



CHILDREN'S & WOMEN'S HEALTH
CENTRE OF BRITISH COLUMBIA

Going Home after Autologous 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,

Weekends and Holidays:

Oncologist on call (604)875-2161

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 to 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 autologous stem cell transplant (their own cells given back).

Discharge Checklist

The following is 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. screening of visitors, handwashing, pets, housekeeping and trying to prevent infections
- Know who to call when you see signs or symptoms of infection

Know Central Line Care (for CVC)

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



Diet/Fluids/Food Preparation

- Review your child's diet with the dietician
- Know your child's fluid needs
- Review NG tube feeding and have supplies, if applicable
- 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

When to Call

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

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



Housekeeping/Laundry

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

Before discharge, clean your home as follows:

Recommended routine cleaning:

- Dust and vacuum. Do not allow your child to be in the same room while doing this
- Change towels, sheets, washcloths and pillowcases. 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
- Do not use humidifiers (this is an easy place for germs to grow)
- Change furnace/ air conditioning filters
- Your child should avoid playing in the dirt or with live plants. (*Fungus lives in dirt and on some plants.*)

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 oncologist before starting any renovation.

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
- Avoid crowds until ANC is 1.0 or greater
- Your child should 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 thorough 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 on a hospital ward
- 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.



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

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 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 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 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 handwashing 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, chicks, birds, exotic pets, or fish

Wash hands thoroughly if contact does occur.

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 a moisturizer of your choice. Avoid lotions with perfume on sensitive skin.

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
- If your child has problem 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 hang on rack with the other toothbrushes



- Do not let anyone else share a drink from your child's glass or use his/her toothbrush. Toothbrushes should be changed at least every 6 months

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 developing this, please discuss it with your clinic nurse and oncologist.

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 you leave the hospital, the dietician will review your child's diet with you. If you have any questions, she is available during your clinic visits. Please call to make an appointment with her.

Enteral Feeding by NG feeding tube

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

Physical Activity

Your child may tire easily. Your child should be encouraged to get back into a normal routine as quickly as possible. Normal activity and exercise is important for growth and development as well as psychological well being. 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. Increase your child's activities as tolerated.



Here are some guidelines:

- Avoid contact sports
- Plan for rest periods. Your child's energy level will guide you. If your child feels energetic, don't force him/her to nap
- Check with your oncologist before your child starts swimming

School:

We suggest that your child may return to school when ANC is 1.0 or greater and when he/she is feeling well. When your child returns to school, continue to monitor for chicken pox, measles, mumps and other communicable illnesses.

Talk to the school nurse, principal or teacher.

Immunizations

Discuss this with your oncologist.

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, irritable or listlessness
 - 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
- 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 persists for more than 5-10 minutes or recurs after applying pressure for 20 minutes
- Your child or any member of your family is exposed to, or gets chicken pox, measles, mumps, or any other communicable diseases
- Your child cannot take his/her medications
- 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.

When you return to the clinic:

- Bring all medications your child will need for the day
- Your child should wear a mask when his/her ANC is less than 1.0
- Do not visit other inpatients or outpatients, i.e., do not visit 3B
- Report to the reception desk

NB: 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
- 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
- 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, i.e.: Maple Leaf lounge
 - ask if you can be the last passengers to board the plane and the first passengers 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, 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. 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?

Your child's taste buds have been changed due to the chemotherapy. Some foods your child used to like "don't taste the same". Your child's stomach may not be used to having food, so it will take time to build back his/her appetite. Until then, your child may be on tube feeds as well as eating. We suggest trying to eat small, frequent meals and snacks that are nutritious and full of calories.

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?

Most of the medications your child is on decrease the risk of infection (Bactrim or Septra, Acyclovir). Once the immune system regains function (six-to-nine months post-transplant), or as advised by the doctor, your child will be able to stop these drugs.

Other resources:

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