



FREQUENTLY ASKED QUESTIONS AUTOLOGOUS BLOOD AND MARROW TRANSPLANTS (BMT)

Your child is going to have an autologous BMT. We know that families have lots of questions about BMT; we hope this booklet helps. If you have more questions, please ask your nurse or doctor.

Note: we will use both “he” and “she” throughout this booklet.

Here are some words you might hear:

Autologous transplants are when your child gets stem cells from himself. He may donate stem cells for himself from blood (he will be hooked up to a special machine that takes out just the stem cells) or he may donate stem cells from his bone marrow (he will go to the operating room and have many bone marrow aspirations to get the stem cells he needs). Sometimes this is called a “rescue”, since we are not giving him a new immune system, but rescuing him from effects of high dose chemotherapy.

DMSO: this is added to stem cells that are collected from a donor who is far away or when the stem cells are not being given right away. It preserves the stem cells so that your child’s body can use them when they are infused into her.

Engraftment: when the new stem cells show signs they are growing. For example, when your child’s blood counts start to go up.

Preparative Regimen: the chemotherapy (and maybe radiation therapy) used to prepare your child’s body to receive the stem cells.

Stem Cells: Stem cells are the “seeds” out of which all blood cells develop. They are produced and grow in the bone marrow. Stem cells are found in:

- bone marrow (in the center of big bones)
- the bloodstream, especially after chemotherapy or when some medications are given to “push” the stem cells into the bloodstream
- umbilical cord blood of a newborn

ABOUT THE INPATIENT UNIT AND THE ONCOLOGY PROGRAM

For more information about the inpatient unit and the Oncology Program refer to the Parent Handbook. Hardcopies are given to each family admitted to the program and can be found in the Family Resource Library. It is located on the 2nd floor of the Ambulatory Care Building and online:

<http://www.bcchildrens.ca/our-services/support-services/resource-centre>

What room will we be in? Can we choose our room?

On the inpatient unit rooms 102-109 are the BMT rooms. If you have a room preference we will consider that. Note: Room assignments are based on the needs of each child; we will work hard to honor your room request. Please understand if we are not able to do so.

What do the rooms look like?

Each room contains a:

- Bathroom with a bathtub
- TV with an Xbox/DVD player
- Fridge
- Microwave
- Pull out bed and a recliner chair

What can we bring into the room?

Any clean personal items from your own home or those that are new (keep the plastic wrap on them if possible).

- **Plastic, glass, even electronics** such as a tablet or computer: can be wiped with a disinfectant before they come into the room and weekly (more often if they get soiled).

Note:

- dishwasher-safe toys may be run through the dishwasher and immediately bagged as described below.
- bath toys that retain water should not be used when your child's immune system is low

- **Clothes:** should be washed in hot water, dried on high heat and immediately double bagged directly from the dryer (put into a bag, sealed or tied, put into another bag and sealed again). You may also use large plastic bins to store clothes and cleaned personal items. You may wash clothes/toys in cold water if you use detergent for cold water in amounts recommended. Your own clothes do not need special cleaning. However, make sure you wear clean clothes every day. There is a washer/dryer outside the inpatient unit on level 8 by the main doors that you can use. If you need to store your own clothes please double bag them or put them in plastic bins. It is best (but not mandatory) to have a pair of brand new shoes solely worn inside the transplant room, both for the patient and the caregivers. Shoes that can be easily cleaned (e.g. Crocs or plastic Birkenstock sandals) are ideal.
- **Cloth/stuffed toys:** clean as you would clothes. Make sure they are in the dryer long enough to get dry. Stuffing may take a very long time to dry. This should be done weekly and whenever they get soiled, as long as your child is in isolation.
- **Books and other paper products**, e.g.: cardboard: only from home or new ones (not library books or those from other children). Paper products cannot be wiped down.

Note: If a cardboard box or board has a "finish", i.e. it's coated and won't absorb the solution we use to wipe things, you can wipe it and bring it into the room.

- **Pictures or posters** for the walls should be new, wrapped in plastic, or laminated. There is one magnetized wall in each BMT room where you can put up posters/pictures with magnets. The only tape permitted to be used on the room walls is painters green tape.
- **Food and drinks:** meals should be brought into the room as soon as possible. Food left at room temperature, including meal trays, should be removed within 2 hours. Food may be stored in the fridge until container expiry if food is in individually wrapped portions or if clean utensils are used to remove a serving from a larger container. Refrigerated home cooked foods must be labelled, dated, and consumed or discarded within 24 hours. Take-out food is allowed but only from well known, established restaurants. Ask them to make the food fresh and ensure the time it takes to get food from the restaurant to the child is less than one hour. Parents are allowed to eat in the rooms as long as you adhere to the same BMT diet as your child.

Note: Re-usable water bottles for parents can be kept in the room as long as you want if they are capped. They should be washed with soap and water daily. Disposable bottles cannot be reused; they should be discarded after 24 hours. For patients, if the cap stays on and he doesn't drink directly from the bottle, it can stay in for 24 hours; if he drinks from the bottle or it is uncapped, remove after 2 hours.

Not allowed: live plants or flowers, pets, latex balloons or diffusers

Can they have visitors?

Only 2 visitors are allowed in the room at a time. Because his immune system will be knocked out, it will be harder to fight infections. This is why it is best to limit the numbers of people with whom he comes into contact. So choose about 3-5 people to visit inside the room. These people must be healthy. Screen visitors carefully; if anyone has had a cough, fever, vomiting, rash, diarrhea, has a runny nose or signs of a cold or the flu in the past 3 days, or has been exposed to a childhood or communicable disease (for example, measles, mumps, chicken pox or whooping cough in the past 3 weeks) or recently been given a live vaccine, they should not visit. Others can wave from the hallway outside the anteroom. No other children, except siblings who are healthy and have been screened, can visit. This includes other patients or patients' siblings. Visitors may not use your child's bathroom.

ABOUT THE BLOOD AND MARROW TRANSPLANT

How are the stem cells collected?

Stem cells are collected by *Peripheral blood stem cell harvest or apheresis*. Your child will get a special IV and be hooked up to a machine that separates the blood. The stem cells are removed, taken to the lab, frozen, and stored until they are needed. Your nurse will explain how this is done and will give you a pamphlet that explains it.

What will happen before the transplant?

Your child will have many tests and exams done before he is admitted for the transplant. These can be done as an outpatient, through the Oncology Clinic. Your doctor or nurse will explain them to you. Many are blood tests, some are x-rays or CT scans. Your child will also see some specialists, like the dentist and

cardiologist. This helps us see how he is before the transplant and helps us compare how she is during and after the transplant.

Your child will be admitted to the T8 Inpatient unit about a week before the transplant. We start his “countdown” when he is admitted. This means, we count the days until the day of transplant (Day 0). Your child will be admitted around Day -7 or -10. This time might be different, depending on your child’s protocol. He will start the countdown by getting strong medications, called chemotherapy. We give chemotherapy for 2 reasons:

- to get rid of any cancer cells or parts of the blood system that are causing your child’s problem
- to clear the bone marrow space to make room for the new cells. The exact schedule, drugs and their side effects, will be explained by your doctor and nurse. You will be given a calendar and drug information sheets.

What will happen on transplant day (Day 0)?

Your child will be moving into the BMT room either on Day 0 or Day -1. This is the room in which she will be receiving her stem cells, recovering, and waiting for engraftment. This room will be specially cleaned using a “BMT” protocol. Before entering the room, your child will take a bath (shower or in a tub), and put on the clothes you have specially cleaned (see guidelines above).

Your child will be getting cells that have been preserved in DMSO. In order to prevent a reaction to DMSO, we will give your child medications before infusing the stem cells. Some side effects of the DMSO include nausea, vomiting, headache, pain in the abdomen, low blood pressure, slower heart rate and a red color in the urine (this is only for a short time). As the stem cells go into your child, you may notice a strong smell. Some people say it smells like garlic, others say it smells very strong and unpleasant. You can use some aromatherapy in the room when DMSO is used to help with the smell.

The stem cells, which have been put into a blood transfusion bag, are filtered in the lab where they remove fat, small pieces of bone and some fluid. They are frozen, and, when needed, thawed in the lab and brought to your child’s room. They are given as a blood transfusion, through the central line, over a few hours.

The stem cells find the bone marrow spaces and within a few weeks grow and make new blood cells. Risks of the stem cell infusion are

- Fluid overload (we will give her medications to help her urinate if this happens.)
- Anaphylactic reaction (an allergic reaction which we treat immediately).

We will watch your child very closely, taking her vital signs (blood pressure, heart rate, respiratory rate, temperature, oxygen level in the blood) very often, even after the stem cells have gone in. This will be done using a cardiac monitor.

What do I need to do to go into the BMT room?

The first time you enter the room, the nurse will review:

- **Hand hygiene:**
 - Anyone entering the room (staff, family and visitors) must perform hand hygiene

- Remove all rings and watches and roll your sleeves up past your elbow. Nail polish and artificial nails should be removed.

What are the problems and side effects of a BMT?

The preparative regimen, itself, will cause some side effects. Chemotherapy affects the cancer cells, but also the fastest growing cells in the body. These are found in the intestines, the hair follicles, and the bone marrow. This explains some of the side effects you might see. Other side effects may be related to problems with her organs or with engraftment.

- **Nausea/vomiting:** mainly at the time chemo is given. We will give medications to control it.
- **Hair loss:** she will lose all the hair on her head and maybe other parts of her body (eyebrows and eyelashes). This is usually temporary and will start to re-grow (you may see this start in about a month) when the chemotherapy is out of her system. Hair may grow in as a different colour and texture.
- **Lack of blood cells:** She will need transfusions of red blood cells and platelets. White blood cells (WBC), called neutrophils, are usually the first cells to come back; platelets are usually the last. We will watch her blood counts daily or more often if needed. When her blood counts come up we will know that she is engrafted.
- **Infections:** her WBCs will be very low. This means that it will be very hard for her to fight off infections. If she has a fever or other signs of infection, she will need medications to help her fight the infection. We will do blood cultures to make sure we are giving the right drug for the type of infection she has. Infections are the main problem that BMT patients have.
- **Mucositis (mouth sores):** may be sores in her mouth and through her intestines, depending on what drug we use. It may get very uncomfortable and require intravenous (IV) pain medication. When her blood counts come up, the mucositis will be better and then go away.
- **Nutrition:** good nutrition is very important in helping your child get better. Stem cells grow better when your child's body is well nourished. It is very hard for children to maintain the best nutrition when they are getting a BMT. They may try very hard to eat or may be turned off of food. If she can't eat, no amount of encouragement will help. Check the guidelines for diet and nutrition and food safety tips at the end of this pamphlet.

We usually need to feed her through a small feeding tube (called an NG tube - goes in through her nose and down into her stomach). This is the best way to give her nutrition since it keeps the gut working. We will place the NG tube right before or right after she gets her stem cells. We have to do it before she has mouth sores. Your nurse will explain this to you and your child. Your dietitian will go over your child's feeding plan in the hospital and when you are ready to go home.

Some children need TPN (total parenteral nutrition), which is feeding her nutrients through her central line. When she is admitted, the dietitian will meet with you to talk about the nutrition plan.

- **Problems with the liver:** The liver cleans the blood, stores energy, breaks down drugs and helps digestion. We will be doing blood tests and exams to watch for any signs of problems, like weight gain, holding on to water (puffiness in face, hands, feet, or body). For example, *veno-occlusive disease* is a problem that BMT patients sometimes get. If your child gets this, your doctor and nurse will talk to you about treatment. We will likely give her some medication to try to prevent liver problems.
- **Effects on other organs:** chemotherapy does not only effect the bone marrow, but other organs as well. We use those tests of his heart, lungs, kidneys he had before the transplant to help us see how his organs are doing. Some patients may have organ damage as a result of the chemotherapy.

Note: Sometimes transplant patients may need the special services of the Intensive Care Unit (ICU). If your child is very sick, needs breathing support, or if he needs special monitoring or medication to support his blood pressure or other body functions, and we cannot care for him on T8, it may be safer for him to be cared for in the ICU. The most likely reason for going to the ICU is an infection. While he is there, the ICU team will be caring for him and making the day to day decisions. The transplant team will help guide BMT decisions and care. We work closely together to give your child the best care. As soon as he does not need these special services, he will come back to T8.

There is a small risk that she could die from the side effects of the BMT. The major cause of death is overwhelming infection. We will talk with you more about this if needed.

What will our days look like when we are in the BMT room?

Your daily schedule will depend on your child. She may be having side effects and need a lot of care (i.e., blood and platelet transfusions, IV fluids, pain medications, antibiotics, etc.) She may not feel like doing much. Each day, your nurse will review the plan for the day. This has to be flexible - it will depend on your child's needs. You can expect:

- Wake up at 8 AM
- A nurse will be doing:
 - vital signs (temperature, blood pressure, heart rate, respiratory rate) at least every 4 hours around the clock (may be more often if needed)
 - physical exams (at least at the beginning of every shift; more often if needed)
- A doctor will be checking her at least once a day and as needed
Bloodwork will be done every day and as needed, usually between 4 and 6 AM. This is so the doctors will have the most up to date information when they plan each day's care.
- Other tests (i.e., x-rays, scans, etc.) will be done as needed, depending on your child's condition
- Twice daily weights are usually done around 10 AM and 6PM

- Daily baths. If he is too sick to take a bath, he will have a sponge bath. He will use a mild soap. After rinsing thoroughly (use hand held shower head if possible), generously apply a moisturizing cream. We provide the soap and moisturizers. Linens are changed daily and as needed. The linens on your parent bed should also be changed daily.

Note: Because your child's skin is sensitive after a BMT, you may not use your own skin care products. Even products labeled for sensitive skin often contain chemicals that can irritate. Many are not fragrance-free.

- Toileting: After a bowel movement or if using diapers, clean with damp wipes. After both a bowel movement and passing urine, dry gently and well. If her skin is irritated, we will use a cream to protect her skin and treat/prevent skin breakdown. After toileting patients clean their hands with soap and water or hand sanitizer.
- Mouth care: this is very important since she will not be able to fight off infections. She will need to do mouth care at least 4 times each day with a toothbrush or toothette and rinse with a bicarbonate solution. She may need to suction thick saliva that is hard to spit out on her own.
- Exercise: It is important that your child get out of bed and move as much as she can. Even sitting on the side of the bed or in a chair is better than lying in bed. If your child needs it, your nurse will be there to help. Of course, all this depends on how your child feels and her medical needs. If moving and exercise are tough for your child, the nurse can contact the physical therapist for help. Talk to your nurse about this.
- The *child life specialist* will work with your child daily, if he feels up to it. Check with her to see what time is best.
- The *music therapist* is available at times throughout the week. She will check in with you.
- Others who might spend time with your child include the dietitian, spiritual care, social worker, psychologist, teacher, and occupational therapist.

Tip: When others are with your child, use the time for yourself: rest, exercise, meals. Plan to have a friend meet you for a coffee break or a walk.

What can we do to help prevent infections?

Most infections in BMT patients are from bugs that are already in their own bodies. We can't prevent those infections. But we can try to prevent infections that come from outside his body. So the most important things you can do:

- Good hand hygiene: before you come into the room, if your hands get dirty in the room, after helping your child with toileting
- Daily baths
- Good mouth care, at least 4 times each day. Your nurse will show you how.
- Do not leave unrefrigerated food in the room for more than 2 hours

- Do not leave open drinks in the room for more than 2 hours. (Capped bottles can stay in for 24 hours)
- Exercise and walk around the room as much as possible

Here are some more things you and your child should do:

- Make sure anything that comes into the room is cleaned (see above)
- Do not walk with bare feet. Have a pair of shoes or sandals that are easy to slip on and easy to clean (Crocs and plastic Birkenstock sandals work well.)
- Consider the floor “dirty”: anything that drops on the floor has to be kicked out of the room. It cannot come back in until it has been properly cleaned.
- Keep the door to your room closed at all times
- Choose visitors carefully (see above)
- No live plants or flowers

How will we know that the new cells are growing (engraftment)?

Usually within 14-21 days we see signs of engraftment: blood counts begin to come up. This means that she will be able to fight infections better; if there is any mucositis, it should get better; and the need for blood product transfusions will decrease. The neutrophils are usually the first to grow, and the platelets are usually the last. As the new cells grow, you may see the blood counts go up and down. This is normal. We will be watching this very closely.

How long will we have to stay in the BMT room?

Because your child is receiving an autologous transplant he does not have to stay inside the room at all times. However, he must stay within the inpatient unit. Decisions about isolation depend on your child’s health and safety. Check with your nurse about what is safe for your child.

When can my child go home? After stepdown

isolation, you can go home when:

- ANC is 0.5 or higher for at least 2 days together
- Able to keep up her nutrition by NG tube feedings or by mouth
- No fever or signs of infection
- Limited need for transfusions
- Able to take medications by mouth or NG tube

When we see signs of engraftment, we will start talking to you about going home. The nurses will start discharge teaching and you will receive a pamphlet called “Going Home After an Autologous Transplant”.

OTHER QUESTIONS

Can we get flu shots?

Yes! We encourage you to get flu shots. Visit the Family Immunization Clinic (by Starbucks) to see about getting yourself and your family vaccinated. Check with your oncologist or nurse about flu shots for the child who will be getting a BMT.

Where can I get more information?

Please ask your doctor or nurse for more information or if you have questions. You can also get information from:

- The Family Resource Library. It is located on the 2nd floor of the Ambulatory Care Building and online: <http://www.bcchildrens.ca/our-services/support-services/resource-centre>
- Internet resources that you might find helpful:
 - UCSF Childrens Hospital: <https://www.ucsfbenioffchildrens.org/education/>
 - National Cancer Institute:
<http://www.cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant>
- Blood and Marrow Transplant resources and links:
<https://www.aboutkidshealth.ca/Article?contentid=1575&language=English>

Autologous Stem Cell Transplants: A Handbook for Patients

Written by a transplant survivor, Susan K. Stewart, this book is a helpful guide for people going through an allogeneic or autologous transplant. She talks about the details of the transplant itself as well as the emotional stress that comes with the experience. The book also contains a chapter for parents whose child is undergoing a transplant.

Website for siblings

Super Sibs!

www.alexislemonade.org/campaign/supersibs-sibling-support-childhood-cancer-families

Created in 2002, this website provides information and resources to support siblings of children diagnosed with cancer. The website has sections designed for siblings of different ages and circumstances, which are updated monthly. As well as providing a dynamic online support environment, siblings can find:

- education and outreach resources
- comfort and care packages for siblings
- areas where they can join sibling camps
- SuperSibs! newsletter which contains letters, poetry and photos from siblings in different age groups

Books for kids

Me and My Marrow: A Kid's Guide to Bone Marrow Transplants

By Karen Crowe

This is a children's book inspired by a 13-year-old transplant survivor named Christina Cuzzone. By telling Christina's story, this book helps guide children through the transplant experience, and is filled with colourful illustrations. Me and My Marrow can help kids understand:

- what a transplant is

- how it is done
- what treatment will feel like
- how to cope during difficult times

I'm having a Bone Marrow Transplant

This is a colouring book that children may find useful during their stay in the hospital. It helps children understand what it is like to have a blood and marrow transplant. Children can also draw their own pictures as well.

This book can be ordered through the Leukemia & Lymphoma Society.

When Someone has a very Serious Illness

By Marge Heegaard

This is a workbook which helps children express their feelings about serious illness. It is a great resource that helps children cope with someone else's disease. This may be a helpful resource for both your child and siblings.