PATIENT & CAREGIVER EDUCATION

Going Home After Your Allogeneic Stem Cell Transplant at MSK Kids

This information explains how to care for yourself or your child after an allogeneic stem cell transplant. In this resource, the words “you” and “your” mean you or your child.

As you read, write down or mark the places where you have questions. This will help you remember to ask your questions the next time you see your care team. There are no right or wrong questions. No concern is too small.

Going home after your transplant

You may be very happy and feel ready to go home after your transplant. You may also have some worries. It’s common to have worries about managing your care at home. Feeling confident and comfortable managing your care takes time.

Your care team will review the information in this resource with you. We will work with you and your family to make sure you’re ready to go home.

Contact information

Call your care team if you have any questions, concerns, or any problems listed here. You can reach them Monday through Friday from 9 a.m. to 5 p.m. at ________________________________.

After 5 p.m., during the weekend, and on holidays, call **212-639-7900 or 212-639-2000**. Ask to speak with the pediatric BMT fellow or attending physician on call.

Call **911** right away if you have a life-threatening emergency, such as trouble breathing or seizures (uncontrollable shaking).

When to call your care team

Call your doctor right away if you have any of the following:

- A fever of 100.4° F (38° C) or higher.
    - **Do not take acetaminophen (Tylenol®)** unless your healthcare provider tells you to.
    - You don’t have to take your temperature each day. But check it every 4 to 6 hours if you don’t feel well.
    - Take your child’s temperature orally (under their tongue) or axillary (under their armpit). **Do not check your child’s temperature through their rectum (anus).**
- Shaking or chills, especially while or after flushing your central venous catheter (CVC), such as an implanted port, such as a Mediport® if you have one.
- Shortness of breath or wheezing.
- Trouble taking medicine.
- Trouble eating or drinking.
- You or any close contacts are exposed to chickenpox, shingles, measles, German measles (rubella), or mumps.
- Coughing, sneezing, runny nose, or chest discomfort.
- Redness, swelling, or pain in your throat or eyes.
- A skin rash anywhere on your body. Rashes often look like redness, pimples, or blisters.
- Stomach pain.
- Nausea (feeling like you’re going to throw up).
- Vomiting (throwing up).
- Diarrhea (loose or watery bowel movements).
- Blurred vision or other changes in your eyesight.
- Urinating (peeing) more often than usual, a burning feeling when you urinate, or both.
- Redness, tenderness, swelling, drainage, or all of these around your CVC site.
- Trouble flushing your CVC, if you have one.
- Irritation, burning, or pain around your rectum.

We cannot predict all the possible symptoms you may have after your stem cell transplant. If you’re concerned about any symptoms, call your doctor at any time.

Prevent infection

It usually takes 6 to 12 months for your immune system to recover from your transplant. During that time, you’re at risk of infections and may catch viruses more easily. An infection can be more serious for you than others as your immune system builds up. Call your care team right away if you have any signs of infection, such as fever, shaking or chills, or wheezing.

There are certain things you can do to lower your chances of getting an infection. Follow the guidelines in this resource. Your care team will check your blood to see how well your immune system is working. They may give you more instructions to follow based on your results.

If you’re staying in a hotel or housing facility, you must stay in your room and avoid common areas. This is to lower your risk of infection. Parents or caregivers don’t need to wear masks when they are in your room like they did in the hospital. But, when they leave your room, they should wash their hands before going back in.

Talk with your social worker about housing, if needed

If you live further than 1 to 2 hours from MSK, we may ask you to stay near the hospital. This is to make sure you can come back to the hospital easily if you need to. We recommend this for at least the first month after your transplant, but your care team may give you other instructions.

MSK has arrangements with local hotels and housing facilities, such as The Ronald McDonald House. They may give you a discount. Your social worker can talk with you about your options and help you make reservations. You can also call 212-639-8315 to talk with the Pediatric Patient Services Coordinator.

How to get your home ready

Keep your home clean

It’s important to keep your home clean after your stem cell transplant. Keep it free of dust and dirt as much as possible to lower your risk of infection.

Avoid construction, renovations, or any home projects, including those done in the past 3 months. They may cause dust and make it hard to clean your home. Don’t repaint your walls or put new carpet until your care team says it’s safe to do so.

Before you leave the hospital, have someone clean your home so it’s ready for you.

They should:

- Vacuum all floors, rugs, and furniture. Make sure to get underneath beds and large furniture pieces.
- Dust all surfaces, including baseboards, ceiling fans, blinds, and lamp shades. Don't use a feather duster. They don't clean well.
- Clean bathtubs, toilets, and sinks with disinfectant or bleach. Check for mold.
- Clean the refrigerator.
- Clean or replace the filters in your heater, air conditioner, and air filtration systems.

Once you go home, your parent or caregiver should clean your home 1 to 2 times a week.

- When they clean, stay in a separate room with the door closed.
- Stay out of any room for 30 minutes after someone has dusted or vacuumed.
- Keep your bathroom very clean, especially the tub and toilet. Make sure it's cleaned with disinfectant regularly.

Do not use a humidifier

Do not use a humidifier. Bacteria and mold may grow in it. Instead, a pan of water placed near a heat source may help in the winter. **If you do this, have someone change the water every day**.

Stay out of damp areas

Stay out of musty areas where mold might grow, such as a damp basement. You can use an air filtration system in your home or dehumidifier, but you don't need to.

Take care around household plants

You can have plants in your home. But, for the first few months after your transplant:

- Don't touch the soil from household plants unless you wear gloves and a mask. There may be bacteria or mold in the soil.
- Don't touch the water in a vase of flowers. Someone else should change the water in the vases every day.
- Don't garden. This is to avoid harmful bacteria, animal feces, or other hazardous things.

Do not share household items

- Don’t share eating utensils (such as forks, spoons, or knives) or dishware (such as cups, bowls, plates).
- Don’t share towels, washcloths, or linens. This includes hand towels that may be hanging in your bathroom.
- Wash your eating utensils, towels, and linens carefully. They don’t need to be washed separately from the rest of your household.
- Wash all eating utensils well with hot water and dishwashing detergent or use a dishwasher.
- Wash your towels twice a week.
- Wash your bed linens once a week.

Talk with your care team if you have pets

Animals can carry diseases. They may put you at higher risk for infection while your immune system is recovering. If you have pets, talk with your care team before you leave the hospital. They may recommend you find someone to take care of them while you’re recovering.

Don’t handle or care for birds, lizards, snakes, turtles, hamsters, or other rodents while you’re recovering. If you have an aquarium and you have to clean it yourself, protect yourself by wearing gloves.

If you have a cat or dog at home, follow these guidelines until your doctor gives you other instructions.

- Be sure that your pet is up-to-date with immunizations and any booster shots.
- Have your pet’s veterinarian check their stool (poop) for parasites every year.
- If you have a cat, get it tested for feline leukemia and toxoplasmosis every year.
- Have your pet treated for fleas. If your pet walks through wooded areas, have it checked for ticks every day during tick season (May to November). Talk with your pet’s veterinarian about using a flea and tick collar.
- Don’t clean cat litter boxes or clean up after your dog. Have someone else do these things for you.
- Keep your pets indoors or on your own property whenever you can. This is to help keep them from getting diseases from other animals.

- Avoid pets in your bed.
- If you plan to get a pet after your transplant, it's best that you choose a healthy dog or cat that's more than 1 year old. Have it spayed or neutered. Outside of your home, avoid close contact with animals on a farm or a petting zoo.

What to do around family and visitors

You can have close physical contact with people in your close family. But, do not have close contact with someone who has a cold or any signs of being sick. This includes your tutor or physical or occupational therapist. Wear a mask if you must be in the same room with someone who has a cold or is sick.

Your family members and close friends should have a yearly flu shot. This will help protect you from the flu.

You can have visitors but limit them to small groups. Try not to have more than 2 visitors at a time.

Do not visit with anyone who has:

- A cold.
- Chickenpox.
- Recently been exposed to chickenpox.
- Recently been exposed to shingles.
- Recently been exposed to the herpes simplex virus (a virus that causes cold sores or fever blisters).
- Recently been exposed to any other type of virus or infection.
- Recently got a vaccine (shot) with a live virus. There are very few of these, but if someone in your household needs one, tell their doctor that you're immune suppressed and live in the same household. Some examples of live viral vaccines include:
    - Live polio vaccine.
    - Live influenza vaccine (vaccine sprayed into the nose).
    - Rotavirus vaccine (given to babies to protect them against a virus that causes vomiting and diarrhea).
    - Live chicken pox (Varivax®) or Shingles (zostavax).
    - Measles, mumps, and rubella (MMR) vaccine.

Call your doctor right away if you or any other family member is exposed to chickenpox, shingles, measles, German measles (rubella), or mumps.

Do not smoke and avoid secondhand smoke

After your transplant, your organs need time to recover. Do not smoke cigarettes, cigars, marijuana, vapes, or any other tobacco product. Doing so can harm your lungs and places you at a higher risk for lung infection.

It's also important to avoid secondhand smoke. **No one should smoke anywhere near you.**

How to care for yourself at home

Wash your hands

Washing your hands is the best way to prevent the spread of infection. Wash your hands often with antibacterial soap and water or clean them with an alcohol-based hand sanitizer. Wash your hands after using the toilet and before eating. Don't touch your mouth, lips, eyes, or nose without washing your hands first.

Take a shower or bath every day

Shower or bathe every day. It's important to keep yourself clean while you're recovering from your transplant. This can help prevent infection.

- Use a mild soap, such as Dove® or Basis®. Don't use Ivory® or deodorant soap. They can dry out your skin. If your skin is dry, talk with your care team
- Be sure to wash your underarms and groin.
- If you were using a 4% chlorhexidine gluconate (CHG) solution antiseptic skin cleanser (such as Hibiclens®) while in the hospital, use it at home until your CVC is taken out.
- If you still have a CVC, cover the dressing with a one-time-use waterproof cover, such as Aquaguard®. You can buy waterproof covers online. Don't let your dressing soak in water.

Use new cleaning solution and makeup

- You can wear contact lenses, but make sure they're cleaned well before you put them in. Do not reuse cleaning solution. Throw cleaning solutions away when they expire.
- You can wear makeup but buy all new products after your transplant. Do not share makeup with others. Replace your eye makeup every 3 months to lower your

chances of getting an infection.

Take care of your nails and hair

New nails will grow and replace your old nails. This will happen gradually over 3 to 4 months after your transplant. Don’t get a manicure or pedicure in a nail salon until your doctor says it’s OK. You can paint your own nails, but **do not use a nail clipper**. Use a nail file.

Hair usually starts to grow back about 3 months after your transplant. Keep your hair and scalp clean. Don’t use hair products with alcohol or fragrances. They can dry out your hair.

Take care of your mouth

- You may have a dry mouth after your transplant. This raises your risk for infection. It’s important to keep your mouth clean.
- Your care team will tell you when you can start using an ultra-soft toothbrush. This will be when:
  - Your absolute neutrophil count (ANC) is higher than 500 (sometimes called 0.5).
  - Your platelet count is 20,000 (sometimes called 20) or higher.
- Ask your doctor or dentist when you can floss and brush your teeth with a regular toothbrush.
- Use a mouthwash with fluoride (such as Biotene ®) after your mouth has fully recovered and isn’t very dry. Let the mouthwash sit in your mouth for at least 1 minute, then spit it out. Don’t rinse.
- Tell your care team if you notice any sores, white patches, or bleeding in your mouth or on your lips.

Caring for your CVC

It is just as important to keep your CVC clean at home as it was in the hospital. Your nurses will teach you how to care for it at home. You’ll have a chance to practice with them.

Food and nutrition after your transplant

You can slowly go back to eating your normal diet when you leave the hospital. This will take time. Your tastebuds and the lining of your stomach and intestines were affected by your treatment. This means foods may taste different.

It’s important to be extra careful to avoid foodborne illnesses (food poisoning). Foodborne illness is when you get sick from bacteria, viruses, or parasites on foods. How you prepare food is extremely important. Read *Eating Well After Your Stem Cell Transplant* (www.mskcc.org/pe/eating-well-sct) to learn how to safely prepare food and how to get enough calories and proteins in your diet. Talk with your clinical dietitian nutritionist to learn more.

How to take care of yourself outside your home

Take regular walks outside but avoid dirty areas and construction sites. Walking is an excellent way to build up your strength.

During the first few months after your transplant, avoid places with a lot of people, such as:

- Supermarkets
- Shopping malls
- Movie theaters
- Schools
- Places of worship, such as churches, synagogues, and mosques
- Restaurants
- Public transportation
- Concerts
- Sports events
- Block parties

When you must be in a public place, such as a hospital or clinic, wear a mask and gloves. Carry a mask with you at all times.

Talk with your care team about how long you’ll need to follow these precautions.

Protect yourself from the sun

Your skin will be more sensitive and may burn more easily after your transplant. The medicine you’re taking may add to this. You may also have a higher risk of getting graft versus host disease (GVHD) or melanoma. Being in the sun for a long time may also reactivate cold sores or fever blisters.

Whenever you’re in the sun, protect your skin with a sunblock that has an SPF of at least 30. Reapply it often.

Limit your time in direct sunlight. If you'll be in direct sunlight for 20 minutes or more, wear a hat and clothing that protects the skin.

Swimming

Do not swim if you have a CVC. If you do not have a CVC, your doctor will tell you when it's OK to swim or use a hot tub. This is based on how strong your immune system is.

When you can swim, pay attention to alerts about beaches from local health departments. Do not swim if the water has a high bacteria count. If you swim in a pool, make sure the water is chlorinated.

Going back to your activities

Daily activities

The time it takes to recover after a transplant varies. It usually takes about 3 months, but it's also normal to take more or less time.

The time after your transplant is a time of cell recovery and growth. The cells in your mouth, stomach, intestine, hair, and muscles will all regrow. Your bone marrow will grow. This takes a lot of calories and energy. You may feel more tired than you expected. Remember, this fatigue and weakness is common. Each week, you should feel stronger.

Around the 3rd month after your transplant, you may feel well enough to start going back to your usual level of activity. From this point on, you'll probably feel better and better every day. But most people are still recovering during the first 6 months to 1 year after their transplant.

Staying active

It's important to exercise, play, and stay active after your transplant, but be careful. Avoid activities that may cause bleeding or bruising until your platelet count is over 100,000. This includes weightlifting, contact sports, riding a bike or scooter, or jumping in bounce houses.

Remember to wear a helmet once you can safely ride a bike or scooter.

You should also avoid activities that may get you dirty, such as gardening or playing in sandboxes.

Traveling

Talk with your care team if you plan to travel out of the country for the first few years after your transplant. You may need to get certain vaccines to travel to some countries. You may also need to take medicine to prevent infections, such as diarrhea or malaria. Visit www.cdc.gov/travel to learn more about infection prevention when traveling.

Hobbies

Some hobbies, such as woodworking, painting, and model building, use products that can be toxic. Always work in a room with plenty of fresh air. Keep windows open. Use nontoxic paints and glue. Talk with your care team if you have questions about what hobbies are safe to keep doing.

Going back to school or work

Your doctor will tell you when it's safe to go back to school or work based on how strong your immune system is. Your teacher in the hospital can help connect you with a tutor so you don't fall behind in school.

Your care team is here to talk with you about going back to school or work. You can speak to a social worker, nurse, psychiatrist, or your doctor. We can work with you to find ways to make your transition easier.

About your follow-up care

Your follow-up visits will be scheduled before you leave the hospital. You will have your follow-up visits in the Pediatric Ambulatory Care Center (PACC). You can get there from the main hospital lobby at 1275 York Avenue. Take the B elevators to the 9th floor and check in at the desk.

You'll have a follow-up visit at least 2 times a week for the first few months after your transplant. If you're doing well, your appointments will be scheduled further apart. You may find it helpful to bring a list of questions that may have come up since your last visit.

Bring your medicine list with you

Bring the medicine list your care team gave you and all your medicines to your first follow-up visit. After that, you can just bring your medicine list, unless you were prescribed a new medicine. If you were prescribed a new medicine, bring it with you. Your care team will go over your medicine list with you at every visit.

If you're taking medicine that requires levels (such as cyclosporine (such as Gengraf

®, Neoral ®, Sandimmune ®), tacrolimus (such as Protopic®), or sirolimus (such as RAPAMUNE®)), **do not take the medicine before your appointment**. Bring it to your appointment. You can take it once the nurse has taken your blood level.

Refilling your medicine

Always check how much of each of your medicines you have before each appointment. If you need any refills, call the pharmacy where you got your medicine from. If you do not have any refills left on your prescription, your doctor will give you new prescriptions during your visit. We will try to fill your prescription at our MSK pharmacy. Some insurance companies may want you to pick it up from your local pharmacy instead.

These are the phone numbers for the most often used pharmacies:

- MSK Outpatient Pharmacy (OPD): 646-888-0730
- Natures Cure: 212-545-9393
- Cherry’s Pharmacy: 212-717-7797

If you need refills between visits, call the week before your medicine is about to run out. Try to avoid calling Friday afternoon or during the weekend. Many pharmacies are closed at night or may not have the medicine that you need in stock.

What to expect at your follow-up visits

Blood tests

During your follow-up visits, you’ll have blood tests to check your blood counts, electrolyte levels, and liver and kidney function. You may also have a blood test to check the medicine levels in your blood.

IV treatments

You may need to have intravenous (IV) treatments, such as antibiotics and blood transfusions. If you do, your care team will tell you:

- Why you need them.
- How long you’ll need them.
- How often you’ll need them.

These appointments will usually be scheduled on the same days as your follow-up visits.

Bone marrow aspiration

Bone marrow aspiration is a procedure where your healthcare provider takes a small sample of your bone marrow. Your bone marrow has many stem cells in it. Your healthcare provider will check your stem cells to see how you're responding to your stem cell transplant.

Your care team may recommend you have a bone marrow aspiration done 1 month and another 1 year after your transplant. How often you need a bone marrow transplant depends on your treatment plan.

Spinal taps after treatment for acute leukemia

If you had a transplant to treat acute leukemia, you may need to get a spinal tap (also called lumbar puncture) once a month after your platelets recover. This is especially true if you had or are at risk of getting leukemia in your spinal fluid.

A spinal tap helps your doctor send chemotherapy into your spinal fluid. In children, this is generally done under short-term anesthesia. This chemotherapy won't give you side effects such as low counts, hair loss, or nausea or vomiting. To learn more, read *About Your Lumbar Puncture* (www.mskcc.org/pe/lp).

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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Yes
○ ✓
Somewhat
○ ✓
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