Patient and Family Education
intermountainhealthcare.org

Bone Marrow Transplant:
What to expect during your hospital stay

Intermountain Healthcare

WELCOME TO EAST 8!

We look forward to caring for you during your stay here. Please let us know if there is anything we can do to make your stay more comfortable.

What's Inside:

INTRODUCTION

The fact that you are having a bone marrow transplant means that you are entering a new chapter in your care.

We've put together this booklet to help answer any questions that you and those close you may have.

- Section 1 provides information specifically related to your care and any symptoms you might experience.
- Section 2 focuses on what your family and friends can do to help you through the process and when you get home.
- Section 3 provides a list of services available at LDS Hospital and in the community.

Should you have any additional questions or concerns, please let us know how we can help.

Section 1: What to Expect During Your Stay

IN THIS SECTION:

- What to expect during your stay
- Frequently-asked questions
- Commonly-used medicines and side effects

LDS Hospital's East 8 unit is Intermountain Healthcare's center for bone marrow transplants. Here, you and your family will find the care and support you need during this critical time in your treatment.

How long you need to stay with us will depend on your diagnosis, but it can range between 10 days to 6 weeks.

During this time, you'll have **induction chemotherapy** and a bone marrow transplant, and be monitored for infections and other problems. It will take some time for your blood counts to recover, and this will also be monitored.

Your healthcare team will let you know when it's safe for you to go home.

BONE MARROW AND BLOOD CELLS

Three types of blood cells are made in your bone marrow (the soft, spongy, material found in the center of most bones). These are:

1. **White blood cells** to help your body fight infections
2. **Red blood cells** to carry oxygen throughout your body
3. **Platelets** to help your blood to form clots and stop bleeding

Cancer and other certain diseases can damage your bone marrow. Cancer treatments, especially high-dose chemotherapy [kee-moh-THAIR-eh-pee] or radiation therapy, can also destroy the bone marrow.

During your stay, your care team will take many blood samples. This is to check your blood cells to see how many of each type you have and how healthy they are. These tests help your doctors know how well you are healing and when the transplant is beginning to work — a process called **engraftment** [en-GRAFFT-mehnt].

You probably have a lot of questions about what will happen during your bone marrow transplant stay. Most people do. We've provided answers to some of the most frequently-asked questions in the next few pages.

Frequently asked questions

What do I do while I'm in the hospital?

Your "job" will be to eat, drink, and walk. You need calories and fluids to help your body stay strong and build new blood cells. You will need to walk at least 30 minutes every day so that your body has the strength it needs to heal and to help prevent infections like pneumonia.

During your stay, a registered dietitian nutritionist (RDN) will work with you to figure out the right amount of calories you need and how much you should drink each day. Giving your body the fuel (food) it needs, as well as doing strength-building exercises, will help speed up the recovery process.

Can I bring things from home to make me more comfortable?

You may bring pillows, blankets, and clothing from home to use during your stay in the hospital. However, we do encourage you to use our bedding so it can be washed on a daily basis. Any blankets and clothing you bring will need to go home with a loved one and be washed at least once a week or more often if they are visibly soiled.

You may also bring:

- Electronic tablet and headphones
- Movies
- Music
- Smartphone
- Laptop computer
- Books
- Board games
- Wall decorations (only if you use removable hooks)

If you have any questions about what is allowed, ask a member of your care team.

AM I ALLOWED TO EAT FOOD FROM OUTSIDE OF THE HOSPITAL?

Yes. However, the food needs to be prepared fresh and in a clean environment. Also, it can't be allowed to sit out for more than 1 hour.

If you have questions about getting food from restaurants, check with your nurse.

For more specific instructions, refer to the food safety booklet provided by your registered dietitian nutritionist (RDN).

FEELING OVERWHELMED WITH VISITORS?

You can restrict the number of visitors you have in a day and request quiet time for yourself. Simply let the nursing staff know, and we can put a sign on the door asking guests to check in with us before entering your room.

How can my family and those close to me help during this time?

To help you stay healthy, **all** family members, caregivers, or others who live with you must be current on all their vaccinations. They must also get a flu shot and the pneumonia vaccine.

A loved one or close friend may act as a spokesperson for you. Direct other members of your family and friends to your spokesperson for updates.

Loved ones and friends can also:

- Help you keep track of how much you eat and drink
- Make sure you walk on schedule
- Keep a journal or blog to help you remember your experience in the hospital
- Be your cheerleaders and support system

Can I limit the number of people who can get information during my stay?

While in our care, you have the right to:

- Restrict who gets any information about your health
- Limit the amount of information that our staff shares with family members or friends

To help our staff and your caregivers, we suggest using a password system. Choose a number or word that your family or friends can provide to us or your spokesperson. Only those who have the password will receive information about your condition and care.

Can anyone come to visit?

No one who is sick can visit. In addition, no one who has had a vaccine that contains a live virus can visit immediately after getting their vaccine. This is because the virus may be transmitted to you. Please ask the pharmacist if you or a loved one have any questions about a specific vaccine.

Video chat services, such as Skype or FaceTime, can help you keep in touch with those who are not allowed to visit you.

Are children allowed to visit?

Yes. Children may visit as long as they are not sick and are current on their vaccinations. However, children should not visit if they:

- Have recently been ill and are not free of all symptoms
- Are under age 13 and it is during cold and flu season

If you have questions about a child's visit, please ask the nursing staff. We will recommend whether or not they should visit. **When visiting, all children must be supervised by an adult visitor (not you).**

Can my visitors bring flowers and plants?

No. Live flowers or plants are not allowed in your room. Live plants may introduce mold or fungus into your environment. When your immune system is weakened from chemotherapy, molds and fungi can cause an infection.

If you or your visitors bring live flowers or plants, they can be kept at the front desk for you to look at when you walk in the halls. Artificial flowers and plants are allowed in your room as long as they don't contain moss.

Am I allowed to have sex with my significant other?

Yes, if you follow these precautions:

- Don't have sex during your chemotherapy treatment and for 48 hours after your chemotherapy is completed. This is because these medicines can be transferred to your partner through bodily fluids for 48 hours after the last dose. As these medicines are designed to kill cells, they can be extremely harmful to your partner's health.
- If you choose to have sex while receiving chemotherapy, use 2 forms of birth control, with 1 form being a condom.
- Be cautious with any physical activity as you are at an increased risk for bleeding during treatment.

If you have any questions, please ask the nursing staff.

CAN I HAVE PEOPLE STAY OVERNIGHT?

Yes. We allow one visitor to stay overnight.

Will I lose my hair?

It is very likely that after chemotherapy you will lose your hair, and possibly your eyebrows and eye lashes. That is because chemotherapy targets cells that are rapidly dividing, such as cancer cells and other healthy cells, like those in the hair root. Hair loss is not permanent, but it may take several weeks after treatment for it to regrow.

The time it takes for hair, brows, and lashes to fall out is different for each person because every treatment plan is different. However, it usually happens about 2 to 4 weeks after chemotherapy ends. Your hair may fall out little by little, or in clumps.

When you are ready, our staff or your family can help with shaving your head. We have shavers available on the floor. If you are interested in scarves or wigs, let us know and a social worker can give you more information.

Where can I learn more?

You can find more information on chemotherapy and hair loss at the following links:

- **American Cancer Society:** www.cancer.org
- **Cancer.net:** www.cancer.net
- **National Cancer Institute:** www.cancer.gov

What complications or side effects should I be aware of?

Graft-versus-host disease

Graft-versus-host disease (GVHD) is a complication that can occur in patients who received an allogeneic transplant. (You are not at risk if you had a autologous transplant.) GVHD happens when immune cells from the donor attack your tissues. It can happen suddenly (acute) or occur over time (chronic) and can be mild to severe. You will be given medicine to help prevent GVDH.

Side effects

Besides chemotherapy, you will need to take other medicines to help prevent infections, manage your pain and nausea, keep water from building up in your tissues, and treat other complications. Some of these medicines have side effects. The following 2 pages list the most commonly-used medicines and their side effects.

Questions for my care team

Common side effects for frequently used medicines

MEDICINE	WHAT IT'S USED FOR	COMMON SIDE EFFECTS
IMMUNE SUPPRESSION MEDICINES ☐ Tacrolimus ☐ Cyclosporin ☐ Mycophenolate ☐ Prednisone	**Prevents or treats Graft-versus-host disease (GVHD)**	High blood pressure, insomnia, decreased magnesium and potassium, diarrhea, tremor, weakness, abnormal kidney function, headache, rash, fever, abdominal (belly) discomfort, abnormal liver tests, or infection
NAUSEA RELIEF MEDICINES ☐ Ativan (lorazepam) ☐ Compazine (prochlorperazine) ☐ Dronabinol (Marinol) ☐ Phenergan (promethazine) ☐ Zofran (ondansetron)	**Relieves nausea**	Headache, drowsiness, dizziness, or confusion. **Note:** Phenergan may cause dry eyes or mouth, burning, redness, swelling, pain, and tissue damage IF not given intravenously.
ANTIBIOTICS ☐ Penicillin ☐ Levaquin (levofloxacin) ☐ Primaxin (imipenem/cilistatin) ☐ Maxipime (cefepime) ☐ Flagyl (metronidazole)	**Prevents or treats bacterial infections**	Diarrhea or constipation, nausea, stomach upset, or headache. **Notes:** • When combined with alcohol, Flagyl may cause severe vomiting and a metallic taste in the mouth. • Primaxin may increase risk of seizure.
ANTIFUNGAL MEDICINES ☐ Mycamine (micafungin) ☐ Cancidas (caspofungin) ☐ Ambisome (amphotericin) ☐ Fluconazole (diflucan) ☐ Noxafil (posaconazole) ☐ Vfend (voriconazole)	**Prevents or treats yeast or fungal infections**	Headache, nausea, vomiting, diarrhea, rash, fever, lower blood pressure, lower white blood cell count, abnormal liver function tests, abnormal kidney function test. **Note:** Vfend may cause hallucinations and visual changes.

MEDICINE	WHAT IT'S USED FOR	COMMON SIDE EFFECTS
ANTIVIRAL MEDICINES ☐ Zovirax (acyclovir) ☐ Valtrex (valacyclovir) ☐ Valcyte (valganciclovir)	**Prevent or treats viral infections**	Fatigue (tiredness), depression, headache, nausea, vomiting, rash, fever, difficulty sleeping, abnormal kidney or liver function test. **Note:** Valcyte may cause low white blood cell counts.
ANTICOAGULANT MEDICINES ☐ Lovenox (enoxaparin) ☐ Coumadin (warfarin)	**Prevent blood clots**	Bleeding, bruising at the injection site, fever, fatigue, or rash.
PAIN MEDICINES ☐ Roxycodone (oxycodone) ☐ Dilaudid (hydromorphone)	**Relieve moderate to severe pain**	Constipation, dizziness, drowsiness, itching, nausea, vomiting, or headache. **Note:** Do not take with Tylenol (acetaminophen) or Motrin (ibuprofen).
MOUTH CARE ☐ Mycelex ☐ Nystatin ☐ Peridex ☐ Biotene ☐ Normal Saline	**Prevent mouth sores**	Taste changes, abnormal liver function tests, nausea, or vomiting. **Note:** Peridex may increase tartar on teeth.
STOMACH ACID REDUCERS ☐ Prilosec (omeprazole) ☐ Prevacid (lansoprazole) ☐ Pantoprazole (protonix)	**Treats stomach ulcers**	Headache, diarrhea, or constipation.
DIURETICS ☐ Lasix (furosemide)	**Removes extra fluid in the body through the kidney and urine (water pill)**	Frequent urination, low blood pressure, dizziness, headache, rash, low electrolytes, hearing impairment, sun sensitivity, or anemia.

Section 2: For Family, Friends, and Caregivers

IN THIS SECTION:

- How to help your loved one
- How to prevent infection by:
  - Handwashing
  - Managing pets
  - Preparing your home

How to help your loved one

We know that the family members, friends, and caregivers to someone recently diagnosed with cancer must have a lot of questions, concerns, and fears. Your lives have changed dramatically. You may feel like you don't know what to do, or how to do it. We want you to know that the East 8 care team is here to help you during this challenging time. We can provide information and guidance as you learn to adjust to your new role. You can help in 3 important ways:

① **Do not be afraid to ask questions!** If at any time you do not understand something, let us know. Your loved one is going through treatment that requires a lot of their energy and willpower. Luckily, they have you at their side. You can help them remember and understand things. We encourage you to take notes and ask questions of the medical team. You'll be a second set of ears in understanding information and treatment options.

② **Be an advocate** (someone who looks out for the best interests of another). We strive every day to provide the best care and service to our patients, but you know them best. You can let us know if there is a problem or something we can do to make their stay a little better.

As a caregiver, you will be involved with patient care when it's time to go home. Use this time in the hospital to be an active participant in the patient's medical care. This will help educate and prepare you when your loved one is ready to go home.

③ **Be a cheerleader!** Your loved one will have good days and bad days, and sometimes it will seem as if the bad days outweigh the good. It will be easy for them to feel overwhelmed. However, when you cheer them on to do things that will help make them better, like walking and eating enough, it will be easier. With your help, the finish line won't seem so far away.

Finally, please know that we understand just how stressful this time can be for everyone. We encourage you to work with your medical team, social worker, and care coordinator. Each plays a role in helping before, during, and after the hospital stay.

Preventing infection

During treatment, the patient's immune system will be weakened by chemotherapy. After treatment, it will take at least 12 to 18 months, or even longer, for their immune system to fully recover. **Immunosuppressive** [im-myoo-no-suh-PRES-sehv] medicines can lengthen the amount of time they are at increased risk for infection.

Because it takes time for their immune system to fully recover, any infection could be more serious. Report any signs of illness, including fevers, immediately.

Handwashing

The most important thing you can do to prevent the spread of infection is to wash your hands.

Wash with soap and water before and after:

- Handling your central line
- Every step in food preparation
- Eating

Always wash your hands after:

- Going to the bathroom
- Blowing your nose
- Handling the garbage
- Touching pets
- Shaking hands
- Any other time you think your hands might not be clean

AVOIDING CONTAGIOUS DISEASES

Avoid people who are ill. Follow strict hand washing practices if you and the sick person live in the same house.

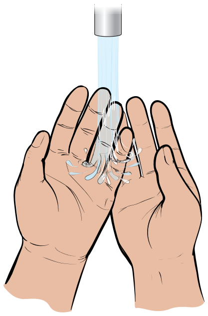
If you become sick, do not prepare food and avoid close contact with your loved one as much as possible. If you must share a bathroom, use bleach to clean all surfaces.

Your loved one should avoid household cleaning as much as possible, especially in bathroom areas. You or another person will need to clean your home.

The right way to wash your hands

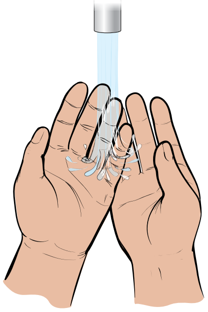
Follow these 5 steps to wash your hands the right way every time:

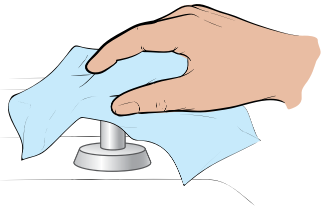
1. Wet your hands with clean, running water (warm or cold), turn off the tap, and apply soap.



2. Rub your hands together with the soap, building a lather. Wash the backs of your hands, between your fingers, and under your nails. Wash for at least 20 seconds. This is the length of the "Happy Birthday" song from beginning to end twice.

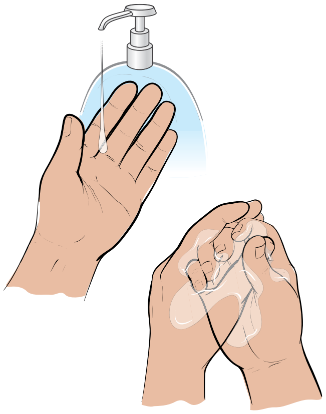
3. Rinse your hands well under clean, running water.





4. Dry your hands using a clean towel, or air dry them. Then, use a paper towel or your elbow to turn off the faucet and to open the restroom door.

5. Washing hands with soap and water is the best way to get rid of germs in most situations. If soap and water are not available, use an alcohol-based hand sanitizer that contains at least 60% alcohol. Rub vigorously for at least 20 seconds.



Pets

Pets that were in the home before your loved one's transplant can remain. Cats and dogs are safe as long as they are not allowed on the bedding, do not have close face contact, and do not get near your loved one's central line. In addition, make sure your loved one:

- Washes their hands after having any contact with a pet.
- Avoids all contact with animal feces (poop), including cleaning the cat litter box, fish aquariums, and bird cages.
- Reports any animal bites or scratches to their doctor.

You and other members of the family need to:

- Keep birds from flying freely within your home. Control cats and dogs when your loved one is walking around so they don't trip and fall over the animal.
- Make sure all pet immunizations and booster shots are up to date.
- Have your veterinarian check your pet's stool (poop) yearly for parasites.
- Have cats tested each year for feline leukemia and for toxoplasmosis.
- Treat for fleas.
- Have your pet screened for ticks every day during tick season (May to November) if the pet walks through wooded areas.
- Keep pets indoors or on your own property so they don't pick up diseases from other animals.

Preparing your home

Housecleaning

Avoid vacuuming, dusting, and any other activities that expose your loved one to dust during their treatment. They should leave the room during these activities and stay away for at least 30 minutes afterwards to allow dust to resettle.

Laundry, bed linens, and towels

There is usually no risk of infection from doing laundry.

- Change the bed linens at least once a week.
- Change towels every 2 days.
- Your loved one should never share towels with anyone else.

Carpet cleaning

Carpets can be cleaned using a steam system as long as they will be completely dry before your loved one gets home. It is best to clean carpets using a chemical system and avoid using water. This helps prevent mold from forming underneath the carpet.

Bathrooms

Bathrooms should not have any visible mold or fungus. Have someone clean the bathrooms on a regular basis. Make sure bleach is used in the shower to prevent mold growth. Your loved one should take care not to get any cleaning products on their skin or breathe in the fumes.

PLANTS

Plants can remain in the house, but your loved one should avoid close contact with them. Remove plants from the room they sleep in.

Do not allow your loved one to work directly with plants or soil (like pulling weeds, mowing the lawn, or raking leaves) for at least six months after the transplant and only after permission from the transplant doctor.

Watering plants is allowed, but they should wash their hands afterwards.

Air quality

Basements

Your loved one should avoid living in the basement if there is a possibility for increased exposure to dust and mold. If they must live in the basement, have every area in the basement inspected for any mold or dampness and address any issues before they come home.

Open windows

It is best to keep the windows closed if:

- Your loved one's white blood cell count is low (neutrophil count <1000 / µL)
- The wind is blowing dust up into the air.

Filtered air systems

Air conditioners, evaporative coolers, and heating systems need more attention when the immune system is weakened. Change all filters more often so that cleaner air is circulated in the home. Do this for the first year after your loved one's transplant (or longer if they are on immunosuppressive therapy). Check with your manufacturer's recommendations for information on how often to change the filters. **Don't allow your loved one to change the filters.**

For swamp coolers, have the drip pads replaced and run the cooler for at least 30 minutes daily to avoid water stagnation. If a humidifier is used, make sure the water is changed daily.

Fans

It is acceptable to use fans during warm weather. If you are using a fan, have someone other than your loved one dust the room and the fan blades 3 times per week.

Section 3: Support Services

Support groups for cancer patients and families

Use this list of online support resources to get the help and support you and your family needs at this time:

- **Leukemia Lymphoma Society: lls.org**
  Provides information, resources, and support to those affected by blood cancers.
- **Stupid Cancer: stupidcancer.org**
  This is the largest charity that comprehensively addresses young adult cancer through advocacy, research, support, outreach, awareness, mobile health, and social media.
- **LiveStrong: livestrong.org**
  Their cancer navigation services can provide you with free, personalized support and resources for your cancer journey.
- **Cancer Support Community: cancersupportcommunity.org**
  This site has online cancer support groups, cancer discussion boards, and a cancer support helpline.
- **Instapeer: instapeer.org**
  This mobile device app that offers anonymous, one-to-one peer matching for patients and caregivers.

Hospital worship services

LDS worship services are held each Sunday from 10:30 – 11:30 AM on the 2nd floor of the education center next to the cafeteria.

A meditation room is located on the 6th floor next to the ICU waiting room.

Protestant communion is available on an individual basis.

A religious leader from most religious denominations can be reached by talking to your nurse or social worker.

HOSPITAL GIFT SHOP

The gift shop is located on the first floor near the hospital entrance and is open from 9:00 AM to 7:00 PM on weekdays. It is closed Saturday and Sunday.

The shop offers clothing, magazines, candy, cards, books, flowers, balloons, decor, and personal care items.

The gift shop can be reached at 801-408-1125.

Questions for the care team

To find these and other resources, go to:

intermountainhealthcare.org/services/cancer-care/

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