



Going home after an Autologous 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

Autologous 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. 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 autologous BMT (their own cells given back).

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.

Discharge Checklist

The following is a list of information and skills that you will need to know or do before discharge. You may want check each box when 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 who to call if your child has 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 (e.g., screening visitors, hand hygiene, pets, housekeeping, 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 general guidelines
- Know important phone numbers
- Know when to call the doctor, nurse or other team members

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 blood counts are still low, and he is at risk for an infection, it is important to keep where you are living as clean as possible

Before discharge, clean the place where you will be living:

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 before going home and 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 her clothes to an unusual amount of dirt or dust, wash 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 or diffusers (this is an easy place for germs to grow)
 - If you have carpets, have them deep cleaned and dry before your child comes home.
 - 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. 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 renovation.

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 not unusual for children to be admitted to the hospital for infections after transplant. This does not mean you didn't do something right. When the blood counts are low, infections often happen.

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 anything particularly dirty
 - after touching animals
 - after coughing or sneezing
 - after going out in public areas
 - 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.

- Stay away from crowds until his ANC is at least 1.0 or greater. Check with your doctor or nurse.

This includes:

- grocery stores and shopping centres
 - movie theatres
 - restaurants* (see foodsafe guidelines for more about this)
 - school
 - parties
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- Avoid contact with family members or friends who are, or recently have been, sick.
 - Screen all visitors, especially children:
 - runny nose
 - cold sores
 - sore throat

- diarrhea
- vomiting
- rashes
- fever
- red or runny discharge from eyes
- chicken pox exposure
- 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 sick
- If a person living with you becomes sick:
 - try to limit contact with your child for as long as he is sick
 - the sick person 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 communicable or childhood diseases.
- Your child should not visit with other patients in the clinic or other areas of the hospital.
- Take your child's temperature if he:
 - 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.

Your child should avoid playing in the dirt 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 that 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 for infections.

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

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

Note: if your pet has 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' feces. 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, do not allow pet to scratch 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 talk to 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
- birds
- exotic pets
- 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

- After bathing, skin should be rinsed thoroughly before drying.
- Keep skin moist, especially in very cold and very hot weather. Keep exposed skin moisturized, i.e. hands, face and nostrils. Use fragrance-free products of your choice.

Note: if your child has had problems with his/her skin during transplant, your doctor or nurse may give you other tips about how to care for his skin.

- Some of the medications that your child takes may make him 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
- If your child has problems with mouth sores, 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 share a drink from your child's glass or use his toothbrush. Toothbrushes should be changed at least every 6 months.

It is very important that your child have good mouth care to reduce the risk for infections. If you notice your child having problems, please talk to your nurse or doctor.

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 you leave the hospital, the dietitian will go over your child's diet plan with you. If you have any questions, she is available during your 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 and dietician 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 wellbeing. 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 she feels energetic, don't force her to nap, but try to get her to pace herself.
- Check with your nurse or doctor before swimming, wading or playing in pools, ponds, rivers, streams, etc.

School:

Your child may be able to return to school when his ANC is 1.0 or greater and when he is feeling well. Check with your nurse or doctor before sending him to school. In the meantime, you can ask the school to help him keep up with his class by sending work home.

When your child returns to school, talk to the school nurse, principal or teacher; ask them to let you know if anyone has chicken pox, measles, mumps or other communicable and childhood diseases.

Immunizations

Discuss this with your nurse or doctor. You and your family can visit the family immunization clinic to ensure everyone else is up to date on their vaccinations.

When to Call the Clinic/Physician

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

- Signs and symptoms of infection:
 - feeling unwell, irritable or listless

- 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
- 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
 - bleeding/nose bleed that lasts longer than 5-10 minutes or starts again after applying pressure for 20 minutes
- 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 his medications
- Change in how the central line site looks
- 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.

When you return to the clinic:

- Bring all medications your child will need for the day
- Your child should wear a mask while in the hospital, when her ANC is less than 1.0
- Do not visit other inpatients or outpatients
- Report to the reception desk

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
- 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.
- 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 passengers to board the plane and the first passengers 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. Your child 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 to gain 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?

This depends on your child's medical condition. When her immune system grows stronger, (usually around 3-6 months after the transplant) she may be able to stop some of the drugs.

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: