



Going Home after an Allogeneic BMT

Information for Patients and families



Emergency Phone Numbers

Monday-Friday, 8:00 am – 5:00 pm:	Oncology Clinic (604) 875-2345 local 7079
Weekdays, 5:00 pm – 8:00 am, Weekends and Holidays:	Oncologist on Call (604) 875-2345 ask the operator to page the oncologist on call

Allogeneic Blood and Marrow Transplant (BMT) DISCHARGE INFORMATION

Going home after a BMT is exciting, but can also seem scary at first. You might have questions about how to care for your child outside of the hospital and what you need to do before discharge. We hope this pamphlet will help answer your questions and will help you care for your child after discharge. But these are only guidelines. Every child is different, so your child's medical team may ask you to do things a little differently at home. Check with the medical team about any changes. Write these changes in this pamphlet so you can keep all this information together.

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

Note: we will use both "he" and "she" throughout this pamphlet.

Note: Please check with your doctor/nurse before doing any construction in your home.
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Discharge Checklist

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

Watch for Infections

- Have a thermometer at home
- Know how to take a temperature
- Know how to read a thermometer
- Know what a fever is

- Know what to do and who to call if there is a fever

Prevent and Manage Infections

- Know signs and symptoms of infections
- Understand the special things you need to do to try to prevent infections (eg, isolation, screening visitors, hand hygiene, masks, pets, housekeeping and laundry).
- Know who to call when you see signs or symptoms of infection

Know Central Line Care

- Know how to access the central line videos
- Know how to change the dressing
- Know how to heparinize the line
- Know how to change the cap
- Have discharge supplies
- Know about line problems and what to do and who to call
- Know how to clamp/cover/call

Diet/Fluids/Food Preparation

- Review your child's diet plan with the dietitian
- Know how to feed your child: understand the diet plan and how to prepare food safely
- Know your child's fluid needs
- Know how to give NG tube feedings and have supplies (if your child has an NG tube)
- Know who to call if you have questions

Mouth Care

- Know how to do mouth care
- Know how often to do mouth care
- Know who and when to call for problems in the mouth or throat

School

- Know the importance of keeping up with school work
- Update the school; discuss the best way to help your child keep up with her class
- Arrange a home tutor if needed
- Know when your child can go back to school



When to Call

- Know when to call the doctor, nurse or other team members
- Know important phone numbers
- Know who to call and when

Medications

- Know discharge medications: dose, when and how to give them, side effects
- Get prescriptions for discharge medications and fill them at the Outpatient Pharmacy located on the 1st floor of the ambulatory care building (Starbucks floor) – section #6
 - Hours of operation for the out patient pharmacy are 9am – 4:30pm Mon-Fri (closed weekends and STAT holidays)
 - You can call 604-875-2205 to refill any prescriptions you may need

Follow-up/Outpatient

- Review the plan for follow up with the doctor or nurse
- Be sure you have an appointment for your child's clinic visit
- Make sure you have the equipment and supplies you need before discharge

Other

- Review skin care
- Discuss immunizations for patient, immediate family and any visitors.

Housekeeping/Laundry

Because your child's new immune system is very young, it is important to keep where you are living as clean as possible.

One week before discharge, clean the place where you will be living. This includes all window coverings, windows, surfaces, floors, appliances, walls, etc

Routine Cleaning:

- Dust and vacuum before going home and 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 clothes to an unusual amount of dirt or dust, wash his clothes separately. Wash any new clothes or linen before using.
- Wash dishes in hot soapy water or use a dishwasher.
- Do not use humidifiers or diffusers (this is an easy place for germs to grow).
- Before your child comes home, change furnace/air conditioning filters.
- If you have carpets that are dirty, have them deep cleaned and dried before your child comes home.
- Use a disinfectant (any commercial disinfectant, such as Lysol is fine) for washing, cleaning and disinfecting. Be sure to rinse with water and let dry.
 - Use disinfectant in the "dirtiest" areas, including sinks and drain areas, toilet flush handles, and faucet handles, weekly and as needed.
 - Clean the bathroom that your child uses weekly (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 and as needed.
 - Clean cribs, change table, diaper pail and high chair with disinfectant weekly or as needed.
 - 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, e.g: paints, cleaning fluid, paint thinner and stripper, etc. If these agents are used, be sure there is good ventilation and your child is away from the area.

Do not do any home renovations just before your child goes home and when he is discharged. Check with your doctor/nurse practitioner before starting any type of construction.

Guarding Against Infections

Bacterial, viral or fungal infections can be very serious if they occur after your child has had a BMT. Even though you are very careful, your child may still get an infection. It is common for children to be admitted to the hospital for infections after

transplant. This does not mean you didn't do something right. After a transplant, your child's immune system is new and not at "full strength" yet.

Here are some things you can do that might help your child from getting an infection.

- Everyone living with you, including your child, should wash their hands:
 - before and after meals
 - after using the toilet
 - after touching any animals
 - after coughing or sneezing
 - after touching anything particularly dirty
 - after going out in public places
 - before and after doing dressing changes
 - after touching dirt, plants, flowers

Use soap and water; scrub them well. You may also use alcohol-based hand sanitizer.

- Your child should avoid crowds. This includes:
 - grocery stores and shopping centres
 - movie theatres*
 - restaurants* (see foodsafe guidelines for more about this)
 - school
 - parties
- Your child should wear a mask until day +100, or as long as your doctor/nurse practitioner advises:
 - anywhere in the hospital (other than in an isolation room in clinic or emergency department cubicle)
 - when in crowds that can't be avoided
- Screen all visitors, especially children, for:
 - runny nose
 - cold sores
 - sore throat

- diarrhea
- vomiting
- rashes
- fever
- red or runny discharge from eyes
- chicken pox exposure
- any other symptoms that lead you to believe the visitor may be sick.

Note:

- all visitors must wash their hands using soap and water or alcohol-based hand sanitizer when they enter your home.
- Avoid contact with family members or friends who are, or recently have been, sick.

- If anyone living with you becomes sick:
 - try to limit contact with your child for as long as he is sick
 - the person who is sick should wear a mask whenever she has to be with your child
 - follow strict hygiene measures, especially hand hygiene
- If anyone living with you is exposed to or gets chicken pox, call your nurse or doctor right away. Your child may need to be isolated and/or given medication.
- 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 or any other childhood or communicable diseases.
- 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 sick
 - is not acting like himself

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 not play in dirt, a sandbox, or with live plants. (*Fungus lives in dirt and on some plants.*)
- Stay away from any construction or excavation sites
- Stay away from any place that has bird or bat droppings
- Watch for signs and symptoms of infection:
 - shortness of breath, coughing
 - runny nose
 - if she doesn't react/wake, or reacts/wakes up slower than usual (eg: if you have an unusually hard time waking her up)
 - 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
 - rashes
 - need to pass urine often

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

Pets

Do not adopt any new pets. Check with your doctor or nurse to see when this might be safe.

Before going home, all pets should be checked by your veterinarian:

- Dogs:

- Check for worms and overall health
 - Vaccinations (not with live vaccines) up to date
 - Bathe
- Cats

- Check for toxoplasmosis and overall health
- Vaccinations (not with live vaccines) up to date

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

Feed your pets 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 possible, cats should not be allowed outside.

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 feces; your child should not clean the litter boxes, tanks, or cages – these should be cleaned regularly or more often if needed.
A note about litter boxes: they should not be placed in the kitchen or dining room, or where food is prepared, cooked, or eaten. They should be cleaned daily, away from your child so he doesn't touch or breathe near the box. Make sure the litter is put into a bag and thrown away in a covered garbage can. Dust from the litter box can carry germs that may cause a serious infection.
- If you have other pets, please discuss this with your doctor or nurse.
- Anyone touching pets should wash their hands with soap and water or an alcohol-based hand sanitizer.

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.

Note: if you live on a farm, check with your doctor or nurse for other guidelines.

Skin Care

Showering is preferred over bathing and should be done daily. 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 fragrance-free products of your choice.

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

Some of the medications that your child takes may make 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 going outside. Use even on cloudy days: the sun's rays come through clouds, too!
- Wear sunglasses with UVA and UVB protection

Mouth Care

Good mouth care is an important part of your child's care after a BMT.

- Brush teeth after every meal and at bedtime with a soft toothbrush and 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 keep it with the other toothbrushes.
- Do not let anyone else drink from your child's glass or use her toothbrush. Toothbrushes should be changed at least every 6 months.

Some children have a very dry mouth after BMT. This is called xerostomia and can be caused by Graft vs. Host disease or from the radiation your child may have had. If your child has a very dry mouth or his saliva is thick and stringy, he may have xerostomia. It is very important that your child do good mouth care to prevent infections. If you notice your child is having problems, please talk with your nurse or doctor.

For children with dry mouths

- brush teeth at least 4 times each day, using a fluoridated toothpaste
- rinse with bicarbonate 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 help your child get better. Good nutrition also helps the new stem cells grow. You may have to encourage your child to eat, since her appetite may be off. Before your child leaves the hospital, the dietitian will go over the diet plan with you. If you have any questions, she is available during your child's clinic visits. Please call to make an appointment with her. Some guidelines for feeding your child and preparing food can be found at the end of this pamphlet.

If your child has been fed through an NG tube, your nurse will teach you how to use it at home.

Exercise/Activity

Your child has just been through a lot of treatment. Getting back into a normal routine is important for his growth and development, and his general well being. But it may take a little time; it is normal to feel tired and a bit unsure. If your child's platelets are low, he should be careful doing some activities. If your child is a



toddler, watch closely when she is learning to walk. If your child is older, an activity, such as bike riding, may have to be put off. We will tell you exactly what exercise/activities are safe for your child.

Here are some things to remember:

- Avoid contact sports
- Plan for rest periods: your child's energy level will guide you. If he feels energetic, don't force him to nap, but try to get him to pace himself.
- Avoid swimming for the first 6 months or longer. Swimming in public pools, creeks, lakes or the ocean may not be a good idea, at least for a while. Check with the nurse or doctor before swimming, wading or playing in pools, ponds, rivers, streams, etc.

School:

Arrange for home tutoring so that she can keep up with her class. Tutors should be screened for infections, as described above, and should perform hand hygiene before working with your child. Your doctor will tell you when your child may return to school (usually around 6 months after transplant). You should continue to watch for chicken pox, measles, mumps and other communicable diseases in the school. Talk to the school nurse, principal or teacher.

Immunizations

Your child is not to receive any vaccinations for about 1 year. Check with your doctor or nurse.

Anyone living in your home may receive vaccines. Check with your nurse or doctor before having a vaccine.

When to Call the Clinic/Doctor

Call the clinic or the oncologist on call if you see:

- 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 central line site
- sneezing, runny nose
- sores, white patches, redness and/or pain in the mouth and gums
- rapid or irregular breathing
- Your child or anyone living with you is exposed to, or gets, chicken pox, measles, mumps, or any other communicable or childhood diseases
- Your child cannot take her 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 last longer than 5-10 minutes or starts again after applying pressure for 20 minutes
- Change in how the central line site looks
- Signs and symptoms of graft-vs-host disease (GVHD):
 - change in your child's bowel movements: if the color changes, they become looser or come more often
 - 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
 - less or thicker saliva or if she has a hard time swallowing
 - aches or stiffness in joints
 - shortness of breath, whether she is moving or not
 - activities wear her out more than usual



- You have any questions or concerns.

Note: if your child needs emergency medical care (eg: difficulty breathing, becomes unconscious, bleeding that you can't stop, etc), call 911.

Here is a list of phone numbers to call:

Monday-Friday, 8:00 am – 5:00 pm:

Oncology Clinic

604-875-2345 local 7079

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 BMT
 - have to stay within driving distance of Children's Hospital (within 1 hour drive) or see about Ronald McDonald House
- *After the first 100 days, you may be able to go 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 doctor or nurse.

When you come to the clinic:

- Bring all medications your child will need for the day.
***When your child is taking cyclosporine/tacrolimus, 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 when this will happen.**
- Your child should wear a mask while in the hospital
- Do not visit other inpatients or outpatients
- 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 may include:

- Assessment and vital signs by the nurse
- Assessment and exam by a doctor or nurse practitioner
- Bloodwork and other specimen collection
- Tests and procedures as needed
- Transfusion of blood products as needed
- Giving intravenous (IV) medications as needed
- A chance to talk to any of the members of the team, eg., physiotherapist, dietitian, occupational therapist, social worker, psychologist, etc.
- An appointment slip telling you when to come back

If you are flying home:

Depending on your child's blood counts and immune system, you may need to do some things differently. Ask your doctor or nurse if you have to:

- 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.
 - ask if you can be the last passenger to board the plane and the first passenger to leave the plane.
- When you check in, tell the agent about your child's needs. Ask if they can help.
- Make sure you bring masks, gloves and hand sanitizer.
- On the plane, your child should:
 - wear a mask
 - wash his 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
- Follow the diet and food safety guidelines

Commonly Asked Questions

Why do my child's legs hurt?

When the muscles in your child's legs get tired, they hurt. He 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?

Chemotherapy changes the way your child tastes food. Some foods she used to like don't taste the same. If she hasn't been eating much in the hospital, her stomach can't handle more food. This is normal. Although your child may try hard to eat, sometimes he just can't. We suggest trying to offer small, frequent meals and snacks that are nutritious and full of calories. Talk to your dietitian about this.

When will my child start gaining weight?

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

When does my child stop taking these medications?

This depends on your child's medical condition. When her immune system grows stronger, (usually 6-9 months after the transplant) she may be able to stop some of the drugs. When your child is on cyclosporine to prevent graft-versus-host disease, your doctor will watch her for any signs of the disease and will start decreasing this when he feels your child's body is ready.

When can friends visit?

We think it is best to limit the number of people who come into contact with your child. 2 or 3 friends are OK. They should follow the guidelines listed above.

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?

If this is something your child would like to do, please discuss this with your BMT team.

How clean should my house really be?

Think of the initial cleaning as a "spring" cleaning. See the guidelines above.

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. Talk to your doctor or nurse.

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: