After Your Blood and Marrow Transplant

University of Michigan
C.S. Mott Children’s Hospital

Pediatric Blood and Marrow Transplant Program Patient Guide
Post Transplant Information for Patient

Discharge Planning
The transplant procedure is very intensive and will continue to affect your child and their activities for some time. The following instructions are very important to follow. Your child will follow these guidelines for a minimum of 100 days following transplant, possibly longer in some cases. Your child's doctor will let you know when each of the restrictions and precautions can be stopped. This will vary for each patient.

In general, we follow allogeneic transplant patients in the transplant clinic one to two times a week immediately after discharge. The frequency of future appointments will depend upon how your child is doing. We see autologous transplant patients approximately two times after discharge before they return to the care of their referring doctor.

It is important to return to the clinic for appointments after transplant. In the beginning, appointments will be quite frequent; they will become less frequent as your child recovers, regains his strength, and is less likely to have severe complications. Do not hesitate to contact the clinic or your doctor if you think we need to see your child between scheduled appointments. Even after your child returns to their referring doctor, we are available by phone or appointment.

The transplant team is always available to assist with your child's discharge plan and care after transplant. This section of the handbook will answer many of the questions you have about this phase of transplant. If you have further questions please call the transplant clinic.
Precautions and Restrictions

Your child needs to follow several precautions and restrictions in order to prevent infections and bleeding. Your child’s bone marrow needs time to mature before it is fully recovered. Until that time, there are things to watch for and help prevent. These restrictions will lessen over time, as your child's bone marrow and immune system become fully functioning.

Your child's immune system may remain weak for an extended time period following your transplant. In autologous transplants, it often takes 3-6 months before the immune system fully recovers. In allogeneic transplants, it can take one or more years to fully recover. Even though your child can return to an active life at some point following transplant, it is important that she remains cautious and reports a lingering illness to the transplant team.

Masks

Your child will continue to wear a mask when you come to the hospital for your visit because of the construction around the hospital. A mask will not protect your child from someone who is sick. For this reason your child will need to avoid crowds and public places when he is first discharged. A mask is not necessary when your child is at home or out for a walk.

People

Avoid close contact with anyone who is ill. Avoid crowded areas, especially during cold and flu season. Stay away from anyone who has been exposed to a communicable and/or childhood disease. Even children who have had the specific disease are still at risk after a transplant.

Pets and Animals

Household pets can remain in the home, with the exception of birds and reptiles. Avoid all contact with birds or reptiles and their droppings; they carry many infections. Avoid contacting animal waste. Do not kiss or hug animals. Do not come in close contact with outdoor or farm animals.

Plants and Flowers

Plants and flowers can remain in the home. Avoid gardening, mowing the lawn.
and other activities that stir up soil or the ground. Avoid handling fresh-cut flowers in vases; the water can carry large amounts of bacteria.

**Travel**
Notify your child’s doctor before you travel. In general, your child needs to avoid swimming in lakes, public pools and sitting in hot tubs because of the possibility of exposure to excessive bacteria. Your child’s skin will be very sensitive to the sun. Do not plan a vacation with prolonged exposure to sunlight. Your child may be surprised at the time it takes to regain their pre-transplant energy level and it may be wise not to plan an extended vacation until you see how your child’s recovery progresses.

**Avoiding infection sources**
It is important for your child to avoid infection or items that might carry infections. Stay away from dusty, dirty, moldy things (construction areas, remodeling areas, vacuum cleaner bags, etc.) and standing water (flower vases; vaporizers, de-humidifiers, etc.). Also avoid things that might irritate the lungs such as aerosol spray cans and smoke filled areas. If you are not sure if a specific activity is safe, it’s best to avoid it until you can clarify it with your doctor.

**Sexual Activity**
Sexual activity of teenagers is a sensitive topic. Our doctors are comfortable talking with you and your child about sexual issues and concerns.

**Physical Activity**
It is important that your child keeps up with the activity program the physical therapist outlined for him in the hospital. Remaining active will keep the lungs stronger and help to avoid infections in the lungs that may occur after the transplant. Outdoor activity such as walking is good for your child. Remember to avoid construction areas or anywhere dirt or soil is being moved, as this increases the risk of developing a fungal infection in the lungs or sinuses. Your child may tire easily at first. This is normal after returning home. Try to build endurance slowly; space out activities, do lighter tasks at first and schedule rest periods into the day’s activities. Avoid exhaustion and
fatigue. It could be up to a year before your child regains her energy level.

**Siblings**

It is important to let your childrens’ school know that you must be notified of communicable diseases like measles, chicken pox, etc. Notify your doctor immediately if siblings are exposed to one of these illnesses.

**Driving**

Patients are not able to drive for around three months following transplant. This period may be shorter for patients receiving their own stem cells. The decrease in energy level could lead to a decrease in the reflex time necessary for safe driving. Also, your child may be taking medications that may impact reflex time and make it unsafe to drive a car. Talk with your transplant team before your child returns to driving to make sure it is safe.

**Returning to Work or School**

Your child’s return to school will depend on the type of transplant they receive and how their recovery proceeds. For the first 100 days after transplant, your child will not return to school (these are examples of public places referred to earlier). Patients receiving autologous transplants can expect to return to school sometime after 100 days. Patients receiving an allogeneic transplant can expect to stay away from school for up to a year, but this is not always necessary and some patients with uncomplicated transplant courses can go back to school as early as 6 months after transplant. These are general rules. Remember that every patient is different and your doctor will make decisions based on your child’s physical condition and the school environment.

**Reimmunizations**

Because the transplant impacts the immune system is so intensely, it may longer “remember” the childhood vaccinations your child received before the transplant. For this reason your child will be re-immunized transplant. We will discuss this with you at the appropriate post-transplant return visit, but in general most patients start revaccination around 6 to 12 months after transplant. It is possible to make arrangements with your child’s pediatrician or family doctor to give the necessary vaccines to your child.
Your child will not be able to receive a flu vaccine for 6 months after transplant, but it is very important that any family members and people that they are in close contact with receive the vaccine.

**Diet**
Loss of taste and appetite are common after transplant. Talk to our dietitian if your child is having problems eating a diet with enough calories and protein.

Eating a well-balanced diet after transplant is important to help regain strength and rebuild the normal tissues affected by chemotherapy. Patients must practice good food safety guidelines. Autologous transplant patients do not have to follow a special diet following discharge from transplant.

Following an allogeneic transplant, your child may initially need to follow a “strict low bacteria” diet often called a modified microbial diet or a neutropenic diet. Until their immune system is strong enough (approx. 100 days after transplant), it will be necessary to follow the general guidelines listed below.

**General Food Guidelines after Transplant:**
1. Use common sense in dealing with food.
2. Check expiration dates on perishable food.
3. Check for mold or insect contamination.
4. Do not keep leftovers longer than two days.
5. Discard questionable items.
6. Keep foods at proper temperature.
   - Keep cold foods such as milk and dairy products, in the refrigerator.
   - Keep hot foods hot, not served at room temperature.
   - Portion food into individual servings in a tightly sealed container and cool in the refrigerator or freezer.
   - Thaw frozen foods appropriately either in the refrigerator, microwave on defrost, or by running cold water continuously over meal until thawed.
- Do not thaw food at room temperature.

7. Avoid deli lunch meat or cheeses that are not pre-packaged.
8. Avoid smorgasbords and salad bars.
9. Discard leftovers after two days.
10. Process well water through a filter or tested by the health department.

11. Fruits and vegetables must be washed thoroughly. Cut off bruised areas. Do not eat fresh strawberries, fresh raspberries, raw broccoli, raw cauliflower or sprouts. In general, it is best to avoid uncooked fruits or vegetables that cannot be peeled before eating. Frozen or canned berries are okay.

12. Avoid rare and medium-rare meats.

13. Avoid deli salads not prepared in the home.

14. Do not share eating or drinking utensils.

15. Avoid juices, honey and dairy products that are unpasteurized or gently pasteurized.

16. Your child should take a daily multi-vitamin supplement until her appetite returns to normal. It is not necessary to take large doses of vitamins and minerals, as this may be dangerous as well as expensive. Select a simple, inexpensive, daily multi vitamin without iron, unless advised by the doctor.

17. Notify the doctor if your child develops difficulties eating, swallowing or tolerating food.

Hygiene

It is important to continue routine daily hygiene at home. Remember, frequent hand washing is the best protection against infection. The following are specific guidelines for daily care that will help prevent infections and assist your body in its recovery. Monitor these areas closely and notify your child’s doctor if you notice changes or have concerns:

**Mouth care:** Continue the mouth care regimen practiced in the hospital. If you notice bleeding or if your platelet count is low, use a soft-bristle toothbrush (run hot water over your toothbrush). Notify the doctor if you notice sores, tenderness or other changes in your child’s mouth or
throat. Notify the doctor of plans for dental work. Schedule a dental follow-up visit at six months after transplant.

**Skin care:** Continue good daily hygiene using a mild soap. Your child’s skin is drier than normal. Your child’s skin will be extremely sensitive to the sun. They must always wear a hat and sunscreen with a minimal Sun Protective Factor (SPF) of 30. Remember to use sunscreen on exposed areas, whenever your child is outdoors (even if it’s not sunny).

**Rectal care:** This area will continue to be very sensitive and require special attention. Keep this area very clean, cleanse after every bowel movement. Notify the doctor if you notice pain or tenderness when your child has a bowel movement or other changes in this area. Do not use suppositories or enemas unless your doctor advises you to do that.

**Venous access devices:** Continue to care for your venous access device and the dressing around or over it as instructed in the hospital. Observe the area around the catheter during dressing changes for redness, tenderness, drainage or changes in appearance. Notify the doctor if changes occur.

**Cuts/bruises:** Cleanse all cuts and scratches carefully with a mild soap and water. Keep them covered with a bandage until healed and notify the doctor if the area becomes reddened, tender, sore, develops drainage, or if your child develops a fever. Increased bruising may indicate a decrease in the platelet count. If you notice bruises beginning to develop for no apparent reason, notify the doctor.

**Outpatient Transfusions**
Until your child’s bone marrow is fully recovered, he may need to receive red blood cell and/or platelet transfusions as an outpatient. After receiving a transplant your child can only receive irradiated blood products.

Fever/chills or hives/itching are relatively common reactions to blood transfusions and may occur with the transfusion of blood products. These
symptoms usually occur during or shortly after transfusion. On rare occasions, these symptoms may be noted several hours after the transfusion.

You will receive post-transfusion instructions regarding the signs and symptoms of a transfusion reaction. Notify the doctor immediately if these signs or symptoms occur following your transfusion.

**When to Notify the Doctor**
The following are general rules for notifying your child's doctor. If you are unsure of symptoms or have concerns about something, call your child’s doctor. The transplant team remains available to you after your child’s discharge for medical assistance or to answer questions. Call them at 734-936-9814.

**Notify the doctor for the following:**
- Fever (over 38° C; or 100.4° degrees Fahrenheit)
- New cough, shortness of breath
- Persistent headaches
- Blurred or double vision
- Bleeding (nosebleeds, blood in the stool or urine, vomiting blood, increased bruising or other bleeding)
- Pain during urination or bowel movements
- Reddened, swollen or painful areas
- New diarrhea, constipation or vomiting
- Difficulty swallowing or development of mouth sores
- Changes in your venous access device or the area around it
- Fever/chill or hives/itching following a blood transfusion
Medications

Prescribed medications
Your child will be discharged on several prescription medications. It is common to be discharged with supplements, such as potassium or magnesium that your child will need for several days to a few weeks. Medications for nausea and vomiting may be needed until your child's appetite returns and she resumes regular eating habits. Your child may also need to take oral antibiotics to prevent or treat infection. If your child receives an allogeneic transplant, they will take an immunosuppressive (such as steroids, Tacrolimus, Cyclosporine, Mycophenolate) for six months, or even longer, if they develop graft versus host disease.

It is a good idea to use only one pharmacy at home. They will have your child’s complete records, can advise you on prescriptions and will communicate with the doctor.

"Over The Counter" Medications

Colds/Flu
Your child will be prone to colds and flu for several months after discharge. At the first sign of the illness, call the doctor. If he or she suggests that you take an over-the-counter medication, select a product with no aspirin. Aspirin can alter platelet function, which may cause bleeding. Products that contain acetaminophen or ibuprofen may mask a fever. Do not give these products to your child unless your doctor or clinic nurse approves.

Be sure to read the labels of all your child's medications or ask your pharmacist or doctor to suggest a product that does not contain aspirin. Products containing antihistamines and/or nasal decongestants are best to use for colds or flu.

Avoid decongestant nasal sprays. These can be very irritating to the nasal tissues. Nasal sprays of this type are very short-acting and can do more harm than good.
A persistent cold or flu could be a sign that your child may have a sinus or lung infection that requires an antibiotic. If symptoms persist for more than four days, contact your doctor promptly. If your child is feeling ill, remember to take their temperature frequently (several times a day and whenever they feel warm). Notify your doctor immediately if their temperature is above normal.

**Pain**

Minor aches and pains are normal after discharge. If pain becomes worse or persists, discuss it with the doctor. Pain may be a sign of infection.

If your child needs pain medication, choose one that does not contain aspirin or ibuprofen. Aspirin and ibuprofen products can alter platelet function and increase risk for bleeding.

Your child may take acetaminophen (Tylenol) for minor aches and pains if your doctor approves. Acetaminophen can mask a fever so you must get approval from your doctor or clinic nurse before you give this medication to your child. Many cold and flu products contain acetaminophen. Read your labels carefully.

**Stomach Distress**

Chemotherapy can cause damage to the mucosa of the mouth, esophagus, stomach and intestines that may take a few days to several weeks to completely heal. It is common for the nausea and vomiting to persist for some time after the transplant. Your child may need medication at home for nausea. Over-the-counter antacids can be quite effective in relieving the discomfort, but use them cautiously, especially if your child is taking other oral medications. Antacids "coat the stomach", so they can prevent some medications from being absorbed. Take them at least two hours before or after other medications. If you have specific questions about drug interactions with antacids and medications you are taking, discuss them with the pharmacist, doctor or nurse.

**Diarrhea**

Diarrhea is often a problem during hospitalization and may not resolve totally until your child returns home and resumes their normal activities. You may use
some over-the-counter products that are effective for mild diarrhea. New onset diarrhea, or persistent diarrhea can be a sign of an infection, graft versus host disease or other problems. If your child has severe diarrhea or diarrhea that does not stop even with over-the-counter products, contact the doctor.

For more information and other patient and family resources, visit http://www.mottchildren.org.