

Your Guide to the Hematopoietic Stem Cell Transplant

Welcome to the Hematopoietic Stem Cell Transplant (HSCT) Program. 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 to be sure you receive the best possible care. 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.

These Are the Health Care Professionals on Your HSCT Team:

HSCT Doctors are medical hematologists (blood doctors) and oncologists (cancer doctors) who specialize in bone marrow and stem cell transplant medicine. Your HSCT doctors will work with other members of your team to coordinate your transplant treatment and care.

HSCT Oncology Fellows are doctors training to be specialists in cancer medicine and bone marrow and stem cell transplant. The fellows work closely with your HSCT doctor.

Residents and Interns are doctors training in medicine who work with your team to help with your medical care.

HSCT Nurse Practitioners are nurses with advanced training who care for patients just like doctors do. They work closely with your HSCT doctor to manage your transplant care.

HSCT Nurses are nurses with special training and experience in the care of transplant patients.

- Nurse Director is responsible for the overall management of Lunder 10 and Cox 1, including the HSCT unit.
- Clinical Nurse Specialists are experienced in HSCT and are good resources for the patient, family, and other nursing staff.
- Attending Nurse oversees your overall care while you are on Lunder 10.
- Primary Nurse is responsible for your nursing plan of care, coordinating your care with other health care professionals, and providing your direct nursing care.
- Research Nurse is a nurse trained in HSCT who helps design, coordinate and conduct clinical trials.

HSCCT Patient Care Coordinators work with you and your HSCCT doctor in planning and coordinating all aspects of your transplant including pre-testing, education, and donor searching, as well as insurance approval.

HSCCT Social Workers have expertise in supporting and guiding patients and families during transplant. You will meet with a HSCCT transplant social worker to help you and your family prepare for and cope with the emotional and practical aspects of HSCCT. Social Work support is available to you during your inpatient and outpatient care.

Radiation Oncologists specialize in using radiation to treat cancer. They plan and supervise your radiation therapy if your treatment includes radiation.

Other Medical Specialists such as a dentist, heart doctor (cardiologist), skin doctor (dermatologist), lung doctor (pulmonologist), kidney doctor (nephrologist) or infectious disease doctor will be contacted if you need their specialized care.

Pharmacists coordinate how your medications are prepared and given to you. Pharmacists are available to provide drug information to you and your team.

Physical Therapists work with you on ways to keep up your strength and endurance.

Dieticians teach you how to choose the right foods during and after your treatment. A dietician will meet with you during your hospital stay.

Mass General Chaplaincy supports all religious and spiritual traditions. Chaplains are available through the Chaplaincy Department. If you would like to speak with a chaplain, ask your nurse to contact them for you.

Case Managers work with you and your family to be sure you have whatever services you need in the hospital and at home. They work with the HSCCT team to set up your plans for going home. The case manager helps with communication between you and your insurance providers and handles insurance payment issues.

Support Staff

- Financial coordinators help you with insurance coverage issues.
- Patient care associates/medical assistants help your nurse meet your physical needs.
- Operations associates answer your calls and greet people at the front desk.
- Unit service associates keep the environment clean and clean your room every day.

How Do I Get Ready for My Transplant?

Having a bone marrow transplant 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.

Laundry

- Clothes should be brought to the hospital in a clean suitcase or new plastic bags.

Footwear

- Bring slip-on type slippers.
- 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 hematopoietic stem cell transplant 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 your transplant.

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.
- To protect your scalp from irritation, you may not wear a wig.

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.

Stuffed animals

- You may bring one or two stuffed animals with you. They must be thoroughly washed at home before they can be put in your hospital room.

Pictures

- Pictures are allowed. Photo albums are also allowed as long as the cover is plastic so it can be cleaned.

Mouth care

- You will use a new toothbrush each week for your mouth care. 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

- You may 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.

Central Line

A central line comes in many forms. It is also called a Hickman®, PICC, pheresis catheter, or simply a “line.”

What is a central line?

- A soft plastic tube that is put into a large vein.
- It may have two or three branches that are called lumens.
- Each lumen is closed off with a cap. It may also have a safety clamp.

Why do I need a central line?

- Your central line is used to give you:
 - Stem cells or bone marrow cells
 - IV fluids
 - Medications and chemotherapy
 - Blood or platelet transfusions
 - Special high-calorie liquids

Because you have a central line, we can use it to draw blood for most or all of your daily lab tests. There may be times when the nurses will need to draw blood with a needle through your skin. Your nurse will explain these to you.

How long will I have my central line?

- Your central line will stay in as long as you need IV medications, blood transfusions, or frequent blood tests.
- A central line can be left in place for long periods of time.
- Special care is taken to prevent a central line associated infection. If your line does get infected, it will have to be replaced or removed.
- Your line will be removed when your HSCT doctor decides that you do not need it any longer. Sometimes we can remove your central line before you are discharged from the hospital.

Medical Alert Identification

HSCT patients should wear a medical alert necklace or bracelet 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.

- Order forms are available from a pharmacy, at the Cox 1 HSCT clinic desk, or online.
- The tag should read: HSCT—IRRADIATED BLOOD PRODUCTS ONLY

- You need to wear the medical alert tag for one year if you are an autologous transplant patient, or the rest of your life if you are an allogeneic transplant patient.
- **It is helpful if you order your medical alert tag before you come in for transplant.**

What Happens During HSCT?

Overview

You will be in the hospital for about:

- 1 to 5 weeks for allogeneic HSCT (if you receive bone marrow or stem cells from another person).
- 1 to 3 weeks for an autologous HSCT (if you 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, and 14 to 18 days after an allogeneic 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 a special 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.

You will receive a menu to allow you to choose food for each meal.

A dietician will go over the neutropenic diet with you at the beginning of your stay in the hospital.

Some important rules of the neutropenic diet are:

- No raw vegetables or fresh fruits. There are some exceptions, such as oranges and bananas. You will learn more from your dietician. **No grapefruit** (it affects the levels of some medicines).
- All foods, snacks, or drinks must be packaged in individual, single servings.
- 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?

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 a special mask.
- 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 a special 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. We discourage children from visiting you. Children are exposed to lots of germs at school or day care. They can be contagious before showing any signs of illness.
- No one can go into your room 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.

To keep in touch with people who cannot visit, Mass General offers CarePages. This is a private, personalized Web page you can set up to share information and updates with your family and friends. This also cuts down on the number of calls you might feel you need to make.

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. To make calls outside area code 617 you will need a phone card. You may bring your cell phone but it has to be cleaned and wiped with disinfectant.

You may bring new books (not worn or from the library), new magazines, note cards, notepaper, envelopes, journals, jigsaw puzzles, board games, and playing cards. Your religious material does not need to be brand new.

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 everything before bringing it 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.

Blood and Platelet Donation

Many family and friends want to donate blood products to help a loved one. Mass General has an active blood and platelet donation program (Blood Donor Center), located on the first floor of the Gray Building. There will be times during your stay in the hospital when you will require transfusions of red blood cells or platelets. Any blood products you need will come from the Mass General general blood product supply.

Your friends and family can support the Blood Bank by donating. Blood and platelet donations become part of the general supply to help all patients who need transfusions. For more information about donating blood, please call (617) 726-3620.

Support for You and Your Family

Going through HSCT is a difficult experience for you and your family. It is normal to have worries or concerns. You and your loved ones may react differently to the stress that a HSCT

can have on daily life. Your mental and emotional health is an important part of your care. We want you to take advantage of the services we offer for both emotional and spiritual support. Resources and information to help with practical issues are also available.

Talk with your HSCT social worker if worry, anxiety or depression has increased and is affecting your daily life. If your concerns are about your job, parenting or practical matters, your social worker can listen and help with problem solving, advocacy and recommend the right resources that will help.

Chaplains are also important members of the HSCT team and can offer spiritual support. Chaplains from a variety of beliefs are available to you.

If you speak a language other than English, language interpreters are available 24 hours a day. Translation is usually done using a special phone. Most of our patients from outside the United States use the services of the hospital's International Patient Center. It is located on the first floor of the Blake building.

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

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.

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.

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.

PESC 4.14

© The General Hospital Corporation, d/b/a Massachusetts General Hospital, 2014.

Revised March 2014. All rights reserved.