

Discharge Guidelines Following Allogeneic Hematopoietic Stem Cell Transplant

Congratulations on your upcoming discharge. The Hematopoietic Stem Cell Transplant staff is happy that you are getting ready to go home. You may hear people say Hematopoietic Stem Cell Transplant (HSCT). They may also refer to it as a Bone Marrow Transplant (BMT). Often these terms are used in place of each other.

Recovering from your HSCT (Hematopoietic Stem Cell Transplant) will take time. While you recover, you will feel tired or weak. You might have less interest in eating, and some foods will taste differently to you. Gradually, you will feel stronger and your appetite will improve.

You will require a primary caregiver from the time you leave the hospital until day 100 of your transplant. We want you to take some precautions for the first 100 days of your recovery to prevent problems like infection or bleeding. This book is divided into sections with information that is important to your recovery. You and your family need to read this information and ask questions about anything that is not clear. You will recover in small steps, so be patient and kind to yourself.

Before You Go Home

Housecleaning

- Before you go home, someone needs to clean your house—like a good “spring cleaning.” Floors should be washed. Rugs and carpets need to be vacuumed. If rugs are dirty, they should be shampooed. Curtains and drapes need to be cleaned or washed.
- Your wood furniture should be dusted. Cloth-covered furniture needs to be vacuumed.
- All filters (air conditioners, heaters, humidifiers) must be removed and cleaned or replaced.
- Sinks, tubs, showers, and toilets need to be cleaned.
- Kitchen appliances and countertops should be cleaned.

Pets

- Have your pets bathed and groomed (including nails trimmed), before you go home.
- Check with your veterinarian to make sure that your pets have had all their shots.
- Wash your hands after any contact with your pets or anything they use.
- It is important not to get an accidental bite or scratch from your pet.
- Do not handle litter boxes, bird cages, fish or turtle bowls, or your pet’s food or water bowls.

Medical Alert Identification

HSCT patients should wear a medical alert necklace or bracelet. This is important so health care providers know that any blood products (transfusions) you get have to be irradiated. Irradiated blood products protect you from transfusion associated Graft Versus Host Disease.

- It is a good idea to order your bracelet before you are admitted.
- You can get an order form for a medical alert bracelet from websites, your pharmacy, or at the reception desk in the HSCT clinic.
- The identification tag should say: **HSCT—IRRADIATED BLOOD PRODUCTS ONLY**
- You need to wear the medical alert identification for the rest of your life.

When You Go Home

Discharge Medications

- Your HSCT doctor and nurse will explain all of your discharge medications. You need to know reasons for the medications, the doses, times to take them, and possible side effects.
- Purchase a pill box with spaces for taking pills at least 3 times a day. This will help you keep track of your medications. It may be helpful to create a medication schedule with your nurse.
- You will be discharged on certain medications, like tacrolimus or sirolimus that require a blood level (or trough). You need to take these medications exactly on time and let your doctor know if you cannot swallow these medications or forget to take a dose. Your follow up appointments will be scheduled in the morning before your first dose of the day. Bring these medications to your follow up appointments and take them in the clinic after the blood level is drawn.

Call Your Doctor or Nurse

Call 617-724-3456 right away if you have any of the following:

- Fever—temperature of 100.5° or higher
- Chills
- Trouble breathing or being short of breath
- Bleeding that will not stop
- Leaking or damaged central line
- Bleeding from your nose, mouth, or gums when you cough or throw up
- Blood in your urine
- Tarry, black or bloody bowel movements
- Sudden, severe headache
- Sudden abdominal pain

Call us the next morning if you have any of the following symptoms:

- Nausea and vomiting (2 or more times during the day or night)
- Diarrhea or abdominal cramping
- Decreased appetite or weight loss
- Bruises (black-and-blue marks) or petechiae (small red spots in your skin)

- Coughing
- Pain when coughing, sore throat, runny nose, or sneezing
- Skin problems, like redness, itching, burning or tingling sensations, blisters, “cold sores”
- Jaundice (yellow coloring of the skin or eyes)
- Lumps or bumps in your neck, underarms, or groin
- Night sweats
- Muscle or body aches
- Signs of infection around your central line, such as pain, redness, swelling, or pus
- Central line problems like your line cannot be flushed, caps cannot be changed, or you do not have the supplies you need

If you have a general question for a nurse, you may call the clinician in Yawkey 9E at 617-724-3456 during regular business hours. Evenings, weekends, and holidays, call Lunder 10: 857-238-1000.

Managing Your Medical Care

Central Line Care

- It is possible that you may go home with your central line.
- Your central line will be removed when you do not need any blood products, antibiotics, or other medications. This can be done as an outpatient in the office or in Interventional Radiology.
- Your central line can become infected because your immune system is still recovering from your treatments. Until your central line is taken out, it needs proper care. You or a home nurse can do your central line care (dressing changes and flushes). If you need help with your central line care, it will be arranged by your case manager before you leave the hospital.
- To change your dressing refer to the pamphlet “Your Central Line: What You Need to Know.”
- When you shower, cover the central line with a plastic bag or plastic wrap and tape. If your dressing gets wet in the shower, it needs to be changed!
- If you take a bath, you must still cover your central line. Do not let the ends of your central line get in the tub water. Central line ends that hang in the water can cause an infection in the catheter.

Temperature

Take your temperature twice a day for the first 100 days after your day zero. Also, take it anytime you feel warm, get the chills, or just do not feel well. Call the HSCT doctor right away if your temperature is 100.5° or higher.

Graft-Versus-Host Disease — GVHD

- Graft-versus-Host Disease (GVHD) is a problem that can affect anyone who has had an allogeneic HSCT.
- GVHD develops when the T-cells in the **Graft** (hematopoietic stem cells or bone marrow from the donor) react to cells in the **Host** (the HSCT patient) as “foreign” (not belonging). The **graft** cells try to destroy cells in the **host**.
- The cells that are usually affected by GVHD are the skin, digestive tract, and liver. When GVHD starts, it is called **acute** GVHD. If it lasts for more than 100 days, or starts 100 days after your transplant, it is called **chronic** GVHD.
- Chronic GVHD can affect your eyes, mouth, lungs, vaginal lining, muscles, and joints.
- GVHD varies from mild to severe. If you develop GVHD, your HSCT doctor will explain more about GVHD and its treatment.
- Watch for symptoms of GVHD, and call your HSCT doctor if you have:
 - Skin: redness, rash (especially on the palms of your hands, the soles of your feet, and behind your ears), dryness, itching, tightness, or thickening of the skin.
 - Digestive tract: decreased appetite, difficulty swallowing, nausea and vomiting, frequent watery diarrhea, greenish or bloody diarrhea, abdominal cramping, or weight loss.
 - Eyes: dryness, irritation, burning, itching, sensitivity to light.
 - Mouth: dryness, redness, white patches, sores, taste changes.
 - Lungs: difficulty breathing, being short of breath, less able to exercise, worsening fatigue.
 - Vagina: dryness, burning, itching, frequent infections, pain during sex.
 - Joints: tenderness, stiffness, tightness.

Preventing Infections

Hand Washing

- Hand washing is the most important way to prevent infections!
- Wash your hands thoroughly with soap (liquid soap in a pump dispenser is recommended), dry them with paper towels, and use a hand-cleaning gel.

Always wash your hands:

- Before eating or making meals
- Before changing your central line dressing
- After using the bathroom
- After touching anything dirty
- Upon entering your house after you have been outside
- Everyone should wash their hands when returning home after work, school, shopping, and so on.
- All visitors should wash their hands before visiting with you.
- If in doubt, WASH YOUR HANDS!

Face Masks

- Wearing a face mask is another way to help prevent infections.
- When you go home, you will need to wear an N95 face mask.
- Always use a face mask when you:
 - Come to the hospital for appointments
 - Sit in waiting areas
 - Are near construction sites (construction sites are dusty, and the air could contain fungus, spores, and other germs that may cause lung infections in people whose immunity is low)
- You do not need to wear a face mask:
 - When riding in your car
 - When outside sitting in your yard or taking a walk
 - In a hotel room

Crowds

- Stay away from crowds for 100 days following day zero of your HSCT. Avoid places like sporting events, malls, public transportation, movie theaters, churches, restaurants, and supermarkets.
- Your HSCT doctor will let you know when you are well enough to be in a crowded place.

Eating and Drinking

Well Water and Tap Water

Do not drink or cook with well water until you are off immunosuppressants or your HSCT doctor says it is ok.

- You may drink tap water if it is municipal water.
- You may have ice made from municipal water.
- You may drink a reputable brand of bottled water.

Nutrition and Diet

- You may have little interest in eating. Many foods do not taste the same after HSCT. This is from the chemotherapy or radiation therapy. Your appetite and sense of taste will gradually improve, but this may take time.
- You need to follow the diet given to you by your dietitian. There are several important rules about what you can and cannot eat or drink. The diet helps protect you from infections and bowel irritation.
- Do not eat in a restaurant for 100 days after your transplant. Ask your HSCT doctor when you can eat at a restaurant again.
- Food helps your energy. Eat and drink as well as you can. Eat small amounts of food frequently.

Meals

- Your meals do not need to be made separately from the rest of the family.

Dishes and Silverware

- Keep your dishes and silverware separate from the rest of the family's and wash them in hot, soapy water.
- If you use a dishwasher, it should be on the "hot water" setting.
- If you use paper plates and plastic utensils, throw them away after use.

Barbecue

- You can eat food that has been cooked on a gas or charcoal grill.
- The grill rack must be cleaned before it is used. The food should be fresh and fully cooked.
- Do not put cooked food on the same plates or platters that had uncooked food on them. Uncooked food can cause bowel infections.

Alcohol

Do not drink any alcohol.

- Alcohol can cause liver problems. Your liver needs to be healthy to properly process your chemotherapy and other medications.
- Alcohol also causes problems with your platelets so you might bleed more easily.
- Ask your HSCT doctor before drinking beer, wine, or other alcohol.

Taking Care of Yourself

Personal Care

- Take a shower or bath every day using mild soap.
- For dry skin, you can use baby oil or a mild skin lotion during or after your shower or bath.
- Do not share towels or facecloths with other family members. 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 regular razor until your platelet count is 50,000 or more and you do not need any platelet transfusions. Your HSCT doctor will tell you when it is safe to use a razor.

Mouth Care

- Brush your teeth at least four times a day. Use a soft-bristled toothbrush. Use a fluoride-containing toothpaste.
- Do not use a mouthwash that contains 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, have sores, or are bleeding.
- Have a dental exam and cleaning every six months. Check with your HSCT doctor about

when you should schedule your first dental cleaning.

- If you have a central line or port-a-cath, you may need antibiotics before any cleaning or dental work is done.
- Tell your dentist that you have a central line or port-a-cath before all dental appointments.

Sun Exposure

- Chemotherapy, radiation therapy, and some medications make your skin more sensitive to the sun.
- Protect yourself from direct sunlight, especially between 11 AM and 3 PM.
- If you go to a beach, park, playground, baseball game, or other outdoor activity, always use SPF-30 or higher sunscreen. Wear long pants, a long-sleeved shirt, and a wide-brimmed hat.

Eyes and Contact Lenses

- You should have your usual eye exams with your optometrist or ophthalmologist (eye doctor). Ask your HSCT doctor when you can schedule your first eye exam after your transplant.
- If you wear contact lenses, you need to be careful about eye infections. Be sure that you always wash your hands before removing or replacing your contact lenses. Always clean your contact lenses before putting them in your eyes.
- Dry eyes and sensitivity to light can be problems for HSCT patients. Artificial tears can help the dryness. Wearing dark glasses helps with light sensitivity.

Home Environment

Housecleaning

- Try to keep your home as clean and dust free as possible.
- The following tasks should be done by someone other than you:
 - Dust and vacuum the house.
 - Clean all bathrooms weekly (or more frequently if needed).
 - Clean all kitchen countertops every day.

Clothes and Laundry

- Put on a complete set of clean clothes every day after your shower or bath.
- Wash your clothes separately from the rest of the family's for 100 days after your day zero.
- Wash all new clothes before wearing them.
- Outer clothing, such as jackets, woolen sweaters, and winter coats, should be washed or dry-cleaned before wearing them.
- If it is necessary to use a laundromat, liquid bleach should be added to all wash loads.

Plants and Flowers

- Do not handle any plants or flowers for 100 days after your day zero. Remove all plants and flowers from your bedroom and any other room where you spend a lot of time.

- Do not water or repot plants or flowers. Soil has bacteria, fungus, and molds in it that can cause infections.
- Do not mow the lawn, rake leaves, or garden for 100 days after your day zero.
- You may have a live Christmas tree in a room where you do not spend much time.

Toxic Substances

- Avoid contact with chemicals such as paint, paint thinners, aerosols, antifreeze, nail polish remover, or any product you think could contain or give off toxic fumes. Toxins can harm your new bone marrow and lower your blood counts.

Fireplaces and Wood-Burning Stoves

- You can be in a room with a fire in a fireplace or a wood-burning stove.
- Do not start or tend the fire. Let someone else take care of the fire.
- Do not clean the fireplace or wood-burning stove.

Family and Friends

Who Needs to Use a Face Mask?

- People who live with you do not have to wear a face mask unless they are sick.
- If someone who lives with you has a cold or cough, sore throat, fever, or other signs of being sick, you should have as little contact with them as possible. You can wear a face mask if you and the sick person are in the same room. There is no need for you or the person who is sick to live somewhere else during an illness.
- Healthy visitors (visitors without symptoms of an illness) do not need to wear a face mask when they visit you in your home. Friends or relatives who are sick or live with someone who is sick should not visit you.

Visitors

- Keep visitors to a minimum for the first 100 days after your day zero. We recommend that only 2 or 3 people visit with you at a time.
- Visits should be brief so you do not get too tired.
- It is better if family and friends come to your house to visit rather than you going to their homes.
- All visitors need to wash their hands when they come into your house.
- Friends or relatives who are sick or live with someone who is sick should not visit you. This includes people with colds, coughs, runny noses, sore throats, fevers, vomiting, or diarrhea.
- Ask anyone who smokes to smoke outside.
- If you have been exposed to someone with chicken pox, shingles, measles, or German measles (3-day measles), contact your HSCT physician as soon as possible.
- For the first 100 days after your day zero, we discourage school-age children from visiting you. Children are exposed to lots of germs at school. Children can be contagious before showing any signs of illness.

Infants and Toddlers

- Do not change the diapers or wash the clothing of infants or toddlers—someone else should do these tasks. If you have to care for an infant or toddler, always wear gloves and wash your hands thoroughly after any contact with them or their dirty clothes.
- It is all right to hold an infant or toddler unless the child is sick.
- No one who lives with you should ever get an oral polio, a shingles vaccine or nasal flu vaccine after your transplant.

Wellness

Fatigue

- It is normal to feel tired and weak when you first go home. There are several reasons for feeling tired:
 - You are recovering from a long stay in the hospital.
 - Your blood counts are still low.
 - You are “deconditioned” because your activity has been limited in the hospital.
 - You may have lost some weight.
- Ask family and friends for help with grocery shopping, child care, laundry, and meals. Let people do things for you.
- Food helps your energy. Eat and drink as well as you can. Eat small amounts of food frequently.
- Take a nap when you feel tired.
- Your energy will come back. In the meantime, be kind to yourself!

Activity and Daily Exercise

- Get some exercise every day. For example, take a walk or do the exercises the physical therapist taught you.
- Do things that you enjoy: walk, watch a movie, read a book, listen to music, take a car ride.
- Save your energy for the activities you want to do most.
- Do not do strenuous or rough activities (such as team sports, skiing, snow shoveling). These activities can cause injuries, fatigue, and sore muscles and joints.
- Visiting with family and friends can tire you out. Limit visits until you are feeling stronger. Ask people to call before coming to your house.

Work or School

- It will take weeks to months before you feel well enough to return to work or school, even part-time.
- Being tired will limit what you are able to do.
- If you feel up to it, you can do some schoolwork or work-related activities at home.
- Students might need home tutoring before going back to school.
- Talk about going back to school or work with your HSCT doctor to be sure it is safe.

Sex

- People often find that talking about sex is difficult or embarrassing. We understand that this is a very personal topic. Please do not feel shy or embarrassed to ask any questions you may have.
- At first, you might not have much interest in sex. You may not have much energy. This is common after a long stay in the hospital, the treatments you have had, and the stress of returning home.
- You and your partner could just sit close together, hold hands, kiss, touch, and sleep together for a while.
- You can start having sex when your doctor says your absolute neutrophil count (ANC) and platelets are adequate. Ask your doctor when it is okay to start having sex. It may take some time for you and your partner to feel comfortable and ready for sex—it is different for everyone. Be patient with each other.
- You and your partner should be free of infection—without a cold, cough, open sores or cuts, or active herpes. If you or your partner has genital warts, you must always use condoms.
- For 100 days after your day zero:
 - Use condoms.
 - Do not have oral or anal sex.
 - Do not have multiple partners.
 - Do not use a diaphragm or have an intrauterine device (IUD) put in.
- Both high-dose chemotherapy and total body irradiation (TBI) can cause menstrual periods to be less frequent, irregular, or they may stop. You might have symptoms of menopause, like “hot flashes” and trouble sleeping.
- Women can have vaginal dryness or tightness after their HSCT. Lubricants, gels, or other vaginal creams can help to relieve this discomfort.
- Women should have their usual gynecology exams. Your gynecologist should talk with your HSCT doctor about your follow-up care.

Fertility

- Both men and women are usually unable to conceive children after chemotherapy and TBI. Sterility can be caused by high-dose conditioning chemotherapy, even a long time after your treatment. Not everyone becomes infertile, so you need to use contraceptives. Ask your doctor for more information.
- You may be able to take birth control pills. Sometimes birth control pills are also prescribed to limit or stop menstrual bleeding (especially if your platelet count is less than 50,000).

Swimming

- Do not swim in a lake, pond, or public pool for 1 year after your day zero.
- You may not swim at all if you have a central line.
- If your central line has been removed, you can swim in a private, chlorinated pool starting 100 days after your day zero.
- Before you go swimming, ask your HSCT doctor if it is safe for you.

Saunas, Hot Tubs, and Whirlpools

- Do not use any of these for 100 days after your day zero.
- Do not use any of these if your central line is still in.

Smoking

- DO NOT SMOKE!
- To protect yourself from getting pneumonia or other lung infections, do not smoke cigarettes, cigars, pipes, or marijuana after your HSCT.
- Secondhand smoke can also make you sick. Ask anyone who smokes to smoke outside.
- Smoking is even worse for people who have had radiation of their chest or TBI. Smoking can cause shortness of breath, difficult or heavy breathing, wheezing, and coughing. Call your HSCT doctor if you have these or other breathing problems.

Outpatient Care and Follow-Up

- After you go home, you will have appointments for follow-up care in Yawkey 9E. These visits are important.
- Your HSCT doctor and nurse will check on everything about your recovery. They will talk with you about any questions or concerns you may have.
- Patients with allogeneic transplants come back 2 or more times a week for 1 to 2 months.
- Patients who are discharged on day plus one may need to be seen more often.
- Your follow-up care and visits may include:
 - Checking your temperature, blood pressure, heart rate, breathing rate, and weight
 - Blood tests to check the growth of your stem cells and bone marrow
 - Blood or platelet transfusions
 - Bone marrow biopsies
 - Lumbar punctures (spinal taps)
 - CAT scans, MRIs, bone scans, mammograms, and other X-ray tests
 - Participation in research studies
- All tests and procedures will be explained to you before they are done.
- Each patient will be followed based on their individual needs.

Vaccinations

- You will need to be revaccinated against certain diseases after your transplant. Your HSCT doctor will tell you what you need and when you need it.
- Your HSCT doctor may recommend that you get a deactivated viral or bacterial vaccine, such as a flu shot or pneumonia vaccine.
- You or anyone who lives with you can get the MMR vaccine, but not the oral polio vaccine, shingles vaccine or nasal flu vaccine.
- Talk to your HSCT doctor before anyone gets a vaccination.

Other Health Care

- Women should have their usual gynecology exams. Your gynecologist should talk with your HSCT doctor about your follow-up care.
- Have a dental exam and cleaning every six months. Check with your HSCT doctor about when you should schedule your first dental cleaning.
- If you have a central line or port-a-cath, you may need antibiotics before any cleaning or dental work is done.
- Tell your dentist that you have a central line or port-a-cath before all dental appointments.
- You should have your usual eye exams with your optometrist or ophthalmologist (eye doctor). Ask your HSCT doctor when you can schedule your first eye exam after your transplant.
- About 20% of patients who have had TBI will get cataracts 3 to 6 years after HSCT. Cataracts can be removed with eye surgery.
- Total body radiation can change your lung function. If you need to be put to sleep for surgery (general anesthesia), be sure to tell the anesthesiologist and surgeon about your radiation.

Support for You and Your Family

Feelings and Concerns

You will need to identify a primary caregiver who will be responsible for your care for the first 100 days after your day zero.

An HSCT is not a journey that you take alone, but one that includes your supporters: your family members, friends, and coworkers. As your hospitalization ends and you return to daily life, you may find that the first few weeks at home are difficult. Each person in your family may react differently to the transplant experience and the changes it brings. Learning to adjust is often about finding a “new normal” in your daily life.

Your transplant team Social Worker is a licensed counselor with experience helping individuals and families during and after a transplant.

Your Social Worker will:

- Listen to what is most important to you and your family
- Address your concerns by providing support and guidance

- Help with feelings of sadness, anxiety, or depression
- Point you to resources that can help with more practical issues, such as work, parenting, family communication, relationships, and family finances

Chaplains are also available to offer spiritual care to you and your family.

The following suggestions will help you and your supporters move forward:

- Talk with others about your thoughts and feelings.
- Realize that your strength and the ability to do daily activities will increase slowly.
- Be patient and accept the practical help and support of others.
- Understand that the role of your supporters is to help make your life easier so you can focus on your recovery.
- Let supporters:
 - Help manage your medications
 - Do errands or household tasks
 - Drive you to your appointments
 - Prepare meals
 - Provide child care or rides to activities
- Know that as you become stronger, you will need less and less help from others.

Returning to Work

As you recover from your transplant, you may begin to think about how and when you will return to your daily activities. This may include deciding when to go back to work.

We recommend that you make this decision carefully and take as much time off from work as possible to recover. The following questions can guide you when deciding how ready you are to return to your job.

Talk openly with your doctors about the questions below and your concerns. This discussion will help them make the best recommendations for you.

- How crowded is your work setting? Close contact with many people may increase your risk for infection.
- What is your current energy and fatigue level?
- Can you concentrate and for how long?
- How long is the length of your work day?
- Can you work from home or on a part-time basis?
- Is your employer willing to discuss ways you can pace your return to work?
- Have you considered applying for any short-term or long-term disability programs?

Remember, your treatment team is available to guide you and help you move forward.

We also encourage you and your family members to use the supportive care programs described on the following pages.

Support Services

The Katherine A. Gallagher Integrative Therapies Program

The Katherine A. Gallagher Integrative Therapies Program offers free wellness services for patients with cancer and their loved ones. Through a wide range of services, you can learn tips for coping with symptoms and stress. These programs are designed to enhance quality of life and help manage a broad range of physical and emotional symptoms. A calendar listing the workshops and services are available throughout the Cancer Center and online.

The Marjorie E. Korff Parenting At a Challenging Time (PACT) Program

Gain support and information about helping the children in your life cope with a parent's cancer. For free one-on-one consultation with one of PACT's child psychiatrists or child psychologists, call 617-724-7272.

Healing Garden

The Howard Ulfelder, MD, Healing Garden is a 6,300 square-foot rooftop garden, accessible from the eighth floor in the Yawkey Center for Outpatient Care. The Healing Garden welcomes Cancer Center patients, their families, and staff.