includes all window coverings, windows, surfaces, floors, appliances, walls, etc

Routine Cleaning:

- Dust and vacuum weekly. Do not allow your child to be in the same room while doing this.
- Change towels, sheets, washcloths and pillowcases weekly. Your child should not share a bed or towels with others.
- Launder clothes in the usual way. If a family member's job exposes his/her clothes to an unusual amount of dirt or dust, wash his/her clothes separately. Wash any new clothes or linen before using.
- Wash dishes in hot soapy water or use a dishwasher.
- Do not use humidifiers (this is an easy place for germs to grow).
- Before your child comes home, change furnace/air conditioning filters.
- Use a disinfectant (any commercial disinfectant, such as Lysol is fine) for washing, cleaning and disinfecting. Apply disinfectant to surface and then rinse with water and let dry.
 - Disinfect the most contaminated sites, including sinks and drain areas, toilet flush handles, and faucet handles daily.
 - Clean bathroom that child uses daily (this should include a thorough cleaning and disinfecting of toilet, sink, countertops, shower/tub, and floor)
 - Disinfect kitchen sink. Do not use sponges to clean; change dishcloths daily.
 - Clean and disinfect cribs, change table, diaper pail and high chair with disinfectant daily
 - Pour two cups of bleach solution (3/4 cup bleach to 1 gallon water) down the shower, tub, and sink drains your child will be using, weekly
 - Wash shower curtain(s) weekly (may do this in the washing machine)

Important:

Your child should avoid contact with all chemicals, i.e., paints, cleaning fluid, paint thinner and stripper, etc. If these agents are used, be sure there is adequate ventilation and your child is removed from the area.

Avoid home renovations just before your child goes home and during the post- transplant period. Check with your physician before starting any renovations.



Guarding Against Infections

Bacterial, viral or fungal infections can be very serious if they occur after your child has had a transplant. Here are several precautions you can take to help prevent your child from getting an infection.

- Everyone in the household, including the child, should wash hands before and after meals, after toileting, and after touching anything particularly dirty. Use anti-bacterial soap and scrub them well.
- Your child should wear a mask until day +100, or as long as your doctor advises:
 - anywhere in the hospital (other than in an isolation room in clinic or emergency department)
 - when in crowds that can't be avoided
- Your child should avoid crowds. This includes:
 - grocery stores and shopping centres*
 - movie theatres*
 - restaurants* (see foodsafe guidelines for more about this)
 - school
 - parties

*** These may be attended at "off" or "quiet" times.**
- Avoid contact with family members or friends who are, or recently have been, ill.
- Screen all visitors, especially children, for the following:
 - runny nose, nasal discharge
 - cold sores, sore throat
 - diarrhea, vomiting
 - rashes, fever
 - red or runny discharge from eyes
 - history of chicken pox exposure (see Parent Handbook)
 - infants who have had oral polio vaccination 1-4 weeks before the visit
 - any other symptoms that lead you to believe the visitor may be ill
- If a family member becomes ill:
 - try to limit contact with your child for the duration of the illness
 - the ill member of the family should wear a mask when contact is unavoidable
 - follow meticulous hygiene measures, especially hand washing
- If a family member is exposed to or gets chicken pox, notify your clinic nurse or oncologist immediately. Isolation and/or medication may be required.
- If you have other children who are in school or day care, ask their teacher to let you know if any child in the class gets measles, chicken pox or mumps.
- Your child should not visit with other patients in the clinic or other areas of the hospital.



- Take your child's temperature if your child:
 - feels warm
 - has shortness of breath
 - has a sore throat
 - is tired or irritable
 - feels unwell
 - is not acting like himself/herself

Important:

Do not take rectal temperatures. All temperatures should be taken under the tongue or under the arm.

- Remove live plants and flowers from your home.
- Your child should avoid playing in the dirt or with live plants. (*Fungus lives in dirt and on some plants.*)
- Watch for signs and symptoms of infection:
 - Shortness of breath, coughing, runny nose
 - Changes in level of consciousness, irritability or listlessness
 - Chills
 - Fever greater than 38.5 C under the tongue or 38.0 C under the arm
 - Warm forehead with a flushed or pale face
 - A sore and/or swelling which does not heal
 - Sores in the mouth or throat
 - Vomiting/diarrhea
 - Pain with bowel movement or need to void often
 - Rashes

Important:

Call your doctor or nurse immediately if you see any of these signs.

Liver Complications

The liver is responsible for cleaning the blood, storing energy, breaking down drugs and helping digestion. *Rarely*, patients have problems with their liver due to infection or the medications they have taken. We will draw blood to check liver enzymes when your child comes to the oncology clinic.

You can also watch for these signs at home:

- Yellow colored skin or eyes (the white part of the eyes)
- Pain in the right upper part of the stomach
- Retention of more fluid than normal
- Rapid weight gain

If your child does develop these symptoms please call the primary nurse or physician.



Pets

Before going home, all pets should be checked by your veterinarian for infections.

- Dogs
 - Check for worms and overall health
 - Bathe
- Cats
 - Check for toxoplasmosis and overall health

Note: if your pet develops diarrhea, separate it from your child immediately and have it checked by a veterinarian for cryptosporidium, giardia, salmonella and campylobacter.

Feed your pet high quality commercial pet foods or well cooked eggs, poultry or meat products. Any dairy products should be pasteurized. Pets should not drink water from toilet bowls, and should not have access to garbage. They should not scavenge, hunt or eat other animals' faeces.

If your pets are free of infection, they may stay in your home.

- They may not sleep with your child
- Your child may play with them (no licking and no scratching child if possible)
- Avoid animal faeces; your child should not clean the litter box or cages
- If you have other pets, please discuss this with your child's oncologist
- Do not get any new pets during the post-transplant period
- Please remember that good hand washing is required after touching your pets

Avoid any contact with:

- reptiles (eg: snakes, lizards, turtles, iguanas), their food, and anything that they have touched
- ducklings and chicks
- exotic pets
- birds
- fish

Wash hands thoroughly if contact does occur.

Skin Care

Showering is preferred over bathing and should be done daily if possible. Use a mild shampoo or soap of your choice. Skin should be rinsed thoroughly before drying.



Keep skin moist, especially in very cold and very hot weather. Keep exposed skin i.e., hands, face and nostrils, moisturized. Avoid harsh rubbing to areas that have received radiation for at least 3 months. Use a non perfume lotion or moisturizer of your choice.

Note: if your child has had problems with his/her skin during transplant, your doctor or nurse will tell you how to care for your child's skin

Some of the medications (Septra) that your child is currently taking may make him/her more sensitive to the sun. Follow the Canadian Cancer Society's SunSense Guidelines for Sun Safety.

- Reduce sun exposure between 11 am – 4 pm
- Stay in the shade or create your own shade with an umbrella
- Slip! on clothing to cover arms and legs
- Slap! on a wide-brimmed hat
- Slop! on sunscreen with SPF #30 and UVA/UVB protection. Apply 20 minutes before outdoor activities
- Wear sunglasses with UVA and UVB protection

Mouth Care

Good oral hygiene is an important part of your child's care after transplantation.

- Brush teeth after every meal and at bedtime with a soft toothbrush and a small amount of toothpaste
- Rinse or swab with sodium bicarbonate solution (1/4 teaspoon of baking soda in 1 full glass of water)
- Rinse toothbrush thoroughly and store in a separate toothbrush holder. Do not hang on rack with the other toothbrushes
- Do not let anyone else drink from your child's glass or use his/her toothbrush. Toothbrushes should be changed at least every 6 months

Some children experience a very dry mouth following transplantation. This is called Xerostomia and can be caused by Graft vs. Host disease or from the radiation your child has had. If your child has a very dry mouth or his/her saliva is thick and stringy, your child may be experiencing xerostomia. It is very important that your child maintain excellent oral hygiene to reduce the risk for mouth sores and cavities. If you notice your child is developing this, please discuss it with your clinic nurse and oncologist.

For children with dry mouths (xerostomia)

- brush teeth at least 4 times per day, using fluoridated toothpaste
- rinse with baking soda mouthwash 4-6 times per day
- avoid foods and liquids high in sugar
- sip water to reduce mouth dryness



Nutrition

Eating well-balanced meals is important to maintain/improve your child's general health. Good nutrition also helps the new stem cells grow and mature. You may have to encourage your child to eat, since his/her appetite may be off. Before your child leaves the hospital, the dietician will review the guidelines with you. If you have any questions, she is available during your child's clinic visits. Please call to make an appointment with her.

General "Foodsafe" and Diet Guidelines

1. Scrub all raw fruits and vegetable under clean running water. Peel all produce that is easily peeled (apples, bananas, melon, carrots). Wash all produce with smooth skins that are not easily peeled (tomatoes, plums, grapes and cherries without stems).
2. Shelf 'stable' refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature. The container may require refrigeration once opened (eg. mayonnaise, peanut butter, salad dressing, etc.).
3. Minimize the amount of time food is in the "Danger Zone" (temperatures between 4°C- 60°C or 40°F-140°F).
4. The Ministry of Health recommends the following internal cooking temperatures for these food products:
 - Poultry/stuffing/ground and stuffed meat 165°F
 - Pork (other than ground) 150°F
 - Ground meat (other than poultry) 155°F
 - Other hazardous foods (meats, fish, eggs) 140°F
5. Avoid the spread of germs:
 - Food to food: raw food in contact with cooked food
 - People to food: contaminated hands touching food
 - Contact surface to food: using the same knife and cutting board to cut raw poultry and then to slice cooked poultry or other foods
6. Take-out foods are OK. However, follow the guidelines for your child's diet. Choose well-established restaurants, known for their cleanliness. Avoid deli bars and salad bars.



General “Foodsafe” Tips:

- Wash hands often
- Use utensils to handle food whenever possible
- Use a different cutting board (not wood) for each meat, fish, poultry... etc. Keep this board separate and do not use it for any other food items
- Cutting boards need to be disinfected after every use, especially after cutting raw meat, fish or poultry and before preparing fresh produce
- Keep sinks and countertops clean and disinfect daily with a bleach solution
- Cover and cool left over food by using shallow pans in the refrigerator
- Reheat cold food rapidly ensuring the internal temperature reaches 165°F
- Prepared salads, custards and cream-filled pastries must be refrigerated until served
- Thaw meats, fish, poultry and other frozen foods in the refrigerator
Defrosting food at room temperature is dangerous!

Enteral Feeding by NG feeding tube

Your child may have a feeding tube to help with his/her nutrition; your child may need it at home. By discharge, your child's appetite may not be normal. Also, if he/she had radiation or developed mouth sores during the post-transplant period, your child's taste buds will need time to recover. All these will affect your child's ability to eat, drink and meet his/her nutritional needs. Together with the dietician, you and your child will plan a feeding schedule that will help maintain your child's weight and support him/her until his/her appetite recovers.

Your nurse will help you learn how to set up the feedings, use the pump and give the feeds safely.



Following are guidelines you should follow until day +100 post transplant or until advised by your oncologist

Food Group	Allowed	Not Allowed
Dairy	<ul style="list-style-type: none"> ~ all <i>pasteurized</i> milk and milk products ~ commercially packaged cheese and cheese products made with <i>pasteurized</i> milk (ie. <u>mild and medium</u> cheddar, mozzarella, Parmesan, Swiss) ~ <i>pasteurized</i> yogurt ~ frozen <i>pasteurized</i> whipped topping ~ ice cream ~ frozen yogurt ~ sherbet ~ ice cream bars 	<ul style="list-style-type: none"> ~ <i>unpasteurized</i> or raw milk, cheese, yogurt and other milk products ~ cheese from delicatessens, cheeses containing chili peppers or other uncooked vegetables ~ cheeses with moulds (ie. Blue, Stilton, Roquefort, Gorgonzola) ~ aged or Sharp cheddar, Brie, Camembert, feta, farmer's cheese
Meats and meat substitutes	<ul style="list-style-type: none"> ~ all <i>well-cooked</i> or <i>canned</i> meats (beef, pork, lamb, fish, poultry, shellfish, game, ham, bacon, sausage, hot dogs) ~ <i>well-cooked</i> eggs (<i>pasteurized</i> egg substitutes (Egg beaters®)) ~ <i>commercially packaged</i> bologna, salami, and other lunch meats ~ cooked tofu (cut into 1 inch or smaller cubes, boiled a minimum of 5 minutes in water or broth before eating or using in recipes) 	<ul style="list-style-type: none"> ~ <i>raw</i> or <i>undercooked</i> meat, poultry, fish, game, tofu ~ meats and cold cuts from delicatessens ~ hard cured salami in natural wrap ~ cold smoked fish, lox, pickled fish ~ tempeh (fermented soybeans) ~ beef jerky ~ sushi
Entrees, soups	<ul style="list-style-type: none"> ~ all cooked entrees and soups 	<ul style="list-style-type: none"> ~ all miso products (miso soup)
Bread, grain and cereal products	<ul style="list-style-type: none"> ~ all breads, bagels, rolls, muffins, pancakes, sweet rolls, waffles, french toast ~ potato chips, corn chips, tortilla chips, pretzels, popcorn ~ cooked pasta, rice and other grains ~ all cereals, cooked and ready to eat 	<ul style="list-style-type: none"> ~ raw grain products



Food Group	Allowed	Not Allowed
Fruit and Nuts	~ canned and frozen cooked fruit; ~ fruit juices ~ <i>well-washed</i> raw fruit*, foods containing <i>well-washed</i> raw fruits, dried fruits in packages ~ canned or bottled <u>roasted</u> nuts, nuts in baked products, pasteurized peanut butter (commercially packaged)	~ <i>unwashed</i> raw fruits ~ unroasted raw nuts ~ roasted nuts in the shell ~ <u>unpasteurized</u> fruit juice ~ dried fruit from bulk food section ~ peanut butter from bulk food section
Vegetables	~ all cooked frozen, canned or fresh vegetables and potatoes ~ <i>well-washed</i> raw vegetables* and herbs, dried herbs and spices, shelf stable salsa	~ <i>unwashed</i> raw vegetables or herbs ~ salads from delicatessens ~ commercial salsas stored in refrigerated case (ie. Fresh salsa) ~ raw vegetable sprouts (alfalfa, mung bean etc)

**Scrub all raw fruits and vegetable under clean running water. Peel all produce that is easily peeled (apples, bananas, melon, carrots). Wash all produce with smooth skins that are not easily peeled (tomatoes, plums, grapes and cherries without stems).*



Food Group	Allowed	Not Allowed
Beverages	<ul style="list-style-type: none"> ~ bottled ozone treated distilled or spring water (Evian®, Perrier®), hospital issued sterile water ~ all canned bottled or powdered beverages ~ instant and brewed coffee, tea ~ cold tea brewed with boiling water, brewed herbal teas using commercially packaged tea bags 	<ul style="list-style-type: none"> ~ well water, tap water ~ cold brewed tea made with warm or cold water ~ <u>unpasteurized</u> fruit or vegetable juices
Fats	<ul style="list-style-type: none"> ~ oil, shortening ~ refrigerated lard, margarine, butter ~ commercial shelf-stable mayonnaise and salad dressing (including cheese based salad dressings; refrigerated after opening) ~ cooked gravy and sauces 	<ul style="list-style-type: none"> ~ fresh salad dressings containing aged cheeses (ie. bleu, Roquefort) or raw eggs
Desserts	<ul style="list-style-type: none"> ~ refrigerated commercial and homemade cakes, pies, pastries and pudding ~ refrigerated cream-filled pastries ~ homemade and commercial cookies ~ shelf stable cream-filled cupcakes (Twinkies®, Ding Dongs®), fruit pies (Pop tarts®, Hostess® fruit pies), and canned pudding ~ ices, popsicle like products 	<ul style="list-style-type: none"> ~ unrefrigerated cream-filled pastry products (not shelf stable)
Other	<ul style="list-style-type: none"> ~ salt, granulated sugar, brown sugar ~ jam, jelly, syrups (refrigerated after opening) ~ commercially packaged (pasteurized) honey ~ ketchup, mustard, BBQ sauce, soy sauce, other condiments (refrigerated after opening) 	<ul style="list-style-type: none"> ~ raw or unpasteurized honey, herbal and nontraditional (health food store) nutrient supplements, Chinese herbs, Brewer's yeast if eaten uncooked <i>Non-traditional and herbal supplements should be reviewed with a physician on an individual basis.</i>



Food Group	Allowed	Not Allowed
	~ pickles, pickle relish, olives (refrigerated after opening) ~ candy, gum ~ commercial nutritional supplements and baby formulas (includes liquids and powder)	



Physical Activity

Your child may tire easily. He/she should be encouraged to get back into a normal routine as quickly as possible. Normal activity and exercise is important for your child's growth and development as well as psychological well being. It is normal to feel somewhat uncertain about himself/herself after going through this kind of treatment. If your child's platelets are low, exercise should be approached with caution. If your child is a toddler, he/she should be closely watched when learning to walk. If your child is older, an activity, such as bike riding, might be restricted. We will tell you exactly what exercise your child will be able to participate in.

Here are some guidelines:

- Avoid contact sports
- Plan for rest periods: your child's energy level will guide you. If he/she feels energetic, don't force him/her to nap
- Avoid swimming for the first 6 months or longer. Check with your child's oncologist
- Generally, your child should not swim in public pools, creeks, lakes or the ocean for at least 6 months. Check with your oncologist before your child starts swimming

School:

We suggest that your child gets tutored at home so that he/she can keep up with his/her class. Tutors should be screened for infections, as described above, and should wash their hands before working with your child. Your physician will tell you when your child may return to school (usually around 6 months after transplant). When this occurs, continue to monitor chicken pox, measles, mumps and other illnesses in the school. Talk to the school nurse, principal or teacher.

Immunizations

Your child is not to receive any vaccinations for about 1 year. These will be done through BCCH or arranged with your family doctor or health unit.

Avoid any immunizations with live vaccines to any member of the family for about 1 year after transplant. This includes MMR & varicella vaccine.



When to Call the Clinic/Physician

Notify the clinic or the oncologist on call for any of the following:

- Signs and symptoms of infection:
 - feeling unwell
 - fever greater than 38°C under the arm or 38.5°C orally
 - chills
 - cough
 - shortness of breath
 - sore throat
 - nausea
 - vomiting
 - diarrhea
 - chest pain
 - redness, swelling or pain anywhere, especially at the VAD/CVC site
 - sneezing, runny nose
 - sores, white patches, redness and/or pain in the mouth and gums
 - rapid or irregular breathing
- Your child or any member of your family is exposed to, or gets, chicken pox, measles, mumps, or any other communicable disease
- Your child cannot take medications
- Signs and symptoms of bleeding:
 - petechiae (small, pinpoint areas of bleeding under the skin) or bruises
 - black, tarry or bloody stools
 - blood in vomit, or vomit that looks like coffee grounds
 - swelling, redness or pain anywhere, especially in joints
 - frank blood from any place
 - redness or oozing from central line site
 - nosebleeds or bleeding that persists for more than 5-10 minutes or recurs after applying pressure for 20 minutes
- Change in appearance of the central line exit site
- Signs and symptoms of graft-vs-host disease (GVHD):
 - change in the frequency, colour and/or consistency of your child's bowel movements
 - redness, rash, skin breakdown, itchiness or any changes in your child's skin, including palms of hands and soles of feet
 - dry or irritated eyes
 - decreased saliva or difficulty swallowing
 - aches or stiffness in joints
 - shortness of breath or decreased tolerance for physical activity
- You have any questions or concerns.



Here is a list of phone numbers to call:

Monday-Friday, 8:00 am – 5:00 pm:

Oncology Clinic

(604)875-2116

Weekdays, 5:00 pm – 8:00 am, Weekends and Holidays:

Oncologist on call

(604)875-2161 (ask the operator to
page the oncologist on call)

Follow-up Clinic Appointments

After discharge, your child will be seen in the Oncology Clinic. How often depends on your child's health.

For at least the first 100 days, you will:

- return to clinic at least once a week for the first 100 days after SCT
- have to stay within driving distance of Children's Hospital

*After the first 100 days, you may be allowed to return to your home if you do not live in the area.

Three months (or 100 days) after the transplant, some isolation restrictions may be lifted. Check with your physician.

When you return to the clinic:

- Bring all medications your child will need for the day.
***When your child is taking cyclosporine, he/she may need a blood level drawn. Do not give the morning dose before coming to clinic. You may give this dose after the level is drawn. Ask the nurse on which days your child's level will be drawn.**
- Your child should wear a mask in the hospital outside the isolation room
- Do not visit other inpatients or outpatients, i.e., do not visit 3B
- Report to the reception desk
- You will spend all of the time in the clinic in an isolation room.

Note: You may be spending several hours in the clinic. Meals are not available, so plan to bring or buy food/drinks.



Your visit will include any of the following:

- Assessment and vital signs by the nurse
- Assessment and evaluation by a physician
- Blood sampling and other specimen collection
- Tests and procedures as needed
- Transfusion of blood products as needed
- Administration of intravenous immune globulin (IVIG)
- An opportunity to talk to any of the members of the team, i.e., physiotherapist, dietician, occupational therapist, social worker, etc.
- You will be given an appointment slip for your next appointment before you leave the clinic.

Note: if you are flying home:

Depending on your child's blood counts and immune system, you may need to take some precautions. Ask your doctor or nurse what, if any, of the following precautions you need to take.

- Ask your doctor for a letter that explains your child's condition and details the following
- When you make your reservations:
 - explain your child's condition to the airline.
 - ask for a seat at the front of the plane and by the window.
 - ask if you can wait in an area that does not have a lot of people, ie: Maple Leaf lounge
 - ask if you can be the last passenger to board the plane and the first passenger to leave the plane
- When you check in, ask for the above considerations. Make sure you bring masks, gloves and hand sanitizer
- On the plane, your child should:
 - wear a mask
 - wash his/her hands before eating
 - when going to the washroom, put on gloves, and use the hand sanitizer to clean the toilet seat if your child is going to sit on it
 - use the soap in the washroom to wash your hands, or the hand sanitizer

Additions or changes for my child's care at home

Write in anything else you would like to add about your child's care below:



Commonly Asked Questions

Why do my child's legs hurt?

When the muscles in your child's legs get tired, they hurt. He/she has been in bed a lot and has not been exercising/ walking as usual. It takes a while to rebuild the muscles and strength. Once your child's legs get stronger, the muscles will hurt less.

When will my child feel hungry?

Your child's taste buds have changed from the chemotherapy and/or radiation. Some foods he/she used to like "don't taste the same". The stomach may not be used to having food, so it will take time to regain the appetite. Until then, your child may be on tube feeds. We suggest trying to offer small, frequent meals and snacks that are nutritious and full of calories.

When will my child start gaining weight?

It may take a while. As your child's appetite returns, he/she will gain pounds. Be patient.

When does my child stop taking these medications?

Most of the medications your child is on decrease the risk of infection (Bactrim or Septra, Acyclovir). Once his/her immune system regains function, (6-9 months post-transplant) he/she will be able to stop these drugs, or as advised by the doctor. When your child is on Cyclosporin to prevent graft-vs-host disease, your doctor will monitor him/her for any signs of the disease and will start decreasing this medication based on the assessment.

When can friends visit?

It is preferred that only a couple of friends, whom have been screened for infections, visit at one time.

Can I take my child for a walk and 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 I take my child to the movies?

Yes, but only on "off peak" hours. It would be better for your child to rent video and invite a couple of friends over for movie night. Have lots of popcorn.

How clean should my house really be?

Think of the initial cleaning as a "spring" cleaning. See the guidelines in this booklet.



Can we go to other's 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.

Other resources:

There are several books available at the **Family Resource Library** (on the 2nd floor of the ambulatory care building), which have more detailed information about bone marrow transplantation or stem cell transplantation, if you would like further information.