Autologous Stem Cell Transplant: A Guide for Patients & Caregivers
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Welcome & Overview

We would like to welcome you to the Adult Stem Cell Transplant program at Memorial Sloan Kettering (MSK). We understand that you and your friends and family may feel overwhelmed, and we want you to know that we’re here to help you throughout this process.

This guide is designed to help you and those who care for you understand what to expect throughout your transplant journey. The information in this guide is not meant to replace the information that your transplant team will teach you, but it will be a resource for you to refer to throughout the process. In this guide we will explain some of the challenges that you might have over the course of your transplant and recovery, but it doesn’t mean you’ll have all of them. Because of that, you shouldn’t compare yourself to other people you may know or have heard of that had a stem cell transplant. Each person is unique.

Autologous stem cell transplants have been done for many decades. Advances in research have resulted in significant improvements over that time. However, it is still a complex procedure that requires a commitment from your transplant team, but just as importantly, on the part of you and those who care for you.

Autologous transplants can be done safely in the hospital, however for some people, transplants can also be done outpatient. Outpatient transplants have been shown to be feasible and safe, while improving the satisfaction and experience of people having transplant. An outpatient transplant is not right for everyone, however. Your doctor will talk with you about whether an outpatient transplant might be an option for you. You will read about both in this guide.

Preparing for your transplant is the first part of your journey. If you have an inpatient transplant, you will be in the hospital 24 hours a day before, during, and for some time right after your transplant. If you have an outpatient transplant,
you and your caregiver(s) will stay at an apartment near the hospital approved by your doctor or at a furnished apartment at the 75th Street Residence.

Having a transplant is a long process. At MSK we have a large, integrated healthcare team that will care for you as you go through each phase. We understand that you may have many emotional changes during the transplant process. Your transplant team includes many providers, including social workers, chaplains, psychiatrists, and members of our Integrative Medicine Service. All of these healthcare providers are available to support and help you and your caregiver(s) cope with what you may feel.

The importance of communication

During your transplant journey, it’s very important that you communicate clearly with your transplant team and your caregiver about how you’re feeling. If anything is bothering you, even if it seems minor, tell a member of your transplant team. Whether it’s physical or emotional, it’s very important not to let things build up, otherwise minor issues can become more of a problem. The more information you communicate to your transplant team, the more they can help you. There is usually something that they can do to make you feel more comfortable.

Below are some of the ways you can communicate with your transplant team:

• If it’s between 9:00 AM and 5:00 PM, call your doctor’s office. If it’s after 5:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant. If you’re having an outpatient transplant and it’s between 9:00 AM and 7:00 PM, call the Outpatient BMT Clinic at 212-639-3122. If you’re having an outpatient transplant and it’s after 7:00 PM call 212-639-2000 and ask for the doctor covering bone marrow transplant.

• If you’re inpatient, talk with any member of your inpatient healthcare team or ask to speak with the Charge Nurse, Clinical Nurse Specialist, or Nurse Leader. While you’re inpatient it’s important to talk with your inpatient team, not call the outpatient office. Also, you should choose 1 caregiver to call the nursing station for updates, then that person can relay the information to the rest of your friends and family.

• We also encourage you to use our patient portal, MyMSK. You can use MyMSK to check your appointment schedule, request a prescription refill, contact a healthcare provider, and find educational information. **MyMSK should never be used to communicate any symptoms to your healthcare team.** Instructions about how to enroll in MyMSK are printed on the bottom of your appointment print out, or you can find them on our website at

We Value Your Feedback

We are always trying to improve the information we give to our patients, their families, and their friends. After you’ve read this guide, you may think of ways it could be improved - maybe there’s something that was missing or wasn’t completely clear - email your suggestions to us at patiented@mskcc.org. We will use your feedback when we make the next version of this guide.
How to use this guide

There is a lot of information in this guide to read and understand. Read the entire guide at least once, including the additional resources included in the back of the guide. You may find it easier to read a few sections at a time, rather than trying to read the entire guide at one time. We encourage you to refer to this guide as your treatment progresses.

We recommend that you highlight or write notes as you go through this guide on anything that you don’t understand or have a question about. There is no such thing as a silly question, so please ask about anything that is on your mind.

Glossary

We’ve done our best to limit the number of medical terms in this guide. However, there are some words that you will need to understand. With this in mind, we’ve included a glossary of useful terms at the back of this guide.

Blood and bone marrow basics

Figure 1. How your stem cells divide
What is bone marrow?

Your bone marrow is in the spaces in the center of the larger bones in your body — your hip, breastbone, and pelvis. It’s where blood cells are made. All blood cells originate from stem cells.

Blood supplies your body with the nutrients and other substances your body needs. Blood also has different types of cells with important functions. Blood cells belong to 1 of 3 major categories: white blood cells, red blood cells, and platelets.

- White blood cells help fight infections. They make up your immune system
- Red blood cells carry oxygen throughout your body.
- Platelets make clots to help stop bleeding.

What are stem cells?

Stem cells are baby (immature) cells that can become any kind of blood cell. Stem cells divide constantly to become different types of blood cells in your blood, replacing older blood cells. A very small number of stem cells circulate in your blood. Stem cells can be collected during a process called apheresis (A-fer-E-sis).

Understanding Your Autologous Stem Cell Transplant

An autologous stem cell transplant has been recommended for you because your doctor feels it’s the best way to treat your specific disease. Autologous means “from yourself.”

In an autologous transplant, your stem cells will be collected (harvested) from you, and then frozen. You will then receive high doses of chemotherapy or a combination of chemotherapy and radiation. The high-dose treatment kills cancer cells, but also eliminates the blood-producing stem cells that are left in the bone marrow. Afterward, the stem cells that were collected are given (transplanted) back to you. This allows your bone marrow to make new blood cells.

Currently, most transplants are done an inpatient; however, some are done an outpatient. Your doctor will determine if you are a candidate and discuss your options with you.
Preparing for Your Transplant

Your initial consult visit

During your first visit, you’ll meet with your doctor and other members of your transplant team. Your doctor will take a complete medical and surgical history, do a physical exam, and discuss what he or she thinks is the best treatment plan for you. This plan may also be discussed with other transplant doctors to ensure that there is agreement on what the best plan is for your specific situation. Your doctor also might discuss inpatient and outpatient transplants options.

Getting ready for your visit

During this time, you’ll make practical, physical, and emotional preparations for your transplant. Here is a list of things that will happen and things that you may need to do to get ready:

- **Learn about your transplant** — The information your transplant team will go over with you is meant to inform you, not frighten you. Make a note of anything that you don’t understand about your transplant, anything in this guide that isn’t clear, and any other questions you have.

- **Contact your insurance company** — It’s a good idea to contact your insurance company before your transplant and see if there is a dedicated case manager for you.

- **Choose a caregiver** — Identify a family member or friend to act as your caregiver. Make sure this person understands what the role entails. You can also identify multiple people who will act as your caregivers throughout the transplant process. Give your caregiver a copy of this guide and ask him or her to read it at least once. While undergoing an inpatient transplant it is equally as important, if not more so, for your caregiver to be with you upon discharge from the hospital than while you are inpatient. If you’re having an outpatient transplant you will require a caregiver to remain with you whenever you are not in our outpatient BMT clinic.

- **Fill out a Health Care Proxy form** — A health care proxy is a legal document that identifies the person who will speak for you if you are unable to communicate for yourself. This person is known as your health care agent. This person may be different from your caregiver. You can get more information about this from your social worker or any other member of your transplant team.

- **Meet with a social worker** — Your social worker will explain the psychological, emotional, and financial support services offered by the social work team.
- **Arrange for disability/leave of absence from work** — If you are working, make arrangements to go on disability or take a leave of absence. You should expect to be away from work for about 6 months, though this can vary depending on your transplant course.

- **Make decisions about your fertility** — If fertility (the ability to have children naturally) is a concern for you, speak with your transplant team about your options. Ask for an appointment with a fertility specialist to discuss how your treatment may affect your ability to have children in the future and the steps you may be able to take to preserve your fertility. We have also included the following resources at the back of this guide:

  For men
  
  - *Sperm Banking*  
  
  - *Cancer and Fertility: Information for Men*  

  For women
  
  - *Fertility Preservation: Options for Women Who Are Starting Cancer Treatment*  
  
  - *Selected Fertility Centers*  

- **If necessary, arrange for childcare and pet care** — If you have concerns about talking with your children about your transplant, your social worker can help guide you.

- **Make decisions about your hair** — Think about whether you’d like to cut your hair before you start receiving chemotherapy. Visit a wig store if you decide to wear a wig as soon as you can, that way you can find one that closely matches your natural hair, if you prefer.

- **Have your pretransplant evaluation** — You’ll undergo a series of medical tests. Your clinical nurse coordinator will review which tests are needed and your physician’s office assistant (POA) will work with you to schedule these tests at a time that is convenient for you (as best as possible).

- **Meet with a dietitian** — Your dietitian will review special dietary requirements and safe food handling.

- **Meet with a pharmacist** — Your pharmacist will go over all the medications you will be taking before and after your transplant.
Your transplant team

A team of healthcare providers will care for you throughout your treatment. You will meet many as you progress through your transplant journey. You might not meet some members, such as your doctor’s office assistant, laboratory staff, or our service coordinator, but know that they are all working to help you. Below is a list of your team members and their roles.

- **An attending doctor** will be in charge of your care throughout your treatment. Although 1 specific doctor will be your primary outpatient doctor, different doctors may care you for while you are in the hospital.
- **A fellow** is a doctor who has completed general training and is receiving additional training in cancer care.
- **A nurse practitioner (NP)** is a nurse who has a master’s or doctoral degree. An NP is licensed to examine you, provide medical treatments, and prescribe medications.
- **A physician assistant (PA)** is a medical professional who has graduated from an accredited PA educational program and is nationally certified and licensed by the state to practice medicine under physician supervision. PAs are licensed to examine you, provide medical treatments, and prescribe medications.
- **A BMT clinical nurse coordinator** is a nurse who will communicate and work with you, your caregiver, and your team of doctors to organize and schedule all the testing, procedures, and consultations with other professionals needed before your transplant. Your clinical nurse coordinator will educate you about your specific treatment plan.
- **Nurses** will be working with you when you are seen at outpatient visits, as well if you are hospitalized. They are registered nurses specially trained in the care of people having stem cell transplants. Each outpatient nurse works with attending doctors and will meet you at the time of your initial consultation visit. Your outpatient nurse will see you at many of your outpatient visits after discharge and will follow you along your transplant journey. During your transplant, either inpatient or outpatient, you will have a team of primary nurses that will care for you. The nurses work 12-hour shifts and try to maintain consistency with who will be working with you. Both the inpatient and outpatient nurses work closely with your healthcare team to manage any symptoms and can help you with any questions or concerns you may have.
- **A nursing assistant/patient care technician** provides basic care and support under the direction and supervision of a registered nurse.
- **A hospitalist** is a doctor who sees people only while they are in the hospital. At MSK, there is a hospitalist on duty all night.
- **A clinical pharmacist** who specializes in the care of people having stem cell transplants will review your medications with you and your caregiver, teach you how to take them properly, and inform you of any side effects they may cause.
• A **social worker** will help you, your family, and your friends manage the stress that comes with the transplant process. Social workers understand the issues faced by people having transplants and are available to listen, offer counseling, and refer you or your family members to other resources and services, as needed.

• A **transplant service coordinator** will work with you and your insurance company to determine your transplant benefits. This person is experienced in the insurance issues faced by people having transplants. Each insurance company has its own policies and requirements. When your insurance company requires authorization, your transplant service coordinator will assist with that process.

• **Physician office assistants** provide administrative support to your attending doctors and their nurses. You may speak with them when you submit information, are scheduling an appointment, or have questions for your healthcare team.

• **Session assistants** work in the outpatient areas and monitor the flow of people in and out of the clinic. They help schedule required tests, scans, and treatments ordered by the medical team orders either completed or scheduled. Session assistants also manage everyone’s’ medical records and coordinate their future appointments.

• **Research study assistants (RSA)** work with your healthcare team and will speak with you and explain some of the research studies available to you at MSK. These studies mostly concern collecting sample and data.

• **Patient representatives** are liaisons between patients and their caregivers and the hospital staff. They are here to protect your rights and help explain hospital policies and procedures. Patient representatives can help you with any concerns about your care and help you communicate with members of your healthcare team.

• A **dietitian** is a food and nutrition expert who will assess your nutritional status, manage your treatment-related side effects, and provide dietary consultation to you and your caregiver.

• A **physical therapist (PT)** will work with you to help you maintain your strength and energy during your recovery.

• A **room service associate** will orient you to room service. They will make sure that you receive your menu and deliver your meals.

• A **case manager** will help arrange transfer to home or another facility, if needed.

### Your caregiver

Your caregiver will be an important part of your care during your transplant.

### The role of your caregiver

Everyone having a transplant will benefit from having support from a caregiver before, during, and after a transplant. The caregiver is usually a family member or a close friend
available to help with basic day-to-day medical and practical issues, as well as provide emotional support.

**To have an outpatient transplant, you must have a clear caregiver plan. There are no exceptions.** Your transplant team will review this with you. Your caregiver must be available 24 hours a day, 7 days a week during the transplant. Your caregiver will receive specific instructions from your transplant team about what a caregiver needs to do. Some of these responsibilities will include the tasks explained below.

**Medical support**

- Gathering information from your transplant team.
- Caring for your catheter.
- Making sure you take your medications and keeping a written record of when you take them.
- Taking your temperature every 4 hours while you are awake and away from the clinic. Keeping a written record of your temperatures.
- Keeping a written record of how much liquid you drink every day.
- Noticing any changes in your condition.
- Telling your transplant team about any new symptoms you may have or changes in your condition.
- Calling for medical help in an emergency.

**Practical support**

- Escorting you to and from your daily visits at the hospital.
- Dealing with financial and insurance issues.
- Preparing your meals according to a low-microbial diet.
- Maintaining a clean environment in your 75th Street Residence, apartment, or house.
- Keeping family members and friends up to date about your condition.
- Managing the number of visitors you have and keeping you away from anyone who is sick.

**Emotional support**

- Paying attention to your moods and feelings.
- Communicating with you and listening to you.
- Understanding your needs and your decisions.
Choosing the right caregiver

During an outpatient transplant, being a caregiver is a full-time, 24-hour, 7-day a week responsibility. It is tiring, demanding, and stressful, especially if your condition, schedule, or treatment changes.

During your transplant, your caregiver must take you to and from your daily visits to the Outpatient BMT Clinic. They may not be able to work and will need to stay with you for most of the day and night. While you are in the Outpatient BMT Clinic for daily visits, your caregiver can take some personal time. This is something we strongly recommend.

It is important for your caregiver to maintain a positive attitude, stay calm, and be flexible while providing you with the support and encouragement you need. It’s important for you to understand that the caregiver role is challenging and that your caregiver may at times feel overwhelmed by the responsibilities.

Take time now to think about who you would like to be your caregiver. It should be someone you trust and who can take the time to care for you. Your caregiver should be someone who can offer you the practical and emotional support you need. If you don’t have just 1 person to serve as your caregiver, then it’s okay to have more than 1 person share the role. However, it’s best to limit the number of caregivers to 1 or 2 people.

If your caregiver becomes sick or shows any signs of a cold or flu (cough, temperature, sore throat) 1 week before or any time during your transplant, tell your transplant team right away.

Resources for caregivers

Caregivers can experience physical, emotional, spiritual, and financial distress. Resources and support are available to help manage the many responsibilities that come with caring for a person having a transplant. For support resources and information, contact your transplant social worker. We have included a useful resource titled Caregivers’ Guide for Bone Marrow/Stem Cell Transplant with this guide.

At MSK, our Caregivers Clinic provides support specifically for caregivers who are having difficulty coping with the demands of being a caregiver. For more information, call Dr. Allison Applebaum at 646-888-0020 or go to: www.mskcc.org/cancer-care/doctor/allison-applebaum

Coping with separation from your children

Whether you’re having an inpatient or outpatient transplant, being apart from your children will be difficult for you and your family. We strongly recommend that you talk with your social worker about your concerns and develop a plan to maintain strong ties to your children during your transplant.
Below are some things that others have done to remain in contact with their children during their transplant:

- Talk with children regularly using programs or apps like Skype™, Google Hangouts, or FaceTime. Set up a time that you talk to them each day, such as when they get home from school and before they go to bed. Get into a routine of using the computer to see them and talk to them.

- Paint or create other crafts to send home. Ask a member of your healthcare team to arrange for volunteers from the Patient Recreation Center to bring you supplies.

- Use your cell phone or a tape recorder to record yourself reading your children’s favorite stories. Upload these recordings to the web, give them to your caregiver, or e-mail them to your children. They can read along with these stories while listening to your voice.

- Keep copies of your children’s favorite stories with you in your hospital room. At night, you can use Skype to read along with them before they go to sleep.

- Decorate your hospital room with your children’s artwork and picture of the family.

- Give your children a special coloring book or journal for times when they miss you, or when feelings are difficult. Your caregiver can bring the colorings to you. You can talk with your child about them over Skype or on the phone.

We know that nothing will replace physical contact between you and your children, but we strongly encourage you to use all of the technology that’s available to maintain a strong bond with them while you are away.

For more help maintaining your relationship with your children, contact your social worker.

**Having your pretransplant evaluation**

Before you become a transplant candidate, your overall physical condition will be evaluated. You will need to make several trips to MSK to have tests. We often refer to this as the “work-up” or “restaging” period. During the work-up, you will need to have some, but not necessarily all, of the following tests:

- **Chest x-ray** — This is done to ensure your lungs are clear and there is no evidence of infection or other problems.

- **Blood tests** — These are done to evaluate several things, including kidney function, liver function, blood counts, and past exposure to certain viruses.

- **Urine test** — This is done to determine if there is anything abnormal in your urine.

- **Chest x-ray** — This is done to ensure your lungs do not have any infection or other problems.
• **Computed tomography (CT) scan** — This is a radiology test that provides more detailed images of soft tissue and bone than a standard x-ray. CT scans sometimes require contrast dye that you drink or have injected into your veins. It is very important to tell your doctor if you know you have an allergy to contrast dye, seafood, or iodine. If you have a mild allergy, you can still receive contrast dye, but will need medications before receiving the dye to prevent a reaction.

• **Positron emission tomography (PET) scan** — This is a radiology test that is sometimes used to evaluate the activity and extent of cancer.

• **Skeletal survey** — This is done to look for bone damage caused by cancer and is usually reserved for people with multiple myeloma. It involves taking multiple x-rays of the major bones in your body and can take a few hours to complete.

• **Electrocardiogram (EKG) and Echocardiogram (ECHO)** — This is done to give your transplant team information about your heart.

• **Pulmonary function tests (PFTs)** — These are breathing tests that measure your lung function.

• **Bone marrow aspiration and biopsy** — A bone marrow aspirate is a small sample of bone marrow, usually taken from the back of your hip. Your hip will be numbed, a needle will be inserted into the bone marrow, and a small amount of bone marrow liquid will be taken out. A bone marrow biopsy may be performed at the same time. This biopsy involves collecting a tiny piece of bone for examination. This is done to evaluate how well your bone marrow is producing cells and to check for any sign of cancer in the marrow.

• **Lumbar puncture (spinal tap)** — This is done to check for abnormal cells in the fluid that surrounds your brain and spinal cord. This fluid is called cerebrospinal fluid (CSF). A small needle will be inserted through your lower back and a small amount of CSF will be collected. A lumbar puncture is usually only done for certain types of leukemia and lymphoma. It is also sometimes used to inject chemotherapy into the CSF to prevent cancer from spreading there or to treat cancer if it is already there.

• **Dental exam** — You must have a full dental exam before your transplant. Any cavities, loose fillings, or gum disease should be taken care of before your transplant. This can be done by your own dentist or by our dentist here at MSK. If you see your own dentist, please ask for a letter saying that you have no dental problems. If there are issues, please ask your dentist to contact your doctor’s office to discuss them. Your dental exam can be done up to 3 months before you are admitted to the hospital for your transplant.

These tests are usually done within 30 days of your transplant (Day -30 onwards), but the pretransplant evaluation can sometimes take longer. Your doctor or nurse will explain any other tests that you may need. Your transplant team will work with you and your caregiver to schedule the tests.
The results of the tests will be used to plan your treatment and make sure that it is safe to start your treatment.

**Having your preadmission appointment**

Once your pretransplant evaluation has been done and you have the date of your transplant, you will have your preadmission appointment. This appointment is usually 1 to 2 weeks before you are admitted to the hospital. At this appointment:

- Your doctor will review your treatment plan with you.
- Your doctor will go over the consent forms and you will sign consent for your transplant (if it has not been done already).
- You will meet with your clinical nurse coordinator, who will give you a calendar outlining your treatment plan, review information, and answer any questions you may have.
- You will meet with your clinical pharmacist again to review the medications you will take during and after your transplant.
- You may be asked to sign a consent form for transfusion (if you have not already). This is because you may need blood or platelet transfusions when your blood counts are low after your transplant. For more information about blood transfusions, read the resource *Frequently Asked Questions About Blood Transfusions*, located at the back of this guide.

Between your preadmission appointment and when you’re admitted to the hospital, it is very important to call your transplant doctor’s office if you or anyone in your home have any of the following:

- Signs of a cold, such as:
  - Runny nose
  - Congestion
  - Cough
  - Temperature of 100.4°F (38.0°C) or higher
- Nausea
- Vomiting
- Diarrhea
- Toothache
- Open wound
- Any other new problem, even if it seems minor
Your doctor will decide whether your admission for transplant should be delayed. It could be very dangerous to start your chemotherapy while you have an infection, even if it’s just a cold. This is because your immune system will not be able to fight the infection.

**Having your central venous catheter (CVC) inserted**

You will need a CVC during your transplant. A CVC is a tube that is usually inserted into a large vein (see Figure 2) in the upper chest area (see Figure 3). On the outside of your body, the catheter divides into 2 or 3 smaller tubes, called lumens. A CVC allows your transplant team to transfuse your stem cells, take your blood, and give you fluids, electrolytes, blood transfusions, chemotherapy, and other medications without having to stick you multiple times with a needle. Having a CVC will make your treatment during transplant much more comfortable. The CVC is usually removed 2 to 3 weeks after your transplant.

You will have your CVC placed in MSK’s Interventional Radiology department at Memorial Hospital. Your clinical nurse coordinator will discuss the details of having your CVC placed. If you are outpatient when you have your CVC placed, someone over the age of 18 must take you home. For more information, read the resource *Instructions for Interventional Radiology Procedures*, located at the back of this guide. For information about how to care for your CVC, read *Caring for Your Central Venous Catheter*, located at the back of this guide.

![Figure 2. Veins and your heart](image1)

![Figure 3. Placement of a CVC](image2)

**What to expect while you’re in the hospital**

The information in this section describes some basic information of what to expect if you are admitted to the hospital during any part of your transplant. This applies whether you have an inpatient or outpatient transplant.

There are 2 transplant units in the hospital. The nurses on each unit are specially trained to care for people having transplants, and all the same guidelines are followed on both
floors. You may need to change your room or floor while you’re in the hospital, however we try to avoid this as much as possible.

Your primary nursing team will care for you during your hospital stay. Nurses typically work 12-hour shifts, starting at either 7:00 AM or 7:00 PM. During this time, your nurse will communicate the information about what has happened with you and your care during that shift to the nurse taking over.

The hospital environment

- You will be placed in “protective isolation” to lower your risk of getting an infection. Anyone entering your room must clean their hands and wear a mask and gloves. Sometimes, you may need additional isolation precautions. A sign telling your visitors about the type of isolation and what is required will be placed on the door to your room. Although you are on isolation, you may have visitors 24 hours a day, every day, but we recommend that no more than 2 visitors be in your room at any time. Children 7 years or older may visit as long as they follow our isolation procedures. More information about visitors is discussed below.
- You will be in a private room that has a bathroom for your use only.
- Your room will have Wi-Fi and a TV.
- You will be connected to an IV pole with electronic pumps during most of your hospital stay.
- Your healthcare team will tell you about how to prevent falls while you’re in the hospital. If you are at risk for falling, someone will help you get to the bathroom.

Testing and evaluations

- Before 6:00 AM every day, a member of your healthcare team will weigh you and take a sample of your blood. Your blood will be checked to see how your white blood cells, red blood cells, and platelets are recovering. Other blood tests will be done as needed to check your kidney and liver, monitor for infections, check the level of chemotherapy or other medications in your blood, and to help evaluate your overall condition.
- A member of your healthcare team will take your vital signs (e.g., blood pressure, heart rate, breathing, pain level) every 4 hours, even during the night.
- A member of your healthcare team will measure your urine throughout the day. It’s important that we know how much urine you are making.
Visitors

- Your family and friends are welcome to visit you. One caregiver can stay overnight with you. However, anyone who has symptoms of an illness (e.g., cough, rash, fever, diarrhea) or who feels they may be coming down with an illness should not come visit you. This is also true for people who could have recently been exposed to someone with an infection.

- All visitors must follow the isolation instructions that are posted on your door. Your visitors must remove their mask, gloves, and gown before leaving your room. We consider age 7 to be a reasonable age to be able to follow isolation instructions.

- All visitors must use the visitor's restroom in the hallway, not the restroom in your room. This is to minimize the spread of bacteria in your room.

- All visitors must clean their hands each time before they enter your room. The instructions are listed below:
  
  - To wash your hands with soap and water, wet your hands, apply soap, rub them together thoroughly for 15 seconds, then rinse. Dry your hands with a disposable towel, and use that same towel to turn off the faucet.
  
  - If you're using an alcohol-based hand sanitizer, cover all of your hands with it, rubbing them together until they're dry.

- Fresh-cut flowers and live plants are not allowed in your room. Please tell family and friends not to bring or send them.

Exercise

Even though you will feel tired after your chemotherapy and your transplant, you should still try to remain active and get out of bed every day. It's important to be safe, so ask for help when getting up.

We encourage you to walk around the unit. If your white blood cell (neutrophil) count is high enough, you can walk in the hallway before 7:30 AM and after noon. You must wear a mask and gloves while you are walking around the unit. Your nurse will tell you if you also need to wear a gown when walking in the hallway. You should not leave the floor for walking or exercise. Your physical therapist will evaluate you early during your hospitalization and prescribe an exercise program that's right for you.

Communication

Each room has a call bell that is monitored 24 hours and a day, 7 days a week. If you need something, please say exactly what you need so we can send the right member of your healthcare team member to help you. Your unit assistant will be able to call the
team member directly using a personal voice communicator. It looks like a phone that goes around the neck.

Diet

Your diet will be planned by your transplant team. You will be given a menu and instructions on how to order your meals. Room service will deliver your meals to you.

In general, everyone having a transplant is placed on a low-microbial diet. Your dietitian will discuss this with you. For more information, read the resource **Low-Microbial Diet**, located at the back of this guide. If you keep kosher, have diabetes, or follow other specialty diets, tell your dietitian so that we can prepare your meals properly. Your dietitian is also available to help you plan your meals.

Showering

You will be expected to shower daily. Your patient care technician will be in your room when you’re showering to help you and to make sure you’re safe.

Mouth care

It is important that you take good care of your mouth. This will help to reduce infections and mouth sores. Your nurse will go over this with you.

What to expect in the Outpatient BMT Clinic

During an outpatient transplant, you will receive all of your care, including chemotherapy, transplant, and post-transplant care, in the Outpatient BMT Clinic. The clinic is located on the 4th floor of the hospital. You should arrive at the clinic at your scheduled time. You will visit the clinic every day and will only be admitted to the hospital if you need more care than can be provided to you as an outpatient.

When you come to the clinic, you should wear comfortable clothing that allows for easy access to your CVC (e.g., shirts that open at the front, sweatshirts, or large t-shirts). Do not wear clothing that is difficult to take off or put back on.

- After you check in and are taken to a room, your transplant team will check your temperature, blood pressure, heart rate, oxygen level, pain, and weight, and ask you about any symptoms you may have. They will also examine you and check your blood counts, electrolyte levels, and kidney function.

- After they examine you, you will wait in your room for your test results to return. This can take several hours. This is a good time for your caregiver to take a break, take some personal time, or run errands. You will be safe in the care of your
transplant team. We highly recommend that your caregiver leave the hospital and take this time to relax. You will have an entertainment unit with a TV and a computer to pass the time. Your meals will be provided for you.

- Once they receive the results from your blood tests (sometimes referred to as “labs”), your transplant team will make decisions about your care. The rest of your clinic visit that day will depend on your test results. Based on your test results:
  - Your healthcare provider may give you fluids through your IV.
  - Your healthcare provider may give you an infusion of platelets, red blood cells, or other blood components.
  - Your healthcare provider may change some of your medications.
  - Your treatment could be left as is.

You'll stay in the clinic until all the treatments you need are completed, and then your caregiver will take you back to your nearby apartment or the 75th Street Residence. There, your caregiver will continue to monitor your temperature and how much liquids you drink.

What you should bring to the outpatient clinic

When you come to clinic every day, bring the following:

- A list of all prescription and nonprescription medications you are taking, along with dosages and frequency. This should include patches, creams, vitamins, nutritional supplements, herbal products, and over-the-counter medications.
- All the prescription medications you were instructed to take during the transplant period.
- Your temperature and liquid intake diary. Your caregiver will use this to keep track of your temperature and liquid intake while you’re away from the clinic.
- Books, newspapers, an audio player, a laptop, or tablet computer—whatever you need to pass the time.
- A notebook to write down information and any questions you or your caregiver may have.

While you’re in your home or apartment

When you’re not in the Outpatient BMT Clinic, your caregiver will have the responsibility of caring for you.
Monitoring your temperature and how much you drink

From the time you start receiving your chemotherapy, your caregiver must take your temperature every 4 hours while you are away from the Outpatient BMT Clinic. You will be given a thermometer. Your caregiver must also monitor all of the liquids you drink, write it in the Temperature and Oral Intake Log, and bring it to the clinic every day.

If your temperature is 100.4°F (38°C) or higher, your caregiver needs to take you to Urgent Care Center as instructed in your BMT Emergency Guide. While you are on your way there, call one of the numbers listed below:

- If it is between 8:00 AM and 7:00 PM, call the Outpatient BMT Clinic at 212-639-3122.
- If it is after 7:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant.

Monitoring you for bleeding

If you have any bleeding, always tell someone from your transplant team. If you notice that you’re bleeding and are you’re not in the clinic, take the following steps right away:

1. Apply direct pressure on the bleeding site. If you are bleeding from your nose, apply ice over the bridge of your nose.
2. After applying pressure, follow the BMT Emergency Guide. If it is between 8:00 AM and 7:00 PM, call the BMT Outpatient Clinic at 212-639-3122. If it is after 7:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant.

Call your doctor right away if you have any of the following while you’re not in clinic:

- Black bowel movements, blood in your stool, or rectal bleeding
- Blood in your urine
- A headache that does not get better, blurred vision, or dizziness
- Cough up blood, vomit blood, or get a nosebleed that doesn’t stop after a few minutes with applied pressure or ice

The 5 Phases of Transplant

There are 5 phases of transplant: 1) Conditioning; 2) Transplant day to engraftment; 3) Engraftment to day of discharge; 4) Early convalescence; and 5) Late convalescence (see Table 1). It is important to realize, however, that these phases are not always exact, as everyone’s transplant timeline is unique. Also different, below is a table that describes what we consider the 5 phases of a stem cell transplant. We will go over each phase in
more detail in the following pages. The time frames given are not exact, and there is some usually some overlap from 1 phase to the next.

Table 1: Phases of transplant

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
<th>Time Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1: Conditioning</td>
<td>• You will receive chemotherapy with or without radiation therapy, which will kill any cancer cells that are left. This will make room for new stem cells and suppress your immune system so you don’t reject the donor cells.</td>
<td>Day of hospital admission to Day 0 (transplant day)</td>
</tr>
<tr>
<td></td>
<td>• Phase 1 will be finished when you receive the infusion of stem cells.</td>
<td>*Start date varies depending on which conditioning regimen you will receive</td>
</tr>
<tr>
<td>Phase 2: Transplant Day to Engraftment</td>
<td>• You will feel the effects of your conditioning regimen.</td>
<td>Day 0 to engraftment (blood count recovery)</td>
</tr>
<tr>
<td></td>
<td>• Your white blood cell, red blood cell, and platelet counts will be low.</td>
<td>*Usually between Day +10 and Day +30</td>
</tr>
<tr>
<td></td>
<td>• You may have diarrhea, nausea/vomiting, and/or mouth sores.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Your risk of developing infection will be high.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• You may need to have blood transfusions.</td>
<td></td>
</tr>
<tr>
<td>Phase 3: Engraftment to Day of Discharge</td>
<td>• Your blood counts will recover and gradually increase.</td>
<td>Blood count recovery until discharge</td>
</tr>
<tr>
<td></td>
<td>• You will begin the healing process.</td>
<td></td>
</tr>
<tr>
<td>Phase 4: Early Convalescence</td>
<td>• Your blood counts will be recovering, but your immune system will still not be working properly.</td>
<td>Discharge to 1 year after transplant (or longer)</td>
</tr>
<tr>
<td></td>
<td>• You will still be at risk of developing infection.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• You will remain on certain medications to prevent infection.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• You will continue to be monitored closely by your transplant team.</td>
<td></td>
</tr>
<tr>
<td>Phase 5: Late Convalescence</td>
<td>• Your immune system will be almost fully recovered, and you will return to your normal activities.</td>
<td>1 year after transplant and onward</td>
</tr>
<tr>
<td></td>
<td>• There will still be a chance that you could develop late complications, such as organ dysfunction or recurrence of the original disease.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• You will begin receiving vaccinations you may have had as a child.</td>
<td></td>
</tr>
</tbody>
</table>
Phase 1: Conditioning

Conditioning is another name for the treatment that you will receive to prepare your body for the transplant. During conditioning you will receive high doses of chemotherapy and sometimes, radiation therapy. The chemotherapy you receive depends on your cancer type, treatments you’ve had before, and your treatment plan. The purpose of conditioning is to kill any cancer cells that are still in your body.

The day of your stem cell transplant is called day zero. The days before transplant are negative numbers, and days after transplant are positive numbers. For example, conditioning starts before transplant, so the days of chemotherapy are assigned negative numbers (e.g., day -4, day -3, day -2, etc). Depending on your treatment plan, you may have 1 or multiple days of chemotherapy. Similarly, the days after transplant are assigned positive numbers day (e.g., Day +1, Day +2, etc.).

Your nurse coordinator will work with you to plan your schedule, provide you with a treatment calendar, and tell you the date of your treatment. Your transplant team will usually know an approximate time for the transplant 1 day before stem cell infusion on day 0.

Before you receive your chemotherapy, a number of safety checks will be done to make sure everything is correct. Once all the safety checks have been completed, your nurse will give you IV fluids (to keep you hydrated), medication(s) to keep you from getting nauseous, and chemotherapy through your catheter (see Figure 4).

Figure 4. A person receiving chemotherapy through a catheter
Side effects of conditioning

Conditioning kills cancer cells, but it also kills normal dividing cells. This causes side effects, including fatigue (feeling tired), low blood cell counts, temporary loss of immune function, hair loss, mouth sores, nausea, vomiting, diarrhea, and infertility (not being able to have children naturally).

Your transplant team will help you and your caregiver understand and prepare for these side effects. Before you start treatment, make a list of questions that you would like to ask about these side effects. Talk through these questions with your caregiver and transplant team.

Fatigue

Fatigue is expected from conditioning. You should still try to remain as active as possible throughout your transplant. Limit the amount of time you spend in bed, and walk a little every day. Your physical therapist will recommend activities for you.

Low white blood cell count, neutropenia, and risk for infection

White blood cells make up your immune system. The purpose of your immune system is to protect your body against infections. There are many different types of white blood cells. One type of white blood cell, called a neutrophil, travels to the site of an infection and plays an important role in starting the immune response to fight germs. At some point after conditioning, the number of white blood cells and neutrophils in your blood will temporarily drop to zero. This will put you at risk for serious, life-threatening infections. When neutrophils are at very low levels, it is called neutropenia. Infections that occur in people with impaired immune systems are called opportunistic infections.

To prevent you from getting an infection, you will be started on prophylactic (pro-fe-lac-tic) medications. Prophylactic medications are given before there is an infection. You will get medication to try to prevent bacterial infections (antibacterial), fungal infections (antifungal), and viruses (antiviral) early in your transplant journey. Even with these medications you may still develop fevers in the first 2 weeks after transplant. Fever is an important sign of infection. If you develop a fever during transplant, your transplant team will perform tests, such as blood and urine tests, to look for infection. X-rays or other radiology tests may also be done. You will be given stronger antibiotics through your CVC to help fight the infection. Most infections are treated effectively with antibiotics.

Avoiding sources of infection

During the transplant process, it is critical to avoid possible sources of infection. This is easier said than done. You and your caregiver will need to be careful about seeing
visitors, what you touch, and where you go. **While your white blood cell count is low, you should try to avoid:**

- **Shaking hands:** If you shake hands with someone, use an alcohol-based hand sanitizer, like Purell®, afterward.
- **Contact with animals:** Including your pets — they can’t stay with you during your transplant.
- **Anyone who has symptoms of illness (e.g., cough, rash, fever, diarrhea)** or may have been exposed to a contagious disease.
- **Contact with soil or dirt.** Do not keep any plants in your room.

All visitors should be able to follow infection control precautions, including washing their hands, wearing a mask, and reporting symptoms of an illness. We consider age 7 to be the youngest age able to reliably follow these requirements. You and your caregiver need to watch for visitors that have any signs of illness and ask them not to visit. We know it’s hard to tell friends and family not to visit. We recommend using an app or programs like Skype™, Google Hangouts, or FaceTime to keep in touch with friends and family when you are neutropenic.

**Eating a low-microbial diet**

When you have a low white blood cell count you will need to adhere to what is called a low-microbial diet. This diet helps lower the risk of getting sick from food-borne illnesses.

A low-microbial diet contains fewer microbes (also called microorganisms) than what are usually found in food. Microbes are tiny living organisms, like bacteria, viruses, fungi (yeast, molds). Microbes attach to food and grow, but often cannot be seen, smelled, or tasted. They can grow on any type of food but are more likely to grow on dairy products, unrefrigerated food, undercooked food, certain fruits and vegetables, unpasteurized juices, and vegetable sprouts.

To lower your risk of getting an infection from foods:

- **Eat only foods that you know have been stored properly and are safe to eat.**
- **Store food safely.**
- **Handle food safely.**
- **Eat only food that you know has been prepared and cooked in keeping with a low-microbial diet.**
- **Cook foods thoroughly.**
Read the resource *Low-Microbial Diet*, in the back of this guide. Follow the guidelines very carefully when you or your caregiver is buying, handling, preparing, and cooking food. Also remember to clean your hands before meals and after using the bathroom.

**Showering**

Keeping yourself clean is very important while you are neutropenic. You should shower or bathe daily using Hibiclens® skin cleanser. Hibiclens contains a fast-acting antiseptic called chlorhexidine gluconate (CHG) that kills germs living on your skin and will reduce your risk of infection. It works for up to 6 hours after use.

**Instructions for using Hibiclens**

- If you are washing your hair, shampoo and rinse thoroughly.
- Wash your face with regular soap.
- Rinse your body with warm water from the neck down.
- Apply Hibiclens to a washcloth or directly to the skin being cleansed.
- Wash gently. Do not dilute the Hibiclens.
- Rinse thoroughly with warm water and pat yourself dry.

**Important points to remember when using Hibiclens**

- Do not use Hibiclens if you are allergic to chlorhexidine.
- Do not use Hibiclens on your face, ears, genital area (between your legs), or on deep wounds.
- Do not use regular soap, lotion, powder, or deodorant after washing with Hibiclens.
- Your anal and genital areas should be washed carefully with antibacterial soap.
- Your nurse will instruct you on guidelines for bathing and showering.

**Caring for your mouth**

While you’re neutropenic, you will need to change the way you brush your teeth and care for your mouth. This will help to avoid infection and bleeding.

Follow these guidelines to take good care of your mouth:

- You will be given a mouthwash to rinse your mouth before and after meals and at bedtime. The number of rinses may be increased to every 2 hours, depending on how your mouth feels. Most store-bought mouthwashes contain alcohol, which can irritate and dry your mouth and throat, and should not be used.
- Use an ultra-soft toothbrush.
• You can use store-bought toothpaste.
• Do not use dental floss.
• Avoid licking your lips. It increases dryness and chapping.
• Apply a lubricant like Burt’s Bees®, ChapStick, or A&D ointment after you clean or rinse your mouth and every 2 to 4 hours as needed. This will help keep your lips moist.
• To avoid an infection in your mouth, your doctor may prescribe an oral antifungal medication. Use it as instructed.
• If your mouth becomes sensitive, avoid hot, spicy, acidic, or coarse foods. You may prefer soft or liquid food served chilled or at room temperature.
• If you have a lot pain from mouth sores, your healthcare provider will give you pain medication.

**Anemia**

Red blood cells use a substance called hemoglobin to carry oxygen from the lungs to the tissues in all parts of the body. After conditioning, the number of red blood cells in your blood will drop. This condition is called anemia and results in less oxygen delivery to the body. Anemia is sometimes treated with blood transfusions. Some of signs of anemia include:

• Feeling more tired than usual
• Weakness
• Rapid heartbeat
• Shortness of breath
• Headache, lightheadedness, or dizziness
• Pale skin

**Low platelet count (thrombocytopenia)**

Platelets are the cells that clump together to form a clot to help stop bleeding. After conditioning, the number of platelets in your blood will drop. This condition is called thrombocytopenia and increases your risk for bleeding. The most common areas of bleeding are the nose, mouth, skin, and gastrointestinal tract. Platelet transfusions are given if the platelet counts drop below 10,000 or if you are bleeding.

You will need to take these special precautions if your platelets become very low:

• Avoid sharp objects, such as razors, scissors, and nail clippers. You should only shave using an electric razor. Do not shave with a razor that has a blade.
• Do not have manicures, pedicures, waxes, electrolysis, or tattoos.
• Do not have any dental work done.
• Follow the guidelines for mouth care as previously described.
• Do not use rectal suppositories, enemas, or tampons.
• Do not take your temperature in the rectum.
• If you are straining to have bowel movements, ask someone from your transplant team for a stool softener or laxative.
• Avoid tight clothing or any clothing that you have to strain to put on or take off.

You should avoid any activities that may result in injury. These include:

• Contact sports
• Climbing ladders
• Strenuous exercise
• Bicycling
• Weight lifting

Some medications make it more difficult for your blood to clot and are very dangerous for anyone with a limited ability to clot and heal. You should only take medications prescribed by your medical team. Do not take:

• Aspirin or products that contain aspirin
• Nonsteroidal anti-inflammatory drugs (NSAIDs), like ibuprofen (Advil®)
• Vitamin E

You should always tell your transplant team if you have any bleeding. Call your doctor if you develop any symptoms of bleeding, such as:

• Easy bruising
• Faint, tiny, pin-point red dots on your torso, arms, or legs
• Vaginal spotting or heavy menstrual bleeding
• The appearance of broken blood vessels in the whites of your eyes
• Blood in your urine
• Headache that does not get better, blurred vision, or dizziness
• Coughing up blood, vomiting blood, or a nosebleed that doesn’t stop after a few minutes with applied pressure or ice
• Black stool or blood in your stool
**Nausea and vomiting**

Nausea and vomiting are common side effects of treatment. Chemotherapy acts on a specific part of your brain that may trigger nausea and vomiting. Nausea and vomiting can also be caused by stress or just the thought of getting chemotherapy. Nausea and vomiting can start during conditioning or may be delayed for several hours or days. The amount of nausea and vomiting you have will depend on the type of chemotherapy you will receive. Newer anti-nausea medications have made nausea and vomiting much more manageable now than in the past. To prevent and control nausea, you will be started on an anti-nausea medication before conditioning starts. If the medication you are taking isn’t helping, tell your transplant team. You may need to try a different medication or take more than one kind of antinausea medication to feel better. Your transplant team will work with you to prevent and treat nausea and vomiting.

**Diarrhea**

Diarrhea is frequent, loose, watery bowel movements. It can also cause stomach cramps, gas, and pain in the stomach or rectal area. Diarrhea can be caused by cancer treatments, various medications, infection, stress, or other medical conditions. If you are having a lot of diarrhea, you can become dehydrated from loss of body fluids. If your diarrhea continues for more than 24 hours, call your transplant team. Medications are available to treat diarrhea but do not take any over-the-counter medication until you have been evaluated by your transplant team.

**Constipation**

Constipation is a condition in which there is difficulty in emptying the bowels, usually associated with dry, hardened stool. The normal time between bowel movements varies for each person. If you are having fewer bowel movements than what is normal for you, or if you haven’t had a bowel movement for more than 2 days, you may be constipated. There are many causes of constipation, including not drinking enough liquids, not eating enough fiber, decreased activity, and medications, including chemotherapy, anti-nausea medications, and pain medications. Medications are available to treat constipation. Tell your nurse or medical team if you haven’t had a bowel movement for more than 2 days.

**Mouth sores**

Conditioning sores the cells that line the mouth and digestive tract, resulting in irritation. This is known as mucositis. Mucositis can present as redness, swelling, tenderness, and sores on the lining of your mouth, tongue, and lips. These changes can result in discomfort, pain, or both that make it difficult to eat or swallow. Medications, including pain medications, are available to treat mouth sores. Tell your nurse if you are having any of these symptoms so that they can be treated.

**Hair loss**

Conditioning kills the cells that make your hair, so most people having a transplant lose their hair. We know this can be a very difficult and upsetting experience. Like many people being treated for cancer, you can choose to cut your hair short before your
transplant to take control of this process and to lessen the shock of losing your hair. Talk this through with your caregiver, friends, and family.

Before your transplant, it is also a good time to think about whether you would like to wear a wig. Modern wigs can look very natural and wearing one may make you feel more comfortable. A list of wig stores in New York is included in the resource *Hair Loss During Cancer Treatment*, located at the back of this guide. You can get one while you still have your hair, or bring a clipping of your hair, if you’d like your wig to match your natural hair color. Ask your doctor for a prescription for the wig, as some insurance companies will reimburse some of the cost.

**Skin changes**

Skin changes are common after conditioning and include increased dryness, flaking, discoloration, and darkening. When you bathe, use soap that that is labeled for “sensitive skin.” Use alcohol-free lotions, creams, or oils to help relieve the dryness. Your skin will become more sensitive to the sun and may burn very easily, which in turn will put you at higher risk for skin cancer. Avoid direct sunlight as much as possible. When outdoors, wear a sunscreen with an SPF of at least 30 and protective clothing, like long-sleeved shirts, long pants, and a hat. Skin is the most common site for cancer, and sun protection reduces the risk of skin cancers.

Your nurse will tell you how to manage skin reactions during your treatment.

**Day of rest**

The day between your chemotherapy and your transplant day is a day of rest. This rest day allows time for the chemotherapy to work and then leave your body, so that when you receive your stem cells, there will be no trace of chemotherapy left in your body to harm the newly transplanted stem cells. It is important to note, however, that some conditioning regimens do not have a day of rest. This will be reviewed with you by your clinical nurse coordinator and noted on the calendar you are given prior to admission.

**Transplant day**

Now that you’ve received chemotherapy to kill the cancer cells in your body, it’s time for your stem cell infusion—your transplant.

On Day 0 (transplant day), the stem cells that were collected and stored before transplant will be reinfused into your bloodstream through your CVC. The stem cells will be pushed from a large syringe or transfused from a bag, like a blood transfusion. This will take place at the bedside. After they are infused, the stem cells will travel to the bone marrow and make new blood cells.

**Your stem cell infusion**

- You will be given medications about 30 minutes before your transplant to help reduce side effects that you may experience during the infusion.
- Your stem cells will be brought to the bedside.
Your stem cells will be infused through your CVC. You will be closely monitored and your vital signs will be checked frequently during and after the infusion.

You may experience some side effects during and after your infusion. The common side effects are nausea, vomiting, tickle in your throat, or a cough. Other less common side effects that can occur include fever, chills, and low blood pressure.

It’s important that you communicate with your transplant team and with your caregiver during your transplant. Let your transplant team know how you’re feeling and tell them if you experience any side effects. If you do experience side effects, your transplant team will treat your symptoms.

During and after your transplant, you may notice a strong, garlic-like taste in your mouth. Your urine, sweat, and skin may also have a garlic-like smell. You may not notice the smell but those around you will. This smell is caused by the preservative used to store your stem cells and will gradually go away over 1 to 2 days. The Nutrition Department will give you lemons to cut up and use as safe, natural air fresheners.

Your urine may look discolored, ranging from pink-tinged to bloody, for 24 hours after your stem cells are infused. This color change is due to your body getting rid of the byproducts of the stem cell infusion.

**Phase 2: Transplant Day to Engraftment**

Once you’ve had your transplant, you will enter a period of watching and waiting until your blood counts recover (called engraftment). During this waiting period, your old blood cells will die and your blood counts will drop to their lowest levels. At some point, usually around day +5, your immune system will not work at all until engraftment. During this time you will be at very high risk of getting an infection. You will need to avoid sources of infection by cleaning your hands regularly and eating a low-microbial diet. You will be given some medications to help protect you from certain infections. You will be closely monitored for any signs of infection and will be treated with antibiotics, as needed. In addition to infections, other potential complications during this waiting period include anemia, bleeding, and continued or new side effects from conditioning. The management of these side effects is as described in the Phase 1 section.

Here is a list of things that will happen during this phase:

- **Testing** — You will undergo blood tests and other tests as needed to monitor your progress. You will have blood drawn every day.

- **You may continue to have side effects from the conditioning, as described earlier.** You will be given medication to minimize the side effects and increase your comfort.
- **Low-microbial diet** — Because you are neutropenic, you will eat a diet that contains a low number of potentially harmful microbes.

- **Transfusions** — You may need to receive a blood transfusion to boost the numbers of red blood cells and platelets in your bloodstream.

- **Recovery of your blood counts** — Over time, as your stem cells engraft and begin to produce new blood cells, your blood counts will improve.

- **Exercise** — You will try to remain physically active after your transplant by limiting the amount of time you spend in bed and walking a little each day. Follow the recommendations that your physical therapist gives you.

**Risk of infection**

You will be at risk for bacterial, fungal, and viral infections for several months after your transplant. They are a major risk in the early recovery period until your new bone marrow grows and makes white blood cells to fight infection. You will still be at risk for some infections while your immune system recovers during the first 2 years after your transplant.

Fever is one important sign of infection. If you develop a fever, you will be evaluated for infection with blood and urine tests, at a minimum. X-rays or other radiology studies may also be performed. You will be given strong intravenous antibiotics to help your body fight the infection. Nearly everyone will develop fever during the first 2 weeks after their transplant. Most infections are treated successfully with antibiotics.

Your doctors and nurses will try to prevent you from getting infections. You will likely be given medications that are used to treat infections, which can help prevent infections in people who have had a transplant. You will receive antiviral medications to help prevent some viral infections you may have had in the past from coming back after your transplant. These viral infections can include cold sores, recurrence of genital herpes, and shingles.

People whose immune systems are not working well can get infections that would not occur in healthy people. These are called opportunistic infections. You may need medication to help protect you from these infections. You will be at risk for them until your white blood cell count and immune system return to normal.
Bleeding

Your platelet count will be low. Since platelets form blood clots, you will be at risk for bleeding. The mucous membranes of the nose, mouth, skin, and gastrointestinal tract are most commonly affected. You will have platelet transfusions if your count falls below 10,000 or if you have any bleeding.

Anemia

When your red blood cell count is low, you may experience weakness and fatigue. Your nurse will assist you with your daily activities if you need help. You will be given red blood cell transfusions as necessary. These and all other blood products will be irradiated to prevent harmful side effects.

Phase 3: Engraftment to Day of Discharge

Engraftment

After your stem cells are infused into your bloodstream, they travel to and enter the bone marrow, where they begin to divide and create healthy new blood cells. This process is called engraftment and usually takes about 10-14 days, but varies depending on your disease and treatment. As engraftment occurs, the number of white blood cells, red blood cells, and platelets in your blood will increase. Red blood cells and platelets usually take a little longer to recover than white blood cells.

During engraftment, you may experience bone pain, a rash, and fevers. These are common and we can usually take care of them easily. Once your transplant team decides that your symptoms are well-controlled or gone, you will be discharged from the hospital and resume care with your primary BMT attending doctor in clinic.

Before going home

It’s important for you to take part in planning your care after discharge. Your transplant team will work with you before you go home to make plans for your follow-up care.

MedicAlert jewelry

Before you leave the hospital, you will need to order a MedicAlert bracelet or necklace. Your transplant team will give you an order form and help you fill it out. Your bracelet or necklace should be engraved with the statements “Autologous stem cell transplant” and “Irradiated cellular blood components.” This will let paramedics or hospital staff know what to do if you are in an accident and cannot tell them yourself.
Talk with your transplant team about whether CMV-safe blood components are necessary for you after your transplant. If so, you will also need to have the statement “CMV-safe blood components only” engraved into your MedicAlert bracelet or necklace.

For more information on MedicAlert, go to: http://www.medicalert.org

**Going home**

Even though you may be very happy and feel ready to go home, you may feel nervous. It’s common for people to have some worries and concerns as they get closer to going home from the hospital. At home, you and your friends and family will need to manage your care. Feeling confident and comfortable doing this takes time. During your follow-up visits your social worker can help you get the services you need and give you emotional support.

When you leave the hospital it will take time to adjust to living at home again. You may find that the things you need to do to keep from getting sick may add some stress to your life. Feeling a sense of balance and comfort again will come with time; try to stay as calm and confident as you can.

Your recovery after transplant will be gradual. You probably will not feel the way you did before your illness for a while. You may feel tired and weak, have a less of an appetite, and notice changes in the way things taste and smell. It will also take time for you to get your strength back and to participate in the activities you enjoyed before your illness and transplant.

**Phase 4: Early Convalescence**

Early convalescence extends over a long period of time—discharge to 1 year (or longer) after your transplant. The time frames given here are general guidelines; yours may be different. Your transplant team may give you a more exact time frame.

It’s important to remember that although your blood counts are coming back up to normal, your immune system is still very immature and needs time to develop. You will still need to take medications and take steps to decrease your risk for infection.

**Watch for signs of infection**

It usually takes 3 to 12 months for your immune system to recover from your transplant. The first year after transplant is like your first year of life as a newborn baby. During that time, you are at risk for getting an infection. Your transplant team will monitor you closely and tell you what you need to do to keep from getting sick.

Be aware of the signs of infection. Call your doctor if you have:
• A temperature of 100.4°F (38.0°C) or higher. You do not have to take your temperature daily. However, check it regularly if you do not feel well.
• Flushed appearance of the skin, sweating, or shaking chills
• Coughing, sneezing, runny nose, shortness of breath, or chest discomfort
• Any redness, swelling, or pain in your throat, eyes, ears, skin, joints, or abdomen
• Blurred vision or other changes in your ability to see clearly
• Nausea, vomiting, or diarrhea
• Frequent urination, burning with urination, or both
• Irritation in your rectum, including burning and pain
• A rash
• Small blisters, similar to cold sores, around your mouth or on any other parts of your body.
• If you still have a CVC:
  o If you develop a fever with or without chills
  o If you have any difficulty flushing it

You can catch viruses more easily until your immune system is back to normal. Also, viruses that you had in the past can come back, such as the virus that causes chickenpox and shingles. The virus can come back if you had it as a child. This often starts as pain in your skin with pimples or blisters filled with fluid. The blisters can be tiny or as large as a pencil eraser, and may be painful, itch, or burn. Call your transplant doctor or nurse right away if you have any of these signs. Also call if you are exposed to chickenpox or shingles.

Preventing infection

Once your immune system has recovered, you will need to get your vaccinations again (see Phase 5 section). This usually starts about 1 year after your transplant; however, your transplant team will determine when the timing is right for you.

There are certain precautions you can take to decrease your chance of getting an infection. Below, we provide some guidelines for you to follow.

Personal hygiene

While you are recovering from your transplant, keeping yourself clean is very important to help prevent infections. Follow the guidelines below:
• Shower or bathe every day. Use a mild soap such as Dove® or Caress®. Do not use Ivory® or a deodorant soap because they can dry out your skin. Be sure to wash under your arms and in your genital area. Use a washcloth and towel that are only for your personal use.

• If your skin is dry, avoid using very hot water. Apply baby oil or a skin moisturizer such as Eucerin® or Cerave®. Put it on after bathing, while your skin is still damp. Gently pat your skin dry with a towel. Do not use lotions containing alcohol because they can make your skin more dry.

• Hair usually starts to grow back about 3 months after transplant. It’s possible that your hair will grow back with a different texture. Hair loss can occur months or years after the transplant, but it’s rare.

• Limit your time in direct sunlight. Your skin will be more sensitive and may burn more easily after your transplant. The medications you’re taking may make this even more likely. Whenever you’re in the sun, protect your skin with a sunscreen that has an SPF of at least 30. Reapply it often. If you expect to be in direct sunlight for 20 minutes or longer, cover your skin with cotton clothing and wear a protective hat. Staying in the sun too long can also make cold sores (herpes simplex virus) come back.

• You can wear contact lenses, but be sure that they are thoroughly cleaned before you put them in. Do not reuse cleaning solution. Be sure to throw away cleaning solutions that have expired. If your eyes are dry, use moisturizing drops.

• You can wear makeup. Purchase all new products after your transplant.

• New nails will grow and replace your old nails. This will happen gradually, 3 to 4 months after your transplant.

• Do not get a manicure or pedicure in a nail salon while your immune system is still recovering. You can do this at home with your own equipment.

• If you still have a CVC, do not allow it to soak in water while you bathe.

• Do not get body piercings or tattoos after your transplant. These increase your risk of hepatitis and other infections.

Mouth care

Continue caring for your mouth as described earlier until your transplant team tells you that can start using an ultra soft toothbrush. You can brush your teeth with an ultra soft toothbrush if:

• Your absolute neutrophil count (ANC) is higher than 500 (sometimes reported as 0.5).

• Your platelet count is 20,000 (sometimes reported as 20) or higher.

Ask your doctor or dentist when you can floss and brush your teeth with a regular toothbrush.
If you wear dentures, you must keep them clean to prevent getting an infection. Soak them every day in any standard denture cleaner, following the directions on the product box. Rinse them thoroughly with tap water. Your dentures may need refitting after your transplant.

If any of your medications are mouth rinses, take out your dentures before rinsing or swishing the medication. This will help the medications work better and will prevent your mouth from becoming reinfected. Tell your doctor or nurse if you have pain or discomfort in your mouth.

It’s common to have a dry mouth for 3 months or longer after your transplant. Do not use alcohol-based mouthwashes or hydrogen peroxide because they will dry and irritate your mouth. Instead, use a mild salt-water rinse, which can be made at home by mixing ½ teaspoon of salt and ½ teaspoon of baking soda in an 8-ounce glass of water. Your dentist may prescribe other rinses. Sucking on sugarless candy or lozenges may also be helpful.

After transplant, your mouth may make less saliva (spit). Saliva is important because it normally helps wash bacteria from your mouth. Having less saliva increases your risk of cavities. Use toothpaste with fluoride. You can also use a mouthwash with fluoride once your mouth is back to normal and is no longer too dry. Allow the mouthwash to sit in your mouth for at least 1 minute, then spit it out; do not rinse.

**Your home environment**

Your home must be kept as free of dirt and dust as possible. In general, try not to do any chores like dusting or vacuuming for the first 3 months after your transplant. Depending on your energy level, it is fine for you to cook, wash dishes, and iron. Your bathroom should be kept very clean (especially the tub and toilet). Use a disinfectant regularly.

You should not be around any renovations or construction until your transplant team tells you it's okay. This includes those in process and those done within the past 3 months. Do not repaint your walls or put down new carpets.

Avoid musty areas, like damp basements, where there may be mold. You can use an air filtration system in your home, but it is not necessary.

**Do not use a humidifier.** Bacteria and mold grow easily in it. A pan of water placed near a heat source may help in the winter. You must change the water every day.

Thoroughly wash all forks, spoons, and knives with hot water and dishwashing detergent or use the dishwasher. Wash towels twice a week and bed linens once a week. They do not need to be washed separately from the rest of your household. However, use only
your own towels and washcloths; do not use the same ones as the other members of your household.

It’s okay to have household plants in your home. However, for the first few months after your transplant:

- Do not touch the soil from household plants unless you wear gloves and a mask.
- Do not touch the water in a vase of flowers. Someone else should change the water in the vases daily.

**Pets and animals**

Animals can carry diseases. They may put you at greater risk for infection while your immune system is recovering. Avoid close contact with animals in a farm or a petting zoo.

You can have a pet in your home and touch it, but it is best that you do not have close physical contact. Do not touch the animal’s saliva or stool (poop). Be sure to protect yourself from bites or scratches. Do not handle or care for birds, lizards, snakes, turtles, hamsters, or rodents while you are recovering. If you have an aquarium and you must clean it yourself, wear gloves to protect yourself. If you have a cat or dog, follow the additional guidelines below until your doctor gives you other instructions.

- Be sure that your pet is up-to-date with immunizations and any booster shots.
- Have your veterinarian check your pet’s stool yearly for parasites.
- If you have a cat, get it tested each year for feline leukemia and toxoplasmosis.
- Have your pet treated for fleas. If your pet walks through wooded areas, have it screened for ticks every day during tick season (May to November). Discuss with your veterinarian the use of a flea and tick collar.
- Do not 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 possible. This is to help prevent them from picking up diseases from other animals.
- Do not allow pets in your bed.

If you plan to get a pet after your transplant, it’s best that you select a healthy dog or cat that is more than 1 year old. Have it spayed or neutered.

**Family and visitors**

You can have close physical contact with your family. However, avoid close contact with anyone with a cold or any signs of illness. Wear a mask if you must be in the same room with someone who is sick. People you’re close to should get a flu shot every year.

You can have visitors, but limit them to small groups. Do not visit with anyone who has:
- A cold
- Chickenpox
- Recently been exposed to chickenpox
- Recently been exposed to herpes
- Recently been exposed to shingles
- Recently been exposed to any other type of virus or infection
- Recently received a vaccine with a live virus such as varicella. There are very few of these, but if someone in your household needs one, that person’s doctor should be told that you are immune suppressed and live in the same household.

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

Outside your home

Walking is an excellent way to regain your strength and endurance. Take regular walks outside, but avoid dirty areas and construction sites. During the first few months after your transplant, avoid the following places when they are crowded:

- Supermarkets
- Shopping malls
- Movie theaters
- Schools
- Restaurants
- Public transportation
- Church/synagogue

You can go to these places when there are fewer people. Do not take public transportation for at least 3 months after your transplant. Your doctor will tell you when it’s safe to do some or all of these activities.

You can swim in the ocean after you regain your strength and are more active. Pay attention to alerts from the local health department. You can also swim in a private pool that isn’t crowded. Make sure that the pool is chlorinated. You cannot swim in lakes, rivers, or crowded pools until your immune system has recovered. **Do not swim if your CVC is still in place.**

Bleeding

Platelets are blood cells that help form clots and control bleeding. When your platelet count is low, you are at risk for bleeding. Many people are discharged from the hospital
with a low-platelet count. It can take weeks or months for your body to produce normal numbers of platelets. You may need to have platelet transfusions.

Signs of a low-platelet count include changes in the skin, bleeding, or both. Skin changes may include a lot of bruising or petechiae (pe-tea-key-eye). These are tiny, pinpoint, purplish-red spots on the skin that do not disappear when you press them. You may see them on your lower legs or ankles. If you see many petechiae, call your doctor. Other symptoms of a low-platelet count may include bleeding from your gums or nose.

If you went home with any of these signs and they increase in amount or frequency, call your doctor. You must also call your doctor if you have not had any of these and suddenly develop them. It may mean there is a change in your platelet count. If you have an injury that causes bleeding, do not panic. Remain calm and follow the guidelines below for the type of injury:

- **Open wounds:** If you cut yourself, put a clean, dry gauze pad, towel, or cloth over the cut and press firmly. Apply pressure until the bleeding stops. If the bleeding continues, elevate the wound. For example, raise your arm or prop up your feet. Apply ice to the wound and call your doctor.

- **Nosebleeds:** If you have a nosebleed, sit up and lean forward slightly. Do not tilt your head back. Squeeze the bridge of your nose firmly between your thumb and forefinger for at least 10 minutes without letting go. If it keeps bleeding, continue to squeeze your nose. Apply a small bag of ice to the bridge of your nose until the bleeding stops. If the bleeding continues longer than 30 minutes, call your doctor.

- **Accidents:** If you are in an accident, you may need blood or blood products. They should be irradiated to 3,000 rads. Wear your MedicAlert jewelry at all times—it gives the doctor who will be treating you this information. If you are admitted to another hospital, have the doctor call MSK immediately for guidelines on blood products.

If your platelet count is below 50,000 (50), follow the guidelines below:

- Use an electric razor when shaving.
- Use a soft-bristle toothbrush or an oral irrigator such as a WaterPic® so that your gums don’t bleed. Do not use dental floss.
- Do not take aspirin, products that have aspirin, or aspirin-like medications, such as ibuprofen (Advil®) or naproxen (Aleve®). For more information, see the section titled “Common Medications to Avoid.”
- Avoid blowing your nose forcefully.
- If you are constipated (have trouble moving your bowels), call your doctor. You may need more fiber in your diet or a stool softener.
- Avoid activities or sports that can cause injury. If you have any questions or concerns, talk with your doctor.
Resuming Your Activities

Daily activities

The time it takes to recover after a transplant varies. Most people find that it takes about 3 months, while others may need 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. This requires calories and energy. You may feel more tired than you expected. Remember, this fatigue and weakness are common. Each week, you should regain more of your strength.

Around the third month after your transplant, your hair will start growing more quickly. You may feel well enough to start resuming your usual level of activity. From this point on, you will probably feel progressively better. For most people, however, the first 2 to 3 months to 1 year after transplant remain a time of recovery.

Exercise

Most people find it takes time to regain their strength. It may be helpful to follow a regular exercise plan. When you begin to exercise, start with easy exercises. Your physical therapist can help you decide what type of exercise is right for you. As you feel ready, ask your doctor how to increase your exercise. Do not play contact sports or ski until your platelet count is over 100,000.

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 and good ventilation. Keep the windows open. Use nontoxic paints and glue. If you have questions or concerns about resuming any of your hobbies, ask your doctor.

Returning to school or work

The earliest you can return to school or work is about 4 months from the time of your transplant. This time frame can vary from person to person and depends on many factors. Some people may feel ready to return right away, while others feel concerned after being away for so long. It may help to begin slowly. For example, start with a schedule of half days or 3 days a week. Most people tell us that thinking about returning is almost harder than the actual event.

Making the transition back to your usual lifestyle can be difficult. Some people have talked about feelings related to changes in their appearance. Hair loss, for example, is hard for many people. Others have trouble concentrating or maintaining their attention.
span. Many cannot keep up their former pace. Your transplant 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 ease your transition.

**Traveling**

For the first 3 months after your transplant, avoid traveling outside of the greater New York City area.

If you plan to travel by plane, speak with your transplant team. You must have a high enough platelet count to safely travel by plane.

If you plan to travel out of the country during the first 2 years after your transplant, talk with your transplant team. They may recommend that you see an expert in travel medicine to reduce your risk of infection while abroad, depending on your destination.

**Sexual health**

Before you go home, ask your doctor when it’s safe for you to have sexual activity. It is important for you and your partner to have answers to your questions. If new questions come up, you can discuss them during your follow-up visits.

**Protecting yourself during sexual activity**

Until your doctor tells you that your blood counts and immune system have recovered:

- When your platelet counts are low (less than 50,000), avoid sex that involves penetration or contact with mucous membranes. This includes vaginal, oral, and anal sex, and inserting fingers, vibrators, or other sex toys into your vagina or anus. Hugging, cuddling, gentle touching, and kissing skin are other ways you can be intimate with your partner during this time.

- When your platelet count is above 50,000:
  - Use latex condoms each time you have vaginal, oral, or anal sex.
  - Use a barrier device (condoms or dental dams) any time your partner’s vaginal secretions or semen could enter your mouth.
  - Do not have any sexual activity that could expose your mouth to feces.
  - Avoid sex that involves contact with mucous membranes if a genital infection is suspected or present in either you or your partner.

For more information about being sexually active during and after treatment, talk with a member of your transplant team, or ask for the following resources:

- You can find the following resources on our website, www.mskcc.org:
  - [Sexual Activity During Cancer Treatment: Information for Women](#)
• The American Cancer Society publishes 2 resources about sexuality following cancer treatment. They are available for free from your local American Cancer Society or on the ACS website at the links below:
  o  *Sexuality for the Man With Cancer*
  o  *Sexuality for the Woman With Cancer*

**Information for women**

After your transplant, you may have:

- Fewer menstrual periods
- No menstrual periods
- Vaginal dryness and discomfort

Vaginal moisturizers are nonhormonal, over-the-counter products that help relieve vaginal dryness and discomfort. They are available in most drug stores or on the Internet. Examples are vitamin E liquid capsules, Replens®, Hyalo GYN®, and K-Y® Brand LIQUIBEADS™.

Vaginal lubricants usually come in a liquid or gel form. They are used to supplement a woman’s own lubrication and minimize dryness and pain during sexual activity. Use these lubricants to make sexual intercourse more comfortable and pleasurable. Examples are Astroglide®, K-Y® Jelly, and Pjur® Woman Bodyglide (a silicone-based lubricant). For more information, ask your nurse for the resource *Vulvovaginal Health*, or go to www.mskcc.org/cancer-care/patient-education/resources/vaginal-health

Depending on your treatment, the function of your ovaries may change. This can result in decreased estrogen levels. Your doctor may recommend that you take estrogen supplements after your transplant.

If you need any help or support with these issues, contact the Female Sexual Medicine and Women’s Health Program at 646-888-5076.

**Information for men**

Some men experience decreased sexual desire after their transplant. As you regain your strength and increase your activities, however this may also change.

Some men also experience erectile dysfunction (ED) after their transplant. ED can be treated with medication, including sildenafil citrate (Viagra®) or tadalafil (Cialis®). There are many other ways to treat ED. Your doctor can refer you to a specialist in our
Male Sexual and Reproductive Medicine Program. You can also reach the clinic directly by calling 646-888-6024.

**Drinking alcohol and using tobacco**

After your transplant, your body needs time to recover. Alcohol can harm your liver and your bone marrow, which is still recovering. This harm can be worse if you’re taking medications that can affect your liver. Do not drink alcohol until your doctor tells you it is safe.

Smoking can lead to a serious lung infection. It can also increase your risk of a second cancer. If you need help quitting, contact our Tobacco Treatment Program by calling 212-610-0507, or go to [www.mskcc.org/cancer-care/counseling-support/tobacco-treatment](http://www.mskcc.org/cancer-care/counseling-support/tobacco-treatment).

**Follow-up care**

Your follow-up visits will be scheduled before you are discharged. In general, you will be seen about 1 to 2 times a week for the first 3 months after your transplant. After that, your appointments will be spaced further apart as long as you are doing well. Some people find it helpful to bring a list of questions that may have come up since the last visit.

When you come to the clinic for your follow-up visits, always wear a surgical mask. Bring a list of all the medications you are taking and the dosages of each one. Make a list of any medications that need to be refilled. If you are going to run out of any medications before your follow-up visit, tell your doctor before your appointment. You will be given prescriptions during your visit to be filled either at MSK or your local pharmacy.

You will have blood tests to check your blood counts, electrolyte levels, and liver and kidney function. Bone marrow studies will be done according to your disease and treatment course.

Some diseases will require lumbar punctures after transplant. A lumbar puncture allows your doctor to give you more chemotherapy in your spinal fluid after your transplant. It can also be given through an Ommaya reservoir, if you have one.

You may need to have intravenous treatments, including antibiotics and blood transfusions. If so, your doctor or nurse will tell you how long and how often you will need them. These appointments are usually scheduled at the same time as your follow-up visits.
At some point after your transplant, you may be referred to our survivorship nurse practitioner clinic. A survivorship nurse practitioner is part of the transplant team and works closely with your doctors and nurses to help with your recovery. This nurse practitioner will also communicate directly with your primary care provider so that information about your transplant is included in your overall healthcare.

Dental care

After you have recovered from your transplant, go to your local dentist for routine checks. If you need extensive dental work, you may wish to have your local dentist call a dentist at MSK at 212-639-7644 before treating you. Your transplant doctor will tell you when it’s safe to resume all dental care with your dentist.

Tell your doctor or dentist if you have:

- Taken the medications pamidromate (Aredia®) or zoledronic acid (Zometa®)
- Jaw tightness
- Toothaches
- Discoloration at your gum line or receding gums

Common Medications to Avoid

Do not take aspirin, any medications containing aspirin, or nonsteroidal anti-inflammatory drugs (NSAIDs) until your doctor gives you other instructions. For a list of these medications, ask your nurse for the resource Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs) or go to: www.mskcc.org/cancer-care/patient-education/resources/common-medications-containing-aspirin-and-other-nonsteroidal-anti-inflammatory-drugs-nsa

Check the label of any over-the-counter medications that you are thinking of taking to be sure that they do not contain ingredients you should avoid. If you are not sure about whether or not a medication is safe to take, ask your transplant team. Do not take any herbal supplements or home remedies without talking to your transplant team first.

Phase 5: Late Convalescence

Relapse

A concern for many people is that their cancer will return. Your risk is higher if you had your transplant when you were in an advanced stage of disease or you were not in remission. Your doctor will follow you closely to watch for any sign of relapse.
Continued follow-up care

Immunizations

Having a transplant takes away all the immunity you had gotten during your life before transplant. This includes the vaccines you received as a child. Because of this, you need to be re-vaccinated with childhood vaccines once your immune system has recovered. This usually happens about 1 year after transplant.

Once it is safe for you to receive vaccines, you will be scheduled for them at MSK. This is because it may be difficult for your primary care doctor to get the vaccines. You will receive only “killed” vaccines at first; these are vaccines that don’t have a live virus. If your body responds to those, you will then receive “partially killed” vaccines, such as those used for measles and shingles.

Eye exams

Vision changes, sometimes due to cataracts, are fairly common after transplant. If you develop any of the following symptoms, see an eye doctor:

- Vision that is cloudy, blurry, foggy, or filmy
- Changes in the way you see color
- Problems driving at night, such as glare from oncoming headlights
- Problems with glare during the day
- Double vision

You may only need a change in your eyeglass or contact lens prescription. Be sure to tell your optician or eye doctor what treatment you had. Try to wait until at least 3 months after your transplant before getting a new eyeglass or contact lens prescription, as your vision can continue to change during the recovery process.
There are only four kinds of people in the world:
Those who have been caregivers
Those who are currently caregivers
Those who will be caregivers
Those who will need caregivers.
– Rosalynn Carter, *Helping Yourself to Help Others*

This booklet is dedicated with admiration to BMT caregivers,
past, present and future.

The mission of the National Bone Marrow Transplant Link (nbmtLINK) is to help patients, as well as their caregivers, families and the health care community, meet the many challenges of bone marrow/stem cell transplant by providing vital information and support services.

Founded in 1992, the nbmtLINK is an independent, non-profit organization funded entirely through the generosity of individuals, corporations and foundations. Tax-deductible contributions are welcomed and vital to ongoing programs and services.

The information in this guide should not be construed as medical advice. Please consult with your physician regarding your medical decisions and treatment. The listed resources are not intended to be endorsements.

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Copyright 2003, Revised 2007
The National Bone Marrow Transplant Link (nbmtLINK) would like to acknowledge the transplant patients, survivors, caregivers, and health professionals who generously shared their experiences and recommendations, and the other individuals who reviewed and edited sections of this booklet’s earlier edition.

The nbmtLINK would also like to acknowledge the editors, reviewers, and nbmtLINK staff who helped update this second edition of the Caregivers’ Guide.

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We are also grateful to our dedicated nbmtLINK office volunteers who helped make this booklet possible:

Lori Strager, Chris McClellan, Peg McIvor, and Marilyn Beckham
We gratefully acknowledge the financial support for this Caregivers’ Guide from the following:

**Sustaining Partners**

American Society for Blood and Marrow Transplantation

![ASBMT](image1)

The Blood and Marrow Transplant Program at Northside Hospital

![Northside Hospital](image2)

Children’s Hospital of Michigan

![Children's Hospital of Michigan](image3)

City of Hope Cancer Center

![City of Hope](image4)

Community Cancer Care Specialists

![Community Cancer Care Specialists](image5)

Dana-Farber/Brigham and Women’s Cancer Center

![Dana-Farber/Brigham and Women’s Cancer Center](image6)
Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance

Henry Ford Macomb Hospitals

Henry Ford Transplant Institute

J.P. McCarthy Foundation

Karmanos Cancer Center
Memorial Sloan-Kettering Cancer Center

National Marrow Donor Program

OHSU Center for Hematologic Malignancies

University of Michigan Comprehensive Cancer Center

The University of Texas M. D. Anderson Cancer Center
Supporting Partners

Gift of Life Bone Marrow Foundation

The Leukemia & Lymphoma Society

Siteman Cancer Center at Barnes Jewish Hospital and Washington University School of Medicine

UPMC Cancer Centers/Stem Cell Transplant Program

Collaborating Partners

Aplastic Anemia & MDS International Foundation

Gilda’s Club Worldwide

The Nebraska Medical Center

Rosalynn Carter Institute

Rocky Mountain Blood and Marrow Transplant Program
Marrow or cord blood transplant?  
We’re here to help.

The National Marrow Donor Program (NMDP) helps people who need a life-saving marrow or cord blood transplant. We are committed to helping more people live longer and healthier lives.

Our Office of Patient Advocacy can support you and your family every step of the way, from diagnosis through survivorship.

We can help you:

- Learn about treatment options
- Understand the transplant process
- Overcome financial barriers
- Find the transplant center that is best for you
- Maximize recovery after transplant

Call us. All of our services are free and confidential.

Toll-free in the United States: 1 (888) 999-6743.
Outside the United States: 1 (612) 627-8140.
E-mail: patientinfo@nmdp.org

To learn more, visit us online at: www.marrow.org/patient
Reassurance, Understanding and Peer Support for Bone Marrow/Stem Cell Transplant (BMT) Caregivers

“Peer Support on Call”– is a free service offered by the National Bone Marrow Transplant Link

Caring for someone having a Bone Marrow/Stem Cell Transplant (BMT) is a unique commitment that requires extraordinary physical and emotional effort. It is the goal of the National Bone Marrow Transplant Link (nbmtLINK) to reinforce the important role of BMT caregivers and to help them meet the many challenges they face. Through the “Peer Support on Call” program, emotional support is available through one-on-one conversations with trained peer support volunteers, caregivers themselves, who have successfully faced the BMT experience and cared for their loved one. They understand a caregiver’s feelings and can provide an empathetic point of view.

If you would like to request a phone call from a peer support volunteer, please call our office at 800-LINK-BMT (800-546-5268).

For additional nbmtLINK resources, visit our website at www.nbmtlink.org
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As a transplant physician for almost 20 years, I have had the opportunity to work with many wonderful people. Caring for patients through the transplant procedure and beyond requires a multidisciplinary team of physicians with expertise in multiple specialties, highly-trained nurses, pharmacists, nutritionists, physical therapists, social workers and others. Without these colleagues, it would not be possible to provide the highest levels of care to my patients. Patients themselves are an important part of this team with a very difficult role—complying with complicated
therapeutic regimens despite fatigue, pain and side effects. Their courage and persistence inspire and motivate us.

An equally important, but sometimes more overlooked member of this team is the caregiver. Most often a spouse, parent or child but sometimes other relatives or friends, caregivers play an irreplaceable role in care and recovery of patients. Most come to the transplant procedure with little medical knowledge or skill but quickly gain competence in the language of cancer and transplantation, acquire expertise in the identification and dispensing of medicines, and become able providers of a considerable amount of hands-on medical care. And caregivers provide things that the medical team cannot provide nearly as well—love, hope, encouragement, understanding, a knowledge and appreciation of the patient that goes beyond their illness. When patients are too tired or too sick to effectively communicate their needs, caregivers are their advocates.

Several scientific studies show that patients with supportive relationships fare better than those without caregiver support—and this is true for both children and adults. Though not so scientifically rigorous an evaluation, I know from personal observation that the pain and discomfort of the transplant procedure are borne more easily by those with family and friends to lean on. I feel much more comfortable discharging a patient when I know he or she has a strong support system. I also know that this support is not so easy to give. Caregivers often sacrifice much for their loved ones. There are long days and long nights; there is fatigue and discouragement. Careers and usual social and family roles must sometimes be put aside for long periods. Additionally, the difficulties faced by the transplant recipients are often acknowledged and are the source of sympathy and empathy from the medical team, friends and relatives. However, the difficulties of those sharing the experience with them may be overlooked or minimized.

Yet, there are also rewards. Helping the person you love overcome their illness is the most obvious. Additionally, families and friendships may achieve new levels of intimacy as hardships are faced together. Individuals sometimes find they have strength and skills they never imagined possible. But there are days when it is hard to see the rewards—and only too easy to be discouraged by the difficulties. This book gives you practical suggestions for getting through the hard days from people who have been there. Hopefully, it lets you know that you are not alone, that it is worth the struggle and that your role is critically important and appreciated.
Why a Special Booklet for BMT Caregivers?

by Myra Jacobs and Michelle Bishop

Myra Jacobs, MA, is the Founder and Executive Director of the National Bone Marrow Transplant Link (nbmtLINK). She has been involved in non-profit management, program development and fundraising for over 30 years. Her interest in bone marrow transplantation began while on staff at the Children’s Leukemia Foundation of Michigan for over 10 years. Inspired by the plight and courage of bone marrow transplant patients and families and recognizing their need for information and support, she founded the National Bone Marrow Transplant Link in 1992.

In 2004, Myra received the National Public Service Award from the American Society for Blood and Marrow Transplantation. She is currently a member of the Consumer Advocacy Committee of the Center for International Blood and Marrow Transplant Research (CIBMTR). She is a graduate of the University of Michigan and holds a Master’s Degree in Guidance and Counseling from Oakland University.

Michelle M. Bishop, PhD, is Research Assistant Professor in the Departments of Medicine and Clinical and Health Psychology, at the University of Florida, Gainesville, FL. A licensed clinical health psychologist, Dr. Bishop has 12 years of clinical experience helping patients and families with the psychosocial aspects of acute and chronic illness and its treatment, particularly cancer and blood and marrow transplantation (BMT). She served for four years as the project coordinator of the largest study to date of the long-term quality of life (QOL) of BMT survivors and their spouses, a multi-site project funded by the National Cancer Institute (NCI) involving 40 BMT centers in North America. She recently received her own grant from NCI to conduct an in-depth follow up study of the couples enrolled in the aforementioned study to better understand
There are multiple reasons for publishing Caregivers’ Guide for Bone Marrow/Stem Cell Transplant, Practical Perspectives. Since its founding in 1992, the National Bone Marrow Transplant Link (nbmtLINK) has had the opportunity to work with a host of remarkable people who filled “caregiver shoes.” Early on, we were inspired by stories of BMT caregivers that demonstrated incredible spirit, dedication and perseverance. We asked ourselves, “How could the nbmtLINK address the unmet needs of BMT caregivers?” and “What could the nbmtLINK do to recognize and support the efforts of these caregivers?” It is well known that in this environment of increasing outpatient care, the caregiver’s responsibilities become closely woven into the BMT process itself. In addition, the health care team actually relies upon the caregiver to provide services for the patient. Studies have shown that the caregiver role is critical to the health, adjustment, and quality of life of the BMT survivor. Yet, the physical, emotional, and social impact of the disease and BMT treatment on the family often are not acknowledged. In fact, caregivers experience the same, if not more, distress than the survivors themselves and are usually less likely than survivors to get the help they need.

After much observation and discussion, we concluded that the creation of a special booklet was needed. By focusing on various perspectives, the booklet would offer insights into the BMT caregiver role while acknowledging and affirming its importance. In reality, caring for someone having a BMT is a unique commitment requiring extraordinary physical and emotional effort. The primary medical focus, of course, is directly on the patient, with the hope for a positive treatment. However, the challenge of a BMT for the caregiver becomes life-changing as well. BMT caregiving, depending on the type of transplant, may consume one’s daily living for an extended time. Families may be subjected to intense emotions and challenges in the wake of BMT. Treatment may require lengthy stays at a specialized care center hundreds of miles from home. Families often face financial hardship as careers are put on hold and health care costs accumulate. Many caregivers struggle to balance caring for the survivor with raising children and tending to the household. The caregiving role is not a...
casual responsibility. It is a serious and ongoing promise. BMT caregivers may “wear the hat” of coach, nurse, nutritionist, companion, aid, driver, administrative assistant, spiritual counselor, advocate, and more. They may be signing on for weeks, months or even years of duty. It can be a sobering challenge and responsibility but clearly one worth the effort.

With regard to the long term picture, BMT family caregivers may continue to feel the impact of the cancer/BMT for months or years after the active caregiving stage is over. Although most are remarkably resilient, a substantial minority continue to be negatively impacted by the personal, family, and life changes that occur. Studies have shown that approximately 20% of BMT spouses report symptoms of depression many years after BMT. Many feel lonely with limited social support for themselves and describe fewer of the positive changes, such as new life meaning or personal growth, which many BMT survivors describe. It is important that BMT caregivers be aware that, like BMT survivors, they may experience long term “side effects” of the experience and should seek the help and support that they need and deserve.

In creating this booklet, we hope to address the educational and emotional needs of BMT caregivers to help them successfully cope with their caregiving journey and to know that they are not alone.

Through this publication, we hope to:

• Elevate and legitimize the role of the caregiver.
• Encourage interventions that permit the BMT caregiver to participate as a member of the health care team.
• Encourage family members, friends, and the community to support the caregiver’s efforts and provide some release from daily responsibilities.
• Empower caregivers to seek psychological counseling for themselves when needed. It is a sign of strength, not weakness to ask for help.
• Encourage caregivers to utilize community resources for educational and emotional support.
• Educate caregivers as to why it is vital to take good care of themselves.
• Recognize the potential rewards of the caregiver role in terms of personal growth, family cohesion, and a new appreciation for life.
• Reinforce the fact that caregivers are not alone in their circumstances.

While BMT patients may follow an arduous road to recovery, BMT caregivers walk a parallel path with their own set of unique challenges. With this booklet of practical perspectives, we hope we have made the caregiver journey an easier one.
My Gift to Mom for Her Second Birthday

An Adult Daughter’s Perspective

by Erin Gentry

Erin Gentry was the primary caregiver for her mother, Martha, during her autologous stem cell transplant for non-Hodgkin’s lymphoma at the University of Nebraska Medical Center in Omaha in 2004. She currently resides in Durham, NC and very much hopes that by the time you are reading this, she will have completed her PhD in English. Her caregiving experience has changed her life in many ways: she has become a regular platelet donor; she ran a half-marathon as a fundraiser for The Leukemia & Lymphoma Society; and she is the recipient of a beautiful gift of perspective that regularly reminds her how wonderfully lucky she is to have her mother, alive and healthy, in her life.

I had just started my third year of graduate school when my mother was diagnosed with Diffuse Large B-Cell Lymphoma and a tumor in her abdomen the size of a grapefruit. My mom and I have always been intensely close, and being 1200 miles away as she experienced the repeatedly disappointing results of three increasingly aggressive chemo protocols was, well, gut-wrenching. My first response was to join the National Marrow Donor Program Registry and to cut my long hair and donate it to Locks of Love to be made into a wig for someone; but I was having a hard time just getting out of bed in the mornings because I felt so frustratingly helpless. When the stem cell transplant loomed on the horizon, there was some question as to who would be the primary caregiver. I certainly had the most flexible schedule in my family, and it was with great relief at finally being able to DO something that I took a leave of absence from school and moved back home to Nebraska for four months.

As grateful as my mom was that I could be her caregiver, it was not an easy thing for her—or any parent—to accept. Parents want to do the caregiving, and they want to make things easier and better for their children. My mother felt guilty about “uprooting” my life. It took some time for her to be able to accept that—emotionally—I needed to
be there just as much as she needed me there. And let’s face it: as soon as the diagnosis of “Cancer” is made, everyone’s life gets “uprooted” as plans change and priorities dramatically shift.

Caregiving for a transplant patient disrupts the rhythms of your normal life, substituting doctors’ appointments, blood draws and medication schedules. Time is a funny thing in the transplant world. It is what you are fighting so desperately for more of, and yet what often passes monotonously in waiting rooms in anticipation of the next set of “results.” But time is all about how you choose to fill it. Mom and I carried a favorite word game with us wherever we went (mom still claims it helped with “chemo brain”!) to fill in those waiting spaces. And since both of us are workaholics at heart, we unexpectedly found ourselves with time for leisurely conversations and with bonafide excuses to “goof off” in whatever ways we could invent. We had the kind of time to spend together that grown children and their parents rarely get. Despite the hard, scary and ugly moments, we both remember this time as one of the greatest gifts the transplant process gave us. (Yes, it does give gifts!)

But, along with the gifts, there were most definitely, hard, scary and ugly moments, all requiring different sorts of coping. One of the hardest things for me was my mom’s need to talk about death. People cope with the ever-present specter of death in different ways. My mom, the scientist, needed to face it openly and talk about contingencies, and she needed to know that if it came time, I would let her go. I felt my job as a caregiver was to revive her spirits when they flagged, to cheerlead, to help her fight the fight, and it was hard not to feel failure and despair when my mom talked about her death. But I learned that being able to talk about death was just as much a part of caregiving for my mom as crusading against it. We compromised: I promised I would let her go if it came time, as long as she promised she would fight her hardest until that time came.

The scary moments were of the mind-numbing “this can’t really be happening” variety. It was frightening enough that they predicted a 15% chance of success going into the transplant due to her tumor’s classification as “chemoresistant.” But it was utterly terrifying when mom ran a dangerously high fever for several days, when her lungs filled with fluid, and when her heart rate soared off the charts. Most of all, it was when she stopped being “mom.” The full impact of our role-reversal didn’t hit me until she was so sick that I was no longer just holding her up but was shouldering the decision-making without her input.

During those early post-transplant days, I wondered if I would ever see “mom” again. Those were the lowest days, the kind that had me asking if I was strong enough for this. I was. And I promise, you are, too. Whether you call on faith, on hope or on will, you will find it there when you need it most. And never stop believing. My mother—who bounced back from heart failure in a matter of days and is nearing three years in remission—is proof that statistics are only numbers.
Sometimes it was difficult for me to cope with my own feelings. I felt frustrated, angry, helpless, sorry for myself, then guilty about having any of these feelings in the first place. I was very blessed not to have a job at risk, or a family of my own needing care, and was additionally blessed that my stepfather was also there to provide caregiving respite and to handle all the financial matters. Most people caregiving for a parent have many more needs to juggle and sacrifices to make. Yet, even in my situation, caregiving had its strains, and I had to learn the importance of taking time off and taking care of myself. I still felt guilt: after all, my mom couldn’t ever take “time off” from having cancer! But by allowing myself time to visit old friends or catch a movie—and in so doing, to re-gather my spirits and relieve my frustrations—I was being the very best caregiver I could be. As selfish as it sounds, caregivers need to put themselves first sometimes. And they need their own caregivers, especially someone who is wholly invested in their well-being (as opposed to the patient’s), someone to whom they can admit all their frustrations without fear of judgment and who can remind them to take time for themselves. Support groups, and even other caregivers, can be great sources for letting off steam; just make sure you have someone!

Beyond helping with medications, meals, etc., and keeping that ever-important notebook of details and questions, I found there were other ways I could make a significant difference for my mom’s experience. One such way was in keeping friends and family updated on my mom’s progress. We found an online blog (we used livejournal.com, but caringbridge.org is another great, free site) where we could post daily updates and visitors could leave comments, the most efficient and easiest way to do this. I could also help by supporting my mom as she searched for meaning in this journey (her way of answering the “why me?” question). For my mom, that meant giving back and making something beautiful out of the experience and wisdom she was gaining.

To this day, when my mom reads back over our “livejournal” of the transplant experience, she is shocked by many of the entries I wrote during her sickest moments. The details are wholly unfamiliar to her; she simply has no recollection of them. This is the best gift I can offer to any of you embarking as caregivers on the transplant journey: those days when your loved one is in the most pain, is the most miserable, and you ache the most for them… these are the days they are least likely to remember. It truly is a second birthday for them, and you, too, one day farther along in the healing process, may be able to look back on the experience not with memories of the struggle, but with joy and thanks for the new life it enabled.
Tackling the Challenge

Caregiving from a Husband’s Perspective

by Chris Johnson

Chris Johnson assumed the role of primary caregiver for his wife, Sheryl, when she was told that an autologous stem cell transplant would be the treatment of choice for her breast cancer. (Please note that although stem cell transplant is no longer commonly used for the treatment of breast cancer, the caregiving perspectives in this chapter are nevertheless valuable.) In addition to caring for Sheryl, he also managed parenting responsibilities for their two teenage children. Chris is an attorney and works as General Motors North America Vice President and General Counsel. He is a graduate of West Point and served in the U.S. Army receiving the Army Commendation Medal for Meritorious Service.

“You have Cancer.”

When you first heard those words come out of the doctor’s mouth concerning your spouse, child, parent, or loved one, you probably marked it as one of those days when your life changed forever. Although not the patient, I abruptly moved into a world where I did not speak the language, often felt overwhelmed by the number of decisions to be made, and within a short time, assumed a full schedule as primary caregiver.

After 25 years of marriage, I felt a wide range of emotions. Among these strong feelings, I experienced a huge sense of loss of control. One close friend said, “I feel like our lives have been hijacked.” At the highest level, it goes to loss of control over your destiny. At the most basic level, it goes to what you can eat, drink, and think about day and night. The difficulty and strain of dealing with many of the medical treatments is woven throughout all of the experience.

One of the most promising, as well as challenging treatments for selected cancers and other diseases is a bone marrow/stem cell transplant (BMT). When my wife and I first
heard the diagnosis and treatment options for her, we almost fell out of our chairs! BMT is a demanding treatment, but it offered us hope. Still, there is, with a BMT, like other treatments, that loss of control. It included an extended hospital stay and convalescent period among many other inconveniences that accompany the procedure.

The one positive aspect of a BMT that stood out in my mind was that the patient needs a caregiver. In our case, that was going to be my role. You might question, “Why is that such a good thing?” My immediate answer—it gave me back some of what I felt was lost when we heard that dreaded diagnosis. I was gifted back some personal control over the situation. For the first time since my wife had been diagnosed with cancer, some two years prior, I played a clear and defined role in her treatment. I was to be an important part of this experience. No longer was I just a bystander. No longer was I just a conduit to the nurse or doctor, but rather, I was an integral part of the team. That made me personally feel that I had some control over this “thing” that had taken possession of our lives.

Being on this BMT team comes with a lot of responsibility, and it takes time, courage, stamina, and everything else you have needed to tackle other life challenges. As I think back, I never thought I would find anything that could compare remotely to my plebe year at West Point, or negotiating the “deal of the century” as a successful corporate lawyer, but this BMT experience put all of that to shame. It was, and will remain, the challenge of my lifetime.

I moved into the role of caregiver with gusto. I was empowered being able to serve my wife in this manner. Of course, I had the same emotional concerns as many caregivers. I sometimes felt that strange sense of guilt of being in a hospital and being healthy. It is naturally difficult, sometimes beyond words, to watch your loved one feeling so desperately ill. You, as a caregiver, may wonder, as I did, if you are up for this momentous challenge. Believe me, you are.

What I can recommend to you from my own experience is a playbook, of sorts, just like a football player or coach relies on in sports. Knowing what “plays” you can call and ones that you cannot becomes valuable. It helped me immeasurably to have a flexible “game plan” regarding my caregiving role. An organized notebook is a must! It might include a general written outline that captures everything from medical concerns and questions to keeping a journal recording the emotional journey your patient is taking. I kept track of some special needs including financial issues that arose during the BMT.

It is easy for caregivers, as well as the patient, to experience “information overload” given the circumstances of a BMT. There is plenty of information to track. Being organized was made simplest for me with a caregiver’s notebook. Included in the notebook were calendar pages that permitted entries. It will become, as it did for me, a valued tool. I could, when my mind was “too crowded” with details or the constant flow of information, always refer back to my notebook for reinforcement. Create your
own notebook or purchase one at a bookstore. You can also look online for special caregiver notebooks.

The BMT spousal caregiver experience is, without doubt, the challenge of a lifetime. Being organized, “in control” as much as is possible, and ready to be a team player will serve you well.
Cancer Etiquette

A Survivor’s Perspective on Effective Communication

by Rosanne Kalick

Rosanne Kalick, MA, MLS, is a two-time cancer survivor. She was diagnosed with multiple myeloma in 1993, had two stem cell transplants and has been in partial remission ever since. In 2000, she was diagnosed with breast cancer which was treated by a double mastectomy and chemotherapy. Rosanne was a high school English teacher and then became a college librarian and chairperson of the Library and Learning Resource Center at Westchester Community College in Valhalla, New York. After retiring, she began work on her book, “Cancer Etiquette: What to Say; What to Do When Someone You Know or Love Has Cancer.” Her research, her volunteer work, and her five grandchildren keep her out of trouble.

The Words

Etiquette books abound. You can learn how to fold napkins, what to wear on the golf course, how to behave in a church where the rituals are new to you. We want to say and do the right thing. We look for standards for our behavior. When it comes to cancer, however, we have few guidelines. Too often our emotions take over, and we say or do the inappropriate thing.

Years ago we spoke in whispers about cancer, and there was little we could do as friends, family, or colleagues. Today we speak openly about the disease, and there is much we can do to communicate more compassionately. Words and deeds are powerful.

Often people say the most damaging words during the period just after diagnosis. The shock, memories of family members who had cancer, the individual’s fear of getting cancer cause him to speak before he’s thought of the consequences of his words.

One young woman diagnosed with breast cancer received a sympathy card from her mother. A casual acquaintance asked someone who had a colostomy whether the bags
were paper or plastic. At a luncheon, one woman turned to another and told her not
to touch the glass of another guest because “she has cancer.”

Those are examples of words said, words that hurt. There are many, many others. If
we begin to think in terms of cancer etiquette, we are less likely to err in our words.
“Do I really need to say this?” or “What would I want someone to say to me?” may pre-
vent verbal errors.

It is not uncommon for someone to say to the patient, “You will be fine.” Of course,
you want everything to be fine, so does the patient. By saying that, however, you’re
ignoring cancer reality. The high dose chemotherapy in the bone marrow transplant
process and the threat of infection are part of that reality. While the transplant suc-
cess rate is good, there are likely to be setbacks along the way. That is part of the
process. Saying “I hope everything will be all right” or “You’re in an excellent program;
you’ll be getting excellent care,” are better choices. The patient is facing the greatest
medical challenge of his or her life. Your saying everything will be fine doesn’t give the
patient any “wiggle” room. How can he or she speak to you openly unless you are real-
istic about the medical situation? This is true of most of our questions and words.
Always leave the door to communication open so that the patient can be honest, can
raise issues of concern to him, can speak of his anger, his fears, his family concerns.

“How are you?” Usually we’re expected to give the standard, “OK, fine or great.” The
question and the response aren’t taken too seriously. It’s part of the daily exchange of
words. In the cancer scenario, however, that question is significant. If you’re going to
ask this or any other question, be prepared for the answer. It may be better to say,
“How are you today?” The patient can then speak honestly of how he feels at the
moment. He can speak of how he feels today compared to yesterday.

Be careful, too, about commenting on how the patient looks. Don’t tell the patient
how great he looks. The transplant patient will not look great much of the time. He
knows that. Saying, “You’re looking stronger” or “I’m glad to see you’re walking
around” are better choices. There are two areas that are particularly sensitive. Hair
loss is one. High dose chemotherapy causes the patient to lose his hair. Eyebrows,
eyelashes, and pubic hair can disappear. It will be months before hair growth returns.
Seeing oneself bald every day isn’t easy. Don’t ask how it feels to be bald.

If the patient should make a comment such as, “I’m really worried about dying,” and
you respond, “You’re not going to die,” again, you may be “clogging a verbal artery.”
The patient wants to live. She wants to live to see her children grow up. He wants to
live long enough to meet his grandchildren. Fears about death, pain, finances, per-
manent damage to the immune system are natural for the transplant patient. Your
responsibility as caregiver, friend, family member, or colleague is to listen. Listening
totally, listening without interrupting the patient, listening without planning your
response will be extremely helpful.
If you’re a close family member or friend, probably the most important words you can say are, “I love you.” Joseph Telushkin tells the story of an old man whose wife had just died. The scene is the cemetery. All the guests have left, and only the man and the rabbi are present. The old man keeps repeating, “I loved my wife, I loved my wife” again and again. The rabbi keeps telling the old man that it is time to go. The old man finally says, “But you don’t understand. I loved my wife, and once I almost told her.” During the long transplant period, the two greatest gifts you can give will be your presence and your words of love. Never underestimate the power of a hug, the power of silence, the power of a touch.

Don’t ask questions now that you wouldn’t have asked before the diagnosis. If you discussed your sex life with the patient before his treatment, fine. However, just because your uncle has had prostate surgery doesn’t give you permission to ask about impotence now. If you talked about problems with your teenage daughter before the patient started treatment, you can do so now. If the patient is too tired, she can ask that you talk about it some other time. If you value your friend’s advice about business, you can still ask for it. The fact that he’s having treatment doesn’t mean he is any less intelligent than he was before. There may be times when the drugs will give him a sense of “chemo brain.” Obviously if he seems disoriented or excessively fatigued, postpone the question. When in doubt about what to say, don’t say it. Think before you speak.

Equally personal is the faith question. Again, if you’ve discussed faith with the patient before her illness, it’s probably all right to discuss it now. It’s best to wait for the patient to raise the issue. If you have strong religious views, and you’re not sure of the patient’s, don’t speak about how faith will heal. You may be intruding into an area that is too difficult for the patient at this time.

Generally, your presence is more important than your words. In our society, we seem to think we need to talk whenever we’re with someone. There will be times when silence may be the best connector.

**The Deeds**

“If you need me, I’m here.” “If you need anything, just call.” Variations on these words are common. There are better ways to offer help. Be specific. “Do you want me to bring dinner on Tuesday or Thursday? Do the kids prefer chicken wings or roast chicken?” “I’m going to the library tomorrow. I can return your library books and pick up picture books for the kids.”

Patients undergoing a transplant may feel their life is out of control. Anything you can say or do to restore a sense of control is good. That’s why asking rather than telling works. It gives the patient a chance to make a decision, to assert control. Specific areas of help include planning schedules for carpooling, travel (especially important if the patient is being treated at a cancer center far from home), arranging food shopping and preparation. Remember, bringing dinner means cleaning up as well. Often two or more people need to coordinate these schedules.
Here are some guidelines for gifts:

- Buy pajamas or nightgowns that open in the front. This makes it easier in terms of the catheters the transplant patient has.
- Moisturizers are good, but no gift should be heavily scented. Strong smells can add to the patient’s discomfort.
- Snacks can be great. The patient’s appetite will need stimulation. Providing the doctor approves, almost anything that the patient enjoys is acceptable. Ice cream in the morning? Why not? Interesting teas, nutritional home shakes, and hot chocolate may stimulate a weak appetite.
- Bring CD’s or books that are short and light.
- Consider a magazine subscription for the patient or her children.
- Give a gift certificate for dinner or a manicure/pedicure, a day at the spa, or a cleaning service for one day.
- A gift to a cancer organization honoring the patient is appreciated.
- During the neutropenic period, do not give gifts of flowers or certain fresh food.

The patient will be undergoing treatment for several months. One card or one casserole will not do the trick. E-mails, notes, jokes, videotapes, computer games are all good possibilities. Remember the caregiver with small gifts. Plan for the long haul. Work in community. Your neighbors, church or synagogue, or office mates can collectively do more as a group than you can as an individual.

If there is a mantra for cancer etiquette it is “Stay connected; stay connected; stay connected.” You’d be surprised at how many people “disappear” when someone gets cancer. Understand that you won’t be able to do everything, but you can do something. Cancer etiquette is like a puzzle. What will fit one moment won’t the next. Just keep trying. You can do it!
Top Tips for Parent Caregivers During the BMT Process

Caregiving from a Mother’s Perspective

by Melanie Goldish

Melanie Goldish, MA, is the mother of a bone marrow transplant survivor. In May 1998, her five-year-old son Travis was diagnosed with Acute Lymphoblastic Leukemia (Philadelphia Chromosome). Travis received an unrelated marrow donor transplant in September 1998 from their “hero” donor Marj. Melanie is the Executive Director of SuperSibs!—a nonprofit organization to honor, support and recognize siblings of children diagnosed with cancer (www.supersibs.org). She also serves on the National Marrow Donor Program Board of Directors and The Marrow Foundation Advisory Board. She holds a Master of Arts degree from the University of Minnesota and is the proud mother of two miracle sons, Travis and Spencer.

As a parent who was instantly transformed from a typical devoted and loving, working mother to a “BMT Mom,” I learned firsthand about the immense multitasking and perseverance required to manage through the emotionally and physically draining transplant journey. On its own, parenting is a formidable task. Parenting, self-care, and caregiving for a child before, during and after his transplant is a huge endeavor—one that requires more than a single individual can ever manage alone. Fortunately, many parents have blazed this trail with positive outcomes and shared their experiences so that others may benefit. In the end, this journey will hopefully leave us all with a lasting legacy of better parenting, a solid outlook, powerful perspective, and a
healthy, strong family as a result of this lifesaving transplant procedure.

Everyone’s situation and experience with transplant is unique—so some suggestions may be more applicable to you than others. When reviewing the following tips, use what works best for you.

1. **Remember The Power of Choice**
   
   **For You…**
   
   As difficult as it is, the quicker we can snap ourselves into reality of “what is”—what we’re dealing with—the better we can focus our energy, resources, and creativity to decide on the best course of action for our child and family. We can’t choose the fact that this “event” has happened—that our child needs a transplant; that this is “happening to us”—yet we CAN choose how to respond. This is a powerful principle to help pull you and your child through the many difficult hours, days, and treatments ahead. So give yourself permission to choose, whenever possible. Choose to talk with friends about how you’re feeling. Choose to take a break to collect your thoughts alone, and enjoy a cup of coffee. Choose to join a support group or listserve online. Choose to see a therapist. Choose to focus on the positive, versus the energy-draining “victim mentality” that can be so seductive. Choose to be an involved and informed parent through the transplant process. Choose to cry if you need to—then choose to “get up and keep going.” Choose to explore all available support options at work. Choose whatever works for you. This is where you do have control—in how to respond to this life-challenging event. We can each choose how to respond for ourselves in a way that will best meet our unique individual and family needs.

   **For Children (Patient and Siblings)…**
   
   The power of choice is just as strong for our children facing transplant—and their siblings. Sometimes, the options aren’t as exciting as our kids would prefer, yet having choices in a situation that feels so totally out of their control can be helpful. Whenever possible, offer choices to your children. Let them be in the “driver’s seat” with clear options such as: Would you like to leave now or in 10 minutes? Which leg should get the “poke” (shot)—right or left? Do you want a chocolate malted or a strawberry sundae? Would you like to help arrange the dressing change supplies or have me do that today? While in some situations there may seem to be no options available, try to creatively offer some choices. For example, it may be an absolute that your child must take Cyclosporine medication each day. Perhaps offering your child the option of taking it with chocolate milk or root beer soda will help him be a more willing participant. Even these seemingly small choices give some semblance of “control” in a world where so much seems to happen “to” your child. Choice is the ultimate freedom. Both you and your children may benefit greatly from this approach.

2. **Take a Deep Breath and Seek Support…**
   
   While many of our friends and neighbors may offer support on a one-time basis or even a few occasions, it often quickly becomes a harsh reality that most return to
their own daily lives. Therefore, it becomes vital to reach out for help. And yes, that means we need to ASK. Waiting for the right offers may be...well, a long wait! While we may feel alone in this journey, with few friends or committed helpers, ongoing support can be found through many sources. Check out religious and worship centers, religious groups’ Caring Community Committees, your children’s school parent organizations, their teachers and classmates’ families, a special task force at work, not-for-profit organizations such as the National Marrow Donor Program, Office of Patient Advocacy, National Bone Marrow Transplant Link, The Marrow Foundation, Make-A-Wish Foundation, Ronald McDonald House Charities, and neighborhood outreach groups. Rely on the expertise of your hospital’s transplant coordinator and social service team. And don’t forget your own family members. Many extended family members have been known to say after transplant, “I didn’t know how to help and didn’t want to be in the way. I just wish they’d have asked.” The key is to ask for help and enlist as many people as possible to share the support opportunities.

...And Then Accept This Support—Without Guilt!

As parents, we have been thrust into this terrifying world with no warning and no preparation. We may be entrenched in the cultural norm of “I’d rather give support to others than accept it myself.” Quickly, let go of that belief and accept the caring of others graciously and without guilt. Everyone needs help at some time or another. Now it’s your turn. There’s no question about it—no parent caregiver can muddle through this tremendous transplant challenge alone. So after you’ve asked for help, accept it. Save that energy for focusing on your task—bringing home a healthy child with you and your family intact, to life beyond transplant.

One way many caregivers clear the self-imposed barrier of accepting support is by making a personal commitment to provide help to others in the future—to continue the cycle of giving. This may be the key to giving yourself permission to ask for and then accept available support on an ongoing basis. As a wise person once bluntly said to me, “How dare you deprive us of the only thing we can do to help? PLEASE allow us to help you with meals, lawn mowing, pampering, carpooling, gifts, fundraising and public support. It’s all we CAN do. It makes us feel good. And who knows? We may need your help one day, too. Please don’t shut us out.” With that understanding, it may become easier to accept support from friends, neighbors, and even strangers. Remember how good YOU feel when others accept your help? Offer that same gift to those around you. Accepting support helps others as much as it helps you—maybe even more

3. Focus On What’s Important

After transplant, many parent caregivers are greeted with awe and feedback from others as if they’d performed a superhuman feat. While it’s a challenge to undergo transplant oneself, it’s another thing entirely to manage the transplant process for a child who needs our undivided attention as well as a family that craves our participation, love, and care. One way to juggle this load of stress, strain, and pressure is to
peel away what’s unimportant—at least for the immediate time. The most effective way to manage through transplant with and for our children is to use an ever-present filter of “Is this really important right now?” This “decision-making sieve” will allow you to preserve your attention and strength—and focus that energy where it’s needed. Some things, like paying bills, must be attended to in a timely basis. Other chores can be prioritized as a back-burner task. We can only spread ourselves so thin without breaking—so why not spend our attention and energies on our most urgent short and long-term needs? Focus on what’s really important and jettison the rest.

4. This Is Important—You Come First!
There’s a very sensible reason why, in their safety briefings prior to takeoff, flight attendants tell parents, “In the case of a loss of pressure, oxygen masks will drop down. Put on YOUR mask first. THEN apply your child’s mask and attend to their needs.” This principle applies to us—the transplant parent caregivers—as well. We certainly can’t attend to our child’s needs unless we’ve taken care of ourselves well enough to do so. What may seem like a luxury to you in the scheme of the transplant experience may actually be a necessity to ensure you will be as effective as possible in this role. Let go of the guilt. Here are some reminders of how this works:

- **Just Say No**
  Let go of the need to please others. If answering the phone’s incessant ring is draining, unplug the phone during certain hours. If a procedure is scheduled for your child at a time when it’s most difficult for you, ask if an alternative time is possible. Often, we accept what others impose upon us—at greater consequence to ourselves and our families. (If you’ve forgotten already, go back to the principle above—focus on what’s important.) Right now, the health and survival of your child and family is job #1. Being a pleasant hostess, excellent committee member, or super work performer can wait until another day.

- **Remember Your Identity**
  Somehow, between the incessant pumps beeping in the hospital room, your three changes of clothes you rotate wearing in the hospital room, and the constant concern about your child’s “counts,” it dawns on transplant parent caregivers that their name has become solely “Mom” or “Dad.” (With so many transplant families in and out of the units, most nurses and doctors refer to the generic parent name for everyone!) As strange as it sounds, after rotating night after night in a hospital room or nearby residence, we caregivers can begin to lose a sense of our own identity. Ask friends to remind you what it is that you do well. Ask them to regale you with stories “from the outside.” Read books or magazines that stimulate your special interests during the frequent five-minute quiet breaks. A little personal pampering can go a long way to stay grounded—whether it’s a special soft music tape to take you “away” now and then or a special robe to wear in the hospital, find ways to honor yourself. Yes, you’re an individual that needs to have nurturing, too.
• **Preserve The Journey And Life Lessons**

Many parents find it a healthy catharsis to journal their thoughts, emotions and experiences during and after their child's transplant. Bring a laptop or write in a journal to preserve your experience—or use free communication web pages like www.caringbridge.org and www.carepages.com to help family and friends stay connected with you. While “chemo brain” seems to be a phrase used by transplant patients themselves, it’s also common for parent caregivers to get so sleep deprived that all details get muddled. Many of these memories may be best left on pages unread by anyone other than you—but you won’t know this until months or years later. So record this information now as a remembrance for yourself—and perhaps your child and others—in the years to come.

• **Speak Up!**

Find ways to connect with your friends and loved ones that will squeeze within your child’s busy hospital routine. Perhaps schedule a nightly online chat group for your closest buddies to catch up on the day’s progress and some distracting cyber-laughs that they can bring. Then type like wildfire and enjoy the “company” during the dark and quiet hours between treatments. People want to know how things are going in the isolated world of transplant. While it’s a tremendously personal experience for parent and child, often sharing these thoughts on a special Web site for your child, in a group “e-mail blast” or home voicemail message can be a wonderful way to help others feel engaged and for you to feel supported.

• **You Deserve Better Than Table Scraps**

OK, be honest. How many peanut butter and jelly sandwich crusts have you ingested by the time you’ve read this paragraph? How many of your child’s unconsumed hospital food tray choices have you polished off “because it’s there and it saves a trip to the cafeteria.” Healthy food for you means more energy. Get rest when you can. Even squeeze in a brisk walk or run now and then. And eat from the healthy food groups—now, more than ever!

• **Go With A Pro**

It's OK to seek support from a professional counselor or therapist. For those of you who need to read this twice, yes, it’s OK! Many parent caregivers mistakenly feel that choosing to seek outside support is a sign of weakness. On the contrary, it takes a strong individual to know when outside help can be valuable. Your caregiving style may be vastly different than that of your spouse. You may now be facing strains on your marriage that seemed inconceivable before stepping into the “transplant world.” You may not understand your own reactions, moods, behaviors, fears or decisions. You may be stumped by the mood and energy swings coming from “the child you knew so well” who is undergoing transplant and feeling the effects of steroids, chemo and radiation. You may experience issues with your other children or family members that are difficult to manage, on top of all the
other strains you’re experiencing. All these issues are legitimate—and they are vital to acknowledge and work through. Search for a professional that has experience in dealing with childhood illness and/or family/marriage therapy. Or better yet, ask a trusted friend or workplace Employee Assistance Program (a confidential service often a part of your employee benefits program) professional to do homework for you to select the right counselor(s). Having a skilled and caring professional to listen to your thoughts can provide release, peace, and clarity that will reap rewards for years to come.

5. Do Your Homework, Trust Your Gut, and Don’t Look Back
Take advantage of the many resources available to you. Ask questions of your child's medical team, social worker, nutritionist, and child-life specialists. Read research studies on transplant procedures. View support tapes, such as nbmtLINK's award-winning video *The New Normal*, addressing life after transplant. Choose your transplant team and hospital according to criteria that’s most important to your child’s diagnosis and your family’s particular needs. Use Internet search engines such as Yahoo or Google to find support group links, specialty organizations, listserves, Web sites for your child's diagnosis, and even other families who have traveled this journey. Because not all information is credible, be discriminating with what you learn and discard that which doesn't add value. And as you make each decision, trust your intent that you’ve made the best possible decision, with information available at the time—then go with your gut decisions, and don't waste precious emotional energy on “Why did I do this?” questioning. You will face many decisions along the transplant journey with your child—and multiple course corrections along the way. Give yourself credit for doing the best you can, each step of the way.

6. Bring Out the Child In YOU
During the long, challenging, frightening and often boring hours—before, during and after the actual transplant—your creativity may be tested to its limits. Sometimes, our own playfulness can be the best healing therapy for our children as well as ourselves. So why not allow your child to “tie you up with the Velcro straps” on the empty gurney while you wait for a delayed MRI? Why not bring a book of jokes to prompt silly giggles while you try not to think about the bone marrow aspiration yet to come? Why not invent a treasure hunt in your child's hospital room or use approved window “paints” to decorate your surroundings together? Why not learn a new craft with your teenaged patient during these focused hours? Whatever works for you, your child, or your family—try out new alternatives. Pull out all the stops, and don't be embarrassed at your need to bring laughter, joy, fun, and creativity into this scary world. You’ll be amazed at some of the beautiful moments to treasure as you and your child look back at “those days during transplant.”

7. Look for Beauty
It’s a bold statement to suggest that beauty can be found anywhere near your child's transplant procedure. Yet, many transplant parent caregivers have expressed the
feelings that even amidst the biggest nightmare of their lives, moments of rare beauty have pulled them through. Take a moment to appreciate the cocoon of support that's been blanketed around you, your child, and family. Send thoughts of support or prayers in honor of your child's amazing donor—for the miracle of life this person has provided your child and family. Think about the advances in medicine, and consider the professional support team that has made this day possible. Appreciate the uninterrupted moments of cuddling in your child's hospital bed, giggling over a story together. Be aware that this journey has brought you a rare glimpse of what's really important in life—an insight that many people never get. At times, these beautiful moments may be all that pulls you through one more medicine pump beep in the middle of the night. Seek and acknowledge these treasures.

8. Be Your Child's Advocate

On a very practical level, be aware that you are the best advocate for your child. Don't be shy about asking question after question of the medical team. You are a part of that team—for and with your child. Don't be afraid to challenge decisions that you don't quite understand or agree with—and then do calmly work out an amicable solution together with the medical team and your child. Document everything! One would think that the medical pros will have it all handled, but we're all human and everyone makes mistakes. Also, your child's team (including perhaps you and your family) operates in shifts, so effective transfer of information is critical. You may never need to re-read all these details, yet from time to time, the notes you've kept will be the vital information necessary to determine next steps. Attend the “rounds” meetings each day regarding your child. Typically, the physician and team will gather together in or outside your child's room to discuss clinical progress, challenges, and courses of action. It is in your child's best interest to listen, learn, and participate in these briefings. Don't be shy about being present. And lastly, remember to solicit your child's input and feedback. Many transplant children feel tremendous frustration that they're constantly being talked “around,” rather than being invited to share a comment. YOU can be that advocate to ensure that your child's voice and needs are heard.

9. See Through A Child's Eyes

Look for ways to enhance your child's surroundings during the transplant experience (possibly months long). Bring her softest slippers or his favorite boxer shorts to wear in bed. Stick glow-in-the-dark stars on her hospital room ceiling. Bring a treasured picture to place on the wall near the radiation equipment, so he might be transported to his own happy world during those long moments of standing still through noise, nausea, and fear. Choose and rotate posters in her room. Hang letters and cards on a wall-to-wall string in the room. Write for your teen's favorite idols to send autographed pictures to display. Arrange for videotaped messages from friends, neighbors, and classmates to be made for your child. Borrow a laptop computer to go online and enjoy the many children's Web sites together. Bring decorations at eye level for your child. Make paper chains together to string throughout the room and add color
and cheer for you both. Bring soft and special blankets to comfort you AND your child. As sterile and scary as the room and hospital surroundings may seem to you, remember how your son or daughter perceives them—and then take steps to add delight to those surroundings.

10. Create Opportunities to Honor Siblings
The unfortunate reality is that the transplant process affects siblings in very profound ways. Carve out precious moments for private time with you and your other children, one at a time. Finding time and energy isn’t easy. Yet it is so important to be extra-vigilant attending to sibling’s fears, questions, self-esteem, and needs. Take a daily 15-minute walk together. Somehow, being out of doors brings freedom to sharing thoughts, questions, and feelings. Perhaps schedule a nightly phone call to read a bedtime story together, or sing bedtime lullabies. Or choose a special recurring “date night” with an older child to have coffee and hot chocolate in the cafeteria. Ask questions like, “What’s the hardest part of this experience for you?” “How can we help you feel special through all this?” And then listen to those feelings your child expresses. Just letting them know that you hear them—and honor their thoughts as valid—is sometimes enough to help siblings through their part of the transplant challenge. Create special moments to carve and strengthen a special relationship—and even lifelong memories—together.

• Sibling Support From The Pro’s
Just as it’s helpful for you to have professional support at times, so too can this be a lifeline for the siblings of your child undergoing transplant. Try to arrange for your child to visit with an experienced therapist (or “feelings doctor,” as we called her) or hospital social worker on an occasional basis. Siblings need to know that their concerns and feelings are valid—and that it’s safe to share their thoughts with someone who cares just about them and won’t tell others about these private issues. Sometimes the child may feel guilt or anger about what’s happening to their brother or sister—or tremendous frustration about how you have been consumed with the transplant process and their sibling. The best gift you can provide to this child is the safe, confidential, and caring environment to help him process through these conflicting and confusing feelings.

• Encourage Happy Reminders
Ask neighbors, friends, synagogue, church members, or schoolmates to send “happy cards” to your other children. While your child undergoing transplant may receive daily cards and gifts, it is difficult to watch their siblings race to the mailbox every day and return knowing that nothing is for them. Caring cards and letters can reinforce the feelings that these children are valued and special as well.

• Siblings As Special Heroes
Bestow a hero’s title on these special siblings. While many people will praise the transplant child for being so brave and heroic—or fawn over a sibling
marrow/stem cell donor as being a special hero—often, the other siblings feel left by the wayside, having no special “role” or “value.” You can create a special designation for your other children: “Champion Hero” or “Life Hero.” We call them SuperSibs! Reinforce that this title holds important meaning as well—that the child is special just for being who she is. As well, these sibling heroes add true healing value—by their energy, support, sense of humor, reminders of stories, and “real” life outside the transplant world. Look this child in the eye and tell them sincerely and directly what makes them so very treasured and special to you. Do this often.

• **Choose Your Words Carefully**

Many parents and professionals unfortunately use language that can become a lifelong wound for siblings whose marrow is not a perfect match for the brother or sister in need of a transplant. When parents and others say, “Steven didn't match,” this can become a very challenging and negative imprint for that well sibling. This negative language is an inappropriate and far too heavy burden for siblings to carry the feeling that “I wasn't a match.” Many siblings then feel like they weren't good enough; they didn't do enough; or that they failed in a life-threatening situation. Instead, parents (and transplant professionals) can use this more appropriate language:

*“When no one in the family was a close enough match...”*

This slight change in language can mean the world of difference for the self-esteem and emotional healing for siblings and even impact their lives going forward in a profoundly more positive way. It’s important to reinforce the concept: that the whole family is in this together—that "No one in our family was a match," rather than the sense that “It was all up to you, and you didn't match.”

*“And if there is a sibling match...”*

Remember that a sibling can feel a tremendous amount of pressure and responsibility if he’s called upon to donate marrow or stem cells for his brother or sister. Do make sure he’s informed about the process, in age-appropriate language and in ongoing conversations. Encourage him to ask questions and talk about how he feels to be a donor. If positioned that the survival of their sibling “depends on your stem cells or marrow,” this can feel overwhelming for a child. Rather, parents can position the sibling's donation as a wonderful opportunity to help in a way that gives his brother or sister an even better chance for full health and recovery.

• **Engage The Siblings**

Help siblings understand what’s going on around them, as appropriate to their level of maturity. Rather than shut the siblings out of appointments or hospital visits, help engage them in the healing process. Talk to the hospital transplant team about encouraging sibling visits as part of the healing process. Teach siblings the full hand-washing and anti-microbial cleaning procedures. Enlist their help in being vigilant—and even as the official reminders of others to do so. Older
siblings can take the lead on helping to flush lines or other procedures. Engage all your children in the hopes of life beyond transplant. If you are working with an organization to fulfill a special wish for your transplant child, include all of the siblings. The power of that wish for the future can be as strong for the siblings at home as it is for the child in the hospital.

• **Recognize Sibling Uniqueness**

Just as you are more than “Mom” or “Dad,” so too is the sibling more than the transplant child’s “little/big brother/sister.” Encourage friends, family, neighbors, medical staff, school personnel, and others to refer to these siblings by THEIR names—not always in the context of the transplant child. Their identity is so important. While engaging the sibling in the transplant process is important, it should not be imposed or all-consuming, either. Plan for a flow of involvement, mixed with special interest and conversation about the sibling’s interests, hobbies and school performance. Whatever you and others can do to honor each sibling’s unique and non-transplant-related activities will be a strong foundation to support their “recovery” from this process.

11. **Fasten Your Seatbelt—Before, During, AND After**

A harsh reality that sets in for all transplant parent caregivers is that this is one, loooooooooooooooong roller coaster ride. “Don’t get too excited during the highs, and don’t get too discouraged during the lows. Try to somehow manage in the middle.” Whatever that means, right? While many people (undergoing transplant or just observing from the “outside”) believe that after transplant and homecoming you’re “finally done,” it’s just not that simple. Particularly as parents of children who have undergone transplant, the job of caregiving can increase in intensity once the child is discharged from the hospital. Suddenly all that round-the-clock care that was provided in the hospital (sometimes to you, too!) is now all on your shoulders. Ordering supplies, changing dressings, administering meds, preparing food, transporting back and forth to clinic check-ups, dealing with setbacks, and managing household and family logistics is a huge undertaking. Being aware of this phase of the journey in advance may help as you wonder “Why isn’t this easier now that we’re home?”

**And AFTER Transplant?**

After the return home from months away during our son’s transplant, I recall heaving a sigh of relief, as if I’d held off a huge freight train with my arms locked in front of me. At that point, I apparently “let my arms down,” thinking the “train” was now gone. Somehow, I thought it disappeared after we’d left the hospital. Much to my surprise, the “freight train” ran me over—body and soul. I’d not realized or acknowledged how deeply the transplant process had drained my every source of strength, mentally and physically. In fact, some parent caregivers are officially diagnosed with Post-Traumatic Stress Syndrome as a result of this life challenge. This was true in my case. Through rest, proper nutrition, and excellent counseling, I was able to work through
this latest development. Another lesson I personally learned was that it became too
difficult to be a primary caregiver for my children during the transplant process AND
a working professional all at the same time. Some parents negotiate with their
employers for a paid leave of absence (ideally, in a dream world) or vacation (some-
times with days donated by other colleagues), unpaid days off, or changed perform-
ance expectations to manage through the most difficult months. In my case, I qual-
ified for Short Term Disability leave of absence, due to the official medical diagnosis
of Post-Traumatic Stress Syndrome. While this would have never crossed my mind (I
figured I would just have to quit), it became clear that the benefits coverage to which
I was entitled did in fact apply. This may not be an option for many working parent
caregivers, but the lesson learned is to consider all the options available and acknowl-
dge the tremendous responsibility you have been shouldering. Use your support
resources—and reframe your thinking from “When is this over?” to “Life after trans-
plant” with greater insight and wisdom and commitment to self care.

12. Think Positive
While there are moments during the transplant journey when we as parent caregivers
feel “positively negative”—more often than not, a positive attitude can make a signif-
icant difference to pull our child and ourselves through the darkest moments. Find
others who have successfully moved through and beyond transplant. These people
can be powerful beacons of hope. One phrase that helped our family focus on the pos-
itive during even the most awful and blunt medical conversations was, “Even if the
odds were 99:1, someone would have to be that ‘one.’ THAT’S going to be our child.”
Another helpful thought: As a wise transplant patient once said, “I may have cancer,
but cancer doesn’t have me.” This phrase applies to us as parents of children going
through transplants as well. One thing I know for sure is that a positive attitude might
help—and it surely won’t hurt. Envision life beyond transplant with something excit-
ing to wish for and come true. Picture graduation or a special family trip together. Use
that vision as a powerful draw to guide you through difficult moments and mood
swings together. Then, when this day comes true for you, include your closest friends
and family to celebrate the miracle of life together.

13. Give Forward
One unexpected outcome of having experienced the transplant process with one’s
child is the tremendous knowledge and experience you now carry. This insight can be
of immense value to others not yet as far on this path as you, your child, and your
family. Sharing these stories, information and lessons learned with school classes,
public groups, news media, friends, and other patient families can help further the
research support for marrow and stem cell transplantation. You may interest others
to enter the National Marrow Donor Program Registry as a potential donor. You may
help other families cope with challenging situations. Be available as a resource to par-
ents, children, or organizations that may benefit from your unofficial “Transplant
Graduate Degree.” Become involved in the organizations that helped save your child’s
life (and your sanity). Contribute to a special service at your house of worship—to celebrate life and honor those that are still facing the challenge of survival and cure. Bring your child back to visit the transplant wing of the hospital to thank the medical team for their hard work and caring—and to bring hope to them and others who are experiencing the transplant intensity. You can remind them that there is hope—that there is “life beyond transplant.” You can make a difference in the lives of others, and serve as a role model for your own children, by giving forward to others who may be in need—just as you and your family once were. Honor this gift of life with your caring and insights to enrich the lives of others.
Another Way to Say I Love You

A Wife’s Perspective

by Kay Forsht

Kay Forsht is a graduate of the University of Maryland who has been married to her husband, Woody, for 37 years. As the parents of a son and a daughter, they spent many years involved in school, church, and community activities. Being an only child, Kay first served in the role of advocate and secondary caregiver for her father for the 14 years after he suffered a stroke. However, none of this prepared her for Woody’s diagnosis of AML and the responsibility of being the caregiver for a bone marrow transplant patient. With their commitment to each other—and a lot of hope and optimism—they knew they could face this challenge together. Now, more than five years since Woody’s successful transplant, Kay volunteers with the NMDP Office of Patient Advocacy, using her experiences to benefit other transplant patients and their families.

When my husband, Woody, was diagnosed with acute myelogenous leukemia (AML) in late 1999, he was no stranger to life-threatening illness. In 1986, he had battled Hodgkin’s Disease, which was successfully treated with extensive radiation therapy. With the leukemia diagnosis thirteen years later, it seemed like the past was once again colliding with an uncertain future.

Upon his leukemia diagnosis, Woody entered Johns Hopkins Hospital to begin induction chemotherapy. After one month, he was discharged. Following a six week rest at home, we again returned to the hospital for the second round—a month of consolidation chemo. Following this aggressive treatment regimen, my husband went into remission; sadly he relapsed six months later. When Woody’s disease recurred, his doctors concluded that a bone marrow transplant was his best chance at long-term survival, and the search for a donor began.
Because Woody’s sister was being treated for breast cancer and his brother was not a match, the doctors decided to conduct a search for a matching unrelated donor through the National Marrow Donor Program. While the search was underway, several of our friends organized and underwrote the expense of a community bone marrow drive. Over 150 people turned out to be tested and had their names added to the Registry. Though none of them were a match for Woody, a few have been contacted as potential donors for other patients. In raising awareness for our own plight, hopefully Woody and I have been able to help other patients who are struggling to find a donor.

A matching unrelated donor was eventually found, and Woody began preparing for a non-myeloablative (also known as a “reduced intensity”) transplant. The reduced intensity regimen leaves some of the patient’s immune cells intact so that the patient is not as susceptible to infection immediately after transplant. Also, since the chemotherapy isn’t as intense, there is less chance that a patient undergoing a “reduced intensity” transplant will experience chemo-related toxicity.

Woody’s transplant occurred at the Seattle Cancer Care Alliance on an outpatient basis, meaning that I, as his caregiver, had even more responsibilities throughout his recovery. When doctors told me that I would be playing this critical role in my husband’s treatment, I initially felt overwhelmed and wasn’t sure that I would be able to handle all that comes with caring for a transplant patient. As an only child and as a mother of two, I’ve had a lot of practice caring for others, but I had never administered an injection or cleaned a catheter. The hospital staff provided excellent educational materials to the families and friends of transplant patients to help us feel confident in our new role as caregivers. I feel strongly that by educating caregivers, the hospital staff empowers us and helps to create a sense of being in control of a chaotic situation.

I was also so thankful that I was not on my own in facing the challenges of being a caregiver. Our son was able to visit from California, and our daughter, now a licensed clinical social worker, was able to take three months off from graduate school to help care for her father. Kimberly stayed with us in Seattle and very willingly took on the responsibilities of being a second caregiver. Words cannot express what an incredible support both emotionally and physically this was to us. (Needless to say, I thoroughly enjoyed her companionship on our therapeutic shopping outings too!)

To adhere to a routine, Kim and I awoke each morning and got ready for the day just as though it were any other morning under less stressful circumstances. We found that dressing and putting on our make-up as if we were going out had a positive psychological effect on us as well as on Woody. Maintaining any small semblance of normalcy had a measurable impact on helping us feel more “like ourselves.”

Woody was strictly monitored especially during those first 100 days. Almost daily there were doctors’ visits or lab draws, multiple monitoring and charting of his tem-
perature, hooking up a two liter IV, giving two injections (Woody much preferred Kim's technique to mine!!!), and dispensing and recording of up to 45 pills which were very time sensitive (I frequently had a portable three function kitchen timer set and in my pocket).

After five months, Woody was discharged, and we were finally able to return home to the East Coast. This was wonderful news, but I was a bit anxious. We were no longer going to have around the clock access to an incredible transplant team who had "seen it all." However, we were returning to Woody's former oncologist at Hopkins who greeted us with open arms. Her compassion and commitment to treating Woody guided him to a milestone—the one year transplant anniversary.

After transplant, you define "normal" very differently. Woody has returned to his job, but has modified his schedule so that he can work from home two days a week. He still has to be very mindful of germs and take many precautions to avoid contracting infections. As a very friendly and extroverted professional, it has been hard for Woody not to shake hands with colleagues and acquaintances—a precaution he must take to avoid the spread of germs. To prevent possible infection, we now sit in the back pew at church, and Woody jokes that I have become quite the gentleman—always opening doors for him whenever we are out.

We frequently enjoy parties, weddings and dining out. I use a trick I learned from the hospital staff in determining whether a restaurant seems like a good choice for a transplant patient: I check the restrooms for cleanliness because a restaurant with clean bathrooms is likely to have a spotless kitchen! Woody participates in most activities and events that he enjoyed before his transplant; it just requires a bit of scheduling. He gets fatigued easily, so he is careful to pace himself and plan ahead for what he really wants to do so that he'll have sufficient stamina.

Even though he's again able to drive to work and appointments, I still accompany him to each doctor's visit because four ears are better than two. Throughout Woody's recovery, our relationship has remained strong, though not untested. He got frustrated at times and wanted to break the rules, but I refused to let him. Woody also occasionally felt irritated that I never felt comfortable leaving him by himself; I learned the hard way that things can happen very quickly. So initially, I insisted on waiting until our daughter could be there before going off to run errands. Looking back, Woody says that Kimberly and I probably had a harder time throughout his transplant experience than he did. We remember it all; medication blurred his memory! We were quite fortunate to have incredible support. Our family and friends kept in daily contact and even flew to Seattle to see us and lend a hand when Kimberly returned to school. My other "ace in the hole" was an old friend who had recently moved to the West Coast and became our guardian angel. Caring for Woody was really a team effort!

Since returning home, we've enjoyed some downtime and adapting to our new definition of "normal." Of course, there are many more doctor appointments than any of
our friends experience, but that is a small price to pay. Throughout everything, we’ve always been the best of friends. As my husband approaches his sixty-second birthday, we’re looking forward to retirement and preparing for the future. While we still have many ups and downs, we view any challenge as the small cost of doing business.

Twenty-five years ago if this had been in my horoscope, I would have said I couldn’t do it. Of course, I wish this had never happened to the person I love most, but I’ve been privileged to have the opportunity to witness Woody’s strength, his hope, his faith, his courage, and his determination. Being his caregiver is really just another way to say to him, “I love you!”
Emotional Aspects of Caregiving

An Oncology Social Worker’s Perspective

by Linda Diaz

Linda Diaz, LMSW, ACSW, is a national leader and lecturer in the field of oncology social work. For the past 23 years her primary focus has been on providing psychological counseling to cancer patients and their significant others. Linda has developed numerous support, education and complementary programs, which have been integrated into traditional medical care settings. She currently has a psychotherapy practice at the Birmingham Maple Clinic in Troy, Michigan.

It is normal to have strong feelings when someone you love has been diagnosed with cancer, especially when their treatment includes a bone marrow transplant. Emotions, including sadness, anger, depression, and feeling generally overwhelmed, are common for caregivers going through this experience. Do not be critical of yourself when you feel strong emotions. Caring for a person who is seriously ill may challenge you in ways that are completely new.

Normal emotional reactions of caregivers vary dramatically from day to day. Patients embarking on the transplant process often describe their experience as an “emotional roller coaster.” This roller coaster has many passengers including caregivers. The ride can be intense, and you may find yourself wondering if it will ever be over.

Managing Feelings of Anger and Guilt

Mary underwent a transplant in January, and her family was thrilled when she was finally discharged in February. Her husband, Paul was relieved that her blood counts were high enough to allow her to be home and that he no longer had to run between the hospital and his responsibilities with work, the children, and maintaining the house. The first week home Mary and Paul received lots of support from friends who brought in
meals and helped with the children. However, by week three, Mary was still resting for the majority of the day. Paul began to feel resentful and angry that all of his efforts to keep the ship afloat over the last several months were less often acknowledged by his wife. He was more than ready to have his normal life back. He was exhausted and began feeling trapped and angry.

Then Paul began feeling guilty about having such feelings; after all HIS WIFE WAS FIGHTING FOR HER LIFE! By judging his feelings as “right or wrong,” he was adding guilt to his long list of stresses. This self-criticism put an even greater burden on him and eventually on his family. One strategy is to acknowledge these uncomfortable feelings, perhaps to a trusted friend. This would enable him to receive support and perhaps gain perspective. Talking about these feelings may defuse his anger and sense of powerlessness. Emotional exhaustion for caregivers is a reality. Managing negative feelings becomes easier once they are acknowledged.

Caregivers often describe feeling overwhelmed with medical tasks. Caregivers must become familiar with medical terminology, such as the implications of lab results and blood counts. This is a lot of responsibility for a non-medical person. Try to organize your tasks by writing things down as they are explained to you.

People experiencing serious illness can sometimes become irrational with demands, ungrateful and irritable. Feeling anger is a normal response. Any two people spending a lot of time together may become agitated with one another. Getting a break, even for ten minutes is critical for both the patient and caregiver. It can be constructive to talk about the source of your tension. Such conversations are most productive if you enter into them when you are both reasonably rested and have had some cooling off time. Express your feeling in the least destructive way possible. Avoid statements like “You made me feel…” Rather, begin the discussion with a statement like, “Yesterday when you yelled at me I felt….” If you take responsibility for what you feel, it stands to reason that you can also assume responsibility for feeling better. You can choose not to take negative comments from others personally. Blaming someone else for your feelings gives you the false impression that you have no control over how you respond.

Try to see the situation from the patient’s perspective. This might increase your tolerance and understanding. Talking to a third party about your feelings can also be a constructive way to keep your personal bias in check. Putting energy into regret, anger, and resentments from the past robs you of energy needed to manage the job in front of you. Sadness, worry and fear are particularly difficult emotions for the caregiver to manage.

Caregivers have the role of “cheerleader,” reassuring their loved ones that they can get through this. Encouraging the patient is the best strategy when he or she is feeling particularly vulnerable. However, caregivers need to have an outlet of their own for expression of worry and fear. It may be helpful to join a support group of other
caregivers people with similar experiences that can offer advice and support. Other caregivers understand your situation but are not personally involved with your family and can be objective. Caregivers do not need to take on that “cheerleader” attitude with other caregivers. Your medical center can provide information about available support groups.

Is it ever appropriate for the caregiver to discuss his or her worries and fears with the patient? The answer is “sometimes.” Patients need to know that their caregivers are on the same page as they are, and that they acknowledge the seriousness of the situation. Patients can experience feelings of abandonment when everyone takes the “Don't worry about a thing” approach. The truth is that a transplant is frightening and honest dialogue about that reality can help patients and caregivers feel connected and less isolated.

**Enhancing Communication**

A patient’s need for conversation may change from day to day. Many patients express the need to discuss normal every day things like the weather or politics. They may get bored and agitated with the constant question “How are you?” Alternatively, there may be days when patients are coping with some difficult feelings or decisions and feel that their caregivers are being insensitive to bring up the weather when they are experiencing depression or fear. A statement such as “I'm here to listen if you wish to talk about your feelings, treatment....” can take the guesswork out of cancer-related communication from day to day. Accept that no two people approach the transplant process in the same way.

Communication around sensitive issues like sexuality or finances can present an additional challenge. Choose a time for such discussions when both parties are rested. In the heat of an argument it is unlikely that a conversation will result in creative problem-solving or increased understanding. The goal is to SOLVE PROBLEMS. This is different than “talking about issues.” Talking about issues implies that underlying obstacles exist that will never go away. Solving problems implies that solutions can be found. Professional help can really make a difference. Fortunately most medical institutions have names of social workers, psychiatrists, or health care workers who have experience facilitating effective communication.

**Delegating Responsibilities**

Caregivers frequently take on multiple roles and responsibilities. Delegating tasks is a skill which requires conscious effort. Delegating tasks to others means giving up some control over the specific details of how things are accomplished. For example, if you allow a neighbor to bring in dinner for your family, you have to accept what your neighbor chooses to cook and how they choose to prepare it. Many people find giving up this control difficult. When caregivers fail to share responsibilities, they may exhaust themselves, leaving them depleted for the more urgent tasks. Delegating is also a challenge for people who define themselves by the tasks that they accomplish.
Delegating causes one to confront their sense of identity. If I’m not the cook, bread-winner, driver, who am I? Appreciate that your new job, Caregiver, is more than accomplishing tasks. Lots of people can make a meal; no one else can sit at the hospital and be you.

Delegation of responsibilities can be especially delicate when children are involved. Children may need to take on additional chores that were previously handled by their parents. While some of this is appropriate, it is important that children not be pressured into a level of responsibility that is beyond their capacity or maturity level. Statements like “you’ll have to be the lady of the house now” can feel overwhelming to a young child.

Well-meaning friends and family members may ask caregivers what they can do to help. Prepare a list of tasks that others could do. This avoids duplication of effort, particularly around meal preparation. A prepared list of tasks allows other helpers to select jobs that fit their abilities.

**Managing Family Conflicts**

Getting along in a family can be demanding even in the best of circumstances. Individual personality traits frequently conflict, creating tension and resentment. Many people have the fantasy that when cancer strikes a family, all the pre-existing anger, jealousies and other emotional baggage will go away. “I thought our family would become closer due to this crisis,” is a common idea. Many people do grow closer in a crisis but not because anyone changes their pre-existing personality.

The bad news is that negative personality traits tend to be accentuated when people are under stress. For example, the person who tends to be controlling will become more controlling when under pressure. The critical person will become more judgmental. The person with an addiction will rely on their substance more heavily. Caregivers and patients have their share of unflattering personality problems. Professional counseling may provide specific practical strategies for moderating conflicts during the transplant process. Patients and caregivers who have a history of anxiety, depression or addictions are at higher risk for distress during the treatment period. In these situations counseling can be a real lifeline through the most difficult months. Caregivers who are assisting patients with psychiatric disorders need to remember that they are not responsible or capable of “fixing” the emotional distress of their loved ones.

Criticism from extended family can be difficult to take. Sometimes extended family members or friends are critical of the way you are caring for the patient. It is common for caregivers to feel frustrated with the advice of others to “do more” or “do less.” Remember that you are not helping your loved one through the transplant process to win popularity points with the well wishers. Surround yourself with people whom you respect and who are invested in the well-being of both you and the patient.
Post-Transplant Concerns
 Patients and caregivers often become frustrated with the chronic symptoms that persist after a transplant. For caregivers there is a natural sense of relief when the acute period of treatment ends. However, it is helpful to understand that for the patient the transplant experience is not over, physically or mentally, and the long hoped for feeling of being “finished” is still elusive.

Spouses are obviously affected by the side effects that extend beyond treatment. It is helpful to understand that the physical and emotional symptoms patients are still experiencing are not always obvious. During follow-up visits with the transplant team, the physician may well say, “You are doing great!” Caregivers need to understand that statement may not translate into patients FEELING great in the initial months post-transplant. As caregivers, we can be most helpful by acknowledging the reality of these side effects, which may include fatigue and loss of strength, especially in the post-transplant period when these symptoms can be particularly discouraging.

Helping your loved one cope with fears about recurrence of cancer requires lots of patience and listening. Patients frequently say, “Everyone has moved on, and I’m still back here worrying about my health.” Caregivers may become frustrated with patients who need constant reassurance about their wellness. Encouraging the patient to attend a support group or see a counselor who specializes in medical counseling issues could assist the patient in managing these fears.

Returning to former roles is also an ongoing concern. Roles may include that of cook, financial advisor, lover and more. Stepping back into daily activities of life varies tremendously from patient to patient. There is no prescribed time frame for “readiness” to enter into specific activities. Open dialogue about expectations and feelings can help with this gradual transition from illness back to normalcy.

Caring for Yourself as a Caregiver
 Do not expect yourself to be perfect. You are only human and most likely dealing with many things that you have never been confronted with before. It is natural to make mistakes along the way. Forgive yourself when mistakes do happen. The sooner you shift your thinking to the positive aspects of what you are doing right, the better for you and the patient.

Recognize your physical and emotional limits. Seek help from others before you reach the end of your energy reserves, (see delegating responsibilities.) Understand that you will be a much more effective caregiver if you focus on non-cancer activities periodically. For example, go out with friends; watch a funny movie; and have non-cancer related telephone conversations with others.

Be aware of thoughts along the lines of “I can do it all because I’m not the one who is sick.” While it is true that you are not the patient, that does not mean your energy is limitless. When confronted with your tasks for the day, ask yourself, “How am I going
to accomplish this in a way that promotes energy and health for both of us?" Needless to say, the patient facing transplant needs a caregiver who will remain healthy.

Take in the appreciation that your loved ones send your way. Accept their compliments and gratitude graciously. Focus on your accomplishments. The ability to simply be there is a greater gift than you can imagine.
Jim Myers was diagnosed at age 31 with Chronic Myelogenous Leukemia in 1995 after a routine eye exam. He underwent a bone marrow transplant in September the same year and has been in remission ever since. His wife and three children played an important role in his recovery. Jim is a heating and air-conditioning service technician. In his view, caregivers often share some of the same emotions and physical fatigue experienced by the patients themselves. He recommends that caregivers take a break now and then from their responsibilities and hopes they will receive ongoing support and encouragement from others.

My name is Jim Myers. I was diagnosed with Chronic Myelogenous Leukemia in the summer of 1995. My bone marrow transplant was in the fall of that same year. My wife Kelly and I have three children, oldest to youngest, Zachery, Jeremiah, and Elizabeth. We live in Cheboygan, Michigan.

With the diagnosis of cancer, there are many questions and concerns that arise. Once you have decided on a course of treatment, additional questions and concerns arise. One of these questions for Kelly and me was that of caregiving after I was discharged from the hospital. We live approximately four hours from the hospital where my transplant was to occur. When I finally went home, Kelly was to be my caregiver. The problem was with the period of time between the hospital discharge and when I could go home. We considered all sorts of options, including relocating closer to the hospital, but Elizabeth was just starting kindergarten the same month as my transplant.
Jeremiah was to have a tonsillectomy on the day of my transplant. The solution to our problem came from an unexpected source—a church.

We were helped in so many ways by our families, individuals, churches, schools, my employer, and the institutions that help those facing cancer, its treatment, and specifically bone marrow transplant. But one particular church and what they did for my family and me is one of the fondest memories of my treatment.

**Our Family of Strangers**

There were times that Kelly and other members of my family were able to be in Ann Arbor to stay in the apartment with me and take me to my appointments. But I was not permitted to be alone at any time and thus needed someone to be with me 24 hours a day. The Church of Christ in Ann Arbor, Michigan and its members were about to become family in a whole new way. This is how they did it.

We gave the church all of the dates and times that my family was to be with me. They created a schedule divided into three shifts during the day and a nine-hour shift at night. Then they posted that schedule and asked for people to fill in the times when they would sit with me and if necessary prepare my meals, take me to the emergency room, or to doctor appointments. Basically, they were my babysitters, for after all, I was in a sense given a rebirth. They were my providers and companions when my own family could not be present.

I met a very diverse group of individuals who came together to care for someone that they did not know and would not meet until that first time they came to take their shift. Each one of these people made sacrifices for my family and me and never asked a thing in return.

This group of volunteers saw my need and provided for it. With some, I enjoyed only conversation. With others, I enjoyed conversation and games, a stroll around the complex, or a ride in the countryside. We talked about jobs, families, politics, the past, the future, the Scriptures. Some I barely met at all; they would come in for the night shift just as I was going to bed exhausted; then they would be gone before I awoke, but they were there for me just the same.

These people were indeed, as someone said, a “family of strangers.” I have lost contact with most of them, at least physically but not in my heart. There is one woman that we see and hear from often. We even met the family of some others, family that did not live in the area.

When I was well enough, it was my privilege and honor to preach during an evening service for the Church. It was also my privilege to be able to express to them my family’s gratitude for their sacrifices and their care.

**How about Community?**

I believe that a “family of strangers” can be found very close to home. I have never
given much thought to the word “community,” but it seems to me that, in this con-
text, the word is a combination of two other words: “Common” and “unity”— a group
of people united by a common purpose, goal, or cause.

In addition to focusing on my medical treatment, we had real financial concerns while
waiting for disability benefits. Some friends organized a sock-hop for our benefit. It
drew people not only from our town, but as far away as 30 miles. That’s community!

I know of a man in Wisconsin whose co-workers gave him enough of their own paid
vacation to ensure him a continuous paycheck while he could not work. That’s com-
munity!

May I suggest that if people are willing to promote a “family of strangers” campaign
in their community, they could find volunteers to supply the caregiving needs of the
bone marrow/stem cell transplant patient. One of the nice things about drawing from
your own community is the fact that not all of your caregivers would be total
strangers.

I believe that this can be very good for a community—a shared purpose in order to
achieve a common goal. I believe that this is one way in which to develop a strong
sense of trust and appreciation for one’s community.

Caring for the Caregiver
It was not necessary that this “family of strangers” be the primary caregivers. Sometimes this family of strangers could be the relief for the primary caregiver. So
often people focus all of their attention and energies on the patient and forget about
the family. Kelly and the kids all went through the transplant and recovery. They are survivors too. There were times when Kelly really needed a break from the responsibili-
ties of caregiving. She needed to be able to get out of the house and away from
everything, just to keep her sanity. There were times when she just needed to rest.

Caring for the caregiver—this is a variation on caregiving that deserves more atten-
tion. Not all people who are willing to help can do so in the same way, but every effort
should be made to accommodate their talents and their desire to help. For example,
the bone marrow transplant patient is on a strict diet with many restrictions and food
preparation requirements. This often made it necessary for Kelly to prepare one meal
for me and a separate meal for the rest of the family. There were many times when
people would stop by the house and drop off dinner for the family, already prepared,
only needing to be heated. What a relief this was for Kelly!

Your family of strangers may include those who perform service on behalf of the care-
giver and the rest of the family. Here are a few things that can help the primary care-
giver, but incorporate your own ideas into this “family of strangers” concept:

• Have a regular schedule of people to prepare meals, do laundry, go shopping, or
  help with house cleaning.
• Have someone scheduled to sit with the patient while the caregiver naps, takes a walk, visits a friend, or runs an errand.
• If there are children, have people take them out for ice cream, to the park, or help them with their homework.

Child Caregivers
When I had my bone marrow transplant, our children were five, seven, and nine. Kelly and I got them involved. There was not a lot that they could do, but I think that it is important that children are made to feel a part of things.

We taught the children to wash their hands just like a surgeon does before performing surgery. Then they were allowed to push the heparin into my catheter. Three children—three tubes. It worked out perfectly for us. Your family is like a community in miniature.

The Patient’s Role in Caregiving
The patient has some responsibility. When strangers showed up at my apartment in Ann Arbor, they were often full of questions like, “How should I prepare the food if a meal is required during my shift?” They wanted to know the warning signs, in case something serious happened. They were afraid that they would do something to cause me harm. The patient can dispel, or at least calm, these fears. First, it is important that the patient understand what is required for his or her own care. The patient, along with the health care team, can pass on caregiving information.

In conclusion, I suggest that patients be open to receiving help from others. Don’t be too proud to accept it. Think of the times when you were able to assist someone else and the way it made you feel. Accept the help that people are willing to give, and give them the joy that comes with caregiving.
A large part of the caregiver role is often associated with symptom management. After chemotherapy and bone marrow/stem cell transplant, your loved one may experience a wide variety of side effects and symptoms secondary to their treatment. The purpose of reviewing a variety of different symptoms is to equip caregivers with the knowledge of possible situations and encourage successful problem-solving. As intimidating as this chapter might seem, it was written so that caregivers understand that each patient will experience transplant in a very unique way, and the medical team will support caregivers in any event that may occur.

**Nausea and Vomiting**

Most patients will experience some nausea and vomiting after receiving chemotherapy. Often, anti-nausea medications will be prescribed to help lessen the severity of the nausea. However, there are some other techniques that can aid in decreasing the risk of nausea. If the patient is nauseous, have them avoid heavy foods or milk products. Try a clear liquid diet at first until the patient is feeling better, then advance to a bland diet with easy to digest foods, including noodles, rice, clear soups, toast, or eggs. Try to avoid taking medications on an empty stomach unless instructed specifically to do so. It is often helpful to eat a small amount of food prior to taking pills to help prevent...
nausea associated with medications. Sometimes, taking an anti-nausea pill prior to taking other oral medications can help prevent nausea and keep the oral medications down. It may also be helpful to have the patient take oral medications 15-30 minutes apart. Certain smells can induce nausea, so avoid cooking strong smelling foods near the patient. Give the patient his anti-nausea medications as prescribed by your institution because every person responds differently. Let your medical professional know how the prescribed anti-nausea medication is working. Often medications can be changed or doses adjusted to provide better relief.

**Diarrhea**

Diarrhea is another symptom that is often associated with chemotherapy regimens. Your health care providers will usually prescribe an anti-diarrhea medication after a stool sample has been sent to check for a bowel infection called Clostridium Difficile. If the patient is found to have Clostridium Difficile, he will be started on an oral antibiotic and advised to avoid anti-diarrhea medications so that the infection can be cleared from his intestinal system through bowel movements. Use the anti-diarrhea medications only as instructed because these medications can cause constipation if used incorrectly. It is important to have your loved one drink as much fluid as possible (preferably fluids like sports drinks or fruit juices) when he has diarrhea to avoid severe dehydration. It is recommended that patients avoid milk products and supplement drinks because they may further loosen the stool due to lactose intolerance. It is recommended that you keep your medical professional updated on how much diarrhea the patient has daily and how much fluid he is able to consume. This information, the intake and output, is very important in helping your medical staff treat the patient.

**Pain**

Pain is a symptom that can occur for many reasons. ALWAYS notify your medical professional about any pain that the patient may be experiencing, no matter how minor. Your health care provider will then treat the pain according to type, severity, and location and may order certain tests to find out the cause of the pain. Narcotics are often prescribed and are very effective in treating pain, but they also have side effects, including nausea, lethargy (sleepiness), constipation, and slowed breathing. Take narcotics with food to avoid the nausea associated with taking pills on an empty stomach. It is recommended that pain medications be used only as instructed by your medical professional. Taking pain medications more frequently or at higher doses than prescribed can lead to sleepiness and slowed breathing. If the patient becomes too sleepy or has a severe reaction to the medication, stop the narcotics and call your medical professional immediately! Understand that each patient will react to narcotics differently based on past exposure to pain medications and other medications that the patient may be taking at that time. Let your medical professional know how the pain medication is working. There are often changes in the medication or dose that can be made to improve pain relief and decrease side effects.
Fevers
Fevers can be related to certain chemotherapy agents but are most often related to neutropenia (decrease in white blood cells) or infections. After chemotherapy, the patient will become neutropenic and will have no immune system to protect him or her from infections. During this neutropenic phase, fevers are fairly common. It is essential to treat fevers quickly to avoid the possibility of developing serious infections. Notify the medical provider of any fever >101.0 degrees Fahrenheit so that intravenous antibiotics can be started as soon as possible. The patient should use Tylenol only when instructed because taking Tylenol can hide a fever that may be present. A fever is a sign to your medical provider of a possible infection.

Neutropenia (Low White Blood Cell Count)
High-dose chemotherapy will cause the patient to lose his white blood cells (neutropenia). The patient will remain neutropenic for approximately 2-3 weeks. When a patient has no white blood cells, he has no immune system to protect him from infection. When the patient is neutropenic, avoid public places and sick people that may expose the patient to infection. If the patient has to visit the hospital for any reason, have him wear a TB or surgical mask that can be obtained from your medical institution. It is recommended to avoid all fresh fruits, vegetables, or any uncooked foods that can expose the patient to bacteria and fungal organisms. Good hand washing is the most important thing that patients and caregivers can do to prevent infection. When neutropenic, the patient should have minimal contact with small children. Children often transmit viral infections that they contract from other children in schools or day care facilities. However, the emotional benefit of maintaining these contacts must be considered. With adequate precautions such as avoiding children that are ill and all parties practicing good handwashing, the benefits may well outweigh the risks.

Bleeding related to Thrombocytopenia
Bleeding is related to the low platelet count (thrombocytopenia) that occurs after high dose chemotherapy. When platelets are low, the blood becomes thin and has a decreased ability to clot. Platelet transfusions will be necessary when platelet counts fall below 10,000-20,000, depending on your hospital’s guidelines. During this time, the risk for bleeding is higher and certain measures can be taken to avoid bleeding. Instruct the patient to avoid vigorous nose blowing, shaving, and not to participate in any vigorous sports, strenuous exercise, or heavy lifting during this time. Soft bristle toothbrushes are necessary, and patients should not use dental floss to avoid gingival bleeding. Do not use any rectal suppositories, and avoid using any over-the-counter medications that can cause bleeding, including aspirin, ibuprofen or naproxen. Before beginning sexual activity, consult with a member of your transplant team. Platelets will recover a few days after the patient’s white blood count recovers. Notify your health care professional immediately if you notice any bleeding in the stool or the urine or should the patient experience a sudden onset of a severe, debilitating headache.
Fatigue
Fatigue is an often debilitating symptom that has many contributing factors, including chemotherapy, malnutrition, insomnia and anemia (low red blood cell count). Immediately after transplant, REST is the most important component in combating fatigue. Appropriate sleep and eating patterns can add to the overall well-being of the patient and can help lessen the fatigue. Inform health care providers if insomnia is a problem so that sleeping aids can be prescribed. Blood transfusions can provide a short-term energy boost if the patient’s hemoglobin is low. Exercising post-transplant is recommended to strengthen muscle and boost energy levels once the patient has returned home. Always begin with light exercise, advancing as the patient tolerates. Energy levels generally improve with time but sometimes can take up to 3-6 months to fully recover. Everyone recovers at a different pace. Do not be discouraged if recovery takes longer than the patient expected.

Mouth Pain and Mucositis
Certain chemotherapy agents can cause mucositis (an inflammation of the tissue in the mouth and esophagus) that can be very painful. Good oral hygiene and mouth rinses with oral solutions as prescribed by the health care provider will help with the pain and prevent infection. Let your health care provider know when the patient first experiences a sore throat or mouth pain so that pain medication can be started. Sometimes, the pain can become severe enough that the patient is unable to swallow fluids or medications. During this time, intravenous narcotics and fluids are often needed to control the pain and to keep the patient hydrated. Pain medications only help alleviate the pain, not cure the mucositis. Fortunately, mucositis is temporary and typically resolves when the patient’s white blood cell count recovers.

Anorexia or Loss of Appetite
Patients, post-transplant, will often experience a loss of appetite due to chemotherapy and nausea. During this time, prepare small meals and encourage the patient to eat frequent, small snacks throughout the day. Appetite stimulants can be prescribed but usually are reserved for patients who lose large amounts of weight. Diets high in protein are recommended to help keep the patient nourished despite poor oral intake. Supplement drinks once or twice a day can provide caloric and nutritional boosts essential for malnourished patients.

Skin Rash
Skin rashes, post-transplant, are usually associated with a reaction to a medication or to viral and fungal infections. Your medical professional should be alerted to any new skin rashes and should evaluate the rash daily to determine type and effectiveness of treatment strategies. As a caregiver, it is essential to help keep the patient bathed, avoiding any new lotions, soaps or laundry detergents that can contain ingredients that can lead to allergic rashes. Use only medications prescribed by your medical professional because over the counter creams or lotions can exacerbate many skin rash-
es. Let your medical professional know if itching occurs because medications can be prescribed to alleviate an irritating itch.

**Pulmonary Symptoms**
Shortness of breath and cough are the most common pulmonary symptoms that occur during bone marrow transplant. Shortness of breath and cough can be related to many different things after chemotherapy including fluid overload, lung abnormalities and infection. Notify your health care professional immediately if these symptoms occur so that appropriate medications can be given. A chest x-ray will often be performed to examine the lungs if shortness of breath or cough persists.

**Graft Versus Host Disease (GVHD)**
Graft versus host disease is a condition that is experienced by allogeneic (stem cells from a donor other than the patient) stem cell recipients only. Graft versus host disease is a reaction of the donor cells to the patient. Acute GVHD can affect the skin, the gut, and/or the liver. GVHD of the skin presents as a reddened skin rash over 25-50% of the body that is often very itchy. GVHD of the gut presents as sudden onset of severe nausea, vomiting and large amounts of diarrhea. The nausea and vomiting usually do not respond to typical anti-nausea medications. The diarrhea is often very watery, dark in color and is associated with abdominal cramping. Sometimes the diarrhea and vomiting prevent adequate nutritional intake, making it necessary to start intravenous nutritional support. GVHD of the liver occurs with elevated liver enzymes, which can lead to jaundice (yellow tinge to the skin and eyes), itching, fluid retention in the abdomen, and right abdominal pain. If any of these symptoms occur, notify your medical provider immediately so that treatment can be initiated quickly. Delay in treatment can worsen the GVHD and its symptoms, making it more difficult to control.

**Safety Issues**
Patient safety, after transplant, is a very important caregiver task. Hand washing is an essential step in preventing the spread of infection to the patient.

There are other safety concerns that need to be considered in post-transplant patients. These include any respiratory difficulties, chest pain or neurological changes (confusion, severe headaches, sleepiness or black-outs). Notify your health care provider of any unusual symptoms or changes in the patient, no matter how trivial. Rapid notification leads to a quicker response, often saving the patient from dangerous situations. Safety of the patient is of the utmost importance. If safety is maintained, it can increase the chances of a successful transplant course.

**Post-Transplant Expectations**
Once a patient has successfully engrafted (recovered his white blood cell counts) after transplant, it is usually time for him to return home. The caregiver and the patient will realize that though they have returned home, they will still need assistance for a few weeks after transplant. Profound fatigue can often linger for many
weeks after transplant and generalized fatigue can remain for up to 5-6 months after transplant. A daily exercise regimen and appropriate nutritional intake is essential in optimizing the patient’s recovery once he has returned home. Exercise should be increased gradually and only as the patient tolerates. Post-transplant complications may sometimes occur after the patient has left the hospital. Therefore, it is very important that the patient notify his local physician and his bone marrow transplant team immediately, if any changes or problems should occur.

Upon discharge, the patient will be scheduled for follow-up visits with the bone marrow transplant team. Each institution will have different post-transplant schedules that will be individualized to the patient’s specific needs. It is essential that the patient keeps these appointments and has a caregiver present during these visits in case the patient needs assistance getting to specific tests or when recovering from certain procedures (bone marrow biopsy, catheter removal, etc.).

Psychological stress is another common factor for the caregiver. The demands placed on caregivers may be overwhelming at times. The medical team will be a great resource for you to discuss any concerns and questions you may have. There will be a social worker, psychologist or other mental health care professional to help you or the patient cope with issues that arise during the transplant process. Rely on them for support and to validate your caregiver role. Caregivers really are partners-in-care along with the transplant team and are an essential part of the overall transplant experience. Many find it helpful to talk with previous caregivers who may be able to provide first-hand knowledge and helpful tips during this difficult period.
How to Be a Successful Family Caregiver

An Advocate’s Perspective

by Suzanne Geffen Mintz

Suzanne Geffen Mintz is President/Co-founder of the National Family Caregivers Association, the only organization comprised of and reaching out to all family caregivers. In September 2006, Mintz was named a winner for the first-ever national Purpose Prize, a major new initiative to invest in Americans 60 and above who are leading a new age of social innovation sponsored by Civic Ventures. She is author of “Love, Honor, & Value - A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving,” (Capital Books 2002) and regularly writes for numerous publications on the issues related to family caregiving.

This chapter has been excerpted and edited from a series of agency brochures available from the National Family Caregivers Association.

Defining the Help You Need and Figuring Out How to Get It

Asking for and accepting help is a complex issue. Obviously you first need to admit that having someone help will make a real difference in your loved one’s quality of life, and therefore yours as well. Then you need to define what help you need. Which tasks or chores would be easier to ask others to do? Which do you really want to do yourself? Here are six steps to getting help:

• Recognize that caregiving, like any job, is made up of lots of individual tasks. Not all tasks are of the same importance. The challenge is to know the difference.
• Recognize that asking for help is a sign of strength and not of weakness. It means you truly have a grasp on your situation and have come up with a proactive, problem-solving approach to making things better.
• Create a list of tasks that need to get done in any given week. When you see how long the list is you’ll quickly understand why you are so tired.
• Group your tasks into categories such as personal care tasks, transportation and household chores.
• Write down your caregiving worries. Seeing them in black-and-white helps diffuse some of their emotion. It also allows you to think more rationally and understand how getting help might lessen the stress.
• Share your lists with someone you trust before you reach out for help—a friend, therapist or clergy, perhaps. Then take a deep breath and ask for help or guidance in resolving your worry. Don’t get discouraged if you are rejected at first. It takes perseverance. The goal is better care for your loved one and yourself.

**Tips for Family Caregivers from Doctors**

• Write down questions so you won’t forget.
• Be clear about what you want to say to the doctor.
• If you have lots of things to talk about, make a consultation appointment.
• Educate yourself about the disease.
• Learn the routine at your hospital.
• Separate your anger and sense of impotence about not being able to help your loved one as much as you’d like from your feelings about the doctor.
• Appreciate what the doctor is doing to help, and say thank you from time to time.

**Tips for Doctors from Family Caregivers**

• Be open and forthright.
• When you prescribe medications, be sure caregivers understand potential side effects so they know what to expect.
• Be accessible—especially when a caregiver is opening his or her heart.
• Be sensitive about where you talk to caregivers about difficult subjects—waiting rooms and corridors are not appropriate.
• Now and then ask the caregiver, “How are you?” Let them know you understand that illness is a family affair.
Share the Caring, Helpful Hints for Caregivers and Those That Care about Them

If you’re a caregiver who needs help or if you’re a friend who wants to provide it, use these handy checklists to help create an action plan:

**Checklist...Help I need:**
- A night out with friends
- A ride to doctor’s appointments
- Mow the lawn or shovel snow
- Dinners prepared
- House cleaned
- Shopping done
- A shoulder to cry on
- A handyman
- Pick up prescriptions
- More information on available resources
- Some quiet time alone at home
- A sitter at home
- Someone to ask how I am

**Checklist...Help I can Offer:**
- Dinner and a movie on me
- A ride at pre-assigned time
- A lawn mowed/driveway shoveled
- A meal prepared …times a week
- A maid brigade once a …
- Grocery shopping every …
- A shoulder to cry on
- A couple of hours of my tools/time
- Run errands
- Resource research
- Taking … out for a few hours
- Some of my time to stay with …
- A weekly phone call
Resource Listing

Note: This Resource Listing includes organizations that provide support and information for caregivers. You may find additional resources in the following two booklets and video available from the nbmtLINK:


Survivors’ Guide for Bone Marrow/Stem Cell Transplant, What to Expect and How to Get Through It, by Keren Stronach

Video: The New Normal: Life After Bone Marrow/Stem Cell Transplant

Organizations

Aplastic Anemia & MDS International Foundation, Inc.
PO Box 310
Churchton, MD 20733
800-747-2820 or 410-867-0242
help@aamds.org
www.aamds.org

BMT Infonet
2310 Skokie Valley Rd., #104
Highland Park, IL 60035
888-597-7674 or 847-433-3313
help@bmtinfonet.org
www.bmtinfonet.org

CancerCare National Office
275 Seventh Ave., Floor 22
New York, NY 10001
800-813-HOPE or 212-712-8400
info@cancercare.org
www.cancercare.org

Family Caregiver Alliance
180 Montgomery, #1100
San Francisco, CA 94104
800-445-8106 or 415-434-3388
info@caregiver.org
www.caregiver.org

Family Voices
2340 Alamo SE, #102
Albuquerque, NM 87106
888-835-5669 or 505-872-4774
kidshealth@familyvoices.org
www.familyvoices.org

Friends’ Health Connection
P.O. Box 114
New Brunswick, NJ 08903
800-483-7436 or 732-418-1811
info@friendshealthconnection.org
www.friendshealthconnection.org

Gift of Life Bone Marrow Foundation
800 Yamato Rd., #101
Boca Ratan, FL 33431
800-9MARROW or 561-988-0140
info@giftoflife.org
www.giftoflife.org

Gilda’s Club Worldwide
322 Eighth Ave., #1402
New York, NY 10001
888-445-3248 or 917-305-1200
info@gildasclub.org
www.gildasclub.org
Organizations

Lance Armstrong Foundation
PO Box 161150
Austin, TX 78716
866-235-7205 or 512-236-8820
livestrong@laf.org
www.laf.org

The Leukemia & Lymphoma Society
1311 Mamaroneck Ave.
White Plains, NY 10605
800-955-4572
infocenter@lls.org
www.lls.org

National Alliance for Caregiving
4720 Montgomery Lane, 5th Floor
Bethesda, MD 20814
301-718-8444
info@caregiving.org
www.caregiving.org

National Bone Marrow Transplant Link
20411 W. 12 Mile Rd., #108
Southfield, MI 48076
800-LINK-BMT (800-546-5268) or
248-358-1886
info@nbmtlink.org
www.nbmtlink.org

National Family Caregivers Association
10400 Connecticut Ave., #500
Kensington, MD 20895
800-896-3650 or 301-942-6430
info@thefamilycaregiver.org
www.thefamilycaregiver.org

National Marrow Donor Program
(NMDP)
3001 Broadway NE, #500
Minneapolis, MN 55413
800-MARROW-2 (800-627-7692)
888-999-6743 (Office of Patient Advocacy)
www.marrow.org

Patient Advocate Foundation
700 Thimble Shoals Blvd., #200
Newport News, VA 23606
800-532-5274
help@patientadvocate.org
www.patientadvocate.org

Rosalynn Carter Institute for Caregiving
Georgia Southwestern State University
800 GSW Drive
Americus, GA 31709
229-928-1234
rci@canes.gsw.edu
www.rosalynncarter.org

Well Spouse Foundation
63 W. Main Street, #H
Freehold, NJ 07728
800-838-0879
info@wellspouse.org
www.wellspouse.org
Books

Across the Chasm, A Caregiver's Story
by Naomi Zigmund-Fisher, BMT Infonet, 2002

After the Diagnosis: How to Look Out for Yourself or a Loved One
by Donna L. Pikula, DDS, MS, 2006

And Thou Shalt Honor: The Caregiver's Companion
edited by Beth W. McLeod, 2002

Being a Cancer Patient's Carer: A Guide
by Wesley C. Finegan, 2005

Cancer Etiquette: What to Say, What to Do, When Someone You Know or Love Has Cancer
by Rosanne Kalick, 2005

Cancer as a Turning Point: A Handbook for People with Cancer, Their Families, and Health Professionals
by Lawrence LeShan, 1990

Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspectives, National Bone Marrow Transplant Link, 2007

Caring and Competent Caregivers

Caring for You, Caring for Me: Education and Support for Caregivers
by D. Haigler, K. Mims, and J. Nottingham, 1998

The Caregiver's Companion
by Theola Jones, 2000

The Caregiver Helpbook
by V. Schmall, M. Cleveland, M. Sturdevant, 2000

by Avrene Brandt, 1997

Caregiving: A Step-by-Step Resource for Caring for the Person with Cancer at Home
by Peter Houts and Julia Bucher, 2000

Caregiving for Yourself While Caring for Others
by Lawrence Brammer, PhD, 1999

Caregiving Sourcebook
by Joyce Brennfleck Shannon, 2001

Caregiving: The Spiritual Journey of Love, Loss and Renewal
by Beth McLeod, 2000

Childhood Leukemia: A Guide for Families, Friends and Caregivers
by Nancy Keene, 3rd ed. 2002

Daily Comforts for Caregivers
by Pat Samples, 1999

Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and their Families
by Ernest H. Rosenbaum and Isadora Rosenbaum, 2005

Gifts of Caregiving
by Connie Goldman, 2002

Helping Yourself Help Others: A Book for Caregivers
by Rosalynn Carter, 1995

Help Me Live: 20 Things People with Cancer Want You to Know
by Lori Hope, 2005
Books

**Homecare Management of the Blood Cell Transplant Patient**
by Cathy H. Kelley, Susan Randolph, Linda McBride, 1998

**Living with Childhood Cancer: A Practical Guide to Help Families Cope**
by Leigh Woznick, 2001

**Love, Honor and Value—A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving**
by Suzanne Mintz, 2002

**100 Questions and Answers about Caring for Family or Friends with Cancer**
by Susannah L. Rose and Richard Hara, 2005

**Pebbling the Walk: Surviving Cancer Caregiving**
by Steve Reed, 2000

National Bone Marrow Transplant Link, 2006

**Share Care—How to Organize a Group to Care for Someone who is Seriously Ill**
by Cappy Capossela and Sheila Warnock, 2004

**Supportive Cancer Care: The Complete Guide for Patients and Families**
by Ernest H. Rosenbaum, MD, et al, 2001

**Surviving your Spouse’s Chronic Illness: A Compassionate Guide**
by Chris McGonigle, 1999

**The Professional and Family Caregiver—Dilemmas, Rewards and New Directions**
by Jack and Joanne Nottingham, 1990

**When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients**
by Elise NeeDell Babcock, 1997

Videos/DVD’s

**Educated Caregiver**
by Nancy Van Camp (3 tape series), Life View Resources, Inc., 1998

**The Grit and Grace of Being a Caregiver: Maintaining Your Balance as You Care for Others**
Willowgreen Productions, 1997

**Home Nursing Care: A Practical Guide for Family Caregivers**
by G. Timpane and M. Wholey, AYA, Inc., 1998

**The New Normal: Life After Bone Marrow/Stem Cell Transplant**
National Bone Marrow Transplant Link, 2001
Information on the Internet

The Internet is a valuable tool. It offers a wealth of information, some helpful, some misleading. Rely on credible sources for information, such as hospitals or medical associations. Proceed with caution when searching the Internet. Evaluate material by asking:

– What is the source of this information?
  – Is it factual or opinion?
– Is it based on someone’s experience?
  – How current is the information?
– Is this site set up to promote a product?

When evaluating the Internet sites, check the address (URL). The final segment of the address offers a general idea of who is sponsoring the web site. Examples include:

- .edu… site sponsored by an educational institution
- .gov… site sponsored by a government agency
- .org… site sponsored by a non-profit organization
- .com… site sponsored by a commercial company

Internet Resources for Caregivers:

American Association for Retired Persons . . . . . www.aarp.org/families/caregiving
Association of Cancer Online Resources . . . . . . www.acor.org
Caregiver’s Marketplace . . . . . www.caregiversmarketplace.com
Caregiving.com . . . . . . . . . . . . . . . . . . . . . . . . www.caregiving.com
CaringBridge . . . . . . . . . . . . . . . . . . . . . . . . . . . . www.caringbridge.org
Kids Konnected . . . . . . . . . . . . . . . . . . . . . . www.kidskonnected.org
Lotsa Helping Hands . . . . . . . . . . . . . . . . . . www.lotsahelpinghands.com
MedlinePlus . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . www.medlineplus.gov/caregivers
National Bone Marrow Transplant Link . . . . . . www.nbmtlink.org
National Respite Locator Service . . . . . . . . . www.archrespite.org
Strength for Caring . . . . . . . . . . . . . . . . . . . . . . www.strengthforcaring.com
The Healing Project . . . . . . . . . . . . . . . . . . . . www.thehealingproject.org
The Never-Ending Squirrel Tale . . . . . . . . . . www.squirreltales.com
Today’s Caregiver Magazine . . . . . . . . . . . . . . . www.caregiver.com
Resources and Reassurance
When You Need Them Most

The mission of the National Bone Marrow Transplant Link (nbmtLINK) is to help patients, as well as their caregivers, families and the health care community meet the many challenges of bone marrow/stem cell transplant by providing vital information and support services.

Founded in 1992, the nbmtLINK is an independent, non-profit organization funded entirely through the generosity of individuals, corporations and foundations. Tax-deductible contributions are welcomed and vital to ongoing programs and services.

National Bone Marrow Transplant Link
20411 W. 12 Mile Road, Suite 108
Southfield, Michigan 48076

248-358-1886
Fax: 248-358-1889
Toll Free: 800-546-5268
E-mail: info@nbmtlink.org
www.nbmtlink.org

“A Second Chance at Life Is Our First Priority”
This glossary explains terms that you may read in this guide, or hear from your healthcare team. If you hear a word or expression not listed here, don’t be afraid to ask your doctor or nurse.

**Absolute neutrophil count** - The percentage of polys and bands that are part of your total white blood count. If your ANC is less than 1,000 (or 1.0), you are at high risk for infection.

**Ablative therapy (ab-lay-tive)** - Treatment that removes or destroys the function of an organ or system. For example, high-dose chemotherapy and radiation before a stem cell transplant is considered ablative therapy because it wipes out your immune system.

**Afebrile** - Having no fever; normal temperature.

**Allogeneic stem cell transplant** – A type of transplant where stem cells are taken from a donor and given to a patient.

**Alopecia** (al-o-pee-shuh) – See hair loss.

**Ambulatory** - The ability to walk; not confined to bed.

**Anal** - Related to the anus.

**Analgesic** - A medication used to reduce pain.

**Anaphylaxis** - An allergic reaction ranging from relatively mild (hives) to very serious (shock).

**Anemia (uh-neem-ee-uh)** - Low red blood cell count, which can cause you to feel fatigued and have shortness of breath. Anemia can be caused by a variety of conditions and diseases.

**Anesthesiologist (an-es-the-zee-ol-o-jist)** - A doctor who specializes in giving medications or other substances that prevent or relieve pain, especially during surgery.

**Anesthetic** - A medication or other substance that causes a loss of feeling or awareness. Local anesthetics cause a loss of feeling in 1 small area of the body. Regional anesthetics cause a loss of feeling in a part of the body, such as an arm or leg. General anesthetics cause a loss of feeling and a complete loss of awareness that feels like a very deep sleep.

**Antibiotic** – Medication used to kill organisms that cause disease. Since some cancer treatments can reduce your body’s ability to fight infection, antibiotics may be used to treat or prevent these infections.

**Antibody** - A protein produced by immune system cells and released into your blood. Antibodies defend against foreign substance such as bacteria. For example, if you get a
tetanus vaccine, you will make a protein (antibody) which protects against tetanus, called a tetanus antibody. Each antibody works against a specific substance called an antigen.

**Anticoagulant** - Medication that reduces your blood’s ability to clot.

**Antiemetic (an-ti-eh-meh-tik)** - A medication that prevents or relieves nausea and vomiting.

**Antifungal** - A medication that kills fungi (organisms that cause infections). Patients undergoing treatment for cancer are especially vulnerable to fungal infections.

**Antigen (an-tuh-jen)** - A substance that causes your body’s immune system to react. This reaction often involves the production of antibodies. Cancer cells have certain antigens that can be found by laboratory tests. They are important in cancer diagnosis and in watching response to treatment.

**Antihistamine** - A medication used to relieve the symptoms of allergies, such as hives, stuffy nose, etc.

**Antimicrobial** - A substance that kills microorganisms such as bacteria or mold, or stops them from growing and causing disease.

**Antinausea** – See antiemetic.

**Antioxidants (an-ti-ox-uh-dents)** - Compounds that hold back chemical reactions with oxygen and are thought to reduce the risk of some cancers. Examples are vitamins C, E, and beta-carotene.

**Apheresis** - A procedure in which blood is collected, part of the blood (such as platelets or white blood cells) is taken out, and the rest of the blood is returned to the donor. Also called pheresis.

**Aplastic anemia** – A disease in which the bone marrow is not able to make enough blood cells.

**Artery** - A vessel that carries oxygen-rich blood from your heart to your tissues. Blood is under pressure in arteries.

**Autologous** - Taken from an individual’s own tissues, cells, or DNA.

**Autologous stem cell transplant** – A type of transplant in which a person’s own stem cells are harvested, preserved, and returned to them.

**Axilla (ax-il-la)** - Your armpit.

**Bacteria (singular bacterium)** - Small germs that can cause infection.

**Benign** - Not malignant or cancerous.

**Biopsy (buy-op-see)** - The removal of a sample of tissue to see whether cancer cells are present and to determine an exact diagnosis. There are several kinds of biopsies.
Blast cells - Immature blood cells.

Blood - The body fluid that flows through all your vessels except the lymph vessels and performs a number of critical functions. Blood is composed of a liquid portion called plasma and 3 other components: red blood cells, white blood cells, and platelets.

Blood chemistries - Multiple chemical determinations of your blood content. These tests are helpful in assessing your kidney and liver function.

Blood count - A lab study to evaluate the amount of white blood cells, red blood cells, and platelets in your body.

Blood culture - A blood sample taken to find infection in the blood.

Blood transfusion - The infusion of red blood cells or platelets into your bloodstream to replace blood loss or to treat anemia.

Blood typing and cross matching - Making sure that the blood from a donor is compatible with yours before a blood transfusion. Blood cells contain factors that are not the same in all people. Before a transfusion can be given, blood samples from you and the donor are typed, or classified, according to which of these factors are present. The 4 principal red blood cell types or groups are A, B, AB, or O. Other factors such as Rh factor must also be checked.

Bone marrow - The spongy material in the center of bones where blood cells are made.

Bone marrow aspiration and biopsy - A procedure in which a needle is placed into the cavity of a bone, usually the hip or breast bone. A small amount of bone marrow is removed and examined under a microscope.

Bone marrow, stem cell, or cord blood transplant - A treatment for cancer, which severely injures or destroys your bone marrow. You are given high-dose chemotherapy with or without radiation (total body irradiation) to kill the cancer cells. The medications also destroy your remaining bone marrow, preventing your body’s natural ability to fight infection. In allogeneic transplantation, the donor of the stem cells is another person. Stem cells can come from bone marrow, blood, or umbilical cord blood. In autologous transplantation, stem cells are taken from the patient. Some of your own bone marrow or stem cells are removed and set aside before treatment and then reinfused into your body. Blood cells start being produced a few weeks later.

Bone scan - An imaging method that gives important information about the bones, including the location of cancer that may have spread to the bones. A low-dose radioactive substance is injected into a vein and pictures are taken to find any abnormalities.

Bowel - Pertaining to your intestines.

Bowel movement - Movement of feces through the bowel and out the anus. Also called defecation.
Brain scan - An imaging method used to find anything abnormal in the brain, including brain cancer and cancer that has spread to the brain from other places in the body. A radioactive substance is injected into a vein and pictures are taken to find any abnormalities.

Breastbone - The long, flat bone that forms the center front of your chest wall. Your breastbone is attached to your collarbone and your first 7 ribs. Also called the sternum.

Capillaries - Tiny blood vessels located throughout the tissues of your body. They connect your arteries with your veins. Substances pass through them to nourish your cells.

Cardiac - Pertaining to your heart.

Cardiomyopathy - Damage to the heart muscle affecting the way the heart pumps blood through the body.

CAT scan or computed axial tomography - A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called computed tomography scan, computerized axial tomography scan, computerized tomography, and CT scan.

Cataracts - A clouding of the lens of the eye that can result from radiation therapy.

Catheter (cath-eh-tur) - A thin, flexible tube through which fluids enter or leave the body; e.g., a tube to drain urine.

Central venous catheter - A thin, flexible tube that is inserted into a vein in the upper arm, thigh, neck, or below the collarbone. It is guided (threaded) into a large vein near the heart called the vena cava or into the right atrium of the heart. It is used for taking blood samples and giving liquids, blood transfusions, chemotherapy, and other medications. It avoids the need for repeated needle sticks.

Central venous line - A method of giving IV fluids, blood products, and medications. A catheter is inserted into a neck vein and into your other large blood vessels. There are many different types of central line catheters that may have multiple ports or lumens. Multiple ports allow more than one IV solution to be given at one time. Blood can also be drawn from this type of catheter.

Chemotherapy - Medications used to destroy cancer cells. Chemotherapy is often used with surgery or radiation to treat cancer.

Chimerism studies - A test that shows how much of the blood is from the patient and how much is from the donor.

Clinical trials - Human research studies that test new drugs or treatments and compare them to current, standard treatments. Before a new treatment is used on people, it is studied in the lab. If the lab studies suggest the treatment works, it is tested with people. These human studies are called clinical trials. Your doctor may suggest a clinical trial. Participation is voluntary.
Clot - To change from a liquid form into a solid or semi-solid; for example, when blood clots, it changes from a liquid to a semi-solid, helping to stop bleeding.

Colon - Your large intestine.

Colony stimulating factors (CSF) - Types of growth factors that promote growth and division of blood-producing cells in bone marrow. CSFs are naturally produced in the body. Extra amounts may be given to reduce or prevent side effects of chemotherapy. See growth factors.

Complementary therapy - Therapies used in addition to conventional therapy. Some complementary therapies may help relieve certain symptoms of cancer, relieve side effects of conventional cancer therapy, or improve a patient’s sense of well-being.

Complete blood count (CBC) - A blood test to measure the type and number of blood cells. The values are expressed in percentages.

Constipation - Difficulty having a bowel movement.

Contagious - An illness that can be spread from one person to another. Cancer is not contagious.

Creatinine clearance - A test that compares the level of creatinine in urine with the level of creatinine in the blood. Creatinine is a breakdown product of creatine, which is an important part of muscle. The test helps provide information on kidney function.

Culture - A procedure using a sample of blood, urine, throat secretions, or other biological material. It determines the specific germ (bacteria, fungus, or virus) responsible for an infection. Cultures also help determine which antibiotics may work best.

Cytogenetics - The process of analyzing the number and shape of cell chromosomes. The normal number of chromosomes is 46. Chromosomes may change when a patient develops cancer.

Cytomegalovirus (CMV) - A virus that can cause serious illness in people who have weak immune systems.

Decongestant - A medication that helps shrink mucous membranes and decrease the production of mucus.

Dehydration - Excessive loss of fluids from your body.

Diagnosis - Identifying a disease by its signs or symptoms and by using imaging procedures and laboratory findings.

Diarrhea - Frequent, loose, and watery stools.

Dietitian - A health professional with special training in nutrition who can help with dietary choices. Also called a nutritionist.
Diuretic - Substance that increases the elimination of water and salts (urine) from your body.

Dizziness - A sensation of instability and sometimes a feeling that you are about to fall.

Donor leukocyte infusion - A transfusion of whole blood or isolated lymphocytes that contain a calculated dose of T lymphocytes. This is sometimes given to treat a recurrence of a patient’s original disease or for the treatment of certain viral infections.

Dose - The amount of medication taken, or radiation given, at one time.

Dysphagia - Difficulty swallowing.

Dyspnea - Shortness of breath.

Dystonic reaction - Tightening of your facial and neck muscle. It is a possible side effect of some antiemetic medications.

Echocardiogram (ultrasound cardiography) - A method of obtaining a graphic picture of the internal structure, position, and motion of your heart. It is done by using sound waves directed through your chest.

Edema - Build up of fluid within the tissues; swelling.

Electrocardiogram (EKG) - A method of evaluating your heart’s rhythm and muscle function by measuring electrical impulses.

Electrolytes - A general term for the many minerals needed to provide the proper setting for the cells of your body. Common electrolytes include calcium, sodium, potassium, and chloride.

Emesis - To vomit.

Engraftment - When stem cells infused into the body start to fix in place, grow, and make new blood cells.

Epstein-Barr virus (EBV) - The virus that causes mononucleosis (also called “mono” or “kissing disease”). In patients whose immune system is not normal, it can cause an EBV-associated lymphoma. Symptoms include fever and swollen lymph nodes.

Esophagitis - An inflammation of the esophagus.

Esophagus - A tube that carries swallowed food to your stomach.

Excision - Surgical removal of tissue.

Expectorant - Medication that makes mucus in your respiratory tract thinner and easier to cough out.
Febrile - Fever; elevated body temperature.

Fellow - A physician who has completed residency. May be a fully trained pediatrician or internist and is doing further study to become a subspecialist in a field of interest.

Fertility preservation - A type of procedure used to help preserve a person’s ability to have children. A fertility preservation procedure is done before a medical treatment that may cause infertility, such as radiation therapy or chemotherapy. Examples of fertility preservation procedures include sperm banking, egg freezing, in vitro fertilization with embryo freezing, and certain types of surgery for cervical and ovarian cancer.

Filgrastim - A medication used to increase the number of white blood cells in people who are receiving chemotherapy. Also called Neulasta® or pegfilgrastim.

Fractionated radiation - The total dose of a radiation treatment divided over several days.

Fungi (singular fungus) - A group of microorganisms larger than either bacteria or viruses. They can cause a serious infection when your immune system is compromised.

Gamma globulin - A protein component of blood plasma. It contains antibodies that are helpful against certain infections.

Gastroenterologist (gas-tro-en-ter-ol-o-jist) - A doctor who specializes in diseases of the digestive (gastrointestinal) tract.

Gastrointestinal tract/GI tract - The digestive tract. It is made up of the organs and structures that process and prepare food to be used for energy, such as your stomach, small intestine, and large intestine.

GCSF (granulocyte colony-stimulating factor) - Medications that stimulate the production of neutrophils (a type of white blood cell). These include filgrastim (Neupogen®), pegfilgrastim (Neulasta®), and plerixafor (Mozobil®).

General anesthetic - A medication that puts you to sleep to prevent pain during a surgery.

Genital - Refers to the genitalia (external and internal sex organs and glands).

Gland - See lymph node.

Graft - New stem cells that are growing

Graft versus host disease (GVHD) – A reaction of donor cells (graft) against the patient’s (host) body; can be short-term (acute) or long-term (chronic).

Groin - The area of your body where the legs join the abdomen.

Growth factors - A naturally occurring protein that causes cells to grow and divide. Too much growth factor production by some cancer cells helps them grow quickly. Other growth factors help normal cells recover from the side effects of chemotherapy.
Hair loss - This often occurs as a result of chemotherapy or from radiation therapy to the head. In most cases, the hair grows back after treatment ends.

Harvest - The removal of bone marrow or peripheral blood stem cells to be used for a hematopoietic blood stem cell transplant (HCT).

Hematocrit - The percentage of the volume of whole blood that is made up of red blood cells.

Hematopoietic blood stem cell transplant (HCT) – See bone marrow, stem cell, or cord blood transplant.

Hematologist (hem-uh-tahl-o-jist) - A doctor who specializes in diseases of the blood and blood-forming tissues.

Hematology - The study of blood and blood-forming organs.

Hematology/oncology (HEME/ONC) - A branch of medical science that treats disorders of the blood, blood-forming tissues, and tumor cells.

Hematoma (hem-uh-to-ma) - A collection of blood outside a blood vessel caused by a leak or an injury; a bruise.

Hematuria - Blood in the urine. Urine may be pink, red, or brown (cola colored).

Hemoglobin - The substance in red blood cells that carries oxygen.

Hemorrhage - A term for loss of blood from injury to the blood vessels or by a lack of certain blood elements, such as platelets.

Hemorrhagic cystitis - Bleeding into the bladder that causes bloody urine. It can be caused by certain viruses, as well as certain chemotherapy medications such as ifosfamide or cyclophosphamide.

Heparin - A medication that decreases the ability of blood to clot. It is often used to prevent clotting in central line catheters.

Hepatitis - An inflammation of the liver usually resulting in jaundice.

Herpes simplex - A virus that usually produces fluid-filled blisters on the skin and mucus membranes.

Herpes zoster - A virus that causes shingles, which are painful skin eruptions.

Hives - Itching welts caused by an allergic reaction.

HL-A (human leukocyte antigens) - Proteins (antigens) that appear on white blood cells, as well as cells of almost all other tissues. By typing for HL-A antigens, donors and recipients of white blood cells, platelets, and organs can be “matched.” This helps to make sure the transfused and transplanted cells will survive.
**Hodgkin’s disease** - A type of cancer that affects the lymphatic system. It occurs in lymph nodes. Named for the doctor who first identified it.

**Hospitalist** - A doctor who specializes in the care of hospitalized patients.

**Host** - The person into whom stem cells have been infused.

**Hydration** - A reference to the amount of water in the body. You may be dehydrated, well hydrated, or excessively hydrated (edematous).

**Hyperglycemia** - High blood sugar.

**Hypertension** - High blood pressure.

**Hypocalcemia** – Not enough calcium in the blood.

**Hypoglycemia** - Low blood sugar.

**Hypokalemia** - Not enough potassium in the blood.

**Hypotension** - Low blood pressure.

**Ileus** - Severe constipation.

**Iliac crest** - The top edge of your hip bone. Marrow is usually taken from it for a diagnosis of blood cell diseases.

**Immune reaction** - A reaction of normal tissues to substances recognized as “foreign” to the body.

**Immune system** - The system that defends the body against infection from bacteria and viruses. The immune system may also help the body fight some cancers.

**Immunity** - The state of your body’s defenses against an infection or possibly against a certain cancer.

**Immunizations** - Vaccines given to help your body resist disease.

**Immunosuppression (im-mune-no-suh-preh-shun)** - A state in which your immune system does not respond properly. This condition can be present at birth. It can also be caused by certain infections (such as human immunodeficiency virus or HIV), or by certain cancer therapies.

**Immunotherapy (im-mune-no-ther-uh-pee)** - Treatments that promote or support your immune system’s response to a disease such as cancer.

**Implantable port (such as Port-a-Cath®, Infuse-a-Port®, or Mediport®)** - A device that delivers fluids, medications, or blood directly into a vein. The entire device is implanted under the skin during surgery and can be used for an extended period of time.
**Incubation period** - The period between exposure to a germ and the first sign of illness (e.g., chicken pox, from 8 to 21 days).

**Indwelling catheter (such as Broviac® or Hickman®)** - A central line surgically placed (usually in the chest) and into a large vein in your neck. It is used to give medications, fluids, and blood products. May also be used to draw blood for testing.

**Infection** - Invasion of the body by disease-producing organisms.

**Infectious disease** - A disease caused by germs; one that can be passed from one person to another. Cancer is not an infectious disease.

**Infertility** - Not being able to produce children.

**Inflammation** - The triggering of local body defenses. It results in the outpouring of defensive cells (“polys”) from the circulation system into the tissues. Frequently associated with pain and swelling.

**Informed consent** - A legal document that explains a course of treatment and the risks, benefits, and possible alternatives. The process by which patients agree to treatment. If you are under 18 years of age, your parents or legal guardian must also sign this form.

**Infusions** - The introduction of a fluid into a vein.

**Injections** - Injections may be given intramuscularly (into a muscle), intravenously (into a vein), subcutaneously (just under the skin), or intrathecally (into the spinal column space).

**Inpatient** - A patient who is admitted to the hospital for treatment requiring an overnight stay.

**Intern** - A doctor in the first year of training following graduation from medical school.

**Interstitial pneumonia** - Inflammation of the lung caused by a virus or due to damage from chemotherapy and/or radiation therapy.

**Intrathecal (IT)** - Within the spinal column. IT medication is given directly into the spinal column.

**Intravenous (IV)** - The administration of a medication or fluid directly into the vein.

**Investigational drugs** - Medications being studied by clinical investigation.

**Irradiated** - Treated with radiation.

**Irradiated blood products** - Blood products that have been exposed to a radiation source to inactivate the lymphocytes that could otherwise cause graft versus host disease.
**Jaundice** - A yellow color of the skin and white portion of the eyes. It is from a buildup of bilirubin, which is a broken down product of hemoglobin. It is a sign of liver disease or a blockage of the major bile ducts.

**Kidney** - The main organ involved in the filtering of certain bodily wastes. Also maintains the proper mineral and water balance.

**Laxative** - A substance that encourages bowel movements.

**Lesion (lee-zhun)** - A change in body tissue; sometimes used as another word for tumor.

**Leukapheresis** - The process of filtering white cells, leukocytes, or “polys” from the blood of the patient or a healthy donor. These cells may be given to you if you have a severe infection and a shortage of “polys.”

**Leukemia (loo-key-me-uh)** - Cancer of the blood or blood-forming organs. If you have leukemia, you may have a noticeable increase in white blood cells (leukocytes).

**Leukocytes** - White blood cells that play a major role in the body’s defense system. The cells are divided into granulocytes, lymphocytes, and monocytes.

**Leukocytosis (loo-ko-sigh-toe-sis)** - Having more than the usual number of white blood cells.

**Leukopenia** - Decrease in white blood cell count.

**Liver** - An organ in your body that performs many complex functions. These include processes related to digestion, production of certain proteins, and elimination of many of the body’s waste products.

**Local anesthetic** - A medication given by injection into a part of your body to prevent pain in the area without putting you to sleep.

**Long-term survivor** - A person who is 5 years from the last sign of disease and at least 2 years off therapy.

**Low microbial diet** - A diet designed to minimize bacteria, viruses, yeast, and molds in food and beverages.

**Lubricant** - An oily or slippery substance.

**Lumbar puncture (LP)/spinal tap** - A procedure in which a thin needle is placed in your spinal canal. It is done to remove a small amount of spinal fluid or to give medication through the central nervous system.

**Lumen** - A tube that forms part of a catheter. Many catheters exit the body and separate into several lumens.

**Lymph nodes/glands** - An important part of your body in the defense against infections.
**Lymphatic system** - The tissues and organs that make and store lymphocytes (cells that fight infection) and the channels that carry the lymph fluid. It includes the lymph nodes, spleen, thymus, and bone marrow. The lymphatic system is an important part of your body’s immune system. Invasive cancers sometimes enter your lymphatic vessels (channels) and spread to your lymph nodes.

**Lymphocytes** - A type of white blood cell that helps your body fight infection. There are 3 main types of lymphocytes: (1) T cells that help fight infections such as viruses and fungi; (2) B cells that make proteins called antibodies that help fight infection. For example, if you receive a vaccination against tetanus, you make a protein (antibody) against tetanus; (3) natural killer cells that help fight viruses and other germs. They are sometimes given to help fight cancer.

**Lymphocytosis** (limf-o-sigh-toe-sis) - Having too many lymphocytes.

**Lymphoma** (lim-foam-uh) - Cancer of the lymphatic system, a network of thin vessels and nodes throughout the body. Lymphoma involves a type of white blood cell called a lymphocyte. The 2 main types of lymphoma are Hodgkin’s disease and non-Hodgkin’s lymphoma. The treatment methods for these 2 types of lymphomas are very different.

**Magnetic resonance imaging (MRI)** - A method of taking pictures of the inside of the body. Instead of using x-rays, MRI uses a powerful magnet and transmits radio waves through the body. The images appear on a computer screen, as well as on film. Like x-rays, the procedure is painless. However, you may find it uncomfortable to be inside the MRI machine.

**Malignant tumor** (muh-lig-nant) - A mass of cancer cells that may invade surrounding tissues or spread to distant areas of the body.

**Metabolism** - A general term for the many chemical processes needed for your body to live.

**Metastasis** (meh-tas-teh-sis) - The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

**Microliter** - A unit of measure. One millionth of a liter.

**Microorganism** - A general name for any small living organism, such as bacteria, viruses, and fungi.

**Milliliter (mL)** - A unit of measure. One thousandths of a liter. There are 30 mL in 1 ounce, 15 mL in 1 tablespoon, and 5 mL in 1 teaspoon.

**Mobilization** - Taking medication to stimulate the growth of stem cells and move them into the bloodstream.

**Monoclonal antibodies** - Antibodies made in a laboratory to target substances called antigens. They can be attached to chemotherapy medications or radioactive substances. Monoclonal antibodies are being studied to see if they can seek out antigens unique to
cancer cells and deliver treatment directly to the cancer. This would kill the cancer cells without harming healthy tissue. Monoclonal antibodies are also used in other ways, for example, to help find and classify cancer cells.

**Mozobil®** - A brand of plerixafor. Plerixafor is a medication used together with granulocyte colony-stimulating factor (GCSF) to help move stem cells from the bone marrow to the blood.

**Mucositis** - Inflammation of the mucous membrane (inside the mouth). It can cause painful mouth sores.

**Mucous membrane** - A lining of the internal surface of the body that produces mucus.

**Myeloma** - Cancer of blood plasma cells, a type of white blood cell.

**Narcotic** - A medication that relieves pain and can make you sleepy.

**Nephrologist (nef-rol-o-jist)** - A doctor who specializes in diseases of the kidneys.

**Neupogen®** - A brand of granulocyte colony-stimulating factor (GCSF)—a medication that stimulates the production of neutrophils (a type of white blood cell). Also called filgrastim.

**Neurology** - The branch of medical science that deals with the nervous system.

**Neutropenia** - A condition in which there is a lower than normal number of neutrophils (a type of white blood cell) in the body. While you are neutropenic, you will need to take precautions to prevent infection.

**Neutrophils (new-trow-fils)** - White blood cells that fight bacterial infection.

**Non-Hodgkin’s lymphoma** - Cancer of the lymphatic system. The difference between non-Hodgkin’s lymphoma and Hodgkin’s lymphoma is a type of cell called the Reed-Sternberg cell. This cell is only present in Hodgkin’s lymphoma. The treatment methods for Hodgkin’s and non-Hodgkin’s lymphomas are very different.

**NPO** - Abbreviation for “nothing by mouth.”

**Nuclear medicine scan** - A method for finding diseases of internal organs, such as the brain, liver, or bone. Small amounts of a radioactive substance (isotope) are injected into the bloodstream. The isotope collects in certain organs. A special camera is used to create an image of the organ and detect areas of disease.

**Nurse practitioner (NP)** - A registered nurse with a master’s or doctoral degree. Licensed nurse practitioners diagnose and manage illness and disease and can prescribe medication. They work closely with your doctor.

**Oncologist (on-call-o-jist)** - A doctor with special training in the diagnosis and treatment of cancer.
**Oncology (on-call-o-jee)** - The branch of medicine concerned with the diagnosis and treatment of cancer.


**Orally** - By mouth; e.g., a medication to be taken orally is one that is swallowed.

**Organ** - Several tissues grouped together to perform one or more functions in the body.

**Orthopedic surgeon (or-tho-pe-dik)** - A surgeon who specializes in diseases and injuries of the bones.

**Osteoporosis** - Brittle bones due to the loss of calcium.

**Outpatient** - A patient who visits a healthcare facility for diagnosis or treatment without spending the night. Sometimes called a day patient.

**Packed red blood cell transfusion (PRBC)** - A transfusion of red blood cells without the serum.

**Palate** - The roof of the mouth.

**Pancreas** - A large gland in the upper part of your abdomen. It secretes enzymes (chemicals) into your intestines for the digestion of food. It makes insulin, which is secreted into your bloodstream.

**Pancreatitis** - Inflammation (swelling) of your pancreas.

**Pancytopenia** - The decrease of all blood cells (red, white, and platelets).

**Parotid gland** - Salivary glands located at the side of your face in front of each ear. These glands become large if you have mumps. Total body irradiation may cause painful swelling of these glands, which is temporary.

**Pathology** - The branch of medicine involved in making diagnoses from the examination of tissues.

**Pedicure** - A beauty treatment in which toenails are trimmed/shaped and often polished or painted.

**PET scan** - A scan used to look at the organs and the way they function in the body. A small amount of radioactive sugar is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body. Also called a positron emission tomography scan.

**Petechiae** - Tiny, localized hemorrhages from small blood vessels just below the surface of the skin. They are often caused by a low platelet count. They clear up as the platelet count increases.
**pH** - A symbol that means acidity or alkalinity. A solution of pH 7 is neutral. Below 7 is acidic and above 7 is alkaline. The urine is usually slightly acidic, with a pH of 5.3.

**Pharyngitis** - Inflammation of the throat; sore throat.

**Pharynx** - Your throat.

**Pheresis/apheresis** - A special method of collecting blood when only one part of the blood is needed.

**Phlebitis** - Inflammation of a vein. Signs include pain, swelling, and tenderness in an area. If a superficial vein is involved, the phlebitis can be felt as a cord-like thickening along the vein.

**Physician assistant (PA)** - A licensed medical professional who practices medicine under physician supervision. Physician assistants diagnose and manage illness and prescribe medications.

**Plasma** - The liquid portion of the blood in which blood cells are suspended. It contains many proteins and minerals necessary for normal body function.

**Platelet** - A part of the blood that helps repair (plug) holes in blood vessels after an injury. If you have a low platelet count, you are at risk for bleeding. Chemotherapy can cause a drop in the platelet count. This is called thrombocytopenia.

**Plerixafor** - A medication used together with granulocyte colony-stimulating factor (GCSF) to move stem cells from the bone marrow to the bloodstream.

**Pneumonia** - Infection of the lung.

**Polys (neutrophils or granulocytes)** - The group of white cells that helps to resist bacterial infection. A “poly” count of less than 1,000 means that you have an increased risk of infection.

**Postop** - After surgery.

**Potassium** - An element found normally in your blood; it is important for heart and muscle function.

**Preop** - Before surgery.

**Prognosis (prog-no-sis)** - A prediction of the course of disease; the outlook for a cure. A prognosis is based on the average result in many cases. It may not accurately predict your outcome, since the course can vary from patient to patient.

**Prophylactic** - Treatment designed to prevent a disease or a complication that has not yet become clear.

**Protocol (pro-teh-call)** - A formal outline or plan, such as a description of what treatments you will receive and exactly when each should be given.

**Pulmonary** - Concerns or affects your lungs.
**Pulmonary fibrosis** - Thickened tissue in your lungs that causes coughing, difficulty breathing, and x-ray changes.

**Pulmonary function tests (PFTs)** - Special tests that are designed to evaluate the function of your lungs.

**Radiation oncologist** - A doctor who specializes in using radiation to treat cancer.

**Radiation recall** - Inflammation (swelling) of exposed skin and organs in areas of radiation therapy.

**Radiation therapy** - Treatment with high-energy x-rays to kill cancer cells or shrink tumors. The radiation can come from outside of the body (external radiation) or from radioactive materials placed directly in the tumor (internal or implant radiation). Radiation therapy can be used to reduce the size of a tumor before surgery or to destroy any remaining cancer cells after surgery. Or, in some cases, it may be the main treatment.

**Rectal** - By or having to do with the rectum. The rectum is the last several inches of your large intestine closest to your anus.

**Rectum** - The last part of your large intestine.

**Red blood cell** - A cell that carries oxygen to all parts of the body. Also called erythrocyte and RBC.

**Regression** - The reduction of cancer, usually as the result of therapy. It is shown by the decreased size of the tumor or tumors.

**Reinduction** - To start over, i.e., a new treatment or protocol.

**Rejection** - The body’s inability to accept transplanted stem cells.

**Relapse** - Return of cancer after a disease-free period.

**Remission** - When the signs and symptoms of cancer fully or partly disappear. The period during which a disease is under control. A remission may not be a cure.

**Renal** - Pertaining to your kidneys.

**Resident** - A physician in the second or third year of training after completing medical school.

**Resistance** - Your ability to fight off and avoid disease.

**Respiration** - The process of breathing.

**Respiratory tract** - All parts of your body used for breathing.

**Scan** - A study using either x-rays or radioactive isotopes to create images of internal body organs.
**Sedative** - A medication given to make you drowsy or sleepy.

**Sedimentation rate (SED)** - The change in speed of the red blood cell count expressed in millimeters per hour. A SED rate that is over 25 or is increasing may indicate infection.

**Septicemia/sepsis** - A very serious bacterial or fungal blood infection. It usually spreads from another site of infection such as skin, bowel, or urinary tract. It can cause high fever, shaking chills, and heavy sweating. It is more likely to occur in patients with a very low white blood cell count.

**Shingles (herpes zoster)** - A viral infection of the nerve endings in the skin. It can cause blisters, crusting, and severe pain along the nerve. It is the same virus that causes chicken pox. Children who have not had chicken pox may get it from contact with someone who has shingles.

**Simulation** – A procedure that is done to plan radiation therapy; measurements and x-rays are taken and actual radiation treatment fields are determined.

**Sinuses** - Hollow spaces in the bones of your head.

**Spinal cord** - The cord or nerve tissue that runs through the center of your spinal column. It connects your brain to other parts of your body.

**Spleen** - An organ that filters your blood. It removes debris and old or dying cells from circulation. It also removes bacteria from the blood during the early stages of severe infection. It often becomes enlarged in those with leukemia and certain other diseases.

**Stem cells** - Primitive blood-forming cells in the bone marrow that give rise to white blood cells, red blood cells, and platelets.

**Sternum** - The long, flat bone that forms the center front of your chest wall. Your breastbone is attached to the collarbone and your first 7 ribs. Also called the breastbone.

**Stomatitis** - Mouth sores; this can be a side effect of some kinds of chemotherapy.

**Suppository (rectal or vaginal)** - A medication prepared for insertion into the anus or vagina, where it is generally absorbed into the bloodstream.

**Susceptible** - Tendency to develop a disease if exposed to it; not having immunity.

**Symptom** - A change or sign in the body or its function that indicates disease or infection.

**T cell-depleted blood stem cell transplant** - A type of transplant in which T cells are removed in a laboratory after donor stem cells are obtained. This process reduces the likelihood of graft versus host disease that is caused by the donor’s T cells.

**T cell or T lymphocyte** - A type of white blood cell or lymphocyte that plays a major role in the body’s defense against viral and fungal infections.
**Testicular mass** - A swelling of the testis or testicle, the male reproductive gland.

**Thrombocytopenia (throm-bo-sigh-toe-teen-e-uh)** - A decrease in the number of platelets in your blood.

**Thrombophlebitis** - An inflammation of a vein.

**Tinnitus** - Ringing in your ears.

**Tissue** - A collection of cells similar in structure and function.

**Tissue typing (human leukocyte antigen, HLA)** - A special test of white blood cells to check the genetic match between a donor and the patient.

**Total body irradiation (TBI)** - Radiation treatments given to the whole body.

**Total lymphoid irradiation (TLI)** - Radiation treatments given to the parts of the body where most of the lymphatic system is located.

**Toxicity** - A word used to describe the side effects caused by a medication.

**Toxins** - Poisonous substances; may be produced by germs.

**Trachea** - Your windpipe.

**Transfusion** - A procedure in which a person is given an infusion of whole blood or parts of blood, such as red blood cells or platelets. The blood may be donated by another person or it may have been taken from the patient earlier and stored until needed. Also called a blood transfusion.

**Transfusion reaction** - An allergic response to blood products. Symptoms include hives, chills, or headaches ranging from mild to severe.

**Tumor** - An abnormal lump or mass of tissue. Tumors can be benign (not cancerous) or malignant (cancerous).

**Ulcer** - A wearing away of normal tissues. It can be from corrosive chemicals (e.g., acids), infection, impaired circulation, or cancer. It can cause bleeding.

**Ultrasound** - An imaging method that uses sound waves to outline a part of your body. It can be done to any part of the body. A tumor or infection can be monitored this way.

**Unpasteurized** - Relating to perishable food that has not been pasteurized (heat-treated to kill potentially harmful microbes).

**Urinalysis** - The process by which your urine is examined for various factors.

**Urinary tract** - The organs that have to do with the production and elimination of urine, i.e., kidneys, bladder, ureters, and urethra.

**Varicella** - Chicken pox, an infection caused by a virus. Children with cancer may have a problem with this infection if they have not had it before.
**Vein** - A blood vessel carrying blood from your tissues towards your heart and lungs. Veins are used to draw blood samples and administer IV liquids because blood in veins is not under pressure.

**Veno-occlusive disease (VOD)** - A disease caused by a blockage in the flow of blood in the liver. It results in weight gain, an enlarged liver, and yellowing of the skin. It can cause mild, moderate, or severe liver damage or death.

**Vertigo** - Dizziness, especially the feeling that your surroundings are swirling.

**Virus** - A small germ that may cause infection, such as measles, mumps, chicken pox, and the common cold.

**White blood cells (WBC)** – The cells in your blood that are most important in fighting infection. Examples are neutrophils, or “polys”, and lymphocytes, or “lymphs.”

**X-ray** - A form of radiation that can be used at low levels to produce an image of the body on film. It can be used at high levels to destroy cancer cells.

**Zoster - varicella zoster** - See shingles.
Additional Resources

- Autologous Peripheral Blood Stem Cell Harvesting
- Bone Marrow Harvesting for Autologous or Allogeneic Bone Marrow Transplants
- Bone Marrow Transplant Emergency Guide
- Building Your Family after Cancer Treatment: Information for Men
- Caring for Your Central Venous Catheter
- Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)
- Fertility Preservation: Options for Women Who Are Starting Cancer Treatment
- Frequently Asked Questions about Blood Transfusions
- Giving Yourself an Injection of Filgrastim (Neupogen®) or Pegfilgrastim (Neulasta®) With a Prefilled Syringe
- Hair Loss and Your Cancer Treatment
- Instructions for Interventional Radiology Procedures
- Low-Microbial Diet
- MedicAlert® Foundation Brochure
- Outpatient BMT Temperature & Intake Log
- Sexual Activity During Cancer Treatment: Information for Men
- Sexual Activity During Cancer Treatment: Information for Women
- Sexual Health and Intimacy
- Sperm Banking
PATIENT & CAREGIVER EDUCATION

Autologous Peripheral Blood Stem Cell Harvesting

This information explains autologous peripheral (ah-TOL-o-gus per-IF-er-al) blood stem cell harvesting at Memorial Sloan Kettering (MSK).

Autologous peripheral blood stem cell harvesting is a procedure to harvest (collect) stem cells from your body. Stem cells are immature cells that produce all of the blood cells in your body—the white blood cells that fight infection, red blood cells that carry oxygen, and platelets that stop you from bleeding. Autologous means your own stem cells will be harvested, stored, and given back to you later. Peripheral blood is the blood that circulates in your blood vessels.

After your stem cells are harvested, you will receive a very high dose of chemotherapy to kill any remaining cancer cells in your body. This chemotherapy will also destroy most of the blood cells in your bone marrow and bloodstream.

Harvesting your stem cells beforehand allows us to give you this high dose of chemotherapy. Once the chemotherapy is finished, you will receive an autologous stem cell transplant. This means we will return your stem cells to you. Once they’re back in your body, the stem cells will slowly start to grow, mature, and replace the destroyed cells.

Before Your Procedure

Stem cell mobilization and granulocyte colony-stimulating factor injections

There are only a small number of stem cells circulating in your blood. To increase the number of stem cells in your bloodstream, you will receive injections (shots) of a medication called granulocyte colony-stimulating factor (GCSF). GCSF causes your body to make more stem cells than usual. It also
encourages the stem cells to move into your bloodstream, where they can be collected more easily. This process is called mobilization. GCSF medications include filgrastim (Neupogen®), pegfilgrastim (Neulasta®), and plerixafor (Mozobil®). Your nurse will review which injections you need.

You can either be taught to do the injections yourself or you can discuss other arrangements with your nurse. If you’re doing the injections yourself, your nurse will give you the resource *Giving Yourself an Injection of Filgrastim (Neupogen) or Pegfilgrastim (Neulasta) with a Prefilled Syringe*. You must store these medications in the refrigerator. The injections will be every day for about 5 to 6 days.

Common side effects of these medications include bone pain in your sternum, arms, legs, and lower back. They can also cause headaches and flu-like symptoms. Either regular or extra-strength acetaminophen (Tylenol®) may relieve these side effects. If acetaminophen doesn’t help, your doctor will prescribe something stronger.

**Central venous catheter placement**

Before we collect your stem cells, a nurse or doctor will check your veins to see if they’re healthy enough for the procedure. If your veins aren’t healthy enough, you will have a central venous catheter (CVC) inserted into a large vein near your collarbone. The CVC will be used during the harvesting procedure and will remain in place for several weeks or months. It will also be used to take samples of your blood and to give you intravenous (IV) fluids and medications.

After your CVC is placed, your nurse will teach you how to care for it and will give you written information.

**What to eat**

As your stem cells are collected, your blood calcium levels may drop. We recommend that you eat dairy products and other foods that are rich in calcium (cheese, milk or ice cream). This will help to raise the calcium levels in your blood.
The Day of Your Procedure

Where to go

The harvesting procedure is done in the Blood Donor Room. The Blood Donor Room is located at:

MSK Schwartz Building Lobby
1250 First Avenue (between East 67th and East 68th Streets)
New York, NY 10065
212-639-7643

You will have 3 to 5 appointments for harvesting sessions to collect enough cells. The exact number of sessions depends on the number of stem cells that are collected in each session. You will be told each day if you need to return for another harvesting session. Each session will last 3 to 4 hours.

What to expect

The harvesting is done while you’re on a bed or in a recliner chair. You will be connected to a machine either by IV tubes in your arms or by your CVC. Blood will be drawn through the IV line or CVC and circulate through the machine. The machine will collect your stem cells and the rest of your blood will be returned to you.

If you wish, you can watch TV or read during your procedure. A family member or friend may sit with you. You might feel cold during the procedure, so blankets will be available to make you comfortable.

As your stem cells are collected, you may have:

- Muscle cramps
- Twitching
- A tingling sensation around your lips and fingertips

These are signs of low calcium levels in your blood. The staff in the Donor Room will give you calcium carbonate in the form of Tums®, which are a quick and easy source of calcium.
After Your Procedure

After your procedure, if IV lines were placed in your arm(s), you will have a bandage on your arm to prevent bleeding. Leave the bandage in place for at least 3 hours, but not more than 5 hours. If your CVC was used, it will be flushed and recapped.

If there is bleeding when you remove the bandages, apply gentle but firm pressure on the site(s) for 3 to 5 minutes. Call your doctor if the bleeding does not stop.

Your stem cells will be brought to our stem cell laboratory, where they’ll be frozen and stored safely until your transplant day.

After a harvesting session, most people have minimal side effects and can resume their regular activities. The most common side effects are bruising where the needle was inserted and feeling tired.

Call Your Doctor if You:

- Develop a temperature of 100.4° F (38° C) or higher
- Develop flu-like symptoms
- Have any redness, bleeding, drainage, or pain at your catheter or needle insertion site
- Have numbness or tingling in your lips, hands, or feet
- Have significant pain on the left side of your body
### GCSF Injection Schedule

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Donor Room Appointment</th>
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If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call _________________. If there’s no number listed, or you’re not sure, call 212-639-2000.
Bone Marrow Harvesting for Autologous or Allogeneic Bone Marrow Transplants

This information explains bone marrow harvesting for autologous (ah-TOL-o-gus) or allogeneic (all-o-gen-EH-ic) stem cell transplants.

Bone marrow is a substance found in the spaces in the center of the larger bones in your body such as your hip, breastbone, and pelvis. Bone marrow contains a large number of stem cells, which are immature cells that produce all of the blood cells in your body—the white blood cells that fight infection, red blood cells that carry oxygen, and platelets that stop you from bleeding. Bone marrow harvesting (collecting) is a procedure to collect stem cells from your bone marrow.

There are two types of stem cell transplants: autologous and allogeneic.

- For an autologous stem cell transplant, your own stem cells are harvested. They are given back to you on the day of your transplant.
- For an allogeneic stem cell transplant, a donor's stem cells are harvested. They are later given to the person who is receiving the transplant. If you are donating stem cells for someone else, your body will replace the cells 2 to 3 months after your procedure.

Bone marrow can be removed from different sites on your body, such as the front and back of your hips and your breastbone. These are called harvest sites. The most common harvest site is the back of the hips.

Before Your Procedure

Ask about your medications

If you are taking any medications, speak with your doctor or nurse to see if they are safe to take before your procedure. Some medications may suppress bone marrow and will need to be stopped.

Tell your doctor or nurse if you are taking any of the following:

- Aspirin
- Medications that contain aspirin
- Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Motrin®, Advil®) or naproxen (Aleve®)
- Vitamin E
- Blood thinners

These medications can cause bleeding problems. Don’t take them unless your doctor says it is okay. Your nurse will give you information about what medications you cannot take and what you can take instead.

Allergies

If you have any allergies, speak with your doctor or nurse before your procedure.

Arrange for someone to take you home
You must have someone 18 years or older take you home after your procedure. If you don’t have anyone, call one of the agencies below. They will provide someone to accompany you home. However, there is usually a charge for this service and you will also need to provide transportation.

In New York:
Partners in Care  888-735-8913
Prime Care  212-944-0244

In New York or New Jersey:
Caring People  877-227-4649

**Donating blood before allogeneic stem cell transplants**

If you are donating stem cells for someone else, you may need to give a unit of blood 2 weeks before the procedure. This blood will be given back to you in the recovery room. It will help your bone marrow recover. Your doctor or nurse will speak to you about this.

**The Day Before Your Procedure**

**Instructions for eating and drinking before your procedure**

- Do not eat anything after midnight the night before your procedure. This includes hard candy and gum.
- Between midnight and up until 2 hours before your scheduled arrival time, you may drink a total of 12 ounces of water (see figure).
- Starting 2 hours before your scheduled arrival time, do not eat or drink anything. This includes water.

**The Day of Your Procedure**

Your procedure will be done in the operating room. Since the harvest site is usually the back of the hip bones, you will probably be lying on your stomach. You will receive general anesthesia (medication that will make you sleep) before the procedure starts. Once you are asleep, your doctor will insert a needle through your skin and into your bone to take out the marrow. They will do this several times to collect enough marrow. The procedure usually takes about an hour.

**After Your Procedure**

When you wake up, you will be in the Post Anesthesia Care Unit (PACU). You may be sore at your harvest sites. Your nurse will give you pain medication to help with any discomfort. You will get a prescription for pain medication to take home with you.

You will go home once you are awake and able to eat and drink.

**Caring for yourself at home**

- Don’t shower for 24 hours after your procedure. After 24 hours, shower and then remove your dressings.
- Take your pain medication as prescribed. This will help relieve any pain and stiffness.
- Resume taking aspirin, medications containing aspirin, NSAIDs, or vitamin E, as needed.
- Drink at least 6 to 8 glasses of liquids every day for 4 days after your procedure.
• Don’t do any strenuous exercise (e.g., running, jogging, aerobics) or play any contact sports (e.g., football, soccer, basketball) for 1 week after your procedure. You can do light exercise such as walking.
• Don’t soak in a pool, bath tub, or hot tub for 1 week after your procedure.
• Eat a well-balanced diet high in iron (e.g., red meat, spinach) for 2 months after your procedure. Ask your doctor about taking vitamins and iron supplements. Ask your nurse for the resource Iron in Your Diet.

Call Your Doctor or Nurse if You Have:

• Bleeding from your harvest sites
• Redness or drainage at your harvest sites
• Pain at your harvest sites that is getting worse or not improving after 1 day
• Chills
• A temperature of 100.4° F (38° C) or higher
• A cough that does not go away

If you have any questions or concerns, contact a member of your healthcare team directly or call 212-639-2000 for help.
If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at ____________________. After 5:00 pm, during the weekend, and on holidays, please call________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Bone Marrow Harvesting for Autologous or Allogeneic Bone Marrow Transplants
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Last Updated

Monday, April 3, 2017
# Bone Marrow Transplant Emergency Guide

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<td>• Dizziness&lt;br&gt;• Tremors or shakiness&lt;br&gt;• Change in mood&lt;br&gt;• Change in energy level&lt;br&gt;• Unable to sleep</td>
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<tr>
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<td>• Using 1 or more feminine pad per hour&lt;br&gt;• Little red or purple spots on the skin&lt;br&gt;• New or increased bleeding</td>
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<td><strong>Blood sugar</strong></td>
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<td>• Hard to wake up&lt;br&gt;</td>
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<tr>
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<td>• Wheezing with breaths&lt;br&gt;• Gets “winded” more easily with minimal activity&lt;br&gt;• New or persistent cough&lt;br&gt;• Coughing blood or green or yellow material&lt;br&gt;• Trouble breathing when lying flat</td>
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<tr>
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<td>• Uncontrolled diarrhea&lt;br&gt;</td>
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</tr>
<tr>
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<td>• Change in consciousness after fall&lt;br&gt;• Hit head during fall</td>
<td>• Did not hit head during fall&lt;br&gt;• No changes in consciousness after fall</td>
</tr>
<tr>
<td><strong>Fatigue</strong></td>
<td>• Unable to wake up&lt;br&gt;</td>
<td>• Dizziness&lt;br&gt;• Too tired to get out of bed or walk to the bathroom</td>
</tr>
<tr>
<td><strong>Fever or chills</strong></td>
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<td>• Cold symptoms (runny nose, watery eyes, sneezing, coughing)&lt;br&gt;Shaking chills, temperature may be normal</td>
</tr>
<tr>
<td><strong>Mouth pain (mucositis)</strong></td>
<td>• Not breathing&lt;br&gt;• Hard to breathe&lt;br&gt;</td>
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</tr>
<tr>
<td><strong>Nausea or vomiting</strong></td>
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<td>• Blood or “coffee grounds” material in vomit&lt;br&gt;• Anti-nausea medication doesn't control nausea</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td>• Severe chest pain&lt;br&gt;• Severe squeezing or pressure in chest&lt;br&gt;• Severe sudden headache</td>
<td>• New or uncontrolled pain&lt;br&gt;• Chest discomfort&lt;br&gt;• Pounding heart&lt;br&gt;• Heart “flip-flop” feeling&lt;br&gt;• Pain at central line site&lt;br&gt;• Burning in chest or stomach&lt;br&gt;• Burning during urination or bowel movements&lt;br&gt;• Pain during urination or bowel movements&lt;br&gt;• Pain with infusion of medications or fluids in central line</td>
</tr>
<tr>
<td><strong>Rash</strong></td>
<td></td>
<td>• New rash&lt;br&gt;• Rash with pain, itching, or both</td>
</tr>
<tr>
<td><strong>Swelling</strong></td>
<td>• Swelling in throat&lt;br&gt;• Hard to breathe&lt;br&gt;</td>
<td>• Swollen legs, arms, or hands&lt;br&gt;• Sudden swelling with or without pain</td>
</tr>
<tr>
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<td></td>
<td>• Bloody urine&lt;br&gt;• Unable to urinate for more than 8 hours&lt;br&gt;• Pain or burning while urinating</td>
</tr>
</tbody>
</table>

Read the next page for instructions.
For Emergencies

1. **Call 911.**
   Don’t transport the patient without Emergency Medical Services (EMS) support.

2. **Ask to be taken to the Urgent Care Center at MSK.**
   1275 York Avenue
   New York, NY 10065
   - Between 6:00 AM and midnight, enter at 425 East 67th Street (between York and First Avenues).
   - All other times, enter at 1275 York Avenue (between 67th and 68th Streets). Ask for directions at the security desk.

3. **Identify the patient as a bone marrow transplant patient.**

For Homebound Transplant Patients

If you’re enrolled in the Homebound Transplant program and have an emergency, call SeniorCare Emergency Service at **718-430-9700.**

When you call, say, **“Hello, I have an emergency and I need an ambulance.”** The person answering the phone may ask you some questions.

<table>
<thead>
<tr>
<th>If they ask...</th>
<th>Tell them...</th>
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</thead>
<tbody>
<tr>
<td>“What is the address of your emergency?”</td>
<td>The address where you are.</td>
</tr>
<tr>
<td>“Where is the patient located?”</td>
<td>The room, apartment, floor, suite, or office number.</td>
</tr>
<tr>
<td>“What phone number are you calling from?”</td>
<td>Your phone number.</td>
</tr>
<tr>
<td>“What is the nature of your emergency?”</td>
<td>The reason you’re calling, such as “The patient has a fever” or “The patient is having trouble breathing.”</td>
</tr>
<tr>
<td>“Which hospital should the patient be brought to?”</td>
<td>Memorial Sloan Kettering Cancer Center’s Urgent Care Center.</td>
</tr>
</tbody>
</table>

For Non-Emergencies

- **During the day (between 8:00 AM and 8:00 PM)**
  - Call 212-639-3122
  - A Red Team Nurse Practitioner or nurse will talk with you.

- **At night (between 8:00 PM and 8:00 AM)**
  - Call 212-639-2000
  - Ask for the doctor covering Bone Marrow Transplant.
Building Your Family after Cancer Treatment: Information for Men

This information describes options that men have for building a family after cancer treatment is completed.

Male Reproduction

The male reproductive system includes a number of structures (see Figure 1).

![Figure 1. Male reproductive system](image)

Once puberty begins, hormones from the pituitary gland in your brain stimulate your testes (testicles) to make sperm. It takes about 3 months for sperm to mature, after which they are stored in the epididymis. When you are sexually excited, nerves stimulate muscles to push the sperm from your epididymis through your vas deferens. The sperm mix with fluids from the seminal vesicles and prostate gland to form semen. Muscles at the opening of the bladder close, and the semen is propelled out of the penis through the urethra. This is called ejaculation.

If you ejaculate during sex with a female partner around the time of the month when she ovulates (releases a mature egg from the ovary), a single sperm may enter and fertilize the egg. If the fertilized egg begins to divide, an embryo is formed which can implant in the woman’s uterus (womb). The cells continue to divide, forming a fetus that grows and develops during the 9 months of pregnancy.

Effects of Cancer Treatment on Fertility

Cancer treatments may cause fertility problems, including:

- Inability to produce sperm.
• Damage to nerves and blood vessels needed for erection and ejaculation.
• Inability to produce hormones that stimulate sperm production.

Not all cancer treatments cause fertility problems. It depends on:

• Your fertility before treatment.
• The type of surgery you had.
• The type and dose of chemotherapy you received.
• The area of your body treated with radiation and the dose of radiation you received.

Fertility problems from cancer treatment may be temporary or permanent. Some men regain the ability to produce sperm after treatment. This generally takes 1 to 3 years, but can sometimes take longer. Some men never recover sperm production.

Because of the many factors that affect fertility, it is difficult to predict how any one person will be affected by treatment. We cannot know for sure who will regain fertility after treatment is completed and who will not.

Common Questions about Fertility and Family Building After Cancer Treatment

How long must I wait after treatment to try to father a child?

The length of time you need to wait depends on your diagnosis and the treatment you received. If you have had chemotherapy or radiation, we generally suggest waiting at least 1 year after treatment is finished before trying to have a child. This allows time for sperm that may have been damaged from treatment to be cleared from your body. However, some people may not need to wait this long, while others may need to wait longer. Check with your healthcare provider to find out how long he or she recommends that you wait.

How will I know if I am fertile after treatment?

You can have a semen analysis done at a sperm bank to see if you are producing sperm and to analyze your sperm count and motility (ability to swim). Wait at least 1 year after completing treatment before having a semen analysis so that your testes have time to recover. If they do not find sperm in the specimen, remember that it can take a number of years for some men to start producing sperm again. You can repeat the semen analysis 6 to 12 months later. If you want a more in-depth evaluation, ask your doctor to refer you to a reproductive urologist.

Will a child conceived after my cancer treatment be healthy?

There is no evidence that children conceived after cancer treatment are at an increased risk for birth defects or other health problems. However, it is important to use birth control during treatment to ensure you do not conceive with sperm that may have been damaged from exposure to chemotherapy or radiation. This might affect the health of the child. We recommend that you continue to use birth control for 1 year after completing chemotherapy and radiation therapy to ensure all damaged sperm have been cleared from your body.

Some cancers are hereditary, or passed down from parents to children. Ask your doctor or nurse if you have a hereditary cancer. If you do, you can meet with a genetics counselor to learn how this may affect the health of a child.
If you have a specific genetic mutation that can be passed on to a child, you may want to consider preimplantation genetic diagnosis (PGD). PGD is a method that can test embryos that have been created by in vitro fertilization for the mutation you have. If you want, you can then select only those embryos that do not have the genetic mutation when you are ready to attempt pregnancy.

**What if I have a low sperm count?**

Some men recover sperm production after cancer treatment but have a low sperm count and may not be able to conceive naturally. However, you may still be able to have a biologic child through in vitro fertilization (IVF). There are several steps involved in IVF, including:

- **Ovarian stimulation:** Your female partner takes hormone injections for about 10 days to stimulate a group of eggs in her ovaries to mature.
- **Egg retrieval:** While your partner is asleep under anesthesia, a very thin needle is passed through the wall of her vagina to remove the mature eggs from her ovaries. This procedure takes 10 to 20 minutes.
- **Fertilization:** The eggs are fertilized with your sperm in a laboratory. If your sperm count is low, they will inject a sperm into each egg (intracytoplasmic sperm injection, or ICSI). The fertilized eggs are kept in the laboratory for 3 to 5 days to make sure they start to divide and form healthy embryos.
- **Embryo transfer:** One or 2 embryos are placed in your partner’s uterus to attempt pregnancy. The others are frozen and stored for possible use in the future.

**What if I am no longer fertile, but banked sperm before treatment?**

To use the sperm you froze before treatment, you and your partner will need to work with a reproductive endocrinologist. The method used to fertilize your female partner’s eggs will be based on the quality of the specimens you were able to freeze before treatment.

- **Intra-uterine insemination (IUI or artificial insemination):** One or 2 vials of your sperm are thawed and drawn up into a thin, soft catheter. This is placed in your female partner’s uterus and the sperm are released. This is done around the time she ovulates (releases a mature egg).
  - It takes most women 3 to 6 attempts at IUI before they are successful, so most patients who sperm banked will not have enough sperm to use this method. However, it may be a good option for you if your partner is young and has no fertility problems, and if you have many vials of sperm with high sperm counts and good motility.
- **In vitro fertilization (IVF):** This method is used by most people using their thawed sperm. There are several steps involved:
  - **Ovarian stimulation:** Your female partner takes hormone injections for about 10 days to stimulate a group of eggs in her ovaries to mature.
  - **Egg retrieval:** While your partner is asleep under anesthesia, a very thin needle is passed through the wall of her vagina to remove the mature eggs from her ovaries. This procedure takes 10 to 20 minutes.
  - **Fertilization:** The eggs are fertilized with your sperm in a laboratory. If you have a high sperm count with good motility, the sperm may be mixed with the eggs to fertilize on their own. The other option is to inject a sperm into each egg (intracytoplasmic sperm injection, or ICSI). The fertilized eggs are kept in the laboratory for 3 to 5 days to make sure they start to divide and form healthy embryos.
  - **Embryo transfer:** One or 2 embryos are placed in your partner’s uterus to attempt pregnancy. The others are frozen and stored for possible use in the future.

**What if I am no longer fertile and did not sperm bank before treatment?**
Even when no sperm are found in a semen sample, some people produce small amounts of sperm after cancer treatment. To try to obtain sperm to attempt pregnancy, you would need to see a reproductive urologist and undergo a procedure called testicular sperm extraction (TESE). This is an outpatient procedure done under anesthesia while you are asleep. A small incision is made in your scrotum. Your doctor removes pieces of tissue from your testes. These are examined to search for sperm. If sperm are found, they can be used to attempt to fertilize your female partner’s eggs. For more information about this procedure ask your nurse for the resource *Sperm Collection by Testicular Sperm Extraction (TESE)*.

If you would like to learn more about this procedure, ask your doctor or nurse to refer you to a reproductive urologist. If you are not interested in considering this, see below to learn about other options to build a family.

**What if I have retrograde (dry) ejaculation?**

Some cancer treatments cause injury to or removal of the nerves and muscles that control ejaculation. With retrograde ejaculation, the semen passes into the bladder instead of coming out through the penis. If you have retrograde ejaculation, but are still producing sperm, there are methods to obtain sperm to attempt pregnancy, including:

- Taking medication to tighten the muscles at the opening of the bladder. This allows the semen to pass forward out through the penis instead of into the bladder.
- Collecting a sample of urine after you stimulate yourself to ejaculate. This is done at a sperm bank, where they can remove the sperm from the urine.

If you are interested in either of these options, ask your doctor for a referral to a reproductive urologist.

**What if I have erectile dysfunction?**

Some cancer treatments cause injury to or removal of the nerves and blood vessels that control erection. If you are still producing sperm, but your penis is not able to become firm enough to enter your female partner’s vagina, the sperm cannot fertilize her eggs. Several treatments can help, including medications and injections. If you are interested in trying these, ask your doctor for a referral to a urologist who specializes in erectile dysfunction.

**What are my other options to build a family?**

Some men do not have the opportunity to sperm bank before treatment or are not successful in having a child using their frozen sperm. Other ways to build a family are using donor sperm or adoption.

**Donor sperm**

This involves using sperm from another man to impregnate your female partner. Young, healthy men provide their sperm to a sperm bank for donation. Most donors are anonymous, but some are willing to have the child contact them when they reach adulthood. You can select a donor based on various characteristics and traits that are shared on the sperm bank website.

You may also have a relative or friend who is willing to donate sperm for you. While this may be a good option for you, even with the best of intentions, problems can arise if expectations are not clearly defined. Sometimes, a relative or friend who wants to help will make an offer without understanding all that is involved. No matter how well you know the person, your donor should have psychological and medical screening, and you should both seek legal consultation.

- The first step is for you and your female partner to see a reproductive endocrinologist. He or she
can recommend particular sperm banks where you can obtain sperm. Once you select a donor, the frozen sperm will be sent to your reproductive endocrinologist.

- **Intra-uterine insemination (IUI or artificial insemination)** is the most commonly used method for using donor sperm to achieve a pregnancy. It is planned for around the time your female partner ovulates. One or 2 vials of sperm are thawed and drawn up into a thin, soft catheter. This is placed in your partner’s uterus and the sperm are released. It takes most women 3 to 6 attempts at IUI before they are successful.

### Adoption

Having a history of cancer does not prevent you from being able to adopt as long as you are healthy now and have been cancer-free for at least a few years. In fact, some states, including New York, do not allow agencies to discriminate against prospective parents based on a history of cancer. You may need a letter from your doctor confirming that you are healthy enough to raise a child. You also need to be a United States citizen or legal permanent resident to adopt in this country.

Adoptions can be domestic (the child is born in the United States) or international (the child is born and lives outside of the United States). International adoptions are highly regulated, and policies vary by country and often change. Some countries do not allow people who have been treated for cancer to adopt.

Adoptions are arranged through an agency or with the help of an adoption lawyer.

- Adoption agencies may be public or private. An agency caseworker is often involved in matching the birth parents with the adoptive parents. The match is based on what the birth parents are looking for in adoptive parents and in the characteristics of the child the adoptive parents are hoping to adopt.
  - Public agencies are part of the state Department of Social Services. They usually work with children who have been taken away from their birth parents due to alleged abuse or neglect.
  - Private agencies may handle domestic adoptions, international adoptions, or both. Each agency has its own standards about who they will accept as adoptive parents. Children adopted through private agencies are usually younger than children adopted through public agencies. With a private domestic agency, you can adopt a newborn child.

- Lawyers can also arrange private adoptions. Adoption laws vary by state, so it is important to work with a lawyer who specializes in adoption and is licensed in the state in which you want to adopt. With a private adoption, you can adopt a newborn child.

There are several ways to find an adoption agency or attorney.

- To find an adoption agency, go to the National Foster Care and Adoption Directory website at [www.childwelfare.gov/nfcad/](http://www.childwelfare.gov/nfcad/). Select your state and the type of agency you are looking for (such as public, private domestic, or private intercountry).
- To find agencies that focus on international adoption, search the Intercountry Adoption website at [adoption.state.gov](http://adoption.state.gov).
- To find an adoption lawyer, search the American Academy of Adoption Attorneys website at [www.adoptionattorneys.org](http://www.adoptionattorneys.org).

The amount of information shared between birth parents and adoptive parents can vary. In the past, closed adoptions were common; birth parents and adoptive parents did not know each other’s identity and had no direct contact after the adoption. Now, open or semi-open adoptions are more common. These allow some contact between the birth parents, the adoptive parents, and the child after the adoption. Everyone involved agrees on the type and amount of contact.
Before you can adopt, a social worker will do a home study to assess your ability to care for a child. The social worker will ask you things that may seem very personal. This is to make sure you understand what is involved and are ready to proceed with an adoption. Your agency or lawyer will tell you the best time to schedule the home study. Once the child is placed in your care, the social worker will stay in contact to help with any issues that may arise.

The following resources can help you learn more about adoption:

- [Adoptive Parents Committee](http://www.adoptiveparents.org)
- [Adoption.com](http://www.adoption.com)
- [Adoption.net](http://www.adoption.net)
- [Adoption.org](http://www.adoption.org)
- [Adoptive Families](http://www.adoptivefamilies.com)
- [Building Your Family](http://www.buildingyourfamily.com)
- [Child Welfare Information Gateway](http://www.childwelfare.gov)
- [Joint Council on International Children’s Services](http://www.jointcouncil.org)

**MSK Resources**

If you would like additional information from one of our fertility nurse specialists, or if you would like to be evaluated by our reproductive urologist, ask your doctor or nurse for a referral.

MSK Fertility website


Fertility Options for Men Before and After Cancer Treatment (videos)


*Sperm Banking*


If you have any questions or concerns, contact a member of your healthcare team directly or call 212-639-2000 for help.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at ________________. After 5:00 pm, during the weekend, and on holidays, please call ________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Building Your Family after Cancer Treatment: Information for Men

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**Last Updated**

Wednesday, March 23, 2016
Caring for Your Central Venous Catheter

This information will teach you about the placement and care of your central venous catheter (CVC).

There are many different types of catheters (thin, flexible tubes) and your doctor will decide which kind is best for you.

All devices have 1 central catheter that enters your body. On the outside, the catheter may divide into 1, 2, or 3 lumens (see Figure 1). Each lumen has a clamp, a needleless connector, and a disinfection cap on the end.

A CVC can be used to take blood samples, as well as give:

- Fluids
- Chemotherapy and other medications
- Blood transfusions
- Intravenous (IV) nutrition

The advantages of having a catheter are:

- You won’t need as many needle sticks.
- It can stay in your body for as long as a few years and be removed when it is no longer needed.

Your nurse will teach you how to care for your catheter. You can have a caregiver, family member, or friend learn with you. You will learn how to use sterile technique to change your dressing. This will minimize your risk for infection. You will also learn how to change your needleless connectors and disinfection caps (SwabCaps®), as well as flush your catheter using a syringe with normal saline solution. You must flush your catheter to keep blood clots from forming inside of it. Once a week, you will change the needleless connectors, disinfection caps, and your dressing, as well as flush your catheter. You may want to mark your calendar to help you remember to do so. After you go home, use this information to help you remember the steps to care for your catheter.
Before Your Procedure

Ask about your medications

You may need to stop taking some of your medications before your procedure. Talk with your doctor about which medications are safe for you. We have included some common examples below.

- If you take medication to thin your blood, ask your doctor what to do. Some examples are aspirin, warfarin (Coumadin®), dalteparin (Fragmin®), heparin, tinzaparin (Innohep®), enoxaparin (Lovenox®), clopidogrel (Plavix®), cilostazol (Pletal®), prasugrel (Effient®), dabigatran (Pradaxa®), rivaroxaban (Xarelto®), apixaban (Eliquis®), and ticlopidine (Ticlid®). These medications can be used to treat blood clots or to prevent a heart attack or stroke.

- If you take insulin or other medications for diabetes, you may need to change the dose before your procedure. Ask the doctor who prescribes your diabetes medication what you should do the morning of your procedure.

- Please review the information in Common Medications Containing Aspirin and Other Nonsteroidal Anti-Inflammatory Drugs for examples of what not to take and what to take instead.

- Do not take vitamin E for 10 days before your procedure, or as directed by your doctor.

Arrange for someone to take you home

You must have someone 18 years or older take you home after your procedure. If you don’t have anyone, call one of the agencies below. They will provide someone to accompany you home, however there is usually a charge for this service and you will also need to provide transportation.

In New York:
  Partners in Care 888-735-8913
  Prime Care 212-944-0244

In New Jersey:
  Caring People 877-227-4649

Tell us if you’re sick

If you develop any illness (e.g., fever, cold, sore throat, or flu) before your procedure, please call a nurse in Interventional Radiology at 212-639-2236. A nurse is available Monday through Friday, 9:00 AM to 5:00 PM. After hours, during the weekend, and on holidays, call 212-639-2000 and ask for the Interventional Radiology fellow on call.

Note the time of your appointment

A staff member from the Interventional Radiology office will call you 2 business days before your procedure. He or she will tell you what time you should arrive at the hospital for your procedure. If you are scheduled for your procedure on a Monday, you will be called on the Thursday before. If you don’t receive a call by noon the business day before your procedure, please call 212-639-5051.

If you need to cancel your procedure for any reason, please call the doctor who scheduled it for you.
The Day of Your Procedure

Things to remember

- Do not eat or drink anything after midnight the night before your procedure. This includes water, gum, and hard candy.

- Take your medications the morning of your procedure as instructed by your doctor. Take them with a few sips of water.

- Do not apply cream or petroleum jelly (Vaseline®). You can use deodorant and light moisturizers.

- Do not wear eye makeup.

- Remove any jewelry, including body piercings.

- Leave all valuables, such as credit cards and jewelry, at home.

- If you wear contact lenses, if possible, wear your glasses instead. If you don’t have glasses, please bring a case for your contacts.

What to bring with you

- A list of the medications you take at home.
- Medications for breathing problems (such as inhalers), medications for chest pain, or both.
- A case for your glasses or contacts.
- Your Health Care Proxy form, if you have completed one.
- If you use a CPAP or BiPAP machine to sleep at night, please bring your machine with you, if possible. If you can’t bring your machine with you, we will give you one to use while you are in the hospital.

Where to go

- Memorial Hospital
  1275 York Avenue, New York, NY 10065

Parking at MSK is available in the garage on East 66th Street between York and First Avenues. To reach the garage, enter East 66th Street from York Avenue. The garage is located about a quarter of a block in from York Avenue, on the right-hand (north) side of the street. There is a pedestrian tunnel that you can walk through that connects the garage to the hospital. If you have questions about prices, call 212-639-2338.

There are also other garages located on East 69th Street between First and Second Avenues, East 67th Street between York and First Avenues, and East 65th Street between First and Second Avenues.

When you arrive at Memorial Hospital, take the M elevator to the 2nd floor. Enter through the glass doors and check in at the desk.
When you enter the building, check in at the reception desk and they will direct you to Interventional Radiology.

**What to expect**

Once you arrive at the hospital, doctors, nurses, and other staff members will ask you to state and spell your name and date of birth many times. This is for your safety. People with the same or similar names may be having procedures on the same day.

**During Your Procedure**

Two areas of your body will be numbed. A small incision (surgical cut) will be made at the base of your neck. A second small incision will be made on your chest, under your collarbone. The catheter will be inserted through the second incision, tunneled under your skin to the first incision, and threaded into your vein.

The incision at the base of your neck will be stitched closed. The stitches will be absorbed and will not need to be removed. Your catheter will be stitched to your skin at the point where it exits your body (exit site) so that it will stay in place (see Figure 1).

**After Your Procedure**

You may have some discomfort at your incision sites and along the CVC tunnel. Ask your nurse for medication to relieve your pain.

Your dressings need to be kept dry following your procedure. Your nurse will change your dressings 24 to 48 hours after your procedure. He or she will teach you how to do this.

Two days after your procedure, you can remove the dressing that covers the small incision at the base of your neck. You do not need to put a new dressing on this site. The strips of adhesive tape that cover this incision should be left in place until they start to peel off. This should happen about 3 to 5 days after your procedure.

Your catheter exit site will still need to be covered with a special dressing. This dressing prevents infection at this site. You will have stitches under your dressing. These stitches keep your catheter in place until the cuff on the catheter becomes anchored in the tunnel under your skin.

Your catheter will not interfere with your usual activities, such as household tasks, job responsibilities, and exercise. However, we suggest that you avoid contact sports, such as football and soccer, while your catheter is in place.

Prepare the following emergency kit and keep it with you at all times:

- 1 toothless clamp
- 1 dressing change kit
- Your doctor's office and emergency telephone numbers

**Changing Your Dressing, Needleless Connectors, and Disinfection Caps**

- Do not change your dressing, needleless connectors, or disinfection caps in the bathroom after a shower. The steam from a shower can create a moist environment under your dressing and affect the adhesive. Make sure you change your dressing, needleless connectors, and disinfection caps on a clean, flat surface.
• You will see the folded Map for Dressing Change: CVC at the end of this resource. Use it to follow the step-by-step instructions for changing your dressing. This is when you will use sterile technique. You will not be able to touch the booklet then because that would break sterile technique. Open the map and spread it out where you can see it.

• You will use a Tegaderm CHG dressing to cover your exit site unless your doctor or nurse gives you another dressing to use. Change your dressing once a week, as long as it stays dry, intact, and clean. Change it on the day you change your needleless connectors and disinfection caps and flush your catheter. You may need to change it more often if it becomes moist, soiled, or peels away from the skin.

• If the gel pad on your Tegaderm CHG dressing becomes swollen, change your dressing. You can test the gel pad by applying pressure to it with your index (pointer) finger. If you see an indent, the gel pad is swollen and your dressing should be changed. This can happen if there is a lot of sweat under your dressing.

• If you have problems with your skin, such as irritability or sensitivity, your nurse may suggest a different type of dressing. In that case, you may need to change it more often than once a week. No matter which dressing you are using, always change it right away if it starts to come off or gets wet. Do not just put another dressing or more tape over it.

• For more information, you can watch How to Change the Dressing, Needleless Connectors and Disinfection Caps on your Central Venous Catheter.

Changing Your Dressing

Supplies

• 1 dressing change kit
• An alternative dressing, if supplied by your nurse
• 1 needleless connector for each catheter lumen
• 1 disinfection cap for each lumen
• Extra alcohol pads
• Nonsterile gloves
• Paper tape
• A mirror that can stand up on a table (a makeup mirror works well)

Sterile procedure for changing your dressing

1. Prepare a clean area in which to work. Remember not to change your dressing in the bathroom after a shower.

2. Gather your supplies. Wash your hands thoroughly with warm water and antibacterial soap or use hand sanitizer.

3. Get into a comfortable position. Unpin the catheter from your clothing, if necessary. Open or remove your clothing to expose the catheter.

4. Check to make sure the catheter clamp(s) is (are) closed.

5. Open the Map for Dressing Change: CVC instructions at the end of this resource and spread it out where you can see it.
6. Open and remove the outer plastic packaging of the dressing change kit. Two masks will be right on top (see Figure 2). Put the mask on. If someone is helping you with your dressing, they will also need to wear a mask. **Do not touch anything else inside the kit.**

7. Put on the nonsterile gloves. Remove the old dressing by gently grasping an edge of the dressing and slowly peeling it off your skin toward the exit site of the catheter. As you peel the dressing back, place your thumb or forefinger on top of the dressing over the catheter to prevent tugging on the catheter. To make it easier to remove, wipe the area underneath the dressing with an alcohol pad as you pull the dressing away from your skin. Make sure the entire gel pad comes off with the dressing. Throw away the gloves and old dressing.

8. Without touching the area, inspect the exit site and the skin around it. It is easier to do this by looking in the mirror. Call your doctor or nurse after you complete the dressing change if you notice any signs of infection or irritation, such as:
   - Red or raw skin
   - Swelling
   - Any drainage from the exit site
   - Leakage around your catheter

9. Unwrap your dressing change kit by pulling back on the corners of the outer wrapping in the following manner:
   - Place the kit in front of you so that the top flap is facing you. Open the top flap away from you.
   - Open the first side flap.
   - Open the other side flap.
   - Open the bottom flap towards you.

   Make sure you don’t touch the inside of the outer wrapping. Take the paper drape out of the kit, touching only the edges. Unfold it and place it on your work area. This is called your sterile field.

   Open the package with the needleless connectors and drop them on your sterile field. If your nurse gave you an alternative dressing to use, drop them on the sterile field.

**Follow steps 10-21 on the Map for Dressing Change: CVC instructions at the end of this resource to complete the dressing change.**

You are now done with the sterile part of the dressing change. Keep your gloves and mask on to change the needleless connectors and disinfection caps.
Changing the Needleless Connectors and Disinfection Caps

21. You will change the needleless connector and disinfection cap on each lumen of your catheter. Make sure you have 3 alcohol pads for each lumen.

22. Check to make sure that the clamps on your lumens are closed before you change the needleless connectors and disinfection caps.

23. Even though your gloves are on, they will no longer be sterile if you touched your skin when you put on your dressing, so do not touch the inner part of the catheter tip or needleless connector. Using an alcohol pad, hold your catheter with your nondominant hand close to, but not touching, the needleless connector (see Figure 3).

24. Using your dominant hand, scrub the connection site for 15 seconds with another alcohol pad and allow it to dry for 15 seconds. Twist off the old needleless connector. Throw away the old needleless connector and alcohol pad.

25. Scrub the end of your catheter with a new alcohol pad for 15 seconds and allow it to dry for 15 seconds.

26. Pick up the new needleless connector with your dominant hand. If there is a cover in place over the new needleless connector, remove it and then twist the new needleless connector onto your catheter (see Figure 4).

27. If you won’t be flushing your catheter immediately, apply the disinfection cap to the end of the needleless connector.

28. Repeat steps 22-27 for the second and third lumens.

29. Remove your mask and sterile gloves. Throw them away.

Flushing Your Catheter

Flush the lumens with normal saline solution once a week, when your catheter is not in use. This is to keep the lines from becoming clogged. For more information, you can watch How to Flush Your Central Venous Catheter.

Supplies

- 1 prefilled, 10 mL syringe containing normal saline solution. You will need 1 syringe for each lumen
- Nonsterile gloves
- Alcohol pads
- 1 disinfection cap for each lumen
Steps to flushing your catheter

1. Gather your supplies.

2. Wash your hands thoroughly with warm water and antibacterial soap. Dry them with a clean towel or a paper towel. Put on a pair of nonsterile gloves.

3. To release the air bubbles in the syringe, gently tap the side of the syringe. Point the syringe up as you do this. Loosen but do not remove the cap on the syringe. Press the plunger on the syringe until the air is pushed out. Retighten the cap.

4. Pick up 1 lumen and unclamp it.

5. If you have a disinfection cap, remove it.

6. If you don’t have a disinfection cap, scrub the end of the needleless connector with an alcohol pad for 15 seconds and allow it to dry for 15 seconds.

7. Remove the cap from the syringe. Throw away the cap. Make sure that nothing touches the clean end of the needleless connector while you are doing this.

8. Carefully push the syringe into the needleless connector and twist it in a clockwise (to the right) direction until the connection feels secure. Try to inject the saline. If you can’t inject the saline, stop and check to be sure there are no twists or other blockages in the tubing. Try to inject the saline again. **If you still can't inject the saline, do not use extra pressure to flush the line.** Remove the syringe, reclamp your catheter, and call your doctor or nurse.

9. Use the following push/pause method to flush your catheter:
   - Quickly inject ⅓ of the saline.
   - Pause.
   - Repeat.
   - Inject the last ⅓ of the saline. After the injection, clamp your catheter.

10. Untwist the syringe from the lumen and throw it away.

11. Attach a disinfection cap to the end of the needleless connector.

12. Repeat steps 3-11 for each lumen.

13. Reclamp the lumens.

14. Secure your catheter in a way that makes you feel comfortable. If you will pin your catheter to your clothing, prepare one 5-inch piece of paper tape. Fold down the edges of the tape (see Figure 5). Leave enough sticky tape so you can wrap it around all of the lumens. Avoid placing tape over the connection site. **Leave the catheter hanging loose only if you are sure it will not be pulled.**

15. Throw away your mask and gloves and wash your hands thoroughly.
Caring for Your CVC

- Do not submerge your catheter in water (e.g., a bathtub or swimming pool).
- Clamp the lumens when your catheter is not in use.
- Keep your catheter secure at all times to avoid pulling it. You can tape the lumens of your catheter to your skin, tuck them into a bra if you wear one, or pin them to your clothing. Ask your nurse about the best way to secure your catheter. Avoid placing tape over the connection site.
- If your catheter is leaking at any time, clamp it above the leak. Use the white catheter clamp on the catheter, if possible. If the white clamp is not available, use the clamp found in the emergency kit. Wipe the area that is leaking with an alcohol pad. Cover the site with tape. Call your doctor or nurse immediately. Catheters can often be repaired.

Guidelines for showering

While your catheter is in place, it is especially important to take good care of your skin to reduce your risk of infection. We recommend that you wash with Hibiclens® every day while your catheter is in place. It contains a fast-acting antiseptic called chlorhexidine gluconate (CHG) that kills germs that live on your skin and will reduce your risk of infection. Hibiclens can work for up to 6 hours after using it. You can purchase it from any local pharmacy or online. You will be sent home with a small bottle when you are discharged from the hospital. For more information, you can watch *Showering While You Have a Central Venous Catheter*.

Instructions for using Hibiclens

- If you are washing your hair, shampoo and rinse thoroughly.
- Wash your face with regular soap.
- Rinse your body with warm water from the neck down.
- Apply Hibiclens to a washcloth or directly to the skin being cleansed. Wash gently. Do not dilute the Hibiclens.
- Rinse thoroughly with warm water and pat yourself dry.

Important points to remember when using Hibiclens

- Do not use Hibiclens if you are allergic to chlorhexidine.
- Do not use Hibiclens on your face, ears, genital region, or on deep wounds.
- Do not use regular soap, lotion, powder, or deodorant after washing with Hibiclens.

You can shower with your catheter in place using a one-time-use waterproof cover that goes over your dressing. Each time you shower, cover the Tegaderm CHG dressing completely with a new waterproof cover to protect it from getting wet.

- To put on the waterproof cover, peel off the top and side strips. Place the top edge above your dressing. Smooth it down over your dressing. Do the same for the bottom part of your dressing, making sure that the bottom edge of the waterproof cover is below your dressing. Make sure the lumens of your catheter are tucked into the waterproof cover and completely covered.
- Do not let the tape on the waterproof cover touch the Tegaderm CHG dressing. It can lift your dressing when you remove the waterproof cover after showering.
- Dry the waterproof cover before removing it.
• Do not shower for longer than 15 minutes. Use warm water, not hot water. This will help prevent the waterproof cover from coming off.

• If your dressing gets wet, change it.

### Call Your Doctor or Nurse Immediately if You:

• Have redness, swelling, or drainage around the area where the catheter exits your body

• Are unable to flush your catheter or if your needleless connector falls off

• Have a temperature of 100.4° F (38° C) or higher or chills

• Have a break or leak in your catheter

• Have an unexplained problem with your catheter

If you have any questions or concerns, please call Interventional Radiology at 212-639-2236. You can reach a staff member Monday through Friday from 9:00 AM to 5:00 PM. After 5:00 PM, during the weekend, and on holidays, please call 212-639-2000 and ask for the fellow on call for Interventional Radiology.
How to Put on Your Sterile Gloves

1. Open the package that contains the sterile gloves. Pull the edges of the package down to keep them flat.

2. Pick up 1 glove by the folded cuff.

3. Still holding just the cuff with 1 hand, slide your other hand into the glove, making sure the outside of the glove does not touch anything.

4. Slip the fingers on your gloved hand under the cuff of the other glove. Hold the glove up and do not let it touch anything.

5. Keep the thumb on your gloved hand pointing up so it is out of the way. Slide your other hand into the glove.

6. Pull the glove all the way up. Be careful not to touch anything, including your wrist.
10. **Wash your hands thoroughly with warm water and antibacterial soap.** Dry your hands thoroughly. Or you can use the hand sanitizer packet provided on the outside of the kit, as instructed by your nurse.

11. Take the package with the sterile gloves out of the tray. Be careful not to touch anything else in the tray. Put on the sterile gloves following *How to Put on Your Sterile Gloves*, touching only the inside of the sterile glove with your bare hand. Be careful not to touch anything except what is in the dressing change tray after your gloves are on. Move everything from inside the dressing change tray onto the sterile drape.

12. Open and remove all the alcohol prep pads from their wrappers. Put the alcohol pads back into the tray. Put the wrappers to the side or drop them in the trash.

13. Pick up the ChloraPrep® applicator with your dominant hand. Pinch the wings on the side together until you hear a click (see Figure 6). This will make the antiseptic soak into the applicator sponge. You must press very hard to make the click sound.

14. Using an alcohol pad, grasp the catheter with your nondominant hand, just above where it separates into lumens. (see Figure 7). Do not touch the catheter itself. Touch only the alcohol pad. Hold the catheter away from your chest.

15. Use your dominant hand to pick up the Chloraprep. Beginning at the exit site, scrub up and down and side to side with the Chloraprep to make a 2-inch box (see Figure 8). Discard the Chloraprep.

16. Allow the site to dry completely. This may take at least 30 seconds. Do not fan or blow on the site to speed up the drying. Hold the catheter away while it dries.

17. While holding the catheter with your nondominant hand, take another alcohol pad in your dominant hand. Place it around the catheter at the incision site and gently, without tugging, clean down the catheter toward the area where it separates into lumens. Discard the alcohol swab in your dominant hand. Continue holding the catheter in your nondominant hand.

18. Pick up a new alcohol pad with your dominant hand. Without tugging, clean down the lumen of the catheter (see Figure 9). Discard the alcohol pad. Repeat this step to clean each lumen.

19. Apply the No Sting Barrier Film to your skin in the shape of an open rectangle about the size of the Tegaderm CHG dressing. **Allow it to dry completely.** The No Sting Barrier Film will help the dressing stick to your skin. Discard the alcohol pad in your nondominant hand.

20. Peel the backing off the Tegaderm CHG (see Figure 10). Center the gel pad over the exit site and smooth down the dressing edge. Do not stretch the dressing when applying.

21. Grasp the round paper tab on the outside and peel the plastic off all the way around the dressing (see Figure 11). Peel the notched tape off of the paper tab. Apply the tape under the tubing and over the dressing edge to secure the catheter. You may press the outside of the dressing to make sure it is intact. Continue the instructions in the booklet.

If the exit site is red, raw, swollen, or has drainage, notify your doctor after you finish the dressing change.
Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)

This information will help you identify medications that contain aspirin and other nonsteroidal anti-inflammatory drugs (NSAIDs). It’s important to stop these medications before many cancer treatments.

Aspirin, other NSAIDs (such as ibuprofen), and vitamin E can increase your risk of bleeding during cancer treatment. These medications affect your platelets, which are blood cells that clot to prevent bleeding.

Read the section “Examples of Medications” to see if your medications contain aspirin, other NSAIDs, or vitamin E.

If you take aspirin, medications that contain aspirin, other NSAIDs, or vitamin E, tell your doctor or nurse. They will tell you if you need to stop taking these medications before your treatment. You will also find instructions in the information about the treatment you’re having.

Before Your Surgery

If you’re having surgery, follow the instructions below.

- Stop taking medications that contain vitamin E 10 days before your surgery or as directed by your doctor.
- Stop taking medications that contain aspirin 7 days before your surgery or as directed by your doctor. If you take aspirin because you’ve had a problem with your heart or you’ve had a stroke, be sure to talk with your doctor.
before you stop taking it.

- Stop taking NSAIDs 48 hours before your surgery or as directed by your doctor.

**Before Your Radiology Procedure**

If you’re having a radiology procedure (including Interventional Radiology, Interventional Mammography, and General Radiology), follow the instructions below.

- Stop taking medications that contain vitamin E 10 days before your procedure, or as directed by your doctor.
- If your doctor tells you to stop taking aspirin, stop taking it 5 days before your procedure or as directed by your doctor. If you take aspirin because you’ve had a problem with your heart or you’ve had a stroke, be sure to talk with your doctor before you stop taking it.
  - If you take low dose aspirin (81 mg), you may not need to stop it before your procedure. Your doctor will tell you if you should stop taking low dose aspirin.
- Stop taking NSAIDs 24 hours before your procedure or as directed by your doctor.

**Before and During Your Chemotherapy**

Chemotherapy can decrease your platelet count, which can increase your risk of bleeding. Whether you’re just starting chemotherapy or you’ve been receiving it, talk with your doctor or nurse before taking aspirin or NSAIDs.

**Examples of Medications**

Medications are often called by their brand name, which can make it hard to know their ingredients. To help you identify medications that contain aspirin, other NSAIDs, and vitamin E, please review the lists below.

These lists include the most common products, but there are others. Check with your healthcare provider if you aren’t sure. Always be sure your doctor knows all
the medications you’re taking, both prescription and over-the-counter.

**Common medications that contain aspirin**

<table>
<thead>
<tr>
<th>Aggrenox®</th>
<th>Bayer® (most formulations)</th>
<th>Equagesic Tablets</th>
<th>Isollyl®</th>
<th>Panasal®</th>
<th>Synalgos®-DC Capsules</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alka Seltzer®</td>
<td>BC® Powder and Cold Formulations</td>
<td>Equazine®</td>
<td>Lanorinal®</td>
<td>Percodan® Tablets</td>
<td>Tenol-Plus®</td>
</tr>
<tr>
<td>Anacin®</td>
<td>Bufferin® (most formulations)</td>
<td>Excedrin® Extra-Strength Analgesic Tablets and Caplets</td>
<td>Lortab® ASA Tablets</td>
<td>Persistin®</td>
<td>Trigesic®</td>
</tr>
<tr>
<td>Arthritis Pain Formula</td>
<td>Buffets II®</td>
<td>Excedrin® Migraine</td>
<td>Magnaprin®</td>
<td>Robaxisal® Tablets</td>
<td>Talwin® Compound</td>
</tr>
<tr>
<td>Arthritis Foundation Pain Reliever®</td>
<td>Buffex®</td>
<td>Fiorgen®</td>
<td>Marnal®</td>
<td>Roxiprin®</td>
<td>Vanquish® Analgesic Caplets</td>
</tr>
<tr>
<td>ASA Enseals®</td>
<td>Cama® Arthritis Pain Reliever</td>
<td>Fiorinal® (most formulations)</td>
<td>Micrainin®</td>
<td>Saleto®</td>
<td>Wesprin® Buffered</td>
</tr>
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<td>ASA Suppositories®</td>
<td>COPE®</td>
<td>Fiortal®</td>
<td>Momentum®</td>
<td>Salocol®</td>
<td>Zee-Seltzer®</td>
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<tr>
<td>Ascriptin® and Ascriptin A/D®</td>
<td>Dasin®</td>
<td>Gelpirin®</td>
<td>Norgesic Forte® (most formulations)</td>
<td>Sodol®</td>
<td>ZORprin®</td>
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<td>Aspergum®</td>
<td>Easprin®</td>
<td>Genprin®</td>
<td>Norwich® Aspirin</td>
<td>Soma® Compound Tablets</td>
<td></td>
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<tr>
<td>Asprimox®</td>
<td>Ecotrin® (most formulations)</td>
<td>Gensan®</td>
<td>PAC® Analgesic Tablets</td>
<td>Soma® Compound with Codeine Tablets</td>
<td></td>
</tr>
<tr>
<td>Axotal®</td>
<td>Empirin® Aspirin (most formulations)</td>
<td>Heartline®</td>
<td>Orphengesic®</td>
<td>St. Joseph® Adult</td>
<td></td>
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</table>

Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)
Common medications that are NSAIDs that don’t contain aspirin

<table>
<thead>
<tr>
<th>Advil®</th>
<th>Celecoxib</th>
<th>Flurbiprofen</th>
<th>Meclofenamate</th>
<th>Nalfon®</th>
<th>Ponstel®</th>
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</thead>
<tbody>
<tr>
<td>Advil Migraine®</td>
<td>Children’s Motrin®</td>
<td>Genpril®</td>
<td>Mefenamic Acid</td>
<td>Naproxen</td>
<td>Relafen®</td>
</tr>
<tr>
<td>Aleve®</td>
<td>Clinoril®</td>
<td>Ibuprofen</td>
<td>Meloxicam</td>
<td>Naprosyn®</td>
<td></td>
</tr>
<tr>
<td>Anaprox DS®</td>
<td>Daypro®</td>
<td>Indomethacin</td>
<td>Menadol®</td>
<td>Nuprin®</td>
<td>Saleto 200®</td>
</tr>
<tr>
<td>Ansaid®</td>
<td>Diclofenac</td>
<td>Indocin®</td>
<td>Midol®</td>
<td>Orudis®</td>
<td>Sulindac</td>
</tr>
<tr>
<td>Arthrotec®</td>
<td>Etodolac®</td>
<td>Ketoprofen</td>
<td>Mobic®</td>
<td>Oxaprozin</td>
<td>Toradol®</td>
</tr>
<tr>
<td>Bayer® Select Pain Relief Formula Caplets</td>
<td>Feldene®</td>
<td>Ketorolac</td>
<td>Motrin®</td>
<td>PediaCare Fever®</td>
<td>Voltaren®</td>
</tr>
<tr>
<td>Celebrex®</td>
<td>Fenoprofen</td>
<td>Lodine®</td>
<td>Nabumetone</td>
<td>Piroxicam</td>
<td></td>
</tr>
</tbody>
</table>

Products with Vitamin E

Most multivitamins contain vitamin E. If you take a multivitamin be sure to check the label. The following products contain vitamin E:

<table>
<thead>
<tr>
<th>Amino-Opt-E</th>
<th>Aquavit</th>
<th>E-400 IU</th>
<th>E complex-600</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aquasol E</td>
<td>D’alpha E</td>
<td>E-1000 IU Softgels</td>
<td>Vita-Plus E</td>
</tr>
</tbody>
</table>

About Acetaminophen

Acetaminophen (Tylenol®) is generally safe to take during your cancer treatment. It doesn’t affect platelets, so it won’t increase your chance of bleeding. However, talk with your doctor before taking acetaminophen if you’re getting chemotherapy.
The following common medications contain acetaminophen.

<table>
<thead>
<tr>
<th>Acetophen®</th>
<th>Datril®</th>
<th>Lortab®</th>
<th>Roxicet®</th>
<th>Vicodin®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aceta® with Codeine</td>
<td>Di-Gesic®</td>
<td>Naldegesic®</td>
<td>Talacen®</td>
<td>Wygesic®</td>
</tr>
<tr>
<td>Acetaminophen with Codeine</td>
<td>Esgic®</td>
<td>Norco®</td>
<td>Tempra®</td>
<td>Zydone®</td>
</tr>
<tr>
<td>Aspirin-Free Anacin®</td>
<td>Excedrin P.M.®</td>
<td>Panadol®</td>
<td>Tylenol®</td>
<td></td>
</tr>
<tr>
<td>Arthritis Pain Formula® Aspirin-Free</td>
<td>Fiorcet®</td>
<td>Percocet®</td>
<td>Tylenol® with Codeine No. 3</td>
<td></td>
</tr>
<tr>
<td>Darvocet-N 100®</td>
<td>Lorcet®</td>
<td>Repan</td>
<td>Vanquish®</td>
<td></td>
</tr>
</tbody>
</table>

**Read the labels on all your medications**

Acetaminophen is safe when used as directed, but there is a limit to how much you can take in 1 day. It’s possible to take too much acetaminophen without knowing because it’s in many different medications.

Make sure to always read and follow the label on the product you are taking. Acetaminophen is a very common ingredient found in over-the-counter and prescription medications. It’s often an ingredient in pain relievers, fever reducers, sleep aids, and cough, cold, and allergy medications.

The full name acetaminophen isn’t always written out, so look for these common abbreviations, especially on prescription pain relievers:

<table>
<thead>
<tr>
<th>APAP</th>
<th>AC</th>
<th>Acetaminophen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetamin</td>
<td>Acetam</td>
<td>Acetaminoph</td>
</tr>
</tbody>
</table>
If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call____________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)

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This information describes fertility preservation options for women who are starting cancer treatment. It explains:

- How cancer treatment may affect your fertility (ability to get pregnant).
- How you may be able to preserve your fertility before beginning treatment.

Basic Reproductive Biology

Understanding basic reproductive biology can be helpful as you make decisions about your fertility.

Ovulation

The female reproductive system has several parts (see Figure 1).

![Female Reproductive System Diagram]

Figure 1. Female reproductive system

Your ovaries have 2 functions:
• They produce hormones (estrogen and progestin).
• They hold your eggs (oocytes). Each egg is contained in a sac called a follicle.

When you start puberty, your pituitary gland (located in your brain) releases hormones that cause a group of follicles to grow each month. The egg inside each growing follicle starts to mature. As the follicles grow, the ovary releases hormones that cause the lining of your uterus (endometrium) to thicken and prepare for a pregnancy.

One egg from the growing follicles fully matures each month. It’s released from 1 of your ovaries into the fallopian tube. This process is called ovulation. The other follicles growing that month break down and the eggs are cleared from the body.

**Pregnancy**

If you’re not using birth control and you have vaginal sex with a male partner around the time you’re ovulating, a single sperm may fertilize the egg. The fertilized egg begins to divide, forming an embryo. If the embryo implants in your endometrium, you become pregnant. The cells of the embryo continue to divide, becoming a fetus. During pregnancy, your uterus expands to hold the fetus as it grows.

**Menstruation**

If the egg released during ovulation doesn’t become fertilized, or if the embryo doesn’t implant in the endometrium, hormone levels drop and cause the lining of the uterus to shed. This bloody discharge forms your monthly menstrual period. The cycle then begins again, with new eggs maturing each month.

**Ovarian reserve**

Women are born with about 1 million eggs. During a woman’s lifetime, only 400 to 500 eggs are released during ovulation. The other eggs die naturally over time, so the number of eggs in the ovaries (called the ovarian reserve) gradually gets lower (see Figure 2). With fewer eggs, it’s harder to become pregnant. Eventually, there are so few eggs that a woman becomes infertile (unable to get pregnant).
Menopause

With the loss of eggs, the ovaries stop producing hormones. This causes monthly menstrual periods to stop. When a woman’s menstrual periods stop, this is called menopause. Most women lose their fertility 5 to 10 years before menopause.

Effects of Cancer Treatment on Fertility

Cancer treatments can impair fertility in a number of ways.

- Some chemotherapy medications destroy eggs. This may lead to infertility after treatment.
  - The risk of infertility depends on the medications used, the doses given, and the age of the woman at the time of treatment. Older women have fewer eggs when they start treatment. This means they are more likely to become infertile after treatment.
  - This loss of eggs in the ovaries from chemotherapy can “age” the ovaries, reducing the chance of pregnancy in the same way that natural aging does. Some women lose so many eggs that they become infertile and begin menopause immediately after treatment. Some women still have eggs remaining after treatment and continue to have monthly menstrual periods after treatment. However, they may develop infertility and menopause at a young age. This narrows the window of
time that a woman can become pregnant.

- Radiation therapy to the pelvis or whole abdomen (belly) destroys eggs in a similar way to chemotherapy. Radiation may also damage the uterus, causing fibrosis (scarring).
  
  - Women who receive high doses of radiation to the uterus will not be able to become pregnant.
  
  - Women who receive lower doses of radiation to the uterus may become pregnant, but their uterus may not be able to fully expand as the fetus grows. These women are more likely to have a miscarriage or premature labor. It’s recommended that they see a maternal fetal medicine specialist (a doctor who specializes in high risk pregnancies).

- Surgery or radiation therapy to the brain may affect the pituitary gland, which releases hormones that stimulate egg maturation and ovulation. However, this doesn’t damage the eggs in the ovaries, and medications that replace these hormones may allow the woman to become pregnant.

- Surgery may require removal of the ovaries, uterus, or all 3.

Because of the many factors that can affect fertility, it’s hard to know how you may be affected by your treatment. We can’t know for sure who will still be able to get pregnant after treatment is finished and who will not. We also can’t know for sure how long a woman will be fertile after treatment. If you have questions about your risk of infertility based on the treatment you will receive, speak with your oncologist (cancer doctor).

Fertility Preservation Options

A number of options are available that may preserve your fertility and increase the chance you will be able to have a biologic child in the future. Not all women starting cancer treatment will need or want to consider these options.

The decision whether to pursue fertility preservation is a personal one. We want you to know what options are available. This will allow you to have all the information that you need to make the best decision for yourself so that you have no regrets in the future.

Fertility preservation options for women include:
Egg or embryo freezing

Egg and embryo freezing are procedures in which mature eggs are removed from your ovary to be frozen and stored for possible use in the future. They can be frozen as unfertilized eggs or fertilized with sperm and frozen as embryos. These procedures are performed by specially trained gynecologists, called reproductive endocrinologists (RE). We don’t have REs at Memorial Sloan Kettering (MSK) but we can make a referral for you.

The process of egg or embryo freezing takes about 2 weeks. There are several steps involved, including:

- Evaluation: Your RE will do a number of tests to help determine how successful egg or embryo freezing may be for you. They will also want to speak with your oncologist to make sure it’s safe for you to undergo egg or embryo freezing. The tests that you may include:
  - A transvaginal ultrasound, in which a thin wand is placed in your vagina. Sound waves from the wand create pictures of your ovaries and uterus. With this test, your doctor can examine your ovaries and count the number of large growing follicles in your ovaries. This is called the antral follicle count. If you’ve never had a gynecologic exam or vaginal sex, your RE may be able to perform the ultrasound using a wand placed on your abdomen rather than in your vagina.
  - Blood tests to measure the levels of hormones related to fertility, including follicle stimulating hormone (FSH) and anti-mullerian hormone (AMH).

- Ovarian stimulation: If you decide to proceed, you will start giving yourself hormone injections each day for about 10 days. A nurse at the fertility center will teach you how to do this. These hormones will stimulate multiple eggs in your ovaries to mature. You don’t need to be at any
particular phase in your menstrual cycle to begin.

- During this period of stimulation, you will see the RE almost every other day for blood tests and ultrasounds. These tests show how your ovaries are responding to the hormones. If needed, your RE may change the doses of the hormones. Once your eggs are fully mature, the egg retrieval will be scheduled.

- Egg retrieval: This is an outpatient procedure, done with anesthesia (medication to make you sleep), so you won’t feel pain. You don’t need an incision (surgical cut).

  - Once you’re asleep, an ultrasound wand is be placed in your vagina so your RE can see your ovaries. A very thin needle is passed through the wall of your vagina up to your ovary to collect the mature eggs (see Figure 3).

  - The entire procedure takes about 20 minutes and most women are discharged within 1 hour.

![Figure 3. Egg retrieval](image)

- Fertilization (if you are freezing embryos): Your mature eggs are fertilized with sperm in the laboratory to create embryos. This is called in vitro fertilization, or IVF. The laboratory will use sperm from your male partner or from a sperm donor.

- Freezing (cryopreservation): Your embryos or unfertilized eggs are frozen. They can be stored for as long as you want.

Before beginning egg or embryo freezing, talk with your oncologist to be sure you can take the time to do this and that the procedure is safe for you. Most
patients only do 1 cycle of stimulation before their cancer treatment. However, the more eggs you’re able to freeze, the greater the chance that you will be successful in having a baby using these eggs in the future. Depending on how many mature eggs or embryos you’re able to freeze, your RE may suggest you undergo a second cycle. If you are considering a second cycle, speak with your oncologist first to be sure this will not delay your cancer treatment longer than is safe for you.

**Deciding between freezing eggs and freezing embryos**

Many women wonder if they should freeze eggs, embryos, or a combination of both. When making this decision, one thing to think about is your age. In younger women, the success rate with frozen eggs is generally the same as with frozen embryos. In older women (after age 35 to 38), eggs don’t survive the process of freezing and thawing as well as in younger women, and freezing embryos may be more successful.

Embryo freezing is a good option for a woman in a stable, long-term relationship. However, keep in mind that you won’t be able to use the embryos in the future without your partner’s permission. This could be a problem if the relationship comes to an end.

Egg freezing is a good option for single women who don’t want to use donor sperm to fertilize their eggs. Egg freezing may also be a good option for people with religious or ethical concerns about freezing embryos. Talk with your RE to help you make this decision.

**Considerations for women with breast cancer**

The hormone medication needed to stimulate your eggs to mature will cause your estrogen levels to rise for 2 to 3 weeks. To lower estrogen levels, we generally recommend that women with breast cancer take a medication called letrozole during stimulation, and for 1 to 2 weeks after the eggs are collected. Your RE will discuss this with you and prescribe the medication.

We can’t say for certain if this short period of estrogen exposure is safe, but there have been no reports that women with breast cancer who undergo egg or embryo freezing are more likely to have the cancer return. Everyone’s situation is different and we encourage you to speak with your oncologist if you are considering this.
Also, women with estrogen receptor positive breast cancer often need to take endocrine therapy for up to 10 years after finishing chemotherapy or radiation therapy. It isn’t safe to become pregnant while on this treatment because there is a risk of birth defects. Most women with estrogen receptor positive breast cancer are advised to wait 10 years before attempting pregnancy. If you are considering interrupting endocrine therapy to try to get pregnant before 10 years are up, discuss this with your oncologist.

**Cost of egg and embryo freezing**

Freezing eggs and embryos is expensive, and unfortunately, most health insurance plans don’t cover the cost. Every fertility center charges a different amount, but most centers offer discounted rates to patients starting cancer treatment. The cost for egg freezing is generally $5,000 to $8,000 and for embryo freezing $8,000 to $11,000. This usually includes all the monitoring visits, egg retrieval under anesthesia, fertilization of the eggs (if creating embryos), freezing, and at least 1 year of storage.

There are additional costs of about $5,000 for the hormone medication needed for ovarian stimulation. If your prescription plan doesn’t cover the medications, there are 2 programs that may help:

- **LIVESTRONG Fertility** works with a pharmaceutical company to provide free medication to patients being treated at participating fertility centers. Eligibility is based on your income.
  - To learn more go to [www.livestrong.org/we-can-help/livestrong-fertility](http://www.livestrong.org/we-can-help/livestrong-fertility)
  - To get an application, go to [https://livestrongfertilityportal.unicentric.com/Login/Index#](https://livestrongfertilityportal.unicentric.com/Login/Index#). You must submit the application and obtain approval before you start ovarian stimulation. To speak directly with one of their navigators, call 855-844-7777.

- **Heartbeat** is a program that offers free medication through a pharmaceutical company and Walgreens. To learn more, go to: [www.walgreens.com/images/adaptive/pharmacy/specialty-pharmacy/Preserving+the+Future-Patient_WEB+09-05-12.pdf](http://www.walgreens.com/images/adaptive/pharmacy/specialty-pharmacy/Preserving+the+Future-Patient_WEB+09-05-12.pdf). Ask your RE if you are eligible and if they can apply for you.
Future egg and embryo storage fees are about $1,000 per year. There are additional costs when you’re ready to thaw and use the eggs or embryos to attempt pregnancy. A financial specialist at the fertility center can determine what if anything will be covered by your health insurance and what you will have to pay yourself.

**How frozen eggs and embryos are used to attempt pregnancy**

If you use your frozen eggs or embryos in the future, they will be thawed when you’re ready to attempt pregnancy. If you froze eggs, they will be fertilized with sperm to create embryos.

If you no longer have regular periods, or are in menopause from your treatment, you will need to take hormones for several weeks to prepare the lining of your uterus for pregnancy. The embryos will be transferred into your uterus. The embryos are drawn up into a very thin, soft catheter that is passed through your vagina and cervix into your uterus. The embryos are released and the catheter is taken out. The procedure is done in an exam room. It does not hurt, so you will not need anesthesia.

If you’re not able to carry a pregnancy yourself, the embryos can be transferred to the uterus of another woman to carry the pregnancy for you. This is called surrogacy with a gestational carrier.

About 2 weeks after the embryo transfer, a blood test is done to see if you, or your gestational carrier, have become pregnant. If the pregnancy test is positive, an ultrasound will be done several weeks later to see if the embryo has implanted to confirm the pregnancy. You will then schedule an appointment with an obstetrician (a doctor who specializes in pregnancy and childbirth) who will care for you during the pregnancy. You may need to continue taking hormones for several months to support the pregnancy.

If the embryo did not implant, and you have other embryos being stored, your RE can perform another embryo transfer when you’re ready.

**Success rates with frozen eggs and embryos**

The chance that you will be successful in having a baby using frozen eggs or embryos depends on a number of factors. These include your age at the time of egg retrieval, your current ovarian reserve, the number of mature eggs obtained.
from the procedure, and the experience of the fertility center where you are being treated.

Not every egg collected can become a baby. For example, if 10 eggs are collected, some will not survive the freeze-thaw cycle, some will not fertilize and develop into embryos, and some may not implant after the transfer. Women under 35 years of age generally have a higher chance of success. Discuss your personal chance of success with your RE after your initial evaluation.

**Ovarian tissue freezing**

Ovarian tissue freezing is an experimental procedure in which an entire ovary, or pieces of an ovary, are removed during a surgery. The ovarian tissue is brought to a special laboratory to be processed. The outer layer of the ovary, which holds the eggs, will be removed, cut into small pieces, and frozen. A small amount of the tissue will be used for research to find the best way to help women have children using ovarian tissue. The rest of the tissue will be stored for your personal use.

One option for using this tissue in the future is to re-implant it into your body, with the hope that eggs in the tissue will mature and be released with ovulation. As of 2017, about 90 babies have been born after re-implantation of ovarian tissue. Another option for using this tissue is to stimulate the eggs to mature in the laboratory (in vitro maturation). The mature eggs could then be fertilized to create embryos for transfer to your uterus. No babies have yet been born using this technique. To learn more about ovarian tissue ask your nurse for the resource freezing *Fertility Preservation: Ovarian Tissue Freezing for Girls and Young Women With Cancer* or search for it on [www.mskcc.org/pe](http://www.mskcc.org/pe)

Ovarian tissue freezing may not be an option for all women. If you would like to learn more, ask your oncologist to refer you to a RE who performs ovarian tissue freezing.

**Ovarian suppression**

Ovarian suppression involves taking monthly injections of a medication called leuprolide to block hormones that stimulate your ovaries. This prevents eggs from maturing, with the hope that this will protect them from the effects of chemotherapy.
The injections usually start 1 to 2 weeks before the first chemotherapy treatment and continue until your treatment is completed. Side effects of the medication may include symptoms similar to those of menopause, such as hot flashes, mood changes, difficulty sleeping, and vaginal dryness. If it is safe for you to take hormones, low-dose birth control pills can be prescribed to prevent these symptoms.

Ovarian suppression has been studied mostly in women with breast cancer and lymphoma. Based on the results of these studies, it is not certain that this medication preserves fertility. We don’t know if ovarian suppression will be helpful for you. Some doctors feel it may help; others feel that it has no benefit. If you are interested in this option, speak with your oncologist.

**Ovarian transposition**

Ovarian transposition may be an option if you are receiving radiation therapy to the pelvis. This is an outpatient surgical procedure that moves your ovaries out of the field of treatment. This will lower the amount of radiation your ovaries are exposed to during your treatment and may help your ovaries keep working properly after treatment. The surgery is done through several small incisions in your abdominal wall. For more information ask your nurse for the resource *About Your Ovarian Transposition Surgery* or search for it on [www.mskcc.org/pe](http://www.mskcc.org/pe). If you are interested in ovarian transposition, ask your radiation oncologist to refer you to a gynecologic surgeon here at MSK.

Even when your ovaries are moved, they may still be exposed to some radiation, possibly destroying some of your eggs. If you will also be getting chemotherapy, this may add to the loss of eggs. If having a biologic child is important to you, you may want to undergo egg or embryo freezing before your ovaries are repositioned. If you are interested in egg or embryo freezing, ask your radiation oncologist to refer you to one of our Fertility Nurse Specialists.

**Alternative treatment for certain early-stage gynecologic cancers**

For women with certain early-stage gynecologic cancers, it may be possible to do limited surgery, or in some cases take medication to preserve fertility. This means your doctor may be able to leave one or both of your ovaries, your uterus, or all 3 intact.
For example, some women who have early-stage cervical cancer can have their cervix removed but have their uterus left in place. This procedure is called radical trachelectomy and may enable you to carry a pregnancy. To learn more about radical trachelectomy, ask your nurse for the resource *About Your Radical Trachelectomy* or search for it on [www.mskcc.org/pe](http://www.mskcc.org/pe).

Not all women are eligible for these limited surgeries. It depends on the location and size of your tumor. If you are interested, ask your gynecologic surgeon if you are a candidate.

**Other Options for Building a Family**

Some women will not be able to preserve their fertility before treatment and some may choose not to for personal reasons. This does not shut the door on having children in the future. Some women will be able to get pregnant naturally without medical help. Some may have a low ovarian reserve but will be able to get pregnant with fertility treatment provided by a RE. If you’re unable to have a biological child in the future, there are other ways of building a family after cancer treatment.

- You can use donor eggs or embryos. Donor eggs are given by young women who undergo a cycle of ovarian stimulation and egg retrieval. These are fertilized with sperm from your partner or a donor to create embryos for transfer into your uterus. Donor embryos are usually given by couples who had infertility treatment, have completed building their families, and do not want to discard their remaining embryos. The cost of using donor embryos is much lower than that of donor eggs.

- You can adopt. Having a history of cancer doesn’t prevent you from being able to adopt as long as you’re healthy and have been cancer-free for several years.

To learn more about these options, ask your doctor or nurse for the resource *Building Your Family after Cancer Treatment: Information for Women* or search for it on [www.mskcc.org/pe](http://www.mskcc.org/pe).

**Making a Decision about Fertility Preservation**
It can be difficult to make a decision about fertility preservation because there is a lot of uncertainty. We can’t predict exactly how or if treatment will affect your fertility. If you do pursue fertility preservation, there are no guarantees that it will be successful. There is also pressure to make a decision quickly, before treatment begins.

Some women are very clear about whether or not they want to pursue fertility preservation. Others have a harder time making this decision. Below are some things to consider as you make a decision for yourself:

- Your oncologist’s opinion about the risk of infertility from your treatment.
- Your oncologist’s opinion about the safety of your undergoing egg or embryo freezing.
- Your comfort with receiving hormones to stimulate your ovaries.
- How important it is to you to have a biological child (from your own eggs).
- The chance of success in having a baby if you freeze eggs or embryos.
- Your feeling about being able to cope with the effort it will take to undergo egg or embryo freezing.
- Your religious, ethical, and personal beliefs about using reproductive technology.
- Your financial resources.
- Your comfort with the possibility of having a child using donor eggs, a gestational carrier, or adoption.
- Your comfort with the possibility of having no (more) children.
- Your partner’s thoughts and wishes.
- The opinions of your friends and family.

There is no “right” decision. Our goal is for you to have all the information you need to make the best decision you can for yourself. Many women find it helpful to see a RE to be evaluated and learn more to help them make a decision.

**Additional Resources**

A number of resources are available to help you learn more and make a decision
about fertility preservation. First, speak with your oncologist to make sure that it is safe for you to pursue fertility preservation. If you would like more information about the options available, or support as you consider these issues, ask your oncologist to refer you to one of our Fertility Nurse Specialists.

In addition, the organizations listed below have information about fertility preservation that may be helpful to you.

**American Cancer Society**
*Fertility and Women with Cancer*
www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/

**CancerNet**
*Fertility Preservation*

**LIVESTRONG/Fertility**
www.livestrong.org/we-can-help/livestrong-fertility

**Oncofertility Consortium of Northwestern University**
*MyOncofertility*
www.myoncofertility.org
*Save My Fertility*
www.savemyfertility.org

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ___________________. After 5:00 PM, during the weekend, and on holidays, please call________________________. If there’s no number listed, or you’re not sure, call 212-639-2000.
Frequently Asked Questions About Blood Transfusions

This information answers frequently asked questions about having a blood transfusion.

Your doctor has recommended that you have a blood transfusion. Many people have questions about why they need a blood transfusion. Some people may worry about the risk of being infected with HIV, hepatitis, or other viruses. The information below will help answer some of your questions.

What is my blood made up of?

Your blood is made up of plasma (fluid in your blood that holds all your blood cells) and 3 types of blood cells:

- Red blood cells that carry oxygen to your tissues.
- Platelets that help form clots and stop bleeding.
- White blood cells that fight infection.

Why do I need to have a blood transfusion?

You may need a transfusion because of the effect of a disease, surgery, chemotherapy, or other treatments on your blood.

You may need a transfusion of your red blood cells, white blood cells, or your platelets. You may need a transfusion of red blood cells if you have lost a lot of blood or your red blood cell count is low (anemia). You may need a platelet transfusion if your platelet count is low (thrombocytopenia). You can also have a white blood cell transfusion, but these are rare and done in very specific situations.
Does it hurt?

It doesn’t hurt to have a blood transfusion. The only pain you may feel is when the needle is inserted into your vein. This pain will go away quickly.

If you have a central venous catheter (CVC), you can get red blood cells or platelets through it. This will not hurt.

If you have a Mediport®, it will be the same type of needle stick that you have for chemotherapy.

How long does it take?

A transfusion of red blood cells usually takes 2 to 4 hours. A transfusion of platelets takes 30 to 60 minutes.

Are there any risks associated with a blood transfusion?

Yes, blood transfusions have some risks. These risks include the very small chance of having an allergic reaction or getting an infection. Your healthcare provider will talk with you about these risks before you receive a transfusion.

How can I be sure the blood is safe?

After it’s donated, the blood is tested for:

- Syphilis
- Hepatitis B and C
- HIV
- A virus associated with a very rare form of leukemia
- West Nile virus
- Trypanosome cruzi (a parasite that causes Chagas disease)
- Zika virus
- Bacteria (platelets only)
If the donated blood tests positive for any of these infections, the blood is thrown away.

**How can I be sure that the blood I receive is the same type as mine?**

Your blood type is either A, B, AB, or O. It’s either Rh positive (+) or Rh negative (-).

Your blood type is checked with a test called a “type and crossmatch”. The results of the test are used to match your blood type with the blood in our blood bank. Your healthcare provider will check to make sure that the blood is the correct match for you before they give you the transfusion.

**Can a friend or relative donate blood specifically for me?**

Yes, friends and relatives can donate both red blood cells and platelets. These are called directed donations. These donations are tested in the same way as other donations. If the blood tests positive for any of the viruses listed above, the donor will be notified privately.

If the donor’s blood type isn’t the same as your blood type, the donation may be given to someone else who may need it.

Directed red blood cell donations are held for you for 25 days. Directed platelet donations are held for you for 4 days. After that, the donations may be given to someone else.

**Can I give blood for myself?**

Sometimes, we encourage people scheduled for surgery to donate their own blood. It’s stored and given back if and when you need it. This is called an autologous donation.

Ask your doctor if you can donate your own blood. If this is possible, arrangements will be made with the blood bank for you to begin banking your blood.
You can donate your own blood several times during the month before your surgery. For more information about autologous blood donations, ask your healthcare provider for the resource *Being Your Own Blood Donor* or search for it on [www.mskcc.org/pe](http://www.mskcc.org/pe)

**What if I don’t want a blood transfusion?**

It’s always your right to refuse a treatment. However, keep in mind that doctors recommend a transfusion only when they think it’s needed. A large amount of blood is lost during some types of surgery. If this blood is not replaced, you can die.

**Are there any substitutes for blood if I need a transfusion?**

There are no substitutes for blood. This is why we are so grateful to the many family members and friends who donate their blood.

**Is there anything to worry about during or after a blood transfusion?**

A blood transfusion can sometimes cause reactions. The most common symptoms are a temperature of 100.4° F (38° C), chills, and hives. These can be treated with medication. Transfusion reactions are rarely life-threatening. Your nurse will monitor you carefully while your blood transfusion is taking place.

**Call Your Doctor if You Have:**

- A temperature of 100.4° F (38° C) or higher
- Chills
- Redness and warmth in your face
- Hives, rash, or itching
- Trouble breathing or shortness of breath
- Low back pain
- Nausea or vomiting
- Weakness or fainting
- Dark-colored urine

**If you have chest pain, call 911 immediately.**

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call____________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Frequently Asked Questions About Blood Transfusions

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Giving Yourself an Injection of Filgrastim (Neupogen®) or Pegfilgrastim (Neulasta®) With a Prefilled Syringe

This information will teach you how to give yourself a subcutaneous (below the skin) injection with filgrastim (Neupogen®) or pegfilgrastim (Neulasta®) in a prefilled syringe. Your nurse will review this information with you.

Medication Information

Name of medication: ______________________________

Medication schedule: ______________________________

Dose: ____________

How to Store Your Medication

- Store your prefilled syringes in the refrigerator. Don’t store them in the freezer. If the medication inside the syringe freezes by accident, allow it to thaw in the refrigerator. If it freezes more than once, don’t use it. Call your doctor or nurse for further instructions.

- A syringe can be left out at room temperature for up to 24 hours. Don’t leave it in direct sunlight.

- If you have any questions about how to store or carry the syringes when you travel, talk with your doctor, nurse, or pharmacist.
How to Give Yourself an Injection

Gather Your Materials

- Prefilled syringe with a clear plastic needle guard attached
- Alcohol pads
- Disposable sharps container or other puncture-resistant container, such as a laundry detergent bottle.
  - See the “How to Store and Dispose of Your Home Medical Sharps” section below for instructions on how to choose a sharps container.
- 2 x 2 gauze pad or cotton ball
- Band-Aid®

Prepare the Injection

1. **Take the prefilled syringe out of the refrigerator 30 minutes before you give the injection so that it can reach room temperature.**

2. Prepare a clean area to work where you can lay out all of your materials. You can work in the bathroom if it’s private and there’s enough space.

3. **Don’t shake the syringe.** Shaking it may damage the medication. If it has been shaken, the medication may look foamy and shouldn’t be used.

4. Check the medication:
   - **Name** – Make sure that the medication name on the package or syringe label matches what your doctor prescribed for you.
   - **Expiration date** – Make sure that the expiration date on the syringe hasn’t passed. If the date has passed, throw away the syringe in the sharps container.
   - **Strength** – Make sure that the strength of the medication is what your doctor prescribed. The strength is listed on the colored dot on the package.
   - **Color** – Make sure that the medication in the syringe is clear and
colorless. **Don’t use it if it looks discolored or cloudy, or if it has crystals in it.**

5. Wash your hands well with soap and water or use an alcohol-based hand sanitizer.

**Choose an Injection Site**

1. Choose an injection site from one of the following areas (see Figure 1):
   - The outer area of your upper arms.
   - Your abdomen (belly), except for the 2-inch area around your belly button.
   - The middle of the front of your thighs.
   - The upper areas of your buttocks.

   Keep track of which site you used last, and use a different site each time. Choosing a new site can help avoid soreness at any one site.

   Don’t inject into an area that’s tender, red, bruised, or hard. Don’t inject into an area that has scars or stretch marks.

2. Fold back any clothing that’s covering the injection site.

3. Tear off any 3 edges on a sealed alcohol pad packet. Hold the packet at the edge you didn’t tear. Carefully open the packet to expose the alcohol pad, but don’t take it out. Set the open packet on your clean work area. You will use this alcohol pad to clean the skin at the injection site just before you give yourself the injection.

**Give the Injection**

1. Take the syringe out of its package.
2. Hold the syringe around the middle, like a pen or dart. Carefully pull the needle cover straight off (see Figure 2). Once the needle cover is off, don’t set the syringe down. **Don’t let anything, including your fingers, touch the needle.** If anything touches the needle, you must throw it out in the sharps container. Call your doctor or nurse for instructions on what to do next.

3. Check the syringe for air bubbles. If there are air bubbles, hold the syringe upright, with the needle pointing up. Gently tap the syringe with your fingers until the air bubbles rise to the top of the syringe, near the needle. Slowly push the plunger up to force the air bubbles out of the syringe.

4. Pick up the alcohol pad with your other hand. Using firm pressure, clean the skin on the injection site. Start at the center of the site and move outward in a circular motion. Let your skin dry before giving the injection.

5. Hold the syringe in the hand you will use to give the injection. Hold it like you would a pen or a pencil when you are ready to write. Use your other hand to pinch a fold of skin at the injection site.

6. Insert the needle into your skin in one quick motion at a 90 degree (straight up and down) angle. (see Figure 3). Don’t place your thumb on the plunger yet.
7. After the needle is inserted, let go of your skin. Use your thumb (whichever thumb is more comfortable) to slowly push the plunger all the way down. Push it until all the medication is injected.

8. When the syringe is empty, pull it straight out of your skin. Place a cotton ball or gauze over the injection site and press down for several seconds. If needed, apply a Band-Aid®.

9. Don’t put the cover back on the needle. Be careful to not poke yourself with the needle. While holding the clear plastic finger grips on the sides of the syringe with one hand, grasp the needle guard with your other hand (see Figure 4). Slide the needle guard over the needle until it’s completely covered (see Figure 4). You will hear the needle guard click into place.

![Figure 4. Grasping and sliding the needle guard](image)

10. Place the syringe and cover into the sharps container. Don’t use a prefilled syringe more than once.

How to Store and Dispose of Your Home Medical Sharps

Storing Your Medical Sharps

- Use an empty plastic container with a screw-on cap, such as a laundry detergent bottle.
  - Pick a container that’s strong enough so that needles can’t poke through the sides.
  - Pick a container that’s not breakable.
  - Don’t store your sharps in glass bottles, soda bottles, milk...
jugs, aluminum cans, coffee cans, or paper or plastic bags.

- Clearly label the container “Home Sharps – Not for Recycling.” Keep it away from children and pets.
- Put the sharps in the container point-first as soon as you use them.
- Don’t overfill the container. When it’s more than half full, stop using it. Wrap the cap with strong tape to create a more secure seal and prevent leakage.
- Keep the container separate from trash that will be recycled.

**Disposing of Your Medical Sharps**

- If you live in New York City, you can place the sealed container in with your regular trash for collection. **Don’t put it in with your recyclables.**
- If you live in a different county of New York or another state, check with your local department of health for instructions.
- You can also bring the sealed container to:
  - Your nurse at your next clinic visit
  - Any hospital or nursing home in New York State
  - A local pharmacy

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call____________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Giving Yourself an Injection of Filgrastim (Neupogen®) or Pegfilgrastim (Neulasta®) With a Prefilled Syringe

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Hair Loss and Your Cancer Treatment

This information will help you understand hair loss during cancer treatment and explains medications that you can take to prevent or help hair loss.

Commonly Asked Questions

What are the causes of hair loss?

Many people with cancer lose their hair because of chemotherapy or radiation to the head. However, there are other causes of hair loss, too. These include being low in certain vitamins, having a family history of hair loss, going through hormonal changes, having certain medical conditions, hairstyles, treatments, and medications and being stressed.

It is important to be seen by a dermatologist to determine the reason for your hair loss and if you have any questions about your hair. Your dermatologist will ask about your history of hair loss and look at the areas where you are experiencing hair loss.

Why will I lose my hair during cancer treatment?

Cancer treatments such as radiation and chemotherapy attack fast-growing cancer cells. These treatments can also affect normal cells that are fast growing, such as hair.

Chemotherapy can cause hair loss on your scalp, pubic area, arms, legs, eyebrows, and eyelashes. Radiation therapy to the head often causes hair loss on the scalp. Sometimes, depending on the dose of radiation to the head, the hair may grow back differently from how it looked before or it may not grow back at all.
When will I begin to lose my hair?
You may start to see your hair thin or fall out 1 to 4 weeks after your first chemotherapy treatment and 4 weeks after you receive radiation therapy.

How much of your hair falls out or thins depends on the type, dose, and timing of your treatments. The speed at which it falls out also varies from person to person. You may first notice hair on your pillow in the morning or see it when you shower or brush your hair.

Some people will experience hair thinning rather than hair loss. Speak with your nurse about what to expect after your chemotherapy or radiation therapy.

When will my hair grow back?
Once your treatments have stopped, your hair should begin to grow back. Hair regrowth can take 3 to 5 months. Your hair may look or feel different in terms of texture or color. In rare cases, your hair will not grow out as fully as it did before.

There is a very small risk that your hair will not grow back after radiation therapy to the head.

Caring For Your Hair and Head
Here are suggestions on how to care for your hair and head while you are experiencing hair loss:

- Wash and condition your hair every 2 to 4 days with a baby shampoo or other mild shampoo and a cream rinse or hair conditioner.
- Always rinse your hair well and pat it dry with a soft towel.
- Wash your hair after swimming in a pool.
- Use shampoos and conditioners that have sunscreen to prevent sun damage to your scalp. Do not expose your scalp to the sun and keep your head covered in the summer.
- In the winter, cover your head with a hat, scarf, turban, or wig to keep it warm. This can also help to contain falling hair.
- Sleep on a satin or silk pillowcase because it is smoother than other fabrics.
and can decrease hair tangles.

- Brush or comb your hair gently with a soft-bristle brush or comb. Start brushing or combing your hair at the ends and gently work your way up to your scalp. You can also finger-comb your hair by moistening your fingers with water.

- If your hair is long, you may want to have it cut short before you begin treatment.

- Tell your hairdresser that you are receiving chemotherapy. He or she may be able to recommend gentle hair products.

- Try using Bumble and bumble™ Hair Powder to cover bald spots and thinning areas of your hair. You can buy it at Sephora® or online from various beauty supply websites.

Do not use the following on your hair during treatment because they can be too harsh or pull on your hair:

- Hair spray, hair dye, bleach, or permanents (perm)
- Clips, barrettes, bobby pins, pony tail holders, or scrunchies
- Hair dryers, curlers, curling irons, or a hair straightener
- Rubber bathing or swimming caps

Do not put your hair in braids, corn rows, or pony tails.

Wigs, Hairpieces, and Head Coverings

Wigs

If you want to wear a wig, try to get one before your hair falls out because it will be easier to match your hair color and style. If you have already experienced hair loss, bring a photo of your usual hairstyle, and if you can, a lock of your hair. This will help you find a wig that looks like your hair did before your treatment started.

When shopping for a wig, you may want to shop around and compare prices. There is a list of places to buy wigs in the section “Where to Buy Wigs and Hairpieces” at the end of this resource.
A wig should fit properly, be comfortable, and be easy to care for. You may want to start wearing your wig as soon as your hair begins to thin. As your hair gets thinner, you may need to have your wig adjusted to make it fit better.

There are many types of wigs and hairpieces. Below is a list of the most common.

**Custom-made wigs**

Custom-made wigs are made by hand and are usually the most expensive type of wig. These wigs are made using your specific head measurements. To get a custom-made wig, you may need to visit the store that sells it several times, for it to be colored, cut, and cleaned. Custom-made wigs are usually made of human hair, but can be made of synthetic (not human hair) materials.

**Customized ready-made wigs**

Customized ready-made wigs can be made of human hair, synthetic blends, or a mixture of both. They are made in standard sizes, but can be altered to fit your head. These wigs can be styled and generally cost less than a custom-made wig.

**Ready-made or stock wigs**

Ready-made or stock wigs are usually made out of a stretchy material and come in 1 size. If you buy a ready-made wig, you can usually take it home the same day that you purchase it. Ready-made wigs are generally the least expensive type of wig.

**Hairpieces**

If you lose your hair in only 1 area, you may want to consider buying a hairpiece rather than a wig. A hairpiece will blend into your own hair when combed. It can be made in any size, color, or shape.

**Head coverings**

**Scarves, turbans, and hats**

- Scarves, turbans, and hats can help hold hair that is falling out and also hide a bald scalp.
- Scarves made from silk can easily slide off your head. A scarf made of a cotton blend can be more comfortable.
- Turbans are sold in many drug stores and come in many different colors.
and textures.

- Hats worn with or without scarves can also be attractive and comfortable.

**Financial Support**

Your health insurance may cover the cost of your wig or hairpiece. For your wig or hairpiece to be covered by insurance, your doctor must write a prescription with a diagnosis code indicating that your hair loss is due to treatment for cancer. Check with your insurance company to see if they cover the costs of wigs or hairpieces and how much they will pay.

Additional resources for financial support include:

**American Cancer Society**

[www.cancer.org](http://www.cancer.org)

Some American Cancer Society offices offer free wigs to cancer patients. If you are interested in this service, go to your local American Cancer Society office or call 800-227-2345.

**Cancer Care**

[www.cancercare.org](http://www.cancercare.org)

Cancer care offers free wigs to cancer patients. Call 800-813-4673 and ask to speak with a social worker.

**The Look Good Feel Better Program**

The Look Good Feel Better program is designed to help people cope with the effects that cancer treatment can have on their appearance. During weekly sessions, makeup artists teach makeup techniques, skin and nail care, and hair styling and head-covering options. To register for a class, call the American Cancer Society at 800-227-2345.

Men can find information at [lookgoodfeelbetter.org/programs/men/](http://lookgoodfeelbetter.org/programs/men/)

**Medications and Supplements for Hair Loss**

Medications and supplements for hair loss can slow thinning of hair and increase coverage of the scalp by growing new hair and enlarging existing hairs. Below are frequently asked questions people have about minoxidil, biotin,
BioSil™, finasteride, and spironolactone.

**Minoxidil**

What is minoxidil?

Minoxidil is a topical (applied on the skin) medication that has been used for over 20 years to help regrow hair. It can be purchased over the counter. One common brand name is Rogaine®.

Minoxidil has only been tested on the scalp. However, your doctor may recommend that you use it also on your eyebrows, as an off-label use. Off-label use means that a medication is used in a way that is different from how it is described on the FDA-approved medication label.

Which product do you recommend?

We recommend the 5% product for both men and women.

Should I use the liquid or foam product?

The foam product is easier to apply if you have some hair and it is less likely to drip down your face. To apply:

1. Dispense ½ capful of foam onto your fingers.
2. Apply directly to your scalp, parting your hair where it is thinning.
3. Massage into your scalp.
4. Wash your hands.
5. Let the foam dry.

If your nurse or doctor tells you to apply minoxidil to your eyebrows, we recommend that you use the foam as well. Protect your eyes and eyelids by placing a cloth over your eyes when applying.

For more information on minoxidil, including how to apply it, go to [www.rogaine.com](http://www.rogaine.com).

How often should I apply it?

Apply it at least once daily, but we recommend applying it twice daily. Using minoxidil more often than this will not make your hair grow faster. Add minoxidil to your daily routine.
Do not use minoxidil if you are using any other topical medication. Wait until you finish the course of your other topical medication, and then start using minoxidil.

**When should I expect to see results?**

It may take up to 4 months to see results.

During the first few weeks of use, some of your hair may shed. This is to make room for the new hairs to grow.

**What are the side effects?**

Uncommon side effects include scalp irritation and itchy or dry scalp. If you experience these side effects, stop applying the medication and call your doctor’s office.

Rare side effects include increased hair growth on the face. If this happens to you, use threading to get rid of the unwanted hair.

You may experience changes in the color or texture of your hair.

If you have history of heart disease, let your cardiologist (heart doctor) know you are applying this medication.

**I am getting some facial hair as a side effect of my cancer treatment. Will the minoxidil increase this growth if I am only applying it to my scalp?**

Unwanted hair growth on the face and other parts of the body has been reported from the use of minoxidil, but these reports have been rare. The hair growth may be caused by the transfer of minoxidil to areas other than your scalp, or by low levels of it being absorbed into your body.

**Are there any alternatives to minoxidil?**

There are no alternative topical medications that we recommended.

**Can I use minoxidil if I am pregnant or nursing?**

No. Do not use this product if you are pregnant or nursing.

**Biotin**

**What is biotin?**
Biotin is a supplement that can strengthen hair and nails.

**How much should I take daily?**
We recommend taking 2,500 mcg (2.5 mg) orally (by mouth) daily.

**Are there any side effects?**
Biotin is usually well tolerated when taken as directed.

**BioSil™**

**What is BioSil™?**
BioSil™ is a supplement that allows your body to make and increase the production of collagen.

**Why do I need collagen?**
Collagen is a protein that we need for healthy hair, skin, nails, healthy bones, and joints. It makes your skin more elastic, your hair thicker and stronger, and your nails harder.

**How long should I take BioSil™?**
You can take it as long as you want, or until you feel your hair and nails have returned to normal after your treatment.

**Can I take BioSil™ with other supplements (i.e., biotin)?**
Yes. There are no contraindications between BioSil™ and any other supplement.

**Are there any side effects?**
Rare side effects include leg swelling and rashes.

**Finasteride**

**What is finasteride?**
Finasteride is a prescription medication that has shown approved by the FDA to treat male pattern baldness. It can also be prescribed to women for off-label use.

**How does finasteride work on hair growth?**
Finasteride works by lowering a hormone called dihydrotestosterone (DHT) which is present in both men and women. High levels of DHT shrink hair follicles resulting in hair loss. Reducing DHT stops the progression of hair loss.
What are some side effects?

Some of the side effects are listed below. Please see the package insert for all side effects.

Some of the common side effects of finasteride include an inability to have an erection, low blood pressure, dizziness, weakness, and decreased interest in sexual intercourse.

Rare side effects include an allergic reaction, enlarged breasts, fluid retention, and decreased semen upon ejaculation.

Do not start this medication if you are planning to be pregnant or are pregnant.

Call your doctor if you experience new or worsening side effects after taking this medication such as swelling, rash, depression, confusion, genital pain, or difficulty urinating.

Spironolactone (Aldactone®)

What is spironolactone?

Spironolactone is a prescription medication used to treat conditions including high blood pressure, and low levels of potassium. It can also slow the production of hormones which are present in hair follicles. This has shown to stop the progression of hair loss.

What are some side effects?

Some of the side effects are listed below. Please see the package insert for all side effects.

Some of the common side effects include stomach irritation, mild nausea, breast tenderness, headache, and difficulty with erections.

Rare side effects include an allergic reaction and high potassium in the blood.

If you develop any new side effects when taking this drug, call your doctor’s office immediately.
Will I need to have special tests done while taking spironolactone?

Your doctor will monitor your potassium, kidney function, and blood pressure while on this medication.

If you take this medication, tell all your doctors (including your oncologist, primary care doctor, and your cardiologist). Tell your doctor if you have liver, heart disease, if you take other water pills, salt substitutes, or other blood pressure medications.

What should I avoid while taking this medication?

Do not start this medication if you are:

- Pregnant
- Planning to get pregnant
- Have high potassium blood levels
- Have an allergy to this medication
- Not able to urinate
- Have kidney disease

Do not eat foods with potassium such as:

- Bananas
- Beans
- Dark, leafy greens such as spinach
- Potatoes
- Squash
- Yogurt
- Fish
- Avocados
- Mushrooms

Do not drink alcohol because it may cause dizziness and low blood pressure.
## Where to Buy Wigs and Hairpieces

### New York

#### Manhattan

<table>
<thead>
<tr>
<th>Andrew DiSimone Wigs</th>
<th>Nicholas Piazza</th>
<th>Angels of New York</th>
</tr>
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<tbody>
<tr>
<td>855 Lexington Avenue</td>
<td>16 West 56th Street</td>
<td>217 East 60th Street</td>
</tr>
<tr>
<td>New York, NY 10065</td>
<td>2nd Floor</td>
<td>Suite 202</td>
</tr>
<tr>
<td>212-717-4000</td>
<td>New York, NY 10019</td>
<td>New York, NY 10022</td>
</tr>
<tr>
<td></td>
<td>212-838-6190</td>
<td>212-838-7888</td>
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<tr>
<td></td>
<td></td>
<td><a href="http://www.angelsofny.com">www.angelsofny.com</a></td>
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#### Brooklyn

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<thead>
<tr>
<th>Claire Accuhair</th>
<th>Yaffa Wigs</th>
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<tbody>
<tr>
<td>1611 Cedar Street</td>
<td>4118 13th Street</td>
</tr>
<tr>
<td>Brooklyn, NY 11230</td>
<td>Brooklyn, NY 11218</td>
</tr>
<tr>
<td>718-998-6043</td>
<td>718-436-4280</td>
</tr>
<tr>
<td><a href="http://www.claireaccuhair.com">www.claireaccuhair.com</a></td>
<td><a href="http://www.yaffawigs.com">www.yaffawigs.com</a></td>
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#### Queens

<table>
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<tbody>
<tr>
<td>116-01 Queens Boulevard</td>
</tr>
<tr>
<td>Forest Hills, NY 11375</td>
</tr>
<tr>
<td>718-544-1848</td>
</tr>
<tr>
<td><a href="http://www.ginzawig.com">www.ginzawig.com</a></td>
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#### Long Island

<table>
<thead>
<tr>
<th>Jacki’s Wig Works</th>
<th>The Wig Salon</th>
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<tbody>
<tr>
<td>3381 Merrick Road</td>
<td>1008 West Jericho Turnpike</td>
</tr>
<tr>
<td>Wantagh, NY 11793</td>
<td>Smithtown, NY 11787</td>
</tr>
<tr>
<td>516-679-4633</td>
<td>631-864-7560</td>
</tr>
<tr>
<td><a href="http://www.jackiswigworks.com">www.jackiswigworks.com</a></td>
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</tr>
</tbody>
</table>
Westchester County

Oggi, Adam, and Eve
770 Central Avenue
Scarsdale, NY 10583
914-472-0010
www.oggiadameve.com

Tiffany Wigs
100 Triangle Shopping Center
Yorktown Heights, NY 10598
800-427-WIGS (800-427-9447)
www.tiffanywigs.com

You can also visit Ricky’s, a store with multiple locations around New York City that carries inexpensive wigs. For more information, call 877-44-RICKY (877-447-4259) or visit www.rickysnyc.com.

New Jersey

AAA Wigs
682 Morris Turnpike
Short Hills, NJ 07078
973-376-8050
www.angelsofny.com

Hair and Scalp Wellness
RBMC Medical Arts Building
2 Hospital Plaza, Suite 480
Old Bridge, NJ 08857
732-416-8336
www.hairandscalpwellness.com

Lillian Lee Salon and Spa
974 Teaneck Road
Teaneck, NJ 07666
201-837-6770

Connecticut

Allura Salon & Day Spa
23 West Putnam Avenue
Greenwich, CT 06830
203-869-1234
www.allurasalon.com

International Hair Salon
201 Summer Street
Stamford, CT 06905
203-358-8888
stamfordbesthairsalon.com

Online Resources

Godiva’s Secret Wigs
www.godivassecretwigs.com
Organizations

The following organizations offer free wigs to people with cancer. Call for more information.

**American Cancer Society (ACS)**
- [www.cancer.org](http://www.cancer.org)
- 800-ACS-2345 (800-227-2345)

**CancerCare**
- [www.cancercare.org](http://www.cancercare.org)
- 800-813-HOPE (800-813-4673)

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at _________________. After 5:00 PM, during the weekend, and on holidays, please call_______________. If there’s no number listed, or you’re not sure, call 212-639-2000.
This information will prepare you for your interventional radiology procedure at Memorial Sloan Kettering (MSK). Your doctor has referred you for a procedure called a(n) _______________________________.

### Before Your Procedure

#### Ask about your medications

You may need to stop taking some of your medications before your procedure. Talk with your doctor about which medications are safe for you to stop taking. We have included some common examples below.

If you take medication that affects the way your blood clots, ask the doctor performing your procedure what to do. The doctor’s contact information is listed at the end of this resource. Some examples of these medications are:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Brand Name</th>
</tr>
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<tbody>
<tr>
<td>apixaban (Eliquis®)</td>
<td>dalteparin (Fragmin®)</td>
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<tr>
<td>meloxicam (Mobic®)</td>
<td>ticagrelor (Brilinta®)</td>
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<tr>
<td>aspirin</td>
<td>dipyridamole (Persantine®)</td>
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<tr>
<td>nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil®) or naproxen (Aleve®)</td>
<td></td>
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<tr>
<td>tinzaparin (Innohep®)</td>
<td>celecoxib (Celebrex®)</td>
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<tr>
<td>pentoxifylline (Trental®)</td>
<td>warfarin (Coumadin®)</td>
</tr>
<tr>
<td>cilostazol (Pletal®)</td>
<td>edoxaban (Savaysa®)</td>
</tr>
<tr>
<td>prasugrel (Effient®)</td>
<td>enoxaparin (Lovenox®)</td>
</tr>
<tr>
<td>clopidogrel (Plavix®)</td>
<td>Fondaparinux (Arixtra®)</td>
</tr>
<tr>
<td>rivaroxaban (Xarelto®)</td>
<td>dabigatran (Pradaxa®)</td>
</tr>
<tr>
<td>heparin (shot under your skin)</td>
<td>sulfasalazine (Azulfidine®, Sulfazine®)</td>
</tr>
</tbody>
</table>
Whether they recommend you stop taking it will depend on the reason you are taking it. **Do not stop taking any of these medications without talking with your doctor.**

Please review the information in the resource *Common Medications Containing Aspirin and Other Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)*. It includes important information about medications you’ll need to avoid before your procedure and what medications you can take instead.

If you take insulin or other medications for diabetes, you may need to change the dose before your procedure. Ask the doctor who prescribes your diabetes medication what you should do the morning of your procedure.

If you take any diuretics (medications that make you urinate more often), you may need to stop taking them the day of your procedure. Some examples are furosemide (Lasix®) or hydrochlorothiazide. Speak with your doctor.

**Arrange for someone to take you home**

You must have someone 18 years or older take you home after your procedure. If you don’t have someone to do this, call one of the agencies below. They will provide someone to accompany you home; however, there is usually a charge for this service and you will also need to provide transportation.

In New York:

- Partners in Care: 888-735-8913
- Prime Care: 212-944-0244

In New York or New Jersey:

- Caring People: 877-227-4649

**Tell us if you’re sick**

If you develop any illness (fever, cold, sore throat, or flu) before your procedure, please call a nurse in Interventional Radiology at 212-639-2236. A nurse is available Monday through Friday from 9:00 AM to 5:00 PM. After 5:00 PM, during the weekend, and on holidays, call 212-639-2000 and ask for the Interventional Radiology fellow on call.
Note the time of your appointment

A staff member from Interventional Radiology will call you 2 business days before your procedure. They will tell you what time you should arrive at the hospital for your procedure. If your procedure is scheduled on a Monday, you will be called on the Thursday before. If you don’t receive a call by noon the business day before your procedure, please call 212-639-5051.

If you need to cancel your procedure for any reason, please call the doctor who scheduled it for you.

Instructions for eating and drinking before your procedure

- Do not eat anything after midnight the night before your procedure. This includes hard candy and gum.

- Between midnight and up until 2 hours before your scheduled arrival time, you may drink a total of 12 ounces of water (see figure).

- Starting 2 hours before your scheduled arrival time, do not eat or drink anything. This includes water.

The Day of Your Procedure

Things to remember

- Take only the medications your doctor told you to take the morning of your procedure. Take them with a few sips of water.

- Do not apply cream or petroleum jelly (Vaseline®). You can use deodorant and light moisturizers. Do not wear eye makeup.

- Remove any jewelry, including body piercings.

- Leave all valuables, such as credit cards and jewelry, at home.

- If you wear contact lenses, wear your glasses instead, if possible. If you
don’t have glasses, please bring a case for your contacts.

**What to bring with you**

- A list of the medications you take at home
- Medications for breathing problems (such as inhalers), medications for chest pain, or both
- A case for your glasses or contacts
- Your Health Care Proxy form, if you have completed one
- If you use a CPap or BiPAP machine to sleep at night, please bring your machine with you, if possible. If you can’t bring your machine with you, we will give you one to use while you are in the hospital.

**Where to go**

- **Memorial Hospital**
  
  1275 York Avenue (between East 67th and East 68th Streets), New York, NY 10065

  Parking at MSK is available in the garage on East 66th Street between First and York Avenues. To reach the garage, enter East 66th Street from York Avenue. The garage is located about a quarter of a block toward First Avenue, on the right (north) side of the street. A pedestrian tunnel connects the garage to the hospital. For questions about pricing, call 212-639-2338. There are also nearby commercial garages on East 69th Street between First and Second Avenues and on East 65th Street between First and Second Avenues.

  When you arrive at Memorial Hospital, take the M elevator to the 2nd floor. Enter through the glass doors and check in at the desk.

- **Memorial Sloan Kettering Westchester**

  500 Westchester Avenue, West Harrison, NY 10604

  When you enter the building, check in at the reception desk and they will direct you to Interventional Radiology

**What to expect**
Once you arrive at the hospital, doctors, nurses, and other staff members will ask you to state and spell your name and date of birth many times. This is for your safety. People with the same or similar names may be having procedures on the same day.

Contact Information

If you have any questions or concerns, please call Interventional Radiology at 212-639-2236. You can reach a staff member Monday through Friday from 9:00 AM to 5:00 PM. After 5:00 PM, during the weekend, and on holidays, please call 212-639-2000 and ask for the fellow on call for Interventional Radiology.

Instructions for Interventional Radiology Procedures

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PATIENT & CAREGIVER EDUCATION

Low-Microbial Diet

This information will help you follow a low-microbial diet. Eating a low-microbial diet will lower your risk of getting sick while your immune system is weak, such as when you have leukopenia (a low number of white blood cells), after chemotherapy, radiation therapy, or a bone marrow or stem cell transplant.

The first section of this resource has information on how to keep your food safe. The second section explains what foods and drinks are safe to eat and drink while on a low-microbial diet. Don’t make any changes to this diet until you have talked to someone on your healthcare team. This includes your doctor, nurse, nurse practitioner, or dietitian.

People who had an allogeneic or autologous stem cell transplant should follow this diet for the first 100 days after their transplant. Please speak to your healthcare team about whether you need to keep following the diet after the 100-day period is over.

Food Safety Guidelines

About microbes

Microbes are tiny living things such as bacteria, viruses, yeast, and molds. They can get into food by infecting the animal the food comes from. Microbes can also get into food when it’s being processed or prepared. When microbes get into foods and you eat the foods without proper preparation, they can cause infections. People with leukopenia are at an especially high risk for infection.

Microbes can attach to foods and grow, but you can’t always see, smell, or taste them. They’re more likely to grow on:

- Milk and other dairy food items that aren’t refrigerated.
- Unpasteurized cheeses (such as Brie, blue cheese, and feta).
• Undercooked and raw eggs and foods that have raw eggs (such as cookie dough and Caesar salad dressing).
• Undercooked or raw meat, poultry, and seafood (including smoked seafood such as smoked salmon and trout).
• Certain fruits and vegetables (see the Fruits and Vegetables list in the “What to Eat on a Low-Microbial Diet” section).
• Unpasteurized or untreated juices (such as fresh-squeezed juices).
• Vegetable sprouts (such as raw alfalfa, soy bean, and radish sprouts).

Buying foods that are safe to eat

• Check containers for the expiration date. Buy and use food before that date.
• Don’t buy fruits and vegetables that have cuts, bruises, or mold.
• Don’t buy pre-cut fruits and vegetables at the grocery store. Buy whole produce and clean and cut it at home.
• Don’t buy canned foods if the can has dents or is swollen.
• Don’t buy food in jars if the jar is cracked or the lid isn’t tightly closed.
• Don’t buy packaged or boxed food that isn’t properly sealed.
• Buy only pasteurized dairy products, honey, and fruit and vegetable juices.
• Only buy eggs that are refrigerated. Open the carton to make sure no eggs are broken or cracked.
• Don’t buy foods from self-service bulk containers or bins.
• Don’t taste free samples.
• Don’t buy meats, cheeses, or salads from the deli counter or salad bar.
• Separate ready-to-eat and raw foods. Put raw meat, poultry, seafood, and other raw foods in plastic bags before they go into your shopping cart.

Pick up your milk and other cold and frozen foods at the end of your shopping trip. This decreases the time these items will spend outside of the refrigerator or freezer.

Transporting food safely
After grocery shopping, go directly home and put your perishable food (food that can go bad quickly) into the refrigerator or freezer right away.

Never leave perishable foods in a hot car.

- If you need to make a stop after grocery shopping or if your trip from the grocery store to your home is long, place perishable foods in an insulated bag or cooler with ice or frozen gel packs.

**Storing food safely**

- Store food right after shopping.
- Put eggs and milk on a shelf inside the refrigerator. Don’t store them in the door. The inside of the refrigerator stays cooler than the door area.
- Never leave perishable food out of the refrigerator for more than 1 hour.

**Keeping your kitchen clean**

- Keep an area of your kitchen clean for preparing and eating food. This will help keep microbes from spreading.
- Use paper towels or a clean cloth to clean kitchen surfaces. Don’t use sponges.
- Use an antibacterial cleaning spray to clean surfaces. Look for products that have bleach or ammonia. Examples are Lysol® Food Surface Sanitizer and Clorox® Clean-Up Cleaner.

**Using cutting boards and equipment**

- Use thick plastic, marble, glass, or ceramic cutting boards. These materials are nonporous, meaning that food or liquid substances can’t absorb into them. Don’t use cutting boards made from wood or other porous surfaces that can absorb food and liquids.
- Throw out worn or hard-to-clean cutting boards.
- Wash cutting boards and knives with hot soapy water before using them to cut the next food.
- As an extra precaution, you can also wash your cutting boards with a kitchen sanitizer. Rinse off the sanitizer with hot water before using the
• Use separate cutting boards for fresh produce and for raw meat, fish, seafood, or poultry.
• Never place cooked food on a cutting board or plate that previously held raw food.

Handling food safely

• Wash your hands thoroughly with soap and warm water for 20 seconds:
  ○ Before preparing or eating food
  ○ After preparing raw poultry, meat, fish, or seafood
  ○ After handling garbage
• Thoroughly rinse fresh fruits and vegetables. Never use bleach or detergent to wash produce.
  ○ To properly wash produce, run under warm tap water and scrub skin with a clean vegetable brush.
  ○ Even if you plan to peel a fruit or vegetable, wash the skin and rind before cutting or peeling (for example, bananas, oranges, melons, and avocados).
• Separate and thoroughly wash all salad greens. Re-wash all produce even if it’s “pre-washed”.
• Thaw foods by using one of the following methods:
  ○ Put the food item in the refrigerator 1 day before cooking.
  ○ Use the defrost setting on a microwave. Cook right away.
• Keep your refrigerator at a temperature of 33°F to 40°F (0.6°C to 4.4°C). Keep your freezer at a temperature of 0°F (-17.8°C) or below.
• Don’t eat hamburgers and other meat products if the meat looks undercooked. Cook the meat until it’s grey and the juices run clear.
• Cook fish until it flakes and shellfish until it’s cooked-through and opaque.
• Cook egg whites and yolks until they’re firm.
• Use a food thermometer to check that all foods are cooked to the minimum
internal temperatures listed in the chart below. Check the temperature at the center of the thickest part of the food.

- Don’t share food with other people.
- Always remember: when in doubt, throw it out!

<table>
<thead>
<tr>
<th>Food</th>
<th>Safe Minimum Internal Temperatures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Egg and Egg Dishes</strong></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>Cook until yolk and white are firm</td>
</tr>
<tr>
<td>Egg dishes</td>
<td>160° F (71° C)</td>
</tr>
<tr>
<td>Egg sauces</td>
<td>160° F (71° C)</td>
</tr>
<tr>
<td><strong>Ground Meat and Meat Mixtures</strong></td>
<td></td>
</tr>
<tr>
<td>Turkey and chicken</td>
<td>165° F (74° C)</td>
</tr>
<tr>
<td>Beef, hamburgers, veal, lamb, and pork</td>
<td>160° F (71° C)</td>
</tr>
<tr>
<td><strong>Fresh Beef, Veal, and Lamb</strong></td>
<td></td>
</tr>
<tr>
<td>Well done</td>
<td>170° F (77° C)</td>
</tr>
<tr>
<td><strong>Fresh Pork</strong></td>
<td></td>
</tr>
<tr>
<td>Well done</td>
<td>170° F (77° C)</td>
</tr>
<tr>
<td><strong>Ham</strong></td>
<td></td>
</tr>
<tr>
<td>Raw or fresh</td>
<td>160° F (71° C)</td>
</tr>
<tr>
<td>Precooked, cured ham</td>
<td>140° F (60° C)</td>
</tr>
<tr>
<td><strong>Poultry</strong></td>
<td></td>
</tr>
<tr>
<td>All products</td>
<td>165° F (74° C)</td>
</tr>
<tr>
<td><strong>Seafood (Fish and Shellfish)</strong></td>
<td></td>
</tr>
<tr>
<td>All (raw or fresh)</td>
<td>145° F (63° C)</td>
</tr>
</tbody>
</table>
Eating leftovers

- Refrigerate leftovers in shallow containers right after eating.
- Reheat the following leftovers to an internal temperature of at least 165°F (74° C) for at least 15 seconds:
  - Poultry
  - Stuffed meat, poultry, or fish
  - Ground meat
  - Pork, beef, veal, and lamb
  - Hard-boiled eggs
- When reheating leftovers in the microwave, stir, cover, and rotate the food so that it heats evenly.
- Sauces, soups, and gravies should be reheated by bringing them to a boil.
- Be sure to let the food cool so you don’t burn your mouth.
- Eat reheated leftovers within 1 hour of reheating.
- Don’t eat leftovers more than 2 days old.
- Don’t eat any food that has already been reheated once.

What to Eat on a Low-Microbial Diet

Breads, Grains, and Cereals

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>- All breads, rolls, bagels, English muffins,</td>
<td>- Undercooked or raw brewer’s yeast</td>
</tr>
<tr>
<td>waffles, French toast, muffins, pancakes,</td>
<td></td>
</tr>
<tr>
<td>and sweet rolls</td>
<td></td>
</tr>
<tr>
<td>- Potato chips, corn chips, tortilla chips,</td>
<td></td>
</tr>
<tr>
<td>popcorn, and pretzels</td>
<td></td>
</tr>
<tr>
<td>- Any cooked or ready-to-eat cereal purchased</td>
<td></td>
</tr>
<tr>
<td>prepackaged from a store</td>
<td></td>
</tr>
<tr>
<td>- Rice, pasta, and other cooked grains</td>
<td></td>
</tr>
</tbody>
</table>
## Milk and Dairy Products

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>All <strong>pasteurized</strong> dairy products, including:</td>
<td>All <strong>unpasteurized</strong> dairy products, including:</td>
</tr>
<tr>
<td>• Commercially available milk and milk products (such as sour cream and whipped cream)</td>
<td>• Raw milk</td>
</tr>
<tr>
<td>• Yogurts, including those made with live cultures (such as Dannon®, Chobani®, and Stonyfield®)</td>
<td>• Homemade eggnog and yogurt</td>
</tr>
<tr>
<td>• Processed pre-packaged cheese slices and spreads, cream cheese, cottage cheese, and ricotta cheese</td>
<td>• Cheese made from <strong>unpasteurized</strong> milk, often including soft cheeses such as Brie, farmer's cheese, Camembert, Mexican-style cheese (such as queso blanco and queso fresco), goat cheese, and some mozzarella cheese. These are okay to eat if cooked until melted.</td>
</tr>
<tr>
<td>• Commercially packaged pasteurized cheese such as American, cheddar, mozzarella, Monterey jack, Swiss, and Parmesan</td>
<td>• Mold-ripened cheeses such as Roquefort, Stilton, Gorgonzola, and blue cheese</td>
</tr>
<tr>
<td>• Soft cheeses clearly labeled as “made from pasteurized milk,” including goat and feta</td>
<td>• Avoid eating the rind on cheeses, as it often contains mold (such as Brie)</td>
</tr>
<tr>
<td>• Prepackaged ice cream, frozen yogurt, sherbet, popsicles, ice cream bars, puddings, and fresh homemade milkshakes</td>
<td>Other dairy products:</td>
</tr>
<tr>
<td>• Commercially sterile, ready-to-feed, and liquid concentrate infant formulas</td>
<td>• Soft serve ice cream or yogurt</td>
</tr>
</tbody>
</table>

### Eggs

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Well-cooked eggs (firm white and yolk) and pasteurized egg products (such as Egg Beaters®, powdered eggs, or liquid egg whites)</td>
<td>• Undercooked unpasteurized eggs and egg products</td>
</tr>
<tr>
<td>• Pasteurized eggs, like those served at MSK, may be eaten runny. One example is Davidson’s Safest Choice® Pasteurized Eggs, which are stamped with a red P. To see if they’re sold in your area, use the store locator at <a href="http://www.safeeggs.com/store-locator">www.safeeggs.com/store-locator</a></td>
<td>• Raw eggs and foods containing raw eggs (such as homemade Caesar dressing, freshly made mayonnaise and aioli, and raw cookie dough)</td>
</tr>
</tbody>
</table>
## Meat, Meat Substitutes, Poultry, and Seafood

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Well-cooked meat and poultry (such as pork, beef, lamb, chicken, and turkey)</td>
<td>• Undercooked or raw meats, poultry, and fish, including rare or medium-rare items</td>
</tr>
<tr>
<td>• Thoroughly cooked fish and seafood (such as salmon, tilapia, cod, shrimp, lobster, crab, and canned tuna or salmon). Take extra caution with shellfish that’s in the shell (such as lobster) and be sure to cook it fully through until it’s opaque.</td>
<td>• Uncooked or raw tempeh, miso products, and tofu</td>
</tr>
<tr>
<td>• Cooked tofu or pasteurized or shelf-stable tofu</td>
<td>• Freshly sliced deli meats and meats from street vendors</td>
</tr>
<tr>
<td>• Cooked fermented products, including miso and tempeh</td>
<td>• Raw or partially cooked fish and shellfish, including caviar, sashimi, sushi, and ceviche (“lemon-cooked” or cured fish)</td>
</tr>
<tr>
<td>• Commercially prepared hot dogs and pre-sliced deli meats sold in a sealed package (such as salami, bologna, ham, and turkey) that are cooked until steaming hot. Throw away extras within 48 hours of opening.</td>
<td>• Raw or cooked clams, mussels, and oysters</td>
</tr>
<tr>
<td>• Well-cooked bacon and sausage</td>
<td>• Smoked seafood, such as salmon or trout labeled as “Nova style,” “lox,” “kippered,” “smoked,” or “jerky” (unless cooked to 160° F or contained in a cooked dish or casserole)</td>
</tr>
<tr>
<td>• Canned meats and commercially packaged beef or turkey jerky</td>
<td>• Refrigerated pâtés and meat spreads</td>
</tr>
<tr>
<td>• Canned and shelf-stable smoked fish</td>
<td>• Hard-cured salami in natural wrap</td>
</tr>
</tbody>
</table>

## Fruits and Vegetables

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Well-washed raw fruits and vegetables without cuts, bruises, or mold. Examples include apples, pears, peaches, peppers, salad greens, carrots, cucumbers, and tomatoes.</td>
<td>• Unwashed raw or frozen fruits, vegetables, and herbs</td>
</tr>
<tr>
<td>• Well-washed and peeled thick-skinned fruits and vegetables. Examples include citrus fruits, bananas, avocados, mangos, and melons.</td>
<td>• Any raw or frozen “rough-textured” fruits and vegetables that can’t be thoroughly washed (such as strawberries, raspberries, blackberries, broccoli, and cauliflower). These are okay if cooked.</td>
</tr>
<tr>
<td>• Cooked and canned fruits and vegetables</td>
<td>• Pre-cut fresh fruits and vegetables (such as pre-cut melon)</td>
</tr>
<tr>
<td>• Well-washed frozen fruits and vegetables</td>
<td>• Unpasteurized and fresh-squeezed fruit and vegetable juices (unless prepared at home)</td>
</tr>
<tr>
<td>• Pasteurized juices and frozen concentrates</td>
<td>• Fresh fruit or vegetable salsa found in the grocery refrigerator case</td>
</tr>
<tr>
<td>• Commercially packed dried fruits</td>
<td>• Vegetarian sushi, unless it’s homemade,</td>
</tr>
<tr>
<td>• Shelf-stable bottled salsa (refrigerate after opening)</td>
<td></td>
</tr>
</tbody>
</table>
• Fresh, well-washed herbs
• Dried herbs and spices

because it may be prepared near raw fish
• All uncooked vegetable sprouts (alfalfa, bean, clover, and all others)
• Salads from delis or salad bars

Drinks

<table>
<thead>
<tr>
<th>What to drink</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Tap water and ice, if your water is from a city water supply or a municipal well serving a highly populated area</td>
<td>• Unpasteurized eggnog, apple cider and other unpasteurized fruit or vegetables juices</td>
</tr>
<tr>
<td>• Water from private wells or small community wells only if the well is tested daily for bacteria. If the well isn’t tested daily, boil the water before using it.</td>
<td>• Unpasteurized beer (such as microbrewery beers and those that aren’t shelf-stable) and wine. Talk with your doctor before consuming any alcoholic beverages.</td>
</tr>
<tr>
<td>• Commercially bottled distilled, spring, and natural waters</td>
<td>• Fountain soda and other fountain beverages</td>
</tr>
<tr>
<td>• Pasteurized fruit and vegetable juices</td>
<td>• Tea made with loose leaves, cold brewed tea, sun-tea, kombucha, and mate tea</td>
</tr>
<tr>
<td>• Bottled, canned, or powdered beverages</td>
<td>• Iced or cold brewed coffee or tea from restaurants or coffee shops</td>
</tr>
<tr>
<td>• Hot coffee</td>
<td></td>
</tr>
<tr>
<td>• Hot teas using commercially packaged tea bags</td>
<td></td>
</tr>
<tr>
<td>• Homemade iced tea and iced coffee made from hot brewed (boiling) tea or coffee, as long as you store it in the refrigerator and drink it within 2 days</td>
<td></td>
</tr>
<tr>
<td>• Pasteurized soy milk and other non-dairy milks (such as almond, rice, and coconut milk)</td>
<td></td>
</tr>
<tr>
<td>• Commercially made liquid nutritional supplements (such as Ensure® and Boost®)</td>
<td></td>
</tr>
</tbody>
</table>

Nuts

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Factory-packaged roasted nuts</td>
<td>• All nuts that are sold open and in bulk, as in some health food or specialty stores</td>
</tr>
<tr>
<td>• Factory-packaged raw almonds or hazelnuts (required by law to be pasteurized), or other raw nuts labeled as “pasteurized”</td>
<td>• Unpasteurized raw nuts</td>
</tr>
<tr>
<td>• Nuts in baked goods</td>
<td>• Roasted nuts in the shell (such as pistachios or peanuts in the shell)</td>
</tr>
<tr>
<td>• Commercially packaged nut butters (such</td>
<td>• Freshly ground peanut butter or nut butters (not commercially packaged)</td>
</tr>
</tbody>
</table>
**Condiments and Miscellaneous**

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salt and sugar</td>
<td>Raw or unpasteurized honey and honeycomb</td>
</tr>
<tr>
<td>Jellies, syrup, and jams (refrigerate after opening)</td>
<td>Whole or fresh ground black pepper served tableside at restaurants</td>
</tr>
<tr>
<td>Pasteurized or flash pasteurized honey</td>
<td>Shared condiment containers at restaurants (ask for individual packets)</td>
</tr>
<tr>
<td>Packaged ground black pepper, herbs, and spices</td>
<td>Fresh salad dressings (stored in grocer’s refrigerated case) containing raw eggs or cheeses, such as Caesar salad dressing</td>
</tr>
<tr>
<td>Ketchup, mustard, BBQ sauce, and soy sauce, (refrigerate after opening)</td>
<td>Herbal and nutritional supplement preparations</td>
</tr>
<tr>
<td>Pickles, pickle relish, and olives (refrigerate after opening)</td>
<td></td>
</tr>
<tr>
<td>Vinegar</td>
<td></td>
</tr>
<tr>
<td>Vegetable oils and shortening</td>
<td></td>
</tr>
<tr>
<td>Refrigerated margarine and butter</td>
<td></td>
</tr>
<tr>
<td>Commercially made, shelf-stable mayonnaise and salad dressings, including Caesar, blue cheese, and other cheese-based salad dressings (refrigerate after opening)</td>
<td></td>
</tr>
<tr>
<td>Cooked gravy and sauces</td>
<td></td>
</tr>
</tbody>
</table>

**Desserts**

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refrigerated, commercially made, and homemade cakes, pies, pastries, and pudding</td>
<td>Unrefrigerated, cream-filled pastry products (not shelf stable)</td>
</tr>
<tr>
<td>Refrigerated cream-filled pastries</td>
<td>Soft serve ice cream and frozen yogurt</td>
</tr>
<tr>
<td>Cookies, both homemade and commercially prepared</td>
<td>Ice cream scooped at a restaurant</td>
</tr>
<tr>
<td>Shelf-stable, cream-filled cupcakes and fruit pies</td>
<td></td>
</tr>
<tr>
<td>Packaged ice cream and frozen yogurt from the grocery store</td>
<td></td>
</tr>
<tr>
<td>Candy and gum</td>
<td></td>
</tr>
</tbody>
</table>
## Eating Outside the Home and Take-Out

<table>
<thead>
<tr>
<th>What to eat</th>
<th>What to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>● All foods recommended in previous food groups must come directly off the grill or stove and not be served on steam tables or stored under heat lamps. Examples of foods that are safe to eat include freshly made pizza (not sliced or reheated); hamburger directly off a grill; just-cooked French fries; and whole, just-cooked rotisserie chicken moved directly from rotisserie to package by a gloved employee.</td>
<td>● Any food that isn’t freshly made to order</td>
</tr>
<tr>
<td>● Single-serving condiment packages (no pump serve containers)</td>
<td>● Unpasteurized fruit juices and dairy products (such as juices ordered from a juice bar)</td>
</tr>
<tr>
<td>● Hot black coffee or hot tea from a coffee shop, without mixing by staff or using shared, un-refrigerated milk containers.</td>
<td>● Raw fruits and vegetables and desserts with fresh fruit</td>
</tr>
<tr>
<td></td>
<td>● Deli meats and cheeses sliced at the deli counter</td>
</tr>
<tr>
<td></td>
<td>● Salad bars, buffets, smorgasbords, potlucks</td>
</tr>
<tr>
<td></td>
<td>● Sidewalk vendors</td>
</tr>
<tr>
<td></td>
<td>● Soft serve ice cream and yogurt</td>
</tr>
<tr>
<td></td>
<td>● Fast food (such as McDonalds® and Subway®)</td>
</tr>
<tr>
<td></td>
<td>● Reheated foods</td>
</tr>
</tbody>
</table>

## Eating out at restaurants

You can eat out while on a low-microbial diet **unless you had a stem cell transplant.** If you had a stem cell transplant, see the “Guidelines for people who had a bone marrow or stem cell transplant” section below.

It’s important to choose the restaurant carefully. Local health departments inspect restaurants to make sure that they’re clean, and that they follow safe food practices. You can find out how your local restaurants did on a recent health inspection by going to your local Department of Health (DOH) website. To find out about restaurants in New York City, go to the following website: [www1.nyc.gov/site/doh/services/restaurant-grades.page](http://www1.nyc.gov/site/doh/services/restaurant-grades.page)

You can also ask your local restaurants about their food safety training rules. When you go out to eat, follow the guidelines below.

- Order all foods to be fully cooked and meats to be well done.
- Don’t order foods that may have raw eggs (such as Caesar salad dressing, fresh mayonnaise or aioli, and hollandaise sauce).
- Ask the wait staff if you aren’t sure of the ingredients in your meal.
- Don’t eat foods from buffets and salad bars.
• Ask that your foods be cooked fresh and not served from steam tables or stored under heat lamps.

• Ask for single-serving condiments, such as ketchup and mustard packets. Open containers may be used by many customers.

• Don’t eat soft serve ice cream and soft serve frozen yogurt. The dispensers may contain bacteria if they’re not cleaned often.

• Always order a whole or personal pizza. Don’t order individual slices, since they’re often stored under heat lamps.

Guidelines for people who had a bone marrow or stem cell transplant

People who had an allogeneic or autologous stem cell transplant shouldn’t eat out at restaurants for the first 100 days after their transplant. Please speak to someone on your healthcare team if you have any questions or concerns about eating out before or after the 100-day period.

Avoid supplements

Don’t take supplements, homeopathic remedies, or herbal products (such as St. John’s wart, traditional Chinese medicines) unless discussed with your MSK medical team. Because there are no federal standards for these products in the United States, the way they’re processed and stored may pose a health risk. Microbes in these items can also cause an infection. Also, the products themselves could interfere with or change the activity of a prescription medication.

Safe drinking water

Never drink from lakes, rivers, streams, springs, or wells.

If you’re unsure if the tap water is safe, check with the local health department or boil or filter the water. Drink bottled water if you think the tap water may not be safe. Note that most water filtration devices will not make the water safe if the water supply hasn’t been chlorinated.

If you use well water that isn’t tested daily for bacteria, you must boil it. Bring the water to a rolling boil for 15 to 20 minutes. Store boiled water in the refrigerator. Throw away any boiled water that you don’t use within 48 hours.
Resources

Use the resources below to find additional information about preventing foodborne illness and the safe handling, storage, and preparation of food.

Government websites with information and news about foodborne illnesses, recalls, and regulations:

- **United States Department of Agriculture (USDA) Food Safety and Inspection Service**
  www.fsis.usda.gov

- **U.S. Department of Health & Human Services Food Safety Information**
  www.foodsafety.gov

- **U.S. Food & Drug Administration (FDA)**
  www.fda.gov/ForConsumers/default.htm

- **Centers for Disease Control and Prevention Food Safety**
  www.cdc.gov/foodsafty/

**Fight BAC! Partnership for Food Safety Education**
A website with practical tips about how to keep food safe.
www.fightbac.org

**USDA “Ask Karen”**
A web-based question and answer system that allows visitors to read previously asked questions and submit new questions about foodborne illnesses and safe food handling, storage, and preparation.
www.fsis.usda.gov/wps/portal/informational/askkaren

**NYC Department of Health and Mental Hygiene Restaurant Inspection Information**
A website where you can search for New York City restaurant inspection results and grades.
www1.nyc.gov/site/doh/services/restaurant-grades.page
The Safe Food Information Line
Call this number to contact the U.S. FDA by phone.
888-723-3366

Nutrition services at MSK
Call this number to schedule an appointment with one of MSK’s registered dietitians or nutritionists.
212-639-7312

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at _________________________. After 5:00 PM, during the weekend, and on holidays, please call_____________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Low-Microbial Diet
©2017 Memorial Sloan Kettering Cancer Center - Generated on October 15, 2017
# Mail-in Order Form

Mail form with payment to MedicAlert, PO Box 21009, Lansing, MI 48909

## INFO FOR PERSON WEARING THE ID

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td>FULL NAME</td>
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<tr>
<td>DATE OF BIRTH</td>
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<td>GENDER</td>
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<td>PRIMARY ADDRESS</td>
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<td>UNIT/APT #</td>
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<td>CITY</td>
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<td>STATE</td>
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<td>ZIP</td>
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<td>PHONE NUMBER</td>
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<td>Cell</td>
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<td>Work</td>
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## SELECT YOUR MEDICAL ID

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## SELECT AN ADD-ON SERVICE

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<tbody>
<tr>
<td>ADD-ON SERVICE</td>
<td>PRICE</td>
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</table>

## ENGRAVING YOU WOULD LIKE

Engraving character limits vary. List most important items first.

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<th>Details</th>
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<td>LINE 3</td>
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<tr>
<td>LINE 4</td>
<td></td>
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</tbody>
</table>

Go online or call after enrollment to complete health and emergency contact information.

## CALCULATE PAYMENT

<table>
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<tr>
<td>ID PRICE</td>
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<tr>
<td>ADD-ON PRICE</td>
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<tr>
<td>SHIPPING &amp; HANDLING</td>
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<td>$7.00</td>
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<td>TOTAL</td>
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## PAYMENT INFORMATION

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<td>Discover</td>
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<tr>
<td>CREDIT CARD NUMBER</td>
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<td>EXP DATE (MM/YY)</td>
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<tr>
<td>CREDIT CARD HOLDER’S NAME</td>
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<tr>
<td>CREDIT CARD HOLDER’S BILLING ADDRESS</td>
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<tr>
<td>SIGNATURE FOR CARD AUTHORIZATION</td>
<td></td>
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</tbody>
</table>

## SIGNATURE OF MEMBER

By signing above you agree to our terms & conditions as shown online at www.medicalert.org/consent. A parent or guardian signature is required for members under 18.
My MedicAlert Services

When purchasing a MedicAlert medical ID you receive a suite of services designed to protect you in the event of an emergency. These services are connected to your medical ID for one-year.

Select from our three optional add-on services:

24/7 Emergency Response
First responders and medical professionals are trained to recognize MedicAlert IDs and call our 24/7 Emergency Response Center. We immediately connect them to your medical history, ensuring you receive quick treatment and proper medical care.

24/7 Family Notification
We will communicate with your loved ones to inform them of your emergency and location, ensuring you are quickly reunited with family/friends.

Emergency Health Record
We provide an electronic Emergency Health Record that you can maintain and access from anywhere, at any time. The information from your health record is communicated to first responders and health professionals during an emergency to speed your treatment and ensure quality care.

Physician Notification
We will contact your physician to notify them of your emergency. This service allows for your physician to communicate directly with the treating facility to understand your situation and the type of treatment provided; allowing for exceptional follow up care.

Contact Center Support
We provide live customer support agents to assist you with medical information updates, service upgrades, engraving recommendations, and medical ID purchases. Support is available Mon-Fri (6AM – 5PM PST).

Global Services
Our dedication to safeguarding your health in the event of an emergency expands beyond our borders into more than 50 countries, and translation services are available in 140 languages.

Advantage

PRICE: $29.99 for 1 year
Our première service plan which provides comprehensive protection. In additional to the My MedicAlert services, Advantage customers receive medical document storage and exclusive discounts. *Advantage service required if purchasing medical ID for DNR purposes.*

KID SMART

PRICE: $19.99 for 1 year
Our première service plan for kids (age 18 and under) which provides comprehensive protection. In additional to the My MedicAlert services, Kid Smart customers receive medical document storage and exclusive discounts.

PRICE: $26.99 for 1 year
In partnership with the Alzheimer’s Association, we have created this specialized program to provide 24/7 wandering protection and emergency response services for individuals living with Alzheimer’s or other related dementias who are at risk for wandering and becoming lost.
**CHAIN BRACELETS**

**CLASSIC STEEL WITH COLOR** - $27.99
- Red
- White
- Blue
- Black
- Green
- Pink
- Orange
- Purple
- Light Blue

Sizes available: 4” - 10” in ½” increments

**CLASSIC**
- Steel X-Sm ID - $27.99
- Steel Sm ID - $37.99
- Steel Lg ID - $39.99
- 10K Gold Sm ID - $169.99
- 10K Gold Lg ID - $189.99
- Sterling Silver Sm ID - $89.99
- Sterling Silver Lg ID - $99.99

Sizes available: 4” - 10” in ½” increments

**CLASSIC CONTRAST**
- Sm ID - $47.99
- Lg ID - $49.99

Sizes available: 4” - 10” in ½” increments

**STANDARD** - $34.99
- Option 1
- Option 2
- Option 3

Sizes available: 4” - 10” in ½” increments

**LINKING HEARTS** - $44.99

Sizes available: 4” - 10” in ½” increments

**INTREPID TITANIUM**
- Sm Red - $49.99
- Sm Black - $49.99
- Lg Red - $59.99
- Lg Black - $59.99

Sizes available: 6.5-7” (for Sm only), 7.5-8”, 8.5-9” (for Lg only)

**SWEETHEART** - $27.99

Sizes available: 4” - 10” in ½” increments

**NOTE:** This ID has limited engraving space

**STERLING SILVER SWEETHEART** - $89.99

Sizes available: 4” - 10” in ½” increments

**NOTE:** This ID has limited engraving space

**SPECIAL STERLING SILVER BAR**
- Sm - $99.99
- Lg - $149.99

Sizes available: 4” - 10” in ½” increments

**EXECUTIVE STERLING SILVER BAR**
- Sm - $129.99
- Lg - $149.99

Sizes available: 4” - 10” in ½” increments

**SANTA ROSA ELITE STERLING SILVER**
- Sm - $99.99
- Lg - $119.99

Sizes available: 4” - 10” in ½” increments

**CABLE CHOICE STERLING SILVER** - $159.99

Sizes available: 4” - 10” in ½” increments

**BEADED BRACELETS**

**CRYSTAL** - $79.99
- Iridescent
- Rose
- Amethyst
- Onyx
- Green
- Blue

**Sizes available:** 7”, 8”

**SPARKLE EMBOSSED** - $44.99
- Orange
- Pink
- Blue
- Black
- Red

**Sizes available:** 6”, 7”, 8”

**SPARKLE** - $37.99
- Orange
- Pink
- Blue
- Black
- Red

**Sizes available:** 6”, 7”, 8”

**STRETCH BANDS**

**EMBOSSED**
- Sm Steel - $37.99
- Lg Steel - $39.99
- Sm Gold Tone - $47.99
- Lg Gold Tone - $49.99

**Sizes available:** 5-6”, 6.5-7.5”, 8-9”

**CLASSIC CONTRAST**
- Sm - $47.99
- Lg - $49.99

**Sizes available:** 5-6”, 6.5-7.5”, 8-9”

**CHARM BRACELETS**

**SWEETHEART CHARM** - $27.99

Sizes available: 4” - 10” in ½” increments

**NOTE:** This ID has limited engraving space

**CLASSIC**
- Sterling Silver - $89.99
- 10K Gold - $159.99

**Sizes available:** 4” - 10” in ½” increments

**NOTE:** This ID has limited engraving space

**CABLE CHAIN WITH TOGGLE** - $159.99

Sizes available: 4” - 10” in ½” increments

**NOTE:** This ID has limited engraving space
### Necklaces

- **Compete** - $34.99
  - Red
  - Black
  - White
  - Yellow
  - Violet
  - Green
  - Purple
  One-size fits most. Trim to correct size.

- **Play** - $24.99
  - Red
  - Black
  - White
  - Yellow
  - Violet
  - Green
  Sizes available: 6”, 6.75”, 7.5”

- **Reflective** - $34.99
  - Black
  - Pink
  - Yellow
  - Blue
  Sizes available: Small=5”-6”, Medium=6.5”-8”

- **Classic Adult** - $34.99
  - Black
  - Blue
  - Purple
  - Red
  - Navy Blue
  - Orange
  Sizes available: Small=5”-6.5”, Medium=6.5”-8”, Large=8”-9.5”

- **Classic Kid** - $34.99
  - Black
  - Pink
  - Yellow
  - Blue
  - Navy Blue
  - Red
  Sizes available: Small=4”-5”, Medium=5”-6”, Large=6”-7.5”

- **Vibrant** - $29.99
  - Black
  - Pink
  - Blue
  - Orange
  - Purple
  Sizes available: 5.5”, 6”, 6.5”, 7”, 7.5”, 8”, 8.5”

- **Two-Tone** - $34.99
  - Grey/Black
  - Red/Black
  - Blue/Black
  Sizes available: Sm.=5”-5.75”, Med.=6”-6.75”, Lg.=7.25”-8”

- **Sweetheart** - $34.99
  - Steel on 26” or 30” curb chain

- **Sterling Silver French Elite Teardrop** - $109.99
  - Comes on a 24” sterling silver french rope chain.

- **Sterling Silver Box Elite** - $119.99
  - Comes on a 24” sterling silver rope edge chain.

### Sports Bands

- **Silicone Bands**

- **Compete** - $34.99
  - Red
  - Black
  - White
  - Yellow
  - Violet
  - Green
  - Purple

- **Play** - $24.99
  - Red
  - Black
  - White
  - Yellow
  - Violet
  - Green

- **Reflective** - $34.99
  - Black
  - Pink
  - Yellow
  - Blue

- **Classic Adult** - $34.99
  - Black
  - Blue
  - Purple
  - Red
  - Navy Blue
  - Orange

- **Classic Kid** - $34.99
  - Black
  - Pink
  - Yellow
  - Blue
  - Navy Blue
  - Red

### Paracord Bracelets

- **Vibrant** - $29.99
  - Black
  - Pink
  - Blue
  - Orange
  - Purple
  Sizes available: 5.5”, 6”, 6.5”, 7”, 7.5”, 8”, 8.5”

- **Two-Tone** - $34.99
  - Grey/Black
  - Red/Black
  - Blue/Black
  Sizes available: Sm.=5”-5.75”, Med.=6”-6.75”, Lg.=7.25”-8”

### Dog Tags

- **Stainless Steel** - $24.99
  - Black
  - Steel
  - Comes on a 30” beaded chain.

- **Aluminum** - $29.99
  - Blue
  - Red
  - Green
  - Pink
  - Comes on a 30” beaded chain.

- **Titanium** - $59.99
  - Black
  - Red
  - Comes on a 28” chain.
Outpatient BMT
Temperature & Intake Log

Use this form to keep track of your temperature and how much you drink. Bring it to all appointments. We will give you a new form each week.

Take your temperature every 4 hours while you’re awake and write it in the chart below.

<table>
<thead>
<tr>
<th>Date</th>
<th>4 AM</th>
<th>8 AM</th>
<th>Noon</th>
<th>4 PM</th>
<th>8 PM</th>
<th>Midnight</th>
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<tbody>
<tr>
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</table>

Call your doctor or nurse practitioner if your temperature is 100.4°F (38°C) or higher.

If you feel a chill, take your temperature, and then call your doctor or nurse practitioner.

8:00 AM to 8:00 PM - 212-639-3122

8:00 PM to 8:00 AM - 212-639-2000 and ask for the doctor covering bone marrow transplant

Measure all the liquids you drink. Write the type and amount in the chart below.

Your goal is to drink 2 liters (64 ounces) every day.

8 ounces = 1 cup

<table>
<thead>
<tr>
<th>Fluid Intake</th>
<th>Type</th>
<th>Ounces</th>
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<table>
<thead>
<tr>
<th>Date</th>
<th>mm/dd</th>
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</table>
Sexual Activity During Cancer Treatment: Information for Men

This information provides guidance for men on sexual activity during cancer treatment.

Most men can be sexually active throughout their cancer treatment, but it’s important to do so safely. If you have any questions about the information below, speak with your doctor or nurse. If you have any concerns about how to follow these suggestions based on your religious observances, we advise you to speak with your religious leader.

Use Birth Control to Prevent Pregnancy

It’s important to prevent pregnancy while you’re getting cancer treatment. If you become pregnant with an egg that has been damaged by exposure to radiation, chemotherapy, or other anticancer medications, or if an embryo or fetus is exposed to these treatments during its development, you may have an increased risk for miscarriage or birth defects.

If your partner is a female who could become pregnant, use birth control (contraception) throughout your cancer treatment. Don’t rely on withdrawing before ejaculation (“pulling out”) or on avoiding sex during fertile times of her menstrual cycle (the “rhythm method”). These methods are not effective in preventing pregnancy.

Types of birth control

- If you have only 1 female partner, you could use condoms. You could also ask your partner to see the healthcare provider (HCP) who manages her gynecologic care to help her select a method of birth control that is best for her. Examples include birth control pills and intrauterine devices (IUDs).
- If your partner chooses not to use birth control, or if you have more than 1
partner, use a condom each time you have sex. Condoms not only prevent pregnancy, but they also protect you from sexually transmitted infections (STIs), including HIV. See the section “Barrier Devices” for information on buying and using condoms.

- A vasectomy is a permanent method of birth control for people who are sure that they don’t want any (more) children. This is a minor surgery that is done to block sperm from being released with your semen.

Other considerations

Continue to use birth control for a period after your treatment ends in order to prevent pregnancy.

- If you’re getting chemotherapy or radiation directed to an area near your testes, continue to use birth control for at least 1 year after your treatment ends. This allows time for damaged sperm to clear from your body.

- If you’re getting targeted or immunotherapy, the amount of time you should use birth control will vary based on the medication you’re taking. Ask your doctor or nurse how long you should continue to use birth control after treatment.

If you plan to have children after treatment, ask your doctor when it will be safe for you to start trying.

Some cancer treatments may affect your fertility (the ability to have a biological child). If you have questions about this, ask your doctor or nurse.

Protect Yourself from Infection

If you or your partner have sex with multiple partners, and you don’t use barrier protection (see the section “Barrier Devices”), you’re at risk for sexually transmitted infections (STIs), including HIV, if you do not use barrier protection. In addition, certain cancer treatments can cause low blood cell counts for long periods of time which may increase your risk of infection. Your doctor or nurse will tell you if this is a concern for you.

To prevent infection:

- Wash your hands and genitals before and after having vaginal, oral, or anal
To protect yourself from STIs (including HIV), consider using a condom each time you have vaginal, oral, or anal sex throughout your treatment.

If you use sex toys, wash them with hot soapy water every time you use them.

If you are expected to have very low blood cell counts for a long period of time, your doctor or nurse may recommend that you use a barrier device during sex, such as condoms or dental dams. See the section “Barrier Devices” for more information.

- In some situations, your doctor may recommend for you to avoid sex that involves penetration or contact with mucous membranes while your blood counts are low. This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or sex toys into your anus.

- Hugging, cuddling, gentle touching, and kissing skin are other ways you can be intimate with your partner during this time.

Some men develop yeast infections under the foreskin of the penis during treatment, especially if they’re taking steroids or antibiotics. Symptoms include itching, irritation, and discharge from the penis. If you suspect you have a yeast infection, avoid sex and call your doctor or nurse.

If you had stem cell transplant, you are at an increased risk of infection for many months after your treatment. Until your doctor tells you that your immune system has recovered:

- Use a latex condom each time you have vaginal, oral, or anal sex.

- Use a condoms or dental dam any time your partner’s saliva, vaginal secretions, or semen could enter your mouth. See the section “Barrier Devices” for more information.

- Do not perform any sexual activity that could expose your mouth to feces.

Consider Steps to Avoid Exposing Your Partner to Chemotherapy and Other Anticancer Medications
We don’t know how much anticancer medication gets into a man’s semen or if this poses any risk to a sexual partner. If this is a concern for you or your partner, you may want to use a condom whenever your semen could enter your partner’s vagina, mouth, or anus. This will prevent your partner, regardless age or sex, from being exposed to any medication that may be in your semen.

We don’t know how long these medications may be in semen, but you could use a condom each day you receive anticancer treatment and for 1 week afterward.

Make sure to use condoms throughout treatment if needed for birth control or to protect yourself from infection. See the section “Barrier Devices” for more information.

If your partner is pregnant during your treatment, we don’t know if the medications in your semen would pose any risk to the fetus. Scientific studies on animals suggest this is possible, so we recommend using a condom each time you have sex. See the section “Barrier Devices” for more information.

**Barrier Devices**

**Condoms**

- You can buy condoms at any drug store. We recommend latex condoms, but if you or your partner is allergic to latex, use polyurethane condoms.
- Spermicides do not provide any added protection.
- You can use lubricated condoms or use a separate water- or silicone-based lubricant.
- Before you use a condom, check the expiration date on the wrapper. Expired condoms are more likely to break.
- To use a condom correctly:
  1. Be careful when opening and handling the condom. Don’t use your teeth, scissors, or other sharp objects to open the wrapper. Don’t use the condom if it is torn, brittle, or stiff.
  2. Wait until your penis becomes firm before putting on the condom.
  3. While pinching the tip of the condom, unroll it over your penis as far as it
will go. The extra space at the tip is needed to collect your semen.

4. Smooth out any air bubbles because they can cause the condom to break.

5. After you have ejaculated, but before your penis becomes soft, hold the base of the condom (where the ring is) and carefully pull your penis out of your partner so that nothing spills.

6. Carefully slide off the condom and throw it in the trash.

A condom can tear if it’s too tight or it can fall off if it’s too loose. If this happens while you’re having vaginal sex, your female partner may want to consider taking emergency contraception if she isn’t using another form of birth control. Emergency contraception includes levonorgestrel (Plan B®), also known as the “morning-after pill.”

**Dental dams**

- A dental dam is a thin, rectangular sheet of latex or silicone that covers the genitals of a woman receiving oral sex.

- You can buy these online, get them from the New York City Department of Health and Mental Hygiene, or make one out of a condom.

- If you want to make a dental dam out of a condom, cut off the tip and cut down the side of the tube to make a sheet.
  - You may want to avoid condoms with a spermicide or lubricant, as the taste may be unpleasant.

- To use a dental dam, have your female partner hold the sheet over her vulva or anus while you are giving her oral sex.

**Resources**

**Memorial Sloan Kettering (MSK) Male Sexual and Reproductive Medicine Program**
646-888-6024
Call for help with issues related to male sexual function.

**American Cancer Society**
*Sex and the Man with Cancer*
www.cancer.org
Call 1-800-ACS-2345 to request printed material.

**American Congress of Obstetricians and Gynecologists**
www.acog.org/patients

**New York City Department of Health and Mental Hygiene**
www1.nyc.gov/nyc-resources/service/1428/condom-information
Has information on getting and using male and female condoms.

**Planned Parenthood**
www.plannedparenthood.org

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If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call______________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

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Sexual Activity During Cancer Treatment: Information for Men

©2017 Memorial Sloan Kettering Cancer Center - Generated on June 29, 2017
This information provides guidance for women on sexual activity during cancer treatment.

Most women can be sexually active throughout their cancer treatment, but it’s important to do so safely. If you have any questions about the information below, speak with your doctor or nurse. If you have any concerns about how to follow these suggestions based on your religious observances, we advise you to speak with your religious leader.

Use Birth Control to Prevent Pregnancy

It’s important to prevent pregnancy while you’re getting cancer treatment. If you become pregnant with an egg that has been damaged by exposure to radiation, chemotherapy, or other anticancer medications, or if an embryo or fetus is exposed to these treatments during its development, you may have an increased risk for miscarriage or birth defects. Becoming pregnant can also prevent you from receiving the best diagnostic tests and treatments for your cancer, as these may harm a fetus.

If there is any chance you could become pregnant, use birth control (contraception) throughout your cancer treatment. Don’t rely on your partner withdrawing before ejaculation (“pulling out”) or on avoiding sex during fertile times of your menstrual cycle (the “rhythm method”). These methods are not effective in preventing pregnancy.

It’s important to pick a birth control method that is effective and fits your lifestyle. Make an appointment with your healthcare provider (HCP), who manages your gynecologic care and speak with them about an option that’s best
for you.

No matter what method you choose, use your birth control as instructed or you may become pregnant. If you have any problems with your birth control, talk with your HCP to find another option.

**Types of birth control**

**Nonhormonal birth control**
The following forms of birth control don’t contain hormones and are safe for most women.

**Copper intrauterine device (IUD)**
A copper IUD is a small, T-shaped device your HCP places inside your uterus. It can stay in place for 10 years or it can be removed earlier. Copper IUDs may cause heavier blood flow during your monthly periods, so check with your oncologist (cancer doctor) to see if this is safe for you.

**Male condoms**
Male condoms can prevent pregnancy and protect you from sexually transmitted infections (STIs), including HIV. If this is your only form of birth control, have your partner use a condom each time you have vaginal sex. See the section “Barrier Devices” for information on buying and using condoms.

Female condoms are not effective in preventing pregnancy.

**Surgical sterilization**
Surgical sterilization is a permanent method of birth control for people who are sure that they don’t want any (more) children. One type of surgical sterilization is a tubal ligation (having your “tubes tied”) which permanently blocks your fallopian tubes. Another type is the placement of a device in your fallopian tubes to block them.

**Hormonal birth control**
These forms of birth control contain hormones, either a combination of estrogen and progestin, or progestin alone. Hormonal birth control is very effective in preventing pregnancy, but does not protect against STIs, including HIV.
Some medical conditions make it unsafe to use hormonal birth control, so they aren’t right for everyone. Women who shouldn’t take hormonal birth control include those with a hormone-sensitive tumor (such as certain kinds of breast cancer), a personal or family history of blood clots, a history of migraines with aura, impaired liver function, and those who are 35 years of age or older and smoke. There are other medical conditions that also make it unsafe to use hormonal birth control, so talk with your oncologist and HCP to see if hormonal birth control is right for you and which type is best.

There are several different kinds of hormonal birth control.

**Birth control pill**
These pills are taken once a day. Skipping a day or more may increase your chance of becoming pregnant.

**Injectable contraception (Depo-Provera ®)**
This is a shot your HCP gives you every 12 weeks.

**Implantarble contraception (Implanon ®, Explanon ®)**
This is a small rod your HCP implants under the skin of your arm. It can stay in place for 3 years or be removed earlier.

**Intrauterine device (LNG IUD, Mirena ®, Skyla ®)**
This is a small, T-shaped device your HCP places inside your uterus. It releases the hormone progestin. The Skyla® IUD can stay in place for 3 years and the Mirena® IUD can stay in place for 5 years, but they can be removed earlier.

**Other considerations**
Continue to use birth control for a period after your treatment ends in order to prevent pregnancy.

- If you’re getting chemotherapy or radiation directed to an area near your ovaries, continue to use birth control for at least 1 year after your treatment ends. This allows time for damaged eggs to clear from your body.
- If you’re getting targeted or immunotherapy, the amount of time you should use birth control will vary based on the medication you’re taking. Ask your doctor or nurse how long you should continue to use birth control.
If you plan to have children after your treatment, ask your doctor when it will be safe for you to start trying. Depending on your situation, your doctor may recommend you wait more or less time.

Some cancer treatments may affect your fertility (the ability to become pregnant with a biological child). If you have questions about this, ask your doctor or nurse.

**Protect Yourself from Infection**

If you or your partner have sex with multiple partners, and you don’t use barrier devices (see the section “Barrier Devices”), you’re at risk for STIs, including HIV. In addition, certain cancer treatments can cause low blood cell counts for long periods of time, which may increase your risk of infection. Your doctor or nurse will tell you if this is a concern for you.

To prevent infection:

- Wash your hands and genitals before and after having vaginal, oral, or anal sex.

- To protect yourself from STIs (including HIV), consider using a condom each time you have vaginal, oral, or anal sex throughout your treatment, even if you’re using another form of birth control.
  - Your partner can use a condom, or you can use a female condom. The female condom is a polyurethane pouch placed inside your vagina before sex. Don’t use a male and female condom at the same time. Female condoms are not an effective form of birth control, so you should not rely on them to prevent pregnancy.

- If you use sex toys, wash them with hot soapy water every time you use them.

- If you’re expected to have very low blood cell counts for a long period of time, your doctor or nurse may recommend that you use a barrier device during sex, such as condoms or dental dams. See the section “Barrier Devices” for more information.
In some situations, your doctor may recommend for you to avoid sex that involves penetration or contact with mucous membranes while your blood counts are low. This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or sex toys into your vagina or anus.

Hugging, cuddling, gentle touching, and kissing skin are other ways you can be intimate with your partner during this time.

- Chemotherapy and radiation to the pelvis may cause your vagina to become dry and irritated. This may cause pain during vaginal sex and lead to infection. If you have vaginal discomfort, use a condom with a water-based lubricant. Ask your nurse for information on vaginal moisturizers and lubricants to help with vaginal dryness. You may also want to avoid vaginal sex until your tissues heal.

- Some women develop vaginal yeast infections during treatment, especially if they are taking steroids or antibiotics. Symptoms include vaginal itching, irritation, and white and lumpy discharge (like cottage cheese). If you think you have a yeast infection, avoid sexual activity and call your doctor or nurse.

If you had a stem cell transplant, you’re at an increased risk of infection for many months after your treatment. Until your doctor tells you that your immune system has recovered:

- Use a latex condom each time you have vaginal, oral, or anal sex.

- Use a condom or dental dam any time your partner’s saliva, vaginal secretions, or semen could enter your mouth. See the section “Barrier Devices” for more information.

- Do not perform any sexual activity that could expose your mouth to feces.

Consider Steps to Avoid Exposing Your Partner to Chemotherapy and Other Anticancer Medications

We don’t know how much anticancer medication gets into a woman’s vaginal fluids or if this poses any risk to a sexual partner. If this is a concern for you or your partner, you may want to use a barrier device whenever your partner may...
have contact with your vaginal fluids. You can use a condom for vaginal or anal sex and a dental dam when you’re receiving oral sex. This will prevent your partner, regardless of age or sex, from being exposed to any medication that may be in your vaginal fluids.

We don’t know how long these medications may be in vaginal fluids, but you could use barrier devices each day you receive anticancer treatment and for 1 week afterward.

Make sure to use condoms throughout your treatment if needed for birth control or to protect yourself from infection. See the section “Barrier Devices” for more information.

**Barrier Devices**

**Condoms**

- You can buy condoms at any drug store. We recommend latex condoms, but if you or your partner is allergic to latex, use polyurethane condoms.
- Spermicides don’t provide any added protection.
- You can use lubricated condoms or use a separate water- or silicone-based lubricant.
- Before you use a condom, check the expiration date on the wrapper. Expired condoms are more likely to break.
- To use a condom correctly (instructions for your male partner):
  1. Be careful when opening and handling the condom. Don’t use your teeth, scissors, or other sharp objects to open the wrapper. Don’t use the condom if it is torn, brittle, or stiff.
  2. Wait until your penis becomes firm before putting on the condom.
  3. While pinching the tip of the condom, unroll it over your penis as far as it will go. The extra space at the tip is needed to collect your semen.
  4. Smooth out any air bubbles because they can cause the condom to break.
  5. After you have ejaculated, but before your penis becomes soft, hold the base of the condom (where the ring is) and carefully pull your penis out of
your partner so that nothing spills.

6. Carefully slide off the condom and throw it in the trash.

- A condom can tear if it is too tight or it can fall off if it is too loose. If this happens while you are having vaginal sex, and you are of childbearing age, consider taking emergency contraception if you're not using another form of birth control. Emergency contraception includes levonorgestrel (Plan B®), also known as the “morning-after pill.”

**Dental dams**

- A dental dam is a thin, rectangular sheet of latex or silicone that covers the genitals of a woman receiving oral sex.

- You can buy these online, get them from the New York City Department of Health and Mental Hygiene, or make one out of a condom.

- If you want to make a dental dam out of a condom, cut off the tip and cut down the side of the tube to make a sheet.
  
  - You may want to avoid condoms with a spermicide or lubricant, as the taste may be unpleasant.

- To use a dental dam, hold the sheet over your vulva or anus while your partner is giving you oral sex.

**Resources**

**Memorial Sloan Kettering (MSK) Female Sexual Medicine and Women’s Health Program**

646-888-5076

Call for help with issues related to female sexual function.

**American Cancer Society**

*Sex and the Woman with Cancer*

www.cancer.org

Call 1-800-227-2345 to request printed material.

**American Congress of Obstetricians and Gynecologists**

www.acog.org/patients
New York City Department of Health and Mental Hygiene
www1.nyc.gov/nyc-resources/service/1428/condom-information
Has information on getting and using male and female condoms.

Planned Parenthood
www.plannedparenthood.org

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at __________________________. After 5:00 PM, during the weekend, and on holidays, please call________________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Sexual Activity During Cancer Treatment: Information for Women

©2017 Memorial Sloan Kettering Cancer Center - Generated on June 29, 2017
This information explains how to maintain sexual health and intimacy during cancer treatment.

It is common for people to feel changes in their body during and after cancer treatment. There may be things you can see right away, like surgical scars, drainage tubes, and catheters. You may experience a loss of hair, a change in your weight, pain, or fatigue. These physical changes may affect how you feel about yourself or how you relate to your partner. They can affect your interest in sexual activity. They may also lessen your enjoyment and pleasure. Below, you will find some suggestions and resources to help you adjust and cope during this time.

**Feeling Better About Yourself**

- Recognize the things that you enjoy about yourself or make you feel special. These may be related to your family, friends, personal interests, or work life.
- Spend time doing activities and being with people that you enjoy.
- If your faith is important, maintain your spiritual or religious practices.
- Choose clothes that make you feel good.
- Have your favorite clothes altered to fit better.
- Wear scarves, attractive caps, or a favorite hat.
- Take part in the “Look Good Feel Better” program (see information below).

**Maintaining Physical Intimacy With Your Partner**

- Talk with your partner about your physical relationship. Talk about what
you think would help you feel close and give you both pleasure. Share your concerns so that you can find solutions together.

- Increase intimate and sensual touching. Hug, caress, cuddle, touch, and hold hands to feel closer to each other.

- If intercourse is difficult or uncomfortable:
  - Consider different sexual positions. Some may be less tiring or more comfortable.
  - Vaginal moisturizers and lubricants can be helpful for women.
  - Medications to help with erections can be helpful for men.

**Special points related to sexual activity**

- Consider being intimate at times when you have more energy.

- Being relaxed can help improve sexual enjoyment. Select a time and place when you can relax and have privacy.

- If pregnancy is possible, use birth control (contraception) during your cancer treatment. If you have any questions about birth control, or for help deciding the type of birth control that’s right for you, talk with your healthcare provider.

- Ask your healthcare provider how long you should use birth control after your treatment is over.

- Ask your healthcare provider if your blood cell counts are high enough for you to have safe sex. Your white blood cell count should be high enough to prevent infection. Your red blood cell count should be high enough to prevent bleeding. Ask if there are any safety measures you should use for different types of sexual activity (oral, anal, and vaginal).

- Use a condom to protect yourself from sexually transmitted infections (STIs), including HIV, especially if you have more than 1 partner.

- Speak with your healthcare provider if:
  - You have vaginal dryness or tightness that makes sexual activity painful. Simple solutions are available to help. You can also be referred to our Female Sexual Medicine & Women’s Health Program (see contact information below).
- You have difficulty getting or keeping an erection, have a low testosterone hormone level, or have fertility concerns. Your healthcare provider can recommend medication that may help. You can also be referred to our Male Sexual & Reproductive Medicine Program (see contact information below).

- You have difficulty with incontinence (involuntary leakage of urine or feces). Your healthcare provider can give you a referral to the Sillerman Center for Rehabilitation (see contact information below).

**Memorial Sloan Kettering (MSK) Support Services**

**Female Sexual Medicine & Women’s Health Program**
646-888-5076
Get more support and information about issues of vaginal health and intimacy after cancer treatment.

**Male Sexual & Reproductive Medicine Program**
646-888-6024
Get help with issues related to erectile or ejaculatory function, low testosterone hormone level, or fertility issues.

**Sillerman Center for Rehabilitation**
515 Madison Avenue (Entrance on East 53rd Street, between Park and Madison Avenues)
New York, NY 10022
646-888-1900
Some types of cancer and treatments damage the pelvic muscles. This can cause back and pelvic pain and urinary or fecal incontinence. If you are experiencing ongoing pain or incontinence, ask your healthcare provider for a referral to one of physical therapists.

**Counseling Center**
641 Lexington Avenue, 7th Floor (on East 54th Street between Third and Lexington Avenues)
New York, NY 10022
646-888-0100
You can talk to a counselor about your emotional concerns. He or she will help you process any issues and work with you to solve problems. Your partner can attend these sessions with you, if you would like.

**Look Good Feel Better Program**
800-227-2345
Learn techniques to help you feel better about your appearance by taking a workshop or visiting the program online at [www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org).

**Selected Resources**

**American Cancer Society (ACS)**
[www.cancer.org](http://www.cancer.org)
The ACS has free booklets on cancer and sexual health called Sexuality for the Man With Cancer and Sexuality for the Woman With Cancer. You can get copies by calling 1-800-ACS-2345 or by going to the website listed above.

**National Cancer Institute (NCI)**
[www.cancer.gov](http://www.cancer.gov)
Contact the NCI to learn more about sexual health and cancer.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call________________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

Sexual Health and Intimacy
©2017 Memorial Sloan Kettering Cancer Center - Generated on September 20, 2017
Sperm Banking

This information answers some frequently asked questions about sperm banking and provides a list of local sperm banks.

What is sperm banking?

Sperm banking is the collection, freezing, and storage of sperm for possible use in the future.

Why should I do this?

Many cancer treatments damage the cells that grow into sperm. If you are no longer able to produce sperm, you will be infertile. This means that you will not be able to have a biologic child. Sometimes these cells recover, but sometimes they do not. We cannot say for certain how your treatment will affect your future fertility.

You may not be thinking about being a father right now. However, one day this may be important to you. Sperm banking before treatment will increase your chance of being able to father a child in the future using your own sperm. Many young men who did not bank sperm before treatment regret this decision if they are infertile when they want to start a family. Many say they wish they had been pushed more by their families and doctors to do this. Because of this, we encourage all teens and young men to bank their sperm before treatment that may affect fertility.

Where can I do this?

Sperm banking is usually done at a licensed laboratory or fertility center. A number of local sperm banks are listed at the end of this resource.
How do I do this?

Once you select a sperm bank, call to make your first appointment. Explain to them that you will be starting cancer treatment. Think about who you will feel most comfortable being with when you go. This may be your parents, a friend, your spouse or partner, or someone else. You may prefer to go alone.

When you arrive, you will be given a number of forms to complete and will then be brought to a small private room for the collection.

After washing and drying your hands, you will stimulate yourself to ejaculation by masturbating. The fluid that comes out of your penis is called semen, and it contains your sperm. You will collect the semen in a sterile cup. Do not use saliva, spit, or lubricants to masturbate, as these can destroy the sperm. You can ask for mineral oil if this will help you to ejaculate, but use this only at the base of your penis to avoid mixing it in with your semen.

Some men are not able to ejaculate by masturbating because they feel too sick, are in too much pain, feel too embarrassed or distressed, or are not allowed to masturbate because of religious or cultural beliefs. If you feel you cannot collect a specimen by masturbating, please tell your doctor or nurse. There are other methods of collecting sperm, and we can discuss these options with you.

When should I do this?

You must bank your sperm before you begin treatment. If your treatment does not have to start immediately, we suggest you collect 3 specimens. For the first collection, it is best if you don’t ejaculate through intercourse or masturbation for 2 to 5 days before the collection. Then, skip 2 to 3 days between each collection. This will help you collect the highest possible number of sperm.

If your treatment will be starting too soon for this timing, you can begin collecting immediately and schedule the collections with only 1 day between each one. Even collecting only 1 or 2 specimens is worthwhile, because there are new techniques available to fertilize eggs with very few sperm.

If you will be having a scan with a radioactive isotope, such as a positron emission tomography (PET) scan, you can’t collect for 24 hours after the scan. Keep this in mind when scheduling your appointments with the sperm bank.
What if I am not able to collect at a sperm bank?

If you feel you cannot collect a specimen at a sperm bank, some sperm banks will allow you to collect at home. They will give you a sterile cup for this.

If you are in the hospital, you will need to collect the specimen in your hospital room. We have arranged with one of the sperm banks in New York to pick up the specimen for a small fee and bring it to their laboratory for processing.

If you are having a family member or friend transport the specimen to the sperm bank, the specimen must be delivered within 60 minutes of collection. It should be put in a pocket close to the body to keep it at body temperature.

What does the sperm bank do with the specimen?

The sperm bank will analyze your semen, counting the number of sperm. They will divide the specimen into small vials and freeze the sperm for storage. Some sperm die during the freezing and thawing process. However, the sperm that survive are not damaged while they are frozen.

Sperm can be stored for as long as you want, even for many years. You will have to pay a yearly storage fee as long as the sperm bank holds your specimens. We recommend you consider storing these until you have completed building your family.

You will need to complete a form to indicate what you want done with your specimens in case something happens to you in the future, such as if you were to die unexpectedly. This is to ensure your wishes are honored.

If you are considering discarding your sperm, talk with your doctor first to ensure you will not need any additional treatment.
How much will this cost?

Most insurance plans do not cover sperm banking. The cost varies from one sperm bank to another. The cost in the New York area ranges from about $700 to $1,300 for 3 collections, including the first year of storage. The sperm bank may also require that you have blood and urine tests for certain infectious diseases, which may add to the cost.

Ask the sperm bank if they offer discounted rates to cancer patients, either on their own or through the LIVESTRONG Fertility program. To find out if you are eligible through LIVESTRONG and for an application, look on their website: http://images.livestrong.org/downloads/we-can-help/LF_App_Men_FINAL_v4.pdf?_ga=1.113354372.226511752.1413988424.

If the cost of storage after the first year is more than you can afford, you can arrange to transfer the specimens to another sperm bank. Repro Tech provides discounted rates for long-term storage for people with cancer. Visit their website at: www.reprotech.com/financial-assistance.html.

Where can I learn more?

If you would like additional information, ask your doctor or nurse for a referral to one of our Fertility Nurse Specialists.

Finding a Sperm Bank

**Manhattan**

**Manhattan CryoBank**
211 East 43rd Street, Suite 1701 (between Second and Third Avenues)
New York, NY 10017
212-396-2796

**MAZE Laboratories**
110 East 40th Street, Suite 704
New York, NY 10016
914-683-0000
Repro Labs
332 East 30th Street (between First and Second Avenues)
New York, NY 10016
212-779-3988

Long Island

New York Cryo
900 Northern Boulevard, Suite 230
Great Neck, NY 11201
516-487-2700

Reproductive Specialists of New York
200 Old Country Road, Suite 350
Mineola, NY 11501
516-739-2100

or
2500 Nesconset Highway, Building 23
Stony Brook, NY 11790
631-246-9100

Westchester

MAZE Laboratories
2975 Westchester Avenue
Purchase, NY 10577
914-683-0000

New Jersey

Reproductive Medicine Associates of New Jersey
140 Allen Road
Basking Ridge, NJ 07920
973-656-2823

The Sperm and Embryo Bank of New Jersey
187 Mill Lane
Mountainside, NJ 07092
908-654-8836
If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call________________________. If there’s no number listed, or you’re not sure, call 212-639-2000.