

Allogeneic Stem Cell Transplant Discharge Instructions

Victoria General (VG) Site, QE II



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Allogeneic Stem Cell Transplant Discharge Instructions

Getting ready for your discharge starts as soon as you are admitted to the hospital. We encourage you to work with your health care team to get ready physically, mentally, and socially to go home.

It can be challenging to cope with the changes after your transplant. Some people find recovery during the first couple of months at home is the hardest time of their transplant experience.

- You may feel pressure that things should be back to normal now that you are home.
- People may congratulate you for the transplant being over, when you may still feel like it is not.
- Getting back to a new normal takes time and patience.
 - › Some people recover quickly and are back to work and their usual daily activities within months.
 - › For others, recovery is slower and can take many months, depending on fatigue and other side effects.
- It is common to have periods of feeling sad or low. **Try to take one day at a time.**
- Even though you would like to be doing more, you may not be ready physically, mentally, or socially. **Remember, you are still healing.**
 - › How you look may be very different from how you feel.
 - › It is important to tell your loved ones what you can do for yourself, and what you need help with.
 - › Your needs will change as you recover. It is important to keep telling your loved ones as your needs change.
- You may not be interested in eating, and food might taste different. As you recover, you will feel stronger and your appetite will improve.
- A social worker and other team members can help to support you as an outpatient.

You must have a care partner until Day +100. This role may be shared by more than 1 person.

Preventing complications

To help prevent the risk of complications (like infection) during the first 100 days after your transplant:

Before going home

- Have your house cleaned, including:
 - › Washing the floors
 - › Vacuuming rugs and carpets
 - › Cleaning or washing curtains and blinds
 - › Dusting furniture
 - › Cleaning bathrooms with disinfectant, including sinks, tubs or showers, and toilets
 - › Cleaning kitchen appliances and countertops

Pets

- Have their nails trimmed, and have them bathed, if possible.
- **Do not** let pets lick your face.
- Always wash your hands after petting your pets.
- Try to avoid accidental bites or scratches.
- Have someone else clean up after your pets (like change the litter box, pick up dog poop, clean up your pet's vomit, clean a birdcage or a fishbowl).

MedicAlert® identification (ID)

- We encourage you to wear a MedicAlert® bracelet or necklace after your transplant. This will help first responders give you the best care in an emergency. You can order a MedicAlert® ID online.
- Please include the following information:
 - › Any allergies you have
 - › HSCT (can only receive irradiated blood products)

Medications

- When you are discharged, it is common to be taking more medications than before your transplant. Before you are discharged, your CTTP doctor or NP, nurse, and pharmacist will review all of your medications with you.
- It is important for you and your care partners to know:
 - › Why you are taking these medications
 - › The doses (amounts)
 - › When to take them
 - › Possible side effects
- **It is very important to take your medications as prescribed. This is even more important for your immunosuppressant, as it helps to prevent graft versus (vs.) host disease (GVHD).**
- If you have problems swallowing or taking these medications after you are discharged, tell the CTTP nurses or NP.
- You may find it helps to use a pill box. This can help you organize your medications and remind you when to take them.
- **Do not** stop taking any medication without first talking to your CTTP doctor or nurse practitioner (NP).
- Some over-the-counter medications can interact with (have an effect on) your medications. **Do not take over-the-counter medications without asking your doctor, NP, or pharmacist.**
- **If you miss a dose, do not double the next dose. Ask your CTTP doctor, NP, or pharmacist what to do.**

Outpatient care

After you are discharged, most of your care will be in the Systemic Therapy/ Supportive Care Unit (STU). You will also be seen regularly in the Hematology Clinic.

If you live within a 45-minute drive from the hospital:

- You can go home when you are discharged.
- You will come back to the hospital each day for outpatient treatment.

If you are from Nova Scotia and you live more than a 45-minute drive from the hospital:

- You must stay near the hospital for outpatient care.
- You may stay with family or friends, or at The Dr. Susan K. Roberts Lodge That Gives, or the Lord Nelson Hotel & Suites.

Supportive care unit (STU)

4th floor, Victoria Building
Victoria General (VG) Site, QE II

Hours:

- › 7:30 a.m. to 5 p.m., Monday to Friday
- › 7:30 a.m. to 3:30 p.m., weekends and holidays
- Since everyone is different, it is not possible to know how long or how often you will need care in the STU. For most people, outpatient care is every day or every other day, and lasts for 3 to 8 weeks. Over time, you will have appointments less often. The length of each appointment will vary. It may be 30 minutes to several hours, depending on the care you need.

What care is provided in the STU?

You will be checked by a nurse at every visit. This may include:

- › Physical and emotional assessment
- › Blood work
- › Review of blood test results
- › Talking with the doctor about your lab results and STU visits
- › I.V. medications, blood products, and fluids
- › Central line care
- › Teaching and support for you and your loved ones
- › Referrals to other health care providers, as needed

Before coming to the STU

- If you will be late, or if you need to cancel or change your appointment:
 - › Phone: **902-473-6038**

- **Please arrive 10 minutes before your appointment time.**
- Register for each visit at the registration desk across from the Victoria Building elevator on the 4th floor.
- Plan to be at your first appointment for at least 1 hour.
- Wear comfortable clothes and shoes.
- If you would like your care partner to join you for your appointment, please ask staff ahead of time. Space is limited.
- Your care partner is responsible for getting you to and from your appointments. **Do not drive while you are recovering from your transplant.**
- There is a small kitchen with a microwave, a fridge, coffee, tea, and snacks.
- You will get a sandwich and a drink at lunchtime. You can bring your own food and drink if you prefer.
- **Drink only bottled water and ice made from bottled water.** There is bottled water in the kitchen and ice in the freezer. **Remember, do not drink tap water at the VG Site.**

What should I bring to my outpatient appointments in the STU?

- › A list of all your current medications (including prescription and over-the-counter medications, inhalers, creams, eye drops, patches, herbal medications, vitamins, and supplements)
- › Medications you will need to take during your appointment
- › A list of any questions you or your care partner have
- › Items that may help you pass the time (like books, magazines, music, a craft project, or a laptop). Free Wi-Fi is available. Please bring your own headphones so you will not disturb others.
- **Do not** bring any valuables (like jewelry, money, cheques, credit cards). **The hospital is not responsible for the loss of any items.**
- Please **do not** wear scented products when you come for your appointments. Nova Scotia Health is scent-free.

Hematology Clinic

4th floor

Victoria General (VG) Site, QE II

Hours:

- › 8:30 a.m. to 4:30 p.m., Monday to Thursday
 - › 8 a.m. to 4 p.m., Friday
 - You will be checked regularly by a CTPP NP and/or a CTPP doctor in the Hematology Clinic.
 - Your Clinic appointment will usually be coordinated with a STU appointment. Although most tests and procedures are done in the STU, some procedures are also done in the Hematology Clinic (like a bone marrow biopsy).
 - You will be followed by the CTPP for at least 6 years.
- If you will be late, or if you need to cancel or change your appointment:
 - › Phone: **902-473-6605**

Monitoring for complications after discharge

Go to the nearest Emergency Department right away (do not wait for your next appointment) if you have any of these symptoms after you are discharged:

- › Fever (temperature above 38 °C or 100.4 °F). **Do not take Tylenol®.** Remember to show your *Yellow Fever Card* as soon as you arrive.
- › Diarrhea (loose, watery poop) more than 3 to 4 times in 24 hours
- › Headache with a change in vision, cognition (thinking), or consciousness
- › Vision (seeing) changes
- › Bleeding that will not stop
- › Sudden stomach pain

Graft versus (vs.) host disease

- Graft vs. host disease (GVHD) is a condition that can happen when you receive stem cells or bone marrow from a donor.
- GVHD is when the donor's white blood cells attack your tissues. This usually happens after engraftment.
 - › After your transplant, the stem cells must travel through your bloodstream to the center of your large bones, and back to the bone marrow. Once they are in your bone marrow, they can start to make new white blood cells, red blood cells, and platelets. This is called engraftment.
- There are 2 types of GVHD:
 - › **Acute:** Happens between engraftment and Day +100
 - › **Chronic:** Happen after Day +100
- A small amount of GVHD may be helpful. As the donor's cells attack your tissues, they are also attacking any cancer cells that are left. This is called the **graft-versus-leukemia effect** or the **graft-versus-tumour effect**.

Symptoms of acute GVHD

- Your health care team will check you closely for symptoms of GVHD, while you are in the hospital and after you are discharged.
- Acute GVHD usually affects the:
 - › Skin: Check for redness (especially on the palms of your hands, the soles of your feet, or behind your ears), dryness, itching, tightness, or thickening of the skin.
 - › Gastrointestinal (GI) tract: You may have less appetite (not feel as hungry), trouble swallowing, nausea (feeling sick to your stomach), vomiting (throwing up), diarrhea that may be green or bloody, stomach cramps, or weight loss.
 - › Liver: You will have blood work to check how well your liver is working. It is important to also watch for jaundice (yellowing of the skin and white parts of the eyes).

Symptoms of chronic GVHD

- Your NP and your doctor will check for chronic GVHD. The symptoms may be mild or severe (very bad). If your GVHD does not get better, you may need to be admitted to the hospital or take medication long-term.
- Chronic GVHD can affect any organ in your body.
- Chronic GVHD usually affects the:
 - › Skin: Check for redness (especially on the palms of your hands, the soles of your feet, or behind your ears), dryness, itching, tightness, or thickening of the skin.
 - › Eyes: Your eyes may be dry, irritated, burning, itchy, or sensitive to light.
 - › Mouth: Check for dryness, redness, white patches, sores, or taste changes.
 - › Lungs: You may have trouble breathing or fatigue that is getting worse, or while doing an activity.
 - › Vagina: Check for dryness, burning, itching, having infections often, or pain during sex.
 - › Joints: You may have tenderness, stiffness, or tightness.

Important: Get medical help right away if you have any of these symptoms, especially if you have diarrhea you cannot control (cannot get to the bathroom in time).

- You may need to be admitted to the hospital if your GVHD causes complications.

Lowering your risk of infection

- **It is important to stay away from people who are sick or have any type of infection (like the flu or a cold, an eye or wound infection).**
 - › We understand that it can be stressful and disappointing to tell people that they cannot visit if they are sick, or for you to miss an event because it takes place in a large crowd. **Until your white blood cell count (WBC) is up, you need to protect yourself.**
- Remember, most infections come from within your own body. **It is important to keep your body clean, especially your hands, mouth, genitals (vagina, penis), and rectal (bum) area.**
- Although your new bone marrow is working hard to protect you, your immune system will still be weak for about 1 year after your transplant.
- Check your temperature if you feel hot or do not feel well. Because your new immune system is still getting stronger, **a fever may be the only sign of infection.** If you have a fever, follow the instructions the Hematology Clinic team gave you, or the instructions on your *Yellow Fever Card*.

To prevent illness after your transplant:

- › You will need to take an anti-viral medication called valacyclovir for 1 year.
- › You will need to take a prolonged course of an anti-fungal medication to protect against infection.

Toxoplasmosis

- Toxoplasmosis is an infection caused by a parasite called **toxoplasma gondii**. This parasite lives in the digestive systems of cats. You can become infected by:
 - › Direct or indirect contact with cat poop
 - › Eating undercooked (raw) meat
- You are at higher risk for toxoplasmosis after transplant because your immune system is weak. **When your immune system is weak, a new or reactivated toxoplasmosis infection can be life threatening. If it is not treated, toxoplasmosis can cause organ damage and possibly death.**

To prevent toxoplasmosis:

- **Do not** clean cat litter boxes. If you must clean a cat litter box after transplant:
 - › wear gloves.
 - › wash your hands well after taking off your gloves.
- Keep your cats indoors.
- **Do not** feed your cats raw meat.
- **Do not** eat raw or undercooked meat.

Aspergillosis

- Aspergillosis is an infection caused by a fungus called **aspergillus**. Aspergillus is a fungus that lives in soil, plants, and rotting materials. It can also be found in dust, carpets, heating and air conditioning ducts, some foods (like dried fish), and cannabis.
- Aspergillus enters the body when you breathe in, so it is commonly found in your lungs and sinuses. You are at risk for aspergillosis after transplant because your immune system is weak. If you are infected with aspergillosis, it may move from your lungs to the rest of your body, which can be life threatening.

To prevent aspergillosis:

- Avoid dusty areas. If this is not possible, wear a mask in dusty areas.
- **Do not** do any gardening until your blood counts are in a normal range.
 - › Use gardening and/or rubber gloves to care for indoor plants.
 - › While gardening or doing yard work, wear a mask and gloves. **Do not** touch your face. Wash your hands well after taking off your gloves.

Hygiene

- Take a shower or a bath regularly. Use a mild soap (like Ivory, Dove, or Johnson's® baby bar soap).
- If you have dry skin, use baby oil or a mild skin lotion during or after your shower or bath.
- **Do not** share your towels or face cloths. Replace used towels and facecloths with clean ones every 4 to 5 days, or sooner.
- Use an electric razor for shaving. **Do not** shave with a straight razor until your platelet count is above 50,000, and you no longer need platelet transfusions. Your HSCT doctor will tell you when it is safe to use a razor.

Mouth care

- **It is very important to take care of your mouth during and after your transplant**, even if it is painful. Cleaning your mouth often is important to help lower the risk of infection.
- Brush your teeth, tongue, and gums at least 4 times a day (after each meal and before you go to sleep).
- Use an extra soft-bristled toothbrush and brush gently with a fluoride toothpaste.
 - › **Do not** use a whitening toothpaste. If your toothpaste hurts or burns your mouth, try Sensodyne, Colgate® PreviDent®, or Biotène®.
- Rinse your toothbrush well after each use and store it in a dry place.
- **Do not** use a mouthwash with alcohol if it irritates your mouth.
- Floss every day unless you are told not to. **Do not** floss if:
 - › Your mouth, gums, or teeth hurt.
 - › You have sores in your mouth or on your gums.
 - › Your mouth or gums are bleeding.
- Have a dental exam and get your teeth cleaned every 6 months. Ask your HSCT doctor when you can book your first dental cleaning after your transplant.

Eye care

- Have your eyes checked by an optometrist or an ophthalmologist (eye doctor). Ask your HSCT doctor when you can book your first eye exam after your transplant.
- Your eyes may be dry or sensitive to light.
 - › Artificial tears can help with dryness.
 - › Wearing dark glasses can help with light sensitivity.
- **If you wear contact lenses**, you must try to prevent eye infections:
 - › Always wash your hands before putting in or taking out your contact lenses.
 - › Always clean your contact lenses before putting them in.

Sun exposure

- You need to protect yourself from the sun's harmful rays. Your skin is more sensitive after receiving chemotherapy and a transplant.

- Whenever possible, stay out of the sun from 11 a.m. to 3 p.m.
- Wear a hat, a long-sleeved shirt, and cotton pants (UV-protected clothing is preferred).
- Use sunscreen with a sun protection factor (SPF) of 30 or higher. Apply it often on your hands, face, neck, and any other exposed areas.
- Wear sunglasses that filter UV light. Your eyes may be much more sensitive to light.
- Remember to protect your skin from the sun for the rest of your life.

Keeping your home clean

- Keep your home free of dirt and dust as much as possible.
- Keep your bathroom and kitchen clean. Use disinfectant and rinse well.
- Clean cutting boards and kitchen surfaces as described in the *Safe Food Handling for Immunocompromised Individuals* booklet given to you by your health care team.
- Wash your eating utensils well with hot water and soap.
- Wash washcloths and towels at least 2 times a week.
- Wash sheets once a week in warm, soapy water.

Sexuality

- Your desire and sexual activity (sex) may be affected by:
 - › Side effects of high dose chemotherapy
 - › GVHD
 - › Stress
 - › Low self-esteem
 - › Fatigue
 - › Nausea
 - › Diarrhea
- If you have a vagina, GVHD can affect the lining of your vagina. This can cause pain, burning, irritation, and severe dryness. Scar tissue may develop, causing the vagina to narrow. This is called **vaginal stenosis**. This can make sex hard or painful. A gynecologist (a doctor who specializes in reproductive health) can often help with treatment of vaginal stenosis.
- If you have a penis, it may be hard to get an erection.

- If you have sex while receiving chemotherapy, **do not** let your partner touch your body fluids:
 - › Use a condom.
 - › **Do not** kiss with your mouths open and your tongues touching (French kiss).
 - › **Do not** have oral sex.
 - › **Do not** have anal or rough sex until your blood counts are nearing normal. It is important to protect your skin, vagina, rectum, and the lining of your mouth from tears or injury during sex. Talk to your partner about this before having sex.
- If you are having sex soon after transplant, it is important to shower or bathe before and after sex.
- If your platelet count is less than 50, use a water-soluble lubricant during sex. This can help to prevent vaginal irritation.
- Sexual problems can be frustrating for both you and your partner. If you have questions or concerns, talk with a member of your health care team, like your nurse, or your CTPP doctor or NP.

Going back to work

- You may worry about when you can go back to work. Try to focus on your recovery for the first few months.
- Over time, most people who receive an allogeneic transplant are able to go back to some level of work and/or activities.
- Please tell your nurse if you would like to talk with other people who have gone through the process, or with a social worker.

Vaccinations after a transplant

- High dose chemotherapy destroys the immunity you have built up over the years to diseases and viruses. After your conditioning treatment, you will need to get certain vaccinations to re-immunize you against certain viruses.
- These vaccinations will start **6 months** after your transplant. Your CTPP NP will give you a vaccination schedule after discharge to make sure you get these vaccinations on time. Your primary health care provider may give you the vaccinations, as needed.

Appendix A: Safe Food Handling

Some foods have a risk of infection for people who have had a stem cell transplant. This is because of how they are made or stored.

While you are in the hospital

- In the hospital, food is prepared for you using safe food handling practices.
- Safe food handling practices come from Health Canada. They are listed in the booklet *Safe Food Handling for Immunocompromised Individuals*. You will get a copy of this booklet or you can visit:
 - › www.canada.ca/content/dam/hc-sc/documents/services/food-safety-vulnerable-populations/food-safety-vulnerable-populations/immune-immunitaire-eng.pdf



- This booklet includes lists of foods to avoid until:
 - › Day +100
 - › You are told otherwise
- All fresh fruits and vegetables brought in from outside the hospital must be washed with bottled water (not hospital tap water) unless they were already washed at home.
- Ask for a referral to a dietitian if you have concerns or questions about nutrition, or visit:
 - › <https://food-guide.canada.ca/en/food-guide-snapshot/>

At home

It is important to follow safe food handling practices at home, since some foods have a risk of infection for people who have had a stem cell transplant. This is because of how they are made or stored. **Follow safe handling guidelines for at least 100 days after your transplant.**

Important:

- Keep meat, poultry, fish, and seafood separate from fresh or ready-to-eat foods during shopping, storage, and food preparation.
- Wash your hands, fresh fruits and vegetables, and kitchen surfaces and utensils well.
- Keep hot foods hot and cold foods cold.
- Always cook foods to the correct internal temperature (see chart on page 12 of *Safe Food Handling for Immunocompromised Individuals*) and check foods with a digital thermometer.
- Avoid high-risk foods, like non-dried deli meats, raw or unpasteurized dairy products, soft and semi-soft cheeses, raw hotdogs, patés and meat spreads, raw seafood, raw or undercooked meat or poultry, unpasteurized fruit juice and cider, and raw sprouts.

What are your questions?

Please ask. We are here to help you.

