The discharge process actually begins weeks before your transplant, when the Blood and Marrow Transplant (BMT) team starts helping you learn to live and care for yourself at home after the transplant. You will probably spend 30 to 60 days in the hospital during and after your transplant.

All of these statements must be true before you can leave the hospital:

- You can take and keep down oral medicines.
- Your nausea, vomiting, and diarrhea are well controlled with medicine.
- Your neutrophil count is at least 500/mm³.
- Your calorie intake is at least 1/3 of your daily requirement, and you are drinking at least one liter of fluid daily. These requirements may vary, depending on your weight and what your care team recommends.
- You have no gut graft-versus-host disease (GVHD) that requires closely watching what you eat. If you do have GVHD, you will be placed on a special progression diet. Each step of the diet takes about two days to complete.
- You have a supportive home environment, with someone to help you at home 24 hours a day for at least 100 days after your transplant.

Discharge Location
You must remain near expert medical care for the first 100 days after your transplant. You may return home if you live in one of these areas:

- Salt Lake County
- Davis County
- Utah County
- Weber County
- Grantsville
- Heber
- Park City
- Tooele

If your home is not in the areas listed above, you will need to arrange a temporary place to stay for at least the first 100 days after your transplant.

If you need help finding a place to stay after leaving the hospital, Huntsman Cancer Institute (HCI) offers a booklet of lodging options in the Salt Lake City area that offer discounted rates for patients. You can request this booklet from your social worker or call HCI’s Resource Coordinator at 801-530-0385, or access it online at www.huntsmancancer.org/lodging.
Living and caring for yourself at home after a stem cell transplant requires special care and attention for the first 100 days after the transplant. This factsheet provides important information to help you care for yourself at home.

Preventing Infections

Infection is one of the biggest risks patients face after a bone marrow or stem cell transplant. The treatments received before the transplant temporarily disable your immune system. You will be given medicines to prevent infections while your body cannot fight them, but both you and your caregiver must make every effort to keep infections away. It can take up to a year for the immune system to recover completely.

Everyone carries germs on the skin and inside the body that do not cause problems unless a person has a weakened immune system. Transplant patients are at high risk for infections caused by these usually harmless germs. Sneezing, coughing, or touching surfaces or other people can transfer germs. The most important thing you can do to prevent infections is to use good hand washing techniques:

- Use plenty of soap and warm water. Scrub your hands for at least 15 seconds (recite the alphabet—that's about 15 seconds). The friction removes germs, and the water washes them away.
- Rinse well and dry hands using paper towels.
- Turn off water using the paper towel.
- Use gel sanitizers when you aren't able to wash hands with soap and water. Gel sanitizer comes in small, easy-to-carry containers.
- Remember, whether using soap or gel sanitizer, the friction removes the germs.

EVERYONE must wash or sanitize their hands: family members, friends, nurses, doctors, and, of course, the caregiver and patient.

Wash your hands at these times:

- Before eating, drinking, or taking medication
- After using the bathroom
- Before preparing meals
- Before and after any kind of physical care such as oral care, central line care, and connecting IV tubing
- After touching the eyes, nose, mouth, or any part of the face
- After touching things in your home that others touch frequently
- After shaking hands
- After public outings

Personal Hygiene for Patients

Your skin is the first line of defense against infection. These personal hygiene practices will lower the number of germs on the skin that can cause infections:

- Shower daily using a mild soap.
- Wash hair or head daily using a mild shampoo.
- Check skin daily for rashes, bruising, redness, or swelling. Keep skin folds clean and dry, including genital and rectal areas.
- Change wet or damp central line dressings right away.
- Change towels daily.
- Do not share towels with anyone.
- Brush teeth with a soft-bristled toothbrush after each meal and at bedtime. Floss with caution if your platelet count is low, and stop flossing if bleeding occurs.

Avoid Dangerous Exposures

Crowds of people raise exposure to harmful germs and viruses. Construction sites and homes that are being remodeled are also hot spots for bacteria that can cause pneumonia.

The following activities involve close contact with materials high in harmful germs. DO NOT do any of the following::

- Touch human or animal excrement
- Change baby diapers
- Touch bird droppings
- Clean an aquarium
- Clean up after pets
• Sit on grass, logs, or dirt without a blanket
• Allow skin to touch soil, lawn waste, or compost
• Change the water in flower arrangements
• Handle plants

Reducing the Risk of Falls at Home
• Make sure all throw rugs are removed or secured.
• Wear nonslip socks, slippers, and shoes.
• Turn on lights at night when getting up. Try to leave a nightlight on.
• Sit on the edge of your bed before standing when getting up and down.
• Choose to sit in chairs with arm rests to help you get up and down.
• Reach back with your hands for the chair when you sit down.
• Push up from the chair when you stand up. Do not reach for the walker.
• Go sideways down the stairs, holding the railing with both hands.
• Use a cane or walker when walking, instead of reaching for furniture.
• Move furniture so you have clear paths to walk through.
• Use grab rails when getting in and out of the bathtub. Use a stool in the bathtub if your physical therapy staff tells you to.
• Use grab rails when getting on and off the toilet.

Skin Care and Protection from the Sun
High-dose chemotherapy and total body irradiation raise your risk of skin cancer, so you must avoid getting sunburned. Sunburn can also cause and aggravate graft-versus-host disease. Be especially careful to avoid sunburns for the rest of your life. Your skin may become more sensitive to soaps and detergents. If this happens, use hypoallergenic, unscented soaps and detergents. Dermatologists at Huntsman Cancer Institute (HCI) recommend the following ways to protect your skin from the sun:
• Avoid the sun between 10 a.m. and 4 p.m.
• Use broad-spectrum sunblock containing titanium dioxide or zinc oxide with a minimum SPF of 30.
• Apply sunblock 20 minutes before sun exposure and 20 minutes after you go outdoors. Reapply generously every two hours.
• Wear protective clothing: wide-brimmed hat, long-sleeved shirt, long pants, and sunglasses.

Activity and Exercise
Outdoor Activities
Avoid activities that may raise your risk of infection. For example, walking through the woods may raise your risk of fungal infections because you can disturb decaying leaves and dirt, which release fungus spores into the air. These spores can cause fungal pneumonia if you breathe them in. Fishing or swimming may also raise your risk of infection from organisms in the water. Avoid construction sites because of the dust and disturbed soil.

Please ask your Blood and Marrow Transplant (BMT) providers which outdoor activities are safe for you as your immune system recovers.

Travel
Car travel: You may remove your mask during car travel if you keep the windows and vents closed. You can get a lot of sun exposure even through closed windows, so wear long-sleeved clothing or use a window shade. If using the air conditioner, use the recirculation setting so air is not drawn from outside.

Airplane travel: Avoid airplane travel while you are on immunosuppression. You must avoid exposure to crowds in close quarters. Also, airplanes recirculate the air, which often contains bacteria and other organisms that can cause infection.

Fatigue
You may be more fatigued than you expect, especially for the first few months after your transplant. Listen to your body and allow rest periods during exercise. Gradually increase your level of activity.

Exercise
All patients need to exercise. However, if your treatment regimen includes steroids, it is especially important that you do weightbearing exercise to prevent muscle wasting associated with these drugs.
Develop an exercise plan and set goals. HCI’s exercise specialists with the Linda B. and Robert B. Wiggins Wellness Center work with you to design exercise plans based on your diagnosis, treatment type and phase, and personal fitness goals.

Walking and riding a stationary bike provide excellent exercise. Do not participate in vigorous exercise or contact sports, and avoid swimming or using hot tubs.

Sexual Activity

It is safe to resume sexual activity after chemotherapy and transplant. Men who have had BMT and partners of women who have had BMT should use latex condoms. This practice serves two purposes: it lowers the risk of infection and prevents untimely pregnancies.

Spericides may irritate the penis or vagina. Even though chemotherapy and radiation can cause sterility, you must still use condoms to prevent infection. Anal intercourse is not recommended for at least 100 days after your transplant. Oral sex is acceptable if the partner has no sores of the mouth, lip, or genitals. Herpes virus can be transmitted even when lesions are not present.

Decreased sexual desire is normal after transplant due to changes in hormone levels, anxiety, or depression. The chemotherapy and radiation cause changes in hormone levels. We routinely check hormone levels at 100 days post-transplant and prescribe hormone replacement if needed. Remember that sex is a function of the mind and body. It takes time for both to heal. Some antidepressant agents can affect sexual function. Do not hesitate to discuss any concerns, problems, or discomfort with your nurse or doctor.

Men

Chemotherapy and/or radiation therapy may cause brown or orange semen. This is temporary.

Women

Chemotherapy and/or radiation therapy can cause vaginal dryness. To prevent trauma to the tissue during intercourse, use a water-soluble lubricant. Oil-based lubricants such as Vaseline are not recommended. As part of your follow-up care, you will have an appointment with a gynecologist.

Discuss your specific concerns at this time. The gynecologist may prescribe hormone replacement therapy to ease your symptoms.

These two helpful booklets from the American Cancer Society are available in the BMT Unit:

- Sexuality and Cancer: For the Man Who Has Cancer and His Partner
- Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner

If you prefer, you can call 1-800-ACS-2345, and the American Cancer Society will mail the booklet to you.

Commonly Asked Questions

How long do I have to wear a mask?

The HEPA filter mask protects you against airborne infections, which develop when bacteria, viruses, or fungi are breathed into the lungs.

You must wear your HEPA filter mask when you come to the hospital for appointments and when you are in crowds for at least six months after transplant or until one month off all immunosuppression (cyclosporine, tacrolimus, or prednisone). On windy days, you need to wear your mask when outdoors. Avoid construction areas. Your BMT providers will determine the length of time you should wear your mask. Be sure to follow their instructions.

Do I need a caregiver at all times?

Yes, 24 hours a day.

Do I need to avoid people with the flu or a cold?

Yes, you must avoid people who are sick. All caregivers and family members should get flu shots. Caregivers should not get the nasal mist flu vaccine.

Do I need to avoid people who have had immunizations?

You need to avoid young children who have had live vaccines. Avoid people who have received the chicken pox vaccine for at least two weeks after their vaccination. Oral polio vaccines also carry a risk, but they are no longer given in the United States. Discuss this with a pediatrician.
If you are exposed to chicken pox or herpes zoster (shingles), call your BMT providers immediately. Shingles causes blisters that may appear on your neck, face (especially near the mouth), or trunk area below your rib cage. If you notice these blisters, notify your BMT providers immediately.

After the one-year workup and the end of therapy to suppress the immune system, healthy patients free of chronic graft-versus-host disease get immunizations such as tetanus, MMR, and polio vaccines.

**Will a dog in the home increase my risk of infection?**

In general, dogs do not carry germs that are harmful to humans. If the dog licks you, wash the area with soap and water. You may pet or cuddle your dog. Do not allow the dog to lie on your bedding. Wash your hands after playing with the dog. Avoid cleaning up dog excrement. Avoid new puppies that bite or scratch, as this can cause infection.

If your dog is outside often and brings dirt in on its paws, you may want to think about boarding your animal while you are on immunosuppression. Talk to your BMT provider about this.

**What about cats?**

Cats pose more problems than dogs because their sharp claws can easily scratch your skin, exposing you to infection. The same general rules apply as for dogs, but take extra care to avoid being scratched. Cat feces can carry a germ that causes toxoplasmosis, a serious disease. Do not handle cat feces or change litter boxes.

**What about other animals?**

Avoid birds, reptiles, and farm animals. They are more likely to carry harmful diseases.

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**Do I need to limit contact with plants or avoid doing gardening work?**

Yes. Limit your contact with plants for at least 100 days, or until you are released from the care of the BMT service. Plants may remain in the house but do not keep them in the room where you sleep. Do not repot plants, work in the garden or yard, or mow the lawn until you are off all immunosuppressors.

**Can I use a fan?**

You may use fans to circulate air. You should clean the blades three times weekly. It is best to keep the windows closed.

**When can I return to work or school?**

Under the best circumstances, we suggest waiting one year after your transplant before returning to work or school. Your bone marrow is still recovering, and it will take at least a year for your immune system to function normally. You may still be taking a considerable amount of medication, you may need transfusions, or you may have chronic graft-versus-host disease, in which case you cannot safely return to work or school. Until your immune system is functioning normally, you cannot afford the risks of exposure to communicable diseases that work or school pose.
Safe Activities, Places, and Contacts

The chart below is a quick guide to which activities, places, and contacts are safe during the first 100 days after transplant. If you have questions about any of these activities, please talk with your BMT provider or nurse. Your nurses will tell you whether you are in Category A or Category B. After the first 100 days, ask your providers if there are any changes to safe activities and places.

<table>
<thead>
<tr>
<th>Can I go to, do, or be around . . .?</th>
<th>Category A</th>
<th>Category B</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Taking ONE immunosuppressive medication and/or steroids ≤ 0.5 mg/kg</td>
<td>Taking TWO immunosuppressive medications and/or steroids &gt; 0.5 mg/kg</td>
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<tr>
<td></td>
<td>Example: Either tacrolimus or cyclosporine</td>
<td>Example: tacrolimus and mycophenolate (MMF)</td>
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<tr>
<td>Church</td>
<td>Yes (arrive late, leave early, no handshaking, wear a mask)</td>
<td>No</td>
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<td>School or work</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Crowds</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Restaurants</td>
<td>Yes (follow diet guidelines)</td>
<td>No</td>
</tr>
<tr>
<td>Fast food/ drive-through</td>
<td>Yes (follow diet guidelines)</td>
<td>No</td>
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<tr>
<td>Animals</td>
<td>See below.</td>
<td>See below.</td>
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<tr>
<td>Cats</td>
<td>Yes (do not handle feces, sleep with a cat, or be with a new cat)</td>
<td>Yes (do not handle feces, sleep with a cat, or be with a new cat)</td>
</tr>
<tr>
<td>Dogs</td>
<td>Yes (do not handle feces, sleep with a dog, or be with a new dog)</td>
<td>Yes (do not handle feces, sleep with a dog, or be with a new dog)</td>
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<td>Small caged pets</td>
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<td>Reptiles</td>
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<td>Zoo animals</td>
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<td>Livestock</td>
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<td>No</td>
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<tr>
<td>Construction sites</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Spectator events, movies, games</td>
<td>Yes (no handshaking, avoid crowds, wear a mask)</td>
<td>No</td>
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<tr>
<td>Airline travel</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Hot tub</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Swimming, water parks</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Gardening</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Mow the lawn</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Carpentry work</td>
<td>No</td>
<td>No</td>
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</tbody>
</table>

Remember these general rules:
- Wash hands often. This is the best way to prevent infection.
- Avoid crowds.
- Wear sunscreen.
Graft-versus-host disease (GVHD) is a common, serious complication that can develop after allogeneic bone marrow transplant (BMT). Roughly 20 to 50 percent of people who receive a BMT from a matched, related donor develop GVHD. The risk of GVHD is even higher in older patients and in those who receive peripheral blood stem cells, particularly from an unrelated or mismatched donor.

GVHD happens when certain white blood cells among the donor cells (the graft) identify your body (the host) as “foreign” and launch an attack. Your immune system would normally attack an infection or foreign body in the same way. Your care team will give you medications called immunosuppressants to prevent and suppress GVHD. Even with these medications, GVHD may develop. Most patients only have mild or moderate GVHD. Severe cases of GVHD can be life-threatening and difficult to manage.

Two Types of GVHD: Acute and Chronic

Acute GVHD

Acute GVHD usually happens during the first three months after a transplant, but can happen or recur after that time too. Acute GVHD generally affects three systems in the body: the skin, the liver, and the gastrointestinal tract (esophagus, stomach, and intestines). Acute GVHD can be mild, very serious, or even fatal. The onset of acute GVHD can be gradual or sudden. Treatment depends on how severe the symptoms are.

Gastrointestinal GVHD symptoms include frequent diarrhea (more than four stools per day), usually with cramping and urgency.

Skin GVHD symptoms include a rash that may start on the soles of the feet or palms of the hand, although it may appear anywhere. The rash is usually itchy, but not always.

Liver GVHD usually has no visible symptoms. Your follow-up care will include blood tests to measure liver function. Elevated liver function tests (LFTs) alert your provider that liver GVHD may be present. Your doctor may take a liver biopsy (sample) to confirm the diagnosis.

Report these symptoms of GVHD to your medical team immediately:

- Skin rash
- Persistent or worsening nausea and vomiting
- Frequent diarrhea (more than four stools per day), possibly with cramps or blood
- Yellowing of the skin or whites of the eyes

Chronic GVHD

Chronic GVHD generally occurs beyond the first 100 days following transplant, although symptoms sometimes appear before then. The onset of chronic GVHD is often more gradual than acute GVHD. Chronic forms can range from mild to severe. Chronic GVHD itself is rarely fatal, but treatment for it can lead to life-threatening infections. Often, chronic GVHD worsens in the presence of an active infection.

Report any of these chronic GVHD symptoms to your BMT team:

- Skin: rash, discoloration, tightness, dimpling
- Joints: decreased range of motion
- Hair: thinning or falling out
- Nails: brittleness, weakness, thinness, ridging
- Eyes: dryness, grittiness, irritation, vision changes
- Mouth: dryness, pain, ulcerations, sensitivity to foods or toothpaste, difficulty swallowing
- Weight: unexplained loss
- Temperature: chronic low-grade fevers
- Stool: diarrhea, usually green and slimy, often accompanied by abdominal cramps
GVHD and Infection
Infections cause most deaths among patients with GVHD. GVHD breaks down the barriers of your skin and mucous membranes that normally protect the body from infections. The medications used to prevent and treat GVHD, as well as GVHD itself, weaken your body’s ability to resist and fight infection. In addition, GVHD often gets worse when you have an infection.

It is very important to do all you can to prevent infections. Report any symptoms of infection right away.

Prevention and Treatment of GVHD
Take your immunosuppressive medications. These medications help prevent the donor cells from attacking your body and causing GVHD.

Prevent infections. The immunosuppressive medications you take to prevent GVHD also put you at higher risk for infection. If you get an infection, this will often trigger or cause GVHD. Therefore, preventing infections is a key strategy to prevent and treat GVHD.

Protect your skin from exposure to sunlight. Wear long sleeves and pants, wide-brim hats, and sunglasses when you are outdoors to lower the risk of GVHD.

Medications to Weaken the Immune System
You will be on one or a combination of these medications that weaken the immune system. Refer to the medication section of this binder for more information.
- Cyclosporine—Started pre-transplant
- Tacrolimus—Started pre-transplant
- Mycophenolate mofetil—Started pre-transplant
- Methotrexate—Low-dose chemotherapy given through your IV on days +1, +3, +6, +11 after your transplant
- Methylprednisone—Given for GVHD not controlled by the above medications
Caregivers assume 24-hour responsibility for the patient after a bone marrow transplant. This factsheet describes the caregiver’s roles, which include many important aspects of recovery and care after leaving the hospital.

**Basic Responsibilities**

**Make arrangements**
- Provide or arrange transportation
- Make and keep appointments with the Bone and Marrow Transplant (BMT) Clinic at Huntsman Cancer Institute (HCI)

**Provide emotional support**
- Give encouragement throughout the sometimes difficult recovery
- Be a good listener

**Provide physical care**
- Maintain and care for the patient’s central line
- Organize the patient’s oral medications
- Monitor compliance and keep accurate records of medications taken
- Set up pumps for necessary IV medication (with help from home care nurses)
- Observe changes in the patient’s condition and report them to the BMT team
- Obtain necessary medical supplies from home care service

**Clean and maintain the home**
- Prepare the home for the patient’s arrival
- Keep the home clean after the patient’s return
- Prepare food for the patient

**Be the patient's advocate**
- Help the patient with decision-making
- Protect the patient from visitors who are ill or have not washed hands
- Gather health information, psychological support, financial assistance, and other information for the patient and family

**Provide assistance and support to the patient’s family and friends**
- Serve as a communication link between the patient, family, and friends
- Give support and assistance to the patient’s children as needed

**Preparing the Home for the Patient**

We recommend an overall deep cleaning before the patient comes home from the hospital. One goal is to eliminate as much dust as possible. Another goal is to reduce bacteria and viruses that cause the common cold and flu. Do this by disinfecting household surfaces.

- Clean the carpets unless they have been cleaned less than six months before the patient comes home. We recommend professional cleaning with a truck-mounted extraction system. Ask the cleaners to remove as much moisture from the carpet as possible. Excess moisture can allow fungus to grow. After professional cleaning, allow the carpet to dry for three to four days before the patient arrives. If you clean the carpets yourself, allow seven to 10 days of drying time.
- Clean kitchen appliances (including refrigerator shelves and compartments) and bathroom fixtures with diluted bleach or a commercial antibacterial cleanser.
- Dust furniture with a damp cloth. DO NOT use feather dusters that stir up dust.
- Replace swamp cooler pads and air filters in furnaces and air conditioners.
- Vacuum the outside of heating vents.

**Recommended Cleaning Schedule**

**Daily**
- Clean kitchen counter surfaces, faucets, and sink with diluted bleach or antibacterial cleansers.
- Clean bathroom sinks and counters, especially handles that the patient will touch.
- Disinfect door, cupboard, and drawer handles that the patient touches frequently.
• Do NOT vacuum or dust while the patient is in the immediate area.

**Weekly**
• With a damp cloth, dust heater vents, the top of the refrigerator, and other areas that collect dust.
• Vacuum the entire house.
• Change bed linens.

**Monthly**
• Change vacuum bags. If you use a bagless vacuum, empty the dirt container outside the house.
• Change furnace and AC filters.

**Monitoring the Patient for Infection**
Fever can be a sign of infection. It is important to check the patient’s temperature often, even if he or she does not feel warm or ill. Here are some guidelines:
• Take the patient’s temperature daily, or more often if it appears to be on the rise.
• Wash the thermometer with warm (not hot) water and soap, or wipe it with alcohol after each use.
• Do not allow anyone else to use the patient’s thermometer.
• Do not give Tylenol, ibuprofen, or aspirin to bring the patient’s temperature down until you have reported to a BMT team member and received permission to do so. Giving Tylenol when a temperature is rising interferes with accurate tracking of a possible fever.

**Call the BMT Clinic at HCI if these happen:**
• Chills or shaking occur, even if the patient does not have a fever
• The patient has a fever of 100.5°F (38.0°C) or higher

**BMT Clinic**
801-585-2626 (weekdays until 5 p.m. and weekends and holidays until 2 p.m.)

**BMT Unit**
801-585-2050 (for all other times or in cases where the BMT Clinic does not answer)

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**Celsius to Fahrenheit Temperature Conversions**

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<th>°C</th>
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When taking an axillary (under the arm) temperature, add 0.5° to the Celsius reading for an equivalent oral temperature. For instance, 37.0° C axillary would equal 37.5° C oral.