Your Guide to the Autologous Hematopoietic Stem Cell Transplant
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Welcome to the Hematopoietic Stem Cell Transplant (HSCT) Program. This booklet will help to prepare you for your autologous procedure. In an autologous procedure, you will receive your own stem cells or bone marrow.

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.
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
HSCT Oncology Fellows
Residents and Interns
HSCT Nurse Practitioners
HSCT Nurses
  • Nurse Director
  • Clinical Nurse Specialists
  • Attending Nurse
  • Primary Nurse
  • Research Nurse
HSCT Patient Care Coordinators
HSCT Social Workers
Radiation Oncologists
Other Medical Specialists

Pharmacists
Physical Therapists
Dieticians
Mass General Chaplaincy
Case Managers
Palliative Care
Psychiatry
Pain Team
Support Staff

• Financial coordinators
• Patient care associates/medical assistants
• Operations associates
• Unit service associates
What Happens Before My Transplant?

Mobilization process (collecting your cells)
The first phase of the autologous HSCT is collecting your cells. This is done with or without chemotherapy. It is always done with a drug called Filgrastim.
**Medications:**
Filgrastim is a growth factor that reproduces stem cells in your body. It is a daily self-injection or injections you can do at home for 5-10 days. This medication needs to be kept in your refrigerator and should be taken daily in the morning. Filgrastim may cause bone pain and the use of Tylenol or narcotics are prescribed as needed. Your team may prescribe antibiotics and anti-nausea drugs as well. The addition of Plexifor may be used to assist in the stimulation of your cells. This is an injection that will be given the night before your collections at the hospital. Plexifor may cause diarrhea and nausea.

**Lines:**
The pheresis team will determine if your collection can be done using your veins or if you will need a pheresis line placed. The pheresis line is a central line that is placed by Interventional Radiology. You will go home with this line and Visiting Nurses Association (VNA) services.

**Collection:**
Arrival to the Pheresis center/Jackson is 7am-7:30am. It usually takes 4-6 hours for collection. You may have someone stay with you but space is limited during collection. Collection of your cells can take anywhere from 1-5 days. This is done all as an outpatient.
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 four kinds:

- PICC
- Tunnel PICC
- Pheresis
- Port-a-Cath

How Do I Get Ready for My Transplant?

Having an autologous HSCT is a difficult process. It may be easier if you know what to expect during your hospital stay. We put together the following information to help you get ready for your transplant. As you read through this booklet, 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. After your stay, you will have follow-up visits with your healthcare team.
Personal Care

Clothes
• You may wear your own clothes or hospital clothes.
• If you bring your own clothes, they should be loose and comfortable.
• You will need a complete change of clean clothes every day.
• Clothes should be brought to the hospital in a clean suitcase or new plastic bags.

Footwear
• Bring slippers or shoes to wear around your room.
• You will need a pair of athletic shoes if your physical therapist wants you 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 start to fall out about 10 to 14 days after your first treatment. Your HSCT doctor or nurse can tell you whether your chemotherapy or radiation will make you lose your hair.
• 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.
• If you plan to wear hats or scarves, bring enough so you can put on something clean every day after you shower.
• We recommend you not wear a wig because it cannot be washed everyday.
**Personal bedding**

- Your bedding is changed every day. If you bring anything from home, it must be replaced with clean items each 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**

- You will use a new toothbrush each week. You may use hospital toothbrushes or bring soft-bristled toothbrushes from home.
- We will give you toothpaste.
- 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 so a dietician can help you choose foods you can eat without dentures.

**Toiletries**

- Check with your nurse before using any deodorant or lotions.
- Anything you use must be new and unopened when you come to the hospital.
- Choose mild products that are unscented or lightly scented and do not contain alcohol.
- A special soap will be given to you for your shower.
- Your comb or hairbrush needs to be new as well.
- Only electric razors are allowed for shaving any part of your body.
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 because your white blood cell and platelet counts will drop to low levels from your treatments.
• 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.
• No nail polish can be worn during your stay in the hospital. Please remove all nail polish and artificial nails before coming to the hospital.

Makeup
• We recommend you not wear makeup while you are in the hospital.
• You may use new lipstick, lip gloss, or lip balm.
• 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.
• Only a wedding band may be worn during your stay in the hospital. If your hands swell, your ring may need to be removed.
• Earrings may not be worn because the holes in your earlobes can get infected.

Tattoos and piercings
• Do not get any new tattoos or body piercings.
What Happens During HSCT?

Overview
You will be in the hospital for about:

• 1 to 3 weeks for an autologous HSCT (you will receive your own stem cells or bone marrow).

These times can vary and may be much 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 your 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 8 to 12 days after an autologous HSCT. In certain circumstances it may take much 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

Because your blood counts will be very low for 1 to 3 weeks, you will be at risk for infection and bleeding. For your safety, you will be in a “protective environment” — a special room.

All the rooms have 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 our rooms have large windows. You may also walk in the halls wearing an N95 mask.

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.
The floor of your room is clean—but not clean enough! If you drop something on the floor, do not pick it up with bare hands. Call your nurse for help. Whenever you are out of bed, you must wear slippers or shoes and remove them before getting back in or on your bed.

Another way to keep things clean is to put books, magazines, CDs, etc. in the bedside drawers or in the closet. Extra wrapped silverware and new packages of food (candy, potato chips, cookies, drinks) 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 eat a restricted diet (called neutropenic) while you are in the hospital and for a few months after you go home. 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.

Some important rules of the neutropenic diet are:
- You may only have well washed vegetables or fresh fruits. You will learn more from your dietician.
- Frozen, single-serving meals are allowed. They can be labeled with your name and the date and kept in a freezer on Lunder 10.
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 3 or 4 times a day, 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 mask later in the 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.
• You will be allowed to visit the family lounge when your absolute neutrophil count (ANC) is over 500.

**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 sanitzer (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. Mass General has a limited number of cable TV stations. 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.

You need to wear gloves when handling newspapers, magazines, books, and personal mail.

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.

• Only water-based paints are allowed.

• Do not bring anything that will require scissors or other sharp objects.

• Please check with your HSCT clinical nurse specialist or primary nurse before bringing in arts and crafts.
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 30 of your transplant. We want you to take some precautions for the first 30 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 developing complications from transfusions after your transplant.

• 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 will wear a medical alert identification for one year.

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.

• 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 vet to make sure your pets have had all their shots.

• For 30 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 to you before you go home. They will go over the reasons for the medications, the doses, times to take them, and possible side effects.

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

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
• Damaged or leaking 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
• Blurred or double vision
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)
- Cough
- 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: 857-238-1000.
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 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 30 days following your day zero. 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.
  - Autologous HSCT patients may use well water 30 days after their stem cell transplant.
- You may drink tap water if it is municipal water. You may also have ice made from this 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.
- 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.
- Food helps your energy. Eat and drink as well as you can. Eat small amounts of food often.

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 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.
- 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.
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. Limit visits until you are feeling stronger. 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 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.
  - Do not wear your contacts for the first 100 days after your day zero.
  - Always wash your hands before taking out or replacing your contacts.
  - Always clean your contact lenses before putting them in your eyes.

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 30 days 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.

Saunas, Hot Tubs, and Whirlpools
• Do not use any of these for 30 days after your day zero.
• Do not use any of these if your catheter 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 30 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 30 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 stove, or pellet stove.
• Do not start or tend the fire. Let someone else take care of the fire.
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 30 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, 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 30 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.

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 who have autologous transplants usually come back 1 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 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, 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.
• TBI 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.
• 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

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.