

Going home after an allogeneic stem cell or bone marrow transplant



**Information for patients and families from the
Bone Marrow Transplant Team**
5th Edition

Contacting Your Transplant Healthcare Provider

Contact number 905-387-9495

Please identify that you had a stem cell transplant and have your JCC chart number ready if available.

Describe your problem to the secretary and they will direct your call to the appropriate person.

Appointment change

JCC Clinic:

If you need to change your appointment at the Juravinski Cancer Centre, Monday to Friday between 9:00 a.m. and 5:00 p.m., call 905-387-9495 and choose option: "If you are calling to change your appointment, press 1" and ask for Clinic F.

Oncology Day Services

If you need to change your appointment at the Juravinski Hospital – Oncology Day Services, Call 905-521-2100, ext 43772.

Urgent problems: Monday to Friday, from 9:00 a.m. to 5:00 p.m.

If you have an urgent problem and need to speak with your doctor or nurse practitioner.

- Call the Hematology Department at the Juravinski Cancer Centre at 905-387-9495
- Choose option: "If you need to speak with your health care team, press 2"
- Then choose "For Hematology patients, press 1"

Please identify that you had a stem cell or bone marrow transplant and have your JCC chart number ready if available. Describe your problem to the secretary and your call will be directed to the appropriate person.

Urgent problems are considered to be any change in condition such as:

- fever of 38.0°C or higher
- chills
- bleeding
- diarrhea
- severe nausea or vomiting
- difficulty breathing
- pain
- skin rash

If you become very short of breath or develop severe chest pain, call 911 or go directly to the Emergency Department.

Urgent problems after hours

- Call CAREChart@Home 877-681-3057.
- Let them know you are a transplant patient. They will re-direct calls from recent transplant patients to the Hematologist on-call at the Juravinski Hospital.



Going home after an allogeneic stem cell or bone marrow transplant

Reading this book can help you and your family prepare for going home from the hospital after you transplant.

If you were not in the hospital for your transplant, the book provides information on recovering after a transplant.

You will need to follow the precautions outlined in this book for at least 12 months after your transplant.

Your transplant nurse will review this information with you, please ask her to clarify what you do not understand.

If you have questions, please ask any member of the team.

The Bone Marrow Transplant Team
Juravinski Hospital and Cancer Centre
Hamilton Health Sciences

My JCC chart number is: _____

While at home, call us with your questions or concerns. Please refer to the Telephone instructions page on the inside cover.

- ✓ Please provide us with an alternate contact numbers for you if you are not staying at home.

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Getting ready to go home

Thinking about going home

Thinking about going home can be exciting. You may be looking forward to getting home and having your family and friends around you. You may want to leave the hospital as soon as possible. However, after spending weeks in the hospital you may be worried or fearful.



This is a natural feeling shared by most people who have had a transplant. Sometimes, you may have both of these feelings. This is a normal reaction. It may take a little time to feel confident about going home.

Resuming your home life means getting used to living together as a family again. The need to take precautions to protect your health may be stressful for you and your family. Be aware that the person who supports you the most may feel even more stress than yourself. However, most people adjust very quickly. You may find that the precautions soon become a routine part of your day.

Recovering

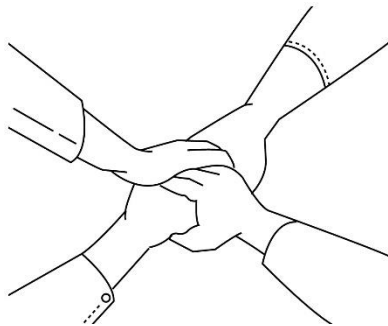
You and your family may expect you to feel and act as you did before your illness and treatment. This will not happen immediately. Most patients feel weak and tired, and have less appetite. The most common feeling is impatience in getting back energy and stamina. Keep in mind that you will need help and time to recover. It will take a few months to regain your strength and your ability to take part in daily activities. During this time, it is normal to have good days and bad days. As you get stronger, you will be able to do more. You can expect that most limitations will go away in time.

Planning your recovery

During the next few months, your plan for recovery will include:

- taking steps to avoid infection
- watching for possible health problems
- doing your personal care and taking care of your catheter (Hickman or PICC)
- making sure you eat well and follow food safety guidelines
- taking many medications safely and watching for possible side effects
- balancing rest and activity
- getting help and support from others
- getting follow-up care

The Transplant Team will be available to give you information and support during your recovery at home.



Preventing health problems

It is possible to develop health problems after a BMT. Possible health problems include infection, bleeding and graft-versus-host disease (GVHD). The Transplant Team will help you learn how to prevent health problems. However, there is still a chance that a problem could occur.

It is important to recognize the signs of health problems so that you can get help right away. A list of these signs is on page 6.

Infections

During the first year after transplant, your body is less able to fight infections. Your new bone marrow can meet some of the challenges of everyday life. However, your risk for infections will be higher until your immune system matures and becomes stronger. This may take several months.

The Transplant Team will help you learn how to prevent infections at home. The information in this book can help you remember what to do. During your follow-up visits to the clinic, the Transplant Team will regularly check your immune system, especially during the first 3 months. If there are any problems, the team will respond right away.

If you are not feeling well, check and record your temperature 2 times a day; once in the morning and once in the evening. Bring this record to your clinic visit. If you are taking Tylenol for any reason this may affect your temperature. Avoid taking Tylenol unless approved by your nurse or doctor.

If you or a family member has been exposed to someone with chicken pox, call the Transplant Team immediately and page the hematologist on-call at the Juravinski Hospital at 905-387-9495

Bleeding

Platelets are usually the last type of blood cell to start growing again in your new bone marrow. Platelets help form the clots that control bleeding. Your platelet level will be checked at your clinic visits. If the level is too low, you may need platelet transfusions.

If your platelet count is below 50 you will need to take extra care to prevent bleeding:



- shave with an electric razor
- clean your teeth with ultra-soft toothbrush (preferred) or toothette
- blow your nose as gently as possible
- try to avoid accidents or injuries – for example avoid sharp objects that could cut you or exercises (sports) that could cause injury
- do not take aspirin or any products that contain aspirin
- take acetaminophen (Tylenol) instead
- do not use enemas, suppositories or a rectal thermometer
- women should not use tampons

What to do if you have an injury:

- If you cut yourself put a clean, dry gauze pad over the cut. Keep firm pressure on the gauze until the bleeding stops.
- If your nose bleeds sit up and lean forward slightly. Try not to swallow the blood as it may make you feel sick. Squeeze the bridge of your nose with your thumb and forefinger for 10 minutes without letting go. If it is still bleeding, apply a small bag of ice to the bridge of your nose for another 10 minutes. If it continues to bleed, call your doctor.
- If you need medical care at another hospital, have the doctor talk with us. If you are in an accident and need blood products they must be irradiated first to prevent graft-versus-host disease.

It is important to wear a medical alert bracelet that reads “BMT transplant: irradiated blood products required”.



Graft-Versus-Host Disease (GVHD)

When your new bone marrow begins to grow, there is a chance that graft-versus-host disease may develop. GVHD is the reaction of the donor's immune system, which is in the marrow, against your own body. GVHD often affects the skin, the gastrointestinal tract (stomach and bowels) or the liver. You will take medications such as cyclosporine to help control this reaction.

There are 2 forms of GVHD:

- **Acute GVHD** occurs within 100 days of transplant. The symptoms of acute GVHD may be mild or severe.
- **Chronic GVHD** develops after 100 days. If you do not develop acute GVHD, it is less likely that you will develop chronic GVHD.

At your clinic visits the Transplant Team will check for any signs of GVHD. This may include blood tests to check if your liver is working normally or has signs of this disease.

Late GVHD (chronic) may affect the mouth and eyes. Women may have changes in the vagina. If you do develop GVHD, the doctor on the Transplant Team will discuss the treatment plan with you.



**If you notice any of these signs,
call the Transplant Team right away at
905-387-9495**

		Possible Health Problems			
		Infection	Low platelets	Acute GVHD	Chronic GVHD
Body	• fever: a temperature over 38° C (100 ° F)	■			
	• shaking or chills	■			
	• difficulty flushing your central line catheter or chills after you flush your catheter	■			
	• pain in your throat, joints or abdomen	■			
Breathing	• a persistent or nagging cough	■			
	• sneezing or a runny nose	■			
	• chest discomfort or feeling short of breath	■			
Eyes	• your vision becomes blurred or unclear	■			
	• the white part of your eyes becomes yellow			■	■
	• your eyes are red, painful or draining	■			
Skin	• your skin is flushed (red) or sweating	■			
	• redness, swelling or pain on any area of your skin – especially around your collarbone or the site of your central line catheter	■			
	• small blisters like cold sores around your mouth or any part of your body	■			
	• a skin rash develops or gets worse	■		■	
	• a skin rash or itching, especially on the palms of your hands or soles of your feet				■
	• your skin becomes yellow (jaundice)			■	■
	• bleeding from around your nose or mouth		■		
	• bruising		■		
	• tiny “pinpoint” red or purple spots on the skin		■		
Urine	• frequent or painful urination (burning)	■			
	• blood in your urine		■		
	• a change in the colour of urine			■	
Bowel Movements	• diarrhea: frequent or watery bowel movements	■		■	
	• stinging or irritation around your anus, pain in your rectum or when you have a bowel movement	■			
	• blood in bowel movements		■		
	• change in colour of bowel movements – pale, like clay			■	■

Follow-up care

During the first 3 to 6 months at home, it is best to call the Transplant Team if you have any questions or concerns.

Please refer to the Telephone Instructions page on the inside cover.

Oncology Day Services (B4)

It is very important to get regular follow-up care at the Oncology Day Services (ODS). We will arrange for your first visit to the ODS before you leave the hospital.

During the first few months after your transplant you will visit the ODS often. At your follow-up visits the doctor and nurse practitioner will check your progress, discuss your care and concerns, and answer any questions you may have. If you wish, you may continue to meet with the social worker. Please let us know if you would like the social worker to be available during your clinic visits. Anytime you have an urgent concern, please call the social worker who was involved in your care during treatment or a new referral can be made through the Juravinski Cancer Centre Supportive Care Program.

At first, you will have blood tests at every ODS visit. You may also need to receive intravenous fluids or blood products. These first visits usually last a long time. Bring everything you will need for the day such as medications, food or a glucometer and supplies if needed. Please have someone come with you, until you get comfortable with the routine and your energy level is higher.

Later on, if everything is going well, you will not need to visit ODS as often. After about a year post-transplant, you will be followed at the clinics in the Juravinski Cancer Centre.

You should wear a procedure “face” mask to your ODS appointments until day 100.

Handwashing is the most important thing you can do when you are in public areas.



What to remember for clinic visits:

- On some days you will be asked to be at ODS early, by 8:30 am or earlier at 7:15 am.
- Do not take your morning dose of cyclosporine before your ODS or clinic visit, if you are having blood levels taken. Bring your dose with you so you can take it after your blood work is done.
- Wear a mask to the hospital until after day +100. If you are in your own patient room in the hospital, you will need to wear a mask only when outside of the room. The mask needs to be changed after about 30 minutes.



Family doctor

Your family doctor is an important person in your care and will be notified when you leave the hospital. We will send your family doctor a letter outlining the details of your stay in the hospital and what follow-up visits are planned.

Make an appointment to see your family doctor soon after you get home.

Immunizations

Do not have any immunizations (vaccinations, boosters) until you have discussed this with your transplant doctor. Your doctor will give you immunizations if necessary, depending on the results of your blood tests.

You may not have any immunizations while you are taking medications that suppress your immune system (immunosuppressive therapy), which is about a year. During this time, some immunizations are not safe and some may not work.

Family and close contacts will be asked to get a flu shot.



Dental care

Continue to visit your dentist regularly to check that your teeth, gums and mouth are healthy. It is important to tell your dentist that you have had a blood or bone marrow transplant.

Do not have any dental work until your dentist has contacted your transplant doctor. You may need to take antibiotics before dental work to prevent infection.

Caring for yourself

Washing your hands

Washing your hands is the best way to prevent infections. It is important that you, your family and visitors wash their hands well. This means washing your hands, fingers and nails with antimicrobial soap and warm water. Then, rinse with water and dry with a clean towel.

If soap and water are not available, you can use water-less soap (sanitizer). Put a large drop of sanitizer, about the size of a quarter, on your palm. Then rub it over your hands and fingers.

Wash your hands:

- before preparing food or eating
- after using the bathroom
- after going outdoors
- before and after touching wounds
- after touching pets or animals
- after touching dirt or plants
- after touching your mouth or nose
- after touching other people
- after activity
- after changing diapers (someone else should change diapers if possible)



Showering or having a bath

Keeping your body clean also helps prevent infections. Take a shower each day and wash with a mild soap, such as baby soap or Ivory. Wash under your arms and in the groin area very well. If you take a bath, do not let your central line catheter (Hickman or PICC) go under the water.

If you have dry skin, apply a mild moisturizer such as Keri-Lotion to your skin while it is still wet.



Caring for your mouth

Germs can easily grow inside your mouth where it is warm and wet. Keeping your mouth clean can help prevent infections. Brush your teeth after each meal and before bed using an extra soft toothbrush (preferred) or toothette.



If you floss your teeth, you must be very careful and gentle. Flossing can cause infection and bleeding.

Flossing is not recommended:

- for children under 12 years
- if your white blood cell count is less than 1.5
- if your platelet count is less than 60



If you wear dentures, it is very important to keep them clean. Soak them for 30 minutes each day in a solution of 1 part bleach and 3 parts water. Rinse them for about 10 minutes. This may lighten the colour of your dentures, but it will prevent them from having fungus.

It is common to have a dry mouth after a transplant. Try rinsing your mouth several times during the day. Use a solution of 2 ml (½ tsp) baking soda in 250 ml (8 oz) of water. Do not use a mouthwash or hydrogen peroxide as they can irritate the inside of your mouth. If this does not relieve your dry mouth, talk with your dentist or the transplant doctor.

Caring for your catheter (Hickman or PICC)

Your catheter will stay in place until at least day +100. You will go home with a clear dressing that needs to be changed every week. Please keep track of your dressing changes and tell the clinic staff when a change is due. If you will not be at the clinic for a week, we will arrange for home care or our staff may teach you or a family member how to change the dressing.



Keeping your central line catheter and the exit site clean is just as important now as it was in the hospital. Do not allow any tension (pulling) on the catheter. If you have a Hickman catheter, keep it pinned with tape at all times. Do not allow the catheter to go under water. If you have any questions about the care of your central line catheter, please call the transplant nurse.

Life at home

After you leave the hospital, it will take some time to adjust to being home. You may have little energy or strength. You will probably need help at home with:

- cleaning
- shopping
- cooking
- caring for your children
- caring for your pets

Cleaning your home

Some common germs can be found inside your home. Usually these germs would not make you sick. However, after a transplant your body may not be able to fight these germs. So it is important that your home is as free of dirt and dust as possible. This will make your home a safer place for you to recover.

You will need someone to clean your home until you are no longer at risk of getting infections. Here are some instructions to give the person helping with the cleaning:

- Clean and dust regularly, you do not need to go to extremes.
- Keep the bathroom clean by regularly using a disinfectant such as bleach.
- Wash your cutlery (knives, forks and spoons) with hot water and dishwashing detergent. You should not share eating utensils with anyone.
- Wash your towels at least 2 times a week. Wash your bed linen once a week. You should not share towels and sheets with anyone.

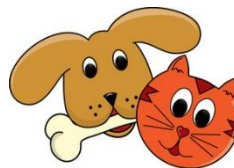


Do not have home repairs or renovations done as this will release dirt, dust and germs into the air.

Do not buy new plants or indoor flowers for the first 3 months at home. It is best not to touch plants or soil. If you cannot avoid this, wear gloves and wash your hands afterwards.

Living with your pet

Most household pets are safe to stay in your home. However, you should not have any contact with these types of pets:



- ducklings and chicks
- exotic pets
- reptiles such as snakes, lizards, turtles or iguanas

Do not touch these animals, their food or anything they have touched. If this contact happens, wash your hands well.

Here are some ways to live safely with your pet:

- Try to limit the amount of close contact you have with your pet. Wash your hands after touching your pet.
- Do not put your pet's litter box or cage in the kitchen or where you prepare and eat food.
- Do not touch any animal waste. You should not pick up dog feces, change litter boxes, clean bird cages or fish bowls. If you must clean up after your pet, wear disposable gloves and wash your hands afterwards.
- Only feed your pet food bought from a store. Do not allow your pet to scavenge, hunt or eat raw foods. Do not allow your pet to drink water from the toilet or eat from the garbage.
- Take your pet to the veterinarian (animal doctor) at the first sign of illness.
- Keep your cat indoors.

**Do not have any contact with animals
that are not your pets.**

We recommend that you do not bring any new pets into your home for the next 6 months or longer if you have graft-versus-host disease.

Avoiding illnesses

While your risk of infection is still high you must try to avoid getting germs from other people. It can help to limit the number of visitors you have (only 2 or 3 at a time). Avoid close contact with anyone who is ill.

Sometimes, close contact is unavoidable, such as when someone in your home has a cold. A person with a cold can reduce the spread of germs by:

- washing their hands often
- sneezing or coughing into disposable tissues, then throwing them away
- wearing a procedure “face” mask



You may want to wear a procedure mask when you are in the room with a person who is sick.

Remember to wash your hands if you touch the person or touch an object he or she has used such as the telephone.

If you or any family members are exposed to a person with chicken pox or shingles, call the Transplant Team immediately. It is important that you receive Zoster Immune Globulin, which contains antibodies to the chicken pox virus. When it is given immediately after exposure to the virus, it can prevent infection or limit its severity.

If you have any questions about illnesses, please call the Transplant Team.



Healthy eating

Healthy eating is good for you and helps you recover.

After your transplant, you may feel tired and have less appetite. This can make it harder for you to get the nutrition you need. You will need to choose foods and drinks that help you regain your strength.

To prevent infection, you must choose and prepare foods carefully for 3 months after your transplant and until you no longer take immunosuppressive medications (for example: cyclosporine or steroids).

If you have any questions about healthy eating for recovery, please talk with the dietitian on the Transplant Team.

Drinking enough fluids

It is important that you continue to drink enough fluids at home. We recommend that you drink 2 litres (8 cups) of fluid each day.



Some cautions about fluids:

- Limit fluids that contain caffeine (such as coffee, tea and cola) to no more than 500 ml (2 cups) a day.
- Check with your doctor before drinking any alcohol. Alcohol can affect your liver and interfere with medications such as prednisone.
- Do not drink water from a well that is not chlorinated. If your water comes from a well, it must be checked regularly to make sure it is safe to drink.
- Do not drink unpasteurized milk, fruit or vegetable juices.

Eating safely

To protect yourself from infection, you will need to make sure your food is safe. Food becomes unsafe to eat when bacteria have grown in or on it. You may not be able to see, taste or smell the bacteria, but they can be harmful to people who have a weak immune system. Follow the guidelines from the “Food safety after a stem cell transplant” booklet.

<http://www.hamiltonhealthsciences.ca/documents/Patient%20Education/FoodSafetyStemCellTransplant-trh.pdf>


Foods to avoid: these foods are not considered safe to eat

Meat and Poultry	<ul style="list-style-type: none">• Raw or undercooked meat and poultry• Deli meats, hotdogs and processed meats• Unpasteurized, refrigerated pates or meat spreads• Use a food thermometer to check the internal temperature• Cook ground beef to an internal temperature of at least 160°F• Cook ground chicken 165°F• Cook red meat 165°F• Cook poultry 180°F• Cook pork 165°F
Seafood and Fish	<ul style="list-style-type: none">• Any raw or undercooked fish, such as sushi or ceviche• Refrigerated smoked fish• Precooked seafood, such as shrimp and crab• Cook fish to an internal temperature of at least 160°F• Cook seafood 145°F
Milk and Milk Products	<ul style="list-style-type: none">• Unpasteurized milk• Yogurt or frozen yogurt• Soft cheeses made from unpasteurized milk such as feta, brie, camembert, blue-veined cheese, queso fresco✓ Soft cheeses that are clearly labeled “made from pasteurized milk” are allowed

Foods to avoid (continued)

Eggs	<ul style="list-style-type: none">• Foods that contain raw or undercooked eggs, such as homemade Caesar salad dressing, homemade raw cookie dough and homemade eggnog.• Cook eggs to an internal temperature of 160°F<ul style="list-style-type: none">✓ At home use pasteurized eggs/egg products when preparing recipes that call for raw eggs.✓ Most pre-made foods from the grocery store, such as Caesar salad Dressing, pre-made cookie dough or packaged eggnog are made with pasteurized eggs.
Tofu	<ul style="list-style-type: none">• Raw or uncooked tofu
Nuts	<ul style="list-style-type: none">• Raw unroasted nuts or nuts roasted in the shell
Fruits and Vegetables	<ul style="list-style-type: none">• Unwashed raw fruits or vegetables• Fresh squeezed/unpasteurized vegetable or fruit juice• Fruits that are difficult to wash such as berries• Raw sprouts (alfalfa, bean or any other sprout)
Grains	<ul style="list-style-type: none">• Raw or uncooked grain products• Raw or uncooked brewer's yeast. You should not touch raw yeast or make your own bread.• Unpasteurized beer, such as home brewed or microbrewery beer
Other	<ul style="list-style-type: none">• Anything that has mould in it, such as cheese• Some naturopathic medicines contain mould and should never be taken without talking to your transplant doctor.• Raw or unpasteurized honey• Mate tea• Any food that is past the "best before date"

Tips for grocery shopping

What to buy	
<ul style="list-style-type: none">✓ Buy fruits and vegetables without spots or damage.✓ Check “best before” dates.✓ Check that all packaged foods are sealed.✓ Buy foods such as meat and cheese that are “packaged on’ the day that you buy them.✓ Pick up hot and cold foods near the end of your shopping.✓ Shop for meat last. Put meat in plastic bags to prevent drips from getting on your hands or other foods.	

What to avoid
<ul style="list-style-type: none">✗ Do not buy eggs that are cracked or broken.✗ Do not buy cans or jars with dents, cracks, bulges or leaks.✗ Do not buy bulk food from self-serve containers.✗ Do not buy foods at or near the “best before” date.✗ Do not taste free samples.

- When you get home, put cold foods in the fridge as soon as possible. Do not keep hot or cold foods at room temperature for longer than 2 hours.
- Wash your hands after shopping and putting groceries away.

Tips for preparing food

- ✓ Keep your kitchen clean to reduce bacteria.
- ✓ Wash your hands with soap and water before touching food.
- ✓ Wash all fruits and vegetables well under running water.
- ✓ After preparing raw poultry, meats or seafood, wash your hands before preparing other foods.
- ✓ Use plastic cutting boards, not wooden boards. Use separate cutting boards for cooked and raw foods. Also use separate cutting boards for meats.
- ✓ Wash all utensils, boards, countertops and appliances with hot soapy water before and after contact with raw foods.
- ✓ Replace your dish cloths and dish towels each day, wash them with bleach. Do not use sponges.

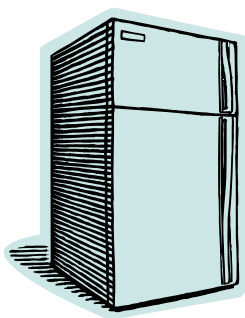
Tips for cooking

- ✓ Thaw foods in the fridge or in the microwave, not on the counter at room temperature.
- ✓ Cook all meats, poultry, fish and eggs until they are well-done. Use a meat thermometer to make sure the meat is well-done.
- ✓ Cut tofu into 2.5 cm (1 inch) cubes and boil for more than 5 minutes before eating.
- ✓ If barbecuing, pre-cook meats to make sure that they are well done.
- ✓ If microwaving, follow the temperature and cooking times recommended for your oven.
- ✓ Do not use slow cookers (crock pots). Bacteria can grow when food is cooked for a long time at a low temperature.

Bacteria grow quickly between 4°C and 60°C (40° F to 140°F).

To keep food safe, shorten the length of time that food is within this temperature range.

Tips for storing food



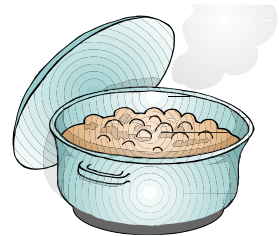
- ✓ Divide large amounts of leftovers into small, shallow containers. These will cool faster in the refrigerator.
- ✓ Keep raw foods such as meat, chicken and fish away from ready-to-eat foods. Put raw foods in their own containers or plastic bags.
- ✓ Refrigerate leftovers within 2 hours of cooking. Throw away leftovers that have been at room temperature longer than 2 hours.
- ✓ Store leftovers in the refrigerator for no longer than 24 hours.
- ✓ Throw away any egg, cream, mayonnaise, cheese or milk containing dishes that have been out of the refrigerator more than 1 hour.

Guidelines for storing food

Food	Fridge 4°C (40°F)	Freezer 0°C (18°F)
Eggs	3 weeks	do not freeze eggs
Cheese	2 to 3 months	3 months
Fruits and vegetables	5 to 7 days	1 year
Beef	2 to 5 days	10 to 12 months
Poultry (chicken, turkey)	3 to 4 days	9 to 12 months
Hamburger and sausage	1 to 2 days	1 to 4 months
Lamb, pork, veal	3 to 5 days	4 to 6 months
Bacon	1 week	1 month
Ham	1 week	1 to 2 months
Fish	1 day	1 month

Tips for reheating foods

- ✓ Reheat leftovers or partially cooked foods to over 75°C (165°F) before serving.
- ✓ Bring leftover soups, sauces and gravies to a rolling boil before serving.



Tips for dining out

- ✓ Choose foods that are prepared fresh, not served from a warmer.
- ✓ Order poultry, fish and eggs well-done.
- ✓ Do not order foods that have raw food in them such as sushi, mousse, Caesar salad or hollandaise sauce.
- ✓ Do not eat at a buffet, salad bar, delicatessen or have foods at a “pot luck” meal.
- ✓ Do not buy food from a street vendor.
- ✓ Do not have soft-serve ice cream or yogurt served from a machine.

If you are not sure how the food is cooked – ask!

Activity and exercise

With time you can expect to return to all your daily activities. A full recovery may take months, but with help and support you can do it. You will need to pace your activities for the first few months. This will allow you to accomplish your interests while building endurance. As your blood counts and energy level improve, your doctor and the physiotherapist on the Transplant Team will let you know when you can resume your usual activities and routines.

Your balance may be affected for a period of time due to weakness or the effects of chemotherapy. This can leave you at risk of falls. You may need a cane or walker for a while. The physiotherapist can show you exercises that will improve your balance.

Exercise is an important part of your recovery.

Start with a little exercise each day. You may tire easily at first, so remember to balance rest with activity. Plan time to nap or rest during the day. Gradually increase your activity and exercise. This will help you regain strength and endurance. New research has also shown that moderate exercise can help with blood count recovery.

Walking is an excellent way to get exercise each day. Start with short walks, 2 to 5 minutes, a few times a day. Do not push yourself if you feel tired or uncomfortable. Gradually take longer walks. It may take several weeks or even months to go longer distances. But each walk will benefit you; so don't give up. Gradually increase your walking up to 30 minutes, 4 to 5 times a week.



If you would like to strengthen your muscles, talk with the doctor or physiotherapist about when it is safe for you to use weights. It is best to use weights when your platelets are over 50. When you begin, start slowly with light hand weights. Gradually increase the number of repetitions and then progress to using a medium weight.

Going outdoors

To prevent infection when you go outside, wear a procedure mask until at least day +100.

While you are recovering, there are some activities and places you should avoid:

- For the first 3 months you should avoid crowded places, such as the grocery store, movie theatre, public elevators or shopping malls. In crowds, you are more likely to have contact with people who have respiratory or other illnesses.
- Do not do activities such as gardening and yard work.
- Avoid dusty areas, such as construction or excavation sites.
- Do not go near chicken coops or other places where birds roost.

The radiation you received before your transplant has made your skin very sensitive to sunlight. Sunburn can trigger the start of graft-versus-host disease.

To protect yourself from the sun:

- wear a hat
- apply sunscreen (SPF greater than 30) to all areas of your skin that are not covered by your clothing
- stay out of direct sunlight

Stay out of the wind. Exposure to the wind can also cause a burn.

Continuing physiotherapy

When you go home, you can continue to have help from a physiotherapist. Call local clinics and ask for a registered physiotherapist with experience helping transplant survivors.

A physiotherapist can:

- discuss your health and goals
- create a specific exercise plan for your recovery
- teach you the correct way to exercise
- teach you how to pace yourself, balancing rest and activity

Personal relationships

Support

During your recovery, you may struggle with your emotions and the changes in your life after your transplant. Your illness and recovery will also affect those around you. This can be a stressful time for you and your family. Having support from others can help.

Here are some ways to get support:

- Talk about your feelings with someone who is close to you.
- Some people find it helps to express their feelings through writing, painting or other creative activities.
- Many people find the Bone Marrow Transplant Support Group helpful. This group meets once a month. In this group you can talk about your concerns with others who have been through a transplant.

It is normal to feel anxious, sad or angry at times. However, if these feelings overwhelm you or affect your daily life, please call us. The Transplant Team is always available to help you.



Sexuality

After a BMT, it is normal to have concerns about intimate relationships and sex. Our patients have shared with us these common concerns and issues.

Men and women may have less desire for sex, especially during the early stages of recovery. At first you may enjoy being affectionate without having sex, by touching, hugging and kissing. Your usual sexual desire will gradually return as your body recovers.

Sexual activity can increase the risk of infection, so you will need to take some precautions. If your blood counts are high enough, you can resume having sex when you feel you are ready.

During the first 3 months after your transplant use condoms to prevent infection. Oral and anal sex are not safe for you during these 3 months, as these are areas that have a lot of germs.

Radiation or chemotherapy can lower a woman's hormone levels. This can lead to hot flashes, dryness of the vagina, changes in mood and, after many years, osteoporosis. Some women have fewer menstrual periods or stop having periods. Talk with your doctor or a gynecologist about the changes in your body. He or she may prescribe a small dose of estrogen to help. A water-soluble lubricant (such as Muko or KY) can help relieve vaginal dryness. Do not use products that contain oil (such as Vaseline) as lubricants because they breakdown the latex in condoms.

Early menopause and loss of fertility may occur, especially in women over age 30. The doses of chemotherapy given for a blood or bone marrow transplant make it likely that most men will become sterile. Although chemotherapy or radiation can affect your ability to have children, these treatments will not affect your ability to enjoy sexual activities.

Before you go home, please discuss any questions or concerns that you may have with your doctor or nurse. It is very important for you and your partner to have any concerns clarified.

You can also get more information and support during your follow-up visits.

Medications

When you go home, you will continue taking several prescription medications for many months. You will need immunosuppressive medications for six months, or longer if you develop GVHD. You may need medications to manage problems such as stomach upset, constipation, diarrhea or headaches.



The number and type of medications you need depends on:

- the kind of transplant you had
- the length of time since your transplant
- your overall health
- how the medications affect your body

If it is possible, have your prescriptions filled at one pharmacy.
Your community pharmacy team:

- will keep a complete record of your medications
- can give you advice and get in contact with your doctor, if needed
- may be able to deliver your medications to your home

- **Take only the medications ordered by your transplant doctor.**
- Do not take any other medications, including “over-the-counter” or non-prescription medications until reviewed by your transplant pharmacist. This includes all herbal, vitamin or mineral supplements and remedies.
- Do not stop taking any of the medications, unless instructed by your transplant doctor.
- If you see other doctors. Tell them what medications you are taking.

Insurance coverage for medications

The cost of medications related to your transplant can add up very quickly. It is important that you know what insurance you have to help pay for medications. You may have insurance coverage from your employer or a private insurance company. You may also be eligible for Ontario Drug Benefits (ODB), including the Trillium Drug Plan.

If you have insurance through your employer or a private company, you need to find out:

- What is your deductible?
- What percent of the cost is covered?
- Is there a maximum amount per year or lifetime maximum?
- Does your plan require pre-authorization for some medication?
Pre-authorization means there is a special process for your plan to pay for certain medications.

When you get a new prescription, remind the staff of your coverage. Then we can take the appropriate steps to provide or address potential problems related to expensive medications.

If the cost of your medications is a concern for you, the social worker or Hospital Pharmacy Team may be able to help.

Information about medications

On pages 26 to 36, there is **general information** about the following medications, commonly prescribed for people who have had a BMT:

- Cyclosporine (Neoral)
- Prednisone
- Mycophenolate (CellCept)
- Fluconazole (DiFlucan)
- Acyclovir
- Cotrimoxazole (Septra)
- Folic acid

If you have questions about your medications, please talk with your transplant doctor or transplant pharmacist.

Cyclosporine (syeh-kloe-spor-in)

Brand names: Neoral, Rhoxal-Cyclosporine, Apo-cyclosporine

Appearance

- Capsules (25 mg, 50 mg, 100 mg)
- Liquid (100 mg/ml)

Why this medication is used

- Cyclosporine is an immunosuppressive medication. It reduces the body's immune response. This medication is used to prevent and treat graft-versus-host disease (GVHD).

How to take this medication

- Cyclosporine is usually taken twice a day; at breakfast and dinner time. This medication works best when it is taken at the same time each day.
- If the 100 mg capsule is hard to swallow, talk with the pharmacist about using smaller capsules. The liquid is oily and is usually taken with a small amount of chocolate milk.
- The dose of cyclosporine will be adjusted depending on the amount of cyclosporine in your blood. If you are coming to the clinic for bloodwork in the morning, do not take your cyclosporine that morning. Bring it to the hospital and take it after your bloodwork. If you are having bloodwork after 11 am, take your morning dose as usual.
- Do not eat grapefruit or drink grapefruit or pomegranate juice while taking this medication. Grapefruit, pomegranate and some other rare fruits increase the amount of cyclosporine in the body.

Special precautions

- Cyclosporine reduces your body's ability to fight infection. Follow the precautions in this book to help prevent infections. Watch closely for signs of infection.
- Cyclosporine may cause tenderness, swelling or bleeding of the gums. Brush and floss your teeth gently. Visit your dentist regularly.
- Do not take any products that contain magnesium (such as antacids or magnesium supplements unless prescribed by your transplant team). This can cause diarrhea, which may be confused with a sign of GVHD. If you need extra magnesium, it will be given by intravenous.
- Cyclosporine interacts with many other drugs. Be sure to have newly prescribed drugs reviewed by a transplant pharmacist.

Continued on the next page ...

Side effects

Some common side effects do not need medical attention. They may lessen or go away as your body gets used to the medication. See your doctor if these effects become bothersome:

- swollen, tender or bleeding gums
- nausea or vomiting– Some patients may need to take anti-nausea medicine 30 minutes before each dose of cyclosporine.
- trembling or shaking of the hands
- cramps in your legs
- hair growth – Hair on the face and arms may become thicker and darker. This new hair will fall out after you stop taking cyclosporine.
- headaches or changes in your vision

Your doctor will check you and your bloodwork for these side effects:

- high blood pressure - Some patients may need medication to lower blood pressure.
- kidney problems
- low magnesium levels
- high cholesterol

Call your doctor right away if you have any of these side effects:

- signs of infection – fever, chills, sore throat, cough, painful urination, or not urinating very much
- seizures

What to do if you miss a dose

- If you miss a dose, take it as soon as you remember. However, if it is within 6 hours of your next dose, do not take it – skip the missed dose and take the next dose at the regular time. Do not take a double dose.

Other information

- The Ontario Government provides cyclosporin free to transplant patients. It is only supplied by pharmacies in certain hospitals. To get this medication free of charge, fill your prescription at the Outpatient Pharmacy at the Juravinski Cancer Centre.

Prednisone (pred-ni-sone)

Brand names: Deltasone

Appearance

- Tablets (5 mg, 50 mg)

Why this medication is used

- Prednisone is a steroid medication used to treat GVHD.

How to take this medication

- Take prednisone with a full glass (250 ml or 8 oz) of water. If prednisone upsets your stomach, try taking it with food or milk.
- If you are to take prednisone once a day, take it in the morning with breakfast. Avoid taking at bedtime.
- The doctor will change the dose of prednisone depending on your body's response to the medication.

Special precautions

- Prednisone may increase the risk of infection and hide some of the signs. Watch closely for signs of infection.
- Do not drink alcohol while taking prednisone.

Side effects

Some common side effects do not need medical attention. They may lessen or go away as your body gets used to the medication. See your doctor if these effects become bothersome:

- nausea
- restlessness or difficulty sleeping
- increased appetite
- dizziness
- headache

Your doctor will check you and your bloodwork for these side effects:

- high blood sugar – Some people need to take medication to lower blood sugar.

Continued on the next page ...

Call your doctor right away if you have any of these side effects:

- signs of infection – fever, chills, sore throat, cough, painful urination
- swollen face, lower legs or ankles
- unusual weight gain
- changes in vision
- increased thirst, frequent urination
- anxiety or mood changes

What to do if you miss a dose

- Please ask your doctor or transplant pharmacist. The instructions will depend on how often you take prednisone.

Stopping Prednisone

- If you have been on Prednisone for some time you should NOT stop it suddenly. Your nurse practitioner or doctor will advise you on how to slowly decrease and stop Prednisone.

Mycophenolate (mye-koe-fen-oh-late)

Brand name: CellCept

Appearance

- Tablets (500 mg)
- Capsules (250 mg)

Why this medication is used

- Mycophenolate is an immunosuppressive medication. It reduces the body's immune response. This medication may be used to prevent and treat graft-versus-host disease.

How to take this medication

- Mycophenolate is usually taken twice a day. This medication works best when it is taken at the same time each day.
- Take mycophenolate on an empty stomach. This means 1 hour before or 2 hours after meals.
- Swallow the tablets or capsules whole. Do not cut, crush or chew them.

Special precautions

- Mycophenolate reduces your body's ability to fight infection. Follow the precautions in this book to help prevent infections.
- Mycophenolate can harm an unborn baby. Two forms of birth control must be used if there is any chance of pregnancy.

Side effects

Some common side effects do not need medical attention. They may lessen or go away as your body gets used to the medication. See your doctor if these effects become bothersome:

- constipation or diarrhea
- headache
- heartburn or stomach pain
- nausea or vomiting
- muscle joint or back pain
- trouble sleeping

Continued on the next page ...

Your doctor will check you and your bloodwork for these side effects:

- high blood pressure – some patients may need medication to lower blood pressure.

Call your doctor right away if you have any of these side effects:

- signs of infection – fever, chills, sore throat, cough, painful urination

What to do if you miss a dose

- If you miss a dose, take it as soon as you remember. However, if it is within 6 hours of your next dose, do not take it – skip the missed dose and take the next dose at the regular time. Do not take a double dose.

Fluconazole (floo-koe-na-zole)

Brand names: Diflucan

Appearance

- Tablets (100 mg)

Why this medication is used

- Fluconazole is used to prevent or treat fungal infections.

How to take this medication

- Fluconazole is usually taken until Day +75 after a transplant. It may be taken longer if there is GVHD.
- This medication works best when it is taken at the same time each day.

Side effects

Some common side effects do not need medical attention. They may lessen or go away as your body gets used to the medication. See your doctor if these effects become bothersome:

- nausea or vomiting

Call your doctor right away if you have any of these side effects:

- a skin rash, itching
- yellow eyes or skin
- dark urine or light grey bowel movements

What to do if you miss a dose

- If you miss a dose, take it as soon as you remember. However, if it is almost time for your next dose, do not take it – skip the missed dose and take the next dose at the regular time. Do not take a double dose.

Acyclovir (ay-sye-kloe-veer)

Brand names: Zovirax

Appearance

- Tablets (200 mg, 400 mg, 800mg)
- Liquid (200 mg/5ml)

Why this medication is used

- Acyclovir is used to prevent or treat certain viral infections.

How to take this medication

- Acyclovir is usually taken twice a day. Take tablets with a full glass (250 ml or 8 oz) of water.
- Acyclovir is usually taken for one year after a transplant.
- The doctor may change the dose of acyclovir if you develop cold sores or shingles (herpes simplex or herpes zoster infections).

Special precautions

- Acyclovir should not be used in pregnancy. Two forms of birth control must be used if there is any chance of pregnancy.

Side effects

Some common side effects do not need medical attention. They may lessen or go away as your body gets used to the medication. See your doctor if these effects become bothersome:

- diarrhea
- nausea or vomiting

Call your doctor right away if you have any of these side effects:

- itching, hives, swelling of the face, throat, trouble breathing
- confusion, trembling, hallucinations

What to do if you miss a dose

- If you miss a dose, take it as soon as you remember. However, if it is almost time for your next dose, do not take it – skip the missed dose and take the next dose at the regular time. Do not take a double dose.

Cotrimoxazole (coe-try-mox-a-zole)

Brand names: Septra, Bactrim, Septa-DS, Bactrim-DS

Appearance

- Tablets (sulfamethoxazole 400 mg and trimethoprim 80 mg)
- Double strength (DS) tablets (sulfamethoxazole 800 mg and trimethoprim 160 mg)

Why this medication is used

- This medication is used to prevent a lung infection called PCP or PJP pneumonia.

How to take this medication

- Take tablets with a full glass (250 ml or 8 oz) of water.
- This medication is usually taken once a day, but only 3 days a week (Monday, Wednesday and Friday).

Special precautions

- Do not take cotrimoxazole if you are allergic to sulfa drugs.
- Drink 6 to 8 glasses of fluids each day.
- This medication may lower your blood counts. Taking folic acid may help prevent this problem.
- Cotrimoxazole can make your skin more sensitive to sunlight.
When outdoors: wear a hat, cover up with clothing, wear sunglasses, use sunscreen with SPF 15 or higher, and stay out of direct sunlight.

Side effects

Some common side effects do not need medical attention. They may lessen or go away as your body gets used to the medication. See your doctor if these effects become bothersome:

- skin rash
- headache
- nausea or vomiting
- diarrhea

Continued on the next page ...

Call your doctor right away if you have any of these side effects:

- signs of infection – fever, chills, sore throat, cough, painful urination
- unusual thirst
- your skin or eyes become yellow
- pale skin, unusual bleeding or bruising

What to do if you miss a dose

- If you miss a dose, take it as soon as you remember. However, if it is almost time for your next dose, do not take it – skip the missed dose and take the next dose at the regular time. Do not take a double dose.

Folic acid (foe-lik as-id)

Other names: folate, folacin

Appearance 1mg

- Tablets (400 mcg)

Why this medication is used

- Folic acid is a B vitamin. This supplement provides building blocks for a recovering bone marrow. It can also help prevent a side effect of cotrimoxazole.

How to take this medication

- Folic acid is usually taken once a day.

Side effects

Folic acid does not usually cause side effects. Some side effects are possible, but happen rarely. See your doctor if you have:

- a skin rash or itching
- trouble breathing

What to do if you miss a dose

- If you miss a dose, take it as soon as you remember. However, if it is almost time for your next dose, do not take it – skip the missed dose and take the next dose at the regular time. Do not take a double dose.

**The Bone Marrow Transplant Team
thanks the patients, families and staff
for their valuable contributions to this book.**

