



Safe Living After Hematopoietic Cell Transplant



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Introduction

Congratulations on your hematopoietic cell transplant otherwise known as stem cell transplant. Transplant patients are at higher risk for infections. This is because of the chemotherapy they receive before transplant and the medicines they take to help prevent graft-versus-host disease (GVHD). GVHD weakens how your immune system fights infections caused by germs. Although you cannot prevent all infections, many can be. This booklet was written by the Infectious Disease Host Defense Program (ID HDP) doctors so you have the information you need to live a safe and happy life after transplant.

Preventing infection: why it is important

The end goal of a stem cell transplant is that your new immune system, from the donor, will take over and be fully functioning. It should recognize your body as its own and any new germ as an intruder. This is what a normal immune system does each day.

When having a stem cell transplant, you will have a period where your white blood cell count will be very low. This is called **pre-engraftment**. During this time, it is hard for your body to fight off germs. Even after the white blood cells come in, called **engraftment**, it will take a very long time for your new immune system to be normal – 2 years, if everything goes according to plan.

Sometimes after a stem cell transplant, the new immune system incorrectly recognizes your body as an intruder. This is called **graft-versus-host disease** (GVHD). Medicines that are given to help prevent GVHD suppress your immune system - this gives your new immune system time to learn your body. These medicines are stopped over time if you do not have any signs or symptoms of GVHD. If you develop GVHD, you may receive more medicines that suppress your immune system.

How it all ties together

Infections and GVHD go hand-in-hand. If you develop GVHD, will get you more medicines to suppress the immune system. This leads to an increased risk of infection. If you develop an infection, your immune suppression medicines may need to be decreased, and this could increase your risk of GVHD. It is a fine balance.

Your transplant team chose the best donor possible to decrease your risk of GVHD, however the risk of GVHD still exists. In the course of your transplant, we do our best to keep your risk of infection low, but we cannot prevent infections entirely. There are many other factors beyond our control, and we need your help to protect yourself from infections.

Control exposures

Think about it this way: if we can minimize your infections, in part by controlling your exposures, you can stay on your roadmap with your GVHD medicines. This means you are weaned from your medicines on the planned timeline. This lowers your risk of infection. In this way your immune system gets as close to normal as fast as it can. This is why infection prevention is so important.

The immune system

The job of the immune system is to protect us against infections. It is our body's defense against the germs that surround us each day. Children, teens, and young adults who have weakened immune systems are immunocompromised. This means their body cannot respond normally to an infection. This makes them at greater risk for infections caused by germs, including bacteria, viruses, fungi, and parasites. Infections in immunocompromised patients can also be more severe for these reasons.

Other factors that increase your risk for infection include:

- low numbers of white blood cells. This includes white blood cells like neutrophils and lymphocytes
- inflamed gastrointestinal tract
- having a central venous catheter (i.e., port, central line), or other indwelling lines
- exposures in the environment

Acute and chronic GVHD

There are times when you are at a higher risk for infection:

- the first 6 months after your transplant
- during therapy for possible acute or chronic GVHD, and for 3 to 6 months after treatment
- if your white blood cell count is very low
- if you get other infections for example, cytomegalovirus (CMV)

Medicines that make you immunocompromised:

- calcineurin inhibitors: tacrolimus, cyclosporine.
- mTOR inhibitors: sirolimus, everolimus.
- biologic response modifiers: infliximab (Remicade®), adalimumab (Humira®), abatacept (Orencia®), etanercept (Enbrel®), rituximab (Rituxan®).
- other: methotrexate, mycophenolate mofetil (MMF), leflunomide, azathioprine, mercaptopurine (6MP), ruxolitinib (Jakafi®), eculizumab (Solaris®).
- chemotherapy or radiation.

Your health care provider will prescribe whatever medicine is best for you.

Common signs and symptoms of infection include:

- fever:
 - temperature more than or equal to 101° Fahrenheit (F) 38.3° Celcius (C) or
 - two temperatures more than or equal to 100.4° F (38° C) taken one hour apart.
- vomiting or diarrhea
- cough, trouble breathing
- pain when urinating
- sores on your lips, mouth, throat
- rashes
- wounds that are red, swollen, or have drainage
- the usual signs of infection may be absent in immunocompromised children

Things like rashes, for example, can also be a sign of GVHD. Contact your transplant team right away with any fever or concerning signs and symptoms of infection.

Ways to prevent infection

Some infections are passed from person to person. Other infections happen after eating or drinking contaminated foods or water or from exposures in the home and environment.

Always follow these general prevention tips:

- Wash your hands well with soap and water or alcohol-based sanitizers. This is the best way to prevent infection and spread of many bacteria and viruses. Wash your hands:
 - before preparing or eating food and drink
 - after using the bathroom
 - after sneezing, coughing, or touching your nose, eyes, mouth, or any wounds
 - after touching pets or animals
 - when around other people
- Avoid contact with people who are sick. This includes those who have a fever, cough, runny nose, vomiting, diarrhea, or a rash.
- Take care of central venous catheters sites.
- Do your oral/dental care each day. Go to the dentist two times a year for checkups and cleaning
- If you are very immunocompromised, your health care provider may want you to wear a surgical mask when outside the home.
- Limit contact with animals. This includes scratches, bites, and licks, even from household pets. Do not bring new or exotic animals into your home until your new immune system is back to normal.
- Avoid gardening, construction work, farming activities, and any other activity that may put dust or soil in the air.

Prevent infection—prevent spread

Infections can be spread in many ways, such as contact with the skin, eyes and mouth, eating or drinking, inhalation, or recreational activities.

Spread though contact

Your skin is a barrier to infections. Keep your skin clean and avoid cuts or scrapes. These allow germs to enter which cause infections.

- If you have a catheter, PICC, or port, do not touch it. If you need to touch it, wash your hands before and after.
- Wash your hands often, especially if you
 - touch other people or animals
 - come in contact with human or animal feces
 - change diapers.
 - have cuts or wounds
 - touch plants, soil or dirt
- Do not walk barefoot outside.
- Avoid body piercings and tattoos.
- Keep finger and toenails clean and trim. Avoid putting your fingers in your mouth. No artificial (fake) nails.
- Avoid any injection drug use.
- Avoid uncovered and community sandboxes.
- Use sunscreen with SPF of 30 or more.

Spread through the air

Your lungs come in contact with many different things as you breathe - pollen, dust, and sometimes germs. There are ways to help minimize the germs you breathe in.

- Avoid close contact with people who have any of the following symptoms
 - cough
 - sneeze
 - runny nose
 - red eyes
- Avoid large crowds. This includes malls and sporting events, especially during flu and respiratory virus seasons. In Ohio, this is typically September through March.
- Do not smoke or be around smoke. This includes tobacco, fireplaces, and bonfires.
- Do not use marijuana or be around people who do. Smoking marijuana contains fungal spores (*Aspergillus*) which cause a very serious lung infection.
- Avoid dusty places. It exposes you to fungus. This includes gardening and landscaping, farming and construction (both inside and outside the home), old buildings, wood piles, caves, and chicken coops and bird droppings.
- Stay away from molding food, plants, wood, and hay.

Spread by food

Viral and bacterial infections may be spread through food that is spoiled or contaminated.

- Wash fruits and vegetables with clean water.
- Look at the expiration or sell by dates on products before eating. Do NOT use if the expiration date has passed.
- Do not share utensils, glasses, cups, or food with other people.
- Do NOT eat or drink any of the following:
 - soft cheeses or cheeses with molds like blue cheeses, feta, and queso blanco fresco
 - unpasteurized, raw, milk products
 - fresh pressed and unpasteurized juices or cider
 - foods that contain raw or undercooked eggs, like soft boiled or over easy eggs, cookie or cake dough, Caesar dressing
 - raw or undercooked proteins such as meat, poultry, seafood, fish, and tofu
 - raw fish, sushi, ceviche, seafood, pates, and smoked proteins such as lox or jerky as they are not fully cooked.
 - raw alfalfa sprouts, raw honey, and miso products
 - public salad bars, standing buffets, picnics, or other foods or other foods that may be sitting out at room temperature for some time
 - street food and vending stands
 - deli salads, pates, and cold cuts
 - salad dressings that contain raw eggs or cheeses.
- Avoid cross contamination of raw foods, utensils, cutting boards and other surfaces. Wash each before using again

- Wash hands, utensils and cutting boards often.
- Do not use loose leaf teas such as mate tea. Tea that is commercially packaged is safe.
- Prepackaged foods such as hot dogs or sausages must be fully re-cooked.
- Refrigerate food made at home within 2 hours of cooking.
- Your refrigerator temperature should be less than 40° F (4.4° C). Your freezer temperature should be 0° F (-17.7° C) or below.
- Eat refrigerated leftovers in 1 to 2 days and reheat them to steaming hot temperatures, which means more than 165°F (73.8 °C).
- Let your transplant team know about any food outbreaks in your local area that you may have been exposed to.

Make sure cooked foods have these internal temperatures

- beef and pork more than 165°F (73.8°C)
- poultry more than 180°F (82.2°C)
- seafood more than 145°F (62.7°C)

Spread by water

- Only drink clean water. If there is a local boil water advisory, use bottled water or make sure to bring the water to a full rolling boil for 1 minute and allow it to cool before drinking. Do the same for the water you use for brushing your teeth and bathing.
- If eating at a restaurant, do not put ice in anything you drink.
- Do not drink well water. If well water is the only water in your home, make sure it is screened often for germs, including bacteria and parasites. Use a water filter that removes the parasite *Cryptosporidium*. Filters that are certified to remove *Cryptosporidium* should have the label NSF 53 or NSF 58 plus cyst reduction or cyst removal on them. For more information, refer to the NSF International consumer line at (800) 673-8010 and http://www.nsf.org/consumer/drinking_water/contaminant_cryptosporidium.asp
- Do not drink or swallow water from rivers, lakes, ponds, pools, or water rides.
- If you travel to areas with poor sanitary conditions, do not drink fruit juices or ice sold from street vendors. Only drink bottled water.
- Do not use hot tubs.
- Avoid public pools and water parks for the first year after transplant and whenever possible. The water may be contaminated with human and animal waste. If you have diarrhea, do not use your private pool for 2 weeks after your stools (poop) are back to normal.
- In the bathtub, avoid toys that retain water. Wash toys each week in the dishwasher. Allow them to fully dry between baths.
- Stay away from any standing water in the home, basement, or surrounding properties. These can breed mosquitoes that transmit infections.

Spread by pets and animals

Pets can be an important part of our life. However, there are infections connected with animals.

- For traditional pets like dogs and cats, make sure they are healthy. Get their required check-ups and keep them up-to-date on their vaccines. Use tick and flea prevention. Discuss infection issues with the veterinarian. This includes how to prevent yourself from getting an infection.
- Do not get a new pet for at least the first year after your transplant and during times of increased immunosuppression (e.g., treatment of GVHD). It does not matter if the pet comes from a reliable breeder or from a shelter, the animal can still have infections that you can get.
- Avoid kittens, hamsters, guinea pigs, rabbits, reptiles (i.e. snakes, turtles, lizards, iguanas, frogs), and other exotic pets.
- Do not keep birds in your home. Avoid baby chicks, ducklings, and eggs that are freshly laid.
- Stay away from all stray animals.
- Do not kiss pets or have contact with their body fluids.
- Avoid getting scratched or bitten by your pet. If this happens, wash the area with soap and water and get medical care.
- Stay away from barn or farm animals.
- Do not feed pets raw, contaminated, or spoiled food.
- Do not clean litter boxes or aquariums. Have someone else do this chore.
- Always wash your hands after touching pets or animals.

Spread by insect and tick bites

Mosquitoes and ticks can spread infections that are harmful to transplant patients.

- Prevent mosquito and tick bites. They occur more often during the early spring through early fall months. Wear proper protective clothing, long pants, and shirts with sleeves, and use insect repellent (DEET) when outdoors during these seasons.
- Remove standing water from your property. These are breeding grounds for mosquitoes that carry viruses.

Spread by sporting and recreational activities

- Do not hunt or fish.
- Avoid activities where soil is disrupted and spread into the air like dirt biking and 4 wheeling.

Spread by sexual activity

Infections can be spread during sexual contact. Protect yourself against sexually transmitted infections (STI).

- You are more likely to get an STI if you have more than one sexual partner or if your partner has had other partners.
- You can get the same STI more than one time even if you have been treated for the STI in the past.
- You can get an STI even if you have sex just one time.
- The withdrawal (pull out) method of birth control does not prevent STI's.
- Some patients with STIs may not have obvious symptoms. For example, patients with a history of mouth herpes may not have active lesions but can spread the virus during sex.
- Use a condom every time you have sex, the whole time you have sex.
- Avoid exposure to feces (poop) during sexual activity.

- See your health care provider if you think you have an STI or have had sex with someone that you know has an STI. Some symptoms may include burning or pain when urinating, discharge, burning/pain, or sores from the vagina, penis, or anus.

Spread by travel

Contact your transplant team if you plan to travel.

- We recommend not traveling to another country for at least the first 6 to 12 months post-transplant, as well as during periods of increased immune suppression like for treatment of GVHD
- If you plan to travel to another country, you may need your health care provider to prescribe preventative medicines or vaccines, depending on where you will be visiting and what you will be doing.
- Avoid adventure travel (kayaking, triathlons, etc.) in foreign countries.
- Take a list of your medicines and take enough medicine for the entire trip (plus some extra). Store the medicines and the list in your carry on not in checked luggage.
- Find out where the closest hospital is before you travel in case you get ill or there is an emergency.

Vaccines

You will need to get vaccines again after transplant to train your new immune system. To protect you, it is important for other people who live with you to get vaccines too.

Talk to your transplant doctor and the ID HDP team about what vaccines you need.

- After your transplant you will need to get both inactivated and routine live vaccines (when ready).
- We have created a vaccine roadmap for the bone marrow transplant team. This will guide your immunizations after transplant. You may start to get vaccines as early as 4 months post-transplant.
- You and those in your home need to get the inactivated flu shot each year, as soon as it is available in your community.
- The mRNA COVID-19 vaccines are recommended for eligible transplant recipients and household contacts.

Contact your health care provider and transplant team right away if you are exposed to:

- chicken pox or shingles
 - COVID
 - measles
 - mumps
 - influenza (flu)
 - whooping cough
 - bacterial meningitis
- Household contacts should receive all the U.S. recommended, age-appropriate vaccines. They NEED to get live vaccines as appropriate for age (exceptions shown below).
 - Transplant patients should not change the diaper of infants who have received the rotavirus vaccine for 4 weeks after it has been given.
 - Transplant patients should avoid contact with rashes in patients who recently received the chicken pox/varicella vaccine. If you have contact, tell your transplant team right away.
 - Household contacts should NOT receive live vaccination with the oral polio vaccine (OPV), smallpox vaccine or the live-attenuated flu vaccine given in the nose.

Medicine you may be prescribed to prevent infections after transplant

Antimicrobial:	Possible brand names:	Given by:	Preventing infections with:
acyclovir or valacyclovir	Valtrex ®	mouth	viruses (hsv, vzv)
valganciclovir	Valcyte™	mouth	viruses (cmv, hsv, vzv)
penicillin, amoxicillin	Penicillin, Amoxil®	mouth	bacteria
trimethoprim-sulfamethoxazole (tmp/s)	Bactrim™, Co-Trimoxazole, Septra®	mouth	bacteria and fungi (pcp)
pentamidine	Pentamidine	intravenous or inhaled	fungi (PCP)
fluconazole	Fluconazole	mouth	fungi
voriconazole	Vfend®	mouth	fungi (molds)
posaconazole	Noxafil®	mouth	fungi (molds)
isavuconazole	Cresemba®	mouth	fungi (molds)

Table 1

Ask your transplant team or call the ID HDP Team if you have any questions or concerns.

Helpful Resources

The ID HDP team finds the following resources very helpful:

<https://www.fda.gov/downloads/food/foodborneillnesscontaminants/ucm312793.pdf>

https://www.fsis.usda.gov/shared/PDF/Food_Safety_for_Transplant_Recipients.pdf

<https://www.fda.gov/Food/FoodborneIllnessContaminants/PeopleAtRisk/ucm312570.htm>

<https://bethematch.org/patients-and-families/life-after-transplant/>

<https://www.cdc.gov/healthypets/specific-groups/organ-transplant-patients.html>

http://www.cdc.gov/vaccines/schedules/index.html?s_cid=cs_001

We are always here to help. If you have any questions or concerns related to infectious diseases after transplant please call the ID HDP team at (614) 722-4452.

We wish you all the best!



Notes

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