

Allogeneic Transplant Home Care

UNC Adult BMT and Cellular Therapy Program



Your UNC Bone Marrow Transplant team wants to be sure that you feel comfortable taking care of yourself at home when you leave the hospital. Carefully read the information in this booklet. Let us know if you have any questions.

| Phone Numbers | |
|--|---|
| BMT Clinic Monday—Friday from 8:00 AM - 4:00 PM Call 984-974-8349 | On Nights, Weekends and Holidays Call 984-974-8280 Bone Marrow Transplant Unit Ask to speak to a Nurse |

Call 911 in an emergency, or go to a nearby Emergency Room.

Call your UNC Transplant team if you have any of the following problems:

- ① A fever of 100.5° or higher
- ① Chills or sweats
- ① Redness, swelling, drainage or pain at an IV site, central line site or wound
- ① Severe headache
- ① New pain or pain that is getting worse
- ① Trouble breathing
- ① Bleeding or bruising that is new or severe
- ① Rash or sores on your skin
- ① Cough or chest congestion
- ① Hives or welts
- ① Burning when you urinate (“pee”)
- ① Change in the color of your urine or stool
- ① Swelling in arms, chest, legs, face or neck
- ① Toothache or sore gums
- ① Nausea and vomiting that lasts more than 24 hours
- ① White parts of your eyes look yellow in color
- ① Unable to take any of your prescribed medicines
- ① Liquid stools, more than 8-10 times in 24 hours
- ① New runny nose
- ① Your caregiver has new cold symptoms, such as fever, runny nose, or cough

It's very important for you to report any new symptoms to a member of your BMT Cancer Care team. Fever and chills are the most common signs of infection. If you are neutropenic, a fever may be the only sign that you have an infection. You should monitor your temperature regularly. If you are feeling hot or flushed, take your temperature.

Medications

Before you are discharged from the hospital, one of the BMT Pharmacists will review all of your medications with you and provide you with a medication calendar. It's very important that you take your medications as instructed and don't miss any doses. Please keep track of your medications and bring your medication list with you to every clinic visit. During your first clinic visit after discharge, a member of the transplant team will go over your medications with you again.

Bleeding Precautions

You may continue to have a low platelet count for a while after leaving the hospital. Platelets are very important because they help your blood clot. During this time you may be at risk for bleeding and might need to get platelet transfusions as an outpatient.

If you have an accident or cut yourself, put a dry gauze pad, towel or cloth over the cut and apply pressure for 10 minutes. If the bleeding continues, raise up the area, apply ice and call the BMT clinic or the BMT unit.

If you are in need of blood products, please remember you will need to receive **irradiated** blood products.

If your platelet count goes **below 50,000**, please follow the instructions below for your safety:

- Use an electric razor if you need to shave.
- Use a very soft toothbrush or a toothette sponge.
- Blow your nose gently and do not pick your nose.
- Do not use aspirin, ibuprofen, or any similar medication. To be safe please check with your doctor or BMT pharmacist before taking any over-the-counter medications.
- Avoid activities or sports that can cause injury from straining or lifting.
- Avoid sexual activity.

If you have any of the signs and symptoms of a low platelet count listed below, please call your transplant team:

- Tiny pinpoint purplish red spots on skin
- Black or tarry stools
- Nosebleeds
- Blood anywhere on your body
- Bruising easily or more than usual
- Bleeding from your gums during mouth care
- Blood in your urine or vomit

Safety Rules after Allogeneic Transplant

Follow these safety rules to help protect yourself. These rules will help to decrease the chance of getting an infection. You will not be able to prevent everything, so just do your best. We want you to try to live as normally as you can until your ability to fight infection is back to normal.



- ◆ **Stay away** from anyone who is or has been sick: runny nose, cough, cold sores, sore throat, diarrhea, vomiting, fever, rash, red eyes, or chicken pox.



- ◆ **Masks.** An N95 mask will be given to you before you leave the hospital. Wear the mask when coming to the clinic or hospital and when you go into a public area. You don't need to wear a mask at home or around visitors who are not sick. You will need to wear a mask when out in the yard. If your caregiver or other people staying with you become sick, let someone on your transplant team know. If you have to be around a sick family member or caregiver, wash your hands often and wear your mask. The sick person should also wear a mask around you until he or she is well.



- ◆ **Handwashing** is the best way to keep from getting an infection. Wash your hands for at least 20 seconds, scrubbing between your fingers and under your nails. Use antibacterial soap and warm water. Everyone should wash their hands after going to the bathroom, before eating, after touching plants, after touching pets and after touching any body fluids. If soap and water are not available, use an antibacterial liquid sanitizer (like Purell) if your hands are not visibly dirty.



- ◆ **Pets.** Contact with common house pets is safe as long as they live in the house and not outdoors. Their immunizations need to be up to date. It's important to avoid litter boxes, pet stool, birds and reptiles.

- ◆ **Avoid** large crowds until you have been cleared by a member of your transplant team. This includes movie theatres, grocery stores, restaurants, places of worship and other outdoor activities.



- ◆ **Gardening.** You should not work in the yard or dig up soil. There can be harmful bacteria or fungus that can cause an infection due to your weak immune system. You should avoid pesticides, solvents, and fertilizers. Avoid areas where there is freshly mowed grass or hay and construction areas.

- ◆ **Swimming** is not allowed in lakes, hot tubs, pools or oceans until cleared by your transplant team.

Taking Care of Yourself

Mouth care: It's important to keep your teeth, mouth, and gums clean. Brush your teeth with a soft toothbrush or toothette sponge and a mild toothpaste. Gargle or swish your mouth with saline or saltwater often but most importantly after each meal and at bedtime. Let your team know if you notice sores, white patches or bleeding in your mouth or on your lips. You should not go to the dentist for any dental work including cleanings until your team tells you it is okay.



Skin Care: Take a shower each day using mild soap and warm water. Use an alcohol-free moisturizing lotion a few times each day to help protect your skin. Some medicines, such as Septra (Bactrim), can make your skin more sensitive to the sun. The sun can trigger Graft vs Host Disease (GVHD). It can make GVHD worse or appear for the first time. Avoid sun exposure between 10:00 am and 5:00 pm. If you do need to go outside, wear a hat, sunglasses, long sleeve shirt and pants. Wear **sunscreen** when you are out in the sun and reapply every hour. Use at least a 30 SPF sunscreen that is "PABA free".



Activity: After your transplant, you may feel more tired than usual or get tired more easily. The time it takes to get your energy back depends on your blood counts, nutrition and activity level. Regular activity will help you get stronger, even if it's only a short walk. Try to do as much as you can for yourself. This will help you get stronger. It's okay to ask for help if needed. Plan your daily schedule so that activities that require more strength are earlier in the day. You may not be physically strong enough to return to work for weeks or months after your transplant. During this time, you can do other activities you enjoy that can also help increase your strength.



Medic Alert Bracelet: Your UNC team will give you a Medic Alert bracelet form to complete. When you fill out the form, your bracelet should have the date of your bone marrow transplant and should read "irradiate all blood products". Let a team member know if you need help with this.



Sexuality: Talk with a member of your transplant team to find out when it's okay to resume sexual activity. You may have sexual intercourse when your platelet count is greater than 50,000 and your absolute neutrophil count (ANC) is greater than 1,000. It's important for you and your partner to wear condoms to avoid infection or a sexually transmitted disease.

Many women and men can have a decrease in their sexual desire after transplant. This is common and can be caused by your illness, recovery time and side effects of the medicines you are taking. Intimacy is an important part of a healthy relationship. Talk with a member of your transplant team if you are having any problems.

Some women have vaginal dryness after a transplant. If this is a problem, use a water based lubricant to make sex more comfortable. Talk with a team member about lubricants you can use during sex.

Many women stop having menstrual cycles or have irregular menstrual cycles. Your transplant doctor may suggest you use estrogen supplements but this depends on your disease and treatment.

Central Line Care: You will go home with your central line. Your BMT nurses will teach you how to take care of your central line at home. Your transplant doctor will let you know how long you need to have the line.

If your central line rips, tears or breaks:

Close your plastic clamps on the catheter. The clamps need to be closed between the exit site and the rip, tear or break on the catheter. Call your UNC BMT Team right away. Be sure that you always keep sharp objects, such as scissors, away from your catheter to prevent tear, rip or break.

Smoking. Do not smoke or let anyone smoke around you. If you or your caregiver need to quit smoking, please talk to a member of your UNC BMT team.



Taking Care of Yourself

House-cleaning: Before you leave the hospital, a thorough cleaning of your home or temporary housing must be done. This helps to limit the amount of dust in your home. When dusting use a damp cloth rather than a feather duster. Vacuum all rugs, floors, and furniture. Clean tubs, toilets and sinks with strong cleaners. Clean or purchase new air filters. Bathrooms and eating areas should be cleaned daily. Dirty sponges should be replaced weekly or they can be cleaned in the dishwasher. You should not do any of the cleaning so that you are not exposed to any dusts or molds.



Immunizations: After having a transplant, you will have long-term weakness to your immune system. This can be caused by the chemotherapy and the immunosuppressive medications you are on to prevent GVHD. These medications work by suppressing your own immune system so that your new bone marrow can grow. Immunizations may not work or work as well while you are on the medications to prevent or treat GVHD. Your transplant team will let you know when you can begin your immunizations. This depends on your medical condition or other medications that you are on.



Contacting your Donor

Some patients and families would like to contact their donor. You can do this one year after the transplant or depending on where your donor lives. Your donor will need to agree to this as well. You can write to your donor before one year if you do not use your name or anything that tells them who you are or where you live. Your nurse coordinator can talk to you more about this if you would like.

Notes:

Nutrition and Food Preparation

Follow these rules about food and food preparation when you are discharged from hospital. **You will not be able to eat fresh berries, raw honey, uncooked pepper, sprouts, uncooked fresh herbs, uncooked deli meats, or unpasteurized milk or honey.** If washed well, you may eat uncooked broccoli and cauliflower. Raw onion may be eaten if washed well after peeling. You will need to follow a special diet until off immune suppressing medicines and discussion with your BMT Provider. Please refer to “**Food Safety for Transplant Recipients.**”

- You need to drink _____ ounces of fluid every day. If you have well water at home, you may drink the water if you can bring us results of the water testing. We encourage that you drink bottled water or you can also boil water before drinking. It needs to be at a rolling boil for 1 minute. Throw away any unused boiled water after 3 days.
- Put “leftovers” in the refrigerator within 2 hours of eating. Only reheat them once before throwing them out. This food should be thrown out if it is not eaten within 3 days. Check all dates on food and don’t keep any foods or drinks longer than the sell-by date.
- Use a dishwasher if you have one.
- If you must eat out at a restaurant., please avoid buffets, cafeterias, salad bars or potlucks. Also, no ice, fountain drinks or lemon wedges. Eat the food while it’s hot and well cooked. For carry out, ensure that delivery is within 2 hours and made fresh.
- Changes in your taste buds are very common after a transplant. Things that you liked to eat before may no longer taste good to you. Some medicines may leave a metallic taste in your mouth. Good mouth care, chewing gum or sucking on hard candy can help with this. Don’t give up on your favorite foods too soon, as this symptom usually goes away over time.
- Eating foods that are high in vitamins, proteins and calories are important in building new healthy cells. Spicy foods and food that have too much acid can irritate your mouth and throat. Greasy foods can be hard to digest and can cause diarrhea.
- It may help to keep your food portions small at first or split your meals into smaller ones throughout the day.



BMT Outpatient Clinic Visits

After you leave the hospital, your BMT team will continue to follow your progress very carefully in the outpatient clinic. You will be seen two to three times a week, depending on how you are doing. Your caregiver should be with you at every visit. Plan to come to the BMT clinic for at least the first 100 days after transplant. You will need to wear the N95 mask as you travel to and from the hospital, including the clinic waiting room. You will primarily be seen by an advanced practice provider that works closely with your BMT doctor to manage your care. If you have any complications after you go home, you may need to go back into the hospital until you are well enough to be at home again.

Preparing for your Clinic Visits

- **Appointment times.** Clinic visits are normally scheduled between 8:00 AM and 11:00 AM if possible. This is so special blood tests can be collected and sent for scheduled lab testing. It's very important that you come to all your clinic visits on time. If for some reason you are not able to come for an appointment or are going to be late, please call the BMT clinic and let us know.
- **Check-in.** You will need to register on the ground floor of the Cancer Hospital. They will then tell you to come to the BMT Clinic on the second floor of the Cancer Hospital. If you are not feeling well enough to sit in the waiting area, please let the clinic receptionist know so that a clinic nurse can be notified.
- **Blood Draws.** You will have your blood drawn at each clinic visit. The blood tests will change depending on the plan of care the provider has for you. The results will be given to you during or after your visit.
- **Treatments.** Depending on your lab results, you may need treatments like IV fluids, IV medications, or blood transfusions. You will go to the BMT infusion clinic on the 3rd floor. Depending on the treatment that you need, you may be in clinic for most of the day. Please feel free to bring snack foods and activities in case you need to stay longer than expected.
- **Medications.** Please bring all of your medicine bottles or an up to date list of your medicines with you to every visit. The nurses will go over all your medicines with you at each visit.
- **GVHD Medications.** The medicines prescribed to you to help prevent GVHD are normally taken every 12 hours. Please do not forget to bring this medicine with you to clinic visits. You will not be able to take this medicine until after you have had your blood drawn. This will make sure that that we can get an accurate drug level. Your dose may change depending on the result of the blood test.

We encourage you to write down questions you have as they come up at home and bring them with you to each visit. Your BMT team will answer any questions you may have about your care. Always keep your discharge instructions with you as they have important information about your care.

Post Transplant Nurse Coordinator

Once you are being followed in the outpatient clinic, a post-transplant nurse coordinator will meet you and will be the point of contact for you and your caregiver. This nurse coordinator is different than the coordinator you had before transplant.

Prescription Refills

Keep track of your medicines and be aware of when you need medicines refilled. **Let a member of the BMT team know during your clinic visit so that we can help you during business hours.** Most pain medicines cannot be called into any pharmacy. We will need to give you a paper prescription that you can take to your pharmacy. If you are not in clinic and are in need of a prescription refill, please call let us know.

Potential Long term effects of the transplant treatment

About 100 days after transplant, patients that are staying locally are generally allowed to return to their home. This depends on many factors. If your BMT team says you are able to return home, we will start to alternate visits between your local oncology doctor and the BMT clinic. You will still need to come to the BMT clinic at least once a month. Once you are no longer on any medications for GVHD, the clinic visits in the BMT clinic may become less frequent. We will continue to follow your progress for at least the next five years. Your BMT team will continue to watch for any signs and symptoms of long term side effects.

Potential long term side effects may include:

- Loss of the ability to have children on your own.
- Woman can experience an early menopause.
- Problems with your thyroid.
- Problems with your eyes.
- Changes of your skin such as dryness, sensitivity, and darkening.
- Dry mouth.
- Problems with your lungs. A disease called interstitial pneumonitis.
- Damage to other organs, like the heart and kidneys.
- Increased risk of bacterial, fungal, and viral infections.
- Chronic Graft vs Host Disease. This can affect many parts of your body. If you had previous GVHD, you are at higher risk for getting chronic GVHD.

Common Questions

| Frequently Asked Questions | Less than 60 days since BMT | Between 60-90 days after BMT | Between 3-6 months after BMT | 6-12 months after BMT |
|--|--|------------------------------|------------------------------|-----------------------|
| Wear a mask in hospital or in crowded areas | Yes | Yes | Yes | Review with your team |
| Go to school or work in an office | No | No | Review with your team | Yes |
| Work with animals (veterinarian, farmers, slaughter house, etc.)** | Avoid | Avoid | Avoid | Avoid |
| Carpentry work/ Woodworking | No | No | No | Review with your team |
| Household | | | | |
| Gardening** | Avoid | Avoid | Avoid | Avoid |
| Indoor Plants (in place prior to transplant)* | Yes | Yes | Yes | Yes |
| Mowing the lawn/Raking the leaves** | Avoid | Avoid | Avoid | Avoid |
| Household cleaning (vacuuming, dusting)** | No | No | No | Yes |
| Animals | | | | |
| New pets/Stray Animals | No | No | No | Yes |
| Cats/dogs (already in the house) | Yes | Yes | Yes | Yes |
| Cat litter box- cleaning** | Avoid | Avoid | Avoid | Avoid |
| Reptiles/Birds/Exotic pets | Avoid | Avoid | Avoid | Avoid |
| Recreational | | | | |
| Hot Tub/Swimming (if no IV line) | No | No | No | Yes |
| Golfing (Wearing Sunscreen) | Yes | Yes | Yes | Yes |
| Spectator events (church, movies, games; no hand shaking) | No | No | Review with your team | Yes |
| Airline travel | No | No | Review with your team | Review with your team |
| Sexual activity (ANC >1.0, Platelets > 50,000) | Yes | Yes | Yes | Yes |
| Drink alcohol (if of legal age) | No | No | Review with your team | Review with your team |
| Operate car or other motorized vehicle | No | No | Review with your team | |
| Travel out of the Chapel Hill area by car | No | No | | |
| Having 24/7 caregiver | Yes | Yes | | |
| Exposure to adults or children with viral infections (cold, flu, etc.) | During the first year or while you are on immunosuppressive medicines, we recommend that patients stay away from infected people until the viral infection has completely gone away and the person has been cleared by their regular doctor. | | | |

*You should not be in a room with live plants.

**Recommend you wear gloves and N95 mask.

After 12 months, please review with your doctor any issue that states “Avoid” at 6-12 months.

Checklist Before Going Home

We want to make sure you have everything you need at home before you leave the hospital. Go over this list with your team to be sure you have everything.

Know important phone numbers:

- Monday to Friday 8 AM to 4 PM: 984-974-8349
- Nights, weekends and holidays: 984-974-8280 and ask for the “Charge Nurse”

Supplies you need at home:

- Thermometer. Be sure to know how to read it and use it at home.
- Masks and gloves.
- Supplies for central line care.

Medicines:

- Know each medicine you are taking and what it’s for.
- Know how much of each medicine you should take.
- Fill all prescriptions before you leave the hospital.

Foods:

- Know what foods you can and cannot eat.
- Know how to store foods safely.

Safety:

- Know when you should wear a mask.
- Understand the importance of handwashing.
- Know other safety rules about visitors, pets, cleaning house, etc.
- Know the date and time of your next clinic visit.
- Apply for your Medic Alert bracelet.



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