

Living and caring for yourself at home requires special attention for 30 days or more after your CAR T cell therapy infusion. This factsheet has information to help you stay safe.

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## After You Leave the Hospital

You must live close to Huntsman Cancer Institute (HCI) for 30 days after CAR T cell therapy. Your home must be within 40 miles or a 60-minute drive of HCI. If not, be sure to set up temporary housing before you leave the hospital. Your social worker can help with this. You must have a 24-hour caregiver every day for those 30 days of close monitoring.

## Who to call for help

For life-threatening emergencies, **call 911.**

### Nurse line

**801-587-4686**

### *During business hours:*

Monday–Friday, 7 a.m.–5 p.m.

BMT/Hematology Clinic **801-585-2626**

### *After hours:*

Monday–Friday after 5 p.m.

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

Call the hospital operator at **801-587-7000**

Ask for the BMT hospitalist.

## Preventing Infection

Your immune system will be weakened for weeks after CAR T cell therapy. Infection is one of the biggest risks you will face after leaving the hospital. Follow these instructions to lower that risk.

**Wash your hands often** with warm water and soap.

- Wash for at least 15 seconds—the time it takes to sing the alphabet song. Here are important times to wash:
  - Before eating
  - After using the bathroom
  - After touching another person
  - After blowing your nose, coughing, or sneezing
  - Before and after handling your central venous line

**Avoid things that have many germs.**

- Do not touch fluids that come from your body. Use tissues or toilet paper.
- Do not handle pet waste.
- Do not change diapers.

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## **Wear your mask.**

Your care team will give you an N95-rated mask to wear after your therapy. You may also buy a cloth mask with replaceable filters. Be sure it is rated N95 or higher.

Wear your mask when you are not in your private living space until your BMT doctor tells you it is OK to go without it. This is usually 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.
- These are times when it is extra important to wear your mask:
  - In the hospital
  - Going to and from clinic visits
  - Outside the clinic room
  - In crowds
  - Outside if air quality is poor or it is windy
  - During cold and flu season or when there is contagious sickness in the community

## **Limit your visitors to small groups.**

- Stay away from people who are sick.
- Avoid people who have been exposed to these diseases:
  - Chickenpox    – Mumps            – Herpes
  - Rubella        – Measles           – Shingles
- Also avoid people who have had chickenpox or varicella vaccinations in the past 3 weeks.
- Call your BMT care team right away if you have been in contact with someone who has been exposed to chickenpox, measles, German measles, or shingles.
- You do not have to stay away from family members who have a cold or the flu, but do these things:
  - 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.

## **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.

- Rinse your mouth.
  - Use mouthwash that does not contain alcohol or hydrogen peroxide. Read the labels to make sure.
  - Or use salt water rinse: Mix ½ teaspoon of salt and ½ teaspoon of baking soda in 8 ounces of water.
- If your mouth is very dry, don't use mouthwash. You can use an artificial saliva product available at drugstores. Sucking on sugarless candy or lozenges can also help.
  - After your mouth recovers from the dryness, you can use a fluoride-based mouthwash. 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.

**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.
- Clean your underarms and groin very well.
- Keep your scalp clean. Use mild shampoos that do not cause dryness.
- Put lotion on while your skin is still damp from your shower.

## **Protect your central line dressing.**

- Do not swim or soak in water while your central line is in place. This includes hot tubs, saunas, hot springs, pools, and any other body of water.
- If a clear dressing covers your central line, tape plastic wrap over it while you shower.
- Call your care team if either of these things happen:
  - Broken seal on your dressing
  - Moisture trapped inside the dressing
  - New drainage or changes in skin around the line

## **Choose gentle products.**

- 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.

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**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 sunblock with both UVA and UVB protection and 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.

**More body care tips.** 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.

## Your Medicines

Your care team will give you medicines to prevent infections while your immune system recovers.

- The pharmacist will talk with you about all your medicines on the day you get out of the hospital.
- 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 BMT doctor says it is OK.

## Bleeding

Your platelet count may stay low after your CAR T cell therapy. This raises your risk for bleeding. Watch for these signs of a low platelet count:

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

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

**When your platelet count is lower than 50,000.** Your care team will tell you when your platelet count is low. If this happens, 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 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.
- 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 care 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 the BMT/Hematology clinic 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 care team.

## Housekeeping

**Before you go home.** If you have carpets in your home steam-cleaned, do it at least 10-14 days before you arrive. It is OK to clean carpets with chemical dry cleaning right before you arrive.

**In your home.** You can do light household chores if you are not too tired.

- Do not do dusting or vacuuming yourself for 30 days after your CAR T cell therapy.
- Wait 30 minutes before going in a room that someone else has dusted or vacuumed.
- Keep the bathroom extra clean, especially the tub and toilet. Use a disinfectant weekly.

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

- If your family member's laundry is very soiled, wash and dry your clothes, towels, and bedding in separate loads. Otherwise, you don't need to separate your laundry from the rest.
- Wash all bedding once a week.

**The air you breathe.** 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.
  - Have the drip pads in your swamp cooler replaced before you return home. Run the 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 and when the air quality is poor.

## Getting Out of the House

**Do not drive or operate heavy machinery for 8 weeks after your treatment.**

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

- Stay away from areas with dirt or dust.
- 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

Avoid buses, trains, subways, and taxis until at least 30 days after your CAR T cell therapy.

Do not travel by airplane until your BMT doctor says it is OK. If your doctor allows you to fly, wear your mask.

## Activity and Exercise

Exercise will help you get back to doing things you enjoyed before your CAR T cell therapy.

It is normal to tire easily as you recover. Rest between activities. Be careful not to do too much at first.

Talk to your 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 [huntsmancancer.org/wellnesscenter](http://huntsmancancer.org/wellnesscenter).

## Integrative Medicine

Ask your BMT doctor before having these therapies:

- Acupuncture
- Massage
- Joint manipulation
- Chiropractic treatment

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

## Having Fun is OK

After day 30, you can do many of the hobbies and activities you enjoy. Ask your care team what is OK for you.

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

- Road biking
- Mountain biking
- ATV riding
- 4-wheeling
- Hunting
- Climbing
- River rafting
- Fishing

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.

If your 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 BMT 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 CAR T cell therapy. 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 CAR T cell therapy. This applies to male patients and the partners of female patients.

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

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

**For women.** Chemotherapy 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 CAR T cell therapy.

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

## Gardening and Yard Work

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

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

Ask your BMT doctor before gardening outside. Do not mow the grass or do yard work until your doctor says it is OK. Wash your hands well afterward.

- When you are working the soil, wear a mask and gloves.
- 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 your pets checked and treated for fleas, ticks, and other parasites.

Don't touch animal saliva, feces, or 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.

**Dogs and cats.** Keep them inside or on your property. Keep them out of parks, forests, and wild lands where they may get diseases from other animals.

Do not let your pet sleep in your bed.

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

## Going Back to Work

Plan to be off work or school for 2-3 months after CAR T cell therapy.

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

## Smoking and Alcohol

Before your CAR T cell therapy, 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.

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

## If You Have Had an Allogeneic Transplant

If you had an allogeneic transplant before CAR T cell therapy, you need to be extra watchful for signs of graft versus host disease (GVHD). You can find more details about this in the GVHD resources in your BMT patient notebook.

**Skin changes.** If you notice any change in your skin, talk to your 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 protective clothing. Your BMT doctor will tell you when it is OK to be in the sun.

Talk to your BMT doctor right away if you have any new pain or changes in your genital area. It could be a sign of skin GVHD.

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