

PATIENT & CAREGIVER EDUCATION

# Allogeneic Stem Cell Transplant: A Guide for Patients & Caregivers



Visit www.mskcc.org/pe/allogeneic\_guide to view this guide online.

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# **Welcome and Overview**

This guide is designed to help you and your loved ones understand what to expect throughout your transplant journey. The information in this guide isn't meant to replace the information that your transplant team will teach you. It's meant to be a resource that you can refer to throughout the transplant process.

In this guide, we'll explain some of the challenges you might have over the course of your transplant and recovery. But, this doesn't mean you'll have all of them. Because of that, you shouldn't compare yourself to other people you know or have heard of who had a stem cell transplant. Everybody is unique.

Stem cell transplants have been done for many decades. They've gotten much better over that time. But, a stem cell transplant is still a complex procedure that requires a commitment from you, your family or caregiver, and your transplant team.

Having a transplant is a long process. Getting ready for your transplant is just the first part of your journey. You'll need to stay within 1 hour of Memorial Sloan Kettering (MSK) for about 100 days (3 months) after the day of your transplant, even after you're discharged from the hospital. If you live further than 1 hour from the hospital, we can help you arrange for a place to stay closer to MSK. Overall recovery time is different from person to person, but you should plan to allow about 1 year for full recovery. All these things will be discussed in more detail in this guide.

At MSK, you'll have a large transplant team working together to care for you as you go through each phase of your transplant. It's normal to have many emotional changes during the transplant process. Your transplant team includes many providers, including social workers, chaplains, psychiatrists, and members of our Integrative Medicine Department. All these healthcare providers are available to support and help you and your caregiver(s) cope with what you may feel.

# The Importance of Communication

Throughout your transplant journey, it's very important to communicate clearly with your transplant team and caregiver about how you're feeling. If anything is bothering you, even if it seems small, tell a member of your transplant team. This is true for how you're feeling both physically and emotionally. It's very important not to let things build up. If you do, small problems can grow into larger problems. The more

information you communicate to your transplant team, the more they can help you. There's usually something they can do to make you feel more comfortable.

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

- While you're an outpatient, call your doctor's office. Between 9:00 AM and 5:00 PM Monday to Friday, your doctor's office coordinator will answer and give your message to the right person (such as your doctor, nurse, clinical nurse coordinator, or social worker). After 5:00 PM, on weekends, and on holidays, MSK's answering service will answer your call. Ask to talk to the hematology fellow on call.
- While you're in the hospital, tell a member of your transplant team. Your transplant team will see you at least once a day. You'll also see your primary nurse throughout the day. Talk with them about any issues during this time.
- **Use your MyMSK account.** MyMSK is MSK's patient portal. You can use MyMSK to ask questions about your appointment schedule, request a prescription refill, or request patient education information. Never use MyMSK to communicate any symptoms to your transplant team. You'll get more information about MyMSK at your initial consult visit. You can also read the resource *Communicating with Your Healthcare Team Using MyMSK*. You can ask a member of your transplant team for a copy or find it online at www.mskcc.org/pe/communicating\_using\_mymsk

#### About PROMIS

Your transplant team will also use MyMSK to check in about how you're feeling physically and mentally over time. The set of questions they'll send is called PROMIS. Your transplant team will send PROMIS questions to your MyMSK account:

- On or near the day you start treatment.
- On the day of your stem cell infusion.
- Every 7 days for the first month after your stem cell infusion.
- Every month for the first year after your stem cell infusion.
- Every 3 months for the second year after your stem cell infusion.

If you report any concerning symptoms when you're filling out the PROMIS questions, you'll either see a message asking you to call your healthcare team or a member of your transplant team will call you to help. Your answers will also help us know how people generally feel after an allogeneic stem cell transplant so we can improve our care for the future.

#### **How to Use This Guide**

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

We recommend that you highlight or write notes on anything that you don't understand or have a question about. There's no such thing as a silly question, so please ask about anything that's on your mind.

# Glossary

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

#### **Stem Cell and Bone Marrow Basics**

Hematopoietic (hee-MA-toh-poy-EH-tik) stem cells (usually just called stem cells) are immature cells that grow into all the blood cells in your body: the white blood cells that fight infection, red blood cells that carry oxygen, and platelets that help control bleeding. Your stem cells are constantly dividing and changing into these different types of blood cells to replace older blood cells. Stem cells also divide to make newer stem cells.

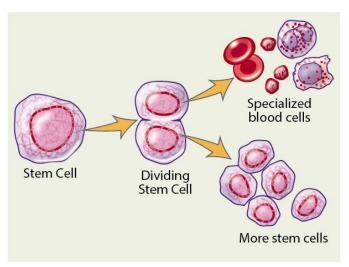


Figure 1. Your stem cells divide and change into the different types of blood cells in your body

Most of the stem cells in your body are in your bone marrow (the soft tissue in the spaces in the center your bones). Bone marrow is mostly found in the larger bones in your body, such as your hip, breastbone, and pelvis. A few stem cells are also found in your bloodstream.

You might hear your transplant called a stem cell transplant or a bone marrow transplant. A bone marrow transplant is a specific type of stem cell transplant. With a bone marrow transplant, the stem cells are taken from the bone marrow. With a stem cell transplant, the stem cells are taken from either the bone marrow or the bloodstream.

# What's the difference between a stem cell transplant and a bone marrow transplant?

A **bone marrow transplant** means the stem cells are taken from the donor's bone marrow.

A **stem cell transplant** means the stem cells are taken from either the donor's bone marrow or their bloodstream.

# **Understanding Your Allogeneic Stem Cell Transplant**

When you have an allogeneic stem cell transplant, stem cells are harvested (collected) from a donor. "Allogeneic" means that the stem cells come from someone else. The 3 general sources of stem cells that can be used in an allogeneic stem cell transplant are:

- **Peripheral blood stem cells.** These are collected from a donor's bloodstream through a process called apheresis (a-feh-REE-sis). To increase the amount of stem cells in their bloodstream, the donor will get injections (shots) of a medication that causes their body to make more stem cells than usual. The stem cells escape from their bone marrow into their bloodstream, where they can be collected easily while the donor is awake.
- **Bone marrow stem cells.** These are collected from a donor's bone marrow through a procedure called bone marrow harvesting. The procedure is done in the operating room while the donor is asleep. The donor usually goes home the same day of the procedure.
- **Umbilical cord blood stem cells.** These are collected from blood from the umbilical cord and placenta when a baby is born. They're frozen and stored in a cord blood bank until they're needed for a transplant.

#### Your Donor

A test called tissue typing is done to find out who is the best donor for you. For a hematopoietic stem cell transplant, the tissue typing is based on your human leukocyte (LOO-koh-site) antigens (HLA). These are markers on the surface of your white blood cells.

There are many HLA markers, and different people can have different patterns of the markers. HLA markers are inherited (passed from a mother and father to their child), so your close family members (siblings, parents, and children) are most likely to have a pattern of HLA markers that's like yours.

People who aren't related to each other can also be a close match. If you don't have a family member with a matching tissue type, we have a team of search coordinators who will look for an unrelated adult volunteer donor or umbilical cord blood units. The National Marrow Donor Program® has millions of people registered who have been typed for this purpose. But, searching for a donor can take weeks or even months. Sometimes, umbilical cord blood can be used if the transplant is urgent, because it's more readily available. If you'll need stem cells from someone who isn't related to you, your doctor will give you more information.

## Conditioning

Before your transplant, you'll get treatment to get your body ready, even if your disease is in remission. This is called conditioning. Conditioning is made up of chemotherapy, radiation therapy, or both. It's done to:

- Kill any remaining cancer cells in your body.
- Make room for the donor stem cells in your marrow spaces.
- Suppress (weaken) your immune system so you can accept the donor stem cells.

There are 2 types of conditioning before an allogeneic transplant.

- With a **myeloablative transplant**, you'll get high doses of chemotherapy with or without radiation. These treatments aim to kill your cancer, but they'll also kill (myeloablate) all the stem cells in your bone marrow. The donor stem cells will then replace the ones killed by the treatment. This type of treatment is very intense and isn't right for everyone.
- With a **nonmyeloablative transplant**, you'll get lower doses of chemotherapy with or without lower doses of radiation. You'll also take medications to weaken

your immune system. The goal of this approach is to weaken your immune system enough to let the donor stem cells take over and make a new immune system that will fight the cancer.

Your doctor will consider many factors when choosing which type of transplant is best for you. These include your disease, other treatments you've had, and your overall health. Your doctor will talk with you about these things in detail.

## Transplant Infusion

When it's time for your transplant, the donor stem cells will be infused (put) into your body through a tunneled catheter. A tunneled catheter is a thin tube put into your upper chest. It's a type of central venous catheter (CVC). You'll learn more about tunneled catheters in the section "What to Expect While You're in the Hospital."

The stem cells may be infused from a bag, like a blood transfusion, or pushed from a large syringe into your tunneled catheter. This will be done in your hospital room.

# Engraftment

Almost right away after the stem cells are infused into your body, they'll travel through your bloodstream to your bone marrow. They'll start to divide and create healthy new blood cells. Engraftment is when your body accepts the transplant and your blood cell counts start to recover.

Engraftment usually takes about 10 to 14 days. It can take longer, depending on the source of your stem cells. Platelets and red blood cells usually take a little longer to recover than white blood cells.

While you're waiting for engraftment, 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. You might also need blood and platelet transfusions.

You'll have a much higher risk of getting an infection after conditioning until engraftment. You'll need to take precautions, including avoiding sources of infection, washing your hands regularly, and following a food safe diet. When you're admitted to the hospital, you'll be given medications to help protect you from certain infections. You'll be closely monitored for any signs of infection and will be treated with antibiotics if we think you might have an infection.

# **Getting Ready for Your Transplant**

#### **Your Initial Consultation Visit**

During your initial consultation visit, you'll meet with your doctor and other members of your transplant team. Your doctor will take a complete medical and surgical history, do a physical exam, and talk with you about what they think is the best treatment plan for you. This plan may also be discussed with other transplant doctors to make sure everyone agrees on the best plan for your specific situation.

# **Getting Ready for Your Transplant**

Before your transplant, you'll make practical, physical, and emotional preparations for your transplant. Here's a list of things that will happen and things you might need to do to get ready:

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

**Contact your insurance company.** It's a good idea to contact your insurance company before your transplant to see if there's a dedicated case manager for you.

**Choose a caregiver.** Identify a family member or friend to act as your caregiver. Make sure this person understands what the role entails. Give your caregiver a copy of this guide and ask them to read it at least once.

**Fill out a Health Care Proxy form.** A health care proxy is a legal document that identifies the person who will speak for you if you can't communicate for yourself. The person you identify is called your health care agent. This person can be different from your caregiver.

For more information, talk with your social worker or any other member of your transplant team. You can also read the resource *Advance Care Planning*. You can find it online at www.mskcc.org/pe/advance\_care\_planning or ask a member of your transplant team for a copy.

**Meet with a social worker.** Your social worker will explain the psychological, emotional, and financial support services offered by the social work team.

**Arrange for disability or a leave of absence from work.** If you're working, make arrangements to go on disability or take a leave of absence. You should plan to be away from work for about 6 months, but the exact length of time is different for everyone.

**Plan where you'll stay.** You'll need to stay somewhere located within 1 hour of MSK for the first 100 days after the day of your transplant. Your social worker can help you arrange this, if needed.

**Make decisions about your fertility.** If fertility (the ability to have children naturally) is a concern for you, talk with your transplant team about your options. Ask for an appointment with a fertility specialist to discuss how your treatment may affect your ability to have children in the future and the steps you can take to preserve your fertility. You can also read the resources below for more information. You can find them online or ask a member of your transplant team for a copy.

- Fertility Preservation: Options for Females Starting Cancer Treatment www.mskcc.org/pe/fertility\_starting\_treatment
- Building Your Family After Cancer Treatment: Information for Men www.mskcc.org/pe/building\_family\_men
- Sperm Banking www.mskcc.org/pe/sperm\_banking

**Arrange for childcare and pet care, if needed.** If you have concerns about talking with your children about your transplant, your social worker can help guide you.

**Make decisions about your hair.** The chemotherapy that kills cancer cells also kills the cells that make your hair. Most people lose their hair during their transplant. Think about if you'd like to cut your hair. If you decide to wear a wig, visit a wig store as soon as you can. That way, you can find one that closely matches your natural hair, if you want to.

**Have your pretransplant evaluation.** You'll have a series of medical tests. Your clinical nurse coordinator will review which tests are needed. Your doctor's office coordinator will work with you to try to schedule these tests at a time that's convenient for you.

**Meet with a clinical dietitian nutritionist, if needed.** If you have specific nutritional needs, you'll meet with a clinical dietitian nutritionist to review special

dietary requirements and safe food handling. If you want to meet with a clinical dietitian nutritionist, ask your nurse for a referral.

**Meet with a pharmacist.** The pharmacist will go over all the medications you'll take before and after your transplant.

# Your Transplant Team

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

An **attending doctor** will be in charge of your care throughout your treatment. Even though one specific doctor will be your primary outpatient doctor, different doctors might care you for while you're in the hospital.

A **fellow** is a doctor who has finished general training and is getting more training in cancer care.

An advanced practice provider (APP) is a healthcare provider who works with your doctor to provide you with care. They can give medical treatments and prescribe medications. They may also sometimes see you instead of your doctor. APPs include nurse practitioners (NPs), physician assistants (PAs), and certified registered nurse anesthetists (CRNAs).

A **clinical nurse coordinator** is a nurse who will communicate and work with you, your caregiver, and your team of doctors to organize and schedule the testing, procedures, and consultations with other professionals needed before your transplant. Your clinical nurse coordinator will teach you about your specific treatment plan.

**Nursing staff** will work with you when you're seen at outpatient visits and while you're in the hospital. They're registered nurses (RNs) specially trained in the care of stem cell transplant patients.

• Each outpatient nurse works with 1 or 2 attending doctors and will meet you at the time of your initial consultation visit. Your outpatient nurse will see you at many of your outpatient visits after discharge and will follow you along your transplant journey.

• When you're admitted, you'll have a team of primary nurses that will care for you during your hospital stay. The inpatient nurses work 12-hour shifts and try to maintain consistency with who will be working with you.

Both the inpatient and outpatient nurses work closely with your transplant team to manage any symptoms and can help you with any questions or concerns you may have.

A nursing assistant or patient care technician (PCT) provides basic care and support under the direction and supervision of a registered nurse.

A **hospitalist** is a doctor who sees people only while they're in the hospital. At MSK, there's a hospitalist on duty all night.

A **clinical pharmacist** who specializes in the care of people having stem cell transplants will review your medications with you and your caregiver, teach you how to take them properly, and tell you about any side effects they might cause.

A **social worker** will help you, your family, and your friends manage the stress that comes with the transplant process. Social workers understand the issues faced by people having transplants and are available to listen, offer counseling, and refer you or your loved ones to other resources and services.

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

**Office coordinators** provide administrative support to your attending doctors and their nurses. You might speak with them when you submit information, are scheduling an appointment, or have questions for your transplant team. Office coordinators are sometimes called physician office assistants (POAs).

**Care coordinators** work in the outpatient areas and monitor the flow of patients in and out of the clinic. They make sure that patients have all of the tests, scans, and treatments the medical team orders either completed or scheduled. Care coordinators also manage patients' medical records and coordinate their future appointments. Care coordinators are sometimes called session assistants (SAs).

An **unrelated donor search coordinator** works with staff at the National Marrow Donor Program to find a donor for people who don't have a suitable donor in their family. They'll give your doctor updates on the results of the search often.

A **clinical research coordinator** works with your transplant team and will talk with you and explain some of the research studies at MSK that you might be able to participate in. These studies don't include anything that's related to your particular treatment. They mostly concern collecting samples or data. Clinical research coordinators are sometimes called research study assistants (RSAs).

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

A **clinical dietitian nutritionist** is a food and nutrition expert who will assess your nutritional status, talk with you and your caregiver about your diet, and give you advice about changing your diet to help manage your symptoms and side effects.

A **physical therapist (PT)**, **occupational therapist (OT)**, or both will see you while you're in the hospital. They'll work with you to help you keep up your strength and stamina during your recovery.

A **room service associate** will explain how the room service works, including the hours it's available and how to use it. They'll make sure you get the right menus and deliver your meals.

A **case manager** will see you while you're in the hospital, give required updates to your insurance company, and help you arrange home care as needed.

#### Your Caregiver

An important step in getting ready for your transplant is choosing your caregiver. Your caregiver will be an important part of your transplant team. This person is usually a family member or a close friend.

Your caregiver will be responsible for some of the medical, practical, and emotional support you need during your transplant. This person needs to be available 24 hours a day, 7 days a week once you're discharged. Some of their responsibilities will include:

## Medical support

- Noticing any changes in your condition.
- Telling your transplant team about any new symptoms you have.
- Telling your transplant team about any changes in your condition.

• Calling for medical help in an emergency.

#### Practical support

- Dealing with financial and insurance issues.
- Keeping family members and friends up to date about your condition.
- Managing the number of visitors you have.
- Keeping you away from anyone who's sick.
- Grocery shopping and preparing meals.
- Laundry and cleaning.

#### **Emotional support**

- Paying close attention to your moods and feelings.
- Communicating with you and listening to you.
- Understanding your needs and decisions.

If there isn't just 1 person who can act as your caregiver, it's okay to have different caregivers scheduled during different times. It's best to limit the number of caregivers to 2 or 3 people, if you can.

It's important for your caregiver to stay positive, calm, and flexible while providing you with the support and encouragement you need. It's also important for you to understand that the caregiver role is challenging and that your caregiver might at times feel overwhelmed by the responsibilities.

Take time now to think about who you want 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 gets sick or shows any signs of a cold or flu (such as a cough, fever, or sore throat) I week before or at any time during your transplant, tell your transplant team right away.

#### Resources for caregivers

Caregivers can have physical, emotional, spiritual, and financial distress. Resources and support are available to help manage the many responsibilities that come with caring for a person having a transplant. For support resources and information, contact your transplant social worker. You may also find the resource *Caregivers' Guide for Bone Marrow/Stem Cell Transplant* helpful. You can find it online at www.mskcc.org/pe/caregivers\_guide\_bmt and at the end of this guide.



At MSK, our Caregivers Clinic provides support specifically for caregivers who are having a hard time coping with the demands of being a caregiver. For more information, go to www.mskcc.org/cancer-care/doctor/allison-applebaum or call Dr. Allison Applebaum at 646-888-0200.

# Coping with Separation from Your Children

Whether you're inpatient or outpatient, being apart from your children will be hard for you and your family. We strongly recommend that you talk with your social worker about your concerns and develop a plan to maintain strong ties to your children during your transplant.

Below are some things that others have done to remain in contact with their children during their transplant.

- Talk with your children regularly using programs or apps like Skype, Google Hangouts, or FaceTime. Set up a time that you talk to them each day, such as when they get home from school and before they go to bed. Get into a routine of using the computer to see and talk to them.
- Paint or create other crafts to send home. Ask a member of your transplant team to arrange for volunteers from the Patient Recreation Center to bring you supplies.
- Use your cell phone or a tape recorder to record yourself reading your children's favorite stories. Upload these recordings to the web, give them to your caregiver, or e-mail them to your children. They can read along with these stories while listening to your voice.
- Keep copies of your children's favorite stories with you in your hospital room. At night, you can use Skype to read along with them before they go to sleep.

- Decorate your hospital room with your children's artwork and pictures of your family.
- Give your children a special coloring book or journal for times when they miss you or when feelings are difficult. Your caregiver can bring the colorings to you. You can talk with your child about them over Skype or on the phone.

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

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

# **Your Pretransplant Evaluation**

Before you become a transplant candidate, your overall physical condition will be evaluated. You'll need to make several trips to MSK to have tests. We often call this the "work-up" or "restaging" period. During the work-up, you'll need to have some, but not always all, of the following tests.

- **Chest x-ray.** This is done to make sure your lungs are clear and there's no sign of infection or other problems.
- **Blood tests.** These are done to check several things, including your kidney function, liver function, blood counts, and past exposure to certain viruses.
- **Urine test.** This is done to see if there's anything abnormal in your urine (pee).
- **Electrocardiogram (EKG)** and **echocardiogram (echo).** These are done to give your transplant team information about your heart.
- **Pulmonary function tests (PFTs).** These are breathing tests that measure how well your lungs work.
- **Computed tomography (CT) scan.** This is a radiology test that gives more detailed images of soft tissue and bone than a standard x-ray. Sometimes, CT scans use contrast dye that you drink or have injected into your veins. It's very important to tell your doctor if you know you have an allergy to contrast dye, seafood, or iodine. If you have a mild allergy, you can still have contrast dye, but you'll need medications before getting the dye to prevent a reaction.

- **Positron emission tomography (PET) scan.** This is a radiology test that's used to look at certain types of cancer, as well as your organs and how they work in your body.
- **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 a dentist here at MSK. If you see your own dentist, ask for a letter saying that you have no dental problems. If there are issues, ask your dentist to contact your doctor's office to discuss them. Your dental exam can be done up to 3 months before you're admitted to the hospital for your transplant.
- **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 put into the bone marrow, and a small amount of bone marrow liquid will be taken out. A bone marrow biopsy might be done at the same time. This biopsy involves collecting a tiny piece of bone for examination. This is done to check how well your bone marrow is making cells and to look for any sign of cancer in the marrow.
- Lumbar puncture (spinal tap). This is done to check for abnormal cells in your cerebrospinal fluid (CSF). This is the fluid that surrounds your brain and spinal cord. A small needle will be put through your back and a small amount of CSF will be collected. A lumbar puncture is only done for certain types of leukemia and lymphoma. Sometimes, chemotherapy is injected into your CSF to keep the cancer from spreading there or to treat cancer if it's already there.
- **Skeletal survey.** This is done to look for bone damage caused by cancer. It's usually only done for people who have multiple myeloma. It involves taking x-rays of the major bones in your body. It can take a few hours.
- Consultation with a radiation oncologist. If you're having radiation therapy as part of your conditioning, you'll meet with your radiation oncologist to go over your treatment plan. You might also have a CT scan, PET scan, or both during this visit. They'll be used to plan your treatment. You'll also have a treatment planning session called a simulation. During this session, several imaging scans are taken, along with measurements of your chest. These are used to make lead shields. Your lungs are very sensitive to radiation and the shields will be used to protect them during some of the treatments.

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 nurse

coordinator will work with you and your caregiver to schedule the tests. The results of the tests will be used to plan your treatment and make sure it's safe to start your treatment.

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

# **Donor Screening**

Around the time you're having your pretransplant evaluation, the donor will be going through the screening process. If the donor is related to you, they'll be screened at MSK. If the donor is unrelated, they'll be screened at the local donor center. Donor screening is done to make sure the donor is healthy enough to donate their stem cells.

## Stem Cell Harvesting

For an allogeneic transplant, the donor's stem cells are harvested (collected) from their body, then given to the person receiving the transplant.

#### Peripheral blood stem cell (PBSC) harvesting

PBSC harvesting is the procedure used to collect stem cells from the donor's blood. Before PBSC harvesting, the donor will have mobilization. This is the process of increasing the number of stem cells made by their bone marrow and released into their bloodstream.

After mobilization, the donor's blood will be collected and separated into its major components (red blood cells, white blood cells, platelets, and plasma). The stem cells will be removed from the other white blood cells and the rest of the blood will be given back to the donor. If you'd like to know more about the PBSC harvesting process, you can read the resource *Allogeneic Donor Peripheral Blood Stem Cell Harvesting*. You can find it online at www.mskcc.org/pe/allogeneic\_PBSC\_harvesting or ask a member of your transplant team for a copy.

In general, the donor's stem cells are collected 1 to 2 days before the transplant. Sometimes, their stem cells are collected at an earlier time and frozen until needed.

#### Bone marrow harvesting

In certain cases, stem cells may be collected from the donor's bone marrow rather than peripheral blood. This is called bone marrow harvesting. With bone marrow harvesting, mobilization isn't needed.

Bone marrow harvesting is done in the operating room while the donor is under general anesthesia (asleep). If you'd like to know more about the bone marrow harvesting process, you can read the resource *About Bone Marrow Harvesting*. You can find it online at www.mskcc.org/pe/bone\_marrow\_harvesting or ask a member of your transplant team for a copy.

# **Your Preadmission Appointment**

Once your pretransplant evaluation is finished and you have the date of your transplant, you'll have your preadmission appointment. This appointment is usually 1 to 2 weeks before you're admitted to the hospital. At this appointment:

- Your doctor will review your treatment plan with you.
- Your doctor will go over the consent forms and you'll sign consent for your transplant (if you haven't already).
- You'll meet with your clinical nurse coordinator. They'll give you a calendar outlining your treatment plan, review information, and answer your questions.
- You'll meet with your clinical pharmacist again to review the medications you'll take during and after your transplant.
- You may be asked to sign a consent form for transfusion (if you haven't already). This is because you may need blood or platelet transfusions when your blood counts are low after your transplant. For more information, read the resource *About Your Blood Transfusion*. You can find it in the "Educational Resources" section of this guide.



Between your preadmission appointment and when you're admitted to the hospital, it's very important to call your transplant doctor's office if you have any of the following:

- Signs of a cold, such as:
  - o Arunny nose
  - Congestion
  - A cough
  - o A fever of 100.4 °F (38.0 °C) or higher
- Nausea (feeling like you're going to throw up)
- Vomiting (throwing up)
- Diarrhea (loose or watery bowel movements)
- A toothache
- An open wound
- Any other new problem, even if it seems small

Your doctor will decide if your admission for transplant should be delayed. It could be very dangerous to start your chemotherapy while you have an infection, even if it's just a cold. This is because your immune system won't be able to fight the infection.

# **Your Hospital Admission**

On your admission day, bring a list of all the prescription and nonprescription medications you're taking, along with the dose you take and how often you take them. The list should include patches, creams, vitamins, nutritional supplements, herbal products, and over-the-counter medications.

You can also bring the following items with you, if you want to:

- Pajamas, sweat pants, or shorts
- Button down or zipper shirts
- Slippers
- Sneakers, socks with traction, or both
- Hat or scarf

- Blanket and pillow from home (brightly colored to distinguish it from hospital linens)
- Photos, posters, or other reminders of home
- Cell phone and charger
- Baby wipes
- Puzzles, books, or magazines
- Notebook and pens and pencils
- A little bit of money
- Radio, iPod, or CD player
- Laptop or tablet (such as an iPad)

#### Don't bring the following items with you:

- Your medications (neither prescription nor over-the-counter)
- Things that will clutter up your room
- Flowers or plants

# What to Expect in the Hospital

# **Having Your Tunneled Catheter Placed**

You'll need a tunneled catheter during your transplant. A tunneled catheter is a type of central venous catheter (CVC). It's a tube that's put into a large vein in your upper chest (see Figure 2). Outside your body, the catheter divides into 2 or 3 smaller tubes called lumens (see Figure 3).

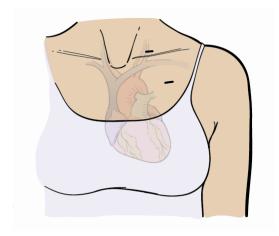


Figure 3. Veins and your heart

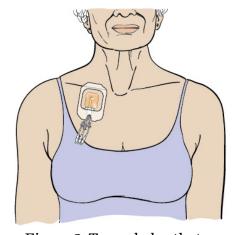


Figure 3. Tunneled catheter

A tunneled catheter lets your transplant team infuse your stem cells, draw your blood, and give you fluids, electrolytes, blood transfusions, chemotherapy, and other medications without having to keep sticking you with a needle. Having a tunneled catheter will make your treatment much more comfortable.

Most people have their tunneled catheter placed on the day they're admitted to the hospital. Sometimes, it may need to be placed a few days before hospital admission. For more information, read the resource *About Your Tunneled Catheter*. You can find it in the "Educational Resources" section of this guide.

The procedure to place your tunneled catheter will be done in the Interventional Radiology department at Memorial Hospital (MSK's main hospital). Your clinical nurse coordinator will talk with you about the details of having your tunneled catheter placed.

#### After Your Tunneled Catheter is Placed

After your tunneled catheter has been put in, you'll be monitored until you're fully awake.

- ☐ If your tunneled catheter is being placed on the day you're being admitted to the hospital, you'll be taken to the inpatient stem cell transplant unit once you're fully awake. The inpatient nursing staff will care for your tunneled catheter while you're in the hospital.
- ☐ If your tunneled catheter is put in a few days before you're admitted to the hospital, you'll be discharged once you're fully awake. You must have a caregiver with you if you're going home after your tunneled catheter is placed. Your nurse will change the dressing, if needed.

Keep your tunneled catheter secure at all times to avoid pulling it. You can tape the lumens of your tunneled catheter to your skin, tuck them into a bra if you wear one, or secure them to your clothing. Ask your nurse about the best way to secure your tunneled catheter. You can find more information about caring for your tunneled catheter in the resource *About Your Tunneled Catheter*.

Your tunneled catheter is usually taken out when you're discharged from the hospital.

# While You're in the Hospital

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

When you're admitted to the hospital, your inpatient transplant team will take a complete medical history, review your current medications, and do a physical exam. Your inpatient transplant team is made up of an attending doctor and a combination of a fellow, APP, primary nurse, and pharmacy specialist.

Your primary nursing team will care for you during your hospital stay. Nurses usually work 12-hour shifts starting at either 7:00 AM or 7:00 PM. When nursing shifts change, your nurse will share the information about what happened with you and your care during that shift with the nurse taking over.

#### What to Expect

- You'll be in protective isolation to lower your risk of getting an infection. Anyone who goes into your room must clean their hands and wear a mask and gloves. For more information, read the resource *Hand Hygiene and Preventing Infection*. You can find it in the "Educational Resources" section of this guide.
  - Sometimes, you might need extra isolation precautions. A sign telling your visitors about the type of isolation and what they need to do will be put on the door to your room.
  - Even though you're in isolation, you can have visitors 24 hours a day, every day. We recommend that no more than 2 visitors be in your room at once.
  - Children 10 years or older can visit you as long as they follow the isolation procedures. For more information about visitors, read the "Visitors" section below.
- You'll be in a private room that has a bathroom for your use only. Your room will have Wi-Fi and a TV with cable channels.
- You'll be connected to an IV pole with electronic pumps during most of your hospital stay.
- Your vital signs will be taken every 4 hours, even during the night.
- Your urine will be measured daily during your hospital stay. It's important that we know how much urine you're making.

## **Testing and Evaluations**

Before 6:00 AM every day, a member of your transplant team will weigh you and take a sample of your blood. Your blood will be checked to see how your white blood cells, red blood cells, and platelets are recovering. Other blood tests will be done as needed to check your kidney and liver, monitor for infections, check the level of chemotherapy or other medications in your blood, and to help evaluate your overall condition.

The day you're admitted to the hospital, every Monday, and right before you're discharged, your nurse will take a nasal swab for testing. This is to see if you have any bacteria that may cause an infection. If you do, your transplant team will give you information about additional isolation precautions needed.

If you're at risk of falling, someone will be available to help you go to the bathroom. Your treatment team will tell you more about how to prevent falls. You can also read the resource *Call! Don't Fall!* You can find it online at www.mskcc.org/pe/call\_dont\_fall or ask a member of your transplant team for a copy.

#### **Visitors**

- All visitors must follow infection control precautions posted on your door, such
  as washing their hands, wearing a mask, and telling someone if they might be
  sick.
- All visitors must clean their hands each time before they enter your room.
- All visitors must remove their mask, gloves, and gown before leaving your room.
- Visitors and caregivers must use the visitor's restroom in the hallway, not the restroom in your room. This is to minimize the spread of bacteria in your room.
- Fresh-cut, live, or dried flowers and plants aren't allowed in your room. Please tell family and friends not to bring or send them.
- The following people shouldn't visit you:
  - Anyone who has symptoms of an illness (such as a cough, rash, fever, or diarrhea)
  - o Anyone who thinks they may be getting sick
  - Anyone who could have recently been exposed to someone with an infectious illness
  - o Children younger than 10 years old

#### Exercise

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

We encourage you to walk around the unit. You must wear a mask and gloves while you're walking around the unit. Your nurse will tell you if you also need to wear an isolation gown. Don't leave the floor for walking or exercise.

A physical therapist will evaluate you early during your hospitalization and prescribe an exercise program that's right for you.

#### Communication

Each room has a call bell system that's monitored 24 hours a day, 7 days a week. If you need something, please use your call bell and say exactly what you need so we can send the right member of your transplant team to help you.

#### Diet

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

In general, everyone having a transplant is placed on a food safe diet. Your clinical dietitian nutritionist will discuss this with you. For more information, read the resource *Eating Well After Your Stem Cell Transplant*. You can find it in the "Educational Resources" section of this guide.

If you keep kosher, have diabetes, or follow other specialty diets, tell your clinical dietitian nutritionist so that we can prepare your meals properly. Your clinical dietitian nutritionist is also available to help you plan your meals.

# Showering

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

#### Mouth Care

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

# **The 5 Phases of Transplant**

There are 5 phases of transplant. They are:

- 1. Conditioning
- 2. Transplant day to engraftment
- 3. Engraftment to day of discharge
- 4. Early convalescence
- 5. Late convalescence

These phases are described in the table below. They're also described in more detail in the following pages.

The phases and time frames aren't exact, and there's some usually some overlap from one phase to the next. Everyone's transplant timeline is unique.

	Description	Time period
Phase 1: Conditioning	• You'll get chemotherapy with or without radiation therapy. This will kill any cancer cells left in your body. It will also make room for new stem cells and suppress your immune system so you don't reject the donor cells.	Day of hospital admission to Day 0 (transplant day). The start date varies depending on which conditioning regimen you have.
	<ul> <li>Phase 1 will be finished when you get the infusion of stem cells.</li> </ul>	
Phase 2: Transplant Day to Engraftment	<ul> <li>You'll feel the effects of your conditioning regimen.</li> <li>Your white blood cell, red blood cell, and platelet counts will be low.</li> <li>You may have diarrhea, nausea, vomiting, or mouth sores.</li> <li>Your risk of getting an infection will be high.</li> </ul>	Day 0 to engraftment (blood count recovery). Engraftment is usually between Day +10 and Day +30.
	• You may need blood transfusions.	

	Description	Time period
Phase 3: Engraftment to Day of Discharge	<ul><li>Your blood counts will recover and gradually increase.</li><li>You'll start the healing process.</li></ul>	Blood count recovery until discharge.
Phase 4: Early Convalescence	Your blood counts will be recovering, but your immune system still won't be working properly.	Discharge to 1 year after transplant (or longer).
	You'll still be at risk of getting an infection.	
	You'll keep taking certain     medications to prevent infection.	
	You'll continue to be monitored closely by your transplant team.	

# **Phase 1: Conditioning**

Conditioning is another name for the therapy given to get you ready for your transplant. Conditioning is usually a combination of 2 or more chemotherapy medications or chemotherapy and radiation therapy. The particular conditioning you'll get is based on a number of factors and is discussed with you at your outpatient visits before admission.

Conditioning starts on a negative-numbered day (such as Day -7). Depending on your treatment plan, the number of days of conditioning will vary. Your stem cell transplant always takes place on Day 0. Every day after your transplant is referred to as a positive-numbered day (such as Day +1, Day +2).

Day -10 to Day -1	Day 0	Day +1
Conditioning (chemotherapy and possible radiation therapy)	Stem cell infusion (transplant)	Start of supportive care

Before you get 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), antinausea medication, and the chemotherapy medication through your tunneled catheter (see Figure 4).



Figure 4. Getting chemotherapy through your tunneled catheter

## Radiation Therapy

The radiation therapy given before a transplant is usually total body irradiation (TBI). With TBI, small doses of radiation will be given to your whole body. If your transplant doctor recommends radiation as part of your conditioning, you'll have a consultation appointment with a radiation oncologist before you're admitted to the hospital. This doctor will explain the process and take some measurements of your body to be sure the radiation is given safely and effectively. They're also responsible for prescribing the appropriate amount of radiation.

These doses are given 1 to 3 times a day and over 1 to 4 days. Each treatment will take 10 to 30 minutes. Having radiation therapy is like having an x-ray. The treatment doesn't hurt.

You may also need a boost (additional radiation treatment) to other parts of your body. The treatment depends on the disease you have. Your transplant doctor and radiation oncologist will explain the details of your treatment plan.

If you're male and have leukemia or lymphoma, you may have a boost to your testes. This is done to destroy cancer cells that may be hidden there.

#### Things to remember

- Don't wear any jewelry during your treatments. The metal may change the radiation dose to that area.
- Stop using any creams, lotions, deodorants, or oils (even lip balm, such as ChapStick®) 2 days before you start radiation therapy. Don't use them at all while you're getting radiation. You can use Aquaphor®, but don't apply it for 4 hours before your treatment.
- Family members can go with you when you have your treatments. They must
  wait outside the treatment room, but they can see you on a video screen and talk
  to you.
- You and your clothes won't become radioactive during or after the treatments. You can't pass the radiation to other people.
- Your nurse will tell you more about how the radiation is given and what you'll do during the treatments.

#### Side Effects of Conditioning

Conditioning should kill some or all of the cancerous cells in your body. It will also get your bone marrow and immune system ready to get your transplant. But, the side effects of conditioning treatments aren't to be taken lightly. They may include the loss of your ability to fight infections, infertility, hair loss, fatigue, nausea and vomiting, diarrhea, mouth sores, or mouth tenderness.

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

## Low white blood cell count (neutropenia)

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

One side effect of treatment 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're 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 germs.

Because your treatment will kill your stem cells, you'll temporarily lose your ability to make new neutrophils. Since your neutrophils aren't being replaced, the number of neutrophils in your bloodstream will drop to a very low level, leaving you at high risk of infection. Your transplant team will watch for any signs of infection. You may be given injections (shots) of a medication called filgrastim (Neupogen®). This medication stimulates the growth of neutrophils to help you recover faster.

#### Showering and bathing

While you're neutropenic (have neutropenia), it's very important to keep yourself clean.

Shower or bathe every day using a 4% chlorhexidine gluconate (CHG) antiseptic skin cleanser, such as Hibiclens®. 4% CHG solution is a fast-acting antiseptic that kills germs that live on your skin. It can work for up to 24 hours after you use it. Showering with 4% CHG solution will lower your risk of infection.

#### To use 4% CHG solution:

- 1. Use your normal shampoo to wash your hair. Rinse your head well.
- 2. Use your normal soap to wash your face and genital area. Rinse your body well with arm water.
- 3. Open the 4% CHG solution bottle. Pour some into your hand or a clean washcloth.
- 4. Move away from the shower stream to. Rub the 4% CHG solution gently over your body from your neck to your feet. Don't put it on your face or genital area.
- 5. Move back into the shower stream to rinse off the 4% CHG solution. Use warm water.
- 6. Dry yourself off with a clean towel.
- 7. Don't put on any lotion, cream, deodorant, makeup, powder, or perfume.

#### When you're using 4% CHG solution:

• Don't put it on your head, face, eyes, ears, mouth, genital area, or on deep wounds. If you have a wound and aren't sure if you should use 4% CHG solution on it, ask your doctor or nurse.

- Don't use regular soap, lotion, cream, powder, or deodorant after washing with 4% CHG solution.
- If you have an irritation or allergic reaction when using 4% CHG solution, stop using it and call your doctor.

#### Caring for your mouth

While you're neutropenic, you'll need to change the way you brush your teeth and care for your mouth. This will help you avoid infection and bleeding. Follow these guidelines to take good care of your mouth:

- You'll be given a mouthwash to rinse your mouth before meals, after meals, and at bedtime. The number of rinses may be increased to every 2 hours, depending on how your mouth feels. Only use the mouthwash that your nurse gives you. Most store-bought mouthwashes contain alcohol, which can irritate and dry your mouth and throat.
- Use an ultra soft toothbrush.
- You can use toothpaste that you buy in the store.
- Don't use dental floss.
- Avoid licking your lips. Licking your lips makes them more chapped and dry.
- Apply a lip balm (such as Burt's Bees®, ChapStick, or A&D® ointment) after you clean or rinse your mouth and every 2 to 4 hours as needed. This will help keep your lips moist.
- Your doctor may prescribe an oral antifungal antibiotic to keep you from getting an infection in your mouth. Use it as instructed.
- If your mouth becomes sensitive, avoid hot, spicy, acidic, or coarse foods. You may prefer soft or liquid food served cold or at room temperature.
- If you have a lot of pain from mouth sores, your healthcare provider will give you pain medication.

## Low red blood cell count (anemia)

Your red blood cells carry oxygen from your lungs to the tissues in all parts of your body. When you're anemic (have anemia), your blood can't carry oxygen as well. Some of the side effects of anemia include:

• Fatigue (feeling more tired than usual)

- Weakness
- Fast heartbeat
- Shortness of breath
- Headache
- Pale skin

If you have anemia, your doctor may prescribe a blood transfusion.

#### 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 treatment, the number of platelets in your bloodstream will drop. This is called thrombocytopenia.

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

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

- Avoid sharp objects, such as razors, scissors, and nail clippers. Only shave using an electric razor or shaver. Don't use a razor that has a blade.
- Follow the guidelines in the "Caring for Your Mouth" section.
- If you're straining to have bowel movements (poop), ask someone from your transplant team for a stool softener or laxative.

Tell your doctor if you have any signs of bleeding. Examples are:

- Easy bruising
- Faint, tiny, pin-point red dots on your torso, arms, or legs
- Vaginal spotting or heavy menstrual bleeding
- Broken blood vessels in the whites of your eyes
- Blood in your urine
- A headache that doesn't get better, blurred vision, or dizziness
- Coughing up blood, vomiting blood, or a nosebleed that doesn't stop after a few minutes with applied pressure or ice
- Black bowel movements (poop) or blood on your bowel movements

#### Nausea and vomiting

Nausea and vomiting are common side effects of treatment. Chemotherapy acts on a 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 depends on the type of chemotherapy you get. You may have nausea during your conditioning, or it may be delayed for several hours or days.

You'll be given medication to prevent and control nausea before your conditioning. These medications work differently for each person. If the medication you're taking isn't helping, tell your transplant team or doctor. You may need to try a different medication or take more than one kind of antinausea medication to feel better. Your transplant team will work with you to prevent and treat nausea and vomiting.

#### Diarrhea

Diarrhea is frequent, loose, watery bowel movements. It can also cause stomach cramps, gas, and pain in your abdomen (belly) or rectal area. Diarrhea can be caused by cancer treatments, medications, infection, stress, or other medical conditions. If you're having diarrhea, you can become dehydrated due to loss of fluids and electrolytes.

Your nursing staff will keep track fluid losses that you may have from diarrhea. It's important that you always use the collection container in the toilet to collect your bowel movements so they can be measured.

## Constipation

Constipation is having hard, dry bowel movements or having fewer bowel movements than usual. It happens when materials move too slowly through your large intestine. The normal length of time between bowel movements is different for everyone. If you're having fewer bowel movements than usual or if you haven't had a bowel movement for more than 2 days, you may be constipated.

There are many causes of constipation, including not drinking enough liquids or not eating enough fiber, a decrease in your activity, not moving around or walking enough, and side effects of chemotherapy, antinausea medications, and pain medications.

Medications are available to treat constipation. Tell your nurse or medical team if you haven't had a bowel movement for more than 2 days.

## Mouth sores (mucositis)

Some treatments affect the cells that line your mouth and digestive tract. This is called mucositis. Mucositis can cause redness, swelling, tenderness, and sores on the lining of

your mouth, tongue, and lips. You may have some mouth and throat discomfort that can make it hard to eat or swallow. Tell your nurse if you're having any of these symptoms so they can be treated.

If you're getting radiation therapy, you may also have discomfort in your salivary glands. Your salivary glands are found on both sides of your neck and under your chin. They may become tender and swollen and you may make less saliva. The swelling will decrease a few days after your conditioning. The decrease in saliva is usually temporary and gets better after several months.

#### Hair loss

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

Losing your hair can be an unpleasant and upsetting experience. Many people choose to cut their hair short before their transplant to take control of this process and to lessen the shock of losing their hair. Talk this through with your caregiver, friends, and family.

Before your transplant is also a good time to think about whether you would like to wear a wig. Modern wigs can look very natural and wearing one may make you feel more comfortable. A list of wig stores in New York is included in the resource *Hair Loss and Your Cancer Treatment*. You can find it in the "Educational Resources" section of this guide.

You can get a wig while you still have your hair or bring a clipping of your hair if you'd like your wig to match your natural hair color. Ask your doctor for a prescription for the wig, as some insurance companies will reimburse some of the cost of a wig.

## Skin changes

Conditioning can cause skin changes such as increased dryness, flaking, discoloration, and darkening. When you bathe, use a body soap that's labeled for "sensitive skin." Discuss the use of products with your nurse. Use alcohol-free lotions, creams, or oils to help relieve the dryness.

Your skin may also be very sensitive to the sun and may burn very easily. Avoid bright sunlight. When you're outside, wear a sunscreen with an SPF of at least 30 and protective clothing, such as long-sleeved shirts, long pants, and a hat. Skin is the most common site for cancer, and sun protection reduces the risk of skin cancers.

Your nurse will tell you how to manage skin reactions during your treatment. For more information, read the resource *Skin Care Guidelines While You Are Receiving Radiation* 

*Therapy*. You can find it online at www.mskcc.org/pe/skin\_care\_radiation\_therapy or ask a member of your transplant team for a copy.

# Transplant Day

After you finish your conditioning regimen, you will get your stem cell infusion—your transplant.

On Day 0, your donor's stem cells will be infused into your body. These stem cells will help you be able to make new blood cells and fight infections again.

You'll be given medications about 30 minutes before your transplant to help reduce any side effects that you may have during the infusion. You'll be closely monitored and your vital signs will be checked often during and after the infusion.

#### Your stem cell infusion

If the stem cells are from a donor that isn't related to you, they're brought to MSK right away. Here, they're processed for an unmodified or T cell-depleted stem cell transplant.

#### Unmodified stem cell transplant

In an unmodified stem cell transplant, the T cells (type of white blood cell that plays an important role in your new immune system) aren't removed from the stem cells before they're given to you. They're infused much like a blood transfusion over a few hours into your tunneled catheter. Red cells or plasma may need to be removed before you get the stem cells if you and your donor aren't the same blood type.

#### T cell-depleted stem cell transplant

In a T cell-depleted stem cell transplant, the T cells are removed from the stem cells before they're given to you. If you're going to have a T cell-depleted stem cell transplant, you'll get it after the T cells are removed in the laboratory. This takes 12 to 24 hours, so you'll get it the day after your donor has given the stem cells. The stem cells will be injected directly into your tunneled catheter from a large syringe. There usually aren't any side effects from the infusion of T cell-depleted stem cells.

#### Umbilical cord blood stem cell transplant

On the day of your transplant, the umbilical cord blood will be thawed in our laboratory and brought to your room in a bag. If you're also getting partially matched T cell-depleted stem cells (haploidentical) from a family member, these will be given either on the same day as you get the cord blood, or on the following day.

The cord blood will be given to you through your tunneled catheter. Sometimes, people have nausea or get high blood pressure during an umbilical cord blood infusion. These issues will be treated as they happen.

Your doctor and nurse will discuss any questions or concerns you may have about the type of transplant you're going to get.

#### Side effects

You may have some side effects during and after your infusion. This is more common if the stem cells are collected ahead of time and stored frozen. Side effects can include nausea, vomiting, a tickle in your throat, or a cough. Other side effects that can happen include low blood pressure, chills, and fever. It's important that you communicate with your transplant team during your transplant. If you do have side effects, your transplant team will treat them.

If the stem cells you got were frozen and preserved, you may notice a strong, garlic-like taste in your mouth during and after your transplant. Your urine, sweat, and skin may also have a garlic-like smell. You may not notice the smell, but those around you'll. This smell is caused by the preservative used to store the stem cells. It will gradually go away over 1 to 2 days. Your nurse will have lemons to use as a safe, natural air freshener during the infusion.

Additionally, if the stem cells you got were frozen and preserved, your urine may look discolored, ranging from pink-tinged to bloody. This can last for 24 hours after your transplant. This is your body's way of getting rid of extra red blood cells that may be with the stem cells but aren't needed.

# **Phase 2: Transplant Day to Engraftment**

Once you've had your transplant, you'll enter a period of watching and waiting for your donor stem cells to start making healthy new blood cells. This process is called engraftment. As engraftment happens, the number of white blood cells, red blood cells, and platelets in your blood will start to increase.

Some complications are possible after your transplant. Infection, bleeding, and anemia are some of the major complications that can happen while you're waiting for your blood counts to return to normal. In most cases, there are steps that you and your transplant team can take to prevent, manage, and treat these complications.

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

- You'll have testing. You'll have blood tests and other tests as needed to monitor your progress. You'll have blood drawn every day.
- You may continue to have side effects from the conditioning. You'll be given medication to help manage the side effects and make you more comfortable.
- You'll follow a food safe diet. Because you're neutropenic, you'll follow a diet that contains a low number of potentially harmful microbes.
- You may get transfusions. You may need to get a blood transfusion to boost the numbers of red blood cells and platelets in your bloodstream.
- Your blood counts will start to recover. Over time, as the stem cells engraft and start to make new blood cells, your blood counts will get higher.
- You'll stay physically active. You'll try to remain physically active after your transplant by limiting the amount of time you spend in bed and walking a little each day. Follow the recommendations that your physical therapist gives you.

#### Risk of Infection

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

Fever is one important sign of infection. If you develop a fever, you'll have a chest x-ray and urine and blood tests. You'll be given IV antibiotics to help your body fight the infection. Nearly all people develop a fever during the first 2 weeks after their transplant. Most infections are treated successfully with antibiotics.

Your doctors and nurses will try to keep you from getting infections. You'll likely be given medications that are used to treat infections. This can help prevent infections in people who have had a transplant. You'll get antiviral medications to help keep some viral infections you may have had in the past (such as cold sores, shingles, or genital herpes) from coming back after your transplant. You'll also get antifungal medication to prevent fungal infection.

People whose immune systems aren't working well can get infections that wouldn't happen in healthy people. These are called opportunistic infections. You may need

medication to help protect you from these infections. You'll be at risk for them until your white blood cell count and immune system return to normal.

## Bleeding

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

#### Anemia

When your red blood cell count is low, you might have weakness and fatigue. Your nurse will help you with your daily activities if you need help. You'll be given red blood cell transfusions as needed. These and all other blood products will be irradiated (exposed to radiation) to prevent harmful side effects.

# Phase 3: Engraftment to Day of Discharge

## Possible Early Complications

Time frames of transplant aren't exact. Some of the side effects or complications reviewed here can happen in more than one phase of your transplant journey.

## Organ complications

You may have complications in your kidneys, liver, lungs, or heart. Organ complications aren't common, but they can be serious. You're at higher risk if you already have a medical condition in any of these organs. This is why we carefully check your organ function before your transplant.

#### Kidneys

Your kidneys filter your blood and make urine to carry waste products out of your body. The chemotherapy and radiation therapy you get before your transplant can affect how well your kidneys work. This may be temporary, but it means that waste products may stay in your blood until your kidney function gets better. It also means that your kidneys will have more trouble getting rid of some of the medications you take.

Your nurses will keep track of the amount of fluids you get. This includes what you drink and what you get through your IV line. They'll also write down how much urine you make. This will help your doctors to know if you're starting to have problems with your kidneys. You'll also have blood tests every day to tell your doctors how your kidneys are working. If needed, your doctors will adjust the doses of some of the medications you're getting to decrease the risk of injuring your kidneys more.

#### Liver

In some people, small blood vessels in the liver are injured. This is called sinusoidal obstruction syndrome or veno-occlusive disease. If this happens, it can cause your liver to become enlarged and may damage your liver cells. Fluid may fill your abdomen. This usually starts within the first 3 weeks after a transplant. Everyone having a transplant gets a medication during their transplant process to help reduce the risk of developing sinusoidal obstruction syndrome or veno-occlusive disease.

If you have any side effects to your liver, your doctor will discuss the treatment options with you in more detail.

#### Lungs

Infections that affect the lungs (such as pneumonia) may cause breathing problems after a transplant. These problems most commonly develop in the first few weeks after a transplant and can be serious. Your transplant team will watch you closely for any sign of pneumonia. Tell them if you notice any change in your breathing. Don't ignore a cough or shortness of breath. The treatment for pneumonia depends on what caused it.

To help prevent problems with your lungs, exercise them. This may help to keep them clear. Your nurse will show you how to do deep breathing exercises. You can also use an incentive spirometer, which is an instrument to help you practice deep breathing. Even getting out of bed and doing breathing exercises helps.

#### Heart

Your heart pumps blood throughout your body. Certain chemotherapy medications may have side effects that damage your heart. Your doctors will watch your heart function carefully while you're in the hospital.

#### Graft versus host disease

Graft versus host disease (GVHD) happens when the donor's immune cells (T cells) start to attack and damage your body's organs. There's a chance that GVHD will develop

when the new stem cells start to engraft. A close match of HLA or tissue type between you and your donor helps lower this risk but doesn't make it go away.

Risk factors for GVHD include your age and the gender of your donor. Anyone whose donor isn't an identical twin gets some type of prevention for GVHD. This prevention includes either removing the T cells from the transplant (T cell depleted) or giving medications to prevent those T cells from causing GVHD. There are good and bad things about each method, and there are reasons that you would get one or the other. Your doctor will discuss these with you before your transplant.

There are two kinds of GVHD: acute GVHD and chronic GVHD.

**Acute GVHD** usually develops within the first 100 days after a transplant, but it can happen later. Symptoms of acute GVHD include:

- A skin rash that appears on parts of your body or your entire body
- Jaundice (yellow skin and eye color) and an enlarged liver
- Abnormal liver blood tests
- Loss of appetite
- Nausea and vomiting
- Mild to severe diarrhea

**Chronic GVHD** usually develops after 100 days but rarely before the first 3 months after transplant. It usually lasts longer than acute GVHD. Symptoms of chronic GVHD include:

- A dark skin rash or dry or thickened skin
- Loss of appetite
- Weight loss
- Diarrhea
- Dry mouth

- Tightness and discomfort in your mouth
- Dry eyes
- Hair loss
- Decreased energy

The symptoms of GVHD may be mild to severe. You may develop only acute GVHD, only chronic GVHD, or both acute and chronic GVHD. If you develop both, you may or may not have symptoms between the time that you develop acute and chronic GVHD.

GVHD may slow the growth of the bone marrow and recovery of the blood counts. This means it will take longer for your immune system to work properly. Because of this, you

can be at an increased risk of infections. GVHD may affect one or more parts of your body.

If you have evidence of GVHD, your doctor will discuss the treatment plan with you.

## Getting Ready for Discharge

Once your blood counts have recovered and any side effects or complications you had have resolved, your inpatient team will start working with you and your caregiver to get you ready for discharge. On average, people can be discharged about 3 weeks from their day of transplant. It may be a few days before that or it may be longer than 3 weeks, depending on your stem cell source and your exact treatment plan.

To be discharged from the hospital, you must:

- Have no fever
- Have blood counts that are in a safe range (neutrophil count higher than 1,000)
- Be eating and tolerating some solid food
- Be drinking 1½ to 2 liters of liquids a day
- Be tolerating your oral medications
- Have a caregiver to help you

Most of the time, your tunneled catheter will be removed right before you're discharged.

Your transplant team will work with you before you're discharged to make plans for your follow-up care. You'll be seen in the outpatient clinic within 1 week of your discharge.

## Medical alert jewelry

Before you leave the hospital, you will need to order a medical alert bracelet or necklace. Your transplant team will help you. Examples of medical alert jewelry companies include MedicAlert® (www.medicalert.org) and ROAD iD (www.roadid.com).

Your bracelet or necklace should be engraved with the statements "Allogeneic stem cell transplant" and "Irradiated cellular blood components and CMV-safe blood components only." This will let paramedics or hospital staff know what to do if you're in an accident and can't tell them yourself.

# **Phase 4: Early Convalescence**

This phase of your recovery extends over a long period of time—from discharge to 1 year after your transplant or longer. It's important to remember that, even though your blood counts are coming back up to the normal range, your immune system is still very immature. You'll still need to take medications and follow precautions to keep yourself healthy and avoid infection.

You may start to notice some complications, especially those that affect your organs. This can happen even if they weren't a problem earlier in your course.

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

# Leaving the Hospital

Even though you may be very happy and feel ready to leave the hospital, you might also feel nervous. It's normal to have some worries and concerns as you get closer to leaving the hospital. After you leave, you and your family will need to manage your care. Feeling confident and comfortable doing this takes time. During your follow-up visits, your social worker can help you get the services you need and give you emotional support.

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

Your recovery after transplant will be gradual. You probably won't feel the way you did before your illness for a while. You may feel tired and weak, have a smaller appetite, and notice changes in the way things taste and smell. It'll also take time for you to get your strength back and go back to doing the activities you enjoyed before your illness and transplant.

# **Preventing Infection**

It usually takes 12 to 18 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're at risk for infection. Your transplant team will check 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's office right away if you have:

- A fever of  $100.4 \,^{\circ}\text{F}$  (38.0  $^{\circ}\text{C}$ ) or higher.
  - Don't take acetaminophen (Tylenol®) unless your healthcare provider tells you to.
  - You don't have to take your temperature every day. But, check it regularly if you don't feel well.
- Flushed (red) skin, sweating, or shaking chills.
- Coughing, sneezing, runny nose, shortness of breath, or chest discomfort.
- Redness, swelling, or pain in your throat, eyes, ears, skin, joints, or abdomen.
- Blurred vision or other changes in your ability to see clearly.
- Nausea, vomiting, or diarrhea.
- Frequent urination, a burning feeling when you urinate, or both.
- Irritation in your rectum, including burning and pain.
- A rash.
- Small blisters (similar to cold sores) around your mouth or on any other part of your body.
- Trouble flushing your tunneled catheter, if you still have one.

You can catch viruses more easily until your immune system is back to normal. One of these is the virus that causes chickenpox and shingles. If you're exposed to chickenpox or shingles, call your transplant doctor or nurse right away. You'll need to be assessed.

Viruses that you've had in the past (such as chickenpox) can also reactivate. 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 right away so you can be treated.

Once your immune system has recovered, you'll start getting your childhood vaccines. This usually starts about 1 year after your transplant, but your transplant team will decide 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're recovering from your transplant, it's very important to keep yourself clean. Doing this can help prevent infection. Follow the guidelines below.

- Shower or bathe every day.
  - Use a mild soap, such as Dove® or Caress®. Don't use Ivory® or a deodorant soap. They can dry out your skin.
  - o Be sure to wash your underarms and groin.
  - o Use a washcloth and towel that are only for your personal use.
  - o 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. Don't use lotions containing alcohol. They'll make your skin drier.
- Hair usually starts to grow back about 3 months after your transplant. It's possible that your hair will grow back with a different texture. Although it's rare, hair loss can happen months or years after your transplant.
- Limit your time in direct sunlight.
  - Your skin will be more sensitive and may burn more easily after your transplant. The medications you're taking may add to this. Whenever you're in the sun, protect your skin with a sunscreen that has an SPF of at least 30. Reapply it often. If you'll be in direct sunlight for 20 minutes or longer, cover your skin with cotton clothing and a protective hat.
  - Being in the sun for too long may also reactivate cold sores (herpes simplex virus) or cause GVHD of the skin.
- You can wear contact lenses, but make sure they're cleaned well before you put them in. Don't reuse cleaning solution. Be sure to throw away cleaning solutions when they expire. If your eyes are dry, use moisturizing drops.
- You can wear makeup. Buy all new products after your transplant.
- New nails will grow and replace your old nails. This will happen gradually 3 to 4 months after your transplant. Don't get a manicure or pedicure in a nail salon while your immune system is still recovering. You can give yourself a manicure or pedicure at home with your own equipment.
- If you still have a tunneled catheter, don't let it soak in water while you bathe. Read the resource *About Your Tunneled Catheter* for more information.

• Don't get body piercings or tattoos after your transplant. These increase your risk of hepatitis and other infections. Discuss any concerns you may have with your transplant doctor.

#### Mouth Care

Keep following the instructions in the "Caring for Your Mouth" section until your transplant team tells you that can start using an ultra soft toothbrush. You can brush your teeth with an ultra soft toothbrush if:

- Your absolute neutrophil count (ANC) is higher than 500 (sometimes 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, 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 well 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 keep your mouth from becoming reinfected. Tell your doctor or nurse if you have pain or discomfort in your mouth.

You may have mouth dryness for 3 to 4 months or longer after your transplant. Don't use store-bought, alcohol-based mouthwashes or hydrogen peroxide. They'll dry and irritate your mouth. Instead, use a mild saltwater rinse. Make it by mixing 1/2 teaspoon of salt and 1/2 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 help.

Your salivary glands may not be as good at washing bacteria from your mouth after your transplant. This increases your risk of cavities. Use toothpaste with fluoride. You can also use a mouthwash with fluoride once your mouth has fully recovered and is no longer too dry. Follow the instructions on the mouthwash bottle.

## Caring for Your Tunneled Catheter

It's just as important to keep your tunneled catheter clean after you go home as it was while you were in the hospital. If you go home with a tunneled catheter, your nurse will

teach you how to care for it at home. You'll have a chance to practice with your nurse watching. Read the resource *About Your Tunneled Catheter* for more information.

#### Your Home Environment

Keep your home as free of dirt and dust as possible. But, you shouldn't go to extremes. Don't repaint your walls or put down new carpets. In fact, you shouldn't be around any renovations or construction until your transplant team tells you it's okay. This includes those in process and those done within the past 3 months.

Stay out of musty areas where mold might grow, such as a damp basement. You can use an air filtration system in your home, but you don't need to.

**Don't use a humidifier.** Bacteria and mold grow easily in it. A pan of water placed near a heat source may help in the winter. **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's fine for you to cook, wash dishes, or iron. Keep your bathroom very clean, especially the tub and toilet. Use a disinfectant regularly. It's best for someone else to do this.

Wash your eating utensils, towels, and linens carefully. They don't 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 a 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.

You can have plants in your home. But, for the first few months after your transplant:

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

#### Pets and animals

Animals can carry diseases. They may put you at greater risk for infection while your immune system is recovering. You can have a pet in your home and touch it, but it's best that you don't have close physical contact. For example, don't hold the animal in your lap. Don't touch the animal's saliva or feces. Be sure to protect yourself from bites or scratches.

Don't handle or care for birds, lizards, snakes, turtles, hamsters, or other rodents while you're recovering. If you have an aquarium and you have to clean it yourself, 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 pet's veterinarian check their stool for parasites every year.
- If you have a cat, get it tested for feline leukemia and toxoplasmosis every year.
- 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). Talk with your pet's veterinarian about using a flea and tick collar.
- Don't clean cat litter boxes or clean up after your dog. Have someone else do these things for you.
- Keep your pets indoors or on your own property whenever you can. This is to help keep them from getting diseases from other animals.
- Don't let pets in your bed.

If you plan to get a pet after your transplant, it's best that you choose a healthy dog or cat that's 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 people in your immediate family. But, don't 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's sick. Your family members and close friends should get a yearly flu shot.

You can have visitors, but limit them to small groups. Don't visit with anyone who has:

- A cold.
- Chickenpox or recently been exposed to chickenpox.
- Recently been exposed to herpes, shingles, or any other type of virus or infection.
- Recently got a vaccine with a live virus (such as varicella or rotavirus). There are very few of these, but if someone in your household needs one, their doctor should be told that you're immune suppressed and live in the same household.



Call your doctor right away if you or a family member is exposed to chickenpox, shingles, measles, or German measles (rubella).

#### **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. But, during the first few months after your transplant, avoid the following places when they're crowded.

- Supermarkets
- Shopping malls
- Movie theaters
- Schools

- Restaurants
- Public transportation
- Places of worship (such as churches or synagogues)

You can go to these places at off-peak hours when there are fewer people.

Avoid taking public transportation (such as a train or bus) for at least 3 months after your transplant. We understand you may need to take a taxi, car service, or other transportation (such as Access-a-Ride) to return for follow-up visits. We recommended that you wear a mask when traveling by this means.

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 the pool is chlorinated.

Don't swim in lakes, rivers, or crowded pools until your immune system has recovered. **Don't swim if your tunneled catheter is still in place.** 

## Bleeding

Platelets are blood cells that help form clots and control bleeding. When your platelet count is low, you're at risk for bleeding. Many people are discharged with a low platelet count. It can take weeks or months for your body to make enough platelets so your count returns to normal. You may need to have platelet transfusions.

Signs of a low platelet count include skin changes, bleeding, or both. Skin changes may include a lot of bruising or petechiae (peh-TEE-kee-ee). These are tiny, purplish-red spots on the skin that don't disappear when you press them. You may see them on your

lower legs or inside ankles. If you see many petechiae, call your doctor. Other symptoms of a low-platelet count may include bleeding from your gums or nose.

If you leave the hospital with any of these symptoms and they increase in amount or frequency, call your doctor. If you haven't had any of these symptoms and suddenly develop them, call your doctor. It may mean that there's a change in your platelet count.

If you have an injury that causes bleeding, don't panic. Stay 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. Press firmly. Keep pressing to apply pressure until the bleeding stops. If the bleeding doesn't stop, elevate the wound. For example, raise your arm or prop up your feet. Apply ice to the wound and call your doctor.
- **Nosebleeds:** If you have a nosebleed, sit up and lean forward slightly. Don't 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 doesn't stop, keep squeezing your nose. Apply a small bag of ice to the bridge of your nose until the bleeding stops. If the bleeding continues longer than 30 minutes, call your doctor.
- **Accidents:** If you're in an accident, you may need blood or blood products. They should be irradiated to 3,000 rads. This is to keep transfused blood from causing GVHD.
  - Wear your medical alert jewelry at all times. It gives the doctor who will be treating you this information. Read the "Medical alert jewelry" section for information about what to write on your medical alert jewelry.
  - o If you're admitted to another hospital, have the doctor call MSK right away for guidelines on blood products.

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

- Use an electric razor when shaving.
- Use a soft-bristle toothbrush or an oral irrigator (such as a WaterPic®) to prevent gum bleeding. Don't use dental floss.
- Don't take aspirin, products that have aspirin, or aspirin-like medications, such as such as ibuprofen (Advil®) or naproxen (Aleve®). For more information, read the section "Common Medications to Avoid."
- Avoid blowing your nose forcefully.

- If you're 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, talk with your doctor.

#### **Resuming Your Activities**

#### Daily activities

The time it takes to recover after a transplant varies. Most people find that it takes about 3 months, while others may need more or less time.

The time after your transplant is a time of cell recovery and growth. The cells in your mouth, stomach, intestine, hair, and muscles will all regrow. This requires calories and energy. You may feel more tired than you expected. Remember, this fatigue and weakness are normal. Each week, you should get more of your strength back.

Around the 3<sup>rd</sup> month after your transplant, your hair will start growing more quickly. You may feel well enough to start going back to your usual level of activity. From this point on, you'll probably feel better and 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 start 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.

Don't play contact sports or ski until your platelet count is over 100,000.

#### **Hobbies**

Some hobbies, such as woodworking, painting, and model building, use products that can be toxic. Always work in a room with plenty of fresh air. 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 go back to school or work is about 4 months from the time of your transplant. This time frame can vary from person to person and depends many things.

Some people may feel ready to return right away, while others feel worried after being away for so long. It may help to start 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 actually doing it.

Making the transition back to your usual lifestyle can be hard. Some people have talked about feelings related to changes in their appearance, such as hair loss. Others have trouble concentrating or maintaining their attention span. Many can't keep up their former pace. Your transplant team is here to talk with you about going back to school or work. You can talk to a social worker, nurse, psychiatrist, or your doctor. We can work with you to find ways to make your transition easier.

## Traveling

For the first 100 days after the day of your transplant, avoid traveling more than about 1 hour away from MSK.

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

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

## Sexual Health

Before you leave the hospital, ask your doctor about resuming sexual activity. It's important for you and your partner to have answers to your questions. If new questions come up, you can discuss them during your follow-up visits.

## Protecting yourself during sexual activity

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

- Avoid sex that involves penetration or contact with mucous membranes while your blood counts are low (a platelet count less 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 every time you have vaginal, oral, or anal sex.

- Use a barrier device (condoms or dental dams) any time your partner's vaginal secretions or semen could enter your mouth.
- Avoid any sexual activity that could expose your mouth to feces.
- Avoid sex that involves contact with mucous membranes if you or your partner have a genital infection or think you might have one.

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

For more information about being sexually active during and after treatment, read the resources below.

- Sex and Your Cancer Treatment www.mskcc.org/pe/sex\_cancer\_treatment
- Sexual Health and Intimacy www.mskcc.org/pe/sexual\_health\_intimacy

The American Cancer Society also publishes resources on sexuality after cancer treatment. They're available for free from your local American Cancer Society (ACS) or on the ACS website at the links below.

- Sex and the Adult Male with Cancer www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html
- Sex and the Adult Female with Cancer: www.cancer.org/treatment/treatments-and-side-effects/physical-sideeffects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html

#### Information for females

After your transplant, you may have:

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

Talk with your BMT doctor before using the products below.

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

Vaginal lubricants usually come in a liquid or gel form. They're used to supplement a woman's own lubrication and minimize dryness and pain during sexual activity. You can use these lubricants to make sexual activities more comfortable and pleasurable. Examples are Astroglide®, K-Y® Jelly, and Pjur® Woman Bodyglide (a silicone-based lubricant). For more information, read the resource *Improving Your Vulvovaginal Health*. You can find it online at www.mskcc.org/pe/improving\_vulvovaginal\_health or ask a member of your transplant team for a copy.

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, your doctor can refer you to a specialist in our Female Sexual Medicine and Women's Health Program. You can also contact the program by calling 646-888-5076.

#### Information for males

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

# Drinking Alcohol and Using Tobacco

After your transplant, your organs need time to recover. Alcohol can harm your liver and recovering bone marrow. This harm can be worse if you're taking medications that can affect your liver. Don't drink alcohol until your doctor tells you it's safe.

Never smoke cigarettes, cigars, other tobacco products, or marijuana. 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're discharged. In general, you'll be seen at least 1 to 2 times a week for the first 3 months after your transplant. After that, your appointments will be spaced further apart as long as you're doing well.

Before your visits, make a list of any medications that need to be refilled. If you're going to run out of any medications before your follow-up visit, tell your doctor before your appointment. You'll be given prescriptions during your visit to be filled either at MSK or your local pharmacy.

If you're taking immunosuppressive medications, don't take the morning dose on the days that you have a follow-up visit, unless your doctor gives you other instructions. Bring the dose to your appointment. During your appointment, you will have blood drawn to see how much of the drug is in your blood. Then, a staff member will tell you to take the medication.

When you come to the clinic for your follow-up visits, always wear a surgical mask. Bring a list of all the medications you're taking and the dosages of each one. Some people find it helpful to bring a list of questions that have come up since the last visit.

You'll have blood tests to check your blood counts, electrolyte levels, and liver and kidney function. Bone marrow aspirations will be done every few months. They're usually done 1, 3, 6, 12, and 24 months after transplant. If needed, your bone marrow may be checked more often or for a longer time after your transplant. Bone marrow tests tell us about the health and growth of your marrow.

If you had a transplant for acute leukemia, you may need to have lumbar punctures (spinal taps). This is especially true for people who have had, or are at high risk for having, leukemia in their spinal fluid. A lumbar puncture lets your doctor give you more chemotherapy in your spinal fluid after your transplant. It can also be given through an Ommaya reservoir, if you have one.

You may need to have IV treatments such as antibiotics and blood transfusions. If you do, your doctor or nurse will tell you how long and how often you'll need them. These appointments will usually be scheduled at the same time as your follow-up visits.

At some point after your transplant, you might be referred to our BMT Survivorship clinic. There, you'll see a survivorship NP. A survivorship NP is part of your transplant team. They work closely with your doctors and nurses to help with your recovery. This NP will also communicate directly with your primary care provider so information about your transplant is included in your overall healthcare.

#### Dental care

After you have recovered from your transplant, go to your local dentist for routine checks. If you need extensive dental work, ask your transplant doctor what you should do. They'll 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 pamidronate (Aredia®) or zoledronic acid (Zometa®)
- Jaw tightness
- Toothaches
- Discoloration at your gum line
- · Receding gums

#### Common Medications to Avoid

Don't take aspirin, any medications containing aspirin, or nonsteroidal anti-inflammatory drugs (NSAIDs) until your doctor gives you other instructions. For a list of these medications, read the resource *Common Medications Containing Aspirin, Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), or Vitamin E.* You can find it online at www.mskcc.org/pe/common\_meds or ask a member of your transplant team for a copy.

Check the label of any over-the-counter medications that you're thinking of taking to make sure they don't contain ingredients you should avoid. If you aren't sure if a medication is safe to take, ask your transplant team.

Don't take any herbal supplements or home remedies without talking to your transplant team first.

## **Phase 5: Late Convalescence**

# Possible Long-Term Complications

In the section "Possible Early Complications," we discussed issues that may come up with your kidneys, liver, heart, and lungs. Other organ systems, such as your endocrine system, may also be impacted.

Your endocrine system makes hormones. It may not return to normal after your transplant. You'll have blood work and exams to check your hormone levels. Some people develop hypothyroidism (an underactive thyroid) after radiation therapy or just as a part of aging. If you develop it, you'll need to take medication to supplement what your thyroid can't make itself.

You'll be followed in our survivorship clinic after your transplant and will be monitored closely for any late side effects you may have. Some of the testing you had as part of your pretransplant evaluation will be repeated, including an EKG, echocardiogram, and pulmonary function tests. We'll monitor you for any thyroid dysfunction, evidence of a hormonal deficiency, and any sign of osteoporosis (bone loss).

Health issues such as thyroid dysfunction or bone loss can develop in any person, even if they haven't had a transplant, but we want to monitor you closely and keep you well.

## Other Possible (Uncommon) Complications

#### Graft failure or rejection

Transplanted stem cells sometimes don't grow successfully inside the body. This is called graft failure. Graft rejection means that your immune system has rejected your new stem cells. You'll get treatments before your transplant to prevent this from happening.

The risk of graft rejection lasts about 2 to 4 weeks after a transplant. Occasionally, graft failure can happen at a later time after a transplant. If this happens, one option may be to get more stem cells from your donor, if they're available. This is called a "boost." Your doctor will discuss treatment options with you if this happens.

#### Relapse

Many people are worried that their cancer will come back. Your risk is higher if you had your transplant when you were in an advanced stage of disease or you weren't in remission. Your doctor will follow you closely to watch for any sign of relapse.

#### Continued Follow-up Care

#### **Immunizations**

After your transplant, you'll lose the protection from the vaccines you got as a child. Everyone who has a stem cell transplant gets childhood vaccines once their immune system has recovered. This usually happens about 1 year after the transplant.

Once it's safe for you to get vaccines, your transplant team will plan them. The vaccines can be given at MSK or your NP can give your primary care doctor a list of the recommended vaccines. Please note that it's sometimes hard for primary care doctors to get the vaccines, so you may need to get them at MSK. You'll get only "killed" vaccines first, and if you respond to those, you'll then get "partially killed" vaccines, such as for measles and shingles.

#### Eye exams

You may develop cataracts if you got radiation therapy or high-dose steroids. See an eye doctor if you develop any of the following symptoms:

- Cloudy, blurry, foggy, or filmy vision
- 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 might only need a change in your eyeglass or contact lens prescription. Be sure to tell your optician or eye doctor what treatment you had.

Try to wait until at least 3 months after your transplant before getting a new eyeglass or contact lens prescription. Your vision can change during the recovery process.

# **Educational Resources**

This section contains the educational resources we referred to throughout this guide. You can find them online, or you can ask a member of your transplant team. You can also search for more educational materials on the Patient and Caregiver Education website, www.mskcc.org/pe.

About Your Blood Transfusion www.mskcc.org/pe/blood\_transfusion

About Your Tunneled Catheter www.mskcc.org/pe/about\_tunneled\_catheter

Advance Care Planning www.mskcc.org/pe/advance\_care\_planning

Allogeneic Donor Peripheral Blood Stem Cell Harvesting www.mskcc.org/pe/allogeneic\_pbsc\_harvesting

Building Your Family After Cancer Treatment: Information for Men www.mskcc.org/pe/building\_family\_men

Call! Don't Fall! www.mskcc.org/pe/call\_dont\_fall

Caregivers' Guide for Bone Marrow/Stem Cell Transplant www.mskcc.org/pe/caregivers\_guide\_bmt

Common Medications Containing Aspirin, Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), or Vitamin E

www.mskcc.org/pe/common\_meds

Communicating with Your Healthcare Team Using MyMSK www.mskcc.org/pe/communicating\_using\_mymsk

Eating Well After Your Stem Cell Transplant www.mskcc.org/pe/eating\_well\_sct

Fertility Preservation: Options for Females Starting Cancer Treatment www.mskcc.org/pe/fertility\_starting\_treatment

Hair Loss and Your Cancer Treatment
www.mskcc.org/pe/hair\_loss\_cancer\_treatment

Hand Hygiene and Preventing Infection www.mskcc.org/pe/hand\_hygiene

Improving Your Vulvovaginal Health www.mskcc.org/pe/improving\_vulvovaginal\_health

Sex and Your Cancer Treatment
www.mskcc.org/pe/sex\_cancer\_treatment

Sexual Health and Intimacy
www.mskcc.org/pe/sexual\_health\_intimacy

Skin Care Guidelines While You Are Receiving Radiation Therapy www.mskcc.org/pe/skin\_care\_radiation\_therapy

Sperm Banking www.mskcc.org/pe/sperm\_banking



#### PATIENT & CAREGIVER EDUCATION

# **About Your Blood Transfusion**

This information explains what to expect before, during, and after your blood transfusion. A blood transfusion is when blood or blood cells are put into your body. You may need a blood transfusion because of how your cancer or cancer treatment affects your blood.

Some people may not want a blood transfusion for religious or other reasons. It's always your right to refuse a treatment. Your healthcare provider will only recommend a blood transfusion if they think it's needed. You can lose lots of blood during some types of surgery. If this blood isn't replaced, you can die.

# **About Blood**

Blood is made up of plasma, red blood cells, platelets, and white blood cells.

- **Plasma** is the liquid part of blood. It holds your blood cells. You may need a plasma transfusion if your blood isn't clotting well.
- **Red blood cells** carry oxygen to all parts of your body. You may need a transfusion of red blood cells if you have a low red blood cell count (anemia). This can help relieve dizziness, shortness of breath, or fatigue (feeling more tired or having less energy than usual).
- **Platelets** help form clots and stop bleeding. You may need a platelet transfusion if you have a low platelet count (thrombocytopenia). This can help stop bleeding or keep you from bleeding too much during a surgery or procedure.
- White blood cells fight infection. White blood cell transfusions are rare and are only done in very specific situations.

# **About Donated Blood**

There are no blood substitutes currently available. The blood or blood cells you get during your transfusion are usually donated by another person.

Sometimes you can donate your own blood so it can be stored and given back to you if needed. This is called an autologous (aw-TAH-luh-gus) donation. For more information, read the resource *Being Your Own Blood Donor* (www.mskcc.org/pe/autologous blood donation).

After it's donated, blood is tested to see what type it is. It's also tested for things such as:

- Syphilis
- Hepatitis B and C
- HIV
- A virus linked to a very rare form of leukemia
- West Nile virus
- Trypanosoma cruzi (a parasite that causes Chagas disease)
- Zika virus
- Bacteria (platelets only)

If the tests show any of these, the blood is thrown away.

## **Directed donations**

A directed donation is when someone donates blood or blood cells specifically for you. Directed donations are tested in the same way as other donations. If the blood tests positive for any of the things listed above, we'll notify the donor privately.

Directed red blood cell donations are held for you for 25 days. Directed platelet donations are held for you for 4 days. After that, the donation may be given to someone else. It will also be given to someone else if the donor's blood type isn't a match for yours.

# **Before Your Blood Transfusion**

Before your transfusion, we'll check your blood type with a test called a type and screen. The blood bank may take 2 to 4 hours to process the test. It may take longer if you have unexpected results. Your healthcare provider will use the results of your type and screen to make sure the blood or blood cells you get during your transfusion are safe for you.

Your healthcare provide will also talk with you about risks associated with having a blood transfusion. There's a very small chance of having an allergic reaction during or after your transfusion. The most common reactions are a fever of 100.4 °F (38 °C), chills, or hives. These can be treated with medication. Transfusion reactions are rarely life-threatening.

# **During Your Blood Transfusion**

When everything is ready, the nurse will access one of your veins.

- If you have a central venous catheter (CVC), such as a tunneled chest catheter or peripherally inserted central catheter (PICC line), the nurse will use it for your transfusion. Accessing your CVC won't hurt.
- If you have an implanted port, such as a Mediport®, the nurse will use it for your transfusion. This will be the same type of needle stick you have for chemotherapy.
- If you don't have an implanted port or CVC, the nurse will put an intravenous (IV) line into one of your veins.

After they access your vein, the nurse will start the transfusion. The transfusion won't hurt.

A transfusion of one unit of red blood cells usually takes 2 to 4 hours. A transfusion of one unit of platelets takes about 30 to 60 minutes. Your nurse will monitor you carefully during your entire transfusion.

# **After Your Blood Transfusion**

If you got your blood transfusion through a vein in your arm or leg, you may have some bruising or irritation in the area where the needle was. If the bruising or irritation is bad, call your healthcare provider.

Blood transfusions can cause an allergic reaction up to 2 days after the transfusion. Call your healthcare provider if you have any of the reactions below.

# When to Call Your Healthcare Provider

Call your healthcare provider if you have:

- A fever of 100.4 °F (38 °C) or higher
- Chills
- Redness and warmth in your face
- Hives, rash, or itching
- Trouble breathing or shortness of breath
- Lower back pain
- Nausea (feeling like you're going to throw up) or vomiting (throwing up)
- Weakness or fainting
- Dark-colored urine (pee)

#### If you have chest pain, call 911 right away.

If you have any questions, contact a member of your healthcare team directly. If you're a patient at MSK and you need to reach a provider after 5:00 PM, during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit <u>www.mskcc.org/pe</u> to search our virtual library.

About Your Blood Transfusion - Last updated on January 11, 2021 All rights owned and reserved by Memorial Sloan Kettering Cancer Center



#### PATIENT & CAREGIVER EDUCATION

# **About Your Tunneled Catheter**

This information explains what a tunneled catheter is and how it's placed. It also has general guidelines for caring for your tunneled catheter at home. A tunneled catheter is a type of central venous catheter (CVC).

# **About tunneled catheters**

A tunneled catheter is a flexible catheter (thin tube) that goes into a vein in your chest. There are many different types of tunneled catheters. Your doctor will decide which type is best for you.

All tunneled catheters are tunneled under your skin and into a large vein near your heart (see Figure 1).

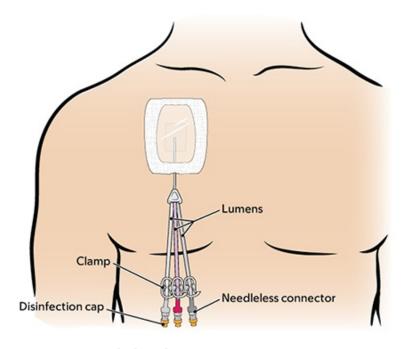


Figure 1. Tunneled catheter

The catheter splits into 1, 2, or 3 lumens (smaller tubes) outside of your body. Each lumen has:

- A clamp.
- A needleless connector (also called a clave).
- A disinfection cap on the end.

Having a tunneled catheter can help you need fewer needle sticks. It can be used to:

- Take blood samples.
- · Give fluids.
- Give chemotherapy and other cancer treatments, such as CAR-T and bone marrow transplant.
- Give intravenous (IV) medications and nutrition.
- Give blood transfusions.

A tunneled catheter can stay in your body for weeks, months, or even years. Your doctor will remove it when you do not need it anymore.

You will have a procedure to place your tunneled catheter. Your nurse will tell you how to get ready for your procedure. They will also teach you how to care for your tunneled catheter after your procedure. It can be helpful to have a caregiver, family member, or friend learn with you.

Most people can do normal activities with a tunneled catheter, such as work, school, sexual activity, showering, and mild exercise. Talk with your doctor or nurse about which activities are safe to do before you start them.

Avoid contact sports, such as football and soccer. Avoid submerging your catheter in water, such as swimming in a pool or ocean, while your catheter is in place.

# What to do before your procedure

#### **Ask About Your Medications**

You may need to stop taking some of your medications before your procedure. Talk with your healthcare provider about which medications are safe for you to stop taking. We've included some common examples below.

#### **Blood thinners**

Blood thinners are medications that affect the way your blood clots. If you take blood thinners, ask the healthcare provider performing your procedure what to do. They may recommend you stop taking the medication. This will depend on the type of procedure you're having and the reason you're taking blood thinners.

Examples of common blood thinners are listed below. There are others, so be sure your care team knows all the medications you take. **Do not stop taking your blood thinner without talking with a member of your care team.** 

- Apixaban (Eliquis®)
- Aspirin
- Celecoxib (Celebrex®)
- Cilostazol (Pletal®)
- Clopidogrel (Plavix®)
- Dabigatran (Pradaxa®)
- Dalteparin (Fragmin®)
- Dipyridamole (Persantine®)
- Edoxaban (Savaysa®)
- Enoxaparin (Lovenox®)
- Fondaparinux (Arixtra®)
- Heparin (shot under your skin)

- Meloxicam (Mobic®)
- Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil®, Motrin®) and naproxen (Aleve®)
- Pentoxifylline (Trental®)
- Prasugrel (Effient®)
- Rivaroxaban (Xarelto®)
- Sulfasalazine (Azulfidine®, Sulfazine®)
- Ticagrelor (Brilinta®)
- Tinzaparin (Innohep®)
- Warfarin (Jantoven®, Coumadin®)

Read *Common Medications Containing Aspirin, Other Nonsteroidal Anti- inflammatory Drugs (NSAIDs), or Vitamin E*(www.mskcc.org/pe/common\_meds). It has information about medications you'll need to avoid before your procedure.

#### **Medications for diabetes**

Before your procedure, talk with the healthcare provider who prescribes your insulin or other medications for diabetes. They may need to change the dose of the medications you take for diabetes. Ask them what you should do the morning of your procedure.

Your care team will check your blood sugar levels during your procedure.

# **Diuretics (water pills)**

A diuretic is a medication that makes you urinate (pee) more often. Hydrochlorothiazide (Microzide®) and furosemide (Lasix®) are common diuretics.

If you take any diuretics, ask the healthcare provider doing your procedure what to do. You may need to stop taking them the day of your procedure.

# Take devices off your skin

You may wear certain devices on your skin. Before your scan or procedure, device makers recommend you take off your:

- Continuous glucose monitor (CGM)
- Insulin pump

Talk with your healthcare provider about scheduling your appointment closer to the date you need to change your device. Make sure you have an extra device with you to put on after your scan or procedure.

You may not be sure how to manage your glucose while your device is off. If so, before your appointment, talk with the healthcare provider who manages your diabetes care.

# Arrange for someone to take you home

You must have a responsible care partner take you home after your procedure. A responsible care partner is someone who can help you get home safely. They should be able to contact your care team if they have any concerns. Make sure to plan this before the day of your procedure.

If you don't have a responsible care partner to take you home, call one of the agencies below. They'll send someone to go home with you. There's a charge for this service, and you'll need to provide transportation. It's OK to use a taxi or car service, but you still need a responsible care partner with you.

Agencies in New Jersey

Caring People: 877-227-4649

#### **Agencies in New York**

VNS Health: 888-735-8913

Caring People: 877-227-4649

# Tell us if you're sick

If you get sick (including having a fever, cold, sore throat, or flu) before your procedure, call your IR doctor. You can reach them Monday through Friday from 9 a.m. to 5 p.m.

After 5 p.m., during the weekend, and on holidays, call 212-639-2000. Ask for the Interventional Radiology fellow on call.

# Note the time of your appointment

A staff member will call you 2 business days before your procedure. If your procedure is scheduled for a Monday, they'll call you on the Thursday before. They'll tell you what time to get to the hospital for your procedure. They will also remind you where to go.

Use this area to write down the date, time, and location of your			
procedure:			

If you don't get a call by noon (12 p.m.) on the business day before your procedure, call 646-677-7001. If you need to cancel your procedure for any reason, call the healthcare provider who scheduled it for you.

# What to do the day before your procedure

# Instructions for eating before your procedure



Do not eat anything after midnight (12 a.m.) the night before your procedure. This includes hard candy and gum.

# What to do the day of your procedure





You can drink a total of 12 ounces of water between midnight (12 a.m.) and 2 hours before your scheduled arrival time. **Do not drink anything else.** 

Do not drink anything starting 2 hours before your scheduled arrival time. This includes water.

# Things to remember

- Take only the medications your doctor told you to take the morning of your procedure. Take them with a few sips of water.
- Do not put cream (thick moisturizers) or petroleum jelly (Vaseline®) anywhere on your chest.
- Do not wear eye makeup.
- Remove any jewelry, including body piercings.
- Leave all valuables at home if you do not need them.
- If you wear contact lenses, wear your glasses instead, if you can. If you do not have glasses, bring a case for your contacts.

# What to bring with you

- Medications for breathing problems, such as inhalers, if you take any.
- Medications for chest pain, if you take any.
- A case for your glasses or contacts.
- Your Health Care Proxy form and other advance directives, if you have completed them.
- Your CPAP or BiPAP machine if you use one. If you cannot bring yours with you, we will give you one to use while you're in the hospital.

# What to expect when you arrive

Many staff members will ask you to say and spell your name and date of birth. This is for your safety. People with the same or similar names may be having procedures on the same day.

#### Meet with a nurse

You'll meet with a nurse before your procedure. Tell them the dose of any medications you took after midnight (12 a.m.) and the time you took them. Make sure to include prescription and over-the-counter medications, patches, and creams.

Your nurse may place an intravenous (IV) line in one of your veins, usually in your arm or hand. If your nurse does not place the IV, your anesthesiologist will do it in the procedure room.

A member of your care team will review your medical history with you to prepare you for sedation (seh-DAY-shun). Sedation is when you're calm, relaxed, or sleepy from medicine you will get before your procedure. They will:

- Ask you if you've had any problems with sedation in the past. This includes nausea (feeling like you're going to throw up) or pain.
- Talk with you about your comfort and safety during your procedure.
- Talk with you about the kind of sedation you'll get.
- Answer questions you have about sedation.

# Inside the procedure room

A member of your care team will give you an injection (shot) of local anesthesia. This is medicine to numb the area where they will place the catheter into your skin.

Once the areas are numb, your doctor will make small incisions (surgical cuts). They will place the catheter through the incision on your chest and tunnel it under your skin to the incision at the base of your neck. Then, they will thread the catheter into your vein (see Figure 2).

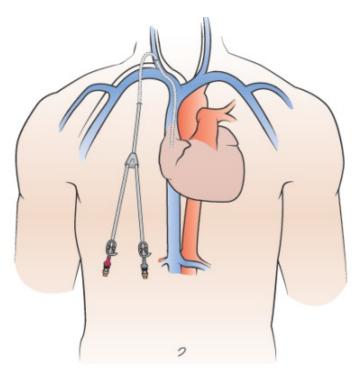


Figure 2. Catheter tunneled under your skin, into a vein

Your doctor will use fluoroscopy (real time X-rays) or ultrasound to help place the catheter. They may also give you an injection of IV contrast. The contrast makes it easier for your doctor to see the area.

Your doctor will use sutures (stitches) to close the incision at the base of your neck. They will put Steri-Strips<sup>™</sup> (surgical tape) over the sutures. Then, they will stitch your catheter to your skin at the place where it leaves your body (the exit site). This will keep the catheter in place.

At the end of your procedure, your doctor will put a gauze dressing (bandage) over the incision on your neck. They'll also put a Tegaderm™ dressing over your catheter exit site.

# What to do after your procedure

After your procedure, your care team will bring you to the recovery room. You will need to stay in bed until the sedation has worn off. You will then go back to your hospital room or go home with your caregiver.

You may have bleeding, discomfort, or pain at your catheter exit site. It can last for up to 3 days after your catheter is placed. Talk with your healthcare provider about what pain medicine is safe to take.

If you have any bleeding from your exit site, apply pressure and a cold compress to the area. Tell your nurse if you have:

- Bleeding. Your care team may need to change your dressing.
- Pain or discomfort that gets worse.
- Any nausea (feeling like you're going to throw up).
- Any symptoms that concern you.

Do not shower for 24 hours after your procedure.

### Your central line discharge kit

Your nurse will give you a discharge kit before your procedure or before you leave the hospital. They will explain how to use the kit.

The discharge kit has:

- 1 toothless clamp
- 1 cannula clamp
- 2 Curos Jet<sup>TM</sup> strips
- 3 needleless connectors
- 1 package of (10-inch x 12-inch) water guards, such as AquaGuard
- ullet 2 (4-inch x 6 1/8-inch) Tegaderm dressings without CHG
- 2 Nitrile exam gloves
- 10 alcohol Pads
- 1 (4-ounce) package of CHG 4% cleansing soap
- Disinfection caps
- Your doctor's office and emergency telephone numbers

**Keep your discharge kit with you at all times.** You'll need it if your catheter is leaking, or if your Tegaderm dressing or needleless connector is damaged or comes off.

# How to care for your catheter exit site

Always have a Tegaderm dressing over your exit site while your tunneled catheter is in place. The Tegaderm dressing helps prevent infection. Call your healthcare provider if your Tegaderm dressing gets dirty, wet, or peels off. They may need to change your Tegaderm dressing.

# Have a nurse change your dressing

Have a nurse change your dressing:

- Within 24 hours (1 day) if you're staying in the hospital after your procedure.
- Within 48 hours (2 days) if you're going home after your procedure and your dressing is gauze and tape. They will replace it with a CHG or non-CHG transparent (clear) dressing.
- Within 7 days if both of these are true:
  - $\circ\,$  You have a CHG or non-CHG transparent dressing.
  - You can see your insertion site (where the catheter goes into your body).

During these dressing change appointments, the nurse will change your needleless connectors, disinfection caps and flush your catheter. If you cannot come to an MSK site, your nurse will help you make other plans. Call your healthcare provider if you have any questions.

### How to care for your neck incision

Two days after your procedure, remove the gauze bandage over the small incision on your neck. You do not need to put a new bandage over the incision.

Leave the Steri-Strips in place until they start to peel off. This can take up to 1 week after your procedure.

# How to care for your tunneled catheter at home

Keep the lumens clamped when you are not using your catheter. Keep your catheter secure at all times to keep from pulling it.

Talk with your nurse about the best way to secure your catheter. You can tape the lumens to your skin or tuck them into your bra. Or, you can wrap them in medical tape and pin the tape to your clothing. Take off the pin when changing your clothes to prevent tugging on the catheter.

Do not put tape over the connection site. The connection site is where the needleless connector connects to the lumens.

Check your exit site every day for redness, tenderness or pain, leakage or drainage, swelling, or bleeding. Call your healthcare provider right away if you have any of these signs or symptoms. These are signs you may have an infection.

### What to do if your catheter is leaking

- 1. Clamp your catheter above the leak. Move the white clamp on the catheter so it's above the leak, if you can. If you cannot use the white clamp, use the toothless clamp in your discharge kit (see figure 3).
- 2. Wipe the area that's leaking with an alcohol pad.
- 3. Call your doctor's office right away.

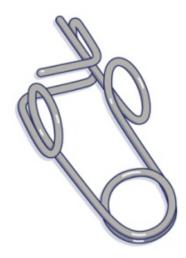


Figure 3. Toothless clamp

# What to do if your Tegaderm dressing is damaged, loose, or dirty

**Call your doctor's office right away.** Do not take off the damaged, loose, or dirty dressing. Put a new Tegaderm dressing from the discharge kit over it.

### What to do if your Tegaderm dressing is wet

**Call your doctor's office right away.** Do not take off the wet Tegaderm dressing or put another dressing over it.

## What to do if your disinfection cap falls off

Throw the disinfection cap that fell off in the trash. Do not put it back on the lumen.

To put on a new disinfection cap:

- 1. Clean your hands with soap and water or an alcohol-based hand sanitizer.
- 2. Get a new disinfection cap from your discharge kit. Remove the cap from the strip.
- 3. Hold the needleless connector in one hand. With your other hand, gently push and twist the new disinfection cap onto the end of the needleless connector.

### What to do if your needleless connector falls off

Throw the needleless connector that fell off into the trash. Do not put it back on the lumen.

To put on a new needleless connector:

- 1. Gather your supplies. You will need:
  - 1 pair of nonsterile gloves
  - 2 alcohol pads
  - 1 new needleless connector
  - o 1 new disinfection cap
- 2. Clean your hands with soap and water or an alcohol-based hand sanitizer. Put the gloves on.
- 3. Get your supplies ready.
  - $\circ\,$  Open 1 of the alcohol pad packets, but leave the alcohol pad inside.
  - Open the needleless connector packet, but leave the needleless connector inside.
  - Pull the tab to take the cover off the disinfection cap, but leave the disinfection cap inside its plastic holder.
- 4. Open the other alcohol pad packet. Using the alcohol pad inside, pick up the lumen with your nondominant hand (the hand you do not write with). Hold it close to the end (see Figure 3).

- 5. Pick up the other, open alcohol pad with your dominant hand (the hand you write with). Scrub the open end of the lumen with the alcohol pad for 15 seconds. Then throw the alcohol pad in the trash. Let the lumen dry for 15 seconds. Keep holding it with the alcohol pad in your nondominant hand.
- 6. Pick up the new needleless connector with your free hand. If it has a cover, take the cover off. You can do this using the knuckles of your other hand. Then, twist the new needleless connector onto the end of the lumen (see Figure 4). Keep holding the lumen with the alcohol pad in your nondominant hand.

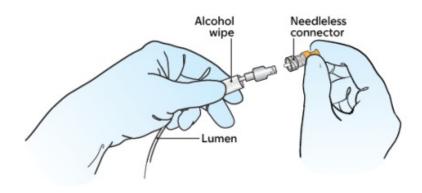


Figure 4. Twisting on the new needleless connector

- 7. Pick up the plastic holder with the disinfection cap with your free hand. Gently push and twist the disinfection cap onto the end of the needleless connector. Once it's attached, pull off the plastic holder and throw it away.
- 8. Take your gloves off. Clean your hands.

Call your doctor or nurse after you change the needleless connector.

# Guidelines for showering with a tunneled catheter

Keep your skin clean to lower your risk of infection while your tunneled catheter is in place.

### Use a waterproof cover

Use a single-use waterproof cover over your dressing, such as Aquaguard<sup>®</sup>, to shower while your catheter is in place. Your discharge kit will have waterproof covers. You can also buy them online.

Each time you shower, cover your Tegaderm dressing completely with a new waterproof cover to keep it from getting wet. To put on the waterproof cover:

- 1. Peel off the top and side strips.
- 2. Place the top edge above your dressing. Do not let the tape on the waterproof cover touch your Tegaderm dressing. It can lift your dressing when you remove the waterproof cover after showering. Smooth the cover down over your dressing.
- 3. Peel off the bottom strip. Make sure 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. Smooth the bottom edge down.

Do not shower for longer than 15 minutes. Use warm water, not hot water. This will help keep the waterproof cover from coming off.

Dry the waterproof cover before you take it off. After your shower, fully dry the connection sites.

#### Use an antiseptic skin cleanser, such as Hibiclens

Wash with an antiseptic skin cleanser, such as Hibiclens, every day while your tunneled catheter is in place. An antiseptic kills germs and bacteria.

Hibiclens comes in liquid form or as wipes. You can buy Hibiclens from any local pharmacy or online. Your care team will send you home with a small bottle when you leave the hospital.

Read *How to Shower Using 4% Chlorhexidine Gluconate (CHG) Solution Antiseptic Skin Cleanser* (www.mskcc.org/pe/chg\_solution) to learn more.

Do not submerge your catheter in water, such as in a bathtub, swimming pool or ocean. Watch *Showering While You Have a Central Venous Catheter (CVC)* (www.mskcc.org/pe/shower\_cvc) to learn more about showering with a tunneled catheter.

#### Use Hibiclens® skin cleanser

While your tunneled catheter is in place, keep your skin clean to lower your risk of infection. Wash with Hibiclens every day while your tunneled catheter is in place.

Hibiclens is a skin cleanser that kills germs for up to 24 hours after you use it. It has a strong antiseptic (liquid used to kill germs and bacteria) called chlorhexidine gluconate (CHG). Showering with Hibiclens will help lower your risk of infection. Hibiclens comes in liquid form or as wipes. Wash with Hibiclens every day while your tunneled catheter is in place.

You can buy Hibiclens from any local pharmacy or online. You will be sent home with a small bottle when you're discharged from the hospital.

#### Instructions for using Hibiclens

- 1. Use your normal shampoo to wash your hair. Rinse your head well.
- 2. Use your normal soap to wash your face and genital area. Rinse your body well with warm water.
- 3. Open the Hibiclens bottle. Pour some solution into your hand or a clean washcloth.
- 4. Move away from the shower stream to avoid rinsing off the Hibiclens too soon.
- 5. Rub the Hibiclens gently over your body from your neck to your feet. Don't put the Hibiclens on your face or genital area.
- 6. Move back into the shower stream to rinse off the Hibiclens with warm water.
- 7. Dry yourself off with a clean towel after your shower.
- 8. Do not put on any lotion, cream, deodorant, makeup, powder, or perfume after your shower.

#### Things to remember when using Hibiclens

- Do not use regular soap, lotion, cream, powder, or deodorant without talking with your nurse first. If you're in the hospital, your nurse might give you a lotion that you can use after using Hibiclens.
- Do not use Hibiclens on your head, face, ears, eyes, mouth, genital area, or on deep wounds. If you have a wound and are not sure if you should use Hibiclens on it, ask your doctor or nurse.
- Do not use Hibiclens if you're allergic to chlorhexidine.
- If your skin gets irritated or you have an allergic reaction when using Hibiclens, stop using it. Call your doctor.

# When to call your healthcare provider

Call your healthcare provider right away if:

- You have a fever of 100.4 °F (38 °C) or higher or chills.
- You have bleeding at your exit site. Your care team may need to change your dressing.
- You have pain or discomfort that gets worse.
- Your catheter breaks or leaks. Your care team may need to change your dressing and check your catheter site.
- Your Tegaderm dressing gets damaged, loose, dirty, or wet. Your care team will need to change your dressing and check your catheter site.
- You have redness, tenderness or pain, leakage or drainage, swelling, or bleeding around your catheter exit site.
- Your needleless connector falls off.
- You have any questions or concerns about your catheter.

If you have any questions, contact a member of your care team directly. If you're a patient at MSK and you need to reach a provider after 5 p.m., during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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PATIENT & CAREGIVER EDUCATION

# Eating Well After Your Stem Cell Transplant

This information will help you plan your diet after your stem cell transplant. It explains how to avoid foodborne illness, get enough calories and proteins from your diet, and manage side effects using your diet.

# **Food Safety After Transplant**

# What is foodborne illness?

Foodborne illness (often called food poisoning) is an illness that comes from a food you eat.

Sometimes, bacteria, viruses, or parasites attach to food and grow. You can't always see, smell, or taste them. When certain bacteria, viruses, or parasites contaminate (get into) the food you eat, they can cause foodborne illness.

#### Who is at risk?

Foodborne illness can happen to anyone, but some people are more likely to get it than others. For example, people who have a weakened immune system from cancer and cancer treatment are at higher risk of getting a foodborne illness.

Some people (such as people who've had a stem cell transplant) may need to take extra steps to avoid foodborne illness. Your healthcare team will tell you if this applies to you.

# What are the symptoms?

Foodborne illness usually happens within 1 to 3 days after eating the contaminated food. But, it can also happen within 20 minutes or up to 6 weeks later. Symptoms of foodborne illness include:

- Vomiting (throwing up)
- Diarrhea (loose or watery bowel movements (poop))
- Pain in your abdomen (belly)
- Flu-like symptoms (such as fever above 101.3 °F (38.5 °C), headache, body aches, and chills)

If you have any of these symptoms, contact your healthcare provider right away.

# What steps can I take to prevent foodborne illness?

It's important to handle food safely to lower your risk of getting a foodborne illness. Foodborne illness can be serious or even fatal.

To help keep yourself safe from foodborne illness, follow these 4 simple steps: **clean**, **separate**, **cook**, and **chill**.



#### Clean

Clean your hands and surfaces often.

- Wash your hands with warm water and soap for at least 20 seconds:
  - Before and after handling food.
  - After using the bathroom, changing diapers, handling garbage, or handling pets.
- Wash cutting boards, dishes, utensils (forks, spoons, and knives), and countertops with hot soapy water after preparing each food item.
- Use a glass or plastic cutting board instead of a wooden one. Glass and plastic are easier to clean.

- Use paper towels to clean up kitchen surfaces, if you can. Bacteria, viruses, and parasites can grow on wet or dirty cloth towels and sponges.
  - If you use cloth towels, wash them often using hot water.
  - If you use a sponge, squeeze out all the water after each use. Replace it every 2 weeks.
- Use an antibacterial cleaning spray to clean surfaces. Look for products that have bleach or ammonia (such as Lysol® or Clorox®).
- Rinse all produce (such as fruits and vegetables) under running water. This includes pre-washed salad greens and produce with skins and peels that aren't eaten (such as bananas and avocados). Scrub firm produce (such as melons, oranges, and lemons) to clean them.
  - o If you use a produce brush, clean it every 2 to 3 days by putting it in your dishwasher or washing it with hot, soapy water.
- Avoid produce that has bruises or blemishes.
- Clean the lids of canned goods before you open them.



Separate
Separate raw meats from other foods.

- Put raw meats, poultry, and seafood into individual bags in your shopping cart and grocery bags. This will keep any liquids that leak from getting onto other foods.
- In your refrigerator, don't store raw meats, poultry, or seafood above produce and other foods that you don't cook before eating.
- Use one cutting board for produce and a separate one for raw meats, poultry, and seafood.
- Never put cooked food on a plate that previously held raw meat, poultry, seafood, or eggs unless the plate has been washed in hot, soapy water.
- Don't reuse marinades used on raw meats, poultry, or seafood unless you heat them to a boil first.



Cook to the right temperature.

- Use a food thermometer to check the internal temperature of meat, poultry, seafood, and egg products when you're cooking them. These foods must be cooked to a certain temperature to destroy any harmful bacteria. This is called the safe minimum internal temperature.
- Color and texture can help you know when foods are cooked, but they're not reliable ways to tell if the food is cooked enough to be safe. The best way is to use a food thermometer.
- Cook eggs until the yolk and white are firm. Only use recipes in which eggs are cooked or heated thoroughly.
- When cooking in a microwave oven, cover, stir, and turn the food to make sure it's cooked evenly. If the microwave doesn't have a turntable, rotate the dish by hand once or twice during cooking. Always wait about 10 minutes after the food is done before checking the food's internal temperature with a food thermometer. This lets the food finish cooking.
- When reheating sauces, soups, or gravy, heat them to a boil.
- Eat reheated leftovers within 1 hour.
- Don't reheat leftovers more than once. If you don't finish the food that you reheated, throw it away. Don't put it back in the refrigerator.

Safe Minimum Internal Temperatures			
Beef, pork, veal, and lamb (steaks, roasts, and chops)	145 °F (63 °C) with a 3-minute rest time		
Beef, pork, veal, and lamb (ground)	160 °F (71 °C)		
Poultry (including chicken, turkey, and duck)	165 °F (74 °C)		
Egg dishes and sauces	160 °F (71 °C) or until the yolk and white are firm (not runny)		

Fish and shellfish	145 °F (63 °C) and flesh is opaque (not seethrough)		
Leftovers and casseroles	165 °F (74 °C)		



**Chill**Chill foods promptly.

- Make sure the refrigerator temperature is 40 °F (4 °C) or below and the freezer temperature is 0 °F (-18 °C) or below.
- Refrigerate or freeze meat, poultry, eggs, seafood, and other perishables (foods that can go bad) within 1 hour of cooking or buying them.
- When it's hot out, use an insulated bag or cooler with ice or frozen gel packs to bring perishables home after shopping.
- Never defrost food at room temperature (such as on the countertop). Defrost food in the refrigerator, in cold water, or in a microwave. If you use cold water or a microwave, cook the food right away once it's defrosted.
- When you marinate food, always marinate it in the refrigerator.
- Divide large amounts of leftovers into shallow containers before refrigerating them. This helps them cool more quickly.
- Eat leftovers within 2 days.

# Are there any foods I should avoid?

Some foods are more likely to cause a foodborne illness than others. It's best to avoid these foods. Examples include:

- Raw or undercooked meat, poultry, seafood (including sushi), eggs, and meat substitutes (such as tempeh and tofu)
- Unpasteurized or raw milk, cheese, other dairy products, and honey
- Unwashed fresh fruits and vegetables
- Raw or uncooked sprouts (such as alfalfa and bean sprouts)

• Cold or uncooked deli meats (cold cuts) and hot dogs

Some other foods aren't as risky as the ones above but still have a risk of causing a foodborne illness. Examples are listed in the table below. You can decide if you want to eat or avoid these foods. Your clinical dietitian can help you decide. You may want to be more cautious during the first 3 months after your transplant.

Food Group	Food Items
Milk and dairy	<ul> <li>Unrefrigerated milk, cheese, and other dairy products.</li> <li>Cheese sliced at a deli counter. Choose sealed, pre-packaged cheese instead.</li> <li>Unrefrigerated desserts or pastries with cream fillings or frosting. Choose packaged, shelf-stable products instead.</li> <li>Soft-serve ice cream, soft-serve yogurt, and ice cream scooped at a restaurant.</li> </ul>
Meat, poultry, seafood, and eggs	<ul> <li>Meat sliced at a deli counter. Choose sealed, pre-packaged deli meat instead.</li> <li>Raw or partially cooked fish and shellfish, including caviar, sashimi, sushi, ceviche, and cold smoked seafood (such as lox).</li> <li>Clams, mussels, and oysters in the shell.</li> <li>Refrigerated pâtés and meat spreads.</li> </ul>
Fruits and vegetables	<ul> <li>Blemished or bruised produce.</li> <li>Salads and produce from a deli or salad bar.</li> <li>Raw or frozen rough-textured fruits and vegetables that can't be washed well (such as strawberries, raspberries, blackberries, broccoli, and cauliflower). These are safer if cooked.</li> <li>Pre-cut fruits and vegetables.</li> <li>Vegetarian sushi, unless you make it yourself at home. Vegetarian sushi made at a store or restaurant may be prepared near raw fish.</li> </ul>
Drinks	<ul> <li>Unpasteurized eggnog, apple cider, or other fruit or vegetable juices.</li> <li>Fresh-squeezed fruit or vegetable juices, unless you make it yourself at home.</li> <li>Unpasteurized beer and wine (such as microbrewery beers and those that aren't shelf-stable). Talk with your doctor before having any alcohol.</li> <li>Fountain soda and other fountain drinks.</li> </ul>

	Water from a water fountain or other shared container.
Nuts and grains	Unroasted nuts in the shell.
Miscellaneous	<ul> <li>Herbal and nutritional supplements, including probiotic supplements.</li> <li>Shared containers used by many people (such as condiments and milk at a coffee shop).</li> <li>Any unpackaged, communal, or shared food items (such as free samples).</li> </ul>

# How can I shop safely?

- Check containers for an expiration date. Buy and use food before that date.
- Don't buy canned, jarred, or boxed foods with dents, swelling, or a broken
- seal. Don't buy foods from self-service bulk containers or bins.
- Pick up cold and frozen foods (such as milk and frozen vegetables) at the
  end of your shopping trip. This helps limit the time they will be outside of a
  refrigerator or freezer.
- If you need to make a stop after grocery shopping, put perishable foods in an insulated bag or cooler with ice or frozen gel packs.
- Put eggs and milk on a shelf inside the refrigerator. Don't store them in the refrigerator door. The inside of the refrigerator stays cooler than the door area.
- If you use a grocery delivery service, make sure all refrigerated and frozen items are at a safe temperature when they're delivered. Put these items into the refrigerator or freezer right away.

#### Can I eat at restaurants?

Most people should avoid eating at restaurants for about 3 months after their stem cell transplant. Talk with your medical team about when it's safe to eat at restaurants.

Once your healthcare team says you can start eating at restaurants, follow the guidelines below to lower your risk of getting a foodborne illness.

- Choose the restaurant carefully. You can see a restaurant's recent health inspection score by visiting the local Department of Health (DOH) website.
- Order food that's properly cooked. Send back any meat, poultry, fish, or eggs that are undercooked. Food that's steaming hot is usually safer than room temperature and cold foods (such as sandwiches and salads).
- Refrigerate any leftovers within 2 hours of eating out. Reheat them until they're steaming hot (165 °F) and eat them within 2 days.
- Avoid foods that may have raw, unpasteurized eggs (such as Caesar salad dressing, fresh mayonnaise or aioli, and hollandaise sauce).

Some restaurant foods are riskier than others. These include:

- Foods from buffets and salad bars.
- Food that isn't cooked to order (such as fast food and other foods stored under heat lamps).
- Containers used by many people (such as condiments and milk at a cafe).
- Any food handled by employees without gloves or utensils.

Take-out food, delivery food, and food from food trucks can also be riskier because food may not be kept hot or cold enough during transit.

# Can I take dietary supplements?

Don't take any supplements, probiotics, homeopathic remedies, or herbal products (such as St. John's wart or traditional Chinese medicines) without talking with your Memorial Sloan Kettering (MSK) medical team first.

In the United States, the way these products are made and stored isn't regulated. This means they may pose a health risk, such as infection or foodborne illness. Dietary supplements can also keep some medications from working as well as they should.

# Is my drinking water safe?

Tap water from most highly populated areas (including New York City) is safe to drink. If you're not sure if the tap water is safe, check with the local health department.

If you use well water that isn't routinely tested for bacteria, use bottled water or boil the well water before drinking it. To do this:

- Bring the water to a rolling boil for 15 to 20 minutes.
- Store the water in the refrigerator.
- Don't drink any water that you don't use within 48 hours (2 days).
- Never drink from lakes, rivers, streams, or springs.

# **General Nutritional Guidelines**

Your body needs a balance of calories and protein to work its best. The tips in this section will help you increase the calories and protein in your diet.

These suggestions may be different from the general nutrition guidelines you already know. Your clinical dietitian nutritionist can help you find an eating plan that works best for you.

# Tips for adding more calories to your diet

- Don't eat foods that are fat-free or reduced in fat. Avoid food and drink labels that say "low-fat," "non-fat," or "diet." For example, use whole milk instead of skim.
- Snack on dried fruits, nuts, or dried seeds. Add them to hot cereals, ice cream, or salads.
- Add butter, margarine, or oils to potatoes, rice, and pasta. You can also add them to cooked vegetables, sandwiches, toast, and hot cereals.
- Use high-calorie dressings on salads, baked potatoes, and chilled cooked vegetables (such as green beans or asparagus).

- Add sour cream, half and half, or heavy cream to mashed potatoes and cake and cookie recipes. You can also add it to pancake batter, sauces, gravies, soups, and casseroles.
- Use mayonnaise, creamy salad dressing, or aioli sauce in salads, sandwiches, and vegetable dips.
- Top your ice cream or unfrosted cakes with sweetened condensed milk.

  Mix the condensed milk with peanut butter to add more calories and flavor.
- Drink homemade shakes and other high-calorie, high-protein drinks (such as Carnation® Breakfast Essentials or Ensure®).

# Tips for adding more protein to your diet

- Eat foods that are rich in protein, such as chicken, fish, pork, beef, lamb, eggs, milk, cheese, beans, and tofu.
- Add powdered milk to creamy soups, mashed potatoes, milkshakes, and casseroles.
- Snack on cheese or nut butters (such as peanut butter, cashew butter, and almond butter) with crackers, fruits, or vegetables (such as apples, bananas, and celery).
- Blend nut butter into your shakes.
- Add cooked meats to soups, casseroles, salads, and omelets.
- Add wheat germ or ground flax seeds to cereals, casseroles, yogurt, and meat spreads.
- Add grated cheese to sauces, vegetables, and soups. You can also add it to baked or mashed potatoes, casseroles, and salads.
- Add chickpeas, kidney beans, tofu, hard-boiled eggs, nuts, and cooked meats or fish to your salads.

# Managing Symptoms and Side Effects with Nutrition

# **Early Satiety**

Early satiety is when you feel full more quickly than usual. For example, you may feel like you can't eat any more when you're only halfway through your meal.

If you feel full quickly, try to:

- Eat small, frequent meals. For example, have 6 small meals instead of 3 large ones.
- Drink most of your liquids before or after meals.
- Choose foods that are higher in calories and protein when making meals.
- Do light physical activity (such as walking). This helps food move through your digestive system.

#### Nausea

Nausea (feeling like you're going to throw up) can be caused by radiation therapy, chemotherapy, and surgery. It can also be caused by pain, medication, and infection.

If food odors (smells) make you nauseated:

- Try cold foods (such as a sandwich or salad). Cold foods don't smell as strong as hot foods.
- Leave the area while hot foods are cooking, if you can.
- Ask someone else to plate your food for you.
- Let your food cool down for a few minutes before eating.
- Avoid places with strong odors.

The following tips may also help you avoid nausea:

• Eat small, frequent meals. This can stop you from getting too full and

help you eat more food throughout the day.

- Drink most liquids between your meals, not with them. This can help you avoid feeling full too fast or feeling bloated.
- Eat slowly and chew your foods well. Avoid moderate or intense physical activity right after meals.
- Eat your meals in a pleasant setting. Choose a relaxing place with a comfortable temperature. Wear loose-fitting clothing to stay comfortable.
- Eat with friends or family. This may help distract you from your nausea.
- Avoid foods that are:
  - High-fat, such as fatty meats, fried foods (such as eggs and French fries), and soups made with heavy cream
  - Very spicy, such as foods made with heavy spices
  - Very sweet

#### Diarrhea

Diarrhea is frequent, loose, watery bowel movements. It causes food to move quickly through your intestines.

- Drink at least 8 to 10 (8-ounce glasses) of liquids daily. This will help replace the water and nutrients you lose when you have diarrhea.
- Avoid foods that are very hot, very cold, high-sugar, high-fat, or spicy.

  These are hard on your digestive system and may make your diarrhea worse.
- Avoid raw fruits and vegetables, whole nuts, and seeds and vegetables that can cause gas (such as broccoli, cauliflower, cabbage, beans, and onions).
- Choose fruits and vegetables that are well-cooked, peeled and puréed, or canned.

# Constipation

Constipation is having fewer bowel movements than usual. Constipation can be caused by many things, including your diet, activity, and lifestyle. Some chemotherapy and pain medications can also cause constipation.

If you're constipated, try eating more high-fiber foods. Add fiber to your diet one food at a time. Examples of high-fiber foods include:

- Fruits
- Vegetables
- Whole grains (such as whole-grain cereals, pastas, muffins, breads, and brown rice)
- Nuts and seeds

Be sure to drink enough liquids to prevent gas and bloating. Try to drink at least 8 to 10 (8-ounce) glasses of liquids per day. This will help keep your bowel movements soft.

# Dry or sore mouth

When your mouth is dry or sore, eating can be hard or painful. Some foods may be hard to chew and swallow. The way you eat can make a difference.

- Cook your foods until they're soft and tender. Use a blender to purée foods. Ask for a copy of the resource *Eating Guide for Puréed and Mechanical Soft Diets* (www.mskcc.org/pe/pureed mechanical soft diets) for more tips.
- Cut your foods into small pieces that are easy to chew.
- Rinse your mouth with water often.
- Drink liquids with your meals. Take small sips between bites.
- Use a straw when you drink. This will keep the liquid from touching your sore mouth.
- If you have dry mouth, try sugar-free mints or gum. This will help you make more saliva.

# Taste changes

Chemotherapy, radiation therapy, and some medications can change your sense of taste. Changes in taste be different from person to person.

If your food seems tasteless, use more spices and flavorings (unless they cause discomfort). For example:

- Add sauces and condiments (such as soy sauce or ketchup) to your food.
- Marinate your meats or meat substitutes in salad dressings, fruit juices, or other sauces.
- Use onion or garlic to flavor your vegetables or meats.
- Add herbs (such as rosemary, basil, oregano, and mint) to your food.

If there's a bitter or metallic taste in your mouth:

- Rinse your mouth with water before meals.
- Maintain good oral hygiene (keep your mouth clean) by:
  - Brushing your teeth (if your doctor says it's okay)
  - Brushing your tongue
  - o Drinking more liquids to stay hydrated
- If meats taste bitter, try marinating them in sauces or fruit juices or squeeze lemon juice on them, if your mouth isn't sore.
- Get some of your protein from meat substitutes (such as dairy products and beans).
- Use plastic utensils to reduce the metallic taste.
- Try sugar-free mints or gum.

# **Fatigue**

Fatigue is feeling more tired or weak than usual. It's the most common side effect of cancer and cancer treatments. Fatigue may keep you from doing your daily activities. It can be caused by many things, such as:

- Poor appetite
- Depression
- Nausea and vomiting
- Diarrhea or constipation

Managing these things can give you more energy and help you feel less fatigued. It can also increase your feeling of well-being. Your healthcare team can help you.

Saving your energy can also help you feel less fatigued. You can do this by:

- Asking family and friends for help with shopping and making your meals.
- Buying premade or takeout foods when your energy is low.
- Keeping ingredients and utensils that you use often close at hand.
- Sitting instead of standing when cooking.
- Eating small, frequent, high-calorie meals or snacks. This may help your body need less energy to digest your food.

Often, doing physical activity may actually increase your energy levels. It can also make it easier to do your usual daily activities, increase your appetite, and help you be in a better mood. Talk with your doctor about doing light-to-moderate intensity activities, such as walking or gardening.

If you live alone and can't shop for food or make meals, you may be eligible for food programs, such as God's Love We Deliver or Meals on Wheels. There may be age or income requirements for some programs. Your social worker can give you more information.

If you have any questions, contact a member of your healthcare team directly. If you're a patient at MSK and you need to reach a provider after 5:00 PM, during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit <u>www.mskcc.org/pe</u> to search our virtual library.

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#### PATIENT & CAREGIVER EDUCATION

# Hair Loss and Your Cancer Treatment

This information will help you understand hair loss during cancer treatment.

# **About hair loss and your cancer treatment**

Many people with cancer lose their hair because of chemotherapy (chemo), immunotherapy, endocrine therapy, or radiation to the head. There are also other causes of hair loss. These are:

- Having a family history of hair loss
- Being low in certain vitamins
- Going through hormonal changes
- Having certain medical conditions, such as hypothyroidism (HY-poh-THY-roy-dih-zum). This is when your thyroid gland does not make enough hormones.
- Having different hairstyles
- Taking certain medicines
- Being stressed

If you're starting to lose your hair, it's important to see your dermatologist (skin doctor). They can help you figure out the reason for your hair loss. They can also answer any questions you may have about your hair. Your dermatologist will ask about your history of hair loss. They will also look at the areas where you're losing your hair.

# **Commonly asked questions**

# Why will I lose my hair during cancer treatment?

Cancer treatments, such as radiation and chemo, attack fast-growing cancer cells. These treatments can also affect normal cells that grow fast, such as hair cells.

Chemo can cause hair loss on your scalp, pubic area, arms, legs, eyebrows, and eyelashes. Radiation therapy to your head often causes hair loss on your scalp. Sometimes, your hair may grow back different from how it looked before. Or, it may not grow back at all. This depends on the dose of radiation to your head.

# When will I start to lose my hair?

You may start to see your hair thin or fall out:

- 1 to 4 weeks after your first chemo treatment.
- 4 weeks after you have radiation therapy.

The amount of hair that falls out or thins depends on the type, dose, and timing of your treatments. The speed at which it falls out is different from person to person. You may first notice hair on your pillow in the morning. Or, you may see it when you shower or brush your hair.

Some people will have hair thinning rather than hair loss. Hair thinning is when your hair feels and looks thinner in texture. Talk with your care team about what to expect after your chemo or radiation therapy.

# When will my hair grow back?

Once your treatments end, your hair should start to grow back. Hair regrowth can take 3 to 5 months. When your hair grows back, it may have a different texture or color. In rare cases, your hair will not grow back as fully as it did before.

There is a very small chance that your hair will not grow back after radiation therapy to your head.

# Caring for your hair and head

Here are some ways you can care for your hair and head while you're having hair loss:

- Wash and condition your hair every 2 to 4 days. Use baby shampoo or other mild shampoo (such as Aveeno® or Vanicream™). You should also use a cream rinse or hair conditioner.
- Use shampoos and conditioners that have sunscreen to prevent sun damage to your scalp.
- Always rinse your hair well and pat it dry with a soft towel.
- Wash your hair after swimming in a pool.
- Do not expose your scalp to the sun.
- 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 catch falling hair.
- Sleep on a satin or silk pillowcase. These are smoother than other fabrics and can reduce hair tangles.
- Brush or comb your hair gently with a soft-bristle brush or comb. Start brushing or combing your hair at the ends and gently work your way up to your scalp. You can also comb through your hair with your fingers. Wet your fingers with water first.
- If your hair is long, you may want to cut it short before you start treatment.
- Tell your hairdresser that you're getting chemo. They may be able to recommend gentle hair products.
- Try using a camouflaging hair powder (such as Bumble and bumble™
   Hair Powder or Toppik™ Hair Building Fibers or Spray). It can help cover
   bald spots and thinning areas of your hair. You can buy it at Sephora® or
   online from beauty supply websites.

Limit use of the following on your hair during treatment. They can be too harsh or pull on your hair:

- Hair spray, hair dye, bleach, or permanents (perms)
- Clips, barrettes, bobby pins, ponytail holders, or hair ties (scrunchies)
  - Do not put your hair in braids, cornrows, or ponytails.
- Hair dryers, curlers, curling irons, or hair straighteners
- Rubber bathing or swimming caps

# Wigs, hairpieces, and head coverings Wigs

If you want to wear a wig, try to get one before your hair falls out. This will make it easier to find a wig that matches your hair color and hairstyle. If you already have hair loss, bring a photo of your usual hairstyle. Bring a lock of your hair too, if you can. This will help you find a wig that looks like your hair did before your treatment started.

A wig should fit well, be comfortable, and be easy to care for. You may want to start wearing your wig as soon as your hair starts 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. Here is a list of the most common types:

#### **Custom-made wigs**

Custom-made wigs are made by hand and are often the most expensive type of wig. These wigs are made using your specific head measurements. You may have to visit the wig store a few times to get your wig colored, cut, and cleaned. Custom-made wigs are often made of human hair but can be made of synthetic (not human) materials.

### **Customized ready-made wigs**

Customized ready-made wigs can be made of human hair, synthetic blends, or a mix of both. They are made in standard sizes but can be adjusted to fit your head. These wigs can be styled and often cost less than a custom-made wig.

### Ready-made or stock wigs

Ready-made or stock wigs are often made from a stretchy material and come in 1 size. Most people can take a ready-made wig home the same day they buy it. Ready-made wigs are often the least expensive type of wig.

# **Hairpieces**

If you lose your hair in only 1 area, you may want to buy a hairpiece rather than a wig. A hairpiece will blend into your own hair. It can be made in any size, color, or shape.

# **Head coverings Scarves, turbans, and hats**

- Scarves, turbans, and hats can help hold hair that is falling out and hide a bald scalp.
- Scarves made from silk can easily slide off your head. You may want a scarf made of a cotton blend because they can be more comfortable.
- Turbans are sold in many drug stores and come in many different colors and textures.
- You can also wear a hat with or without scarves.

To learn more about where to buy wigs and hairpieces, read *Where to Buy Wigs and Hairpieces* (www.mskcc.org/pe/wigs-hairpieces).

# Financial support

When shopping for a wig or hairpiece, you may want to shop around and compare prices. People who lose their hair from cancer treatment may have insurance coverage for a wig or hairpiece. Before you visit any stores or websites, ask your insurance company if:

- They will cover part of the cost of a wig or hairpiece.
- You need a prescription for a wig or hairpiece. If you do, ask your healthcare provider to write a prescription for a cranial prosthesis (KRAY-nee-ul pros-THEE-sis). The prescription should include a diagnosis code showing that your hair loss is due to treatment for cancer.

# Additional resources for financial support

**American Cancer Society (ACS)** 

www.cancer.org

Some ACS offices offer free wigs to people with cancer. To learn more, visit your local ACS office or call 800-ACS-2345 (800-227-2345).

#### Cancer Care

www.cancercare.org

Cancer *Care* offers free wigs to people with cancer. Call 800-813-HOPE (800-813-4673) and ask to speak with a social worker.

# The Look Good Feel Better program

The Look Good Feel Better program helps people cope with the effects that cancer treatment can have on their appearance. During weekly sessions, makeup artists teach makeup techniques, skin and nail care, and hair styling and head-covering options. To register for a class, visit www.lookgoodfeelbetter.org or call 800-395-LOOK (800-395-5665).

Males can find more information at www.lookgoodfeelbetter.org/programs/men

# Medicines and supplements for hair loss

Medicines and supplements for hair loss can slow hair thinning. They can also increase coverage of your scalp by growing new hair and enlarging existing hairs. Ask your healthcare provider for more information.

They will write their recommendations for you in the space below:		

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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PATIENT & CAREGIVER EDUCATION

# Hand Hygiene and Preventing Infection

This information explains how to clean your hands with soap and water or an alcohol-based hand sanitizer.

## Why is hand hygiene so important?

When germs get into your body, they can cause an infection. Everyone is at risk for an infection while in the hospital. Hand hygiene is the best way to prevent the spread of germs and infections. It only takes 20 seconds of washing your hands or using an alcohol-based hand sanitizer (such as Purell®) to kill the germs that cause infections. You can take action by cleaning your hands and asking your visitors to clean their hands.

## When should I clean my hands with soap and water?

- After using the toilet, urinal, or bedside commode.
- If your hands look dirty.
- Before you eat or prepare food.
- If you have an infection with the germ *Clostridium difficile* (*C. diff*) or norovirus.
- After vomiting (throwing up) or coughing up phlegm (mucus).

## What is the correct way to clean my hands with soap and water?

- 1. Wet your hands with warm water. Use liquid soap, if possible. Apply enough soap to cover both of your hands.
- 2. Rub your hands together until a lather forms. Rub the lather over the top of your hands, between your fingers, and in the area around and under your fingernails.
- 3. Keep rubbing your hands for at least 20 seconds.
- 4. Rinse your hands well under warm running water.
- 5. Dry your hands with a paper towel.
- 6. Use a dry paper towel to turn off the faucet and to open the bathroom door, if needed.



Please visit www.mskcc.org/videos/how-wash-your-hands-properly to watch this video.

## When should I clean my hands with an alcohol-based hand sanitizer?

- If soap and water aren't available.
- When you leave your hospital room and when you come back.
- Before eating.

If you can't get out of bed, you can use an individually packaged hand wipe.

## What is the correct way to clean my hands with an alcohol-based hand sanitizer?

- 1. Apply enough sanitizer to cover both of your hands.
- 2. Rub your hands together, and then rub the sanitizer over the top of your hands, between your fingers, and in the area around and under your fingernails.
- 3. Keep rubbing until your hands are dry. If enough sanitizer was used to kill

germs, it should take at least 20 seconds of rubbing before your hands feel dry. Don't rinse your hands with water or dry them with a towel.

## Where can I get more information about hand hygiene?

If you have questions, talk with your doctor or nurse. You can also visit the following website for more information:

**Worl d Health Organization (WHO)** 

www.who.int/gpsc/5may/Hand\_Hygiene\_When\_and\_How\_Leaflet.pdf

### When to Call Your Healthcare Provider

Call your healthcare provider if you have any of the following:

- A fever of 100.4° F (38° C) or higher
- A temperature of 96.8° F (36° C) or lower
- New or worsening chills or sweating
- New or worsening redness around a wound
- New or increased drainage from a wound
- New or worsening shortness of breath or trouble breathing
- A heartbeat that is faster than usual
- New or worsening cough
- New or worsening pain

If you have any questions, contact a member of your healthcare team directly. If you're a patient at MSK and you need to reach a provider after 5:00 PM, during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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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's common for people to feel changes in their body during and after cancer treatment. There may be things you can see right away, like surgical scars, drainage tubes, and catheters (thin, flexible tubes). You may have changes to your body, such as losing your hair, changes in your weight, pain, or fatigue (feeling more tired or weak than usual).

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 in sexual activities.

Here are some suggestions and resources to help you adjust and cope during this time.

## **Managing Your Feelings**

During and after your cancer treatment, you may feel different. To help you deal with this, it's important to talk about how you feel. Family and friends can help. Your nurse, doctor, and social worker can reassure, support, and guide you. Here are some ways you can manage your feelings during and after cancer treatment:

- Figure out what you enjoy about yourself or what things 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.
- Take part in an online or in-person "Look Good Feel Better" program. See the section External Resources" for more information.

## Maintain 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 with them 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.
- Try being intimate at times when you have more energy.
- Being relaxed can help with sexual enjoyment. Select a time and place when you can relax and have privacy.
- If sex is difficult or uncomfortable:
  - Try different sexual positions. Some may be less tiring or more comfortable.
  - Vaginal moisturizers and lubricants can be helpful for women. For more information, read the resource *Improving Your Vulvovaginal Health* (www.mskcc.org/pe/improving vulvovaginal health). You can find it online, or you can ask your nurse.
  - Medications to help with erections (getting hard for sex) can be helpful for men. Talk with your healthcare provider for more information.

### Special points related to sexual activity

The following are special factors you should think about before starting sexual activity during or after your cancer treatment:

- Ask your healthcare provider if there are any safety measures you should use for different types of sexual activity (such as oral, anal, or vaginal sex).
- Ask your healthcare provider if your blood cell counts are high enough for you to have safe sex.

- Your white blood cell count should be high enough to prevent infection.
- o Your red blood cell count should be high enough to prevent bleeding.
- Use a condom to protect yourself from sexually transmitted infections (STIs), including HIV, especially if you have more than 1 partner.
- If there's any chance you or your partner can become pregnant, use birth control (contraception) during your cancer treatment. If you have any questions about birth control, or for help deciding the type of birth control that's right for you, talk with your healthcare provider.
- Ask your healthcare provider how long you should use birth control after your cancer treatment is over.
- Some cancer treatments may affect your fertility (the ability to become pregnant with a biological child). If you have questions about this, ask your healthcare provider.

For more information, read *Sex and Your Cancer Treatment* (www.mskcc.org/pe/sex cancer treatment).

## Talk With Your Healthcare Provider if:

- You have vaginal dryness or tightness that makes sexual activity painful. Simple solutions such as vaginal lubricants or moisturizes can help.
  - You can also ask for a referral to our Female Sexual Medicine and
     Women's Health Program. Call 646-888-5076 to make an appointment.
- You have trouble getting or keeping an erection (erectile dysfunction) or have a low testosterone hormone level. Your healthcare provider can recommend medication that may help.
  - You can also ask for a referral to our Male Sexual and Reproductive Medicine Program. Call 646-888-6024 to make an appointment.
- You have emotional issues affecting your sexual health, such as having a low desire to have sex.
  - You can also ask for a referral to our Female Sexual Medicine and Women's

Health Program or our Male Sexual and Reproductive Medicine Program.

- You have accidental leakage of urine (pee) or bowel movements (poop). This is called incontinence. Your healthcare provider can give you a referral to the Sillerman Center for Rehabilitation or call 646-888-1900 to make an appointment.
- You have any questions or concerns.

## **MSK Support Services**

### Female Sexual Medicine and Women's Health Program

646-888-5076

Our <u>Female Sexual Medicine and Women's Health Program</u> helps women who are dealing with cancer-related sexual health issues. For more information, or to make an appointment, call 646-888-5076.

#### Male Sexual and Reproductive Medicine Program

646-888-6024

Our <u>Male Sexual and Reproductive Medicine Program</u> helps men who are dealing with cancer-related sexual health issues. For more information, or to make an appointment, call 646-888-6024.

#### Sillerman Center for Rehabilitation

646-888-1900 515 Madison Avenue (Entrance on East 53<sup>rd</sup> Street, between Park and Madison Avenues) New York, NY 10022

Some types of cancer and treatments can damage your pelvic muscles (muscles that support your pelvic organs (uterus, bladder, and bowel). This can cause back and pelvic pain and urinary or fecal incontinence. If you're having these problems, ask your healthcare provider for a referral.

### **Counseling Center**

646-888-0200

641 Lexington Avenue, 7th Floor (on East 54th Street between Third

and Lexington Avenues) New York, NY 10022

Many people find that counseling helps them manage their feelings. We provide counseling for individuals and couples to help you process any issues and work with you to solve problems. Your partner can attend these sessions with you, if you would like.

### **External Resources**

#### **American Cancer Society (ACS)**

#### www.cancer.org

800-ACS-2345 (800-227-2345)

The ACS has free booklets on cancer and sexual health called *Sex and the Adult Male With Cancer* and *Sex and the Adult Female With Cancer*. You can search for them on <a href="https://www.cancer.org">www.cancer.org</a> or call to request printed copies.

#### **Look Good Feel Better Program**

www.lookgoodfeelbetter.org

800-395-LOOK (800-395-5665)

This program offers workshops to learn things you can do to help you feel better about your appearance. For more information or to sign up for a workshop, call the number above or visit the program's website.

### **National Cancer Institute (NCI)**

#### www.cancer.gov

Visit the NCI's website to learn more about sexual health and cancer.

If you have any questions, contact a member of your healthcare team directly. If you're a patient at MSK and you need to reach a provider after 5:00 PM, during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit <a href="www.mskcc.org/pe">www.mskcc.org/pe</a> to search our virtual library.

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## **Glossary**

This glossary explains terms that you may read in this guide or hear from your transplant 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're 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're 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. For example, a tube to drain urine.

**Central venous catheter** - A thin, flexible tube that's put 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 put 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 happens 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's 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.

**HLA (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 happens 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 doesn't 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 (for example, 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, treatment of cancer.

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

**Orally** - By mouth; for example, a medication to be taken orally is one that's swallowed.

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

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

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

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

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

Palate - The roof of the mouth.

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

Pancreatitis - Inflammation (swelling) of your pancreas.

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

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

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

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

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

**Petechiae** - Tiny, localized hemorrhages from small blood vessels just below the surface of the skin. They are often caused by a low platelet count. They clear up as the platelet count increases.

**pH** - A symbol that means acidity or alkalinity. A solution of pH 7 is neutral. Below 7 is acidic and above 7 is alkaline. The urine is usually slightly acidic, with a pH of 5.3.

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

Pharynx - Your throat.

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

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

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

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

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

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

Pneumonia - Infection of the lung.

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

**Postop** - After surgery.

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

**Preop** - Before surgery.

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

**Prophylactic** - Treatment designed to prevent a disease or a complication that hasn't 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, such as, 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's 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 happen 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's 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's 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 (for example,

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 hasn't 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, such as, 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.