

Outpatient Autologous Stem Cell Transplant: A Guide for Patients & Caregivers

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Welcome & Overview

Welcome to the Outpatient Autologous Stem Cell Transplant program at Memorial Sloan Kettering Cancer Center (MSK).

About This Guide

The information in this guide will complement the information your healthcare team will share with you.

What's in this guide

This guide will help you learn about autologous stem cell transplantation: what it is, why it is being recommended for you, and what happens in each phase of the transplant.

How to use this guide

You should read this entire guide at least once, as well as the additional materials included at the back of the guide. Refer to this guide as your treatment progresses.

As you read through this guide, make a note of any questions that come to mind. Your healthcare team can answer your questions the next time you see them.

We value your feedback

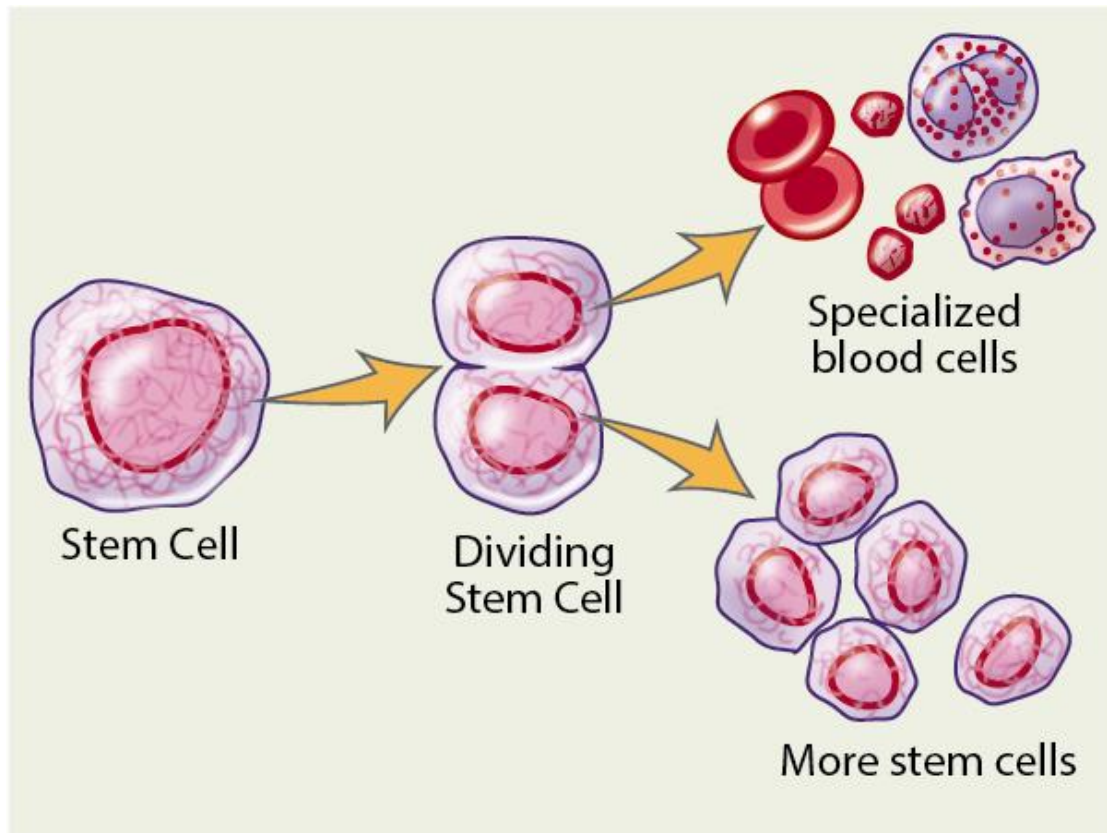
We are always trying to improve the information we give to our patients, their families, and their friends. After you've read this guide, you may think of ways it could be improved (maybe there's something that was missing or wasn't completely clear). Please e-mail your suggestions to us at patiented@mskcc.org.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

Glossary

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

Bone Marrow Basics

What Is Bone Marrow? What Are Stem Cells?



Your stem cells divide and change into the different types of blood cells in your body.

Bone marrow is a substance found in the spaces in the center of the larger bones in your body—your hip, breastbone, and pelvis.

Bone marrow contains a large number of stem cells. 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. Your stem cells are constantly dividing and changing into these different types of blood cells in your body, replacing older blood cells. Some stem cells also circulate in your bloodstream.

You'll hear your transplant referred to as a "bone marrow transplant" or a "stem cell transplant." Technically, stem cell transplant is the more correct term, as you'll be receiving an infusion of stem cells.

Autologous Stem Cell Transplant

An autologous stem cell transplant is being recommended for you because your doctors feel that a transplant is the best treatment for your specific disease.

Autologous means “from yourself.” When you have an autologous stem cell transplant, your stem cells are harvested (collected) from your body and then frozen before you receive chemotherapy. 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 we return your stem cells to you, they will slowly start to make new blood cells. You are literally receiving a stem cell transplant “from yourself.”

This booklet is divided into 3 sections about the autologous stem cell transplant experience.

Before

You will prepare for your stem cell transplant. You will receive medications that stimulate your body to make more stem cells than normal and encourage those stem cells to circulate in your bloodstream. Your stem cells will then be harvested from your bloodstream and stored.

You will have a central venous catheter (CVC) placed into your upper chest wall for your transplant. It may also be used to collect the stem cells. Your veins will be checked to determine the best time for the CVC to be inserted.

During

You will receive your chemotherapy (the “conditioning regimen”) to kill any cancer cells that remain in your body through your CVC. The stem cells remaining in your body and other blood cells will also be killed, and you will lose your ability to make new blood cells. Your immune system will be severely compromised.

Your stem cells will be taken from storage, thawed, and infused into your body through your CVC. This is your stem cell transplant.

After

The infused stem cells will find their way through your bloodstream to your bone marrow. They will begin to divide and create healthy new blood cells. This process is called engraftment. Your immune and vital systems will begin to return to normal. This process takes time, and varies from patient to patient.

The Five Phases of Transplant

	Description	Time Period
<p>Phase 1: Chemotherapy</p> <p>You will receive high-dose chemotherapy with or without radiation.</p>	<ul style="list-style-type: none"> • Chemotherapy will be given to kill any cancer cells that are left, which will make room for new stem cells. • Phase 1 will be finished when you receive the infusion of stem cells. 	<p>Day -10* to Day 0</p> <p>*Start date varies depending on which conditioning regimen you will receive.</p>
<p>Phase 2: Neutropenia</p> <p>You will feel the effects of the chemotherapy you received.</p>	<ul style="list-style-type: none"> • Your white blood cell, red blood cell, and platelet counts will be low. • You may have diarrhea, nausea, and/or mouth sores. • Your risk of developing an infection will be high. 	<p>Day 0 to Engraftment</p> <p>(usually between Day +12 and Day +30)</p>
<p>Phase 3: Early Recovery</p> <p>Your neutrophils will start to recover.</p>	<ul style="list-style-type: none"> • You may develop a fever, rash, and pulmonary infiltrates, known as “engraftment syndrome.” 	<p>Day +5 to Day +7</p>
<p>Phase 4: Early Convalescence</p> <p>Your immune system will still not be working properly, even though your blood counts are normal.</p>	<ul style="list-style-type: none"> • You will still be at risk of developing life-threatening infections. • You will remain on antiviral medications to prevent infections. 	<p>Day +30 to 6 to 12 months</p> <p>You will continue to be monitored closely by your transplant team.</p>
<p>Phase 5: Late Convalescence</p> <p>You will return to your normal activities.</p>	<ul style="list-style-type: none"> • Your immune system will be almost fully recovered. • There will still be a chance that you could develop late complications, such as organ dysfunction or recurrence of the original disease. 	<p>12 months and onward</p> <p>You will begin receiving vaccinations you may have had during childhood.</p>

Outpatient Autologous Stem Cell Transplant

Depending on your condition and treatment, you may receive part of your care as an inpatient in the hospital and part of it as an outpatient in the BMT clinic.

While you're being cared for in the outpatient clinic, you will stay locally at a NY Presbyterian Guest Facility furnished apartment or at an apartment previously approved by your primary doctor. You will be admitted to the hospital only if you develop complications.

While each patient's transplant is different, below is a typical timeline for someone having an outpatient transplant. You'll see that the days leading up to the transplant are given minus numbers, such as Day -3, Day -2, etc. The day of the transplant is Day 0, and the days that follow are Day +1, Day +2, etc. Your healthcare team will use this format when they explain your transplant to you.

- **Day -4:** You and your caregiver will check into the NY Presbyterian Guest Facility or apartment close to MSK's main hospital in Manhattan.
- **Day -3:** If a CVC hasn't already been inserted, you and your caregiver will come to MSK's Interventional Radiology department at the main hospital, where one will be inserted in your upper chest wall. You will return to your NY Presbyterian Guest Facility or apartment in the evening.
- **Day -2:** You will come to the Outpatient BMT Clinic to receive your chemotherapy. You will return to your NY Presbyterian Guest Facility or apartment in the evening. (In some cases, patients will need several days of chemotherapy. Your healthcare team will explain your specific treatment plan to you.)
- **Day -1:** This is a rest day. You will come to the Outpatient BMT clinic for evaluation.
- **Day 0:** This is your transplant day. You will come to the Outpatient BMT Clinic to receive your stem cell transplant. You will return to your NY Presbyterian Guest Facility or apartment in the evening.
- **Day +1 to Engraftment:** You will visit the Outpatient BMT Clinic each day to have blood work done, your vital signs checked, and a physical exam. You'll also receive hydration, electrolytes, and transfusions if necessary. You will have a bedside or chairside entertainment unit with television and Internet access. Your meals will be provided. There is a communal lounge with coffee and tea for caregivers. You will return to your NY Presbyterian Guest Facility or apartment each evening.
- **After engraftment:** When your blood cell counts have recovered and you no longer need frequent treatments, your CVC will be removed. If you live within 1 hour of MSK's main hospital, you may be allowed to return

home. If you live further away, you will stay at your NY Presbyterian Guest Facility or apartment for a few more weeks. You will still visit the Outpatient BMT Clinic regularly.

Your Transplant Team

A team of healthcare professionals from the Adult Bone Marrow Transplant Service will care for you throughout your treatment. You will meet each member of your healthcare team at different times during your treatment. Here is a list of the team members and their roles. While you are here, you will come to know all of the members of your team.

An **attending doctor** will be in charge of your care throughout your treatment. Even though one specific doctor will be your primary doctor, you may be cared for by different doctors during your transplant.

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. The NPs will be responsible for your daily care when you come to the Outpatient BMT Clinic.

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. The PAs will be responsible for your daily care when you come to the Outpatient BMT Clinic.

A **BMT clinical 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 consults with other professionals needed before your transplant. Your clinical coordinator will give you calendars that show your treatment plan over time.

A team of **nurses** will provide your day-to-day nursing care. They are registered nurses specially trained in the care of stem cell transplant patients.

A **nursing assistant** and **patient care technician** provide basic care and support under the direction and supervision of a registered nurse.

A **hospitalist** is a doctor who sees patients 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 patients 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.

Your pharmacist will also review and monitor your medications with the outpatient team.

A **social worker** will help you, your family, and those around you manage the stress that comes with the transplant process. The social workers understand the issues faced by transplant patients and are on hand to listen, offer counseling, and refer you or your family members to other resources and services, as needed.

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 **room service associate** will orient you to room service. He or she will make sure that you receive the appropriate menus, as well as deliver your meals.

A **research study assistant (RSA)** enrolls patients in research studies at MSK and monitors them while they are participating in the studies.

Financial counselors from Patient Financial Services will work with you and your insurance company to determine your transplant benefits. These counselors are experienced in the insurance issues faced by transplant patients. Each insurance company has its own policies, which may be different from other insurers. When your insurance company requires authorization, your financial counselor will assist with that process.

Session assistants check-in patients and monitor the flow of patients in and out of the clinic. They assist the clinical staff, schedule appointments, manage medical records, and track each patient's daily progress. This includes any scans, tests, and treatments given to you.

Physician office assistants provide administrative support to the attending staff. You may speak with this person when you submit information or when you have questions for your physician.

Before Your Transplant

This phase of your treatment begins when you meet your healthcare team on or around Day –30 and continues until the start of your chemotherapy.

Summary and Checklist

In this phase, you'll make practical, physical, and emotional preparations for your transplant. This will be a very busy time for you and your family.

Here is a list of things that will happen and things that you will need to do during this phase. You can check off items as you go along:

- Meet your team** — Meet your doctor and members of your healthcare team. Take this time to ask about your treatment and have them answer your questions.
- Learn about your transplant** — Read this entire guide at least once, along with the additional information at the back.
- Make a list of questions** — Make a note of anything that you don't understand about your transplant, anything in the guide that isn't clear, and any other questions you have.
- Choose a caregiver** — Identify a family member(s) or friend(s) to act as your caregiver. Make sure this person understands what the role entails. Give your caregiver a copy of this guide and ask him or her to read it at least once.
- Get financial clearance** — Meet with a representative from Patient Financial Services (PFS) and speak to your health insurance company. Check that your outpatient stem cell transplant and medications are covered.
- Make decisions about your fertility** — If fertility is a concern for you, speak with your healthcare 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 steps you may be able to take to preserve your fertility.
- Speak to your children about your treatment** — If you have children, talk to them about your treatment to help build trust and their sense of security.
- Arrange childcare** — If you have children, they cannot stay with you at your NY Presbyterian Guest Facility or apartment during your outpatient transplant, so you should arrange for childcare.

- **Arrange pet care** — If you have pets, they cannot stay with you at your NY Presbyterian Guest Facility or apartment during your outpatient transplant, so you should make arrangements for them.
- **Attend orientation** — You and your caregiver will attend the virtual orientation for outpatient autologous stem cell transplant patients. Ask your clinical coordinator for details.
- **Pretransplant evaluation** — You'll undergo a series of medical tests. Your clinical coordinator will schedule these tests with you.
- **Lodging** — Your clinical coordinator will make arrangements for you to stay at the NY Presbyterian Guest Facility and will give you details.
- **Nutrition consultation** — Meet with a dietitian to review special dietary requirements and safe food handling.
- **Social work consultation** — Meet with a social worker who will explain the psychological, emotional, and financial support services offered by the social work team.
- **Mobilization** — You will give yourself injections of a medication to increase the number of stem cells in your bloodstream.
- **Harvesting** — You will visit our Blood Donor Room, where your stem cells will be collected from your bloodstream.
- **Have your CVC inserted** — You will visit the Interventional Radiology department where a CVC will be inserted into your upper chest wall.
- **Learn catheter care** — A nurse will show you and your caregiver how to care for your CVC and change your dressings.
- **Make decisions about your hair** — Think about whether you'd like to cut your hair. Visit a wig store if you decide to wear a wig.
-
- **Prepare for clinic visits** — Purchase a tote bag or rolling case to carry your supplies to the Outpatient BMT Clinic every day.

Meeting Your Team

On or around Day -30, you'll meet with your attending doctor and other members of your healthcare team. Your attending doctor will walk you through your treatment plan. This plan takes into account your disease, your overall health, and other factors. Your healthcare team will update your treatment plan as you undergo tests before your transplant.

The Role of Your Caregiver

Establishing a caregiver plan is an essential part of the transplant process. One of the most important steps in preparing for your transplant is choosing your caregiver. This person is usually a family member or a close friend, and will be an important part of your healthcare team. Your caregiver will be responsible for a lot of the day-to-day medical, practical, and emotional support you need during your outpatient transplant.

If there isn't 1 single person who can act as your caregiver, then it may be possible for you to have different caregivers scheduled during different times. It is best to limit the number of caregivers to 1 or 2 individuals.

Your caregiver will receive specific instructions from your healthcare team about his or her responsibilities. Some of these responsibilities will include:

Medical support

- Gathering information from your healthcare team.
- Caring for your CVC.
- 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 healthcare 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 NY Presbyterian Guest Facility, 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

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.

While you're undergoing your transplant, your caregiver must escort 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, your caregiver can take some personal time. This is something we strongly recommend).

It is important for your caregiver to maintain a positive attitude, calm demeanor, and flexible approach while also 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 somebody 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 your caregiver becomes ill or shows any signs of cold or flu (cough, temperature, sore throat) 1 week before or any time during your transplant, tell your transplant team immediately.

Resources for caregivers

Caregivers can experience financial, physical, emotional, and spiritual distress. Resources and support are available to help manage the multiple responsibilities that come with caring for a transplant patient. 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* at the back of this guide.

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

Financial Clearance

Early on in your journey with us, you will meet with a representative from MSK's Patient Financial Services who will be your financial counselor. He or she will gather information about your treatment plan, contact your insurance company, and find out what aspects of your care are and are not covered. Your financial counselor will be available to answer questions about your medical expenses and bills throughout your treatment.

Stem cell transplants are complex and expensive. The administrative staff from Patient Financial Services will check that your pretransplant tests, high-dose chemotherapy, stem cell infusion, post-transplant care, housing, medications, and other expenses are covered by your insurance plan. If they are, then you will be “financially cleared” to begin treatment.

Pretransplant Medical Evaluation

Before you become a transplant candidate, your overall physical condition needs to be evaluated. You will need to make several trips to MSK to undergo tests. We often refer to this as the “work-up” or “restaging” period. During the work-up, you will need to have some or all of the following tests:

- **Chest x-ray** — This is done to ensure your lungs are clear and there is no evidence of pneumonia or other problems.
- **Blood tests** — These are done to evaluate your kidney and liver function and to assess your white blood cells, hemoglobin level, and platelet counts. Your past exposure to certain viruses is also checked.
- **Urine tests**
- **Electrocardiogram (EKG) or echocardiogram (echo)** — This is done to give your healthcare team information about your heart.
- **Pulmonary function tests (PFTs)** — These are breathing tests that measure your lung function.
- **Computed tomography (CT) scan** — This is an x-ray that provides images of soft tissue and bone. Some scans use contrast dye that you drink or have injected into your body. Tell your doctor if you have a known allergy to contrast dye, seafood, or iodine. If you have an allergy, you may need to be given medications to prevent a reaction to the dye before your scan.
- **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 him or her to provide

a note saying that you have no dental problems. If there are issues, please ask your dentist to contact the MSK dentist.

- **Positron emission tomography (PET) scan** — This is a scan that is used to look at your organs and the way they function in your body.
- **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 will 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.
- **Skeletal survey** — This is an x-ray of the major bones in your body that is done to check for any signs of disease. This can take a few hours to complete.

These tests are usually done in the 30 days before your transplant (Day –30 onwards), but sometimes the pretransplant evaluation can take longer. Your clinical coordinator will work with you and your caregiver to schedule the tests.

The results of the tests will be used to plan your treatment, adjust it to your specific needs, and make sure that it is safe to start your treatment.

Your doctor or nurse will explain any other tests that you may need.

Making Decisions About Your Fertility

Your cancer treatment will affect your fertility. It is likely that you will not be able to conceive a child naturally after high-dose chemotherapy.

In some cases, it's possible to take steps to preserve your fertility before you start treatment. Women can freeze eggs or embryos and men can bank sperm. These steps may allow you to have a biological child in the future. If you have received chemotherapy in the past, there is a risk that your sperm or eggs have already been damaged, so preserving your fertility may not be an option.

We have summarized the most common steps that people take to preserve their fertility before undergoing a stem cell transplant. If you want to learn more about fertility preservation options and other ways you may build a family after your transplant, ask your doctor or nurse for a referral to a fertility expert.

Options for men

Men can freeze sperm before treatment. The first step is to schedule an appointment at a sperm bank, where you will masturbate and collect your ejaculated semen in a sterile cup.

The sperm bank will analyze the specimen to be sure there are healthy sperm to freeze. The semen is then placed in vials and frozen. It can be stored for as long as you want, even for many years. We recommend that men collect 3 separate specimens if possible, abstaining from sex for 2 to 5 days before the first collection and in between the other collections.

For more information, please read the resource titled *Sperm Banking and Cancer and Fertility: Information for Men* included at the back of this guide. These are also available online:

- *Sperm Banking*
www.mskcc.org/cancer-care/patient-education/resources/sperm-banking
- *Cancer and Fertility: Information for Men*
www.mskcc.org/cancer-care/patient-education/resources/cancer-and-fertility-information-men

Options for women

Women can freeze eggs or embryos before treatment. The first step is to schedule an appointment with a reproductive endocrinologist (a gynecologist with special training in fertility). Ask your doctor or a member of your healthcare team to refer you to a reproductive endocrinologist.

Your reproductive endocrinologist will evaluate your fertility and give you advice on how best to proceed.

If these tests show that your eggs can be collected successfully, on or around the second day of your period, you will start giving yourself daily hormone injections. The hormones will stimulate some of the eggs in your ovaries to mature. You will need to take the injections for about 10 days, during which time you will be closely monitored by your reproductive endocrinologist. Once the eggs are fully mature, you will be scheduled for the egg retrieval. This is an outpatient procedure done using anesthesia, so you will be asleep. Your eggs will be collected using a very thin needle passed through the wall of your vagina.

If you are going to store embryos, your eggs will be fertilized with sperm in the laboratory before freezing. This is called in vitro fertilization (IVF). If you are going to store eggs, they will not be fertilized with sperm before freezing. The frozen eggs or embryos can be stored for as long as you want, even for many years.

Another possible option to preserve fertility is ovarian tissue freezing. However, this procedure is experimental.

For more information, please read the information titled *Cancer and Fertility: Information for Women* and *Selecting a Reproductive Endocrinologist* included at the back of this guide. They are also available online:

- *Cancer and Fertility: Information for Women*
www.mskcc.org/cancer-care/patient-education/resources/cancer-and-fertility-information-women
- *Selecting a Reproductive Endocrinologist*
www.mskcc.org/cancer-care/patient-education/resources/selecting-reproductive-endocrinologist-fertility

Financial issues related to fertility preservation

Unfortunately, fertility preservation is not covered by most insurance plans. Sperm banking can cost about \$1,000 and egg or embryo freezing can cost \$10,000 to \$15,000. There are also annual storage fees.

The financial staff at the sperm bank and your reproductive endocrinologist will contact your insurance company to determine if you have coverage.

There are financial assistance programs available, such as the LIVESTRONG Fertility Program, a discount program for eligible patients managed by LiveSTRONG. For more information about this, ask your nurse or a member of your healthcare team for an application or go to the LIVESTRONG Fertility Program website at: www.livestrong.org/we-can-help/fertility-services

Speaking to Your Children About Your Transplant

Being open with your children helps to build trust and a sense of security. During your transplant, your children will not be able to stay with you at your NY Presbyterian Guest Facility or apartment. This can be upsetting for parents and children, so clear communication is recommended. When speaking to your children about your illness and transplant, we recommend that you:

- Always take into consideration your child's age, developmental stage, and individual personality.
- Use the proper names and terms ("bump" or "boo boo" are confusing) when describing your diagnosis and transplant. Prepare your child for changes in your appearance, energy level, and daily routine (e.g., not going to work and having multiple medical appointments).
- Be cautious about promising that you will be home by an exact date, as discharges can be delayed for a number of reasons.

- Invite your child to ask any and all questions. Remember, it is okay not to have all the answers.
- Validate and accept your child's feelings.
- Reassure your child that he or she is not responsible for your illness and that cancer is not contagious.
- Set aside family time in which the transplant is not the only focus.

Making Arrangements for Childcare

Your children won't be able to stay with you during your outpatient transplant. Before you move into the local apartment or NY Presbyterian Guest Facility and undergo your transplant, you will need to make arrangements for childcare. We recommend that you:

- Identify family members or friends who know your children well enough to care for them during the transplant period.
- Maintain your child's daily routine as much as possible.
- Prepare your child for these changes and help him or her adjust to the transition.
- Expect that your child may have some reactions or may show normal signs of adjustment during the transition.
- Engage your children's teachers, counselors, clergy, and other adults involved in their life to support them during this time.
- Educate your child's caregiver about the transplant process in case your child has questions during the separation.

Later in this guide, we suggest ways for you to maintain a strong connection to your children while you are living at the NY Presbyterian Guest Facility or apartment. You'll find it under "Coping With Separation From Children."

For more assistance related to childcare, contact your social worker.

Making Arrangements for Your Pets

Animals can carry diseases and may present risks to you while your immune system is compromised. During your transplant period (chemotherapy through recovery), you should minimize direct contact with animals. Your pets won't be able to stay with you at the NY Presbyterian Guest Facility or apartment, so you should arrange for them to be cared for while you are away from home.

You should also take the following precautions:

- Make sure that your pet is up to date with immunizations and any booster shots. Have your veterinarian check your pet's stool for parasites.
- Have your pet treated for fleas. If your pet walks through wooded areas, have it screened for ticks.
- If you do come into contact with your pets, do not allow them to sleep with you. Do not allow your pets to lick you in the face.
- Wash your hands after touching your pet.
- Protect yourself from bites or scratches.
- Do not clean cat litter boxes or clean up after your dog in the street. Have someone else do these things for you.
- Avoid all contact with birds, lizards, snakes, turtles, iguanas, exotic pets, hamsters, or other rodents while you recover. Contact with bird or reptile waste may expose you to certain infectious germs.

After you have recovered from your transplant, you will be given additional instructions on pet care in the resource at the back of this guide titled *Returning Home After Your Autologous Transplant*.

Moving Into a Nearby Apartment or NY Presbyterian Guest Facility

During your outpatient transplant, lodging will be provided for you and your caregiver at the NY Presbyterian Guest Facility at the Helmsley Medical Tower. A staff member from Patient Financial Services will make the reservation for you.

The Helmsley Medical Tower is located at 1320 York Avenue (between East 70th and East 71st Streets), just 2 blocks from MSK. On the upper east side of Manhattan, this neighborhood offers a wide range of restaurants, pharmacies, dry cleaners, grocery stores, and specialty shops. The NY Presbyterian Guest Facility is designed to meet your unique needs by providing comfort and convenience, along with many amenities.



You will be staying in a fully furnished suite. Each kitchen is equipped with a standard-size refrigerator and stove, a coffeemaker, a microwave oven, and a supply of cookware and dinnerware. The coordinated furnishings include a dining table with chairs and cable television. The size of the suite is based on

availability at the time of your outpatient transplant. You can check in to your suite anytime after 3:00 pm on your reservation day.

During your stay at the NY Presbyterian Guest Facility, you will enjoy special amenities, including:

- 24-hour concierge/doorman service
- Daily maid service
- High-speed internet access
- Free copy of *USA Today* delivered daily
- Cable television in all rooms, including HBO
- Electronic key card access to your room

For additional information on the NY Presbyterian Guest Facility, go to: www.nyphhousing.com

MSK will pay for your room charges only. When you check in, you will be asked to provide your credit card just in case you incur other charges, as described below:

- Parking is a separate charge. The rate is approximately \$45 per day; however, NY Presbyterian Guest Facility guests are given a \$10 per day discount. Parking is in an underground garage with an entrance on East 70th Street.
- A gym pass is available for \$10.00 per day for your caregiver only.
- Copier and fax machines are available for a fee per page.
- Laundry facilities are available; you can purchase a key card to use washers and dryers in the building.

Mobilization and Harvesting

In an autologous transplant, your stem cells are first mobilized and then harvested (“collected”) from your body before you receive chemotherapy.

Mobilization is the process of increasing the number of stem cells produced by your bone marrow and released into your bloodstream.

Stem cell harvesting is the process of collecting and separating whole blood into its major components (red blood cells, white blood cells, platelets, and plasma) then removing stem cells from the white blood cell component.

Once your stem cells have been harvested, they are frozen and stored, then infused into your body after your chemotherapy; this is your stem cell transplant.

Mobilization

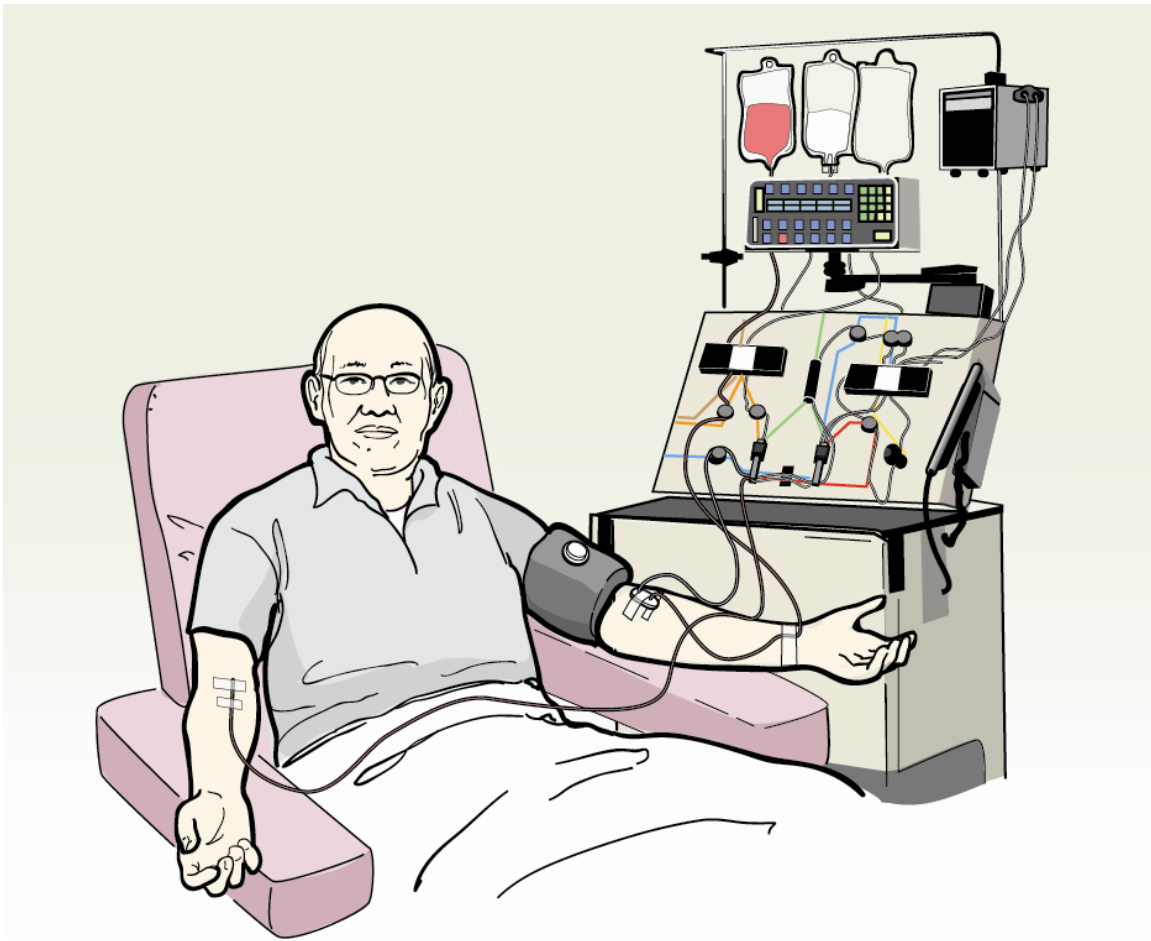
Normally, your stem cells live in your bone marrow, where they are difficult to access and collect for transplantation (although a few circulate in your bloodstream).

To increase the amount of stem cells in your bloodstream, you'll be given injections of a medication called granulocyte colony-stimulating factor (GCSF). GCSF stimulates your body to make more stem cells than usual and encourages the stem cells to move into your bloodstream, where they can be collected much more easily. This process is called mobilization. GCSF drugs include filgrastim (Neupogen®), pegfilgrastim (Neulasta®), and plerixafor (Mozobil®).

In most cases, GCSF injections are self-administered, meaning that you will inject yourself with the medication at home. You'll be given GCSF in prefilled syringes, which you'll keep in your refrigerator. Your clinical coordinator will create a mobilization calendar for you that will tell you when to give yourself the injections. The number of injections you will need depends on several factors, including your weight.

A full guide to giving yourself GCSF injections called *Giving Yourself an Injection of Filgrastim (Neupogen®) or Pegfilgrastim (Neulasta®) With a Prefilled Syringe* is included at the back of this guide. Your nurse will go over this information with you as well.

Some patients will not give themselves injections, but will instead be given a different type of GCSF called plerixafor. If plerixafor is recommended for you, the injections will be given by a nurse in the BMT clinic.



A patient undergoing stem cell harvesting. Blood is withdrawn through an IV line in one arm and circulated through the machine, where stem cells are collected. The rest of the blood is returned through an IV line in the other arm.

Harvesting your stem cells

The GCSF injections will stimulate the growth and mobilization of your stem cells, and then they will be harvested. Harvesting is the procedure used to collect some of these stem cells in your blood.

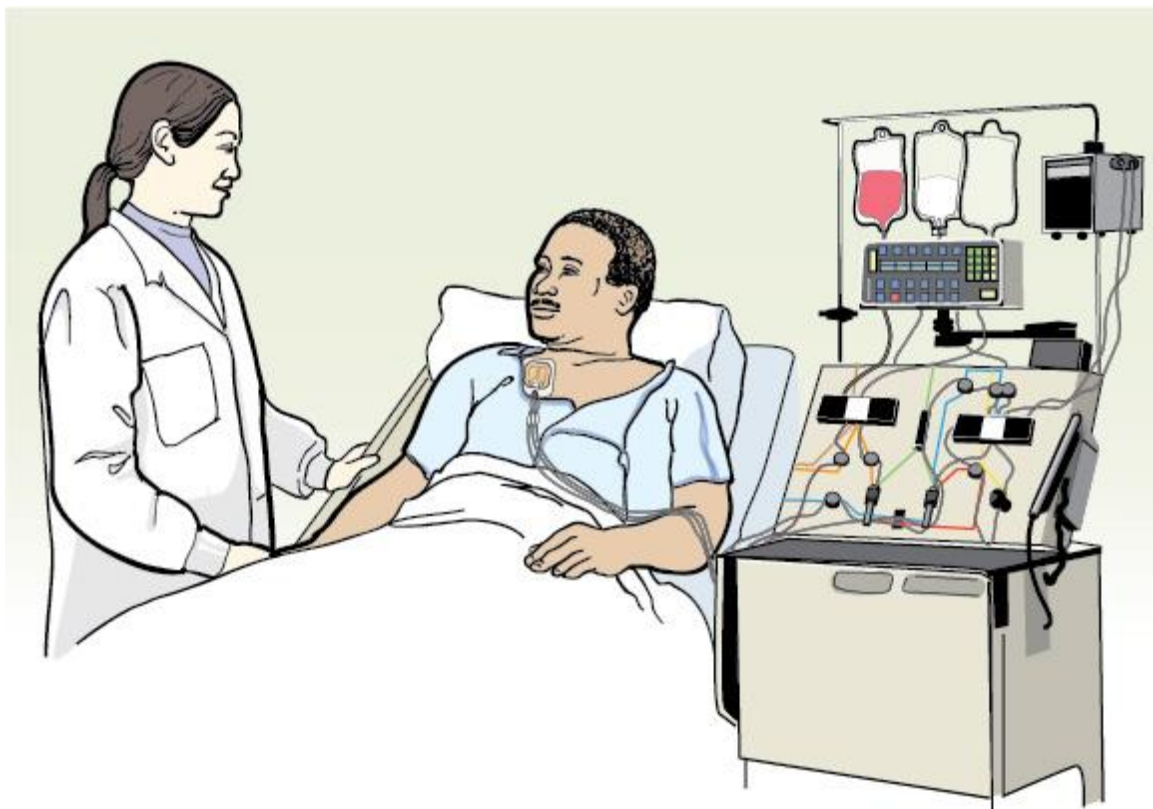
Before you are scheduled for stem cell harvesting, a nurse or doctor will examine your veins to see if they are healthy enough for the procedure. If your veins are not healthy enough, you will have a CVC inserted, which will be used during harvesting to collect the stem cells. The CVC will remain in place for several weeks or months.

The harvesting procedure is done in the Blood Donor Room. You will have 3 to 5 harvesting sessions to collect enough cells. The exact number of sessions is determined by the number of stem cells that are collected in each session. You will be notified each day if you need to return for another harvesting session. Each session will last 3 to 4 hours.

You should eat dairy products and other foods that are rich in calcium the night before and the morning of your harvesting session. Wear comfortable clothes.

During the procedure, you will be lying in a bed or sitting in a reclining chair. You will be connected to a machine either by IV tubes in your arms or by your CVC. Blood will be withdrawn through the IV line or CVC and circulated through a machine that collects your stem cells. 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. Since patients sometimes complain of feeling cold during the procedure, blankets will be available.



A patient undergoing stem cell harvesting using a CVC instead of IV lines. Blood is withdrawn from the CVC and circulated through a machine that collects the stem cells. The rest of the blood is returned through the CVC.

After your harvesting procedure is done, a dressing will be applied to your arm to prevent bleeding. It should remain in place for at least 3 hours, but not more than 5 hours. If your CVC was used, it will be flushed and recapped.

Your stem cells will be brought to our stem cell laboratory, where they'll be frozen and stored safely until your transplant day.

After harvesting, most patients have minimal side effects and can resume their regular activities. The most common side effects are:

- Fatigue
- Low platelet count or low red blood cell count. Either may require a transfusion
- Numbness or tingling in your lips, hands, or feet caused by a temporary decrease in the calcium levels in your blood

Call your doctor if you:

- Develop a temperature of 100.4°F (38°C) or higher
- Develop flu-like symptoms
- Notice any redness, bleeding, drainage, or pain at your CVC or needle insertion site
- Notice any bleeding or bruising
- Notice numbness or tingling in your lips, hands, or feet
- Notice significant pain on the left side of your body

Having Your Central Venous Catheter (CVC) Inserted

Before receiving your chemotherapy treatment, you and your caregiver will come to MSK's Interventional Radiology department at the main hospital to have a CVC inserted into your upper chest wall.

A CVC is a tube that is inserted into a large vein near your collarbone. On the outside of your body, the catheter divides into 2 or 3 smaller tubes called lumens.

A CVC allows your healthcare team to give you liquids, electrolytes, blood transfusions, and chemotherapy and other medications without having to keep sticking you with a needle. Having a CVC will make your treatment much more comfortable.

The CVC will stay in your body throughout your treatment and is usually removed 2 to 3 weeks after you receive your stem cell transplant.

Before your CVC is inserted

Your clinical coordinator will work with you to schedule the procedure to insert your CVC.

The day your CVC is inserted

Your CVC will be inserted at MSK's main hospital. You will most likely already be staying in a NY Presbyterian Guest Facility or apartment within walking distance of MSK's main hospital; if you're not, you should arrange transportation between your lodging and the hospital.

About 2 business days before your procedure, you will receive a call from a staff member of Interventional Radiology. He or she will tell you the time of your procedure and when you should arrive at the Surgical Day Hospital (SDH).

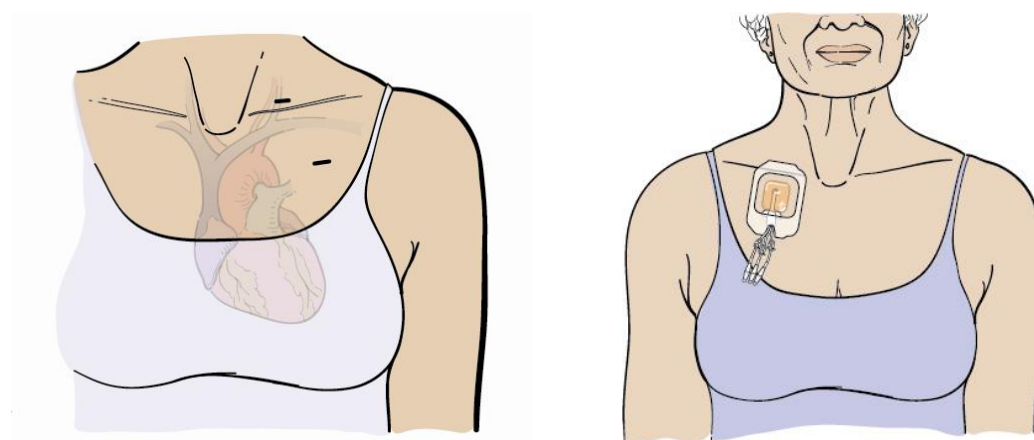
Enter the hospital through the main entrance at 1275 York Avenue. Take the M elevators at the top of the escalator to the 2nd floor. Enter through the glass double doors to the SDH. Check in at the desk. Please arrive on time.

The procedure

The placement of your CVC should take about 30 minutes. First, an IV line will be inserted, and you will be given medication through the line to make you sleepy. Your blood pressure, heart rate, breathing, and oxygen levels will be monitored during your procedure.

A small area near your collarbone will be numbed with a local anesthetic. Depending on the type of CVC recommended for you, either 1 or 2 small incisions (surgical cuts) will be made near your collarbone. The CVC will be inserted through the incision(s) and threaded into the vein.

Once your CVC has been inserted into your chest, the incision(s) near it will be stitched closed. Your body will absorb your stitches. They will not need to be removed. Your CVC will be stitched to your skin at the point where it exits your body so that it will stay in position.



A small area near your collarbone will be numbed. One or 2 small incisions will be made and your CVC will be inserted. Once the CVC has been inserted, it will exit your chest wall and split into a number of lumens—tubes that allow your medical team to access your blood, give you fluids, infusions, etc.

After your CVC has been inserted

After your CVC has been inserted, you will be monitored in the SDH for 2 to 3 hours before being allowed to return to your NY Presbyterian Guest Facility or apartment.

You will need to leave the dressing(s) covering the incision(s) near your collarbone in place and dry for 24 hours. After 24 hours, you can remove these dressing(s) and leave the incision(s) open to the air. The strips of adhesive tape that cover the incisions should be left in place until they start to peel off. This should happen about 3 to 5 days after your procedure.

The point where the CVC exits your body (exit site) will still need to be covered with a dressing. The stitch at this site will keep your CVC in place until the cuff becomes fully anchored. A nurse will change your dressing within 2 days of having the CVC placed.

If you have discomfort at your incision sites or along the tunnel, ask your nurse for medication to relieve your pain.

Taking care of your CVC

Taking good care of your CVC is important. When you visit the Outpatient BMT clinic each day, your nurse will change your dressing and caps on the lumens and flush your CVC as needed. When you are in your NY Presbyterian Guest Facility, apartment, or home (and anywhere else away from the Outpatient BMT clinic) you and your caregiver are responsible for caring for your CVC.

A nurse will teach you how to care for your CVC. You will learn how to change the dressing while making sure that it remains free from germs; this is known as “sterile technique.” Using sterile technique will decrease your risk of infection. Your caregiver will learn how to change your dressing with you. For more information on how to care for your CVC, please read the resource *Caring for Your Central Venous Catheter*, which is included at the back of this guide.

Your nurse will also give you supplies, including dressing change kits, gauze pads, tape, clamps, and other essentials.

Your CVC should not interfere with your day-to-day activities as you get ready for your transplant, but you should avoid strenuous activities and contact sports.

Clamp the lumens when your CVC is not in use. Keep your CVC secure at all times to avoid pulling it. You can tape the lumens of your CVC 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 CVC. Avoid placing tape over the connection site.

Guidelines for showering

While your CVC 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 CVC is in place. It contains a strong antiseptic and antimicrobial skin cleanser that will reduce your risk of infection. You can purchase Hibiclens® from any local pharmacy or on the Internet. You will be sent home with a small bottle when you are discharged from the hospital. If you run out of Hibiclens® at any time, your transplant team can give you additional bottles.

Here are important points to remember when using Hibiclens®:

- Do not use Hibiclens® on your face, ears, or genital area or on wounds. .
- Thoroughly wet the area to be cleansed with Hibiclens®.
- Apply Hibiclens® to a washcloth or directly to the skin being cleansed. Do not dilute the Hibiclens®. Wash gently.
- Rinse thoroughly with warm water and pat yourself dry.
- Do not use lotions, powders, or deodorants after washing with Hibiclens®.

You can shower with your CVC in place using a waterproof cover. This is 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 CVC 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.
- Do not submerge your CVC in water, such as in a bathtub or swimming pool.
- If your dressing gets wet, it must be changed.

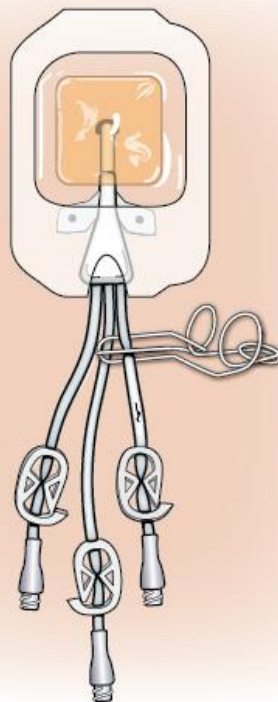
Problems with your CVC

You and your caregiver should be on the lookout for any problems with your CVC. Infection is the most serious complication to watch out for. Look at your CVC site daily. Notify your doctor, NP, PA, or nurse if you experience any of the following:

- Redness, swelling, or drainage (a liquid that can vary in color but may be clear, bloody, or green/yellowish) at your exit site
- Pain or tenderness at your exit site
- A temperature of 100.4°F (38°C) or higher
- Flu-like symptoms or chills

Other complications may be related to the CVC itself. Notify your doctor, NP, PA, or nurse if you experience any of the following:

- A hole, break, or leak in the CVC
- Swelling in your face, neck, or arm, on the same side of your body as your CVC



Clamping the CVC above a leak.

If your CVC is leaking at any time, clamp it above the leak. Use the white catheter clamp on the CVC, 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 and then cover the site with tape. Follow the instructions in your *BMT Emergency Guide* (included at the back of this guide). If it is between 8:00 am and 7:00 pm, call the BMT Outpatient Clinic. If it is after 7:00 pm, call your attending physician or go directly to the Urgent Care Center at MSK, located in the main hospital.

You can find detailed instructions on how to care for your CVC in *Caring for Your Central Venous Catheter*, which is included at the back of this guide. You should read it in full and refer to it when you are changing your dressings and catheter caps and flushing your CVC.

During Your Transplant

Summary and Checklist

There are 2 main activities in this phase of your journey. You'll receive your high-dose chemotherapy. On Day 0, your stem cells will be taken from storage and infused back into your body through your CVC.

Here is a list of things that will happen during this phase. You can check off items as you go along:

- Outpatient BMT Clinic** — You'll start making daily visits to the Outpatient BMT Clinic.
- Conditioning regimen** — You'll receive high-dose chemotherapy to kill your cancer. The chemotherapy will also kill the cells in your blood and damage your immune system.
- Learn about side effects** — The side effects of chemotherapy are significant. Take time to learn about the side effects you'll experience by reading this entire guide along with accompanying information.
- Monitor temperature and liquid intake** — Your caregiver will take your temperature every 4 hours and monitor how much liquid you drink. Your caregiver will record this information in a diary. Your healthcare team will check this information when you and your caregiver come to the clinic.
- Learn about sexuality and transplantation** — Learn about the impact that treatment and transplantation can have on your sexuality.
- Rest day (Day -1)** — You'll come to the clinic for an evaluation.
- Transplantation (Day 0)** — You'll come to the clinic. Your stem cells will be taken from storage and thawed. They will then be infused into your body through your CVC. This is your transplant.

We cover each of these activities in detail later in this section.

The Outpatient BMT Clinic

While you are being cared for on an outpatient basis, you will receive all your care, including your chemotherapy, transplant, and post-transplant care, at the Outpatient BMT Clinic. The clinic is located on the 4th floor of the main hospital. You'll make daily visits to the clinic and will only be admitted to the inpatient BMT unit if you need more care than can be provided to you in the outpatient clinic.

Each day 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). Avoid wearing clothing that is too difficult to take off or put back on.

You should bring these items to the clinic with you each day:

- 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 bone marrow transplant period.
- Your temperature and oral intake diary. Your caregiver will use this to keep track of your temperature and liquid intake while you're away from the clinic. This will be explained later.
- Books, newspapers, an audio player, a laptop, or tablet computer—whatever you need to pass the time.
- A notebook to write down key pieces of information and any questions you or your caregiver may have.

You should arrive at the clinic at your scheduled time. Once you arrive, you'll check in with the session assistant and then you'll be brought to your room. You will have a bedside or chairside entertainment unit with a TV and a computer. Your meals will be provided for you.

Your NP or PA will come to your room and will sit with you and your caregiver. Your NP will ask you a series of questions about how you are feeling and will do a physical exam. Your nurse or a patient care technician will check your vital signs and weight. Your NP or PA will check your temperature and oral intake diary; the diary is explained later in this guide.

Each day, some of your blood will be taken and sent for testing. Your blood will be checked to see how your white blood cells, red blood cells, and platelets are recovering. Your blood will also be used to check the health of your kidneys, measure your electrolyte levels, and identify any signs of infection, such as the presence of harmful bacteria or viruses.

Once you've been examined, you will wait in your room in the clinic for your test results to return. This can take several hours. This is a good time for your caregiver to take a break; he or she can take some personal time or run errands. You will be safe in the care of your healthcare team. We highly recommend that caregivers leave the hospital and take this time to unwind.

After your test results (sometimes referred to as "labs") come back from the lab, your healthcare team will analyze the results and will make decisions about your care. The rest of your visit to the clinic that day will depend on your test results.

Here are some things that can happen based on your test results:

- You could be given IV fluids to hydrate you.
- You could be given an infusion of platelets, red blood cells, or other blood components.
- Your medication could be changed.
- Your treatment could be left as is.

All of this will be explained to you. You'll remain in the clinic until all necessary treatments are completed and then you'll be free to leave. When you leave, your caregiver will take you back to your apartment or NY Presbyterian Guest Facility. There, he or she will continue to monitor your temperature and liquid intake.

If You Are Admitted to the Hospital

The information in this section describes what to expect if you are admitted to the hospital during any part of your transplant. Your attending doctor will determine if this is necessary. Some reasons for admission include (but are not limited to) fever, dehydration, and nausea and/or vomiting. As soon as the inpatient team feels it is safe for you to be discharged, you will be sent back to the Outpatient BMT Clinic.

When you are admitted

Your treatment team will take a complete medical history, ask about your current medications, and give you a physical exam. Bring 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.

Your primary nursing team will care for you throughout your hospital stay.

During your hospital stay

- You will be placed in protective isolation in the hospital to prevent you from getting an infection. A card telling your visitors about the type of isolation will be placed on the door to your room.
- You will be in your own private room. Your room will have a bed, bathroom, and TV.
- You will be connected to an IV pole with electronic pumps during your entire hospital stay.
- Your vital signs will be taken every 4 hours, 24 hours a day.

- Your urine will be measured daily during your hospital stay. It is important that we know how much urine you are making.
- Nurses typically work 12-hour shifts. The shift changes happen at 7:00 am and 7:00 pm every day. During this time, bedside patient handoff will be performed between your nurses.

Testing/evaluation

Before 6:00 am every day, you will be weighed and your blood will be drawn. Your blood will be checked to see how your white blood cells, red blood cells, and platelets are recovering. Your blood will also be used to check the health of your kidneys, measure your electrolyte levels, and identify any signs of infection, such as the presence of harmful bacteria or viruses.

Here are some things that can happen based on your test results:

- You could be given IV fluids to hydrate you.

You could be given an infusion of platelets, red blood cells, or other blood components.
- Your medication could be changed.
- Your treatment could be left as is.

The day you are admitted to the hospital, every Monday, and right before you are discharged, your nurse will take a nasal and rectal swab for testing. This is to see if you have any infections.

If you are at risk of falls, someone will be available to help you go to the bathroom. Your treatment team will tell you more about how to prevent falls.

Visitors

- Family and friends are welcome to visit you. One caregiver can stay overnight with you. However, anyone who has symptoms of a contagious disease (e.g., cough, rash, fever, diarrhea), or those who could have recently been exposed to a contagious disease, should not visit you in the hospital.
- All visitors should be able to follow infection control precautions, such as washing their hands, wearing a mask, and reporting symptoms of contagious disease. We consider age 7 to be a reasonable age to follow these requirements.
- Your caregiver and any visitors must clean their hands before each visitor enters your room using the guidelines 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, be sure to cover all of your hands with it, rubbing them together until they're dry.
- 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.
- Visitors and caregivers must use the visitor's restroom in the hallway and not the restroom in your room. This is to minimize the spread of bacteria in the room.
- Please tell family and friends not to bring or send fresh cut flowers or live plants to you. They are not allowed in your room.

Exercise

You are encouraged to get out of bed daily. We encourage you to walk around the unit. If your neutrophil count is high enough, you can walk in the hallway before 7:30 am and after 12:00 pm. You must wear a mask and gloves while you are walking around the unit. Some patients will need to wear a gown when walking in the hallway. Your nursing team will tell you what precautions you will need to take.

Communication

Each room has a call bell system that is monitored 24 hours and day, 7 days a week by unit assistants. If you need something, please tell the unit assistant exactly what you need to so that we can direct the appropriate team member to help you. The 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 treatment team. You will be given a menu and instructions on how to order your meals.

Showering and hygiene

You will be expected to shower daily. You will be helped or observed when showering. Your patient care technician will arrange a time for you to shower. It is also important that you practice good oral hygiene to prevent infection. Your nurse will go over this with you.

The Conditioning Regimen: Receiving Your Chemotherapy

The conditioning regimen is another name for the high-dose chemotherapy that you will receive before your transplant. The regimen you will receive depends on your disease, previous treatments, and your treatment plan.

The conditioning regimen starts on a negative numbered day. Depending on your treatment plan, you may have 1 or multiple days of chemotherapy. Your stem cell transplant always takes place on Day 0. Remember that every day after your transplant is referred to as a positive numbered day (e.g., Day +1, Day +2, etc.).

Day -14 to Day -2	Day -1	Day 0	Day +1
Conditioning regimen (chemotherapy)	Rest day	Stem cell infusion (transplant)	Start of supportive care

Your clinical coordinator will work with you to plan your schedule and will provide you with a treatment calendar. He or she will tell you the date and time of your treatment.

On the morning of your chemotherapy treatment, you and your caregiver will make the first of your regular visits to the Outpatient BMT Clinic.

Once you have checked in and been evaluated by your NP or PA, you will meet with your clinical pharmacist. Your pharmacist will explain the medications you will take throughout your treatment and will show you how to use your pill box. Your pharmacist will give you all the medications that you will need to take, along with a list that tells you when to take each different medication.

Once you have been evaluated and your pharmacist has spoken to you about your medications, you'll receive your chemotherapy.

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), anti-nausea medication, and the chemotherapy medication through your CVC.



A patient receiving chemotherapy through a CVC.

During your visit on the day you receive chemotherapy, your healthcare team will use this time to talk to you about the rest of your transplant journey.

Your healthcare team will make sure that the logistics of the next few days are clear, including what happens on transplant day and what happens after your transplant.

They will talk to you about the side effects you'll start to experience after your chemotherapy. You'll be given printed materials that explain these side effects in detail and you'll be shown what to do if you need to get help while you are in your apartment or NY Presbyterian Guest Facility.

Monitoring Your Temperature and Liquid Intake

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 and monitor all of the liquids you drink. Your caregiver will write this information in the *Temperature and Oral Intake Diary*. A sample page from the diary is included at the back of this guide.

Your nurse will give your caregiver a thermometer and will show him or her how to use it. Your nurse will show both of you how to use the diary.

You should drink 2 liters or 64 fluid ounces of liquids each day. Try to drink steadily throughout the day—little and often.

Your caregiver should bring the diary to the clinic each day. Your NP or PA will review the diary with you and your caregiver each day at the clinic.

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're 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) 639-2399.
- If it is after 7:00 pm, call (212) 639-2000 and ask for the doctor covering bone marrow transplant.

Rest Day

The day between your chemotherapy and your transplant day is a rest day. This rest day allows the chemotherapy medication to work and then leave your body. When you receive your stem cells, there will be no trace of the chemotherapy medication in your body, so the transplanted stem cells will not be harmed.

On the rest day, you will come to the Outpatient BMT Clinic as usual, where you will be evaluated. Your healthcare team will also use the rest day to speak with you about your stem cell infusion, communicate important information, and teach you and your caregiver useful skills.

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, the stem cells that were separated from your blood and frozen earlier will be reinfused into your body. These stem cells will give you back your ability to make new blood cells and fight infections.

The morning before your transplant

On the morning of Day 0, your transplant day, you and your caregiver should come to the Outpatient BMT Clinic as usual, at your scheduled time. Give yourself extra time to get to the clinic, as you may feel tired after your chemotherapy.

Your stem cell infusion

Before the stem cell infusion, your frozen stem cells will be removed from storage in the stem cell laboratory and brought to your room. The stem cells are stored in clear plastic bags that look like bags of blood. The bags will be placed in a warm water bath to thaw.

You will be given medications about 30 minutes before your transplant to help reduce any side effects that you may experience during the infusion.

Once the stem cells are thawed, your NP, PA, or doctor will infuse the stem cells into your body 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, a tickle in your throat, or a cough. Other side effects that can occur include low blood pressure, chills, and fever.

It's important that you communicate with your healthcare team and with your caregiver during your transplant. Let your healthcare team know how you're feeling and tell them if you experience any side effects. If you do experience side effects, your healthcare 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 into your body. This is your body's way of getting rid of the byproducts of the stem cells that are not needed.

After your stem cells are infused through your CVC, you will remain in your hospital room for 4 to 6 hours for observation. After that, you will be allowed to return home to your NY Presbyterian Guest Facility or apartment to rest.

After Your Transplant

Now that you've had your transplant, you will enter a period of watching and waiting for your stem cells to begin producing new blood cells, a process called engraftment.

As engraftment occurs, the number of white blood cells, red blood cells, and platelets in your blood will return to normal. The amount of these cells, called your "counts," will be monitored daily. You will remain in a nearby apartment or NY Presbyterian Guest Facility and will return to the outpatient clinic each day to have your progress evaluated and to have adjustments made to your treatment.

Summary and Checklist

Here is a list of things that will happen during this phase. You can check off items as you go along:

- Learn about chemotherapy side effects** — You may experience side effects associated with your treatment and transplant. We've compiled a list of these side effects. Read this information and make a note of any questions you or your caregiver have.
- Return to the Outpatient BMT Clinic** — You will make daily visits to the clinic until your healthcare team tells you that you can come less often.
- Testing** — You will undergo blood tests and other tests as needed to monitor your progress. You will have blood drawn each time you return to the clinic.
- Neutropenia** — The low number of white blood cells in your blood will leave you vulnerable to infection, so you will need to take precautions to avoid any sources of infection.
- Low-microbial diet** — Because you are neutropenic, you will eat a diet that contains a low number of potentially harmful microbes.
- Low platelet count** — The low number of platelets in your bloodstream will make you vulnerable to bruising and bleeding. You will need to take care to avoid causes of bleeding.
- Low red blood cell count** — You will experience fatigue.
- Transfusions** — You may need to receive a blood transfusion to boost the numbers of red blood cells and platelets in your bloodstream.
- Personal care** — Because you are neutropenic and have a low platelet count, you will need to take special care when you bathe, shower, and brush your teeth.
- Changes to sexual activity** — Learn how to be sexually active in a safe way after your transplant.

- **Learn about engraftment** — The stem cells that have been reinfused into your body will find their way to your bone marrow and begin to make new blood cells. This is called engraftment. You should read about this process and write down any questions you have.
- **Recovery of your counts** — Over time, as your stem cells engraft and begin to produce new blood cells, your 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.

We will cover each of these topics in detail later in this section.

Post-transplant Care at the Outpatient BMT Clinic

You will receive all your care in the Outpatient BMT Clinic—the same place where you had your chemotherapy and your transplant. Each day, you will return to the clinic, just like you did on the mornings before chemotherapy and your transplant.

Side Effects From Chemotherapy

Chemotherapy will kill the cancerous cells in your body and will prepare your bone marrow to receive your transplant. However, the side effects associated with chemotherapy are not to be taken lightly. These side effects may include the loss of your ability to fight infections, infertility, hair loss, fatigue, nausea and vomiting, mouth sores, or mouth tenderness.

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

Low white blood cell count (neutropenia)

Your chemotherapy will severely damage your ability to fight infections and heal. It's important that you understand why this happens, how to watch for danger signs, and how to avoid infections and injuries.

One side effect of chemotherapy is called neutropenia. Neutropenia is a condition in which you have a lower than normal number of neutrophils (a type of white blood cell) in your bloodstream. Neutrophils play a crucial role in your immune system—they are one of the first types of cells that travel to the site of an infection. Once they reach the site of an infection, they ingest and fight potentially harmful microorganisms.

Because your chemotherapy will kill your stem cells, you will lose your ability to make new neutrophils. Since your neutrophils are not being replaced, the number of neutrophils in your bloodstream will drop to a very low level, leaving you at high risk of infection. You and your caregiver will work together to watch for any sign of infection. You'll keep a record of your temperature, even when you

are in your NY Presbyterian Guest Facility or apartment, and you will have to take very careful precautions to avoid infection.

Low platelet count (thrombocytopenia)

In addition to losing your ability to make neutrophils and other types of white blood cells, you'll also lose your ability to make platelets. Platelets clump together to help stop bleeding. After your chemotherapy, the number of platelets in your bloodstream will be very low, a condition called thrombocytopenia.

You will need to take special care to avoid cuts and strenuous activities that may cause bleeding. You need to take special care of your gums and mouth because it's common for bleeding to happen there.

After your transplant, your healthcare team will take samples of your blood each day to count the number of neutrophils and platelets in your bloodstream.

As your stem cells take hold and start to make new blood cells, the number of neutrophils in your bloodstream (sometimes referred to as your absolute neutrophil count, or ANC) will increase, as will your number of platelets (called your platelet count). All together, these are known as "your counts." When your counts recover, this is a key sign that you are engrafting. You'll hear the term "counts" used frequently by your healthcare team.

More in depth information about living with neutropenia and low platelet levels are included later in this guide.

Fatigue

After chemotherapy, the number of red blood cells in your blood will be very low.

Red blood cells are the cells that transport oxygen around your body. Because the number of red blood cells in your blood will be low (anemia), oxygen will not travel around your body as easily as before. This means that you will feel tired. Your caregiver may need to help you carry out day-to-day activities until your red blood cell count returns to normal. Don't be afraid to ask for help, even with things you used to do with ease.

Even though you will feel tired after your chemotherapy and your transplant, you should still try to remain active.

Nausea and vomiting

Nausea and vomiting are common side effects of chemotherapy. 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 having chemotherapy. The amount of nausea and vomiting you have will depend on your past experience and the type of chemotherapy you will receive. Sometimes, you may experience nausea during your chemotherapy treatment, or it may be delayed for several hours or days. It is important to manage nausea because it can keep you from eating and drinking. It is important that you stay well hydrated.

You will be given medication to prevent and control nausea prior to receiving chemotherapy. You will also be given a prescription for antinausea medication to take home with you. These medications work differently for each person. If the medication you are taking isn't helping, tell your NP or doctor. You may need to try a different medication or take more than one kind of antinausea medication to feel better. Your healthcare 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, medications, infection, stress, or other medical conditions. If you are having diarrhea, you can become dehydrated due to loss of body fluids and electrolytes. If your diarrhea continues for more than 24 hours, call your doctor or NP. Medications are available to treat diarrhea but do not take any over-the-counter medication until you have been evaluated by your doctor, NP, or PA.

Constipation

Constipation is the passage of dry, hard stool that occurs when materials move too slowly through the large intestine. The normal length of 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 are probably constipated.

There are many causes of constipation, including not drinking enough liquids or not eating enough fiber, a decrease in your activity, not moving around or walking enough, and side effects of certain medications including chemotherapy. Medications are available to treat constipation. Talk to your NP, PA, or doctor if you haven't had a bowel movement for more than 2 days.

Mouth sores

Some chemotherapy drugs affect the cells that line the mouth and digestive tract. This is known as mucositis. Mucositis can cause redness, swelling, tenderness, and sores on the lining of your mouth, tongue, and lips. You may experience some mouth and throat discomfort that can make it difficult to eat or swallow.

Skin changes

Skin changes are common side effects of cancer treatment. These changes include increased dryness, flaking, discoloration, and darkening. Your skin will be very sensitive to the sun and may sunburn very easily. Avoid bright sunlight; and when outdoors, wear sunscreen (SPF 30) and protective clothing, such as long-sleeved shirts, long pants, and a hat.

Hair loss

The chemotherapy that kills cancer cells also kills the cells that make your hair. Most patients will lose their hair during their transplant.

Losing your hair can be an unpleasant and upsetting experience. Like many patients, 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 might make you feel more comfortable. There are many wig stores in New York, a list of them is included in the resource *Hair Loss During Cancer Treatment*, which is included 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.

Living With a Low White Blood Cell Count (Neutropenia)

As you know, your chemotherapy will kill not only the cancerous cells in your body, but also healthy stem cells that make the different types of cells in your blood. This is why you received a transplant.

Neutrophils, a type of white blood cell, play a crucial role in your immune system. In the days and weeks after your transplant, you will have a very low number of neutrophils in your bloodstream. This will leave you at high risk for infection.

You and your caregiver will need to take careful precautions to avoid infections while you are neutropenic. These precautions will include eating a special, low-microbial diet (a diet that contains a low number of potentially harmful microorganisms), washing carefully, taking care of your mouth, and other precautions.

Avoiding sources of infection

One of the best ways to avoid infection is to avoid 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 you are neutropenic, you should try to avoid:**

- Shaking hands with people. When you do shake hands with people, use an alcohol-based hand sanitizer, such as Purell®, afterward.
- Contact with animals, including your pets—they can't stay with you during your transplant.

Your caregiver will need to carefully manage who comes to see you while you are neutropenic. He or she needs to make sure that friends, family, and other visitors understand the following precautions:

- Anyone who has symptoms of a contagious disease (e.g., cough, rash, fever, diarrhea), or those who could have recently been exposed to a contagious disease, should not visit you.
- All visitors should be able to follow infection control precautions, such as washing their hands, wearing a mask, and reporting symptoms of

contagious disease. We consider age 7 to be a reasonable age to follow these requirements.

- Your caregiver and any visitors must clean their hands using the hand hygiene guidelines below before each visitor enters your room at the clinic or at your NY Presbyterian Guest Facility or apartment:
 - 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, be sure to cover all of your hands with it, rubbing them together until they're dry.
- You must clean your hands using the hand hygiene guidelines above prior to eating and after using the bathroom.
- While you are in the clinic, visitors and caregivers must use the visitor's restroom in the hallway and not the restroom in your room. This is to minimize the spread of bacteria in the room.
- You should not keep any plants in your NY Presbyterian Guest Facility or apartment and should not accept gifts of flowers or plants. Avoid contact with soil or dirt.

It's difficult to tell people who love you and want to make sure that you're okay that you can't be with them; however, you and your caregiver need to be vigilant. You can explain to them that it's just for a short period of time, and that by taking these precautions, you are making sure that you can see them as soon as possible. They will understand.

We recommend that you use a computer or tablet and programs like Skype, Google Talk/Hangouts, or FaceTime to keep in touch with friends and family when you are neutropenic.

Eating a low-microbial diet

While your counts are returning to normal, and until told otherwise by your healthcare team, you will need to eat what is called a low-microbial diet.

A low-microbial diet contains fewer microbes (also called microorganisms) than would ordinarily be found in everyday foods. Microbes are tiny living organisms, such as bacteria, viruses, yeast, and molds. This diet helps people with weakened immune systems and low blood counts reduce the risk of food-borne illnesses caused by bacteria and other microbes that are found in some foods and drinks. Eating a diet that contains fewer microbes will help prevent you from getting sick.

Microbes can attach to foods and grow, but you can't always see, smell, or taste them. They are more likely to grow on milk, unrefrigerated foods, undercooked foods, certain fruits and vegetables, unpasteurized juices, and vegetable sprouts—but in reality, they can grow on any food.

You will need to take careful precautions with the food you eat, including:

- Buying foods that you know have been stored properly and are safe to eat.
- Storing food safely in your NY Presbyterian Guest Facility or apartment.
- Keeping your kitchen very clean.
- Keeping your refrigerator very clean.
- Handling food safely.
- Eating only food that you know has been prepared and cooked in keeping with a low-microbial diet.
- Cooking foods thoroughly.

Refer to the resource titled *Low-Microbial Diet* at the back of this guide. Follow the guidelines very carefully when you or your caregiver is buying, handling, preparing, and cooking food.

Personal hygiene

While you are neutropenic, keeping yourself clean is very important.

You should shower daily using Hibiclens®. Take extra care to wash yourself thoroughly. Begin with your upper body, then the middle section, and wash the lower area including your feet last. Wash carefully under your arms. Do not let Hibiclens® get into your eyes, ears, mouth, or genital area or on wounds. Do not use lotions, powders, or deodorants after washing with Hibiclens®.

Wash carefully in your anal and genital areas and in any skin folds using soap that can kill germs. Look for the words “antibacterial” or “antimicrobial.” Dial® is one example, but there are many others. Germs tend to live in those moist areas. You can shampoo your scalp with soap once a day.

After you urinate or move your bowels, wash your buttocks and genital area with antibacterial soap. You can also use moist wipes. Pat the area dry. Wash your hands well afterward.

For more information about washing and bathing, including taking care of your CVC, see page 27.

Mouth care

While you're neutropenic and have a low platelet count, 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.
- Use an ultra-soft toothbrush.
- You may use toothpaste that you buy in the store, but only the mouthwash that your nurse gives you. Most mouthwashes that you buy in the store contain alcohol, which could irritate and dry your mouth and throat.
- Do not use dental floss.
- Avoid licking your lips. It increases dryness and chapping.
- Apply a lubricant like Burt's Bees® or Chapstick® 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 antibiotic. 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 pain in your mouth, your doctor will prescribe medication for the pain.

Living With a Low Platelet Count (Thrombocytopenia)

Platelets clump together to help stop bleeding. Because you will have a very low platelet count after chemotherapy, you will need to take special care to avoid cuts and strenuous activities that may cause bleeding. You will need to take special care of your gums and mouth because it's common for bleeding to happen there. You and your caregiver will need to take these special precautions:

- Avoid sharp objects, such as razors, scissors, and nail clippers. You should only shave using an electric razor/shaver and not 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 on mouth care (above).
- Do not use rectal suppositories, enemas, or tampons.
- Do not take your temperature rectally (in the rectum).
- Consider using stool softeners or laxatives if you are straining to have bowel movements.
- 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

You should take precautions when you are having sex. You should use lubrication if needed and avoid anal and oral sex. Avoid strong thrusting, as this can cause bleeding.

You should avoid medications that have not been prescribed to you by your medical team. Do not take:

- Aspirin or products that contain aspirin
- Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil®)
- Vitamin E

All of these medications make it more difficult for your blood to clot and are very dangerous for somebody with a limited ability to heal and clot.

Call your doctor if you develop any symptoms of bleeding. Be on the lookout for:

- Bruising
- A faint red rash on your torso, arms, or legs
- Vaginal spotting or heavy menstrual bleeding

- The appearance of broken blood vessels in the whites of your eyes

If you notice that you are bleeding, take the following steps immediately:

1. Apply direct pressure on the bleeding site. If you are having a nosebleed, 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) 639-2399. If it is after 7:00 pm, call (212) 639-2000 and ask for the doctor covering bone marrow transplant.

Call your doctor immediately if you:

- Have black bowel movements, blood in your stool, or rectal bleeding
- Have blood in your urine
- Have 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

Living With a Low Red Blood Cell Count (Anemia)

Your chemotherapy will cause you to have a very low red blood cell count, a condition known as anemia. Hemoglobin in red blood cells carries oxygen from the lungs to the tissues in all parts of the body. When your red blood cell count is low, your body can't carry oxygen as well. Anemia can make you feel tired and weak. You may also feel dizzy or lightheaded or have shortness of breath when changing positions quickly from lying to standing.

Some of the side effects of anemia include:

- Increased tiredness
- Weakness
- Rapid heartbeat
- Shortness of breath
- Headache
- Pale skin

If you have anemia, your doctor may prescribe 1 or more of the following:

- A blood transfusion

- Rest
- Changes to your diet
- Iron supplements

Receiving a Transfusion

Your doctor may recommend a transfusion to boost the number of platelets or red blood cells in your body.

If your doctor recommends a transfusion, it will be given to you through your CVC during one of your regular visits to the Outpatient BMT Clinic.

A transfusion of red blood cells usually takes 2 to 4 hours. A transfusion of platelets usually takes 30 to 45 minutes.

Sources of blood for your transfusion

The blood used in your transfusion is donated at our blood bank. There is no substitute for real blood, so we are incredibly grateful to the people who donate blood.

Your friends and relatives may donate red blood cells and platelets—this is called a directed donation. Your friends and relatives are eligible to donate if they:

- Are between 16 and 75 years old. No parental consent is required for those who are at least 17 years old.
- Weigh at least 110 pounds.
- Are in good health.
- Have not had an illness such as hepatitis, jaundice, cancer, etc.
- Do not have signs of a cold or active allergy at the time of donation.
- Have not taken aspirin, or any medication that has aspirin or NSAIDs (ibuprofen, Motrin®, Naprosyn®, Anaprox®, Advil®, Aleve®) within 3 days before giving blood.
- Have identification showing their name and photograph or signature.
- Have not consumed alcohol for at least 8 hours before donating.

Blood donations can be arranged by appointment at our Blood Donor Room, which is located at:

MSK Schwartz Building Lobby
1250 First Avenue (between East 67th and East 68th Streets)
New York, NY 10065

For more information about making a directed donation and to make an appointment, your friends and family should call our Blood Donor Room at (212) 639-7643.

If your friend or family member has a blood type that isn't compatible with yours, then their blood will be released for use with other patients at MSK.

Directed donations will be held for you for 30 days. After that, the blood will be released for use with other patients at MSK.

Making sure blood is safe

After it is donated, all blood is tested for:

- Syphilis
- Hepatitis B and C
- Exposure to the HIV virus
- The presence of a virus associated with a very rare form of leukemia
- West Nile virus
- *Trypanosoma cruzi* (a type of microorganism)

The chance of getting any of these from donated blood is very small. Directed donations are tested in exactly the same way as other donations.

Risks associated with blood transfusions

Blood transfusions have some risks. These risks include the very slight chance of having an allergic reaction or of acquiring an infection through tainted blood.

Side effects during and after your transfusion

Transfusions sometimes cause reactions. The most common symptoms are fever, chills, and hives. These can be treated with a variety of medications. Transfusion reactions are rarely life threatening.

Allergic reactions can sometimes occur up to 48 hours after the transfusion. Call your doctor immediately if you have:

- A temperature of 100.4°F (38°C) or higher

- Chills
- Flushing of your face
- Hives, rash, or itching
- Trouble breathing or shortness of breath
- Lower back pain
- Nausea or vomiting
- Weakness or fainting
- Blood in your urine
- Chest pain (**If you are having chest pain, call your local emergency number immediately**)

The Importance of Communication

Throughout your treatment, it's very important that you communicate clearly with your healthcare team and your caregiver about your side effects.

Tell your healthcare team how you're feeling. Describe how your body feels. Describe how you're doing emotionally. Tell them if anything is worrying you. If you notice changes in how you feel, describe what has changed. If anything bothers you, even if it seems minor, tell your healthcare team. The more information you can communicate to your healthcare team, the more they'll be able to help you. There is usually something that they can do to make you feel more comfortable.

Coping With Separation From Children

Separation from your children will be difficult for you and your family. We know from past experience that patients with children experience a range of feelings and reactions related to this separation.

We strongly recommend that you talk to one of our social workers about being separated from your children. Have your caregiver tell any member of your healthcare team that you'd like to speak with a social worker and they will make sure to come and see you. They will listen to your concerns and help you develop a plan to maintain strong ties to your children while you are undergoing treatment.

Here are some things that other patients have done to remain in contact with their children during their transplant.

- Use a computer or tablet and programs like Skype, Google Talk/Hangouts, or FaceTime to talk to your children regularly. 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. Craft supplies can be provided to you by the Patient Recreation Center. Ask a member of your healthcare team to arrange for the Patient Recreation Center to bring supplies to you.
- Use your cell phone or a tape recorder to make an audio recording of yourself as you read 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 apartment, or NY Presbyterian Guest Facility. At night, you can use Skype to read along with them before they go to sleep.
- Ask your children to decorate your apartment, or NY Presbyterian Guest Facility with pictures; your caregiver can bring them to you and you can show them hanging on the wall over Skype.
- Give your child 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 to your child about them over Skype or on the phone.

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

For more assistance related to maintaining your relationship with your children, contact your social worker.

Exercise

Exercise is an important part of the recovery process during and after stem cell transplantation. Benefits of exercise include increasing energy, muscle strength, and bone density. Exercise can also prevent respiratory and circulatory problems, decrease fatigue, and improve your ability to be as independent as possible.

While in the outpatient transplant program, you are encouraged to walk to and from the hospital daily, which will help maintain your conditioning. During the hours you are in the clinic, you are encouraged to walk in the hallways (wearing a mask and gloves) 2 to 3 times daily. While you are staying locally, you are encouraged to walk outside (weather permitting).

If you have special needs, you will be seen by a physical therapist for an evaluation.

Changes to Sexual Activity

Sexual intimacy provides pleasure and comfort for many people after their treatment. The information below can serve as a guide to being sexually active in a safe way after your transplant. You may have questions or concerns regarding your sexual activity. You are encouraged to discuss your concerns openly with your doctor, NP, PA, or nurse.

Birth control

While it's likely that you won't be able to conceive a child naturally after high-dose chemotherapy, you and your partner should use contraception (birth control) during and after your chemotherapy until your doctor tells you it is safe to attempt to conceive. If a woman becomes pregnant with sperm or eggs that have been damaged by exposure to radiation, chemotherapy, or other anticancer medications, she may miscarry or there may be birth defects.

It's important to pick a method of birth control that fits your lifestyle and will be effective. Women can speak with their gynecologists to choose between the many available options. These options include condoms, which are very effective in preventing pregnancy when used correctly.

Protecting your partner from exposure to chemotherapy and other anticancer medications

There is little information about how much anticancer medication gets into a person's body fluids, and even less about whether this poses any risk to a sexual partner. If this is a concern for you, consider using a barrier device whenever your partner may come into contact with your semen (if you are male) or vaginal fluids (if you are female). Barrier devices include condoms and dental dams. We don't know how long these medications may be in your body fluids, but if you are concerned about this, you should use barrier devices each day you have chemotherapy and for 1 week afterward.

Protecting yourself from infection or bleeding during sex

You will be at increased risk of infection during your transplant period and for many months after your treatment.

Until your doctor tells you that your blood counts and immune system have recovered, follow these precautions:

- Avoid sex that involves penetration or contact with mucous membranes while your blood counts are low (your platelet count needs to be more than 50,000). This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or other sex toys into your vagina or anus.
- Use latex condoms each time you have vaginal, oral, or anal sex.
- Use a barrier device (condoms or dental dams) anytime your partner's saliva, vaginal secretions, or semen could enter your mouth.

- Abstain from 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.

Hugging, cuddling, gentle touching, and kissing skin are other ways you can be intimate with your partner during this time. For additional information about being sexually active during and after treatment, see the additional resources at the back of this guide:

- *Sexual Activity During Cancer Treatment: Information for Women*
www.mskcc.org/cancer-care/patient-education/resources/sexual-activity-during-treatment-information-women
- *Sexual Activity During Cancer Treatment: Information for Men*
www.mskcc.org/cancer-care/patient-education/resources/sexual-activity-during-treatment-information-men
- *Sexual Health and Intimacy*
www.mskcc.org/cancer-care/patient-education/resources/sexual-health-and-intimacy

The American Cancer Society publishes 2 well-written books on sexuality following cancer treatment. They are available free of charge from your local American Cancer Society or on the ACS website:

- *Sexuality for the Man With Cancer*
www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf
- *Sexuality for the Woman With Cancer*
www.cancer.org/acs/groups/cid/documents/webcontent/002912-pdf.pdf

Engraftment

Engraftment is when your body accepts the transplant and your white blood cell count starts to recover.

Almost immediately after your stem cells are infused into your body, they will travel through your bloodstream into your bone marrow. Once the stem cells arrive in your bone marrow, they will begin to engraft. Engraftment usually happens about 10 to 14 days after your transplant, but this may vary depending upon your disease and exact treatment. Platelets and red blood cells usually take a little longer to recover than white blood cells.

Each day when you return to the Outpatient BMT Clinic, you will have blood drawn. This blood will be analyzed and the different types of cells in your blood

will be counted. When your stem cells engraft and start to divide, the number of white, red, and platelet cells will increase.

While you are waiting for engraftment, you may need to have blood and platelet transfusions. You'll be given injections of growth factor, which is a medication that will speed up the production of white blood cells in your body.

Remember, you will be very vulnerable to infection during this time. You will need to take precautions, including avoiding sources of infection, washing your hands regularly, and eating a low-microbial diet. You will be closely monitored for any signs of infection.

When your cells start to engraft, you may experience bone pain or a rash on your body. These are common symptoms experienced during engraftment.

Returning Home After Your Transplant

You will remain in your nearby apartment or NY Presbyterian Guest Facility for several weeks following your stem cell transplant, returning to the Outpatient BMT Clinic each day.

When your healthcare team sees that you are ready, they will allow you to return home. You and your caregiver will check out of your apartment or NY Presbyterian Guest Facility. You will still visit the clinic, but less frequently.

Before you return home, it's important that you and your caregiver prepare for this transition. You will still need to follow precautions to keep you healthy and prevent infection.

As you read this information, jot down or mark the place(s) where you have a question. This will help remind you to ask your question(s) the next time you see your transplant team.

The time frames given here are general guidelines and may vary. Your transplant team may give you a more exact time frame.

Before Going Home

It is 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.

MediAlert® jewelry

Before you leave the hospital, you will need to order a MediAlert® 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 staff in any hospital know what to do if you are in an accident and cannot tell them yourself.

Discuss with your transplant team 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 MediAlert® bracelet or necklace.

For more information on MediAlert®, go to: www.medicalert.org

Going Home

You may be very happy and feel ready to go home. However, it is common for people to have some worries and concerns as their discharge date draws near. At home, you and your family will need to manage your care. Feeling confident and

comfortable doing this is a process that takes time. You can meet with your social worker during your follow-up appointments. He or she can help you get the services you need and can give you emotional support.

When you go home, you will need to adjust to living with your family again. You may find that the precautions you must take in the months ahead might add some stress to your life. People have told us that the key to managing this new stress is to remain as calm and confident as you can. Regaining a sense of balance and comfort will come with time.

You will not feel the same way you did before your illness. You may feel tired and weak. Your appetite may not be what it once was. You may have changes in your senses of taste and smell. It may take time for you to regain your strength and to be able to take part in the activities you enjoyed before your transplant.

Preventing Infection

It usually takes 3 to 12 months for your immune system to recover from your transplant. We often tell people that the first year after transplant is like your first year of life as a newborn baby. During that time, you are at risk for infection. Your transplant team will be checking your blood cell counts to see how well your immune system is working. This will help them advise you about any changes to the guidelines you must follow.

Be aware of the symptoms of infection listed below. 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, and/or pain in your throat, eyes, ears, skin, joints, or abdomen
- Blurred vision or other changes in your ability to see clearly
- Frequent urination, burning on urination, or both
- If you still have a CVC, difficulty flushing it, or any chills associated with flushing it
- Irritation in your rectum, including burning and pain

- A rash
- Small blisters, similar to cold sores, around your mouth or on any other part of your body

You can catch viruses more easily until your immune system is back to normal. Also, viruses that you have had in the past can reactivate. One of these is the virus that causes chicken pox and shingles. If you are exposed to either of these illnesses, call your transplant doctor or nurse immediately. You will need to be assessed. The virus can also reactivate in patients who have already had chicken pox as a child. This often starts as pain in the skin with pimples or fluid-filled blisters. If you develop blisters, they can be tiny or as large as a pencil eraser. The blisters may be painful, itch, or burn. If you have any of these symptoms, call your doctor or nurse immediately so you can be treated.

Once your immune system has recovered, you will begin receiving your childhood vaccines. This usually starts about 1 year after 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 and can help prevent infection. Follow the guidelines below.

- Shower or bathe daily. 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 your underarms and groin. 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 you bathe, while your skin is still damp. Gently pat your skin dry with your towel. Do not use lotions containing alcohol. They will increase dryness.
- Hair usually starts to grow back about 3 months after the transplant. It is possible that your hair may grow back with a different texture. Although it is rare, hair loss can happen months or years after the transplant.
- Limit your time in direct sunlight. Your skin will be more sensitive and may burn more easily after your transplant. The medications you are taking may add to this. Whenever you are in the sun, protect your skin

with a sunblock that has an SPF of at least 30. Reapply it often. If you will be in direct sunlight for 20 minutes or longer, cover your skin with cotton clothing and a protective hat. Prolonged exposure to the sun may also reactivate cold sores (herpes simplex virus).

- You can wear contact lenses but sure that they are thoroughly cleaned before you put them in. Do not reuse cleaning solution. Be sure to discard cleaning solutions when they have expired.
- You can wear makeup. Purchase all new products after your transplant.
- New nails will grow and replace your old nails. This will happen gradually over 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

You can brush your teeth with an ultrasoft toothbrush if:

- Your absolute neutrophil count (ANC) is higher than 500 (sometimes called 0.5).
- Your platelet count is 20,000 (sometimes called 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 an infection. Soak them every day in any type of denture cleaner. Use the directions on the product. Then, 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.

Dryness of the mouth is another symptom you may have for 3 to 4 months or longer after your transplant. Do not use commercial, alcohol-based mouthwashes

or hydrogen peroxide. They will dry and irritate your mouth. Instead, use a mild salt water rinse. Make it 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.

Your salivary glands may not be as good at washing bacteria from your mouth after your transplant. This increases your risk of cavities. Use a toothpaste with flouride. You can also use a mouthwash with flouride once your mouth has fully recovered and is no longer very 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. However, you should not go to extremes. Do not repaint your walls or put down new carpets. In fact, you should not be around any renovations or construction until your transplant team approves. This includes those in process and those done within the past 3 months. Stay out of any musty area where mold may grow, such as a damp basement. 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.**

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, or iron. Your bathroom should be kept very clean (especially the tub and toilet). Use a disinfectant regularly.

Wash your eating utensils and linens carefully. They do not need to be washed separately from the rest of your household. 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. Use only your own towels and washcloths, not those of your family members.

Household plants can remain 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

Animals can carry diseases. They may put you at greater risk for infection while your immune system is recovering. 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 feces. Be sure to protect yourself from bites or scratches. Do not handle or care for birds, lizards, snakes, turtles, hamsters, or other rodents while you are recovering. If you have an aquarium and you must clean it yourself, you must protect yourself by wearing gloves. If you have a cat or dog at home, 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).
- 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. 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 is best that you select a healthy dog or cat that is more than 1 year old. Have it spayed or neutered. Outside of your home, avoid close contact with animals in a farm or a petting zoo.

Family and visitors

You can have close physical contact with those in your immediate family. However, do not have close contact with someone who has a cold or any signs of being sick. Wear a mask if you must be in the same room with someone who is sick. Your family members and close friends should get a yearly flu shot.

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, his or her 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.

Outside your home

Take regular walks outside, but avoid dirty areas and construction sites. Walking is an excellent way to regain your strength and endurance. However, 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

You can go to these places at off-peak hours, when there are fewer people. Avoid taking public transportation for at least 3 months after your transplant. Your doctor will tell you when some or all of these restrictions can be lifted.

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 patients are discharged 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, purplish-red spots on the skin that do not disappear when you press them. You may see them on your lower legs or inside ankles after you are discharged. 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 have gone home with any of these symptoms and they increase in amount or frequency, call your doctor. If you have not had any of these symptoms and suddenly develop them, call your doctor. It may mean that 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 it 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.
- **Nose bleeds:** If you have a nose bleed, 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 the bleeding persists, 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.

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® to prevent gum bleeding. Do not use dental floss.
- Do not take aspirin, products that have aspirin, and aspirin-like medications, such as 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, 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 about this, discuss it 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 is not unusual. 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. **Do not swim if your CVC is still in place.**

Hobbies

Some hobbies like wood working, painting, and model building use products that can be toxic. Always work in a room with plenty of fresh air. 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 2 to 4 months from the time of your transplant. 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 patients have talked about feelings related to changes in their appearance. Hair loss, for example, is very hard for many. 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.

Sexual Health

Before you go home, ask your doctor about resuming 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 from infection or bleeding during sex

Until your doctor tells you that your blood counts and immune system have recovered, follow these precautions:

- Avoid sex that involves penetration or contact with mucous membranes while your blood counts are low (your platelet count needs to be more than 50,000). This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or other sex toys into your vagina or anus.
- Use latex condoms each time you have vaginal, oral, or anal sex.
- Use a barrier device (condoms or dental dams) anytime your partner's vaginal secretions or semen could enter your mouth.
- Abstain from 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.

Hugging, cuddling, gentle touching, and kissing skin are other ways you can be intimate with your partner during this time. For additional information about

being sexually active during and after treatment, see the additional resources at the back of this guide:

- *Sexual Activity During Cancer Treatment: Information for Women*
www.mskcc.org/cancer-care/patient-education/resources/sexual-activity-during-treatment-information-women
- *Sexual Activity During Cancer Treatment: Information for Men*
www.mskcc.org/cancer-care/patient-education/resources/sexual-activity-during-treatment-information-men
- *Sexual Health and Intimacy*
www.mskcc.org/cancer-care/patient-education/resources/sexual-health-and-intimacy

The American Cancer Society publishes 2 well-written books on sexuality following cancer treatment. They are available for free from your local American Cancer Society or on the ACS website at the links below:

- *Sexuality for the Man With Cancer*
www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf
- *Sexuality for the Woman With Cancer*
www.cancer.org/acs/groups/cid/documents/webcontent/002912-pdf.pdf

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 MSK resource *Vaginal 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. This could have an impact on your relationship. However, as you regain your strength and increase your activities, this too will 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.

Drinking Alcohol and Using Tobacco

After your transplant, your organs need time to recover. Alcohol can harm your liver and your recovering bone marrow. This harm can be worse if you are taking medications that can affect your liver. Do not drink alcohol until your doctor tells you it is safe.

Never smoke:

- Cigarettes
- Cigars
- Marijuana
- Other tobacco products

Doing so can lead to a serious lung infection. It can also increase your risk of a second cancer. If you need help quitting, contact the MSK Tobacco Treatment Program at (212) 610-0507 or go to www.mskcc.org/cancer-care/counseling-support/tobacco-treatment

Follow-Up Care

Your follow-up visits will be scheduled before you are discharged. Your doctor will determine how often you will need these visits. Some patients find it helpful to bring a list of questions that may have come up since the last visit. Your appointments will be further apart as long as you are doing well.

When you come to your follow-up visits, 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. Your doctor will tell you if and when you will need a bone marrow aspiration.

You may need to have intravenous treatments, including antibiotics and blood transfusions. If so, your doctor or nurse will tell you long and how often you will need them. If you need any, they will be given to you on either the Chemo BMT unit or Chemo unit, both located at the main hospital at 1275 York Avenue. The appointments will usually be scheduled with your follow-up visits.

Immunizations

After your transplant, you will lose the protection from the vaccines you received as a child. All transplant patients receive childhood vaccines once their immune system has recovered. This usually happens about 1 year after the transplant.

Once it is safe for you to receive vaccines, this will be coordinated by your transplant team, or you will be referred to a nurse practitioner in our Immunization Clinic. The vaccines can be given at MSK, or your NP can give your primary care doctor a list of the recommended vaccines. Please note, sometimes it is difficult for primary care doctors to get the vaccines, so you may need to receive them at MSK.

Dental care

After you have recovered from your transplant, go to your local dentist for routine checks. If you need extensive dental work, 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

Eye exams

You may develop cataracts if you received radiation therapy or high-dose steroids. 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 vision prescription, as your vision can change during the recovery process.

Common Medications to Avoid

Do not take aspirin, any medications containing aspirin, and all other nonsteroidal anti-inflammatory drugs (NSAIDs). For a list of these medication, see the resource *Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)*, located at the back of this guide.

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 specific 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.

CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



Practical Perspectives



***nbmt*LINK**

National Bone Marrow Transplant Link

CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



Practical Perspectives

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.

For additional copies of this booklet, please contact:

National Bone Marrow Transplant Link

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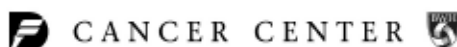


Community Cancer Care Specialists



Dana-Farber/Brigham and Women's Cancer Center

DANA-FARBER/BRIGHAM AND WOMEN'S



Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance



Fred Hutchinson Cancer Research Center
UW Medicine
Children's Hospital and Regional Medical Center

Working together to cure cancer

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Henry Ford Transplant Institute



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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:

Pictured here: Danielle, transplant in 2004, with her son, Jaylen

- 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**

NATIONAL MARROW DONOR PROGRAM®

Creating Connections. Saving Lives.®

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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National Bone Marrow Transplant Link

CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



Practical Perspectives

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Foreword



by Dr. Mary Horowitz



Mary Horowitz, MD, MS, joined the Center for International Blood and Marrow Transplant Research (CIBMTR) [formerly the IBMTR/ABMTR] in 1986 and has served as Scientific Director since 1991. She received her MD in 1980 and MS in Biostatistics/Clinical Epidemiology from the Medical College of Wisconsin (MCW) in 1991. Dr. Horowitz currently holds the Robert A. Uihlein, Jr. Chair in Hematologic Research and is a tenured Professor of Medicine in the Division of Neoplastic Disease at the Medical College of Wisconsin, where she is also an active blood and marrow transplant physician. She is a member

of numerous professional societies and received MCW's Distinguished Service Award in June 2006, MCW's highest honor. She was selected to give the Mortimer M. Bortin lecture at the 2007 BMT Tandem Meetings.

Dr. Horowitz is a member of the editorial boards of the journals Blood, Bone Marrow Transplantation, and Biology of Blood and Marrow Transplantation. She has served on the Board of Directors of the National Marrow Donor Program (NMDP) and on the National Cancer Institute's Cancer Clinical Investigation Review Committee. She is the Principal Investigator of the Data and Coordinating Center of the U.S. Blood and Marrow Transplant Clinical Trials Network. She is also the Research and Project Director of the U.S. Stem Cell Therapeutic Outcomes Database, a component of the C.W. Bill Young Cell Transplantation Program, charged with collecting and assessing outcome data for all U.S. allogeneic transplants.

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

the losses and gains they experienced. She also has conducted qualitative expressive writing studies with BMT spouse-caregivers in the transition phase home after BMT. She currently serves on the Late Effects/QOL subcommittee for the Blood and Marrow Transplant Clinical Trials Network State of the Science Committee and is a member of the Late Effects/QOL committee of the Center for International Blood and Marrow Transplantation Research. Dr. Bishop has received several awards for her research and has presented her work at a variety of state and national meetings. Her research interests include the long-term QOL, health behaviors, and positive changes experienced by cancer/BMT survivors, as well as, the short-term and long-term impact of cancer/BMT on the QOL of spouse-caregivers and the development of support services for BMT families.

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.

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My Gift to Mom for Her Second Birthday

An Adult Daughter's Perspective

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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.

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Cancer Etiquette

*A Survivor's Perspective
on Effective Communication*

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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 prevent 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 success 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 realistic 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, permanent 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 neutrapenic 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!

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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 multi-tasking 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-laugh 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, loooooooooooooooooooooooooooooong 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 (sometimes with days donated by other colleagues), unpaid days off, or changed performance expectations to manage through the most difficult months. In my case, I qualified 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 acknowledge the tremendous responsibility you have been shouldering. Use your support resources—and reframe your thinking from “When is this over?” to “Life after transplant” 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 significant 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 positive 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 exciting 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 parents, 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.

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Another Way to Say I Love You

A Wife's Perspective

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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!"

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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, breadwinner, 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.

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Relying On a Family of Strangers

A Patient's Perspective



by Jim Myers



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 context, 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 community!

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 responsibilities 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 attention. 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 caregiver and the rest of the family. Here are a few things that can help the primary caregiver, 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.

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Symptom Management for Caregivers

An Oncology Nurse's Perspective

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by Maria Thompson



Maria Thompson, ARNP-c, is an Advanced Registered Nurse Practitioner Certified. She worked at Duke University Medical Center BMT Program for six years and currently works at the Cleveland Clinic Florida, Hematology/Oncology Department. She spends most of her free time chasing after her 14 month old twins.

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:

Resource Guide for Stem Cell Transplant, Including Bone Marrow, Peripheral Blood, and Cord Blood, Friends Helping Friends

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 Raton, 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

by R. Moroney, P. Docecki, J. Gates, K. Haynes, N. Noshier, 1998

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

Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love

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

Resource Guide for Stem Cell Transplant, Including Bone Marrow, Peripheral Blood, and Cord Blood

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



National Bone Marrow Transplant Link

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”

CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



Practical Perspectives

**NATIONAL
MARROW
DONOR
PROGRAM®**

***nbmt*LINK**
National Bone Marrow Transplant Link

www.nbmtlink.org

Glossary

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.

Ophthalmologist (of-thuh-mal-o-jist) - A medical doctor who specializes in diseases of the eye.

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 (G-CSF) 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-peen-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.”

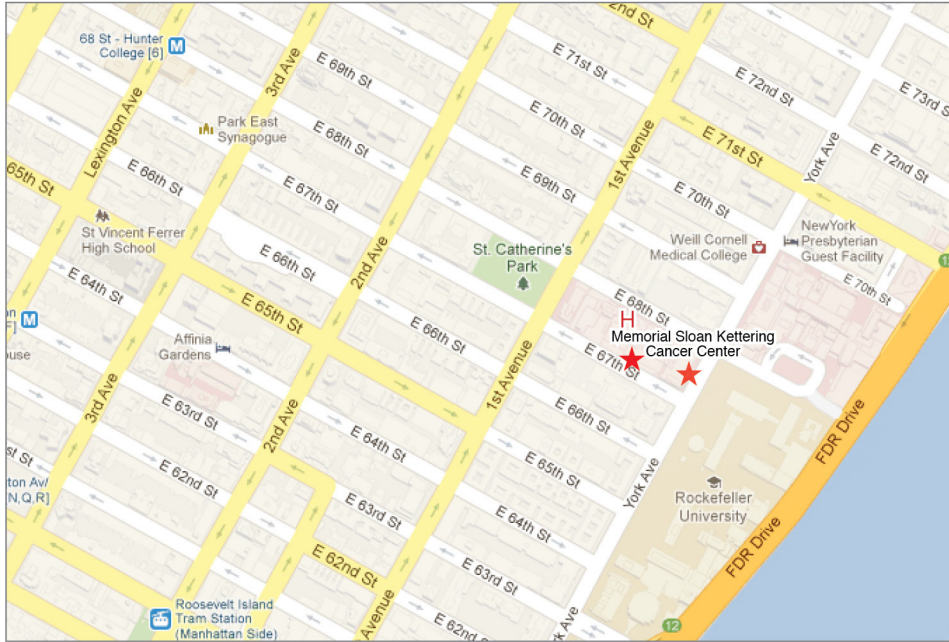
X-ray - A form of radiation that can be used at low levels to produce an image of the body on film. It can be used at high levels to destroy cancer cells.

Zoster - varicella zoster - See shingles.

Additional Resources

- *Bone Marrow Transplant Emergency Guide*
- *Cancer and Fertility: Information for Men*
- *Sperm Banking*
- *Cancer and Fertility: Information for Women*
- *Selecting Fertility Centers*
- *Giving Yourself an Injection of Filgrastim (Neupogen®) or Pegfilgrastim (Neulasta®) With a Prefilled Syringe*
- *Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)*
- *Caring for Your Central Venous Catheter*
 - *How to Put on Your Sterile Gloves*
 - *Map for Dressing Change: CVC*
- *Outpatient BMT Temperature & Intake Log*
- *Sexual Activity During Cancer Treatment: Information for Women*
- *Sexual Activity During Cancer Treatment: Information for Men*
- *Sexual Health and Intimacy*
- *Hair Loss During Your Cancer Treatment*
- *Low-Microbial Diet*
- *MedicAlert® Brochure*

Bone Marrow Transplant Emergency Guide



Memorial Sloan Kettering
Cancer Center™

		Symptom	Action
EMERGENCIES	ALERTNESS	Unable to wake up Seizure Sudden change in vision Suddenly unable to move arms or legs	1. Call 911 Do not transport patient without Emergency Medical Services (EMS) support 2. Ask to be taken to the Urgent Care Center at MSKCC Monday–Friday: 6:00 am–midnight Enter at 425 East 67 th St. All other times enter at 1275 York Ave. and ask for directions at security desk 3. Identify the patient as a bone marrow transplant patient
	BLEEDING	Uncontrollable bleeding Unable to wake up	
	BLOOD SUGAR	Greater than 400 or less than 50	
	BREATHING	Not breathing Choking	
	CENTRAL LINE	Line open to air and short of breath — Clamp line immediately	
	FALL	Hit head during fall Change in consciousness after fall	
	FATIGUE	Unable to wake up	
	MOUTH PAIN MUCOSITIS	Not breathing Hard to breathe	
	PAIN	Severe chest pain Severe squeezing or pressure in chest Severe sudden headache	
	SWELLING	Swelling in throat Hard to breathe	
NON-EMERGENCIES	See symptom reference guide on next page		8:00 am – 7:00 pm Call (212) 639-2399 7:00 pm – 8:00 am Call (212) 639-2000 Ask for the doctor covering Bone Marrow Transplant

Symptom	EMERGENCY	NON-EMERGENCY	
	Go to Urgent Care Center at MSKCC	8:00 am – 7:00 pm call BMT clinic: (212) 639-2399 7:00 pm – 8:00 am call (212) 639-2000 and ask for the doctor covering Bone Marrow Transplant	
ALERTNESS	Unable to wake up Seizure Sudden change in vision Suddenly unable to move arms or legs	New or increased confusion Change in level of alertness Change in mood Change in energy level Unable to sleep Falling down	Dizziness Lethargic Tremors/shakiness Numbness, tingling Not able to get around Difficulty swallowing
BLEEDING	Uncontrollable bleeding Unable to wake up	New or increased bleeding Unable to stop nosebleed Bloody urine Bloody diarrhea Vomiting blood	1 or more feminine pad per hour is used New bruising Little red or purple spots on the skin
BLOOD SUGAR	Greater than 400 less than 50	Blood sugar between 50 and 401 Hard to wake up	
BREATHING	Not breathing Choking	Trouble breathing Feeling as if can't get enough air Trouble breathing when lying flat Gets "winded" more easily with minimal activity	Wheezing with breaths New or persistent cough Coughing blood or green or yellow material
CENTRAL LINE	Line open to air and short of breath Clamp line immediately	Line broken or leaking Swelling of face or neck Swelling, redness, or tenderness at site	Pain at site Drainage from site Unable to flush catheter Line fell out
DIARRHEA		Uncontrolled diarrhea Diarrhea with fever and abdominal cramping	New onset diarrhea Whole pills passed in stool
FALL	Hit head during fall Change in consciousness after fall	Did not hit head during fall No changes in consciousness after fall	
FATIGUE	Unable to wake up	Dizziness Too tired to get out of bed or walk to the bathroom	
FEVER/ CHILLS		Shaking chills, temperature may be normal Temperature greater than 100.4° F (38° C) by mouth Fever greater than 100°F if on steroids Cold symptoms (runny nose, watery eyes, sneezing, coughing)	
MOUTH PAIN/ MUCOSITIS	Not breathing Hard to breathe	Bright red blood in mouth Pain not controlled by medication White patches or sores on gums, mouth or lips Difficulty swallowing food or fluid	
NAUSEA/ VOMITING		Nausea persists without control from anti-nausea medication Uncontrolled, constant nausea & vomiting Blood or coffee ground material in vomit Cannot keep meds down Projectile vomiting Severe stomach pain while vomiting	
PAIN	Severe chest pain Severe squeezing or pressure in chest Severe sudden headache	New or uncontrolled pain New headache Chest discomfort Pounding heart Heart "flip-flop" feeling Burning in chest or stomach Pain or burning during urination or defecation Pain at central line site Pain with infusion of medications or fluids in central line	
RASH		New rash Rash with pain and/or itching	
SWELLING	Swelling in throat Hard to breathe	Sudden swelling with or without pain Swollen legs, arms and/or hands	
URINATION		Unable to urinate for more than 8 hours Bloody urine Pain or burning while urinating	



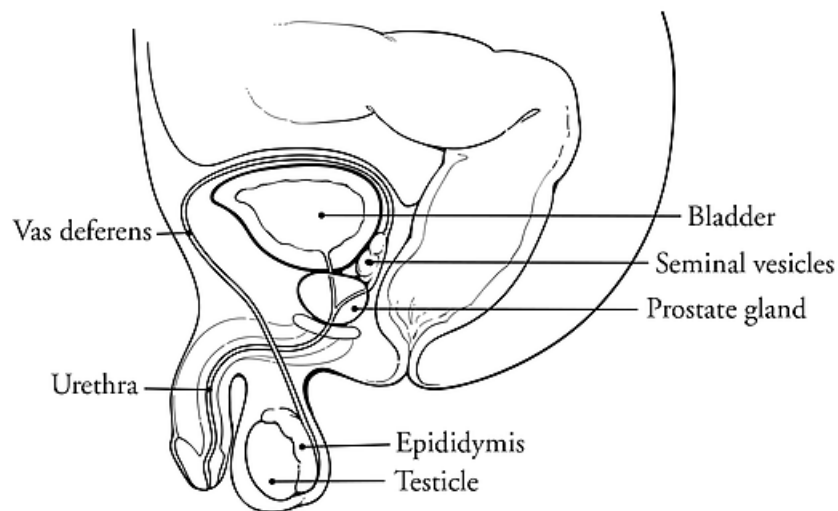
PATIENT & CAREGIVER EDUCATION

Cancer and Fertility: Information for Men

Some treatments for cancer can affect fertility. This resource describes your options for preserving fertility before treatment begins and building a family after treatment is completed.

■ Natural Conception of a Child

Many structures of the body are involved in conceiving a child (see figure). Once puberty begins, hormones from the pituitary gland in the brain stimulate the testes (testicles) to make sperm. It takes about 3 months for sperm to mature, after which they pass into the epididymis. When you are sexually excited, nerves stimulate the muscles in the vas deferens to push the sperm from the epididymis through the 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.



Male reproductive system

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 female's uterus (womb). The cells continue to divide, forming a fetus that grows and develops during the 9 months of pregnancy.

■ Effects of Cancer and Cancer Treatment on Fertility

Some cancers are associated with a low sperm count, and some cancer treatments cause fertility problems. These include:

- 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 have
- The type and dose of chemotherapy you receive
- The dose of radiation you receive and the area of the body that is treated

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 regain their fertility.

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.

Some men ask if they should try to get their partner pregnant before starting treatment. This can create unnecessary pressure if you are not yet ready to start building your family. Fertility preservation before treatment, as described below, can enable you and your partner to attempt pregnancy when you are ready.

■ Preserving Your Fertility Before Treatment

Sperm banking

Sperm banking is the best option for you to preserve your fertility if you do not recover your ability to produce sperm. It involves collecting, freezing, and storing your sperm before you begin cancer treatment. Sperm can be stored for as long as you want, even for many years. Review the MSK resource Sperm Banking for details on what is involved and a list of local sperm banks.

Here are some key things you should know about sperm banking:

- You will need to make an appointment at a sperm bank for your first appointment.
- At your first appointment, you will be given paperwork to complete. You may also have blood drawn.
- You will collect the specimen in a private room at the sperm bank. You will need to bring yourself to orgasm by masturbating. The liquid ejaculate that comes out of the tip of your penis contains the sperm. You will collect this in a sterile cup.
- The sperm bank will analyze your semen, counting the number of sperm. They will divide the specimen into small vials and then will freeze and store the vials. Some sperm die during the freezing and thawing process. However, the sperm that survive are not damaged while they are frozen.
- We suggest you collect 3 specimens before treatment, if possible. For the first collection, it is best if you do not have sex for 2 to 5 days before the collection. This includes intercourse and masturbation. Then skip 2 to 3 days between the other collections. This will help you collect the highest possible number of sperm.
 - If you do not have time to do 3 collections before your treatment is scheduled to begin, there are new techniques to fertilize eggs, even with very few sperm. So, it is still beneficial to collect even

one specimen.

- Most insurance companies do not cover the cost of sperm banking. The cost varies from one sperm bank to another. In the New York area, the cost ranges from \$700 to \$1,300 for 3 collections. Ask the sperm bank if they have any discount programs for cancer patients. If the sperm bank requires blood tests, this may add to the cost.
- You will have to pay a yearly storage fee as long as you want the sperm bank to hold your sperm. We recommend you consider storing the sperm until you have completed building your family. If you are considering discarding your sperm, talk with your doctor first.

If you feel you cannot collect a specimen at the sperm bank, some sperm banks will allow you to collect it at home. They will give you a sterile cup for this. If you collect your specimen at home, you must keep it at body temperature and bring it to the sperm bank within 1 hour. Place the cup with the specimen in a sock and hold it close to your body. You cannot freeze the specimen and store it at home.

If you feel you cannot collect a specimen by masturbating, please tell your doctor or nurse. Reasons for this include feeling too sick, having too much pain, feeling too embarrassed or distressed, or not being able to masturbate because of religious or cultural beliefs or practices. You may be able to collect through a procedure called electroejaculation (EEJ). This is an outpatient procedure performed by a reproductive urologist (a doctor who specializes in male fertility). The procedure is done under anesthesia. A probe that is about 1 inch wide is placed in your rectum where it emits a mild electrical current. This causes you to ejaculate so your semen can be collected while you are asleep. The specimen will be brought to a sperm bank to be analyzed and frozen.

If the sperm bank does not find any sperm in your semen to freeze, you may be able to collect a specimen through a procedure called testicular sperm extraction (TESE). This is an outpatient procedure performed by a reproductive urologist. The procedure is done under anesthesia, while you are asleep. A very small incision is made in your scrotum. Your doctor will remove small pieces of tissue from your testes. The tissue is brought to a sperm bank, where they will look for sperm to freeze.

If you are the parent of a boy who has not reached puberty, your son will not yet be producing mature sperm to collect and freeze. There are experimental options that may be available. If you are interested in learning more, ask your doctor if a referral to a reproductive urologist might be appropriate for your son.

■ **Building a Family After Treatment**

Below are common questions that people have about building a family after treatment.

How long must I wait after treatment to try to father a child?

The length of time to wait depends on your diagnosis and the treatment you received. In general, we suggest waiting at least 12 months after treatment before trying to have a child. However, some people may not need to wait this long, and others should wait longer. Please check with your doctor to find out how long he or she recommends that you wait. Waiting ensures that:

- Sperm that have been damaged by your treatment are cleared from your body.
- Your testes have recovered from the effects of treatment and are more likely to be producing fresh

sperm.

- You have recovered from treatment and are in good health.

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, motility (ability to swim), and morphology (shape). Wait at least 1 year after you have completed treatment before having the semen analysis so that your testes have enough 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. If you want a more in depth evaluation, ask your doctor to refer you to a reproductive urologist.

Some men prefer to attempt pregnancy without having a semen analysis first. If your partner does not get pregnant after 3 to 6 months, you should consider having a semen analysis at that time. Your partner should also consider being evaluated by a reproductive endocrinologist (a gynecologist who specializes in fertility). Your options for building a family are based on the results of these fertility evaluations.

Will a child conceived after I have received cancer treatment be healthy?

It is important to use birth control during and after treatment to ensure you do not conceive with sperm that may have been damaged from exposure to chemotherapy or radiation. This could possibly affect the health of a child conceived from this sperm. However, there is no evidence that children conceived at least 12 months after completion of treatment are at increased risk for any birth defects or other health problems. Because of this, we assume that any sperm that have been damaged have been destroyed or repaired.

However, 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, ask to meet with a genetics counselor to learn more about these risks. Pre-implantation genetic diagnosis (PGD) is a technique that is used to test embryos for specific genetic disorders. You may want to request this if you or your partner has a hereditary cancer or some other genetic disorder.

Can I have a biologic child if I am fertile, but have a low sperm count?

Some men recover sperm production after cancer treatment but have a low sperm count (oligospermia) 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 will take 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 up to her ovaries to remove the mature eggs. This procedure takes 10 to 20 minutes.
- **Fertilization:** The eggs are fertilized with your sperm in a laboratory. Because your sperm count is low, they may inject a sperm into each egg to increase the chances of fertilization (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 the future.

Can I have a biologic child 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 (a gynecologist who specializes in fertility). The technique recommended to fertilize her eggs will be based on the quality of the specimens you were able to freeze before treatment. These techniques include:

- **Intra-uterine insemination (IUI or artificial insemination):** 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. 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 banked sperm will not have enough sperm to use this technique. However, this may be an option for you if your partner is young and has no fertility problems, and if you have many vials of sperm with a high sperm count with good motility.
- **In vitro fertilization (IVF):** This technique is used by most people using their thawed sperm. There are several steps involved:
 - **Ovarian stimulation:** Your female partner will take 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 up to her ovaries to remove the mature eggs. 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 to increase the chances of fertilization (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 the future.

Can I have a biologic child if I am no longer fertile and did not bank sperm before treatment?

Even with no sperm 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 very small incision is made in your scrotum. Your doctor removes small 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 partner's eggs. If you would like to learn more about this procedure, ask your doctor or nurse to refer you to a reproductive urologist.

What are my other options to build a family?

Some men do not have the opportunity to bank sperm before treatment or are unable to conceive using their frozen sperm. However, you can still build a family by using donor sperm or by adopting.

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 may be 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 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 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 partner ovulates (releases a mature egg). 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 ideally have been cancer-free for at least 3 to 5 years. Regulations on adoption are there to protect the well-being of the child, so 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 of the United States. If you are not, it will be very difficult for you to adopt in the United States.

- 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). Private domestic adoptions provide the best chance of adopting a newborn or a child of the same race and ethnicity as you.
- Adoptions are arranged in a variety of ways, including through:
 - **Lawyers:** Adoption laws vary widely 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.
 - **Private agencies:** These agencies may handle domestic adoptions, international adoptions, or both. Each agency has its own standards about who they will accept as adoptive parents. Some states, including New York, do not allow agencies to discriminate against prospective parents based on a history of cancer. Children adopted through private agencies are usually younger than children adopted through public agencies. With a private agency, you can adopt a newborn child.
 - **Public agencies:** These 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.

Can I have a biologic child 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 techniques that may help 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 would be 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.

Can I have a biologic child 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 a vagina, the sperm cannot fertilize the woman's 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.

■ MSK Resources

Fertility website

www.mskcc.org/cancer-care/survivorship/fertility

Fertility Options for Men Before and After Cancer Treatment (videos)

www.mskcc.org/cancer-care/survivorship/videos-survivors/fertility-options-men-and-after-treatment

Sperm Banking

www.mskcc.org/cancer-care/patient-education/resources/sperm-banking

■ Additional Resources

Cancer and fertility

American Cancer Society

Fertility and Men With Cancer:

www.cancer.org/acs/groups/cid/documents/webcontent/acspc-041228-pdf.pdf 

American Society of Clinical Oncology (Cancer.Net)

www.cancer.net/publications-and-resources/what-know-ascos-guidelines/what-know-ascos-guideline-fertility-preservation

MyOncofertility

www.myoncofertility.org

SaveMyFertility

www.savemyfertility.org

Having Children After Cancer: How to Make Informed Choices Before and After Treatment and Build the

Family of Your Dreams. Gina M. Shaw; Celestial Arts, 2011.

For teens and parents of children

Children's Oncology Group

www.childrensoncologygroup.org/index.php/hormonesandreproduction/malereproductivehealth

www.survivorshipguidelines.org/pdf/MaleHealthIssues.pdf 

Teens Health

teenshealth.org/teen/cancer_center/feelings/fertility.html

Infertility

American Fertility Association

www.theafa.org

American Society of Reproductive Medicine

www.reproductivefacts.org

RESOLVE: The National Infertility Association

www.resolve.org

Urology Care Foundation (American Urological Association)

www.urologyhealth.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.

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PATIENT & CAREGIVER EDUCATION

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 and freezing of sperm before you begin cancer treatment. Your sperm will be stored in case you need them in the future to become a father. Sperm can be stored for as long as you want, even for many years.

■ Why should I do this?

Many cancer treatments can damage the cells needed to make sperm. This means you may become infertile (unable to conceive a child). Sometimes the body can recover from this damage, but sometimes it cannot. We have no way of knowing for sure if you will be fertile after your treatment.

We know that right now you may not be thinking about being a father. However, in the future this may be very important to you. Banking sperm now will increase your chance of being able to father a child using your own sperm. Many young men who do not bank their sperm before treatment later regret this decision if they find out they are infertile when they are ready 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 sperm before treatment that may affect fertility.

■ Where can I do this?

Sperm banking is done at a New York State licensed sperm bank. You can choose from among the local sperm banks listed at the end of this resource. Most sperm banks require a prescription from your doctor. If you do not have a prescription, please call your doctor's office and have them send it to you or to the sperm bank.

Call to make your first appointment. When you call, let them know you want to bank sperm before starting cancer treatment and that you have been referred by Memorial Sloan Kettering Cancer Center (MSK).

Think about who you will feel most comfortable being with you when you go. This may be your parents, a friend, your spouse or partner, or someone else. You may prefer to go alone.

■ When should I do this?

You must bank your sperm before you begin treatment. We suggest you do 3 collections if possible. For the first collection, it is best if you don't have sex for 2 to 5 days before the collection. This includes intercourse and masturbation. Then skip 2 to 3 days between the other collections. This will help you collect the highest possible number of sperm.

If your treatment will be starting too soon for this timing, you can schedule the collections with only 1 day

between each one. You should try to bank your sperm even if you are only able to do 1 or 2 collections, because there are new techniques available that can fertilize eggs with very few sperm.

If you will be having a scan with a radioactive isotope, such as a PET scan, you cannot do a sperm collection during the 24 hours after you receive the injection. Keep this in mind when scheduling your appointments with the sperm bank.


■ **How do I do this?**

At the sperm bank you will receive forms to complete. The staff at the sperm bank will explain how to do the collection and then will bring you into a small private room.

Before collecting, wash and dry your hands. You will need to stimulate yourself by masturbating. Do not use saliva, spit, or lubricants, as these can destroy the sperm. The sperm bank may give you mineral oil to help, but use this only at the base of the penis to avoid getting it mixed in with your semen. The fluid (ejaculate) that comes out of the tip of your penis contains the sperm. You will collect all the fluid in a sterile cup. If you feel you cannot collect sperm this way, please tell your doctor or nurse. There may be other ways to collect it.

■ **How much will this cost?**

The cost varies from one sperm bank to another. There are separate fees for analyzing, processing, freezing, and storing the sperm. The cost in the New York area is about \$1,200 for 3 collections. The sperm bank may also need blood tests for certain infectious diseases; this may add to the cost.

When you call to schedule your appointment, ask 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/2014-Men-LIVESTRONG-Fertility-Application.pdf> .

Most insurance plans do not cover sperm banking. Call your insurance company to find out if you have coverage. Explain that you will be starting treatment for cancer that may cause you to become infertile and that your doctor has recommended that you bank sperm. Ask if it would help you to get coverage if they had a letter explaining this from your doctor.

■ **Where can I learn more?**

Please ask your nurse for the resource *Cancer and Fertility: Information for Men*. For additional information and links to other resources, go to the MSK internet site at www.mskcc.org/cancer-care/survivorship/fertility or ask your doctor or nurse for a referral to our Fertility Nurse Specialist.

■ **Finding a Sperm Bank**

Manhattan

California Cryobank

369 Lexington Avenue, Suite 401 (at 41st Street)

New York, NY 10017

(212) 779-1608

www.cryobank.com/About-Us/Locations/New-York/

Offers a discounted rate to eligible patients through LIVESTRONG Fertility

Manhattan CryoBank

110 East 40th Street, Suite 101 (between Lexington and Park Avenues)

New York, NY 10016

(212) 396-2796

www.manhattancryobank.com

Repro Labs

332 East 30th Street (between First and Second Avenues)

New York, NY 10016

(212) 779-3988

www.reprolabinc.com

Offers a discounted rate to eligible patients through LIVESTRONG Fertility

Long Island

New York Cryo

900 Northern Boulevard, Suite 230

Great Neck, NY 11201

(516) 487-2700

www.newyorkcryo.com/new-york-cryo

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

www.rsfnyc.com

Offers a discounted rate to cancer patients

Westchester

M.A.Z.E Laboratories

2975 Westchester Avenue

Purchase, NY 10577

(914) 683-0000

www.mazelabs.com

New Jersey

Reproductive Medicine Associates of New Jersey

140 Allen Road

Basking Ridge, NJ 07920

(973) 656-2823

www.rmanj.com

The Sperm and Embryo Bank of New Jersey

187 Mill Lane

Mountainside, NJ 07092

(908) 654-8836

www.sperm1.com

Pennsylvania

Fairfax Cryobank

3401 Market Street, Suite 205

Philadelphia, PA 19104

(215) 386-1977

www.fairfaxcryobank.com

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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PATIENT & CAREGIVER EDUCATION

Cancer and Fertility: Information for Women

This information explains the options available to women to preserve fertility before treatment.

You will be starting cancer treatment that may affect your fertility and ovarian function. As a result, you may not be able to become pregnant naturally, or you may begin menopause at an early age. This booklet describes options that may be available to you to preserve your fertility potential and discusses issues to consider as you make decisions about these options.

■ Basic Reproductive Biology

Natural Conception of a Child

Many parts of the body are involved in conceiving a child (see Figure 1).

The ovaries contain eggs (oocytes) and secrete hormones. Each egg is in a sac called a follicle. Beginning at puberty, hormones from the brain stimulate the monthly menstrual cycle to begin. Some of the eggs begin maturing each month, and as they mature, the follicles get larger. The most mature follicles are large enough to see on an ultrasound. It takes 3 to 6 months for eggs to mature. Each month only 1 of these eggs fully matures.

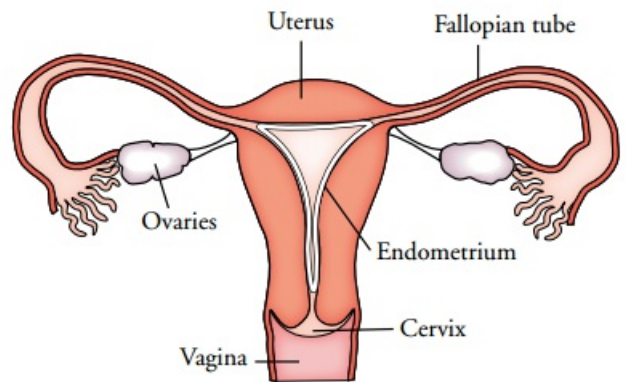


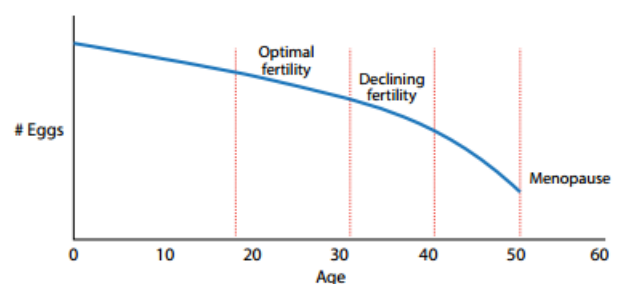
Figure 1: Female reproductive system

The mature egg is released from the ovary into the fallopian tube. This is known as ovulation. If a woman has vaginal sex around the time of ovulation without using birth control, a sperm may fertilize the egg. The fertilized egg begins to divide forming an embryo which passes into the uterus. If it implants on the inner lining of the uterus (endometrium) pregnancy is achieved. The cells continue to divide forming a fetus. During pregnancy, the uterus expands to hold the fetus as it grows.

If the egg released during ovulation does not fertilize, or if the embryo does not implant in the lining of the uterus, 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

Girls are born with about 1 million eggs. During a woman's lifetime, only about 400 to 500 eggs are released with ovulation. The other eggs degenerate naturally over time, so the number of eggs in the ovaries gradually declines. The term “ovarian reserve” refers to the number and quality of eggs a woman has at any point in time.



With fewer eggs, it is harder to become pregnant, and eventually there are so few eggs, that monthly menstrual periods stop and menopause begins. This reduction in ovarian reserve with age is shown in Figure 2.

■ Effects of Cancer Treatment on Fertility

Cancer treatment can impair fertility in a number of different ways.

- Surgery may require removal of the ovaries and/or the uterus.
- Some chemotherapy drugs destroy eggs in the ovary.
 - The degree to which the ovaries are affected depends on the drugs used, the doses of the drugs given, and the age of the woman at the time of treatment.
 - This loss of eggs in the ovaries from chemotherapy can effectively “age” the ovaries, reducing the chance for pregnancy in the same way that natural aging does. It may also cause early (premature) menopause, shortening the period of time during which a woman who is still fertile after treatment can become pregnant.
 - During chemotherapy, monthly menstrual periods may stop.
 - Even if periods begin again after treatment, some women will not have enough eggs to get pregnant naturally.
- Radiation therapy to the pelvis destroys eggs in the ovary in a similar way to chemotherapy, as described above.
- Radiation therapy to the pelvis at high doses may damage the uterus. The blood supply may be affected, and muscles and other tissues may lose their elasticity. As a result, an embryo may not be able to implant, or the uterus may not be able to expand to hold a growing fetus. This can result in complications during pregnancy, such as miscarriage or premature labor.
- Surgery or radiation therapy to the brain may affect the pituitary gland, the part of the brain that secretes hormones to stimulate the ovaries each month. Without these hormones, eggs may not mature. Pituitary gland surgery or radiation does not damage the eggs in the ovaries, and replacing hormones can often lead to pregnancy.

Not all cancer treatments impair fertility. It depends on:

- Your age
- The number and quality of eggs you have before treatment
- The type of surgery you have
- The type and dose of chemotherapy you receive
- The area of the body that is irradiated and the dose of radiation you receive
- Other fertility problems you may have

Because of the many factors that may affect fertility, it is difficult to predict with certainty how any one person will be affected. We cannot know for sure who will regain ovarian function after treatment is completed and who will not.

■ Fertility Preservation Options

A number of options are available that may preserve your fertility and increase the chance you will be able to conceive a biologic child in the future. Not all women starting cancer treatment will need or want to consider these options. We are not recommending that you pursue any of these, but we want you to know about what is available. Our goal is for you to make the best decision you can based on your personal situation so that you have no regrets in the future. We hope the information below will help you understand your options and decide if pursuing fertility preservation before treatment is the right choice for you.

Embryo and Oocyte Cryopreservation

Embryo and egg freezing are procedures in which mature eggs are removed from your ovary and frozen. They can be frozen as unfertilized eggs, or as embryos after fertilization with sperm. They are stored for you to use in the future if you need them.

What is involved?

The process for this generally takes two to three weeks, depending on where you are in your menstrual cycle. Several steps are involved.

- **Referral to a reproductive endocrinologist:** Reproductive endocrinologists (RE) are gynecologists who specialize in fertility. We do not have reproductive endocrinologists at MSKCC but can make a referral for you. At your first visit, the RE will review your medical history and perform a physical examination. You will have blood tests to check your hormone levels and a transvaginal ultrasound to count the number of potential follicles in your ovaries. These tests help determine how successful you may be in collecting eggs. The RE will also want to consult with your oncologist to make sure it is safe for you to proceed with egg collection.
- **Ovarian stimulation:** If you decide to proceed, at the best time during your menstrual cycle (often on or around the second day of your next period), you will start giving yourself daily hormone injections. This medicine stimulates your ovaries so that those eggs that would normally be lost during the cycle will mature (rather than the single egg that fully matures naturally each month). You will need the injections for about 10 days. If you are not at the right time of the menstrual cycle, you can be given medicine to get you to the point where you are able to start sooner. A nurse will teach you how to give yourself these injections. While you are taking these, you will see the RE almost every day for blood tests and transvaginal ultrasounds. These indicate how your ovaries are responding to the stimulation so the dose of the hormones can be changed if needed. As the eggs mature, the follicles get larger. Once they reach a certain size, another injection (HCG) will stimulate final egg maturation. Egg collection (retrieval) will be scheduled about 35 hours later.
- **Egg retrieval:** This is an outpatient procedure, done with anesthesia so you will be asleep. No surgical incision is needed. Once you are asleep, an ultrasound probe is placed in your vagina so the RE can see your ovaries. A very thin needle is passed through the wall of the vagina up to your ovary. The needle punctures each of the large follicles and withdraws the mature eggs. The entire procedure takes 10 to 20 minutes (see Figure 3).

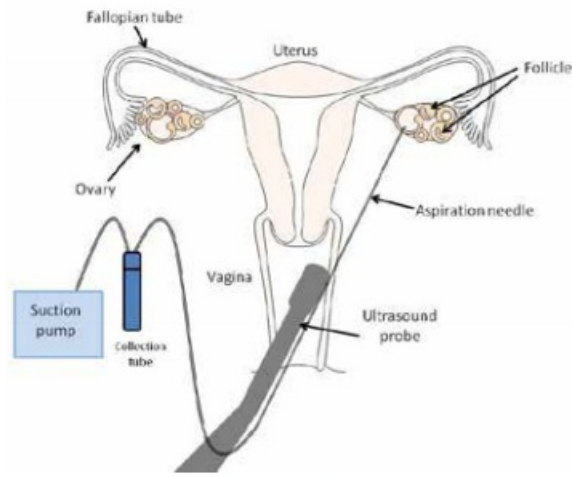


Figure 3: Egg retrieval

- Fertilization:** If you are going to freeze embryos, your eggs are fertilized with sperm in a laboratory (in vitro fertilization, IVF). One method is to mix each egg with thousands of sperm, one of which enters each egg. Another method is to inject a single sperm into each egg (intracytoplasmic sperm injection, ICSI). ICSI is often used because it is more successful at ensuring the eggs are fertilized. The laboratory will use sperm from your male partner or from a sperm donor if you so choose. If donor sperm is to be used, you must select the donor well in advance from one of many commercial donor sperm banks.
- Freezing (cryopreservation):** The day after fertilization, the zygotes (newly fertilized eggs still at the 1 cell stage) will be frozen or they can be monitored in the laboratory for three to five days and frozen as embryos. If you are going to freeze eggs, they are not fertilized and the mature eggs are frozen soon after retrieval. The embryos or unfertilized eggs are stored for as long as you would like. Some of these may be damaged during the freezing and thawing process; however, no known damage occurs while they are frozen.

Before beginning embryo or egg freezing, speak with your oncologist to be sure you can take the time to do this. Most patients only do 1cycle of stimulation before their cancer treatment. 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 to do so.

Is this safe for patients with breast cancer?

The hormone injections needed to stimulate egg maturation will cause your estrogen levels to rise for 2 to 3 weeks. We cannot say for certain if this is safe. To lower estrogen levels, we generally recommend that patients with breast cancer take a medication called letrozole during stimulation, and possibly for a short time after the eggs are retrieved. The RE will discuss this with you.

Should I freeze embryos or eggs?

Embryo freezing is a good option for patients in a stable long term relationship. However, keep in mind that you will not be able to use the embryos without your partner's permission, which could be a problem if the relationship comes to an end. For single women who do not want to use donor sperm to fertilize their eggs, and for those with religious or ethical concerns about freezing embryos, egg freezing is a good option.

How much does it cost to freeze embryos or eggs?

Embryo and egg freezing is expensive. The cost includes many different services and procedures, and

each fertility center charges different amounts for these. The cost in the New York area is generally about \$10,000 to \$15,000. In addition, the hormone medication to stimulate your ovaries generally costs \$3,500 to \$4,500, and the annual storage of the embryos or eggs generally costs \$700 to \$800. You will have additional costs when you are ready to thaw the embryos or eggs and use them to attempt a pregnancy.

Most health insurance plans do not cover embryo or egg freezing for fertility preservation. Call your insurance company to find out about your coverage. Explain that you have not been diagnosed with infertility, but that you will be starting treatment for cancer. Your doctor has explained that treatment may cause you to become infertile and has recommended egg collection before treatment.

Sometimes the insurance company is not clear about what they will cover. They may need specific “CPT codes” to decide. A financial specialist at the fertility center can provide these codes to them. Only then will you know for sure what will be covered and what you will have to pay yourself.

Is there financial assistance for patients with cancer who want to freeze embryos or eggs?

LIVESTRONG has a financial assistance program for embryo and egg freezing called Fertile Hope. Participating REs offer a discounted rate for their services and the hormone injections are provided without charge. This is only offered to patients who are freezing embryos or eggs **before** treatment. To find out if you are eligible, and to get an application, look on their web site (<http://www.fertilehope.org/financial-assistance/egg-and-embryo-freezing.cfm>). You must submit the application and obtain approval before you start ovarian stimulation.

How are my frozen embryos or eggs used to attempt pregnancy?

Before attempting pregnancy, talk to your oncologist. Ask if the timing is right for you or if there are any medical reasons that would make it unsafe for you to become pregnant.

Your RE will help you use your frozen embryos or eggs. If you no longer have regular periods, you will most likely need to take hormone medication for about 2 weeks to prepare the inner lining of your uterus for implantation. If you froze embryos, depending on your age when you froze the embryos, up to 6 may be thawed. If you froze eggs, again depending on your age when you froze the eggs, up to 10 may be thawed and then fertilized with sperm from your partner or a donor to create embryos.

Placing the embryos in your uterus (embryo transfer) is a very simple painless procedure so there is no need for anesthesia. The RE places a speculum inside the vagina like during a routine gynecologist visit. The cervix is washed with moistened gauze, which feels much like a PAP smear. The embryos are drawn up into a very thin soft catheter which is passed through your vagina and cervix into your uterus. The embryos are released, and the catheter is withdrawn.

You will be scheduled to return 12 to 14 days later for a pregnancy test. If you have a positive result, you will have an ultrasound several weeks later to verify the pregnancy is normal and show how many embryos implanted. If necessary, you will continue to take hormones to support the pregnancy for several months. If you are pregnant, you will transfer your care to an obstetrician.

What is the chance I will be able to have a baby using frozen embryos or eggs?

The success rates of these procedures vary based on a number of factors, including:

- Your age (success rates are higher in women under 35 years of age)

- The health of your partner's sperm
- The experience of the fertility team you are working with

Not every egg collected will produce a live baby. For example, if 10 eggs are collected, 7 may fertilize, 5 may survive the freeze-thaw cycle, and 2 to 3 may be good enough to transfer. The Society for Assisted Reproductive Technologies (SART) reported 2010 national success rates based on age for patients undergoing IVF for infertility using thawed embryos as follows:

Age	<35	36-37	38-40	41-42	>42
% transfers that resulted in a live birth	39%	35%	29%	21%	15%

You can go to www.sart.org to see success rates for specific fertility centers. However, to understand your personal chance of success, speak with your RE.

Can I consider freezing embryos or eggs if I will not be able to carry a pregnancy after my treatment is completed?

If it is very important for you to have a biologic child, you can still freeze embryos or eggs and later arrange for another woman to carry a pregnancy for you. This is called using a gestational carrier. Embryos created from your eggs are transferred to the carrier's uterus. You are the “intended parent” and the child is given to you after delivery. The carrier will have no genetic relationship to the child.

In deciding if this would be a good option for you, it is important to know that laws relating to surrogacy and gestational carriers vary by state. In some states, the process is very difficult or even illegal. Costs vary widely and can be up to \$100,000. If you are considering this, it is important to let your RE know in advance since some specific testing and screening is required by the FDA to enable you to use a gestational carrier. You should also consult with a lawyer in your state who specializes in reproductive medicine.

Ovarian Tissue Cryopreservation

Ovarian tissue freezing is an experimental procedure in which an entire ovary, or pieces of an ovary, are removed during a surgery. After the ovary is removed, the outer layer of tissue (cortex) is cut into small pieces, frozen, and stored. One option for using this tissue in the future is to re-implant it into your body. As of 2012, fewer than 25 babies have been born using this technique. This may not be an option if you have a type of cancer in which there is a risk of re-implanting cancer cells that may be present in the frozen ovarian tissue. Another option for using this tissue is to mature eggs in the laboratory (in vitro maturation) and then fertilize them to create embryos. As of 2012, no babies have been born using this technique. 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 medication to block hormones that stimulate the ovaries. This prevents eggs from maturing with the hope that this protects them from the effects of chemotherapy. Research evaluating this approach has been done primarily in women with breast cancer and lymphoma. The results have been conflicting, so we do not know if this will be helpful to 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.

The medication is given as an injection, either once a month or in a larger dose every 3 months. We

generally start it 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, like hot flashes, mood changes, difficulty sleeping, and vaginal dryness.

Ovarian Transposition

Ovarian transposition is an outpatient surgical procedure that moves the ovaries outside of the pelvic field of radiation therapy. The surgery is done laparoscopically through several small incisions in your abdominal wall. Even when the ovaries are moved outside of the field of treatment, they may still be exposed to some radiation. Some of the eggs may still be damaged. If you will also be getting chemotherapy, this can increase the likelihood that eggs will be destroyed. Because of this, you may also want to collect eggs before your treatment in addition to having this surgery.

Alternative Treatment for Certain Early Stage Gynecologic Cancers

For patients with certain early-stage gynecologic cancers it may be possible to do limited surgery, or in some cases take medication. This means your doctor may be able to leave one or both of your ovaries and/or your uterus intact. For example, some patients who have early cervical cancer can have their cervix removed while leaving the uterus in place. This procedure is called radical trachelectomy and may enable you to get pregnant and carry a fetus. Not all patients 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.

■ Alternative Options for Building a Family

Many women chose not to pursue fertility preservation before cancer treatment. 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 and need treatment by a RE. Other options for parenthood you can consider if you have impaired fertility in the future are use of donor eggs and adoption. To learn more about these options, ask your nurse for the MSKCC booklet [*Building Your Family After Cancer Treatment: Options for Women*](#).

■ Making a Decision about Fertility Preservation

It can be difficult to decide about fertility preservation because of the lack of certainty involved. We cannot predict exactly how or if treatment will affect fertility, and even with fertility preservation, there are no guarantees that these procedures will result in the ability to have a biologic baby. In addition to the uncertainties involved is the pressure to make a decision quickly.

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:

- The opinion of your oncologist about the risk of infertility from your treatment
- The opinion of your oncologist about the safety of undergoing fertility preservation if this means you need to delay treatment for about 3 weeks, receive hormones to stimulate your ovaries, and/or undergo a procedure under anesthesia
- Your comfort with delaying treatment for about 3 weeks
- Your comfort with receiving hormones to stimulate your ovaries
- The importance of having a biologically-related child

- The likelihood of success in having a baby if you pursue one of these options
- The degree of distress you are feeling from the cancer diagnosis and planned treatment
- Your feeling about being able to cope with the effort it will take to preserve fertility
- Your religious, ethical, and personal beliefs about using reproductive technology
- Your financial resources to pay for these options
- The support of your friends and family
- 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 children or having no more children
- Your faith or belief that whatever happens is meant to be

Our goal is for you to feel you have the information you need to make the best decision you can for yourself. Regardless of the outcome, we want to be sure you have no regrets.

A number of resources are available to help you as you make this decision. First, speak with your oncologist to ensure 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 the issues, ask them to refer you to our fertility clinical nurse specialist or our Counseling Center.

■ Additional Resources on Fertility Preservation

A number of internet sites have information that may be helpful.

Sites specific to cancer and fertility:

- FertileHope (www.fertilehope.org)
- Oncofertility Consortium Patient Resources
 - MyOncofertility (www.myoncofertility.org)
 - Save my fertility (savemyfertility.org)
 - Patient Navigator (fertilitypreservation.northwestern.edu)
- Fertile Action (fertileaction.org) [for women with breast cancer]
- [American Cancer Society](#)

Sites with general information about infertility and its treatment:

- [Reproductive Facts \(from the American Society of Reproductive Medicine\): Assisted Reproductive Technologies booklet](#) 
- Resolve: The National Infertility Association (www.resolve.org)
- INCIID: International Council on Infertility Information Dissemination (www.inciid.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.

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PATIENT & CAREGIVER EDUCATION

Selected Fertility Centers

This information provides a list of fertility centers that have reproductive endocrinologists who work with cancer patients in New York, New Jersey, Pennsylvania, and Connecticut.

Reproductive endocrinologists are gynecologists with special training in fertility and reproductive health. They can:

- Evaluate your fertility.
- Offer options to preserve your fertility before treatment.
- Offer options to build a family after cancer treatment.

If you're considering fertility preservation before your treatment, they will give you an appointment within a couple of days of your call.

■ Manhattan

Center for Reproductive Medicine (affiliated with Weill Cornell Medical College and New York-Presbyterian Hospital)

1305 York Avenue (at East 70th Street), 6th Floor

New York, NY 10021

646-962-5450

www.ivf.org

Satellite offices in Mount Kisco (Westchester) and Garden City (Long Island) are open Monday through Friday

Center for Women's Reproductive Care (affiliated with Columbia University Medical Center)

1790 Broadway (at Columbus Circle, between West 57th and West 58th Streets)

New York, NY 10019

646-756-8294

www.cumc.columbia.edu/dept/obgyn/services/infertility/index.html

Satellite office in White Plains (Westchester) is open Monday through Friday

NYU Fertility Center (affiliated with NYU Langone Medical Center)

660 First Ave (at East 38th Street), 5th Floor

New York, NY 10016

212-263-7981

www.nyufertilitycenter.org

Reproductive Medicine Associates of New York (affiliated with Mount Sinai Medical Center)

635 Madison Avenue (between East 59th and 60th Streets), 10th Floor

New York, NY 10022

212-756-5777

www.rmany.com

Satellite offices in White Plains (Westchester) and Garden City (Long Island) are open Monday through Friday

■ **Long Island**

Center for Reproductive Medicine (affiliated with Weill Cornell Medical College and New York-Presbyterian Hospital)

1300 Franklin Avenue

Garden City, NY 11530

646-962-5450

www.ivf.org

Reproductive Specialists of New York

2500 Nesconset Highway, Building 23

Stony Brook, NY 11790

631-246-9100

www.rsfnny.com

Or

200 Old Country Road, Suite 350

Mineola, NY 11501

516-739-2100

www.rsfnny.com

■ **Westchester**

Center for Reproductive Medicine (affiliated with Weill Cornell Medical College and New York-Presbyterian Hospital)

657 Main Street

Mount Kisco, NY 10549

646-962-5450

www.ivf.org

Greenwich Fertility and Medical Group

115 Main Street, Suite 300

Tuckahoe, NY 10707

914-793-2990

www.greenwichivf.com

■ New Jersey and Pennsylvania

Reproductive Medicine Associates of New Jersey

140 Allen Road

Basking Ridge, NJ 07920

973-656-2875

www.rmanj.com

Satellite offices throughout New Jersey are open Monday through Friday

Penn Fertility Care

3701 Market Street, 8th Floor

Philadelphia, PA 19104

215-615-4235

www.penmedicine.org/fertility

■ Connecticut

Greenwich Fertility Center

55 Holly Hill Lane, Suite 270

Greenwich, CT 06830

203-863-2990

www.greenwichivf.com

■ Other Locations

If you want to find a fertility center in another region of the country:

- Ask your local gynecologist or oncologist for a suggestion
- Search the “Find a Clinic” under “IVF Success Rate Reports” in the Society for Assisted Reproductive Technologies (SART) website at www.sart.org

To learn more, please refer to the resource *Cancer and Fertility, Information for Women*.

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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PATIENT & CAREGIVER EDUCATION

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: _____

■ Storing Your Medication

- Store your prefilled syringes in the refrigerator. **Do not store them in the freezer.** If the medication inside the syringe becomes frozen by accident, allow it to thaw in the refrigerator. **If it becomes frozen a second time, do not use it.** Call your doctor or nurse for further instructions.
- A syringe can be left out at room temperature for up to 24 hours. Do not 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.

■ 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 or coffee can
 - The container should be strong enough that needles cannot poke through the sides and it should not be breakable.
 - **Do not store your sharps in glass bottles or paper or plastic bags.**
- 2 x 2 gauze pad or cotton ball
- Band-Aid[®]
- Other: _____

■ Prepare the Injection

1. **Remove the prefilled syringe from 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 is private and there is enough space.
3. **Do not shake the syringe.** Shaking it may damage the medication. If it has been shaken, the medication may look foamy and should not be used.
4. Check to make sure that the medication name on the package or syringe label matches what your doctor prescribed for you.
5. Check to make sure that the expiration date on the syringe has not passed. If the date has passed, discard the syringe in the sharps container.
6. Check to make sure that the strength of the medication is what your doctor prescribed. The strength is listed on the colored dot on the package.
7. Check to make sure that the medication in the syringe is clear and colorless. **Do not use it if it looks discolored or cloudy, or if it has crystals in it.**
8. 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 front of your middle thighs
 - The upper areas of your buttocks

Keep track of which site was used last and rotate the sites. Choosing a new site can help avoid soreness at any one site. Do not inject into an area that is tender, red, bruised, or hard. Do not inject into an area that has scars or stretch marks.

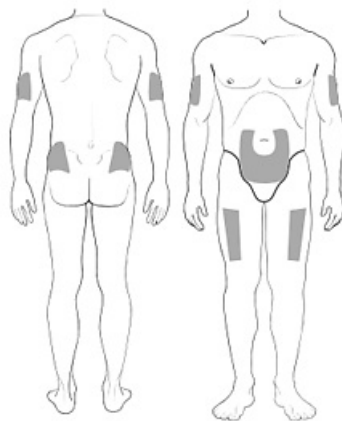


Figure 1: Injection sites

2. Fold back any clothing that is covering the injection site.

3. Tear off any 3 edges on a sealed alcohol pad. Hold the packet at the edge you did not tear. Carefully open the packet to expose the alcohol pad, but do not take it out. Set the open packet on your 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. Remove the syringe from the package.
2. Hold the syringe around the middle like a pen or dart. Carefully pull the needle cover straight off (see Figure 2). **Do not let anything, including your fingers, touch the needle.** If anything touches the needle, you must discard it in the sharps container. Call your doctor or nurse for instructions on what to do next.

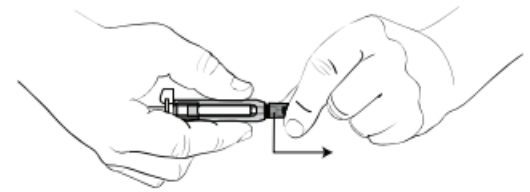


Figure 2: Removing the cover

3. Check the syringe for air bubbles. If there are air bubbles, gently tap the syringe with your fingers until the air bubbles rise to the top of the syringe. 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. Allow your skin to 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.

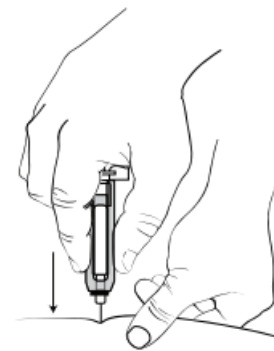


Figure 3: Inserting the needle at 90-degree angle

6. Insert the needle into your skin in one quick motion at a straight up and down angle (90 degrees; see Figure 3) or at a slight angle (45 degrees). Do not place your thumb on the plunger yet.
7. After the needle is inserted, let go of your skin. Use your thumb to slowly push the plunger all the way down (see Figure 4). 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 it for several seconds. If needed, apply a Band-Aid®.
9. Do not recap the needle. Be careful to not stick yourself. 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 5). Slide the needle guard over the needle cap until it is completely covered (see Figure 6). You will hear the needle guard click into place.

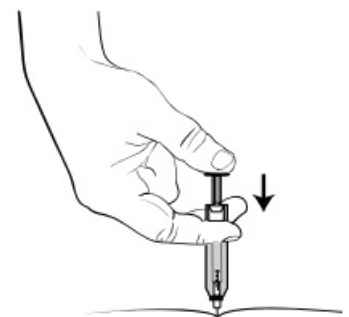


Figure 4: Pushing the plunger

10. Place the syringe and cover into the sharps container. Do not use a prefilled syringe more than once.



Figure 5: Grasping the needle guard

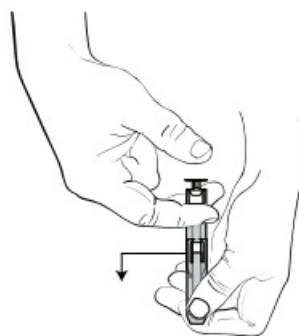


Figure 6: Sliding the needle guard

■ How to Store and Dispose Your Home Medical Sharps

Storing your sharps

- Clearly label the sharps container “Home Sharps.” **Keep it away from children and pets.**
- Keep the container separate from recyclables.
- Do not overfill the container. When it is more than half full, put on the lid and reinforce the cap with strong tape to create a more secure seal and prevent leakage.

Disposing your sharps

- If you live in New York City, you can place the sealed container in with your regular trash for collection. **Do not put it in with your recyclables.** If you live in a different county or 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 nonfederal hospital 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.



PATIENT & CAREGIVER EDUCATION

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.

Medications such as aspirin and other NSAIDs, vitamin E, and COX-2 inhibitors can increase your risk of bleeding during cancer treatment. These medications affect your platelets, which are blood cells that clot to prevent bleeding. If you take aspirin or other NSAIDs, vitamin E, or a COX-2 inhibitor such as celecoxib (Celebrex[®]), tell your doctor or nurse. He or she 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.

If you're having surgery:

- Stop taking medications that contain aspirin or vitamin E 10 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.
- Ask your doctor if you should continue taking a COX-2 inhibitor.

If you're having a procedure in Radiology (including Interventional Radiology, Interventional Mammography, and General Radiology):

- 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 your doctor instructs you to stop taking aspirin, you should stop 5 days before your procedure or as directed by your doctor.
- Stop taking NSAIDs 24 hours before your procedure.
- Stop taking medications that contain vitamin E 10 days before your procedure, or as directed by your doctor.

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.

Medications are often called by their brand name, which can make it difficult to know their ingredients. To help you identify medications that contain aspirin, other NSAIDs, and vitamin E, please review the list of common medications in this leaflet. While this list includes the most common products, there are others. Please 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.

The following common medications contain aspirin:

Alka Seltzer®	Cama® Arthritis Pain Reliever	Genprin®	Roxiprin®
Anacin®	COPE®	Gensan®	Saleto®
Arthritis Pain Formula	Dasin®	Heartline®	Salocol®
Arthritis Foundation Pain Reliever®	Easprin®	Headrin®	Sodol®
ASA Enseals®	Ecotrin (most formulations)	Isollyl®	Soma® Compound Tablets
ASA Suppositories®	Empirin® Aspirin (most formulations)	Lanorinal®	Soma® Compound with Codeine Tablets
Ascriptin® and Ascriptin A/D®	Epromate®	Lortab® ASA Tablets	St. Joseph® Adult Chewable Aspirin
Aspergum®	Equagesic Tablets	Magnaprin®	Supac®
Asprimox®	Equazine®	Marnal®	Synalgos® DC Capsules
Axotal®	Excedrin® Extra-Strength Analgesic Tablets and Caplets	Micrainin®	Tenol-Plus®
Azdone®	Excedrin® Migraine	Momentum®	Trigesic®
Bayer® (most formulations)	Fiorgen®	Norgesic Forte® (most formulations)	Talwin® Compound
BC® Powder and Cold Formulations	Fiorinal®	Norwich® Aspirin	Vanquish® Analgesic Caplets
Bufferin®	Fiortal®	PAC® Analgesic Tablets	Wesprin® Buffered
(most formulations)	Gelpirin®	Orphengesic®	Zee-Seltzer®
Buffets II®		Painaid®	ZORprin®
Buffex®		Panasal®	
		Percodan® Tablets	
		Persistin®	
		Robaxisal® Tablets	

The following common medications are NSAIDs that do not contain aspirin:

Advil®	Children's Motrin®	Indomethacin	Mobic®	Piroxicam
Advil Migraine®	Clinoril®	Indocin®	Motrin®	Ponstel®
Aleve®	Daypro®	Ketoprofen	Nabumetone	Relafen®
Anaprox DS®	Diclofenac	Ketorolac	Nalfon®	Saleto 200®
Ansaid®	Etodolac®	Lodine®	Naproxen	Sulindac
Arthrotec®	Feldene®	Meclofenamate	Naprosyn®	Toradol®
Bayer® Select Pain Relief Formula Caplets	Fenoprofen	Mefenamic Acid	Nuprin®	Voltaren®
Celebrex®	Flurbiprofen	Meloxicam	Orudis®	
	Genpril®	Menadol®	Oxaprozin	
	Ibuprofen	Midol®	PediaCare Fever®	

Most multivitamins contain vitamin E, so if you take a multivitamin be sure to check the label. The following products contain vitamin E:

Amino-Opt-E	Aquavit	E-400 IU	E complex-600
Aquasol E	D'alpha E	E-1000 IU Softgels	Vita-Plus E

Acetaminophen (Tylenol®) is generally safe to take during your cancer treatment. It doesn't affect platelets, so it will not increase your chance of bleeding. The following common medications contain acetaminophen; those in bold require a prescription:

Acephen®	Datril®	Norco®	Tylenol® with Codeine No. 3
Acta® with Codeine Acetaminophen with Codeine	Di-Gesic®	Panadol®	Vanquish®
Aspirin-Free Anacin®	Esgic®	Percocet®	Vicodin®
Arthritis Pain Formula®	Excedrin P.M.®	Repan	Wygesic®
Aspirin-Free	Fiorcet®	Roxicet®	Zydone®
Darvocet-N 100®	Lorcet®	Talacen®	
	Lortab®	Tempra®	
	Naldegescic®	Tylenol®	

 **Read the labels on all your medications.**

- Acetaminophen (Tylenol[®]) 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 is not always written out, so look for these common abbreviations, especially on prescription pain relievers: APAP, AC, Acetaminoph, Acetaminop, Acetamin, and Acetam.

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, so always read and follow the label on the product you are taking. Do not take more than 1 medication at a time that contains acetaminophen without talking with a member of your healthcare team.

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.



PATIENT & CAREGIVER EDUCATION

Caring for Your Central Venous Catheter

This information will teach you about the placement and care of your central venous catheter (CVC).

A CVC is placed in a large vein below the collarbone (see Figure 1). 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. Each lumen has a clamp and a needleless connector on the end.

A CVC can be used to 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. 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[®]),

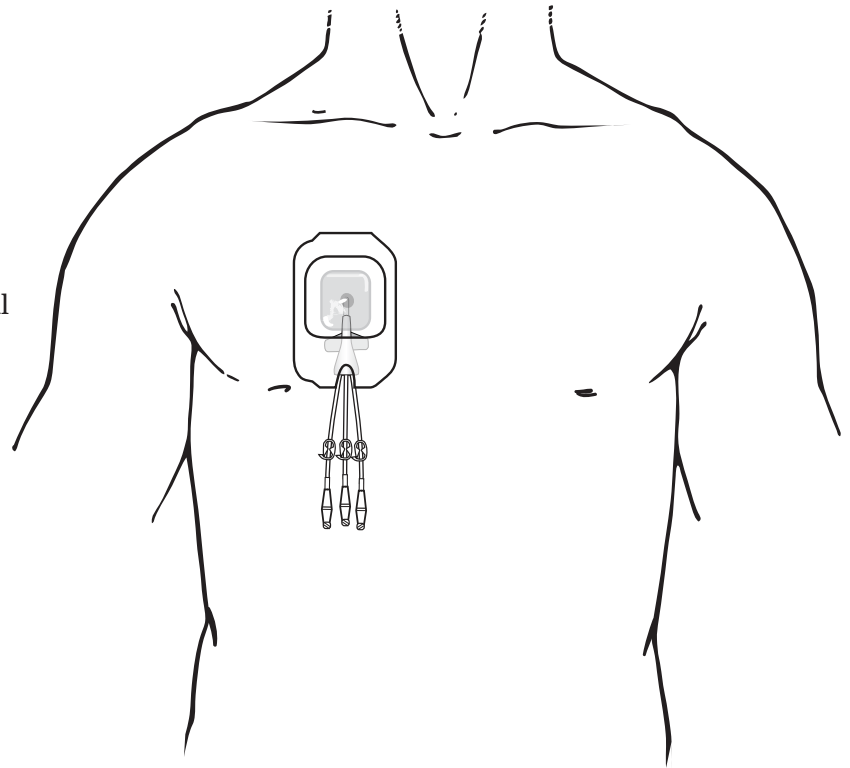


Figure 1: Central venous catheter (CVC)

clopidogrel (Plavix®), cilostazol (Pletal®), prasugrel (Effient®), 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.
- If you take aspirin, ask your doctor if you need to stop taking it before your procedure. Whether he or she recommends you stop taking it will depend on the reason you are taking it. 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 10 days before your procedure, or as directed by your doctor.

Arrange for someone to take you home

If you will be leaving the hospital after your procedure, you must have a responsible adult with you when you're discharged from the recovery area. If you don't have someone who can do this, please call one of the agencies below. They will help find someone to take you home.

Partners in Care (888) 735-8913
Caring People (877) 227-4649
Prime Care (212) 944-0244

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, 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 appointment. 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 12:00 pm 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.
- 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) and/or medications for chest pain
- 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 park

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 toward First Avenue, on the right-hand (north) side of the street. A tunnel connects the garage to the hospital. For questions about prices, call (212) 639-2338.

There are also other garages nearby, including on East 69th Street between First and Second Avenues and East 65th Street between First and Second Avenues.

Where to go

Please arrive at the main building of MSK at 1275 York Avenue between East 67th and East 68th Streets. Take the M elevator to the 2nd floor. Enter through the glass doors and check in at the desk.

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. Patients with the same or similar names may be having procedures on the same day.

During Your Procedure

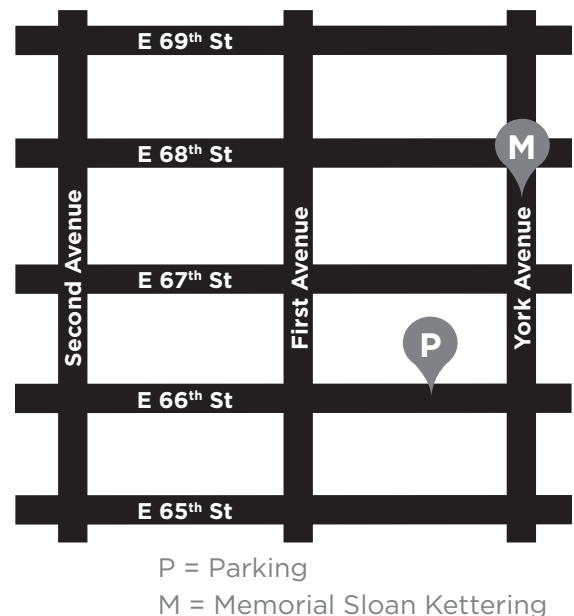
Two areas of your body will be numbed with a local anesthetic. A small incision (surgical cut) will be made above your collarbone. A second incision will be made on your chest, under your collarbone. The catheter will be inserted through this small incision, tunneled under your skin to the first incision, and threaded into your vein.

The incision above your collarbone 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 position.

After Your Procedure

You may have some discomfort at your incision sites and along the tunnel. Ask your nurse for medication to relieve your pain.

Your dressings need to be kept dry for 24 hours following your procedure. You must change your dressings 24 hours after your procedure. Two days after your procedure, you can remove the dressing that covers the small incision near your collarbone. After that, you can leave it open to the air. 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. The point where the catheter exits your skin will still need to be covered with a dressing. The stitch at this site keeps your catheter in place until the cuff 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:

- One toothless clamp
- One dressing change kit
- Your doctor's office and emergency telephone numbers

Changing Your Dressing, Needleless Connectors, and Disinfection Caps

- **Do not do your catheter care in the bathroom after a shower.** The steam from a shower can create a moist environment under your dressing and affect the adhesive.
- You will see the folded *Map for Dressing Change: CVC* inside 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. 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.
- If the Tegaderm™ CHG gel pad 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.

Equipment

- One dressing change kit
- Include alternative dressing and/or needleless connector(s), if supplied by your nurse.
 - You will need 1 needleless connector for each catheter lumen.
- One disinfection cap for each lumen
- Extra mask (if someone is helping you change the dressing)
- 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 equipment. **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 enclosed in this resource and spread it out where you can see it.***
6. Open and remove the outer packaging of the dressing change kit. The mask will be right on top (see Figure 2). Put a 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. As you peel the dressing back, place your thumb or forefinger on the gel pad to secure the catheter. To make it easier to remove, wipe the area underneath the gel pad with an alcohol pad. 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. Take the paper drape out of the kit. Unfold it and place it on your work area.
 - If supplied by your nurse, open the package of the alternative dressing and/or needleless connector(s) onto the sterile field.

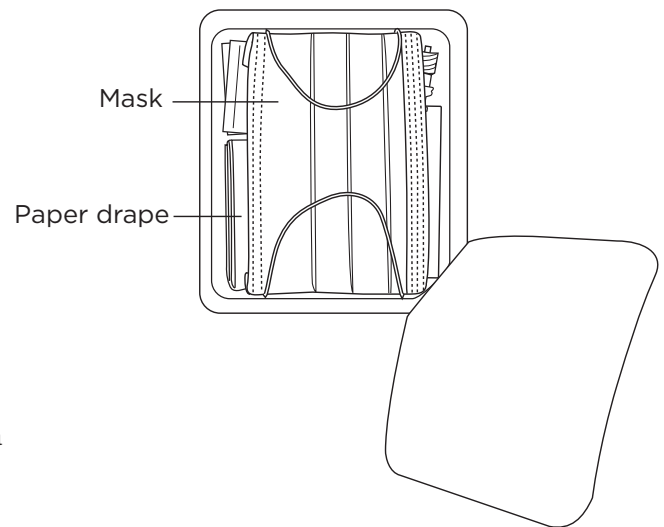


Figure 2: Dressing change kit

Follow steps 10-20 on the *Map for Dressing Change: CVC instructions 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. You will need to do this once a week.

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.

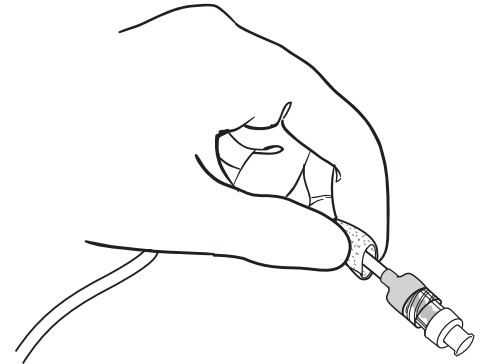


Figure 3: Holding the catheter

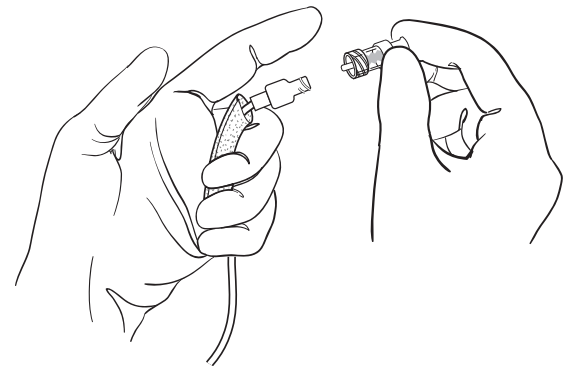


Figure 4: Twisting on the new needleless connector

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.

Equipment

- One prefilled, 10 mL syringe containing normal saline solution. You will need 1 syringe for each lumen
- Nonsterile gloves
- Alcohol pads
- One disinfection cap for each lumen

Steps to flushing your catheter

1. Gather your equipment.
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. 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 $\frac{1}{3}$ of the saline.
 - Pause.
 - Repeat.
 - Inject the last $\frac{1}{3}$ 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. **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.

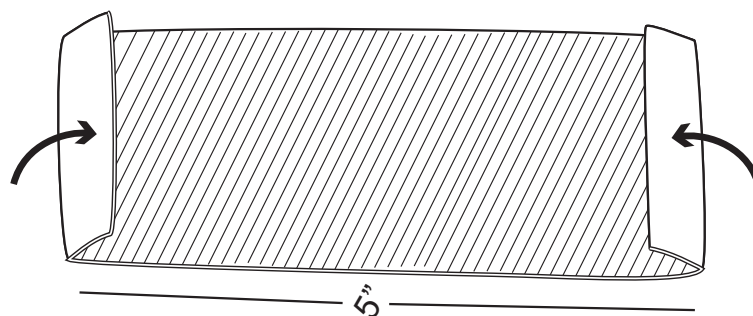


Figure 5: Folding the paper tape

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 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.

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.
- Do not submerge your catheter in water, such as in a bathtub or swimming pool.
- If your dressing gets wet, change it.

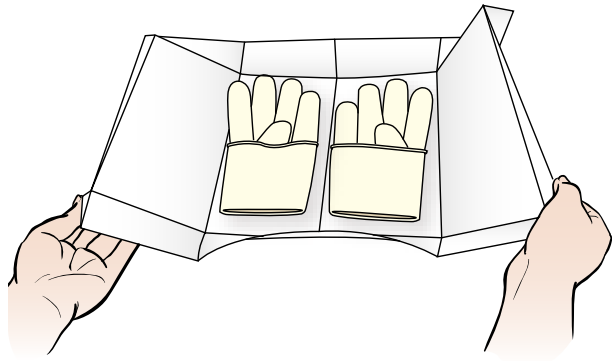
Call Your Doctor or Nurse Immediately if You:

- 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 when you flush your catheter
- Have a break or leak in your catheter
- Have an unexplained problem with your catheter

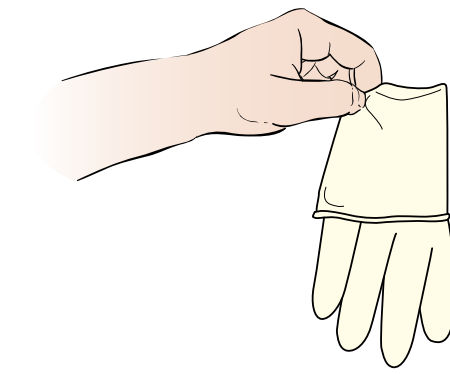
You can contact your healthcare providers directly Monday through Friday from 9:00 am to 5:00 pm. After 5:00 pm, during the weekend, and on holidays, please call (212) 639-2000 and ask for the doctor on call for your doctor.

Notes

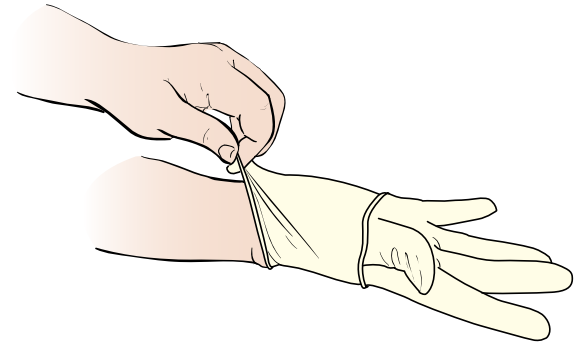
How to Put on Your Sterile Gloves



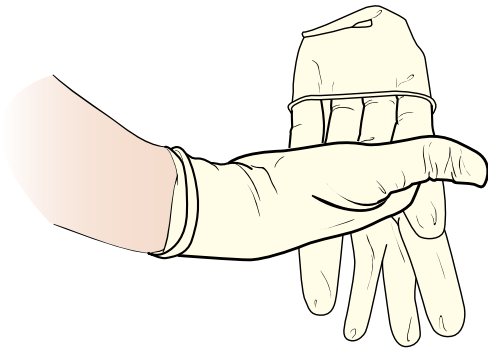
1 Open the package that contains the sterile gloves. Pull the edges of the package down to keep them flat.



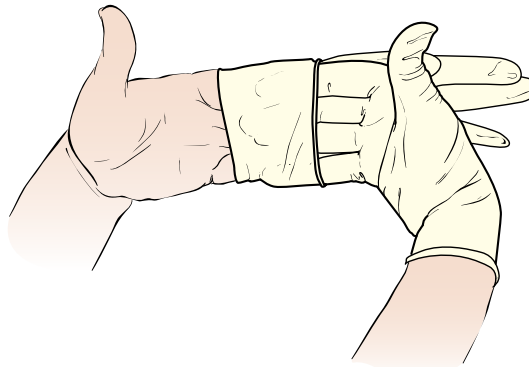
2 Pick up 1 glove by the folded cuff.



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.



Map for Dressing Change: CVC

NOTE: From this point on, do not touch your catheter or your skin except with an alcohol pad. This will decrease your risk of getting an infection.

10. **Wash your hands thoroughly with warm water and antibacterial soap or use the hand sanitizer packet provided on the outside of the kit.** Dry your hands thoroughly.

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, 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 the Chloraprep® applicator by squeezing the tabs (see Figure 1). Open and remove all the alcohol prep pads. 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 1). This will make the antiseptic soak into the applicator sponge. You must press very hard to make the click sound.

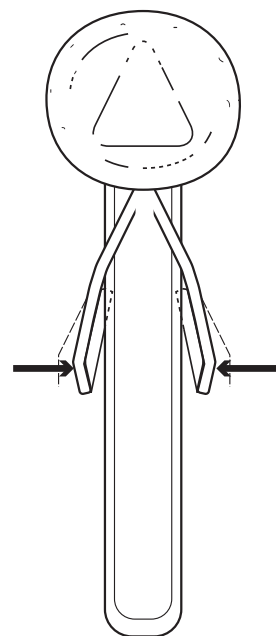


Figure 1:
Chloraprep®
applicator

14. With your nondominant hand, grasp the catheter using an alcohol pad (see Figure 2). Do not touch the catheter itself. Touch only the alcohol pad. Hold the catheter away from your chest.

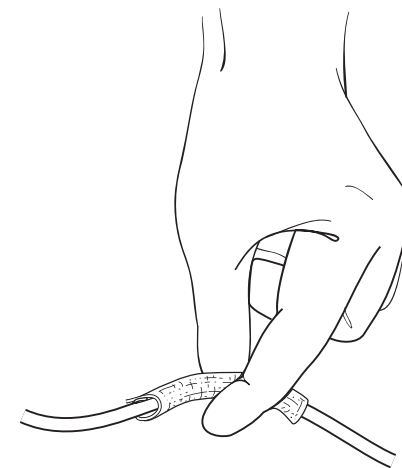


Figure 2: Holding the catheter

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 3). Discard the Chloraprep®.

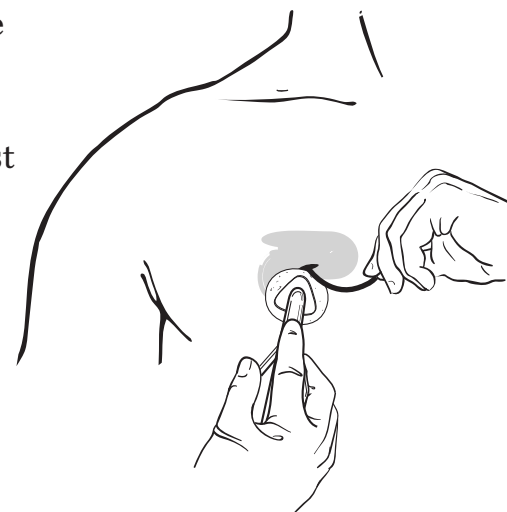


Figure 3: Cleaning the exit site

16. Allow the site to dry for 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. Take another alcohol pad in your dominant hand. Place it around the catheter, just above where it separates into lumens. Grasp the catheter with the alcohol pad. Hold the catheter up and use another alcohol pad in your nondominant hand to clean the catheter. Start at the incision site and gently wipe down to the hub using a new alcohol pad for each lumen. (see Figure 4). Do not pull on the catheter.

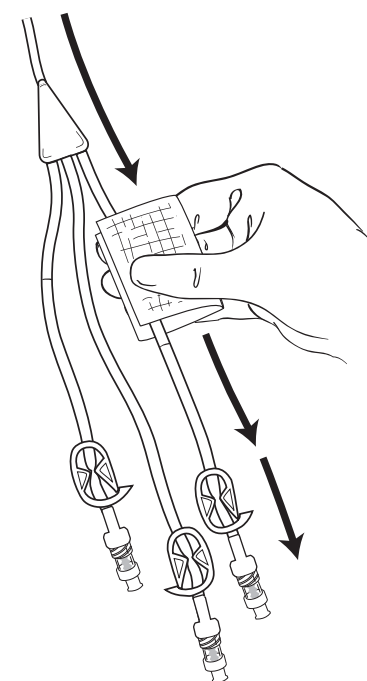


Figure 4: Cleaning the catheter

If the exit site is red, raw, swollen, or has drainage, notify your doctor after you finish the dressing change.

18. Apply the No Sting Barrier Film to your skin. Paint it on 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.

19. Peel the backing off the Tegaderm™ CHG (see Figure 5). Center the gel pad over the exit site and smooth down the dressing edge. Do not stretch the dressing when applying.

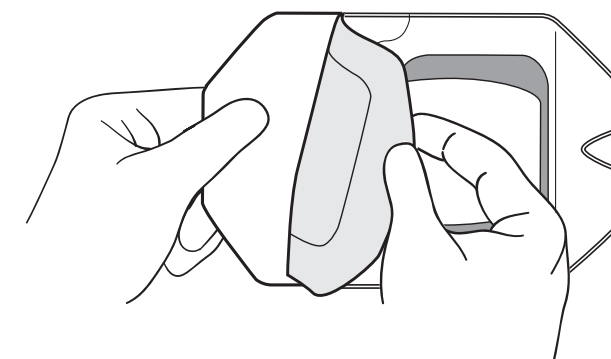


Figure 5: Tegaderm™ CHG dressing

20. Grasp the round paper tab on the outside and peel the plastic off all the way around the dressing (see Figure 6). 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.

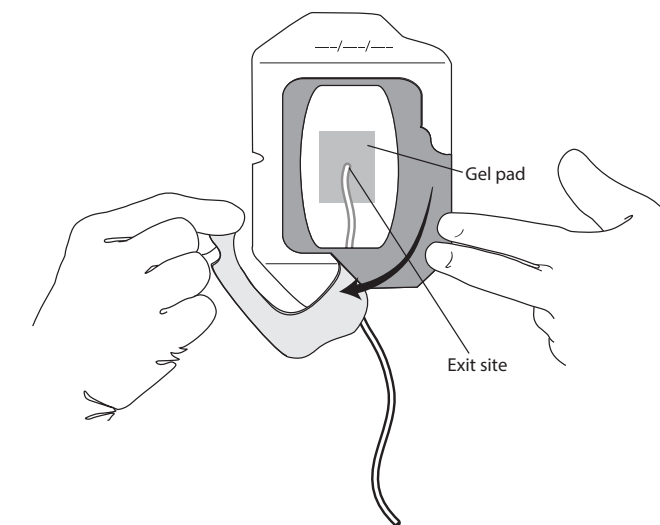


Figure 6: Applying the
Tegaderm™ CHG dressing

Continue the instructions in the booklet.



Name _____

Outpatient BMT Temperature & Intake Log

Use this form to keep track of how much you drink and your temperature. Bring it to all appointments. You will receive a new form every week.

Take your temperature every 4 hours while you are awake and record it in the chart below. Call your doctor or nurse practitioner if your temperature 100.4 F (38 C) or higher. If you feel a chill, take your temperature then call your doctor or nurse practitioner.

8:00 am-8:00 pm (212) 639-2399

8:00 pm-8:00 am (212) 639-2000
and ask for the doctor covering
bone marrow transplant



Date	4 am	8 am	noon	4 pm	8 pm	midnight
mm/dd	temp	temp	temp	temp	temp	temp



8 ounces = 1 cup

Measure all the fluids you drink. Use the chart below to record the type and amount.
Your goal is to drink 2 liters (64 ounces) every day.

Date	Fluid Intake						Total
	type	ounces	type	ounces	type	ounces	
mm/dd							total ounces



PATIENT & CAREGIVER EDUCATION

Sexual Activity During Cancer Treatment: Information for Women

Sexual activity can provide pleasure and intimacy during your cancer treatment. The information below can serve as a guide to being sexually active during this time.

If you have any questions about this information, let your doctor or nurse know. 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

If you become pregnant with an egg damaged by exposure to radiation, chemotherapy, or other anticancer medications, there is a risk of 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 contraception (birth control) throughout your treatment. Do not rely on your partner withdrawing before ejaculation (“pulling out”) or on avoiding sex during fertile times of your menstrual cycle (“rhythm method”). These methods are not effective in preventing pregnancy.

It is important to pick a method of birth control that fits your lifestyle but will also be effective. Make an appointment with your gynecologist, and speak with him or her to be sure you choose an option that is successful for you. No matter what method you choose, use birth control regularly or you may become pregnant. If you have any problems with your birth control, talk to your gynecologist to find another option.

Nonhormonal Birth Control

The following forms of birth control do not contain hormones and are safe for most women:

- Diaphragm

A diaphragm is a small reusable rubber or silicone cup that you place inside your vagina each time you have sex. Your gynecologist will determine what size you need. The diaphragm is inserted 1 to 6 hours before vaginal sex, and kept in place for 6 hours after sex. It should then be removed and cleaned. The diaphragm should not be left in the vagina for more than 24 hours because this can cause an infection.

- Copper intrauterine device (IUD)

This is a small, T-shaped device that your gynecologist places inside your uterus. It can stay in place for 10 years or be removed earlier. Copper IUDs may cause heavier blood flow during your monthly periods, so check with your oncologist to see if this is safe for you.

- Tubal ligation (having your “tubes tied”)

Tubal ligation is a surgical procedure that is done by a gynecologist. It may be an option for you if you are certain you don't want any (more) children.

- Condoms (used by your male partner)

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 “Barrier Devices” below for information on buying and using condoms.

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. However, some medical conditions make these unsafe, so they are not right for everyone. Women who should not take hormonal birth control include those with a hormone-sensitive tumor, 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 to your oncologist and gynecologist to see if this method is right for you and which type is best. These forms of birth control do not protect against HIV or other STIs. Hormonal forms of birth control include the following:

- 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 gynecologist gives you every 12 weeks.

- Implantable contraception (Implanon[®])

This is a small rod your gynecologist implants under the skin of your arm. It can stay in place for 2 years or be removed earlier.

- Intrauterine device (LNG IUD, Mirena[®])

This is a small, T-shaped device that your gynecologist places inside your uterus. It releases the hormone progestin. The device can stay in place for 5 years or be removed earlier.

Other Considerations

If you are getting chemotherapy or radiation directed to an area near your ovaries, continue to use birth control for at least 1 year after your treatment has ended. This allows time for damaged eggs to clear from your body. If you plan to have children after your treatment, ask your doctor when it is safe for you to start trying. Depending on your situation, your doctor may recommend you wait more or less time.

Some treatments may affect your fertility (the ability to become pregnant with a biologic child). If you have questions about this, ask your doctor or nurse.

■ Protect Yourself from Infection or Bleeding

Patients with multiple partners are at risk for sexually transmitted infections (STIs), including HIV. In addition, certain cancer treatments can cause low blood cell counts for prolonged periods of time, which may increase your risk of infection or bleeding. Your doctor or nurse will let you know if this is a concern for you. To prevent infection or bleeding:

- Wash your hands and genitals before and after having vaginal, oral, or anal sex.
- If you have sex with multiple men, consider using a condom each time you have vaginal, oral, or anal sex throughout your treatment, even if you are using another form of birth control. Condoms protect you from STIs, including HIV.
 - 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. Do not use a male and female condom at the same time. Female condoms are not a very effective form of birth control, so you should not rely on them to prevent pregnancy.
- If you are expected to have very low blood cell counts for a prolonged period of time, your doctor or nurse may advise you to use a barrier device during sex—condoms or dental dams. See “Barrier Devices” below for more information.
 - In some situations, you may even be advised to avoid sex that involves penetration or contact with mucous membranes while your 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 or abstain from vaginal sex until the tissues heal. Ask your nurse for information on vaginal moisturizers and lubricants to help with vaginal dryness.
- 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 suspect you have a yeast infection, avoid sexual activity and call your doctor or nurse.
- If you have had a bone marrow or stem cell transplant, you are at increased risk of infection for many months after your treatment. Until your doctor tells you that your immune system has recovered
 - 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 saliva, vaginal secretions, or semen could enter your mouth. See “Barrier Devices” below for more information.
 - Abstain from any sexual activity that could expose your mouth to feces.

■ **Consider Steps to Avoid Exposing Your Partner to Chemotherapy and Other Anticancer Medications**

There is little data about how much anticancer medication gets into a woman's vaginal fluids, and even less on whether this poses any risk to a sexual partner. If this is a concern to you or your partner, consider using a barrier device whenever your partner may have contact with your vaginal fluids—a condom for

vaginal or anal sex and a dental dam when you are receiving oral sex. This will prevent your partner, regardless of his or her age or gender, 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 have chemotherapy and for 1 week afterward. If you have multiple male partners, or if you could become pregnant and are not using any other form of birth control, use condoms throughout your treatment and until your doctor advises you that it is safe to attempt pregnancy. See “Barrier Devices” below 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 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—they can cause condoms 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, call a gynecologist as soon as possible. Ask about emergency contraception (the morning-after pill) if you are not using another form of birth control.

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, you may want to avoid those with a spermicide or lubricant, as the taste may be unpleasant. Cut off the tip and cut down the side of the tube to make a sheet.
- To use a dental dam, hold the sheet over your vulva or anus while your partner is giving you oral sex.

■ Resources

MSKCC Female Sexual Medicine and Women's Health Program
(646) 888-5076

For help with issues related to female sexual function.

American Cancer Society: Sexuality for the Woman With Cancer

<http://www.cancer.org/Treatment/TreatmentsandSideEffects/PhysicalSideEffects/SexualSideEffectsinWomen/SexualityfortheWoman/sexuality-for-the-woman-with-cancer-to-c>

Call 1-800-227-2345 to request printed material.

American Congress of Obstetricians and Gynecologist

http://www.acog.org/For_Patients

National Cancer Institute: Sexuality and Reproductive Issues

<http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/Patient>

Call 1-800-4-CANCER to request printed materials.

Planned Parenthood

<http://www.plannedparenthood.org/>

New York City Department of Health and Mental Hygiene

<http://www.nyc.gov/html/doh/html/condoms/condoms.shtml>

For information on getting and using male and female condoms.

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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PATIENT & CAREGIVER EDUCATION

Sexual Activity During Cancer Treatment: Information for Men

Sexual activity can provide pleasure and intimacy during your cancer treatment. The information below can serve as a guide to being sexually active during this time.

If you have any questions about this information, let your doctor or nurse know. 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

If a woman becomes pregnant with sperm damaged by exposure to radiation, chemotherapy, or other anticancer medications, there is a risk of miscarriage or birth defects. If your partner is a female who could become pregnant, use contraception (birth control) throughout your cancer treatment. Do not rely on withdrawing before ejaculation (“pulling out”) or on avoiding sex during fertile times of her menstrual cycle (“rhythm method”). These are not effective in preventing pregnancy.

There are different types of birth control you can consider.

- If you have only 1 female partner, ask her to see a gynecologist to help her select a method of birth control that will be successful for her. Examples include birth control pills, intrauterine devices (IUDs), and diaphragms.
- If your partner chooses not to use birth control, or if you have more than 1 female 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 “Barrier Devices” below for information on buying and using condoms.

If you are getting chemotherapy or radiation directed to an area near your testes, continue to use birth control for at least 1 year after your treatment has ended. This allows time for damaged sperm to clear from your body. If you plan to have children after treatment, ask your doctor when it is safe for you to start trying. Depending on your situation, your doctor may recommend you wait more or less time.

Some treatments may affect your fertility (the ability to have a biologic child). If you have questions about this, ask your doctor or nurse.

■ Protect Yourself from Infection or Bleeding

Patients with multiple partners are at risk for sexually transmitted infections (STIs), including HIV. In addition, certain cancer treatments can cause low blood cell counts for prolonged periods of time, which may increase your risk of infection or bleeding. Your doctor or nurse will let you know if this is a concern for you. To prevent infection or bleeding:

- Wash your hands and genitals before and after having vaginal, oral, or anal sex.
- If you have sex with multiple female and/or male partners, consider using a condom each time you have vaginal, oral, or anal sex throughout your treatment to protect yourself from STIs, including HIV.
- If you are expected to have very low blood cell counts for a prolonged period of time, your doctor or nurse may advise you to use a barrier device during sex—condoms or dental dams. See “Barrier Devices” below for more information.
 - In some situations, you may even be advised to avoid sex that involves penetration or contact with mucous membranes while your counts are low. This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or sexual 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 are 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 have had a bone marrow or stem cell transplant, you are at increased risk of infection for many months after your treatment. Until your doctor tells you that your immune system has recovered
 - 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 saliva, vaginal secretions, or semen could enter your mouth. See “Barrier Devices” below for more information.
 - Abstain from any sexual activity that could expose your mouth to feces.

■ Consider Steps to Avoid Exposing Your Partner to Chemotherapy and Other Anticancer Medications

There is little data about how much anticancer medication gets into a man's semen and even less on whether this poses any risk to a sexual partner. If this is a concern to you or your partner, consider using a condom whenever your semen could enter your partner's vagina, mouth, or anus. This will prevent your partner, regardless of his or her age or gender, from being exposed to any medication that may be in your semen. We don't know how long these drugs may be in semen, but you could use a condom each day you have chemotherapy and for 1 week afterward. If you have multiple partners, or if you have a female partner who could become pregnant and is not using any other form of birth control, use condoms throughout your treatment and until your doctor advises you that it is safe to attempt pregnancy. See “Barrier Devices” below 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 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—they can cause condoms 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 your partner is of childbearing age, have her call a gynecologist. She should ask about emergency contraception (the morning-after pill) if she is not using another form of birth control.

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, you may want to avoid those with a spermicide or lubricant, as the taste may be unpleasant. Cut off the tip and cut down the side of the tube to make a sheet.
- 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

MSKCC Male Sexual and Reproductive Medicine Program
(646) 888-6024

For help with issues related to male sexual function.

American Cancer Society: Sexuality for the Man with Cancer

<http://www.cancer.org/Treatment/TreatmentsandSideEffects/PhysicalSideEffects/SexualSideEffectsinMen/SexualityfortheMan/index>

Call 1-800-ACS-2345 to request printed material.

American Congress of Obstetricians and Gynecologists

http://www.acog.org/For_Patients

National Cancer Institute: Sexuality and Reproductive Issues

<http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/Patient>

Call 1-800-4-CANCER to request printed materials.

Planned Parenthood

<http://www.plannedparenthood.org/>

New York City Department of Health and Mental Hygiene

<http://www.nyc.gov/html/doh/html/condoms/condoms.shtml>

For information on getting and using male and female condoms.

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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PATIENT & CAREGIVER EDUCATION

Sexual Health and Intimacy

This information explains how to maintain sexual health and intimacy during cancer treatment.

It is common for patients 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 or 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 during your cancer treatment. Ask your doctor how long

you should use birth control after your treatment is over.

- Ask your doctor or nurse 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).
- Speak with your doctor or nurse if:
 - You are a female patient and 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 are a male patient and you have difficulty getting or keeping an erection. Your doctor can recommend medication that may help. You can also be referred to our Male Sexual & Reproductive Medicine Program (see contact information below).
 - You are a male or female patient and you have difficulty with incontinence (involuntary leakage of urine or feces). Your doctor can give you a referral to the Sillerman Center for Rehabilitation (see contact information below).

■ 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.

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 doctor or nurse 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

Learn beauty techniques to help you feel better about your appearance. This program is for both women and men. There are many tips on the program website, www.lookgoodfeelbetter.org. To register for a workshop at MSK, call (212) 639-LOOK. To find out if a group program is available in your area, check the

program website, or call 1-800-395-LOOK.

■ Selected Resources

American Cancer Society (ACS)

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

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.

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PATIENT & CAREGIVER EDUCATION

Hair Loss During Your Cancer Treatment

At Memorial Sloan Kettering Cancer Center (MSK), we understand that it can be difficult to experience hair loss during treatment. This information will help you understand hair loss and describe services available to help you.

■ Commonly Asked Questions

Why will I lose my hair?

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 the scalp and the loss of pubic hair, arm and leg hair, 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 will not grow back the same as it was before treatment.

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. The extent of your hair thinning or loss will depend on the type, dose, timing of your treatments. Some patients will experience hair thinning rather than hair loss. Speak to your nurse about what to expect after your chemotherapy or radiation therapy.

How quickly hair falls out varies from patient to patient. You may first notice hair on your pillow in the morning or see it when you shower or brush your hair.

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 a little different.

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 experiencing hair loss:

- Use a baby shampoo or other mild shampoo and a cream rinse or hair conditioner every 2 to 4 days.
- 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 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**

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 stores that sell wigs and hairpieces at the end of this resource.

Wigs

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, multiple visits to a store are usually needed.

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/stock wigs

Ready-made or stock wigs are usually made out of a stretchy material and come in 1 size. If you buy a readymade 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.

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

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

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 at MSK is designed to help male and female teenagers and adults 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 (212) 639-LOOK.

■ Where to Purchase Wigs and Hairpieces

Manhattan

Angels of New York

161 East 61st Street

New York, NY 10021

(212) 838-7888

www.angelsofny.com

Nicholas Piazza

16 West 56th Street

2nd Floor

New York, NY 10019

(212) 838-6190

*Nina Larsen**

26 East 63rd Street

New York, NY 10065

(646) 301-9087

(917) 517-4544 (cell)

Call to make an appointment

Top Priority Prosthetics for Hair Loss

174 Fifth Avenue

New York, NY 10010

(212) 206-6785

JA Alternatives

12 East 46th Street

New York, NY 10017

(212) 682-6888

www.hairloss-hair-replacement.com

Brooklyn

*Claire Accuhair**

1611 Cedar Street

Brooklyn, NY 11230

(718) 998-6043

www.claireaccuhair.com

*Yaffa Wigs**

4118 13th Street

Brooklyn, NY 11218

(718) 436-4280

www.yaffawigs.com

Queens

*Ginza Wigs**

116-01 Queens Boulevard

Forest Hills, NY 11375

(718) 544-1848

www.ginzawig.com

Long Island

Jacki's Wig Works

3381 Merrick Road

Wantagh, NY 11793

(516) 679-4633

www.jackiswigworks.com

The Wig Salon

1008 West Jericho Turnpike

Smithtown, NY 11787

(631) 864-7560

www.thewigsalonli.com

JA Alternatives

125 Jericho Turnpike

Suite 104

Jericho, NY 11753

(516) 333-1426

www.hairloss-hair-replacement.com

Westchester County

JA Alternatives

141 South Central Avenue
Suite 303
Hartsdale, NY 10530
(914) 682-2825
www.hairloss-hair-replacement.com

Oggi, Adam & Eve

770 Central Avenue
Scarsdale, NY 10583
(586) 985-0576
www.oggiadameve.com

Tiffany Wigs

100 Triangle Shopping Center
Yorktown Heights, NY 10598
(800) 427-9447
www.tiffanywigs.com

New Jersey

AAA Wigs

682 Morris Turnpike
Short Hills, NJ 07078
(973) 376-8050
www.angelsofny.com

*Just For You**

37 Mt. Pleasant Avenue
East Hanover, NJ 07936
(973) 887-5930
www.justforyoucenter.com

JA Alternatives

210 Route 4 East
Suite 103 & Suite 104
Paramus, NJ 07652
(201) 368-8900
www.hairloss-hair-replacement.com

*Lillian Lee Salon and Spa**

947 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

Anthony's Wigs

Hawley Lane Mall
Trumbull, CT 06611
(800) 421-9447
www.anthonystylists.com

* For women only.

■ 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, and BioSil™.

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.

For more information, including how to apply the product, go to: www.rogaine.com for an instructional video.

The 5% product is marked for men. The 2% product is marked for women. Which product do you recommend?

We recommend the 5% product for both men and women.

Is the liquid or foam product easier to apply?

The foam product is easier to apply if you have some hair, and less likely to drip down your face.

How often should I apply it?

Apply it at least once daily, but we recommend applying it twice daily.

What are the side effects?

Uncommon side effects include scalp irritation and itchy or dry scalp. Rare side effects include increased hair growth on the face.

You may experience changes in the color or texture of your hair.

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 uncommon. The hair growth may be caused by the transfer of minoxidil to areas other than the scalp, or by low levels of it being absorbed into the 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 is essential for healthy hair, skin, and nails, as well as healthy bones and joints. It promotes greater skin elasticity, thicker and stronger hair, and harder nails.

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.

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.



PATIENT & CAREGIVER EDUCATION

Low-Microbial Diet

This information will help you follow a low-microbial diet. Eating a low-microbial diet will reduce your risk of getting sick while your immune system is weak, such as 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 beverages are safe to eat and drink while on a low-microbial diet. Do not 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.

Allogeneic and autologous stem cell transplant patients should follow the diet for the first 100 days post transplant. Please speak to your healthcare team about whether you need to continue to follow the diet after the 100-day period is over.

■ Food Safety Guidelines

What are microbes?

Microbes are tiny living organisms, 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 is being processed or prepared. When microbes get into foods, they can cause infections, especially if you have a low white blood cell count (neutropenia).

Microbes can attach to foods and grow, but you can't always see, smell, or taste them. They are more likely to grow on:

- Milk and other dairy food items that are not refrigerated.
- Unpasteurized cheeses (e.g., Brie or feta).
- Undercooked and raw eggs and foods that have raw eggs (e.g., cookie dough and Caesar salad dressing).
- Undercooked or raw meat, poultry (chicken and turkey), and seafood including smoked seafood (e.g. smoked salmon or trout).
- Certain fruits and vegetables (see the Fruits and Vegetable list in the “What to Eat on a Low-Microbial Diet” section).
- Unpasteurized or untreated juices (e.g., fresh-squeezed juices).
- Vegetable sprouts (e.g., raw alfalfa, soy bean, and radish sprouts).

Buying foods that are safe to eat

- 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 is not tightly closed.
- Only buy eggs that are refrigerated in the store. Check the eggs by opening the carton to see if any are

broken or cracked.

- 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 foods at the end of your shopping trip. This decreases the time these items will spend outside of the refrigerator.
- Check containers for the expiration date. Buy and use food before that date.

Transporting food safely

- After grocery shopping, go directly home, so that you can 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 your trip from the grocery store to your home is long, place the perishable foods in an insulated bag or cooler with ice or frozen gel packs. These will keep the food cold until you can store it safely at home.

Storing food safely

- Store food immediately after shopping.
- Put eggs and milk inside the refrigerator; don't store them in the door. The temperature inside the refrigerator will stay cooler than in the door area.

Keeping your kitchen clean

- Keep an area of your kitchen clean for preparing and eating food. This will help prevent the spread of microbes.
- Use paper towels or clean cloths instead of sponges to clean kitchen surfaces.
- 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 cutting boards that are made out of thick plastic, marble, glass, or ceramic. These materials are nonporous, meaning that food or liquid substances can't absorb into them. Don't use wood or other porous surfaces that can absorb food and liquids.
- Wash cutting boards and knives with hot soapy water before using them to cut the next food. As an extra precaution, wash your cutting boards with a kitchen sanitizer. Throw out worn or hard-to-clean cutting boards.

Handling food safely

- Wash your hands thoroughly:
 - Before preparing or eating food
 - After preparing raw poultry, meat, fish, or seafood
 - After handling garbage
- Thoroughly rinse fresh fruits and vegetables under running tap water. Rinse skins and rinds before cutting or peeling. Never use bleach or detergent to wash fresh fruits and vegetables.
- Rub firm-skinned fruits and vegetables under running warm tap water or scrub them with a clean

vegetable brush while rinsing with running tap water.

- Remove and throw away any damaged or bruised areas on fruits or vegetables.
- Cook all foods thoroughly.
- Separate raw meats from ready-to-eat foods.
- 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.
- Use a food thermometer to check the internal temperatures of cooked and reheated foods.
- Don't eat hamburgers and other meat products if the meat looks undercooked. Cook the meat until it is grey and the juices run clear.
- Cook fish until it flakes.
- Cook egg whites and yolks until they are firm.
- Cook all meats to the minimum internal temperatures listed in the chart below.

Food	Safe Minimum Internal Temperatures
Egg and Egg Dishes	
Eggs	Cook until yolk and white are firm
Egg dishes	160° F
Egg sauces	160° F
Ground Meat and Meat Mixtures	
Turkey and chicken	165° F
Beef, hamburgers, veal, lamb, and pork	160° F
Fresh Beef, Veal, and Lamb	
Well done	170° F
Fresh Pork	
Well done	170° F
Ham	
Raw/fresh	160° F
Precooked, cured ham	140° F
Poultry	
All products	165° F
Seafood	
All (raw/fresh)	145° F

Eating leftovers

- Refrigerate leftovers in shallow containers immediately after eating.
- Reheat the following leftovers to an internal temperature of at least 165°F 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. Heat the food until it reaches 165° F throughout, as measured with a food thermometer.
- 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

Food Group	What to Eat	What to Avoid
Breads, Grains, and Cereals	<ul style="list-style-type: none"> ■ All breads, rolls, bagels, English muffins, waffles, French toast, muffins, pancakes, and sweet rolls ■ Potato chips, corn chips, tortilla chips, popcorn, and pretzels ■ Any cooked or ready-to-eat cereal purchased prepackaged from a store ■ Rice, pasta, and other cooked grains 	<ul style="list-style-type: none"> ■ Foods with raw (not cooked or baked) grains (e.g., uncooked corn or raw oats) ■ Undercooked or raw brewer's yeast
Milk and Dairy Products	<p>Pasteurized</p> <ul style="list-style-type: none"> ■ Grade A commercially available milk and milk products ■ Yogurts, including those made with live cultures (e.g., Dannon®) ■ Sour cream ■ Puddings made at home or bought prepackaged from a store ■ Prepackaged ice cream, frozen yogurt, sherbet, popsicles, ice cream bars, and fresh homemade milkshakes ■ Eggnog ■ Commercially sterile, ready-to-feed, and liquid concentrate infant formulas ■ Dry, refrigerated, or frozen pasteurized whipped topping <p>Pasteurized Cheese</p> <ul style="list-style-type: none"> ■ Processed cheese slices and spreads, cream 	<p>Unpasteurized</p> <ul style="list-style-type: none"> ■ Dairy products, such as raw milk ■ Eggnog (homemade) ■ Yogurt (usually homemade) ■ Soft serve ice cream or yogurt ■ Unrefrigerated, cream-filled pastry products ■ Fermented dairy products ■ Products with probiotics added after pasteurization <p>Cheese</p> <ul style="list-style-type: none"> ■ All cheese made from unpasteurized milk including soft cheeses, such as Brie, farmer's cheese, Camembert, Mexican-style cheese (queso blanco and queso fresco), and goat cheese, and unpasteurized mozzarella cheese. ■ All mold-ripened cheeses and soft cheeses, such as Roquefort, Muenster, Stilton, havarti, Edam, Gorgonzola, blue cheese, sharp cheddar, and feta ■ Cheeses from delis

	<ul style="list-style-type: none"> cheese, cottage cheese, and ricotta cheese ■ Commercially packaged hard and semi-soft cheese such as American, mild cheddar, pasteurized mozzarella, Monterey jack, Swiss, and shelf-stable (foods that can be safely stored at room temperature) grated Parmesan (e.g., Kraft®) ■ Cooked soft cheeses, such as Brie, Camembert, feta, and farmer's cheese. 	<ul style="list-style-type: none"> ■ Cheeses that contain chili peppers or other uncooked vegetables
Eggs	<ul style="list-style-type: none"> ■ Well-cooked eggs (firm white and yolk) ■ Pasteurized eggs, pasteurized egg substitutes (such as Egg Beaters®), and powdered egg whites 	<ul style="list-style-type: none"> ■ Undercooked or raw eggs and unpasteurized egg substitutes ■ Salad dressings containing raw eggs (e.g., Caesar salad dressing)
Meat, Meat Substitutes, Poultry, and Seafood	<ul style="list-style-type: none"> ■ Well-cooked meats, such as pork, beef, lamb, chicken, and turkey (see Food Safety Guidelines for cooking temperatures) ■ Cooked tofu (cut into 1 inch cubes and boiled for at least 5 minutes) or pasteurized tofu ■ Cooked fermented products including miso and tempeh ■ Bacon that is crisp and made at home ■ Hotdogs cooked at home until steaming hot ■ Commercially prepared deli meats sold in a sealed package, such as salami, bologna, ham, turkey, and other deli meats that are cooked until steaming hot (throw away within 48 hours of opening) ■ Thoroughly cooked fish and other seafood, including shrimp, lobster, crab, canned tuna, and canned salmon ■ Canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, and hot dogs) ■ Canned and shelf-stable smoked fish (refrigerate after opening) 	<ul style="list-style-type: none"> ■ Undercooked or raw meats, poultry, and fish, including rare or medium-rare items ■ Raw miso products ■ Raw tempeh ■ Freshly sliced deli meats and meats from street vendors ■ Hard-cured salami in natural wrap ■ Beef jerky ■ Raw shellfish, raw fish (including caviar), sashimi, sushi, and ceviche ("lemon-cooked" or cured fish) ■ Raw or cooked clams, mussels, and oysters ■ 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) ■ Refrigerated pâtés and meat spreads
Fruits and Vegetables	<ul style="list-style-type: none"> ■ Well-washed and peeled raw fruits and vegetables ■ Cooked and canned fruits and vegetables ■ Cooked frozen fruits and vegetables ■ Well-washed and peeled thick-skinned fruits without bruises, such as citrus fruits, bananas, cucumbers, and melons ■ Well-washed and peeled apples (thorough washing is important because slicing through the skin or rind can contaminate the inner fruit) ■ Pasteurized juices and frozen concentrates ■ Commercially packaged dried fruits ■ Shelf-stable bottled salsa (refrigerate after opening) ■ Cooked vegetable sprouts (e.g., mung bean) ■ Fresh, well-washed herbs and dried herbs and spices (added to allowed raw or cooked foods) 	<ul style="list-style-type: none"> ■ Unwashed and unpeeled raw fruits, vegetables, or herbs ■ Any fresh or raw fruits and vegetables that can't be thoroughly washed and peeled or cooked (e.g., blueberries, strawberries, raspberries, cherries, peaches, plums, and grapes that tend to get mold around their stems) ■ Any frozen berries and other thin-skinned frozen fruits ■ Unpasteurized fruit and vegetable juices ■ Fresh fruit salsa or fresh vegetable salsa found in the grocery refrigerator case ■ Vegetarian sushi ■ Unpasteurized items containing raw fruits or raw vegetables found in the grocery refrigerator case ■ All uncooked vegetable sprouts (alfalfa, bean, clover, and all others) ■ All salads from delis or salad bars
	<ul style="list-style-type: none"> ■ Boiled well water 	<ul style="list-style-type: none"> ■ Unpasteurized eggnog or apple cider and other

Beverages	<ul style="list-style-type: none"> ▪ Tap water and ice made from tap water ▪ Commercially bottled distilled, spring, and natural waters ▪ Pasteurized fruit and vegetable juices ▪ Bottled, canned, or powdered beverages ▪ Instant and brewed coffee ▪ Hot-brewed teas using commercially packaged tea bags ▪ Pasteurized soy milk ▪ Commercially made liquid nutritional supplements (e.g., Ensure[®], Boost) 	<ul style="list-style-type: none"> ▪ unpasteurized fruit or vegetables juices ▪ Reconstituted protein powder beverages, unless approved by your dietitian ▪ Unpasteurized beer (e.g., microbrewery beers and those that are not shelf-stable) ▪ Wine ▪ Fountain beverages ▪ Tea made with loose leaves
Nuts and Dried Fruits	<ul style="list-style-type: none"> ▪ Factory-packaged nuts and dried fruits ▪ Roasted nuts from a can or bottle ▪ Nuts in baked goods such as peanut butter cookies ▪ Commercially packaged nut butters (such as peanut, almond, and soybean) 	<ul style="list-style-type: none"> ▪ All nuts or dried fruits that are sold open and in bulk, as in some health food or specialty stores ▪ Raw nuts ▪ Freshly made peanut butter (not commercially packaged) ▪ Roasted nuts in the shell
Condiments and Miscellaneous	<ul style="list-style-type: none"> ▪ Salt and sugar ▪ Jellies, syrup, and jams (refrigerate after opening) ▪ Pasteurized or flash pasteurized honey ▪ Packaged ground black pepper, herbs, and spices added before the cooking process ▪ Catsup, mustard, BBQ sauce, and soy sauce, (refrigerate after opening) ▪ Pickles, pickle relish, and olives (refrigerate after opening) ▪ Vinegar ▪ Vegetable oils and shortening ▪ Refrigerated margarine and butter ▪ Commercially made, shelf-stable mayonnaise and salad dressings, including blue cheese and other cheese-based salad dressings (refrigerate after opening) ▪ Cooked gravy and sauces 	<ul style="list-style-type: none"> ▪ Raw or unpasteurized honey and honeycomb ▪ Whole or fresh ground black pepper, unless thoroughly cooked in food ▪ Fresh salad dressings (stored in grocer's refrigerated case) containing raw eggs or cheeses, such as Caesar salad dressing ▪ Herbal and nutritional supplement preparations
Desserts	<ul style="list-style-type: none"> ▪ Refrigerated, commercially made, and homemade cakes, pies, pastries, and pudding ▪ Refrigerated cream-filled pastries ▪ Cookies, both homemade and commercially prepared ▪ Shelf-stable, cream-filled cupcakes and fruit pies ▪ Candy and gum 	<ul style="list-style-type: none"> ▪ Unrefrigerated, cream-filled pastry products (not shelf stable)
Eating Outside the Home and Take-Out	<ul style="list-style-type: none"> ▪ 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 (e.g., freshly made pizza not sliced or reheated, hamburger directly off a grill, just-cooked French fries) ▪ Single-serving condiment packages (no pump serve containers) 	<ul style="list-style-type: none"> ▪ Any food that is not freshly made to order ▪ Unpasteurized fruit juices and dairy products (e.g., juice bar establishments such as Jamba Juice[®]) ▪ Raw fruits and vegetables served at salad bars and desserts with fresh fruit ▪ Deli meats and cheeses ▪ Buffets/smorgasbords ▪ Potlucks and sidewalk vendors ▪ Soft serve ice cream and yogurt ▪ Fast food (e.g., McDonalds[®], Subway[®]) ▪ Reheated foods

Always remember: when in doubt, throw it out!

Eating out at restaurants

You can eat out while on a low-microbial diet (as long as you are not a stem cell transplant patient, see guidelines below), as long as you choose the restaurant carefully. Local health departments inspect restaurants to make sure that they are 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: www.nyc.gov/html/doh/html/services/restaurant-inspection.shtml.

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 (e.g., Caesar salad dressing and hollandaise sauce).
- Ask the waitstaff if you are not 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 catsup 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 not be cleaned on a regular basis.
- Always order a whole or personal pizza. Don't order individual slices, since they are often stored under heat lamps.

Guidelines for bone marrow and stem cell transplant patients

Allogeneic and autologous stem cell transplant patients should not eat out at restaurants for the first 100 days post 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 herbal supplements

Don't take homeopathic remedies or herbal products (e.g., traditional Chinese medicines). Because there are no federal standards for these products in the United States, the way they are 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 are 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.

If you use well water, 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 did not use in 48 hours.

■ Resources

United States Department of Agriculture (USDA) Food Safety and Inspection Service

www.fsis.usda.gov

www.fsis.usda.gov/PDF/Cutting_Boards_and_Food_Safety.pdf 

US Department of Health and Human Services (USDHHS) Food Safety Information

www.foodsafety.gov

USDHHS Food and Drug Administration (FDA)

www.fda.gov/ForConsumers/default.htm

Centers for Disease Control and Prevention Food Safety

www.cdc.gov/foodsafety/

Fight BAC! Partnership for Food Safety Education

www.fightbac.org

USDA “Ask Karen” (web-based question and answer system)

www.fsis.usda.gov/wps/portal/informational/askkaren

NYC Department of Health and Mental Hygiene Restaurant Inspection Information

www.nyc.gov/html/doh/html/services/restaurant-inspection.shtml

FDA (toll-free numbers)

(888) SAFE-FOOD (723-3366)

(888) INFO-FDA (463-6332)

Related Patient & Caregiver Education Resources

[Outpatient Autologous Stem Cell Transplant: A Guide for Patients & Caregivers](#)

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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ABOUT MEDICALERT FOUNDATION

An international charity, MedicAlert Foundation was established in 1956 and pioneered the use of medical identification and information services for medical emergencies. We protect the health and well-being of millions worldwide through our trusted 24/7 emergency support network. We educate emergency responders and health professionals - our partners in everyday emergency situations - about the services we provide during emergencies. And, we communicate your health information, your wishes, and your directives to ensure you receive the best care possible.

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More than a bracelet,[™] it's a safety network.

Our services ensure emergency responders and hospital staff get your up-to-date medical information, the moment they need it, to make informed decisions about your treatment and care.

With MedicAlert Foundation, you can be confident knowing that you are connected to our 24/7 support network – because every moment matters.

A MEDICALERT® MEMBERSHIP TO FIT YOUR NEEDS

INDIVIDUAL MEMBERSHIPS



For Your Child **KID SMART®**

In an emergency, we convey your child's health information to emergency responders and health professionals to ensure your child receives quick and proper treatment. Kid Smart® membership also includes 24/7 Family Notification so that you are notified and quickly reunited with your child.

We understand the fears that weigh on parents' minds - We're here to alleviate those fears so you may rest easy and your child can focus on fun.



For Adults **ADVANTAGE**

We provide a medical record which is available 24/7 to you (for unlimited updates and review) and to professionals to ensure your entire health history is communicated when it's needed. We also connect with your loved ones so you may be quickly reunited during an emergency, and notify your Physician/Provider to improve overall care coordination.

Our comprehensive suite of 24/7 services allows you to enjoy today and live worry-free.



For Adults with Alzheimer's or Dementia **MEDICALERT® + ALZHEIMER'S ASSOCIATION SAFE RETURN®**

6 out of 10 people with Alzheimer's or dementia will wander or become lost. Should your loved one wander, MedicAlert Foundation will work with you, your local Alzheimer's Association chapter, and local law enforcement to provide for the safe return of your loved one.

You can't know when a wandering incident will happen, but you'll know what to do when it does.

PACKAGED MEMBERSHIPS

Connect Yourself to Your Loved One **CAREGIVER MEMBERSHIP**

www.medicalert.org/caregiver

What happens to your loved one should you experience an emergency? We can contact your designated back-up caregiver to keep your loved one safe - this allows you to focus on your personal recovery and overall health.

Connect Your Entire Family **FAMILY MEMBERSHIP**

www.medicalert.org/family

Keeping your family's important health information stored in one secure location can be an invaluable tool for parents. Additionally, in the event of an emergency or disaster situation, we can serve as your family's single connection, ensuring you are all quickly reunited.

SIMPLIFIED ONLINE-ONLY PLANS



ESSENTIAL™

A streamlined membership plan, Essential offers the convenience of a secure health information

platform. In an emergency, Essential members also receive MedicAlert's signature service offering - our live 24/7 emergency response.

Keeping track of your health can be complicated - Essential offers security and simplicity.



ADVANCE DIRECTIVE MANAGEMENT SERVICE (ADMS)

Our Advance Directive Management Service will store your notarized documents and make them available to health professionals or a designated family member/healthcare proxy in the event of an emergency. We also provide the official advance directive forms recognized by each state.

Ensure your healthcare wishes are honored and spare your family the burden of making difficult treatment decisions on your behalf.

	KID SMART® www.medicalert.org/kidsmart \$40/year	ADVANTAGE www.medicalert.org/advantage \$50/year	SAFE RETURN® www.medicalert.org/safereturn \$55/year
24/7 Emergency Response	✓	✓	✓
24/7 Family Notification	✓	✓	✓
24/7 Physician/Provider Notification	✓	✓	✓
EMIR® (Emergency Medical Information Record)	✓	✓	✓
Call Center Concierge	✓	✓	✓
Specialized Medical ID Offer with Enrollment	Free basic medical ID* or \$10 towards any ID purchase	_____	Free basic medical ID*
Free Engraving on Medical IDs	✓	✓	✓
Emergency Wallet Card	✓	✓	✓
Care Consultation Services	_____	_____	✓
Advance Directives Storage DNR Orders	_____	✓	✓
Implanted Device Registration	✓	✓	✓
Wandering Assistance	✓	_____	✓
Global Service	✓	✓	✓
Pet Caregiver Notification	Add on: \$15/year	Add on: \$15/year	Add on: \$15/year

ONLINE ONLY PLANS	
ESSENTIAL™ www.medicalert.org/essential \$10/year	ADMS www.medicalert.org/adms \$10/year
✓	✓
Add on: \$15/year	_____
Add on: \$15/year	_____
✓	_____
Add on: \$20/year	_____
_____	_____
✓	✓
Free downloadable card and \$5 for a plastic card	✓
_____	_____
✓	✓
✓	_____
_____	_____
✓	✓
Add on: \$15/year	_____

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Visit www.medicalert.org/shopids to see full medical ID selection. Prices shown are subject to change without notice.

FREE WITH KID SMART™	FREE WITH SAFE RETURN™	OTHER ID OPTIONS (SEE ALL AT WWW.MEDICALERT.ORG/SHOPIDS)	
<p>RED STEEL BRACELET (\$10)</p>  <p>A126</p>	<p>PURPLE STEEL BRACELET (\$10)</p>  <p>Standard Z102 Large Z101</p>	<p>BLACK SPORTS BAND (\$25)</p>  <p>A797</p>	<p>IRIDESCENT CRYSTAL BRACELET (\$60)</p>  <p>A756</p>
<p>SHOE TAG (\$10)</p>  <p>A661</p>	<p>PURPLE PENDANT (\$10)</p>  <p>Z100</p>	<p>STAINLESS STEEL STRETCH BAND (\$30)</p>  <p>Small A734 Large A733</p>	<p>RHODIUM SILVER BRACELET (\$100)</p>  <p>A117</p>
<p>BLACK DOG TAG (\$10)</p>  <p>A600</p>		<p>BLUE BEADED BRACELET (\$30)</p>  <p>A700</p>	<p>LARGE STERLING SILVER BAR BRACELET (\$170)</p>  <p>A195</p>
<p>CHILD'S STEEL BRACELET (\$10)</p>  <p>A156</p>			



Sample engraving of a personalized MedicalAlert ID.

ID Engraving: In an emergency, response personnel need to be aware of your critical medical information in order to treat you correctly. We will personalize your medical ID with your critical medical information and your unique MedicalAlert member number after we have reviewed your information. Only authentic MedicalAlert medical IDs with the words "MEDIC ALERT" use this review process. No other company provides this free service. We may contact you if we have questions about the information you have provided.

Please Note: Once your MedicalAlert ID has been engraved and shipped, there will be an additional charge for any changes requested. ID engraving is personalized to individual members and cannot be transferred to another individual, altered, sold, or returned. For full terms, conditions and warranty information please go to www.medicalert.org/warranty.

PERSONAL INFORMATION

Yes No

PREVIOUS MEMBER _____ IF YES, MEMBER NUMBER _____

FIRST NAME _____ MIDDLE NAME _____

LAST NAME _____

MAILING ADDRESS _____ UNIT/APT # _____

CITY _____ STATE _____ ZIP _____

PHONE Home Cell Work Home Cell Work _____

EMAIL ADDRESS (STRONGLY RECOMMENDED) _____

DATE OF BIRTH _____ Male Female
GENDER

EMERGENCY CONTACTS*

PRIMARY EMERGENCY CONTACT _____ RELATIONSHIP _____

EMERGENCY CONTACT'S PHONE _____ SECOND PHONE _____

PRIMARY PHYSICIAN _____ PHYSICIAN PHONE _____

MEDICAL CONDITIONS/DEVICES/MEDICATIONS*

ALLERGIES*

NO KNOWN MEDICAL CONDITIONS ALLERGIES MEDICATIONS

* Please attach additional listings if needed

SELECT YOUR MEMBERSHIP

Kid Smart (\$40/yr) _____

Advantage (\$50/yr) _____

MedicAlert + Safe Return (\$55/yr) _____

Essential (\$10/yr) - Available online only

Advance Directive Management Service (\$10/yr) - Available online only

Caregiver Membership - Learn more at www.medicalert.org/caregiver

Family Membership - Learn more at www.medicalert.org/family

SELECT YOUR MEDICAL ID(S)

See select medical ID details on back of form or view all medical IDs online at www.medicalert.org/shopids

ID # _____ Price _____

Wrist size (Please measure your wrist & add 1/2") _____
Need measuring tips? Go to www.medicalert.org/sizing

Shipping and handling _____ \$7.00

TOTAL _____

PAYMENT

Check Money Order

MasterCard® Visa® Discover® AMEX®

No other cards accepted. No CODs. Payment must accompany order.

CREDIT CARD NUMBER _____ EXPIRATION DATE (MM/YY) _____

CREDIT CARD HOLDER'S NAME _____

CREDIT CARD HOLDER'S BILLING ADDRESS _____

SIGNATURE FOR CARD AUTHORIZATION _____

To ensure uninterrupted MedicAlert membership, your credit card will be automatically charged the membership renewal rate on your renewal date.

Check the box if you don't want us to charge your credit card for renewal.

Important: By accepting membership in MedicAlert Foundation, for yourself as member or caregiver and/or as caregiver on behalf of the member named above (collectively, "you"), you authorize MedicAlert to release all medical and other confidential information about you in emergencies and to other health care personnel you designate. If you choose to terminate membership, you must notify us in writing and return your jewelry. MedicAlert relies upon the accuracy of the information that you provide. You, therefore, agree to defend, indemnify, and hold MedicAlert (including its employees, officers, directors, agents, and organizations with which it maintains a marketing alliance for the provision of services hereunder) harmless from any claim or lawsuit brought by member or others for injury, death, loss or damages arising in whole or in part out of your provision of incomplete or inaccurate information to MedicAlert. Furthermore, as caregiver for the member named above, you hereby represent and warrant to MedicAlert that you have full power and authority, as the duly authorized representative of such member, to enroll and act on his or her behalf.

SIGNATURE OF MEMBER _____ DATE _____
(A parent or guardian signature is required for members under the age of 18.)

Prices are subject to change without notice.