

Your Guide to the Allogeneic Hematopoietic Stem Cell Transplant



MASSACHUSETTS
GENERAL HOSPITAL

CANCER CENTER

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WELCOME

Welcome to the Hematopoietic Stem Cell Transplant (HSCT) Program. This booklet will help to prepare you for your allogeneic transplant. In an allogeneic transplant, you will receive bone marrow or stem cells from another person.

You may hear people say HSCT. They may also refer to it as a Bone Marrow Transplant (BMT). These terms are often used in place of each other. While you are here, every resource at the hospital will be available to you. We will give you our most personal and compassionate care so you and your family will be as comfortable here as possible.

To learn more about our program, visit: massgeneral.org/cancer/bmt



Your Hematopoietic Stem Cell Transplant Team

Your HSCT team is made up of many different health care professionals. Each has special training and experience in HSCT medicine. Your team members work and talk with each other. They will check on you and talk with you about your progress every day. Every member of your treatment team is available to answer your questions. Your treatment team includes:

HSCT Doctors	Pharmacists
HSCT Oncology Fellows	Physical Therapists
Residents and Interns	Dieticians
HSCT Nurse Practitioners	Mass General Chaplaincy
HSCT Nurses	Case Managers
• Nurse Director	Palliative Care
• Clinical Nurse Specialists	Psychiatry
• Attending Nurse	Pain Team
• Primary Nurse	Support Staff
• Research Nurse	• Financial coordinators
HSCT Patient Care Coordinators	• Patient care associates/ medical assistants
HSCT Social Workers	• Operations associates
Radiation Oncologists	• Unit service associates
Other Medical Specialists	

How Do I Get Ready for My Transplant?

The following information can help you get ready for your transplant. Write down any questions you have. We are happy to talk with you about your transplant by phone, in the clinic, and during your stay in the hospital.

Personal Care

Clothes

- You may wear your own clothes or hospital clothes.
- The hospital is not able to do personal laundry.
- If you bring your own clothes:
 - You will need a complete change of clean clothes everyday.
 - They should be loose and comfortable.
 - They should be brought to the hospital in a clean suitcase or bag.

Footwear

- Bring slippers or shoes for wearing around your room.
- You will need a pair of athletic shoes to use the equipment in our gym.
- You may bring shower shoes if you like.

Hair loss

- Many HSCT patients lose some or all of their hair. If you lose your hair it will usually start to fall out about 10 to 14 days after your first treatment.
- Some patients cut their hair very short or shave their head to make losing their hair easier to handle.
- Hair loss is temporary. Your hair will begin to grow back about 2 to 3 months after HSCT.

Hats

- Hats, caps, scarves, bandanas, or turbans are good to wear for comfort and warmth after hair loss. Soft, cotton, easily washable head coverings are best.
- We recommend you not wear a wig because it cannot be washed everyday.

Personal bedding

- Your bedding is changed every day. The hospital cannot wash pillowcases, sheets, blankets, comforters, or quilts brought from home.
- You may bring a new pillow of your own.

Mouth care

- We will provide mouthcare items.
- Use a new toothbrush upon admission and replace it with another new toothbrush when you go home.
- If you have dentures, you may wear them during your stay in the hospital. If you get any irritation, sores, or bleeding in your mouth, you may not wear dentures until these heal. Please tell your nurse if you have any problems with your dentures.

Toiletries

- Anything you use must be new and unopened when you come to the hospital.
- Choose mild products that are unscented and do not contain alcohol.
- We will give you antibacterial soap to use when you shower.
- Only electric razors are allowed for shaving.

Nail care

- Cut your fingernails and toenails short before you come to the hospital. An accidental scratch from an untrimmed nail could cause an infection or bleeding.
- Please remove all nail polish and artificial nails before coming to the hospital.
- While you are in the hospital, you can keep your nails short with an emery board. You may not use scissors or nail clippers to trim your nails after you get to the hospital.

Makeup

- We recommend you not wear makeup while you are in the hospital.
- Replace all your makeup at home so it will be new and clean when you return.

Jewelry

- We encourage you to leave all jewelry at home.
- If your hands swell, and you are wearing a ring, it may need to be removed.

Tattoos and piercings

- Do not get any new tattoos or body piercings.

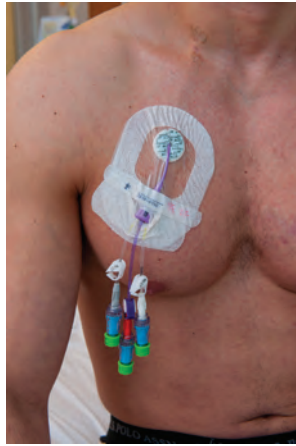
Central Line

A central line is a soft plastic tube that is inserted into a vein. It can be used for blood samples for your lab tests and for transfusions.

A central line comes in many forms. We use 3 kinds:



PICC



Tunnel Catheter



Port-a-Cath

What Happens During HSCT?

Overview

You will be in the hospital for about:

- 1 to 5 weeks for allogeneic HSCT (you will receive bone marrow or stem cells from another person). These times can vary and may be longer if any complications develop.

Transplant steps

You will go through three steps during your HSCT.

1. **Conditioning chemotherapy** — the chemotherapy you get before your transplant. Some patients also get Total Body Irradiation (TBI) during this time. The days during conditioning chemotherapy are called “minus” days because they come before your transplant.
2. **Transplant** — getting donor bone marrow or stem cells. This is day 0.
3. **Engraftment** — the time needed for your transplanted bone marrow or stem cells to start making new white blood cells. It usually takes 14 to 18 days after an allogeneic HSCT. In certain circumstances it may take longer. These are called “plus” days because they come after the day of your transplant.

During the time from conditioning chemotherapy to engraftment, your blood counts may be very low. These counts include your white blood cells, red blood cells, and platelets. You will be at risk for infections, bleeding, and other side effects of the stem cell transplant process. The HSCT team has many ways to protect you from infection and bleeding. They will watch you closely for any sign of a problem.

About Your Room



- The entire transplant unit, including all the rooms, has specially filtered air to lower the risk of getting an airborne infection.
- The door of your room is glass and is kept closed all the time. All of the rooms have large windows.
- Whenever you are out of bed, you must wear slippers or shoes and remove them before getting back into your bed.

Cleanliness in Your Room

- Your room will be cleaned daily by our unit service associates.
- There is a cupboard which contains “Supplies at the bedside.” In this cupboard are plastic drawers of supplies and shelves of linen. In order

to keep this area clean, please do not take anything from this space. You may ask your nurse or PCA to get you supplies from this area. They know how to obtain the supplies in a clean manner.

- Put books, magazines, CDs, or other items in the bedside drawers or in the closet.
- New packages of food should be kept in the bedside drawers or in the refrigerator. Do not keep any opened packages of snacks. Throw away all leftovers.

Flowers, plants, and fruit

- No fresh flowers, plants, or fruit (other than those approved on your restricted diet) are allowed in your room or in public areas of the HSCT Unit.

Neutropenic Diet

You will be on a restricted diet (called neutropenic) for 100 days after your transplant. This diet does not allow any foods that have high levels of bacteria because they can cause infections in transplant patients.

A dietician will go over the neutropenic diet with you at the beginning of your stay in the hospital. You will receive a menu to allow you to choose food for each meal. Frozen, single-serving meals from home are allowed. They can be labeled with your name and the date and kept in a freezer on Lunder 10.

Some important rules of the neutropenic diet are:

- All fruits and vegetables need to be washed well before eating.
- All meats must be well-cooked.
- **No grapefruit or pomegranates** (it affects the levels of some medicines).

What Happens Each Day I am in the Hospital?

Between 4 and 6AM, your nurse will:

- Take a blood sample from your central line for lab tests. The blood is collected early because the results of your tests are used to plan your needs for the day. Other blood tests might be needed during the day, but on most days your blood tests are done just in the morning.
- Check your “vital signs” — your temperature, pulse, blood pressure, oxygen level, and breathing rate.
- Check your weight. (We use the scale built into your bed, so you will be asked to get up out of bed so we can zero the scale).
- Give you any medications you need at that time.
- Remind you to do your morning mouth care. Mouth care is done 4 times a day to lower the risk of infections in your mouth.

Every morning, you will shower using an antibacterial soap, and then put on a complete set of clean clothes.

During the Day

Activity

- Being in the protective environment of your room limits your physical activity and can cause something called “deconditioning.” Deconditioning is a loss of strength and endurance.
- To help you stay as fit as possible, we will help you be active every day. You can do things like getting out of bed to sit in a chair, walking around in your room, and doing the exercises that a physical therapist will teach you.
- You will be allowed to walk in the halls. You must wear an N95 mask. You will see a picture of this later in this booklet.
- You will also be allowed to go to the Lunder 10 exercise room to use the equipment if your physical therapist has taught you to do so.
 - You must arrange for a time to do this with your nurse.
 - You must wear an N95 mask when you are in the hallway walking to the exercise room.
- Ask your nurse or physical therapist about deep-breathing exercises to do during the day.
- The rest of the day can be spent visiting with family and friends, reading, watching TV or movies, listening to music, playing games, or using your laptop.

Visitors

- Children under 12 years old are not allowed on Lunder 10. If children 12 and over do visit, they must have all their immunizations up-to-date.
- No one should visit if they have a cold, cough, sore throat, fever, or have been exposed to someone who is sick. People who have had a recent “live” vaccination should not visit HSCT patients.
- To reduce the risk of infection, everyone who enters your room must:
 - Put on a face mask
 - Use a hand sanitizer (the hospital uses one called “Calstat™”) located outside your room
 - Put on gloves

Your visitors may not eat or drink in your room, use your bathroom, or sleep over. Ask your nurse for the location of visitor lounges and bathrooms.

Protecting your health is our first concern, but we do try to make visiting with your family and friends as comfortable and private as we can.

What Can I Do?

Many patients find it difficult to focus or concentrate during their stay in the hospital. This can be caused by the side effects of medications, fatigue, lack of sleep, or boredom.

All rooms have a TV with remote control. There is no fee for the TV service during your stay in the hospital. Each room has a telephone. You may bring your cell phone.

You may bring books, magazines, note cards, notepaper, envelopes, journals, jigsaw puzzles, board games, and playing cards.

Electronics

- You may bring your own portable electronics to listen to music, watch movies, or keep in touch via the Internet.
- Wireless Internet is available, free of charge.
- Clean all electronics before bringing them to the hospital.

Arts and Crafts

- Some arts and crafts are permitted.
- Water-based paint is the only type of paint allowed.
- Do not bring anything that will require scissors or other sharp objects.

DISCHARGE GUIDELINES

Recovering from your HSCT 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. You will recover in small steps, so be patient and kind to yourself.

Before You Go Home



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 or your pharmacy.
- The identification tag should say: **HSCT — IRRADIATED BLOOD PRODUCTS ONLY**
- You need to wear the medical alert identification for the rest of your life.

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 furniture should be dusted. Cloth-covered furniture needs to be vacuumed.
- Sinks, tubs, showers, and toilets need to be cleaned.
- Kitchen appliances and countertops should be cleaned.
- All filters (air conditioners, heaters, humidifiers) must be removed and cleaned or replaced.

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.

For 100 days after your day zero:

- Do not feed or groom any of your pets.
- 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.

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.
- Bring a copy of your medication list to your follow-up appointments.
- 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.

The prescription line refill number is 617-724-9442.



You will be discharged on certain medications, like **tacrolimus** or **sirolimus**. 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 IMMEDIATELY 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 clinic on Yawkey 9E at 617-724-3456 during regular business hours. Evenings, weekends, and holidays, call Lunder 10 at 857-238-1000.

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, trouble swallowing, nausea and vomiting, frequent watery diarrhea, greenish or bloody diarrhea, stomach cramping, or weight loss.
 - Eyes: dryness, irritation, burning, itching, sensitivity to light.
 - Mouth: dryness, redness, white patches, sores, taste changes.
 - Lungs: trouble 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 flushing 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



N95 mask for patients



Masks for caregivers and visitors

- Wearing a face mask is another way to help prevent infections.
- Always use an N95 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:
 - In your house
 - 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 your day zero. Avoid places like sporting events, malls, public transportation, movie theaters, churches, restaurants, and supermarkets.

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 at the beginning of your recovery. 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. The diet helps protect you from infections and bowel irritation.
- Food helps your energy. Eat and drink as well as you can. Eat small amounts of food frequently.

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. You can shave with a regular razor when you no longer need platelet transfusions. This is when your platelet count is 50,000 or more.

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.
- You may floss every day unless you are told not to. Do not floss if your mouth, gums, or teeth hurt, have sores, or are bleeding.

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 often.
- 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. Light exercise can help you feel less fatigued! 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. Ask people to call before coming to your house.

Sun Exposure

- Chemotherapy, radiation therapy, and some medications make your skin more sensitive to the sun.
- Protect yourself from direct sunlight, especially between 11AM and 3PM.
- Use SPF-30 or higher sunscreen. Wear long pants, a long-sleeved shirt, and a wide-brimmed hat.

Eyes and Contact Lenses

- If you wear contact lenses, you need to be careful about eye infections.
 - Do not wear your contacts for the first 100 days after your day zero.
 - Always clean your contact lenses before putting them in your eyes.
 - Always wash your hands before taking out or replacing your contacts.
- 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.

Sex-Emotional

- 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.
- 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.

Sex-Physical

- You can start having sex when your doctor says your absolute neutrophil count (ANC) and platelets are high enough. Ask your doctor when it is okay to start having sex.
- 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 an internal birth control device.
- 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.

Fertility

- Infertility (not being able to conceive a child) can be caused by high-dose conditioning chemotherapy. Not everyone becomes infertile, so you need to use contraceptives.
- You may be able to take birth control pills. Sometimes birth control is 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, ocean 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.

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.

Home Environment

Clothes and Laundry

- Put on a complete set of clean clothes every day after your shower or bath.
- 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 you must 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 any 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.

Fireplaces and Wood-Burning and Pellet Stoves

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

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.

Visitors

- Keep visitors to a minimum for the first 100 days after your day zero.
- 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, or use hand sanitizer, 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.
- If you have been exposed to someone with chicken pox, shingles, measles, or German measles (3-day measles), contact your HSCT doctor 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, 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.

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 usually come back 2 or more times a week for 1 to 2 months.

- 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.
- You can get the injectable flu and pneumonia vaccines.
- Anyone who lives with you or who will visit you **can** get the variella vaccine (kids) zoster vaccine, MMR, and oral rotavirus (adults) vaccines.
- Anyone who lives with you or who will visit you **cannot** get the oral polio or nasal influenza vaccines.

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 will 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 2 out of every 10 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.

Returning to Work or School

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 or school.

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

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 the 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 day?
- Can you work from home or on a part-time basis?
- Is your employer willing to discuss ways you can pace your return?
- 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 for You and Your Family

Feelings and Concerns

Your transplant team Social Worker is a licensed counselor with experience helping individuals and families during and after a transplant. Chaplains are also available to offer spiritual care to you and your family.

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.
- Will work with you to assess your practical and emotional supports.

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.

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.

Support Services

Bone Marrow Transplant Survivorship Program

As you finish treatment and are recovering, you might be wondering what happens next? The answer is different for every person. Some people return to the lives they were leading before their diagnosis, while others are significantly changed by their cancer experience. The challenge for every survivor is figuring out how to return to everyday life while adjusting to the effects of their illness and its treatments.

The Bone Marrow Transplant Program Survivorship Program is here to help you prepare for life after BMT and to provide helpful strategies to overcome challenges and enhance your self-care. Visit massgeneral.org/cancer/Survivorship/BMT.aspx to learn more.

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 at massgeneral.org/cancer/supportservices.

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

PACT is a free parenting support program for patients diagnosed with cancer. PACT has child psychiatrists and psychologists who are available for inpatients and outpatients to talk about parenting questions. They can help you understand how children think about illness at their own particular stage of development. Information from PACT helps parents support their children and give them a sense of security during a difficult time. (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.

Housing

To learn about overnight accommodations, transportation near Mass General, and for airport information, visit the MGH Visitor Information website at www.massgeneral.org/visit/boston. Or call the Oncology Resource Specialist at (617) 724-0295 to learn about our listing of local lodging options. There are many options based on your needs.

Parking at Mass General

Two parking garages are located in front of Mass General. There are several other garages and parking lots in the area that are within walking distance of Mass General. Some garages or lots may charge less than others, but parking in the Mass General area is expensive.



MASSACHUSETTS
GENERAL HOSPITAL

CANCER CENTER

Cancer Center Community Providers

Through our network of collaborations, patients have access to the latest cancer treatments and targeted therapies, early phase clinical trials, timely referrals for second opinions, and improved coordination of care.

Visit massgeneral.org/cancer/community or ask your care team for more information about what services are offered at each site.

Massachusetts General Hospital Cancer Center

55 Fruit Street, Boston, MA 02114 | 877-726-5130

Mass General Cancer Center at Emerson Hospital – Bethke
131 ORNAC, John Cuming Building, Suite 200
Concord, MA 01742 | 978-287-3436

Mass General/North Shore Cancer Center
102 Endicott Street,
Danvers, MA 01923 | 978-882-6060

Mass General Cancer Center at Newton-Wellesley Hospital
2014 Washington Street,
Newton, MA 02462 | 617-219-1200

Mass General Cancer Center at Cooley Dickinson Hospital
30 Locust Street, Northampton,
MA 01061 | 413-582-2900

Mass General Hematology/Oncology Service at Martha's Vineyard Hospital
1 Hospital Road, Oak Bluffs,
MA 02557 | 508-693-0410

Mass General Hematology/Oncology Service at Nantucket Cottage Hospital
57 Prospect Street, Nantucket,
MA 02554 | 508-825-8100

Mass General Radiation and Hematology/Oncology Services at Exeter Hospital
5 Alumni Drive, Exeter, NH 03833
603-580-7336

Mass General Hematology/Oncology Service at Southern New Hampshire Medical Center
8 Prospect Street, Nashua,
NH 03060 | 603-577-3089

Mass General Cancer Center at Mass General Waltham
52 Second Avenue, Suite 1110
Waltham, MA 02451 | 781-487-6100