



# Bone Marrow Transplant: *What to expect when you go home*

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### **THANK YOU!**

Congratulations on finishing your treatment! And thank you for trusting us with your care. We hope we have surpassed your expectations.

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## INTRODUCTION

Congratulations on getting through this milestone in your care. You probably have a lot of questions about what will happen next. Most people do.

We've put together this booklet to help answer your questions about:

- Follow up care and clinic visits
- When to call your care team for help
- Managing your medicines
- Getting back to your life

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

# Leaving East 8: Follow-up Care

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## HOW TO CONTACT US BY PHONE

### *Intermountain Bone Marrow Transplant Clinic*

**Phone:** 801-408-1262

- **Hours:** 7:00 a.m. to 5:00 p.m. Monday through Friday.

Calls during these hours will be answered by a clinic triage nurse

- **After hours and on weekends:** All calls will go to a mid-level provider through an answering service.

If you need to talk to a provider, please ask the answering service to page the provider on-call. **Do not leave a voicemail for emergencies.**

## Clinic appointments

- Outpatient clinic hours are from 7:00 a.m. to 5:00 p.m. Monday through Friday, and 8:00 a.m. to 12:00 p.m. on weekends and holidays.
- You will receive a reminder call the day before your scheduled appointment. Please let us know if you are going to be more than 15 minutes late for your appointment, or if you cannot make your appointment.
- Any after-hour phone calls will be sent to an answering service. They will page the on-call provider for you (see “How to Contact Us by Phone” at left).

## Medicine refills

- If you are out of medicine that requires a written prescription to refill, bring those medicines with you to clinic visits. These may include pain, anti-viral, or immune suppression medicines.
- Call your pharmacy for any other medicine refills. They will contact us.

## What to bring with you

- Bring your pain and nausea medicines with you to all appointments.
- Limit the number of people who come with you to clinic appointments. We encourage children to stay home during clinic appointments. If they must come, you'll need to bring another adult to watch them.
- Don't bring children under the age of 14 to clinic visits during flu and RSV (Respiratory Syncytial Virus) season. If they must come, bring another adult with you to watch them in the family waiting room.
- Please do not bring visitors to the clinic who have received the FluMist nasal vaccination. It is a live virus vaccine and could actually infect our patients.



### *When should I call my care team?*

If you have any of the following signs and symptoms, report them to your bone marrow transplant (BMT) team right away:

- A fever of 100.9° F (38.3° C) or higher, or chills. Take your temperature if you think you might have a fever or are just not feeling well.
- A cough that doesn't go away, sneezing, or runny nose. Note the color of any phlegm (sputum).
- Shortness of breath, a feeling of tightness in the chest, chest pain, or any swelling.
- Feeling really tired all of the time (fatigue).
- Redness, inflammation, drainage, or tenderness at your central line site. Report any problems with flushing your central line.
- Bleeding in your nose, mouth or gums, urine, stool (may look black), phlegm, or bruising or bleeding under your skin (small, red or purplish spots on your skin).
- Any unusual headaches.
- Dizziness or feeling light-headed.
- Changes in your thinking (slowed thinking process, confusion).
- Blurred or double vision.
- Difficulty emptying your bladder or painful urination.
- Diarrhea or constipation.
- Any sores or injuries that occur. Watch for areas of redness, swelling, pain or drainage.
- Any skin rashes or skin changes, including blisters on any part of the body, or a yellowing of the skin or whites of the eyes.
- Nausea, vomiting, or inability to keep food, fluids, or medicines down.

In addition, if you are going home with a central line in place, report the following symptoms:

- Redness, inflammation, drainage, or tenderness at your central line site
- Problems with flushing your central line
- Chills that occur after you flush your central line
- Any broken or damaged claves (caps) or clamps

## **EMERGENCY BLOOD TRANSFUSION OR SURGERY**

If you are in an accident, you may need blood, blood products, or emergency surgery.

You or a family member must alert the medical team that you have specific needs related to blood products. Have the healthcare provider call the BMT team at 801-408-1262 for guidance.

# Graft-versus-host-disease

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Graft-versus-host disease (GVHD) is a complication that can occur in patients who received an allogeneic transplant. (Autologous donors are not at risk.) It may occur after you are discharged from the hospital. This means you will need to watch for symptoms and report them right away. You will be given medicine to help prevent GVHD.

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.

## Acute GVHD symptoms

**Acute GVHD** usually occurs early (within the first 3 months) and comes on quickly. It commonly affects the skin, gastrointestinal tract (gut), or liver as follows:

- **Skin:** GVHD usually shows up as a rash but may also include peeling, sores or blistering. It can affect the skin anywhere on the body.
- **Gastrointestinal:** GVHD symptoms may come and go or be persistent (always there). They include loss of appetite, cramping, nausea, and watery or bloody diarrhea.
- **Liver:** GVHD is diagnosed by blood work and an assessment by your transplant doctor. Symptoms include jaundice [JAWN-diss] (yellowing of the eyes or skin), changes in urine or stool color, or tenderness in the abdomen (belly) due to a larger-than-normal liver. In some cases, you may need a liver biopsy to make sure the diagnosis is correct.

## Chronic GVHD symptoms

**Chronic GVHD** may begin during or after the third month after transplant. Patients with chronic GVHD usually experience skin problems, including a dry itching rash, a change in skin color, and tautness or tightening of the skin. Other common symptoms of chronic GVHD include:

- Liver changes
- Dry or burning eyes
- Dry mouth
- Mouth sores
- Infections
- Stomach irritation

Less often, patients experience skin scarring, partial hair loss (once it has returned), or severe liver problems. People with chronic GVHD may also have vision problems, heartburn, stomach pain, nausea and vomiting, difficulty swallowing, weight loss, or breathing difficulties.

**Report ANY symptoms to your transplant doctor. Chronic GVHD can affect each person in different ways.**

## GVHD treatment

If you develop GVHD, your doctor will prescribe a steroid to help keep your immune system from attacking your organs.

If your symptoms are mild, you may only need a **targeted** treatment, like a cream for your skin or a medicine that only treats your intestinal tract (gut).

If your symptoms are more severe, you may need **systemic** treatment (medicine that goes throughout your body) with steroids. Also, your transplant doctor may delay the tapering off your other immunosuppressive medicines (tacrolimus, cyclosporine, Cellcept) that you started when you were admitted to the hospital.

Because these medicines suppress your immune system, the more medicines you require for GVHD, the more susceptible you are to infections. Please call your transplant doctor with any new symptoms immediately.

### GLOSSARY OF TERMS

- **Allogeneic** [al-oh-JUH-nee-ik] **bone marrow transplant:** Stem cells are donated from a genetically-matched person. This can come from a relative, an unrelated person, or from umbilical cord blood.
- **Autologous** [aw-TAHL-uh-guhs] **bone marrow transplant:** You are your own donor (self-donor). Stem cells are collected before high-dose chemotherapy or radiation therapy and are frozen for later use.
- **BMT:** Bone Marrow Transplant
- **GVHD:** Graft-versus-host-disease
- **Immunosuppressive** [im-myoo-no-suh-PRESS-ehv] **medicine:** These medicines curbs the body's immune (disease-fighting) system so transplanted tissue is less likely to be rejected.
- **Neutrophil** [NOO-truh-fil]: A white blood cell that helps fight infection.
- **Platelets:** Cells that help you body form blood clots and stop bleeding.
- **Systemic medicine:** Medicine that affects all parts of the body.
- **Tapering off:** To gradually use less of a medicine or substance.
- **Targeted medicine:** Medicine that treats only certain areas, such as your skin or gut
- **µL:** Microliter, or one millionth of a liter (used in bloodwork reports, for example, to describe your platelet counts).

# Preventing Infection

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After treatment, it can take at least 12 to 18 months for your immune system to fully recover. **Immunosuppressive** medicines can lengthen the amount of time that you have an increased risk for infection.

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

## Handwashing

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

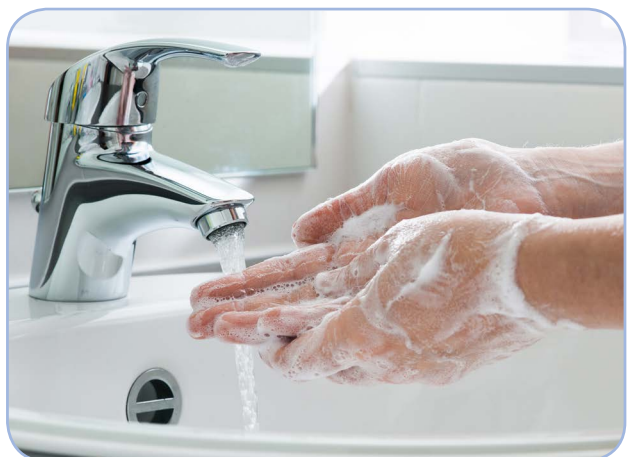
Wash with soap and water before and after:

- 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

You may use hand sanitizers or soap and water for hand washing, but use soap and water after you use the bathroom or if there is something on your hands.

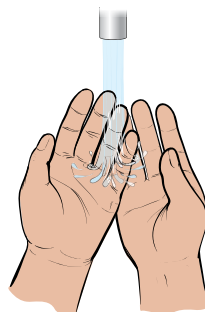


## The right way to wash your hands

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

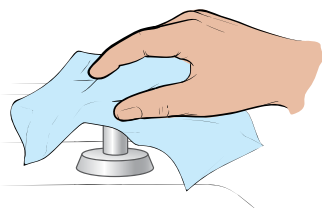
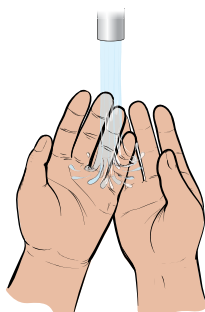
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- 1** Wet your hands with clean, running water (warm or cold), turn off the tap, and apply soap.



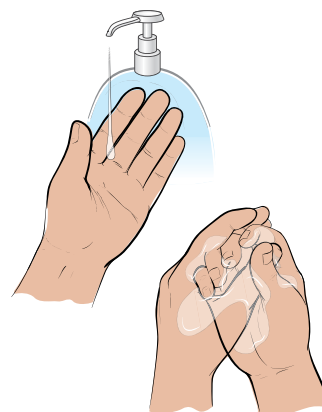
- 2** Rub your hands together with the soap, building a lather. Wash the backs of your hands, between your fingers, and under your nails. Wash for at least 20 seconds. This is the length of the "Happy Birthday" song from beginning to end twice.

- 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.



## Vaccinations

Because of your transplant, you lost the protection from the vaccines you received as a child. You'll need to repeat all childhood immunizations once it is safe to do so. This usually happens about 1 year after the transplant. Your transplant doctor will give you specific instructions for these vaccinations once it is safe to get them.

### VACCINATIONS FOR CAREGIVERS AND FAMILY MEMBERS

Until your immune system is fully functioning and you have been re-immunized, you are at high risk for catching contagious diseases (ones that you can get from other people). Because of this, we recommend that caregivers and people who live with you get an annual flu shot.

Be aware that there are a few vaccinations that are a "live virus" vaccination. The most common types are:

- Nasal influenza vaccine (FluMist)
- MMR (Measles, mumps, and rubella) vaccine
- Shingles vaccine

Because your immune system is not working well (suppressed), there is a chance that you can become infected by a person who just received one of these vaccines.

If someone in your household needs a vaccine, make sure they tell their doctor that you are immune-suppressed and live in the same household.

## Avoiding contagious diseases

Avoid people who are ill. If someone living in your household is sick, be sure to follow strict handwashing practices. Do not let them prepare your food, and avoid close contact as much as possible. If you must share a bathroom, use bleach to clean all surfaces.

As much as possible, avoid household cleaning, especially in bathroom areas. Have your caretaker or another person clean your home.

## Central line care

Call your care team right away if you have any signs of an infected central line, including:

- Redness around the insertion site
- Drainage
- Tenderness
- Fever
- Swelling
- Having chills after your line is flushed

Routine central line care involves:

- **Changing your dressing:** It is okay if the edges of your dressing start to pull up a little around the outside. However, the dressing needs to be changed if it pulls up within one inch of where the catheter enters your body.
- **Checking the line:** Check the area to make sure that the claves (caps) on the ends of the lines are snug and that all of the clamps are closed.
- **Protecting the insertion site:** Your dressing is waterproof, but you should still cover it when showering. Do not soak in a bath tub, get into a swimming pool, or use a hot tub.

## HEPA filter mask

An N95 hepa filter mask offers protection against airborne infections. If bacteria, viruses, or fungi in the air are breathed into your lungs, you can get an infection. Wear this mask when you are:

- In a crowd
- In the public area of any medical facility (exam rooms are okay)
- Outside, if it's windy or dusty
- In any other situation where you are unclear about the infection risk. For example, if someone can come within 6 feet of you and don't know if they are sick or not, wear your mask.

How long you will need to wear a mask depends on whether or not you received Total Body Irradiation (TBI).

- For those who **did not** have TBI: Wear the mask until 3 months after transplant, or until your immune system is stable. Your transplant doctor or oncologist will tell you when it is okay to stop.
- For those who **did** have TBI: Wear the mask until 6 months after transplant or until your immune system is stable. In either case, your transplant doctor or oncologist will determine when it is safe to stop wearing the mask.



## MOUTH CARE

Check your mouth, teeth and gums every day.

Report any unusual findings to your transplant doctor at your next appointment.

Use a soft-bristle toothbrush and avoid flossing when your platelet count is below 50,000/ $\mu$ L to prevent bleeding. If your neutrophil count is less than 1000/ $\mu$ L, you should brush your teeth after each meal.

If your mouth is dry, you can use an over-the-counter artificial saliva product. You can also rinse frequently with a salt-water solution made with  $\frac{3}{4}$  teaspoon salt and one quart of warm water.

Your dentist will check your teeth during routine visits. However, if you need any dental work, tell your dentist to contact our transplant clinic. You will probably need to start on an antibiotic before your dental work is done. Your transplant doctor will tell you when it's safe to resume all regular dental care.

## Skin care and daily hygiene

Thorough skin care and daily cleansing will help lower your risk for infection. Be sure to:

- Shower daily using a mild non-medicated soap. Apply moisturizing lotion after you shower and at bedtime.
- Use an electric razor when shaving until your platelet count is greater than 50,000/ $\mu$ L (to prevent bleeding issues) and your neutrophils are greater than 1000/ $\mu$ L (to minimize infection risk).
- Avoid using medicated or heavily perfumed products, lotions, and soaps that contain large amounts of alcohol or lanolin.
- Use make-up, after-shave and perfume in small amounts. If you have a skin reaction, stop using the product and report the reaction to your transplant team.

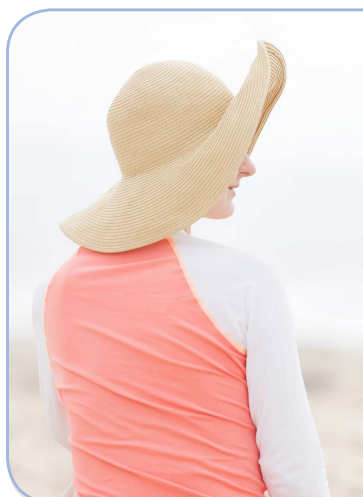
## Skin changes and sensitivity

Skin changes are common after transplant due to both chemotherapy and radiation. Common skin changes include dryness, flaking, and skin discoloration or darkening. Although skin changes are common, you should report any new changes to your transplant doctor.

## Avoiding sun damage

Always use sunscreen to protect against skin cancer and the risk of a GVDH flare caused by sunburn.

Avoid bright sunlight, and wear long-sleeved shirts, pants, and a hat with a brim when you are out in the sun. Cover any exposed skin surfaces with a 30 SPF sunscreen. Reapply at least every 2 hours or according to the manufacturer directions.



### SUN SENSITIVITY AND YOUR MEDICINES

Certain medicines, such as tacrolimus, cyclosporine, some antibiotics, can make your skin more sensitive to sun exposure, which means you are more likely to get a sunburn if you don't cover up when enjoying the outdoors.

# Preventing infection at home

## Pets

Pets that were in the home before your 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 central line. In addition, make sure you:

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

You and other members of the family need to:

- Keep birds from flying freely within your home. Control cats and dogs when you are walking around so you 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 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.



## Housecleaning

Avoid vacuuming, dusting, and any other activities that expose you to dust during their treatment. 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.
- Never share towels with anyone else.

## PLANTS

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

Don't 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 your transplant doctor.

Watering plants is allowed, but wash your hands afterwards.

## Carpet cleaning

Carpets can be cleaned using a steam system as long as they will be completely dry before you get 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. Take care not to get any cleaning products on your skin or breathe in the fumes.

## Air Quality

### Basements

Avoid living in the basement if there is a possibility for increased exposure to dust and mold. If you must live in the basement, have every area in the basement inspected for any mold or dampness, and address any issues before you get home.

### Open windows

It is best to keep the windows closed if:

- Your white blood cell count is low (neutrophil count less than 1000/ $\mu$ L)
- 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 transplant (or longer if you are on immunosuppressive therapy). Check the manufacturer's recommendations for information on how often to change the filters. **Be sure to have someone else change the filters. Doing it yourself can increase your risk of getting sick.**

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 yourself dust the room and the fan blades at least 3 times per week.

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.

# Managing Your Medicines

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The medicines you take after your transplant play a vital role in your treatment. Follow these guidelines for a safe and healthy recovery.

- Bring your medicine list to all clinic appointments (this list was given to you at discharge). Your transplant doctor will review your medicines at each clinic appointment.
- Do not stop or start taking any medicines without talking with your transplant doctor first.
- Certain medicines (pain medicines, anti-nausea medicines, sleep medicines, etc.) require a written prescription. Plan ahead for refills to avoid extra trips to the hospital. Refills are only provided during regular business hours and will not be authorized by the on-call doctor.
- Call your pharmacy for all prescriptions refills, except those required in writing (see above). The pharmacy will contact our office if a new prescription is needed. Give the pharmacy at least 2 days notice to contact us for refills.
- Check with the transplant team before taking any over-the-counter remedies (such as allergy pills or cough syrup). They may interact with your prescription medicines. Do not use products containing aspirin or ibuprofen unless instructed by your transplant doctors.
- Be aware that some medicines may alter your mood, concentration, and ability to drive. Discuss any concerns with your transplant doctor.

## 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.

### ABOUT ACETAMINOPHEN

Acetaminophen (Tylenol) is an over-the-counter medicine. It is often taken on a different schedule than your other pain medicines. **Do not take Tylenol unless told to do so by your care team.** Tylenol can make it difficult to notice a fever if you get an infection.

## Common side effects for frequently used medicines

MEDICINE	WHAT IT'S USED FOR	COMMON SIDE EFFECTS
<b>IMMUNE SUPPRESSION MEDICINES</b> <input type="checkbox"/> Tacrolimus <input type="checkbox"/> Cyclosporin <input type="checkbox"/> Mycophenolate <input type="checkbox"/> Prednisone	<b>Prevents or treats Graft-versus-host disease (GVHD)</b>	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
<b>NAUSEA RELIEF MEDICINES</b> <input type="checkbox"/> Ativan (lorazepam) <input type="checkbox"/> Compazine (prochlorperazine) <input type="checkbox"/> Dronabinol (Marinol) <input type="checkbox"/> Phenergan (promethazine) <input type="checkbox"/> Zofran (ondansetron)	<b>Relieves nausea</b>	Headache, drowsiness, dizziness, or confusion. <b>Note:</b> Phenergan may cause dry eyes or mouth, burning, redness, swelling, pain, and tissue damage IF not given intravenously.
<b>ANTIBIOTICS</b> <input type="checkbox"/> Penicillin <input type="checkbox"/> Levaquin (levofloxacin) <input type="checkbox"/> Primaxin (imipenem/cilistatin) <input type="checkbox"/> Maxipime (cefepime) <input type="checkbox"/> Flagyl (metronidazole)	<b>Prevents or treats bacterial infections</b>	Diarrhea or constipation, nausea, stomach upset, or headache. <b>Notes:</b> <ul style="list-style-type: none"> <li>• When combined with alcohol, Flagyl may cause severe vomiting and a metallic taste in the mouth.</li> <li>• Primaxin may increase risk of seizure.</li> </ul>
<b>ANTIFUNGAL MEDICINES</b> <input type="checkbox"/> Mycamine (micafungin) <input type="checkbox"/> Cancidas (caspofungin) <input type="checkbox"/> Ambisome (amphotericin) <input type="checkbox"/> Fluconazole (diflucan) <input type="checkbox"/> Noxafil (posaconazole) <input type="checkbox"/> Vfend (voriconazole)	<b>Prevents or treats yeast or fungal infections</b>	Headache, nausea, vomiting, diarrhea, rash, fever, lower blood pressure, lower white blood cell count, abnormal liver function tests, abnormal kidney function test. <b>Note:</b> Vfend may cause hallucinations and visual changes.

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

## PAIN RELIEF WITHOUT MEDICINE

Other ways to try to reduce your pain without using pain medicine include:

- Applying cold or heat
- Guided imagery/ distraction
- Physical therapy or exercise
- Relaxation or meditation
- Massage
- Spiritual/emotional counseling

## Pain management

Good pain management allows your body and mind to focus on healing. It doesn't mean taking away your pain completely. The goal of your pain management plan will be to:

- **Be able to move around more easily.** If you feel less pain, you can start to do therapy exercises (such as walking or breathing exercises) that will help you get your strength back more quickly.
- **Have fewer complications.** When your pain is well controlled, you are likely to have fewer problems, such as pneumonia and blood clots, because you are able to do move more and do your therapy exercises.
- **Feel less stress.** Feeling comfortable reduces the stress that comes with pain. Less stress means both your mind and body can focus on healing.

## Talking with your doctor about pain

If your pain gets worse or is not controlled by pain medicine and you are taking your medicines as prescribed, call your doctor. Your medicine may need to be changed.

When you call, tell your doctor how much pain you're feeling. You will also need to describe the pain. Here are some ways you might describe it:

- ☐ Where does it hurt?  
*It hurts in my shoulder, hip, knee, back, neck, etc.*
- ☐ When does it hurt?  
*It comes and goes, or it hurts all the time.*
- ☐ What does it feel like?  
*It is sharp, dull, aching, throbbing, burning, etc.*
- ☐ What level is your pain?  
*My level is 8 on a scale of 1–10.*
- ☐ What makes it worse?  
*It feels worse when I stand, sit, walk, eat, etc.*

## Taking pain medicine

Your healthcare provider may give you 1 or more prescriptions for pain medicine. There are many different pain medicines, and they control pain in different ways.

**Prescription pain pills** include opioid [OH-pee-oid] medicines, such as morphine, oxycodone, hydrocodone, and dilaudid, among others. These drugs are powerful but can be safe and effective when used as directed.

Opioid medicines can cause side effects. **Slow or decreased breathing is the most serious side effect**, and it can be deadly. Your risk is higher if you take too many pain pills or mix them with alcohol or street drugs.

**Family members should CALL 911 if you have decreased breathing, decreased level of consciousness or if they cannot wake you up.**

Constipation is the most common side effect. Drinking extra water and other fluids and taking stool softeners and laxatives can help.

Whatever the pain medicine, use it **ONLY** as directed. If your pain improves after the first few days, tell your healthcare provider. You may be able to take fewer doses or decrease the dosage.

## Tracking your pain medicine

To prevent medicine mistakes, don't use a pillbox for your pain medicine. It's better that you and your caregivers write down when you take your medicine and how much you take. This will help you if you've taken your pills, and help keep you from taking too many.

The chart below is an example of how you should track your medicine:

MEDICINE	TIME	HOW MUCH?
Percocet	1:15 p.m.	1 tablet

## LEFTOVER MEDICATION?

Don't keep leftover medicines around the house. Find out where to take them at [useonlyasdirected.org](http://useonlyasdirected.org).

## Pain medicine safety

If you have problems controlling your pain or staying awake, follow the instructions below. To stay safe when taking opioid pain medicine:

- **Don't take more medicine** than your healthcare provider tells you to.
- **Never use alcohol or street drugs** when taking opioid pain medicines. The combination could kill you.
- **Don't take your medicines with any other pills** unless your healthcare provider says it's okay. This includes vitamins, herbs, or any other supplements.
- **Don't drive or use any heavy machinery** until you know how the medicine affects you.
- **Keep the medicine in the bottle** it came in. The label has instructions and information you need.
- **Don't share your pain medicine** with anyone. Don't give your pills to friends or family members, even if the person is in pain.
- **Lock up medicine where it's safe.** Don't keep your pills in your medicine cabinet where anyone can find them.

## WHEN SHOULD I CALL MY HEALTHCARE PROVIDER?

Have the person(s) caring for you call your healthcare provider right away if you:

- Can't stay awake or are hard to wake up
- Have more pain, or pain that you can't tolerate
- Feel numbness, tingling, or weakness where you don't expect it
- Feel sick to your stomach or have vomiting
- Are constipated
- Have itching or a skin rash
- Are dizzy, feel lightheaded, or have fainted
- Have a fever
- Have ringing, buzzing, or a whistling sound in your ears
- Have numbness or tingling around your mouth and lips
- Have blurred vision
- Have redness, swelling, or drainage around a central line or PICC line

**A family member should CALL 911 if you have decreased breathing, decreased level of consciousness, or if you cannot be woken up.**

# Getting Back to Your Life

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## Activity and exercise

Keep in mind that your body will be recovering for some time. Know that it is very normal to feel fatigued (tired) for 3 to 12 months after your transplant.

At times, you may feel frustrated that the fatigue lasts so long. Exercise will help, even though you may not feel like doing it. Committing to a steady and consistent exercise program is the best thing you can do for yourself.

Walking is an easy way for you to get your strength and energy back. Other types of exercise are also allowed with some exceptions. Talk with your transplant doctor to be sure your exercise plan is safe.

Avoid heavy activities or contact sports until your:

- Central line is removed
- Platelet count is above 100,000 /  $\mu$ L

When exercising, it's best to start slow and increase your effort little by little. Always listen to your body for clues that you may be overdoing it.



## Nutrition

For nutrition information, please refer to the plan and food safety booklet given to you by your registered dietitian nutritionist. We encourage you to follow these recommendations for at least 2 to 3 months after transplant or as long as you are on immunosuppressant therapy.

## Returning to work

It is best if you wait to return to work until your energy level has improved and your infection risk has gone down. Your immune system is still not strong when you go home from the hospital. This puts you at increased risk for catching a contagious diseases. This risk is even higher if you are being treated for GVDH (see [page 6](#)).

Of course, the time frame for going back to work needs to be based on the type of work you do and your financial situation. Talk about your concerns with your transplant doctor during your clinic visits. Together, you can determine when it will be safe for you to return to work.

## Maintaining intimacy

After your transplant, you may have concerns about sexual activities. At first, you may find that you are less interested in sexual activity. This can affect your relationship with your partner. However, as you regain your strength and increase your activities, this should improve.

If you are receiving a treatment with certain chemotherapy medicines (such as Vidaza, Cellcept, or Dacogen), you should not have intercourse during treatment and for at least 48 hours (2 days) after treatment. 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 do choose to have sex during this period, use a condom to protect your partner. If you are a woman of childbearing age, use 2 forms of birth control to avoid pregnancy as these medicines are known to cause serious birth defects.

Here are some guidelines for you and your partner:

- Before having intercourse, your platelet count should be over 50,000 /  $\mu$ L.
- You are at an increased risk for bleeding during treatment, so be cautious with any physical activity.
- Avoid anal intercourse and penetrating toys because of your higher risk of bleeding and infection.
- Avoid oral sex until your neutrophil count is greater than 1000 /  $\mu$ L due to the risk of infection. Oral sex without barrier protection (condoms) is discouraged due to the risk of viral diseases.

If you have any questions, be sure to ask your care team for clarification.

### Women

After treatment, women may have fewer menstrual periods, no menstrual periods, or decreased vaginal secretions (fluids). Water-based lubricants can relieve vaginal dryness. They do not require a prescription.

Depending on your treatment, the function of the ovaries may change. This can result in lower estrogen levels. Estrogen supplements may be recommended after transplant.

### Men

Men may have less sexual desire. If you have erectile dysfunction (ED) or less sexual desire, medicines such as sildenafil (Viagra) or tadalafil (Cialis) may help. Discuss these medicines with your transplant doctor before using them because they may interact with other medicines you are taking.

**After a transplant, you or your partner must always use a condom during sex.**

## Mental and emotional health

As you know, undergoing a blood or marrow transplant is an emotionally and physically stressful time. When you leave the hospital, you will want to put everything behind you and return to your previous lifestyle. But some find this task more difficult than expected.

### Emotional challenges

Patients and caregivers often have feelings of sadness and depression after transplant. Ongoing worries or anxiety about a relapse (cancer coming back) are common. You are not alone with these feelings. Nearly every cancer survivor has them. We have found that this anxiety seems to be worse just before and during follow-up visits to the transplant clinic.

Sorting through your emotions is part of your recovery. Talking with someone you trust can help, whether that is a transplant social worker, a family member, or a friend. But sometimes, that is not enough. If you are struggling, don't be afraid to talk with your doctor about using antidepressant or anti-anxiety medicine to help you cope with these feelings.

### Cognitive challenges

After treatment, you may notice changes or problems with thinking. These are called cognitive problems and commonly referred to as “chemo brain.” Some changes you might experience include:

- Changes in the way your brain processes information
- Memory lapses
- Poor concentration
- Stuttering
- Difficulty spelling
- Difficulty performing tasks

Although this is frustrating, you will find ways to adjust to these changes. Some suggestions include making lists or leaving notes around the house to remind you of things you need to do. Caregivers can be frustrated by these changes as well. Being open with your family about what you are experiencing and working together to find solutions can help cut down on tension and frustration.

Part of recovery is learning to trust your body again. It is hard to know which aches and pains are normal parts of recovery and which need to be reported to the transplant team. If you are not sure, call your transplant team. Keep a copy of the “When to call the doctor” list (see [page 20](#)) on your refrigerator or another easy-to-see location.



To find these and other resources, go to:  
[intermountainhealthcare.org/services/cancer-care/](https://intermountainhealthcare.org/services/cancer-care/)



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