
Stem Cell Transplant Discharge Education



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Goals

- **When you have finished reading this material you should...**
 - Understand your risks for infection and ways to prevent infection.
 - Know what to expect after discharge.
 - Identify signs and symptoms of Graft vs. Host Disease and understand common treatments
 - Identify your medications, their purpose and common side effects.



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Risks of Infection



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Risks of Infection

- **Why do stem cell transplant patients have an increased risk of infection?**
 - The transplant regimen (chemo and/or radiation) destroys the white blood cells, including T-cells. The body needs T-cells to recognize what belongs to the body and what does not, including viruses, bacteria, fungi and parasites.
 - Transplant medicines like Cyclosporine can affect the white blood cells ability to fight infection.



Risks of Infection

- **When will T-cell function and ability to fully fight infection return?**
 - Autologous transplant (Stem cells from self)
 - WBC count returns in 10-14 days
 - T-cell function usually returns in 6 to 9 months.
 - Allogeneic transplant (Stem cells from another person)
 - WBC count returns in 14-28 days
 - T-cell function usually returns in 9 to 12 months



Risks of Infection

- What can cause infection?
 - Self
 - Others
 - Environment



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Risks of Infection

- Where do infections arising from self come from?
 - Bacteria in the mouth
 - Bacteria on the skin
 - Bacteria in the GI tract (stomach and intestines)
 - Viruses that are dormant (sleeping) in the body may reactivate: Herpes (common cold sore), shingles, CMV, EBV (mono)
 - Yeast



Prevention of infection from Bacteria in the Mouth

- Mouth care daily with an approved product, such as Chlorhexidine (Peridex)
- Use an ultrasoft toothbrush.
- Toothettes should be used if bleeding occurs or if the platelet count is less than 20,000.



Prevention of infection from Bacteria on the Skin

- Bathe daily unless advised otherwise
- Lubricate skin with fragrance free product, such as Lubriderm, Aquaphor or Eucerin
- Change central line dressing weekly or more frequently if wet, loose or soiled.
- Talk with your nurse about the current policy on changing your central line caps.
- Remember diligent and careful line care is a very important way to prevent infection in your child.



Viruses that are dormant in the body may reactivate

- Herpes Simplex I and II viruses cause a painful small, blistering rash in the mouth and throat (cold sore) or genital area.
- Shingles is a small blistering rash from the virus that causes chicken pox. It may cause pain and itching.
- Cytomegalovirus (CMV)
- Epstein-Barr virus (EBV): the cause of mono.



Prevention of infection from Bacteria in the GI tract

- Infections can come from bacteria normally found in the GI tract (stomach and intestines).
- Antibiotic use may change the normal bacteria in the stomach and intestines.
- Bacteria can enter the bloodstream through the GI tract.



Prevention of infection from Yeast

- Overgrowth of yeast may occur on the skin or mouth.
- Especially common in moist, warm areas such as the mouth and diaper/genital area.
- A yeast infection in the mouth is called thrush and looks like small white patches on the inside of the cheeks and on the tongue.
- A yeast infection in the diaper area produces a red bumpy rash.
- Medications like fluconazole help prevent these types of infection.
- Regular bathing and keeping diaper areas dry will also help prevent yeast from overgrowing.



Infections Arising from Contact with other People

- Most viruses are spread by contact.
- Good hand washing is important in decreasing the spread of viruses and other infections.
- Avoid all crowds and wear a mask if being in a crowd is absolutely necessary.
- Limit number of visitors to 2 or 3 healthy people in your home or at Ronald McDonald if you are staying there.
- Avoid people who have been immunized with live viruses such as the flu mist.
- Not able to attend school until T-cell function has returned AND approved by your Physician.



Infections arising from the environment

- Food
- Water
- Animals
- Plants
- Fire
- Soil



Water

- City regulated tap water can be used, but be aware of any water contamination in your area.
- Well water should not be consumed.
- Use only bottled water that has been processed to remove *Cryptosporidium*. (List available)
- Avoid fountain drinks and ice cream from a machine; avoid ice from bulk ice machines



Food

Foods to avoid at home and in restaurants:

- Raw and undercooked meats and fish
- Aged cheeses such as Brie, bleu, sharp cheddar
- Unpasteurized dairy products
- Raw and undercooked eggs
- Raw seeds, nuts, and grains
- Unpackaged items that sit out in open bins
- Herbal and Non-traditional supplements

Reference: Trefilio S. et al, Biol Blood Marrow Transplant 18:1390, 2012



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Food

Tips for Eating Restaurant Food:

- AVOID buffets, salad bars, and places where food can sit out for a long time
- Go to restaurants that are busy-the food will not sit out
- Ask that food is made to order for you/your child: this way it will not have the chance to grow germs.
- Ask that foods be fully cooked. Send it back if it looks undercooked.
- Carry out food should be either eaten or refrigerated within one hour of purchase.
- *****You must be cleared by your doctor or nurse practitioner to go to restaurants while you are in isolation from large crowds, until then follow the carry out guidelines*****



Food

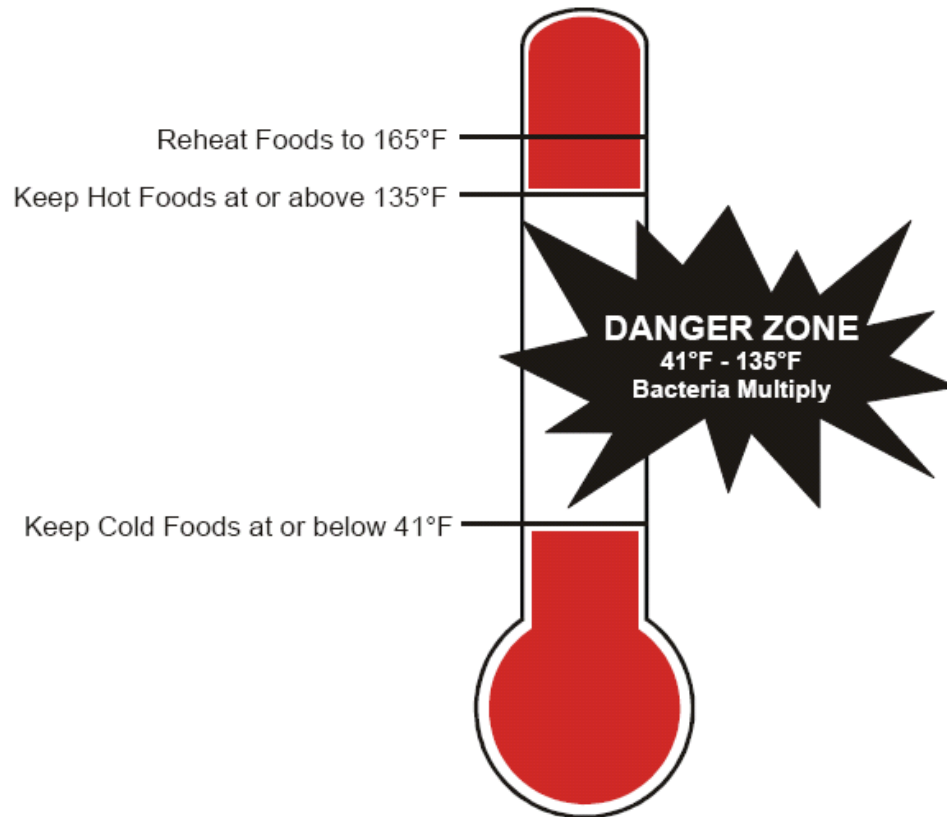
- Remember the Four Tips for Food Safety
 - 1. **Clean:** wash hands, utensils, and surfaces well
 - 2. **Separate:** raw meat, poultry, and seafood from other foods in your refrigerator; if possible use separate cutting board for raw meats
 - 3. **Chill:** refrigerate perishables and prepared foods, thaw food in refrigerator not at room temperature
 - 4. **Cook:** Always use a food thermometer to ensure it is cooked thoroughly, when cooking in a microwave oven, make sure to cover, stir, and rotate
- For more safe food handling tips,

Visit: www.fightbac.org; www.foodsafety.gov; www.cdc.gov/foodsafety.



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Keep Hot Foods Hot & Cold Foods Cold

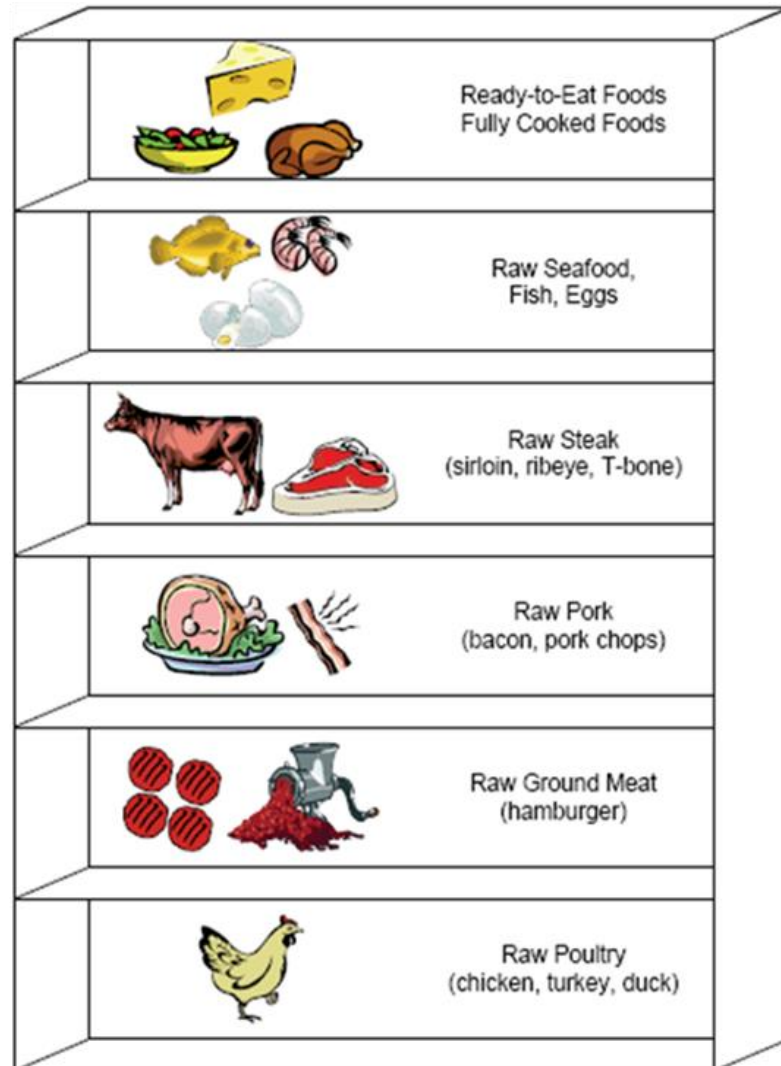


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Food

Refrigerator Organization

- To prevent dangerous cross-contamination, stack foods top to bottom as shown



Animals

- No bathing animals or clean up of animal waste.
- No reptiles (lizards, turtles or iguanas)
- Cats and dogs should not be hugged or kissed. Patient should not sleep with pets
- Birds should not be kept in the house.
- Wash hands after ALL animal contact.
- Fish tanks must have a filter and be kept in a room away from the patient.



Plants

- No live Christmas trees or other live plants or flowers.
- Avoid dried plants and flowers.
- Avoid outdoor leaves, especially blowing or wet leaves.
- Do not rake leaves.



Fire

- Avoid open fire pits, bonfires
- No wood-burning stoves



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Soil

- Avoid construction areas.
- Avoid fields with blowing dirt.
- Do not play in sandboxes.
- No gardening.



Hand Washing

- Remember an important and simple way to prevent infection is good hand washing.
- Encourage anyone coming in contact with your child to wash their hands.
- Ways to wash your hands are with soap and water for 30 seconds or hand sanitizer.
- Examples of times you should wash your hands are before eating, after using the restroom, after sneezing or coughing, before handling food and medications.



Discharge from the Hospital



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Discharge from the Hospital

- Home vs. Ronald McDonald House
- Visits to Riley Outpatient Center,
Hematology/Oncology MSA 3 (3rd floor)
- Transfusion Needs
- Reasons to Call the Nurse Practitioner or Physician
- School



Ronald McDonald House

- Patients and caregivers who live more than 30 to 45 minutes away are asked to stay at the Ronald McDonald House until blood counts and oral intake are stable.
- Social Work will help you make these arrangements, as well as, finding resources for funds if loss of work becomes an issue.



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Visits to Riley Outpatient Hem/Onc - MSA 3

- Initially patients are seen 2 to 3 times per week in the outpatient MSA (clinic).
- Patients should wear a mask on the hospital campus and while in waiting rooms and hallways.
- Try to sit away from others in crowded waiting rooms.
- Masks may be removed once in clinic rooms and doors should be kept shut.



Transfusion Needs

- Patients will often need transfusions of red blood cells or platelets until their stem cells make adequate levels on their own.
- These transfusions will usually be in the outpatient MSA (clinic) or the emergency room (ER) if problems occur at night or over the weekend.
- Blood counts will initially be checked 1 to 3 times per week depending on a patients need.
- Visits to the outpatient MSA may take several hours depending on the need for transfusions, IVIG, pentamidine, etc.



Reasons to Call SCT Nurse Practitioner or Physician

- Fever greater than 100.5°F (38°C)
- Shaking chills, sweating or flushed skin
- Bleeding
- Cough, chest pain or shortness of breath
- Pain, redness or swelling
- Diarrhea (more than 4 stools per day), severe nausea or vomiting
- Rash or any changes in skin appearance
- Painful or dry eyes, or blurred vision
- Inability to swallow or keep down oral medications
- New mouth sores



School

- After stem cell transplant, patients will not attend school until their T-cell function returns and it is approved by the physician.
- Social Work is available to help work with the school to set up homebound instruction and help if the patient has difficulty with isolation or depression.



Graft-Versus-Host Disease (GVHD)



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Graft-Versus-Host Disease

- What is graft-versus-host disease (GVHD)?
- What are the signs and symptoms?
- How can it be treated?



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What is graft-versus-host disease?

- Graft-Versus-Host Disease (GVHD) occurs when the donor cells see the recipient's cells (cells in the patient's body) as foreign and attacks them.
- The parts of the body commonly affected are the skin, liver, bone marrow, and GI tract (mouth, stomach and intestines).



What are the signs and symptoms of GVHD?

- Skin: bumpy, red rash that may begin on the chest, back, hands and feet, mild itching.
- Liver: yellowing of the skin and eyes (jaundice), abnormal liver tests.
- GI: nausea/vomiting, crampy abdominal pain and diarrhea with mucous and blood
- Bone marrow: decreased blood counts.



How is GVHD be treated?

- Drugs such as Prednisone and Cyclosporine are used to suppress the immune system
- If the patient is already on these medications, additional medications may be used, such as MMF, Infliximab and FK506.
- New research trials are being developed to treat GVHD.
- Patients should avoid exposure to the sun because it can activate skin GVHD. Use of sunscreen is very important.



Medication Module

Your child may be on other medications. The following is a list of medications we wanted to ensure you learned about!



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Cyclosporine

- Cyclosporine (CSA) suppresses the immune system to prevent graft-versus-host disease (GVHD).
- This medication will make your child more susceptible to infections.
- Steady drug levels are very important.
- Take this drug at the scheduled times twice per day.
- Hold the morning dose on clinic appointment days until drug level is drawn.
- A side effect of increased hair growth, especially on the face, is common but will gradually return to normal as the medication is tapered.
- Other side effects are high blood pressure, tremors, and kidney damage
- Make sure your pharmacy gives you Neoral or Gengraf brands
- Do not dilute or mix this medication with other liquids



Tacrolimus

- Tacrolimus (Prograf, FK506) is a medication used to prevent graft-versus-host disease (GVHD).
- This medication will make your child more susceptible to infections.
- Steady drug levels are very important.
- Hold the morning dose on clinic appointment days until drug level is drawn.
- Taking this medication on time each day and on an empty stomach is very important.
- Do not take within 2 hrs of any antacids.
- Common side effects are high blood pressure, tremors, kidney damage and sun sensitivity.



Mycophenolate

- Mycophenolate (CellCept, MMF) is a medication used to prevent graft-versus-host disease (GVHD).
- This medication will make your child more susceptible to infections.
- Taking this medication on time each day and on an empty stomach is very important.
- Do not crush, open or mix capsules or administer within 2 hrs of antacids.
- Common side effects are nausea/vomiting and stomach pain.



Prednisone

- Prednisone suppresses the immune system to prevent graft-versus-host disease (GVHD).
- This medication causes stomach upset and should be taken with food or milk.
- Side effects of increased blood pressure, increased appetite, and weight gain, as well as a “moonface” are temporary and will decrease when the medicine is gradually tapered.



Fluconazole

- Fluconazole (Diflucan) is a medication to prevent or treat yeast and fungal infections.
- This medication is taken daily.



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Acyclovir

- Acyclovir is a medication to prevent or treat viral infections, such as chicken pox and herpes simplex.
- Drinking plenty of fluids is important while taking this medication.



Septra

- Septra (Bactrim) is a medication used to prevent pneumonia (*Pneumocystis jiroveci*) which can occur in patients whose immune systems are compromised.
- Septra should be taken twice daily for 3 consecutive days per week, such as Friday, Saturday, and Sunday.
- Allergic reactions may occur.
- Contact your physician immediately if you have difficulty breathing, wheezing, hives, itching or difficulty swallowing.



Pentamidine

- Pentamidine is a medication used to prevent pneumonia (*Pneumocystis jiroveci*) for patients that are allergic to Septra or with low blood counts.
- This medication is usually a monthly intravenous (IV) infusion.
- Nausea is a common side effect, and Zofran or Kytril may be given before the infusion if this occurs.



Amlodipine

- Amlodipine is a medication to help lower blood pressure.
- This medication should be taken at the same time each day.
- Headache, dizziness and flushing are common side effects.



Intravenous Immune Globulin

- Intravenous immune globulin (IVIG) is an IV infusion of antibodies to help prevent viral and bacterial infections.
- Common side effects include chills, fever and nausea.
- Antibody levels (IgG) will be monitored to evaluate whether this infusion is necessary.



Questions? We are here for you!



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Contact Information

Pediatric Stem Cell Transplant

Call 911 for Emergencies

- Appointments: **317.944.2143**
- Questions: (8am–4:30pm) **317.944.2143**
- Nights and Weekends: **317.944.5000**
 - Ask for the PEDIATRIC Stem Cell Transplant Physician on call



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References

- Indiana University Health Pediatric Stem Cell Transplant Standard Operating Procedures
- Riley Pediatric Stem Cell Transplant Parent & Patient Education Book
- Lexi-Comp's Pediatric Dosage Handbook: 15th Edition
- Crowe, K. *Me and My Marrow*. (2010). Astellas Pharma US, Inc.



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