

Home Care after Transplant

Utah Blood and Marrow Transplant Program

This factsheet has information to help you stay safe after your stem cell transplant. Your immune system is still recovering. You must do these things to help avoid infection and other serious problems.

After You Leave the Hospital

You must live close to Huntsman Cancer Institute (HCI) for a while after you get out of the hospital:

- Allogeneic transplant: 100 days
- Autologous transplant: 30 days

Your home has to be within 40 miles or a 60-minute drive of HCI. If your home is farther away, you must stay in temporary housing. You must have a supportive home environment with a 24 hour a day caregiver for:

- Autologous transplant: From the time you leave the hospital until at least 30 days after your transplant (Day 0)
- Allogeneic transplant: From the time you leave the hospital until at least 100 days after your transplant (Day 0)

Your Medicines

- On the day you get out of the hospital, the pharmacist will talk with you about all your medicines.
- Please follow the pharmacist's instructions for taking your medicines.
- Bring all your medicines to every clinic appointment.
- If you run low, ask for refills at your appointments.
- Do not take any other medicines or supplements unless your transplant doctor says it is OK.
- If you are taking cyclosporine, tacrolimus, or sirolimus:
 - On the days you come to the clinic, do not take the morning dose. Bring it to the clinic with you.
 - Take it after we draw your blood for the lab tests.

For more information, see the *Pharmacy Services for BMT Patients* factsheet in your BMT patient education binder.

When to Call for Help

Follow the instructions on the When to Call for Help factsheet in your BMT patient education binder. It includes a list of signs and symptoms that if you're experiencing you should call the transplant team.

Nurse Lines

During business hours:

Monday–Friday, 8 a.m.– 5 p.m.

Multiple Myeloma diagnosis: 801-587-4687

All of other diagnoses: 801-587-4686

After hours:

Weekends and holidays (Clinic closed New Year's Day, Thanksgiving Day, and Christmas Day)

Call the hospital operator: 801-587-7000

Ask for the BMT hospitalist.

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Bleeding

Your platelet count may stay low after your transplant. This raises your risk for bleeding. Watch for these signs of low platelets:

- Bleeding gums
- Nosebleeds
- Easy bruising
- Blood in urine or stool
- Small red spots on your skin

Talk with your transplant care team right away if you have any of these signs.

When your platelet count is lower than 50,000, follow these instructions:

- Do not use medicines that can cause bleeding such as aspirin or ibuprofen. Aleve® and Advil® are products that have ibuprofen. Talk with your transplant care team about any medicine or supplement you take.
- Use ONLY an electric razor for shaving.
- Use a soft toothbrush. Do not floss your teeth. You may use a cleaning tool such as Waterpik®.
- Avoid activities where you could get hurt or bruised.
- Be very gentle when blowing your nose.
- If you have hard stools, do not push hard when using the bathroom. Talk with your transplant team about ways to prevent constipation.

Nosebleeds. When the inside of your nose gets dry, the risk for nosebleeds goes up. Saline nasal spray can help keep the inside of your nose from drying out.

Follow these steps if you get a nosebleed:

- Sit up and lean your head forward.
- Squeeze the bridge of your nose with your fingers for at least 10 minutes.
- Hold an ice pack on your nose.
- If bleeding lasts more than 30 minutes, call for help.

Cuts. Follow these steps if you get a cut that bleeds:

- Press the bleeding area with a clean, dry cloth for at least 10 minutes.
- Put an ice pack on the wound.
- If you can, hold the wounded area higher than your heart.

- Clean the wound with warm water and soap. Cover it with a sterile bandage.
- If bleeding lasts longer than 30 minutes, call your transplant care team.

Preventing Infection

You will still have a high risk for getting infections when you leave the hospital. Follow these instructions to lower that risk.

Handwashing. Wash your hands often with cold or warm water and soap. Wash for at least 20 seconds—the time it takes to sing the alphabet song. Here are important times to wash:

- Before eating
- Before, during and after preparing food
- After using the restroom
- After touching another person
- After blowing your nose, coughing, or sneezing
- Before and after handling your central venous line
- After handling garbage
- After touching an animal or animal feed
- Do not touch fluids that come from your body. Use tissues or toilet paper.
- Do not handle pet waste.
- Do not change diapers.
- Limit your visitors to small groups.

Wearing a Mask. You are required to wear an N95-rated filtered mask after your transplant. You may also buy a cloth mask with replaceable filters. Be sure it is rated N95 or higher. You are required to wear your mask during the following times:

- Inpatient: any time you are outside of your inpatient room.
- Outpatient:
 - Going to and from clinic visits
 - Outside the clinic room
 - In public spaces
 - Outside if air quality is poor or it is windy
 - During cold and flu season or when during high risk periods of contagious sickness in the community
 - Periods of hospital construction

- Your transplant care team will tell you when it's okay to stop wearing your mask. For allogeneic transplant patients, this is usually about 100 days. For autologous transplant patients, it's about 30 days.
- Keep your mask in a clean bag when you are not wearing it. Replace your mask or filter if it becomes visibly dirty.

Stay away from people who are sick. If this is not possible, do the following things to limit your risk:

- Avoid kissing on the lips or mouth.
- Throw away used tissues right away.
- Be extra careful to wash your hands often.
- Wear your mask when you are in the same room with the sick person.
- Think about sleeping in separate bedrooms until signs of cold or flu are gone.

Avoid people who have been exposed to these diseases. Call your transplant care team right away if you have been exposed:

- Chickenpox
- Herpes
- German measles
- Measles
- Shingles
- Mumps Rubella

Your family members and caregivers need to be current on their vaccinations, including annual flu shots.

The vaccines should be inactive, not live. If family members or caregivers get a live vaccine, they should be in contact with you as little as possible for at least 7 days.

- It's OK for children to have the live MMR vaccine. The disease cannot be transmitted this way.
- Chickenpox vaccine is also live. There is a very small risk of transmission. If the recently vaccinated child shows a rash, talk with your transplant care team.

Hygiene

Mouth care. Taking good care of your teeth and mouth is important while your immune system recovers.

- Brush your teeth every day. Use a soft or ultrasoft toothbrush.
Your absolute neutrophil count must be greater than 500 and platelet count greater than 20,000 to use a toothbrush. If your counts are lower than this, use these alternatives:
 - Commercial mouthwash that does not contain alcohol or hydrogen peroxide. Read the labels to make sure.
 - Salt water: Mix ½ teaspoon of salt and ½ teaspoon of baking soda in 8 ounces of water.
- If your mouth is very dry, you can use an artificial saliva product. Sucking on sugarless candy or lozenges can also help.
- After your mouth recovers from the dryness, you can use a fluoride-based mouthwash such as Biotene®. Hold the mouthwash in your mouth for at least 1 minute, then spit it out. Do not rinse afterward.
- If you wear dentures, it is important to keep them clean. Soak them every day in denture cleaner, following the product instructions. Rinse the dentures under tap water before putting them in your mouth.
- If you use mouthwash, take out your dentures first and replace them afterward.
- Skin care. It is important to take good care of your skin with gentle products that do not cause dryness.
- Take a shower every day.
 - Do not share towels or washcloths with anyone else. Have a set for your use only.
 - Use mild soap such as Dove® or Caress®. Other soaps can be very harsh and drying. Soaps that have deodorants are also hard on your skin.
 - Clean your underarms and groin very well. These areas can have many germs.
 - Keep your scalp clean. Use mild shampoos that do not cause dryness.

- Protect your central line dressing.
 - If a clear dressing covers your central line, tape plastic wrap over it while you shower. Call your transplant care team if any of these things happen:
 - The seal on your dressing breaks
 - Moisture gets trapped inside the dressing
 - If you have a Mefix dressing over the central line, it is OK to get it wet. Change the dressing right away after you take a shower.
- Do not use deodorants that are medicated or have perfume.
- Use skin products such as lotions, makeup, and aftershave that do not have alcohol or perfumes.
- Put lotion on while your skin is still damp from your shower.

Contact lenses. If you wear contact lenses, keep them very clean.

- Use fresh cleaning solution every time. Do not use expired solution.
- If you wear disposable contacts, use fresh lenses every day.

Sun protection. You need to be very careful to protect your skin from the sun.

Use broad-spectrum (both UVA and UVB protection) sunblock with SPF30 or more whenever you go outdoors.

- If you will be in direct sunlight, wear long pants, a long-sleeved shirt, and a wide-brim hat.
- For more protection, you can use laundry products such as SunGuard® when you wash your clothes or purchase UV clothing. If you had an allogeneic transplant and you notice any change in your skin, talk to your transplant care team right away. It could be a sign of skin GVHD, which needs to be treated right away.
- If you have skin GVHD, stay out of direct sunlight, even with sunblock and UV clothing. Your transplant doctor will tell you when it is OK to be in the sun.

More body care tips. If you had an allogeneic transplant, do not get salon manicures or pedicures until your doctor says it is OK.

Do not get body piercing or tattoos unless your doctor says it is OK.

The vaccines should be inactive, not live. If family members or caregivers get a live vaccine, they should be in contact with you as little as possible for at least 7 days.

- It's OK for children to have the live MMR vaccine. The disease cannot be transmitted this way.
- Chickenpox vaccine is also live. There is a very small risk of transmission. If the recently vaccinated child shows a rash, talk with your transplant care team.

Housekeeping

Before you go home. Your caregiver will need to ensure the following is done before you return home.

- Clean all carpets at least 10 days before
- Deep clean the entire home. Use a cleaning product that kills germs. Give extra attention to high touch surfaces.
- Put in new swamp cooler pads and air filters for furnaces and air conditioners.
- Vacuum the outside of heating vents.

Chores and Cleaning Schedule. You can do light household chores if you are not too tired. Your caregiver should be following the cleaning schedule found in *The Caregiver's Role* factsheet, located in the BMT patient education binder. If you do light household chores, do not dust or vacuum for 3 months after your transplant and at 30 minutes before going into a room that someone else has dusted or vacuumed.

Laundry. You need to take special care of your clothes and bedding.

- Wash and dry your clothes, towels, and bedding in separate loads from other family members' laundry.
- Wash all bedding once a week.

You need to be very careful about dust, germs, and mold as you recover.

- Keep your home extra clean and free of dust and dirt.

- Stay out of musty areas such as damp basements.
- Do not use a humidifier. Swamp coolers and air conditioners are OK.
 - If the air in your home is dry, put a pan of water near a heat source. Change the water every day.
 - Run the swamp cooler at least 30 minutes each day to keep the water fresh.
 - Have air conditioners in your home and car cleaned and serviced before you use them.
- Keep windows and doors closed when it is windy, or the air quality is poor

Getting Out of the House

Regular walks outside your home will help you gain back your strength.

- Stay away from areas with dirt or dust.
- Public spaces.** It's okay to visit these areas when they are not crowded. Wear a mask while you are there.
- Movie theaters
 - Supermarkets
 - Restaurants
 - Farmers markets
 - Churches
 - Stores and malls

Driving. You may drive when your doctor says it is OK.

Public transportation. Avoid buses, trains, subways, and taxis until at least 100 days after transplant. You may travel short distances by these modes after day 100 if your transplant doctor tells you it is OK.

- If you must travel this way, wear a mask and be extra careful about washing your hands.

Traveling. Do not travel by airplane until you are off immune suppressant medicines.

- If you must travel by air before that, talk with your transplant doctor first.
- If your doctor allows you to fly, wear your mask.

Activity and Exercise

Exercising will help you get back to doing things you enjoyed before your transplant.

It is normal to tire easily as you recover. Take rests between activities.

Be careful not to do too much at first. Talk to your transplant care team about which activities are OK as you recover.

Do not do these activities until your platelet count is higher than 100,000:

- Lift heavy weights
- Play contact sports
- Go skiing

The Linda B. and Robert B. Wiggins Wellness and Integrative Health Center can help you with fitness, nutrition, and other quality of life concerns. For more information, call 801-587-4585 or visit www.huntsmanccancer.org/wellnesscenter.

Integrative Medicine

Acupuncture can help with pain and other side effects. Acupuncture is allowed after day 100, when off immune suppressive medicine and you don't have GVHD.

Talk with your transplant doctor before having massage, joint manipulation, or chiropractic treatment.

Don't use herbal, essential oil, or home remedies unless your transplant doctor tells you it is OK.

Having Fun is OK

After day 100, you can do many of the hobbies and activities you enjoy.

Talk with your transplant doctor before these activities or similar ones:

- Road biking
- Mountain biking
- ATV riding
- 4-wheeling
- Hunting
- Climbing
- White-water rafting

Wear a mask for outdoor activities such as camping and hiking. Be sure to wear it when you are near a campfire and when the weather is windy, dusty, or smoky.

When fishing, wash your hands right away after touching fish.

If your transplant doctor allows you to do woodworking and other crafts, do these things to be safe from fumes and sawdust:

- Use non-toxic materials, if possible.
- Wear the right respirator or mask.
- Work in an area with plenty of fresh air.

Sexual Activity

Talk with your transplant doctor about when it is OK to start having sex again. Usually this will be after your ANC is more than 500 and your platelet count is 50,000 or more.

Your interest in sex may be less after the transplant. This is normal.

We strongly advise you to limit the number of sexual partners. This will lower the chance of disease and infections.

Use latex condoms for 6 months after the transplant. This applies to male transplant patients and the partners of female transplant patients.

Avoid using spermicides. They can irritate the penis and the vagina.

Oral sex is OK as long as neither the patient nor the partner have sores on the genitals, mouth, or lips. We recommend using barrier protection.

Do not have anal sex until you are off immune suppressive medicines, and your transplant doctor says it is OK.

For Men

You may find it difficult to get and keep an erection. Some medicines may help. Talk with your transplant team or a specialist in sexual health for information.

For Women

Chemotherapy and radiation therapy can make your vagina very dry. Use a water-soluble lubricating jelly to prevent pain during sex.

Be sure to see your gynecologist for a check-up after your transplant.

Talk with your transplant team about any concerns you have. They can refer you to specialists if needed.

If you had an allogeneic transplant, talk to your transplant doctor right away if you have any new pain or changes in your genital area. It could be a sign of skin GVHD, which needs to be treated right away.

Gardening and Yard Work

You may keep house plants and cut flowers in your home.

- Do not touch the soil or water in the vases. If you do, wash your hands right away.

If you have an autologous transplant, you can garden and do yard work after day 30.

If you had an allogeneic transplant, you can garden and do yard work after day 100 and when you are off all immune suppressive medicines.

Your transplant doctor may change the date, depending on your situation.

- When you are working in the soil, wear a mask and gloves.
- Wash your hands well afterward.
- Be careful not to get pricked by plant thorns.

Pets

Your pet can stay in your home. If it's a dog or cat, you can even rub its ears and scratch its belly.

Before You Go Home

Have your pet bathed and groomed, including nail trimming.

Make sure all immunizations are up to date.

Have pets checked and treated for fleas, ticks, and other parasites.

Dogs and Cats

Keep your pets inside or on your property. Keep them out of parks, forest, and wild lands where they may get diseases from other animals.

Don't let your pet sleep in your bed.

Be careful not to let your pet bite, lick, or scratch you.

All Pets, Including Dogs and Cats

Don't touch animal saliva, feces, and urine.

Have someone else clean food and water bowls, litter boxes, cages, and aquariums.

Do not handle or care for birds, lizards, turtles, snakes, or rodents such as mice or hamsters.

Going Back to Work

Plan to be off work or school for several months after your transplant:

- Autologous transplants: 2–3 months
- Allogeneic transplants: 6–12 months

Think about starting part-time and working back into your old schedule slowly. Talk to your transplant doctor first.

Smoking and Alcohol

Before your transplant, you agreed not to use tobacco, alcohol, and some other harmful products. Once you are out of the hospital, we can't make you follow that agreement, but we encourage you not to start again.

We hope you will not smoke tobacco or marijuana, vape, or use other tobacco products after you leave the hospital.

- It can raise your risk for serious lung infections.
- It can raise your risk of getting another cancer.

Do not drink alcohol unless your BMT doctor says it is OK.