

Stem Cell Transplant: A Guide for Patients and Caregivers



Important Phone Numbers for Stem Cell Transplant Program

(518) 262-3804

Monday—Friday 8:30 am—5:00 pm

(518) 265-1189

After 5:00pm, weekends and holidays

(518) 262-6696

Main NYOH/Albany Medical Center office

A member of our Stem Cell Transplant Team is always available or on call to answer your questions. If you leave a voicemail, your call will be returned as quickly as possible.



You and Your Caregiver

Going through a peripheral blood stem cell transplant (PBSCT) can be an intense experience—both physically and emotionally. To successfully complete the procedure as an outpatient, we require that every patient choose a primary caregiver. This is someone who can be with you 24 hours a day for the duration of your treatment and is capable of assisting you with medication, meals, bathing, etc.

At New York Oncology Hematology, we also recommend that you line up one or more back-up caregivers, who can be available to take over from your primary caregiver, if needed. You should arrange for these caregivers in advance and provide this brochure for them to review.

Please know that you and your caregiver are never alone—at NYOH, someone is always available to answer questions. We are here for you.

Symptoms to Report

Below, you will find a list of symptoms to watch for. If you should have questions, please do not hesitate to contact your nurse or physician. Keep in mind, some of the symptoms may require you to come to the hospital for an evaluation by your doctor. If in doubt, please call.

PROBLEM	SYMPTOM TO REPORT	WHAT TO DO
Fever	Temperature greater than or equal to 100.5F or chills (rigors). Take temperature each evening.	Call physician
Cold Symptoms	Cough, sore throat, or runny nose.	Call physician
Bleeding	Vomiting blood or material that looks like coffee grounds or passing bloody, or maroon-colored bowel movements, vaginal bleeding greater than a period, nose bleed that continues after 15 minutes of direct pressure, severe bruising or blood/pink tinged urine.	Call physician
Changes in Level of Consciousness	Inability to wake up or speak, severe headache, stiff neck, confusion, dizziness or lightheaded-	Call 911 and physician
Nausea and Vomiting	Inability to keep medications or food down. Having 3 or more vomiting episodes in an 8 hour	Call physician
Diarrhea	Any diarrhea not controlled by Imodium. Increase in frequency or amounts.	Call physician
Abdominal Pain	Severe pain or cramping.	Call physician immediately
Chest Pain	Pain in chest, pressure down arms sweating or shortness of breath.	Call 911 and physician
Urinary Problems	Painful, burning, blood tinged urine, or noticeable decrease in amount of urine.	Call physician
Shortness of Breathe	Sudden or severe shortness of breath that is different than your normal immediately breathing pattern.	Call physician immediately



Monitoring Vital Signs

Temperature: You and your caregiver will be taught how to take your temperature. Your temperature should be taken if you don't feel well. Call the doctor if temperature is 100.5F or greater. If you have a shaking chill, call the doctor, even if your temperature does not rise.

Weight: You will be weighed daily in the clinic and a five pound or higher weight gain may require adding Lasix, either orally or interveniously to your schedule.

Blood Counts

You will become accustom to hearing about your blood counts. Your blood is made up of:

White Blood Cells: Cells that have the main function of fighting infection.

Absolute neutrophil count: Percent of white blood cells that are neutrophils, which is the best type of infection fighting white blood cells.

Red blood cells: Cells that carry oxygen from lungs to other parts of body and then take carbon dioxide back to lungs to exhale. You will receive red blood cell transfusions when your counts are low.

Platelets: Cells that help blood to clot. Platelet transfusion will be given when the count is low.

Neutropenia and Infection

Neutropenia is defined as a decrease in the white blood cell count. This condition occurs after transplant. You will be at risk to develop infection. Below, you will find how to reduce this risk.

What to do:

Wash hands thoroughly and frequently. This is the most important way to reduce the risk of transmitting an infection.

Shower or bathe daily and wear clean clothes. If your skin is dry, use lotion to prevent cracking.

Maintain good mouth care.

Limit visitors, especially people with colds, flu and children who have just received live vaccines. Children should receive inactivated form of polio vaccine.

Monitor temperature if you feel sweaty, weak or chilled.

Clean rectal area gently, but thoroughly after each bowel movement. Remember to wipe front to back.

Make sure that all foods are properly handled, washed, and thoroughly cooked.

Things to avoid:

Crowds (i.e. grocery stores, restaurants, churches). Go out at times when there will be fewer people around.

Gardening until you are told that it is safe to do so.

Avoid being near small children other than your own. If your children show the slightest sign of illness, ideally, they should stay with someone else during that time. Small children often have viral infections, which could be minor for a person with a normal immune system, but may be very serious for your fragile immune system. Even though your white blood cell count may be normal, your immune system lags behind for a couple of months.

Avoid zoos, parks, animals, animal areas, and areas heavily populated with birds. If you own a pet, do not clean up after the animal, especially litter boxes.

Raw fresh fruits and vegetables.

Restaurants where food is not hot and fresh.

Avoid taking Tylenol/Aspirin/Ibuprofen without checking with your nurse or doctor first. With fever, do not take any medications until you have discussed it with the nurse or doctor.

Scratching dry skin.

Cuts or tears of the cuticle of nail. Do not have manicures when counts are low.

Avoid artificial nails.

Anemia

Anemia is described as a decrease in the red blood cells that are responsible for carrying oxygen to vital parts of our body.

Symptoms include:

Shortness of breath

Pale coloring

Ringing in ears

Fatigue or tiredness

Headaches

Dizziness or lightheadedness

Heart palpitations

What to do:

Get plenty of rest.

Move slowly to avoid dizziness.

When getting up from a lying position, sit up for several minutes before standing.

Eat a well balanced diet.

Report these symptoms to your nurse or doctor. A blood transfusion can help reduce these symptoms and will make you feel better.



Thrombocytopenia and Bleeding Precaution

Your platelet count will be very low during the transplant, so you must take care to avoid injury. You will be at a higher risk for bleeding and bruising. A low platelet count is called thrombocytopenia.

Symptoms include:

Bleeding from any opening of body (nosebleeds, blood in urine or stool).

Petechiae (red freckles, or spots on arms, legs, body).

Easy bruising.

What to do:

Remove all loose rugs or hazards in your home or hotel.

Use toothette instead of tooth brush to reduce the risk of bleeding.

Keep lips, mouth and throat moist.

Use an electric razor.

Avoid:

Vigorously blowing your nose or straining with a bowel movement.

Taking any medication without first checking with your nurse or physician. This includes aspirin or ibuprofen.

Using regular razors, suppositories, douches, rectal temperatures or enemas.

Using waterpiks or toothpicks.

Notify MD if:

You experience bleeding from any opening of your body.

Have black tarry stools or blood in stool, vomit, urine or sputum.

You are constipated.

Bruising or clusters of red spots that look like freckles occur.

Bleeding in mouth or gums occur.

Headaches or change in vision occur.

Difficulty in speaking, sudden weakness or confusion occur.

Skin Care

High dose chemotherapy can cause changes to your skin (dryness, itchiness, redness, scaling and color changes).

What to do:

Good handwashing.

Shower daily.

Keep catheter dressing dry.

Report rashes.

Avoid sun (Wear sunscreen with SPF 15).

Apply lotion as needed.

Mouth Care

The care of your mouth during your treatment is extremely important. High dose chemotherapy can cause your mouth to be painful, dry and sore. Your physician will prescribe pain and other medications that will decrease the pain and help numb the lining of your mouth and throat.

What to do:

Gently brush your teeth at least twice a day with a soft toothbrush or toothette sponge.

Apply a lubricant to lips as needed.

Rinse with normal saline/Peridex as directed by physician.

Avoid:

Using commercial mouthwashes.

Waterpiks.

Notify MD if:

Mouth pain is not controlled.





Medications

During the transplant, you will be receiving many different medications. Our nurses are available for consultations, so feel free to contact them at (518)-262-2770 if you have any questions.

After the transplant, you will be placed on prophylactic medications to reduce the risk of infections (bacterial, fungal and viral). Electrolyte replacements, such as potassium and magnesium may also be utilized as needed. If you are having difficulty taking the medications due to size, taste, or mouth

tenderness, please contact your nurse. We may be able to make suggestions as to how medications may be taken.

We will use a "medication box" to help you with the daily medications you are required to take during your transplant recovery. Please be sure to bring the "box" in to the clinic, one day before it needs to be refilled.

Please note: You will be asked to continue taking some of these medications for up to one year after your transplant has been completed.

Intravenous Medications

During your transplant it will be necessary to administer fluids and medications intravenously (by IV). This includes in the clinic as well as at home (or hotel). You will be sent home (or to your hotel) with IV fluids daily. The home hydration will be monitored by an infusion pump that will be programmed by your nurse or pharmacist to monitor the flow of the fluids.

You and your caregiver will be given detailed instructions concerning the use of the pump and you will have a home care nurse visit nightly, to check the pump for you. You may also call (518) 265-1189 if you have any questions about the pump, before or after your evening nursing visit.



Catheter Care

Your catheter allows us to draw blood from you without sticking your arm. You will receive all chemotherapy, IV fluids, blood and blood products through your catheter. We will keep your catheter in as long as you need it. When your counts are recovered and you are able to drink two quarts of fluid a day, your catheter will be removed. Generally, catheters can be taken out around 30 days after transplant.

Things to avoid:

While showering, having any water directly on the exit site of the catheter.

Baths or submerging yourself completely in water.

Swimming pools and hot tubs.

Using scissors around catheter or dressing.

Notify MD if:

Catheter area is tender or there is pain at site, neck or arm.

Catheter has hole or tear.

Fever >100.5 F.

Chills without fever.

Activity and Exercise

As you proceed through your transplant, you will notice your body becoming more tired. Light exercise, such as short walks, may decrease fatigue and allow you to sleep and eat better. This is also the case after your blood counts recover. Remember to start slowly and build up your exercise by small amounts each day.

Be mentally prepared that your body will take one to three months to return to a normal activity level. It is important that you do not become overtired. Taking short naps often helps, allowing you to participate in activities you enjoy. As your blood counts recover, the need for naps usually decreases.

Patients typically return to work within three months of transplant. Some find it helpful to begin working on a part time basis as they regain their strength.

Things to do:

Walk/stationary bike for short periods of time (5-10 mins)

Nap when tired, listen to your body.

Know that you will get better.

Be cautious until platelets are within a safe range.

Increase activity gradually.

Get outside for fresh air, when possible.



Things to avoid:

Strenuous exercise (i.e. tennis, aerobics.etc.)

Sunbathing (always protect your skin when outdoors)

Swimming

Hot tubs

Sauna

Pushing yourself to the point of exhaustion.

Notify MD if:

You experience ANY shortness of breath, lightheadedness, or chest pain.

Have ANY bleeding.

Have difficulty sleeping.

Feel depressed.

Environment

While at home or at the hotel, a clean environment is a must. No special cleaning measure, such as having the ducts cleaned, is necessary. However, regular, thorough cleaning is necessary.

Areas of particular concern are the kitchen and bathrooms. Only you and members of your household should use your bathroom.

Things to do:

Use antibacterial cleaners in the kitchen to prevent spread of germs from meat and poultry.

Use paper towels rather that dish cloths or sponges.

Someone other than the patient should do the cleaning.

Change air filters as recommended by the manufacturer.

Change bed sheets weekly.

Vacuum furniture.

Things to avoid:

Cleaning litter boxes, birdcages, or animal waste.

Exposure to fumes and chemicals. They have the potential to suppress your bone marrow.

Close contact with family members when they are ill. Speak to your nurse if this is an issue.

Do not see visitors who have colds, infections or flu.

Do not garden or do lawn maintenance for 30 days following transplant.

While blood counts are low, do not have live flowers in standing water.



Sexual Activity

In general, as your physical tolerance and resistance to infections improves (ANC greater than 1500), you may resume sexual intercourse. Having concerns regarding sexual activity and the impact of high dose chemotherapy is normal. You and your partner may discuss any uncertainties regarding sexual intimacy with your nurse or physician.

Things to do:

Be gentle.

Communication is very important. Talk through concerns that you or your partner may have.

Women should use water-soluble lubricant (KY jelly, Replens) to relieve vaginal dryness.

May resume vaginal, oral or anal intercourse when platelet count is greater than 100,000 and ANC >1500.

Do not be sexually intimate when you partner has a known infection.

Food Safety Guidelines During and After Transplantation

Bacteria and other pathogens may exist in common foods. The majority of these organisms occur at low enough levels to be of little risk to the average healthy person. However, infection is of major concern in patients undergoing marrow or stem cell transplantation and the food you eat must be safe.

By following safe practices, patients and caregivers can reduce the risk of food borne illness.

Home Sanitation Checklist

Wash hands with soap and warm, running water before and after every step in food preparation. Use paper towels, instead of cloth towels for hand drying.

Wash hands after using the bathroom, before eating, handling garbage, and touching pets.

Use separate cutting boards and utensils for cooked and raw foods.

Wash cutting boards in hot soapy water or in dishwasher after each use. Disinfect weekly using a solution of one part bleach to 10 parts water.

Keep appliances, counters and kitchen surfaces free of food particles.

Use disposable cloths for dishes and cleaning instead of dish cloths, sponges or dishtowels.

Freeze all foods that you don't plan to use within 2-3 days. Patient should not eat any prepared food that is more than 72 hours old.

Safe food handling:

Keep foods at safe temperatures; cook hot foods to a minimum internal temperature of 160 F and keep cold foods below 40 F.

Cook meats until well done; there should be no remaining pink. Red meats should be cooked to an internal temperature of 165 F and poultry to 180 F.

Thaw meat, fish or poultry in the refrigerator or microwave in a dish to catch drips. Use defrosted foods immediately: do not refreeze.

Never leave perishable foods out of the refrigerator for over 2 hours. Egg dishes, creams, mayonnaise-based foods should not be left unrefrigerated for more that 1 hour.

Wash fruits and vegetables thoroughly under running water before peeling or cutting.

Wash tops of canned foods or soda before opening.

During food preparation, do not taste the food with the same utensil used for stirring.

Cook eggs until the whites and yolks are completely hard.

Never taste food that looks or smells strange.

If home-canned foods are used, review the processing procedure to be sure it was appropriate for the pH of the food, size of container and elevation above sea level. Look for mold or leaks. Check seals. If you suspect that a home-canned food may not have been properly prepared, if the lid bulges, or if food has any unusual odor or look, discard it! It is recommended that home-canned food be used within one year of processing.

Microwave cooking:

Microwave cooking can leave cold spots in food where bacteria can survive. Dishes being cooked should be placed on a rotating turntable or manually turned, at least twice, during the cooking time.

When reheating leftovers, use a lid or plastic wrap for thorough heating. Stir several times during reheating.



Check dates and buy only the freshest products.

Check that packages are properly sealed and do not accept damaged, swollen or rusted cans.

Select unblemished fruits and vegetables.

Avoid foods from self-select, bulk containers.

Avoid foods from the deli.

Avoid yogurt and ice cream products dispensed from a soft-serve machine.

Avoid tasting free food samples.

Reject cracked or unrefrigerated eggs.

Store groceries promptly, never leave in a hot car.

Dining out:

Eat early to avoid crowds.

Ask that food be prepared fresh in fast food establishments.

Request single serving condiment packages; avoid self-serve bulk condiment containers.

Avoid high-risk food sources: salad bars, delicatessens, buffets, smorgasbords, potlucks and sidewalk vendors.

Diet Guidelines for Immunosuppressed Patients

Persons with decreased immune function due to chemotherapy are at increased risk of developing a food-related infection. On the following pages is a chart for you to post on your refrigerator to help avoid specific foods that are more likely to contain infection-causing organisms while

allowing maximum food choices.

This food plan should be followed while your blood counts are low. Your transplant nurse will discuss when the list should be followed and when you will be able to return to an unrestricted diet.

Use the table on the following pages as a guideline to keep your >>> diet safe and healthy.



Category	Foods allowed	Foods not allowed
Dairy	All pasteurized milk and milk products. Commercially packed cheese Pasteurized yogurt Refrigerated, frozen whipped topping Ice cream, frozen yogurt, sherbet, homemade milkshakes Commercial nutritional supplements	Unpasteurized or raw milk, cheese, yogurt and other milk products. Cheeses from delicatessens Cheese containing any uncooked vegetables Cheeses: Blue, Stilton, Roquefort, brie, camembert, feta or farmer's
Meat and Meat Substitutes	All well cooked or canned meats, poultry, fish, game or tofu Well cooked eggs Pasteurized egg substitutes Commercially packaged luncheon meats Canned or commercially prepared hard smoked fish (refrigerate after opening).	Raw or undercooked meat, poultry, fish, game, tofu, salmon, lox Meats and cold cuts from the delicatessen Hard cured salami in natural wrap Cold smoked salmon, lox Tempeh products
Fruits and Nuts	Canned and frozen fruit and fruit juices Well washed raw fruits Dried fruits Canned or bottled roasted nuts Nuts in baked products	Unwashed raw fruit Unroasted raw nuts Roasted nuts in shells Unpasterized fruit and vegetable juice
Vegetables	All cooked, frozen, canned or fresh vegetables and potatoes Well washed raw vegetables Fresh, well washed herbs, dried herbs and spices	Unwashed raw vegetables and herbs Salads from delicatessens Commercial salsas stored in refrigerated case
Breads, Grains and Cereals	All bread, bagels, rolls, muffins, pancakes, sweet rolls, waffles, French toast Potato,corn,tortilla chips, pretzels, popcorn Cooked pasta, rice and other grains All cereals cooked and ready to eat	Raw grain products
Beverages	Tap water and ice made from tap water Commercial bottled distilled, spring, and natural waters All canned, bottled powdered beverages tea made with boiling water Brewed herbal tea using commercially prepared tea bags Commercial nutritionals	Well water, unless tested prior to transplant and found to be free of coliforms Cold brewed tea made with cold or warm water
Desserts	Refrigerated commercial and homemade cake, pies, pastries and pudding Refrigerated cream filled pastries Homemade and commercial cookies Shelf-stable cream filled cupcakes, fruit pies, and canned or dairy puddings Ices, popsicle-like products	Unpasteurized fruit or vegetable juices Unrefrigerated, cream filled pastry products
Fats	Oil and shortening Refrigerated lard, margarine, and butter Commercially shelf-stable mayonnaise and salad dressings Cooked gravy and sauces	Fresh salad dressings containing aged cheese or raw eggs, stored in refrigerated case
Other	Salt, granulated and brown sugars Jam, jelly, syrups refrigerated after opening Commercially packaged, pasteurized honey Ketchup, mustard, BBQ sauce, soy sauce & other condiments that are refrigerated after opening Pickles, pickle relish, olives Candy & gum	Raw or unpasteurized honey Herbal and nutrient supplemental preparations Brewers yeast, if eaten uncooked

Medications to Avoid During and Post-Transplant

Many drugs should be avoided because they can increase bleeding by blocking the clotting mechanism of the platelets. These include all drugs containing aspirin, all non-steroidal anti-inflammatory drugs. Before taking any new medications, always review with the physician or nurse. Common drugs to avoid are listed below:

Non-Steroidal Anti-Inflammatory Products

Anaprox Nuprin

Clinoril Pamprin IB

Indocin

Naprosyn

Relafen

Advill

Ibuprofen

Motrin IB

Aspirin Products

Ascriptin Ecotrin

Alka-Seltzer Excedrin

Anacin Fiorinal

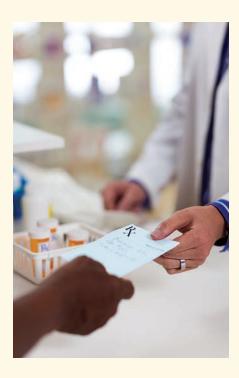
Bufferin Midol

Arthritis Pain Formula Percodan

Darvon Lortabs

Doan's Percodan

Empirin Salicylates



Miscellaneous Products

Coumadin

Pepto-Bismol

Persantine

Sine-Aid

Vanquish

Tylenol-like products

Glossary

Absolute neutrophil count

(ANC): The percent of neutrophils in the white blood cell counts. The neurtophils are the primary infection fighting white blood cells.

Anemia: A decrease in red blood cell count

Antibiotics: A drug used to fight bacterial infections.

Apheresis: A painless procedure by which your blood is withdrawn and circulated through a machine that removes the stem cells and then returns remaining cells back into your blood stream.

Bone marrow: Sponge tissue inside the bone where the blood cells are produced.

Bone marrow harvest:

Surgical procedure for obtaining bone marrow for transplantation.

Chemotherapy: Anticancer drug or combination of drugs designed to kill cancerous cells.

Colony stimulating factor:

Proteins that stimulate the production and growth of

blood cells.

Conditioning regimen/preparative regimen: The high-dose chemotherapy given to you to kill cancer cells before you receive stem cell support.

Engraftment: The process in which reinfused stem cells begin to grow in the bone marrow and manufacture new blood cells.

Heparin: A drug used to thin the blood and keep it from clotting. Used to keep blood in pheresis catheter flowing freely.

High-dose chemotherapy:

Higher than standard doses of anticancer drugs which are sometimes needed to destroy tumor cells.

Mobilizaton: Using chemotherapy and/or colony stimulating factor to move stem cells from the bone marrow into the blood stream for apheresis.

Neupogen (Filgrastim):

A colony stimulating factor given by injection which mobilizes stem cells from bone marrow into the blood stream.

Neutropenia: A decrease in white blood cells.

Neutrophil: The primary

white blood cell responsible for fighting infection.

PBSCT: Short for peripheral blood stem cell transplant

Pheresis catheter: Flexible plastic tube inserted in the chest, which fluids, drugs and stem cells are delivered to the body by.

Platelets: Cells that are needed for blood to clot.

Red blood cells: Cells that pick up oxygen from the lung and take it to tissues throughout the body.

Restaging: The process of evaluating how well your cancer is responding to treatment.

Stem cells: The "parent" cells from which all other blood cells develop; also known as progenitor cells.

Stem cell collection: The process of taking stem cells out of the blood. Also known as pheresis.

Subcutaneous injection:

Injection into the fatty layer under the skin.

Thrombocytopenia: A decrease in the platelet count.

White blood cell count (WBC):

The blood cells that fight infection.

Adapted from Amgen's Stem Cell Support: *Making delivery*

Important Phone Numbers for Stem Cell Transplant Program

(518) 262-3804

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After 5:00 pm weekends and holidays

(518) 262-6696

Main NYOH/Albany Medical Center office



Stem Cell Transplant at Albany Medical Center	(518) 262-6696
ADDITIONAL LOCATIONS	
Albany	(518) 489-0044
Amsterdam	(518) 843-0020
Clifton Park	(518) 831-4434
Hudson	(518) 822-8484
Rexford	(518) 399-4600
Troy	(518) 272-2097