



Memorial Sloan Kettering
Cancer Center

PATIENT & CAREGIVER EDUCATION

CAR T Cell Therapy: A Guide for Adult Patients & Caregivers



To view this guide online, visit www.mskcc.org/pe/car_t_adult

Table of Contents

Welcome and Overview	4
The importance of communication	5
How to use this guide	6
Antigen and T cell basics	7
Understanding your autologous CAR T cell therapy	8
Getting Ready for Your CAR T Cell Therapy	9
Your initial consultation visit	9
Getting ready for your CAR T cell therapy	9
Your CAR T team	11
Your caregiver.....	13
Your pretreatment evaluation	17
Your preadmission appointment	19
Having your central venous catheter (CVC) placed.....	20
What to Expect in the Hospital	21
While you're in the hospital.....	21
What to Expect in the Cellular Immunotherapy Unit	24
What to bring to the Cellular Immunotherapy Unit.....	25
What to do in your home or apartment.....	25
Phases of CAR T Cell Therapy	28
Phase 1: T cell collection	29
Phase 2: T cell modification.....	30
Phase 3: Lymphodepleting chemotherapy (conditioning).....	31
Phase 4: CAR T cell infusion.....	31
Phase 5: Early recovery.....	33
Phase 6: Long term recovery	33

Welcome and Overview

This guide is designed to help you and your loved ones understand what to expect throughout your chimeric antigen receptor (CAR) T cell therapy. It isn't meant to replace conversations with your CAR T team. Your CAR T team will teach you about your therapy and what to expect. You can use this guide to help you remember and refer to it throughout the therapy process.

In this guide, we'll explain some of the challenges you might have over the course of your CAR T cell therapy and recovery. But that doesn't mean you'll have all of them. Try not to compare yourself to other people you know or have heard of who had CAR T cell therapy. Everyone is unique.

CAR T cell infusions can be done safely whether you're staying in the hospital (inpatient) or not staying in the hospital (outpatient). This guide has information about both inpatient and outpatient infusions. Your doctor will talk with you about whether an outpatient infusion is an option for you.

CAR T cell therapy is a long process. Getting ready for your infusion is just the first part of your journey.

- If you have an inpatient infusion, you'll be in the hospital 24 hours a day before, during, and for some time right after your infusion.
- If you have an outpatient infusion, you and your caregiver(s) will stay in an apartment near the hospital that's approved by your doctor or in a furnished apartment at MSK's 75th Street Patient Residence. You'll visit the outpatient Cellular Immunotherapy Unit every day before, during, and for some time right after your infusion.

These things will be discussed in more detail in this guide.

You'll have a large healthcare team working together to care for you as you go through each phase of your CAR T cell therapy. It's normal to have many emotional changes during your CAR T cell therapy process. Your CAR T team includes many providers, including social workers, chaplains, psychiatrists, and members of MSK's Integrative Medicine Service. 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

It's very important to communicate with your CAR T team and your caregiver about how you're feeling both physically and emotionally. If anything is bothering you, even if it seems small, tell a member of your CAR T team. Don't let things build up. If you do, small issues can become more of a problem. The more information you share with your CAR T team, the more they can help you.

Here are some of the ways you can communicate with your CAR T team.

Over the phone

Between 9:00 AM and 5:00 PM, call your doctor's office. After 5:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant.

If you're having an outpatient CAR T cell infusion, between 9:00 AM and 7:00 PM, call the Cellular Immunotherapy Unit at 646-608-3150. After 7:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant.

In person

If you're in the hospital, talk with any member of your inpatient healthcare team or ask to speak with the Charge Nurse, Clinical Nurse Specialist, or Nurse Leader. While you're inpatient, it's important to talk with your inpatient team, not call the outpatient office.

If you're in the hospital, you should also choose 1 caregiver to call the nursing station for updates. That person can share the information with the rest of your friends and family. You'll be given the nursing station phone number when you're admitted to the hospital.

Via MyMSK

MyMSK is MSK's patient portal. You can use it to check your appointment schedule, request a prescription refill, contact a healthcare provider, and find educational information.

How to enroll

Instructions for enrolling in MyMSK are printed on the bottom of your appointment print out. You can also read the resource *Communicating with Your Healthcare Team Using MyMSK*. You can ask a member of your CAR T team for a copy or find it online at www.mymaskcc.org/pe/communicating_using_mymask.

About PROMIS

Your CAR T 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 CAR T team will send PROMIS questions to your MyMSK account:

- On or near the day you start CAR T treatment.
- On the day of your CAR T cell infusion.
- Every 7 days for the first month after your CAR T cell infusion.
- Every month for the first year after your CAR T cell infusion.
- Every 3 months for the second year after your CAR T 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 CAR T team will call you to help. Your answers will also help us know how people generally feel after CAR T cell therapy so we can improve our care for the future.

How to use this guide

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

It's a good idea to highlight or write notes on anything you don't understand or have a question about. There's no such thing as a silly question. Please ask about anything that's on your mind.

Medical terms

We've done our best to limit the number of medical terms in this guide. If you don't understand a medical term, ask your healthcare provider. You can also search the National Cancer Institute (NCI) Dictionary of Cancer Terms at www.cancer.gov/publications/dictionaries/cancer-terms.

Antigen and T cell basics

About antigens

Antigens are substances that activate (turn on) your immune system. Your immune system helps your body fight infections and other diseases.

Antigens are found on the surface of some things made inside your body, such as cells. They're also found on the surface of some things from outside your body, such as bacteria and viruses (see Figure 1).

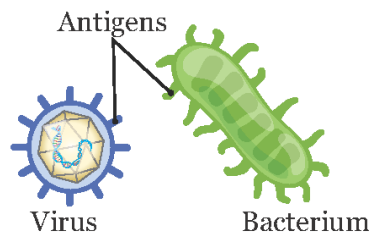


Figure 1. Antigens on a virus and bacterium

About T cells

T cells help your immune system tell which antigens don't belong in your body. T cells are a type of white blood cell (lymphocyte).

T cells have receptors that attach to certain antigens. Once a T cell attaches to an antigen, it sends messages to other cells in your immune system. These cells help kill the thing with the antigen and get it out of your body.

About chimeric antigen receptor (CAR) T cells

CAR T cells are T cells that have been genetically modified in a lab so they attach to antigens on cancer cells (see Figure 2). Once a CAR T cell attaches to the cancer cell, your immune system sends other types of immune cells to kill the cancer cell and get it out of your body.

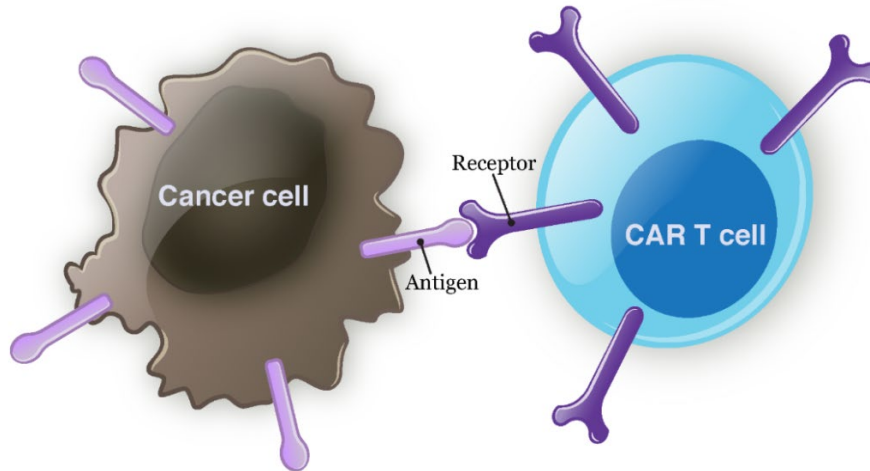


Figure 2. CAR T cell attaching to cancer cell

Understanding your autologous CAR T cell therapy

Autologous means “from yourself.” With autologous CAR T cell therapy, some of your T cells will be collected (harvested) from your blood. They’ll be sent to a lab to have a new gene added to them. This is called genetic modification. The new gene will help them find and kill cancer cells. Once the T cells have this new gene, they’re called CAR T cells.

Once the CAR T cells are ready, you’ll get low doses of chemotherapy. This will help get your body ready so the CAR T cells can work as well as possible. It isn’t done to kill cancer cells. Once your body is ready, the CAR T cells will be infused (put) into your bloodstream.

For more information about what to expect, read the section “Phases of CAR T Cell Therapy.”

Getting Ready for Your CAR T Cell Therapy

Your initial consultation visit

During your initial consultation visit, you'll meet with your doctor and other members of your CAR T team. Your doctor will review your medical and surgical history, do a physical exam, and talk with you about what they think is the best treatment plan for you. They might also discuss this plan with other CAR T doctors to make sure everyone agrees on the best plan for you.

Blood Donor Room appointment

You'll have an appointment in the Blood Donor Room to see if your veins are big enough for your T cells to be collected from a vein in your arm. If they aren't, a type of intravenous (IV) catheter called a leukapheresis (LOO-kuh-feh-REE-sis) catheter will be used for your T cell collection.

The donor room nurse will tell your healthcare team if you need a leukapheresis catheter. If you do, your healthcare team will give you more information. You can also read the section "Phase 1: T Cell Collection" for more information.

Getting ready for your CAR T cell therapy

After your initial consultation visit, you'll start making practical, physical, and emotional preparations for your CAR T cell infusion. Here's a list of things that will happen and things you might need to do to get ready.

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

Choose a caregiver. Identify a family member or friend who can act as your caregiver. Make sure they understand what the role involves. Give your caregiver a copy of this guide and ask them to read it at least once. Read the section "Your Caregiver" for more information.

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. This person is known as 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 CAR T team or read the resource *Advance Care Planning*. You can find it online at

www.mkscc.org/pe/advance_care_planning or ask a member of your CAR T team for a copy.

Meet with a social worker. Your social worker will explain the psychological, emotional, and financial support services offered at MSK.

Arrange for disability or a leave of absence from work. If you're working, decide if you want to go on disability or take a leave of absence. You should plan to be away from work for about 6 months. The exact length of time is different for everyone.

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

Have your pretreatment evaluation. You'll have a series of medical tests. Your clinical nurse coordinator will talk with you about which tests are needed. Your doctor's office coordinator will work with you to try to schedule these tests at a time that works well 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 talk about your diet and safe food handling guidelines. If you want to meet with a clinical dietitian nutritionist, ask your nurse for a referral.

Meet with a pharmacist. They'll go over all the medications you'll take before and after your CAR T cell therapy.

Coping with being away from your children

Whether you're having an inpatient or outpatient CAR T cell infusion, you'll probably spend more time away from your children than usual. Being away from your children will be hard for you and your family. We strongly recommend talking with your social worker about your concerns and making a plan to keep strong ties to your children during your treatment.

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

- 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 make other crafts to send home. Ask a member of your healthcare team to arrange for volunteers from the Patient Recreation Center to bring you supplies.
- Keep copies of your children’s favorite stories with you in your room. At night, you can use Skype to read along with them before they go to sleep.
- 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.
- 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 hard. Your caregiver can bring their work to you. You can talk with your children about them over Skype or on the phone.

We know nothing will replace physical contact between you and your children, but we strongly encourage you to use all 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 CAR T team

A team of healthcare providers will care for you throughout your CAR T cell therapy. You’ll meet many of them as you go through your CAR T cell therapy. You might not meet some members, such as your doctor’s office assistant, laboratory staff, or the CAR T cell service coordinator, but know that they’re all working to help you. Below is a list of your CAR T team members and their roles.

An **attending doctor** will be in charge of your care throughout your treatment. One specific doctor will be your primary outpatient doctor, but 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 care. They can give medical treatments and prescribe medications.

They may also sometimes see you instead of your doctor. **Nurse practitioners (NPs)**, **physician assistants (PAs)**, and **certified registered nurse anesthetists (CRNAs)** are all APPs.

A **clinical nurse coordinator** is a nurse who will communicate and work with you, your caregiver, and your doctors to organize and schedule the testing, procedures, and consultations you'll need before your infusion. They'll also teach you about your specific treatment plan.

Nurses will work with you during your outpatient visits and while you're in the hospital. They're registered nurses (RNs) who are trained to care for people having stem cell transplants and CAR T cell therapy. Each outpatient nurse works with 1 or more attending doctors. You'll meet your outpatient nurse during your initial consultation visit. They'll see you at many of your outpatient visits after discharge and will follow you along your CAR T cell journey. During your treatment (either inpatient or outpatient), you'll have a team of primary nurses who will care for you. The nurses work 12-hour shifts and try to maintain consistency with who will be working with you. Your nurses work closely with other members of your healthcare team to manage any symptoms you have. They can help you with any questions or concerns you have.

A **nursing assistant** or **patient care technician (PCT)** works with your nursing team to give basic care and support.

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 caring for people having stem cell transplants and CAR T cell therapy 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 going through CAR T cell therapy. Social workers understand the issues people having treatment may face. They're available to listen, offer counseling, and refer you or your loved ones to other resources and services.

A **CAR T cell service coordinator** will work with you and your insurance company to figure out what your treatment benefits are. They're familiar with the insurance issues people having CAR T cell therapy may face. Each insurance company has its own policies and requirements. When your insurance company needs authorization, your CAR T cell service coordinator will help with that process.

An **office coordinator** provides administrative support to attending doctors and outpatient nurses. You might speak with them when you submit information, are scheduling an appointment, or have questions for your CAR T team.

A **care coordinator** works in an outpatient area and keeps track of the flow of patients in and out of the clinic. They make sure all the tests, scans, and treatments your medical team orders are either completed or scheduled. Care coordinators also manage your medical records and coordinate your future appointments.

A **clinical research coordinator** works with your healthcare team. They'll talk with you and explain some of the research studies at MSK that you might be able to participate in. The studies mostly involve collecting samples or data.

A **patient representative** is a liaison between you, your family, 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 CAR T 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. The PT will work with you to help you keep up your strength and stamina during your recovery. The OT will work with you to help you keep doing your daily activities.

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

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

Your caregiver

Everyone having CAR T cell therapy benefits from having support from a caregiver before, during, and after their infusion. Caregivers are usually a family member or close friend. They need to be available to help with basic day-to-day medical and practical issues and provide emotional support.



If your caregiver gets sick or shows any signs of a cold or flu (such as a cough, fever, or sore throat) 1 week before or any time during your CAR T cell therapy, tell your CAR T team right away.

For outpatient CAR T cell infusions

You must have a clear caregiver plan to have an outpatient CAR T cell infusion. There are no exceptions. Your CAR T team will talk with you about this.

During your CAR T cell therapy, your caregiver must take you to and from your daily visits to the Cellular Immunotherapy Unit. They may not be able to work and will need to stay with you for most of the day and night. While you're in the Cellular Immunotherapy Unit for daily visits, your caregiver can take some personal time. We strongly recommend they do.

Your caregiver must be available 24 hours a day, 7 days a week during your treatment. Your CAR T team will give them specific instructions about what they need to do. Some of these responsibilities will include the following tasks.

Medical support

- Gathering information from your CAR T team.
- Making sure you take your medications.
- Keeping a written record of when you take your medications.
- Measuring your temperature every 4 hours while you're awake and away from the Cellular Immunotherapy Unit.
- Keeping a written record of your temperatures.
- Keeping a written record of how much you drink every day.
- Knowing how to take care of your central venous catheter (CVC).
- Noticing any changes in your condition.
- Telling your CAR T team about any changes in your condition or new symptoms you have.
- Calling for medical help in an emergency.

Practical support

- Taking you to and from your daily appointments.
- Dealing with financial and insurance issues.
- Handling food safely to prevent foodborne illness (food poisoning).
- Keeping the place you're staying clean.
- 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.

Emotional support

- Paying attention to your moods and feelings.
- Communicating with you and listening to you.
- Understanding your needs and your decisions.
- Feeling comfortable contacting your healthcare team if they're worried about your emotional state.

For an outpatient CAR T cell infusion, being a caregiver is a full-time, 24-hour, 7-day a week responsibility. It's tiring, demanding, and stressful, especially if your condition, schedule, or treatment changes. Your CAR T team will do everything they can to help your caregiver care for you. They can also refer your caregiver to other support services to help them manage their role.

For inpatient CAR T cell infusions

If you'll be admitted to the hospital for your CAR T cell infusion, it's important to have a caregiver plan for when you're discharged from the hospital. In general, we recommend that you have a full-time, 24-hour a day, 7-day a week caregiver for the first 2 weeks after discharge. The exact length of time you'll need 24/7 caregiver support may vary.

Your CAR T team will give your caregiver specific instructions about what they need to do. Some of these responsibilities will include the following tasks.

Medical support

- Making sure you take your medications.
- Making sure you're drinking enough and getting enough nutrition.

- Noticing any changes in your condition.
- Calling for medical help in an emergency.

Practical support

- Taking you to and from your daily visits at the hospital.
- Dealing with financial and insurance issues.
- Handling food safely when preparing your meals.
- Keeping the place you're staying clean.
- 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.

Emotional support

- Paying attention to your moods and feelings.
- Communicating with you and listening to you.
- Understanding your needs and your decisions.
- Feeling comfortable contacting your healthcare team if they're worried about your emotional state.

Choosing the right caregiver

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 someone you trust and who can take the time to care for you. Your caregiver should be someone who can give you the practical and emotional support you need.

If you don't have just 1 person to serve as your caregiver, it's okay to have more than 1 person share the role. It's best to limit the number of caregivers to 1 or 2 people.



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 CAR T cell therapy.

Contact your social worker for support resources and information. 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 or ask a member of your CAR T team for a copy.

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, call Dr. Allison Applebaum at 646-888-0200 or visit www.mskcc.org/cancer-care/doctor/allison-applebaum.

Your pretreatment evaluation

Before you become a CAR T cell therapy candidate, your overall physical condition will be evaluated. This will help us make sure you're ready for treatment. It will also help your CAR T team notice any changes later.

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 if you've been exposed 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 CAR T 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 makes 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 so you don't have a reaction.
- **Positron emission tomography (PET) scan.** This is a radiology test that's used to look at certain types of cancer. It's also used to look at your organs and how they work in your body.
- **Brain magnetic resonance imaging (MRI) scan.** This is done to look at your brain and how it works.
- **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.
- **Bone marrow aspiration and biopsy.** A bone marrow aspirate is a small sample of bone marrow. It's usually taken from the back of your hip. To take the sample, your hip will be numbed, a needle will be put into the bone marrow, and a small amount of bone marrow 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.

These tests are usually done in the 30 days before your CAR T cell infusion (Day -30 onwards). But sometimes the pretreatment evaluation can take longer. Your CAR T team will work with you and your caregiver to schedule the tests. The results of the tests will be used to plan your treatment and make sure it's safe to start.

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

Your preadmission appointment

Once your pretreatment evaluation is finished and you know the date of your CAR T cell infusion, you'll have your preadmission appointment. This appointment is usually 1 to 2 weeks before your scheduled CAR T cell infusion. During this appointment:

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



Between your preadmission appointment and when you're admitted to the hospital, it's very important to call your CAR T cell doctor's office if you have any of the following:

- Signs of a cold, such as:
 - A runny nose
 - Congestion
 - A cough
 - 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 (poop))
- A toothache
- An open wound (such as a wound that's bleeding or not healing)
- Any other new problem, even if it seems small

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

Having your central venous catheter (CVC) placed

You'll need a CVC during your CAR T cell therapy. A CVC is a catheter (thin, flexible tube) that's put into one of your larger veins. Outside your body, the catheter divides into 2 or 3 smaller tubes called lumens.

A CVC lets your CAR T team infuse your CAR T 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 CVC will make your treatment much more comfortable.

There are 2 main types of CVCs:

- A **tunneled chest catheter** is put into a large vein in your upper chest. Tunneled chest catheters are sometimes called Hickman catheters. For more information, read the resource *About Your Tunneled Catheter*. You can find it in the "Educational Resources" section of this guide or online at www.mskcc.org/pe/about_tunneled_catheter.
- A **peripherally inserted central catheter (PICC)** is put into a large vein in your arm. For more information, read the resource *About Your Peripherally Inserted Central Catheter (PICC)*. You can ask a member of your CAR T team for a copy or find it online at www.mskcc.org/pe/about_picc.

Your doctor or nurse will tell you which type of CVC you'll have. CVCs are usually removed 2 to 3 weeks after your CAR T cell therapy is finished.

Notes _____

What to Expect in the Hospital

This section has basic information about what to expect if you're admitted to the hospital during any part of your treatment. This applies whether you have an inpatient or outpatient CAR T cell infusion.

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 stem cell transplants and CAR T cell therapy. All the same guidelines are followed on both units. You may need to change your room or floor while you're in the hospital, but we try to avoid this as much as possible.

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 information about what happened with you and your care during that shift with the nurse taking over.

The hospital environment

- Follow any instructions that are specific to your floor.
- Keep your hands clean. For more information, read the resource *Hand Hygiene and Preventing Infection*. You can find it in the “Educational Resource” section of this guide or online at www.mskcc.org/pe/hand_hygiene.
- 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.
- If you're at risk for falling, someone will help you get to the bathroom. Your healthcare team will tell you more about how to keep from falling while you're in the hospital. You can also read the resource *Call! Don't Fall!* You can find it online at www.mskcc.org/pe/call_dont_fall or as ask a member of your CAR T team for a copy.

Testing and evaluations

- A member of your healthcare team will weigh you and take a sample of your blood before 6:00 AM every day. 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 function, watch for infections, check the level of chemotherapy or other medications in your blood, and to help evaluate your overall condition.
- A member of your healthcare team will take your vital signs (your blood pressure, heart rate, breathing, and pain level) every 4 hours, even during the night.
- A member of your healthcare team will measure your urine throughout the day. It's important that we know how much urine you're making.
- You'll have tests to check your neurological (brain) function. For example, your nurse might ask you simple questions.

Visitors

- Your family and friends are welcome to visit you, but the following people shouldn't visit:
 - Anyone who has symptoms of an illness (such as a cough, rash, fever, or diarrhea).
 - Anyone who thinks they might be getting sick.
 - Anyone who could have recently been exposed to someone with an infectious illness.
- All visitors must always clean their hands before entering 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, dried, and live flowers and plants aren't allowed in your room. Please tell your family and friends not to bring or send them.

Exercise

Even though you'll feel tired after your chemotherapy and CAR T cell infusion, 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 may need to wear a mask and gloves while you're walking around. Your nurse will tell you if you also need to wear an isolation gown. Don't leave the floor when you're walking or exercising.

A physical therapist will meet with 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, use your call bell and say exactly what you need so we can send the right member of your healthcare team member to help you.

Diet

Your CAR T team will plan your diet. You'll be given a menu and instructions for ordering your meals. Room service will deliver your meals to you.

If you keep kosher, have diabetes, or follow other special diets, tell your clinical dietitian nutritionist so 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. A patient care technician will be in your room when you're showering to help you and make sure you're safe.

Mouth care

It's important to take good care of your mouth. This will help reduce infections and mouth sores. Your nurse will go over this with you. You can also read the resource *Mouth Care During Your Cancer Treatment* for more information. You can find it online at www.mskcc.org/pe/mouth_care or ask a member of your CAR T team for a copy.

What to Expect in the Cellular Immunotherapy Unit

During an outpatient CAR T cell infusion, you'll get most or all your care in the Cellular Immunotherapy Unit. You'll visit the unit every day and will only be admitted to the hospital if you need more care than can be given to you as an outpatient.

When you come to the Cellular Immunotherapy Unit, arrive at your scheduled time. Wear comfortable clothing that allows for easy access to your CVC, such as a shirt that opens at the front, a sweatshirt, or a large t-shirt. Don't wear clothing that's hard to take off or put back on.

- After you check in and are taken to a room, your CAR T team will check your vital signs and weight and ask you about any symptoms you have. They'll also examine you and check your blood counts, electrolyte levels, and kidney function.
- After they examine you, you'll wait in your room for your test results to be ready. This can take several hours. You'll have an entertainment unit with a TV and computer to pass the time. Your meals will be provided for you.
 - This is a good time for your caregiver to take a break, take some personal time, or run errands. You'll be safe in your treatment team's care. We highly recommend that your caregiver leaves the hospital and takes this time to relax.
- Once they get the results from your blood tests (sometimes called "labs"), your CAR T team will make decisions about your care. The rest of your visit that day will depend on your test results. Based on your test results:
 - Your healthcare provider may give you fluids through your CVC.
 - Your healthcare provider may give you an infusion of platelets, red blood cells, or other blood components.
 - Your healthcare provider may change some of your medications.
 - Your treatment could be left as is.

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

For more information about the Cellular Immunotherapy Unit, read the resource *About Your Appointments in MSK's Cellular Immunotherapy Unit*. You can find it online at www.mskcc.org/pe/about_cellular_immunotherapy_unit or ask a member of your CAR T team for a copy.

What to bring to the Cellular Immunotherapy Unit

- A list of all prescription and nonprescription medications you're taking, along with dosages and how often you take them. This should include patches, creams, vitamins, nutritional supplements, herbal products, and over-the-counter medications.
- All the prescription medications you were told to take during your CAR T cell therapy.
- Your *Outpatient Cellular Therapy Temperature & Intake Log*. Your caregiver will use this to keep track of your temperature and liquid intake while you're away from the unit.
- Things to pass the time, such as books, newspapers, an audio player, a laptop, or tablet computer. Don't forget the charger for any electronic device(s) you bring.
- A notebook to write down information and any questions you or your caregiver have.

What to do in your home or apartment

When you're not in the Cellular Immunotherapy Unit, your caregiver will be responsible for caring for you.

Have the following resources easily accessible when you're not in the Cellular Immunotherapy Unit. A member of your CAR T team will give you a copy, or you can access them online.

- Outpatient Cellular Therapy Temperature & Intake Log
www.mskcc.org/pe/cellular_therapy_log
- *Outpatient Cellular Therapy Emergency Guide*
www.mskcc.org/pe/cellular_therapy_emergency_guide

Carry your outpatient cellular therapy emergency card with you

If you're having an outpatient CAR T cell infusion, you'll get an Outpatient Cellular Therapy Emergency Card. **Keep this card with you at all times.** It has important information about who to call and where to go if you have a medical emergency.

If you need emergency medical care, show this card to the medical professional helping you.

Keep track of how much you drink

Drink 2 liters (64 ounces) of liquids every day. Try to drink small amounts throughout the day. Your caregiver must keep track of all the liquids you drink in the *Outpatient Cellular Therapy Temperature & Liquid Intake Log*.

Keep track of your temperature

From the time you start getting your chemotherapy, your caregiver must take your temperature every 4 hours while you're awake. You'll be given a thermometer.



If you have a fever of 100.4 °F (38 °C) or higher, your caregiver needs to take you to Urgent Care Center as instructed in your *Outpatient Cellular Therapy Emergency Guide*. While you're on your way there, call one of the numbers listed below.

- Between 8:00 AM and 7:00 PM, call the Cellular Immunotherapy Unit at 646-608-3150.
- After 7:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant.

Watch for bleeding

Always tell someone from your CAR T team if you have any bleeding. If you notice you're bleeding and you aren't in the Cellular Immunotherapy unit, take the following steps right away:

1. Apply direct pressure on the bleeding site. If you're bleeding from your nose, also apply ice over the bridge of your nose.
2. Follow the Outpatient Cellular Therapy Emergency Guide.
 - Between 8:00 AM and 7:00 PM, call the Cellular Immunotherapy Unit at 646-608-3150.
 - After 7:00 PM, call 212-639-2000 and ask for the doctor covering bone marrow transplant.

Your care team will give you more instruction depending on the specific type of CAR T cell you get.



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

- Black bowel movements, blood in your bowel movements, or rectal bleeding
- 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

Move around and exercise

Even though you'll feel tired after your chemotherapy and CAR T cell infusion, you should still try to stay active. A physical therapist will talk with you and prescribe an exercise program that's right for you.

For more information about why it's important to stay active and what your healthcare team can do to help, read the resource *Staying Active During Stem Cell Transplant*. You can find it online at www.mskcc.org/pe/active_sct or ask a member of your CAR T team for a copy.

Phases of CAR T Cell Therapy

There are 6 phases of CAR T cell therapy. The following table gives a summary of each phase. Keep reading for more information about each of the phases.

	Description
Phase 1: T cell collection	<p>Some of your T cells are collected from your blood. The T cells are then sent to a lab to be genetically modified.</p> <p>T cell collection is done about 4 to 6 weeks before your infusion. It takes about 2 to 4 hours.</p>
Phase 2: T cell modification	<p>While your T cells are being genetically modified into CAR T cells, you'll have your pretreatment evaluation and pretreatment testing. You'll also use this time to finish planning for your CAR T cell infusion and recovery. You might also get other treatment during this time to lower your disease level before your CAR T cell treatment begins.</p> <p>T cell modification takes about 3 to 4 weeks.</p>
Phase 3: Lymphodepleting chemotherapy (conditioning)	<p>Once your CAR T cells arrive at MSK, you'll get chemotherapy to get your body ready for them.</p> <p>Lymphodepleting chemotherapy is given about 3 days before your infusion. Your CAR T team will tell you how long it'll take.</p>
Phase 4: CAR T cell infusion	<p>Your CAR T cells will be infused into your bloodstream. This might be done in the Cellular Immunotherapy Unit or in the hospital.</p> <p>CAR T cell infusion takes about 5 to 30 minutes.</p>
Phase 5: Early recovery	<p>You'll have appointments daily or every few days. Your CAR T team will see how you're doing and manage your side effects. You'll stay in the hospital or nearby.</p> <p>Early recovery lasts for about 4 weeks after your infusion.</p>

<p>Phase 6: Long-term recovery</p>	<p>You'll have appointments every few weeks or months. Your CAR T team will see how you're doing and manage your side effects. You'll come back to MSK for these appointments. If you're coming from another hospital, you may be seen by the doctor who referred (sent) you to MSK in between your visits to MSK.</p> <p>Long-term recovery lasts for about 100 days or longer after your infusion.</p>
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Phase 1: T cell collection

Your T cells will be collected in MSK's Blood Donor Room. It'll take about 2 to 4 hours.

Before your T cell collection

Have a leukapheresis catheter placed, if needed

If a leukapheresis catheter will be used for your T cell collection, it'll be placed 1 to 2 days before your collection. Your nurse will give you information about what to expect. You can also read the resource *About Your Tunneled Catheter*. You can find it online at www.mskcc.org/pe/about_tunneled_catheter or in the "Educational Resource" section of this guide.

The leukapheresis catheter will be put into a large vein in your upper chest. It's usually removed a few hours after your collection.

Eat high-calcium foods

For 1 to 2 days before your collection, eat dairy products and other foods that are high in calcium. You should also bring a high-calcium snack to eat during your collection. This can help keep the level of calcium in your blood from getting too low during your collection. Your nurse will give you a list of foods that are high in calcium.

During your T cell collection

Your collection will be done while you're on a bed or in a recliner chair. If you want to, you can watch TV or read during your procedure. You might feel cold during the procedure, so blankets will be available to make you comfortable.

During your collection, some of your blood will be collected from your bloodstream through an IV line or leukapheresis catheter. The blood will flow through a machine

that filters out the T cells and other white blood cells. The rest of your blood will be given back to you through another IV line.

Your donor room nurse will watch for side effects and give you medications if you need them. If you feel numbness or tingling in your fingertips or around your mouth, tell your donor room nurse. These are signs that your calcium level is low. Your donor room nurse can give you calcium tablets to help with this.

After your T cell collection

If you had an IV line in your arm(s), your donor room nurse will remove it and apply a bandage to prevent bleeding. They'll tell you when you can remove the bandage. If you're still bleeding when you remove the bandage, apply gentle but firm pressure on the site for 3 to 5 minutes. Call your doctor if the bleeding doesn't stop.

If a leukapheresis catheter was used for your collection, your donor room nurse will schedule an appointment for it to be removed soon after your collection.

Most people can go back to doing their regular activities right after their T cell collection.

Phase 2: T cell modification

After your T cells are collected, they'll be sent to a lab. There, they'll have a new gene added to them that allows them to recognize the cancer cells. This is called modification. T cells that have been modified are called CAR T cells.

While your T cells are being modified, you'll complete your pretreatment evaluation and preadmission testing. You may also have chemotherapy to control your cancer.

This is also a good time to finish planning for your CAR T cell therapy. It's especially important to make sure you've made plans for where you'll stay and who your caregiver will be during your CAR T cell therapy. Read the sections "Getting ready for your CAR T cell therapy" and "Your caregiver" for more information.

Your CAR T cells will be ready about 3 to 4 weeks after your collection.

Phase 3: Lymphodepleting chemotherapy (conditioning)

Once your CAR T cells arrive at MSK, you'll get chemotherapy to help get your body ready for the CAR T cell infusion. This is called lymphodepleting chemotherapy. Lymphodepletion is the process of lowering your white blood cell numbers with chemotherapy. It's done to help get your body ready for the CAR T cells.

Most people get their lymphodepleting chemotherapy in the Cellular Immunotherapy Unit. It's usually done a few days before the CAR T cell infusion. Your clinical nurse coordinator will give you your schedule and talk with you about what to expect. Your schedule depends on your specific medications and treatment.

Phase 4: CAR T cell infusion

If you're having an inpatient CAR T cell infusion, you'll be admitted to the hospital. This usually happens the day before your infusion. Your infusion will be given while you're in your hospital room.

If you're having an outpatient CAR T cell infusion, your infusion will be given at the Cellular Immunotherapy Unit.

Before your CAR T cell infusion

The day of your CAR T cell infusion, you'll have a general check-up and neurologic tests. You'll also get medications to help keep you from having a reaction to the infusion. If you don't have a CVC, a staff member will place an IV line in one of your veins.

Your CAR T team will tell you what time you can expect to get the infusion.

During your CAR T cell infusion

Your nurse or doctor will give you the CAR T cell infusion through your CVC or IV line. The infusion can take as little as 5 minutes or up to 30 minutes, depending on your treatment plan. A staff member will be in the room with you for at least the first 15 minutes of your infusion. They'll probably stay with you for the entire infusion.

After your CAR T cell infusion

After the CAR T cell infusion, you'll be watched closely for side effects. Cytokine release syndrome (CRS) and neurological changes are common side effects of a CAR T cell infusion. CRS is a group of symptoms that happen when T cells attack cancer cells.

Common symptoms of CRS include:

- A fever of 100.4 °F (38 °C) or higher
- Flu-like symptoms, such as:
 - Muscle aches
 - Headaches
 - Chills
- Feeling unusually tired
- Nausea or vomiting
- A faster heart rate than usual
- Feeling dizzy or lightheaded

Common neurologic changes include:

- Confusion
- Trouble finding words
- Tremors
- Seizures
- Sleeping more than usual
- Feeling very drowsy and responding more slowly than usual

Not everyone gets the same type of CAR T cell therapy, and everyone responds differently to each type of therapy.

These side effects aren't permanent. Your care team will watch you carefully for side effects. They'll manage any side effects you have. It's very important for you or your caregiver to tell a member of your healthcare team if you think you're having any of these side effects.

Phase 5: Early recovery

The first 4 weeks after your CAR T cell infusion are considered the early recovery phase.

If you had an inpatient CAR T cell infusion, you'll stay in the hospital for 1 to 2 weeks or longer after your infusion. How long you stay in the hospital depends on how your body reacts to the cells. Your CAR T team will care for you and keep watching for side effects. Some side effects need to be watched more closely and may result in transferring you to the Intensive Care Unit (ICU). Once you're ready, you'll be discharged from the hospital. You'll stay in an apartment near the hospital or at MSK's 75th Street Patient Residence.

If you had an outpatient CAR T cell infusion, you'll have daily appointments for the first 2 weeks after your infusion. Your appointments will be at the Cellular Immunotherapy Unit. During your visits, your CAR T team will check how you're doing and help manage any side effects you're having. You'll be admitted to the hospital if needed.

Starting about 2 weeks after your infusion, you may be able to have appointments less often. This depends on how you're feeling. Side effects are still common during this time, so it's important to come to all your scheduled appointments.

About 4 weeks after your CAR T cell infusion, you'll start having your appointments in your physician's regular clinic instead of the Cellular Immunotherapy Unit.

Phase 6: Long term recovery

Long term recovery is different for everyone. It depends on your specific situation and how the cancer reacts to your CAR T cell therapy. Your CAR T team will tell you what to expect.

You'll have appointments with your CAR T team about 30 days, 100 days, and 1 year after your CAR T cell infusion. During these appointments, you'll have tests to check how you're doing. These tests might include:

- A physical exam
- Blood tests
- Imaging scans (such as a PET scan or CT scan)
- Bone marrow aspiration and biopsy

Your CAR T team will use the results of these tests to plan your care during your recovery.

Your CAR T team will talk with you about going back to seeing your primary doctor during your long term follow-up. If you do start seeing your primary doctor, please be sure to update your CAR T team on how you're doing.

Some people need to come back to the CAR T team for more care. This may include being seen in the outpatient clinic or being admitted to the hospital.

Educational Resources

This section contains the educational resources we referred to throughout this guide, as well as some additional educational resources you may find helpful. You can find these resources online or ask a member of your CAR T team for a copy. 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 Peripherally Inserted Central Catheter (PICC)

www.mskcc.org/pe/about_picc

About Your Tunneled Catheter

www.mskcc.org/pe/about_tunneled_catheter

Advance Care Planning

www.mskcc.org/pe/advance_care_planning

Building Your Family After Cancer Treatment: Information for Men

www.mskcc.org/pe/building_family_men

Building Your Family After Cancer Treatment: Information for Women

www.mskcc.org/pe/building_family_after_cancer_women

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

Communicating With Your Healthcare Team Using MyMSK

www.mskcc.org/pe/communicating_using_mymsk

Fertility Preservation: Options for Women Who Are Starting Cancer Treatment

www.mskcc.org/pe/fertility_women_starting_treatment

Food Safety During Cancer Treatment

www.mskcc.org/pe/food_safety

Hand Hygiene and Preventing Infection

www.mskcc.org/pe/hand_hygiene

Improving Your Vulvovaginal Health

www.mskcc.org/pe/improving_vulvovaginal_health

Mouth Care During Your Cancer Treatment

www.mskcc.org/pe/mouth_care

Outpatient Cellular Therapy Emergency Guide

www.mskcc.org/pe/cellular_therapy_emergency_guide

Outpatient Cellular Therapy Temperature & Liquid Intake Log

www.mskcc.org/pe/cellular_therapy_log

Sex and Your Cancer Treatment

www.mskcc.org/pe/sex_cancer_treatment

Sexual Health and Intimacy

www.mskcc.org/pe/sexual_health_intimacy

Sperm Banking

www.mskcc.org/pe/sperm_banking

Staying Active During Stem Cell Transplant

www.mskcc.org/pe/active_sct



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 www.mskcc.org/pe to search our virtual library.

About Your Blood Transfusion - Last updated on January 11, 2021

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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's put 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. Outside of your body, the catheter divides into 1, 2, or 3 smaller tubes called lumens. Each lumen has a clamp, a needleless connector (also called a clave), and a disinfection cap on the end (see Figure 1).

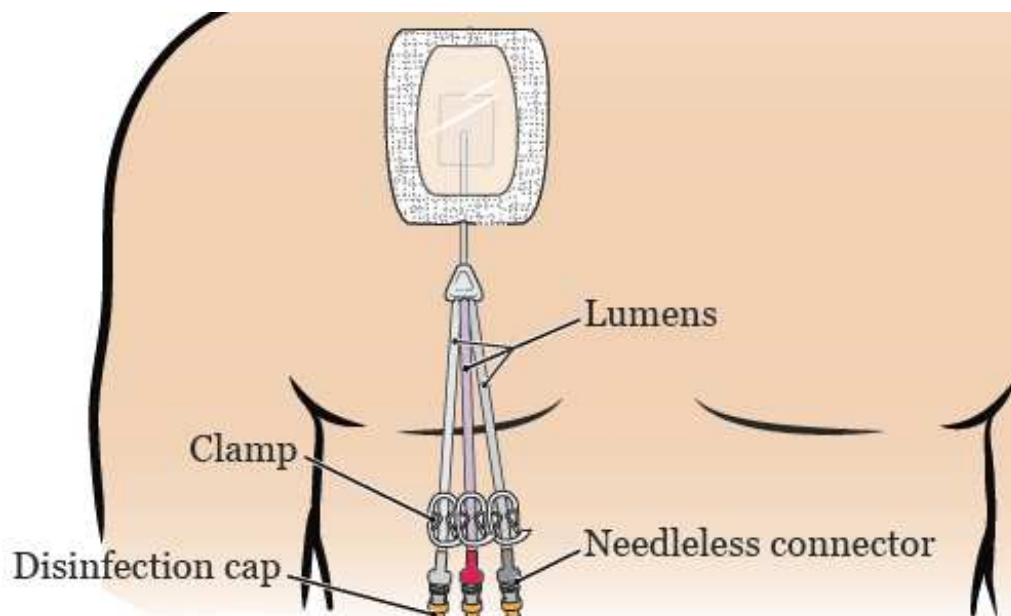


Figure 1. Tunneled catheter

A tunneled catheter can be used to:

- Take blood samples
- Give fluids
- Give chemotherapy and other medications
- Give blood transfusions
- Give intravenous (IV) nutrition

Having a tunneled catheter can help you need fewer needle sticks. A tunneled catheter can stay in your body for as long as a few years. Your doctor will remove it when you don't need it anymore.

Having a tunneled catheter shouldn't keep you from doing your normal activities, such as work, school, sexual activity showering, and mild exercise. Avoid contact sports, such as football and soccer, while your catheter is in place. Ask your doctor or nurse about any activities before you start them.

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. You can have a caregiver, family member, or friend learn with you.

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 have included some common examples below.

Blood thinners

If you take a blood thinner (medication that affects the way your blood clots), ask the healthcare provider performing your procedure what to do. Their contact information is listed at the end of this resource. Whether they recommend you stop taking the medication depends on the type of procedure you're having and

the reason you're taking blood thinners.

Don't stop taking your blood thinner medication without talking with your healthcare provider.

Examples of Blood Thinners			
apixaban (Eliquis®)	dalteparin (Fragmin®)	meloxicam (Mobic®)	ticagrelor (Brilinta®)
aspirin	dipyridamole (Persantine®)	nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil®, Motrin®) or naproxen (Aleve®)	tinzaparin (Innohep®)
celecoxib (Celebrex®)	edoxaban (Savaysa®)	pentoxifylline (Trental®)	warfarin (Jantoven®, Coumadin®)
cilostazol (Pletal®)	enoxaparin (Lovenox®)	prasugrel (Effient®)	
clopidogrel (Plavix®)	Fondaparinux (Arixtra®)	rivaroxaban (Xarelto®)	
dabigatran (Pradaxa®)	heparin (shot under your skin)	sulfasalazine (Azulfidine®, Sulfazine®)	

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

(www.mskcc.org/pe/common_meds). It has important information about medications you'll need to avoid before your procedure and what medications you can take instead.

Medications for diabetes

If you take insulin or other medications for diabetes, ask the healthcare provider who prescribes your medication what you should do the morning of your procedure. You may need to change the dose before your procedure. Your healthcare providers will be checking your blood sugar level during your procedure.

Diuretics (water pills)

If you take any diuretics (medications that make you urinate more often), ask the healthcare provider performing your procedure what to do. You may need to stop taking them the day of your procedure. Diuretics are sometimes called water pills. Some examples are furosemide (Lasix®) and hydrochlorothiazide.

Remove devices from your skin

If you wear any of the following devices on your skin, the manufacturer recommends you remove it before your scan or procedure:

- 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.

If you're not sure how to manage your glucose while your device is off, talk with the healthcare provider who manages your diabetes care before your appointment.

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 and report concerns to your healthcare providers, if needed. 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 usually a charge for this service, and you'll need to provide transportation. It's okay to use a taxi or car service, but you must still have a responsible care partner with you.

Agencies in New York

Partners in Care: 888-735-8913

Caring People: 877-227-4649

Agencies in New Jersey

Caring People: 877-227-4649

Tell us if you're sick

If you get sick (such as have a fever, cold, sore throat, or the flu) before your procedure, call your doctor in Interventional Radiology. You can reach them Monday through Friday from 9:00 AM to 5:00 PM. After 5:00 PM, during the weekend, and on holidays, call 212-639-2000 and ask for the Interventional Radiology fellow on call.

Note the time of your appointment

A staff member from Interventional Radiology will call you 2 business days (Monday through Friday) before your procedure. If your procedure is scheduled on a Monday, they'll call you on the Thursday before. If you don't get a call by 12:00 PM the business day before your procedure, call 646-677-7001.

The staff member will tell you what time to arrive at the hospital for your procedure. They'll also remind you where to go.

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

If you need to cancel your procedure for any reason, call the healthcare provider who scheduled it for you.

The Day Before Your Procedure

Instructions for eating before your procedure



Do not eat anything after midnight the night before your procedure. This includes hard candy and gum.

The Day of Your Procedure

Instructions for drinking before your procedure



You can drink a total of 12 ounces of water between midnight 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.
- Don't apply cream (thick moisturizers) or petroleum jelly (Vaseline®) anywhere on your chest.
- Don't wear eye makeup.
- Remove any jewelry, including body piercings.
- Leave all valuables (such as credit cards and jewelry) at home.
- If you wear contact lenses, wear your glasses instead, if you can. If you don't have glasses, please bring a case for your contacts.

What to bring with you

- A list of the medications you take at home.
- Medications for breathing problems (such as inhalers), 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.
- If you use a CPAP or BiPAP machine to sleep at night, bring your machine with you, if you can. If you can't bring your machine with you, we will give you one to use while you're in the hospital.

What to expect

Once you arrive at the hospital, doctors, nurses, and other staff members will ask you to say and spell your name and date of birth many times. This is for your safety. People with the same or a similar name might be having a procedure on the same day.

During Your Procedure

First, you will get a numbing injection (shot) at the base of your neck and on your chest under your collarbone. 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). They will use an imaging scan to help them see the catheter while they do this.

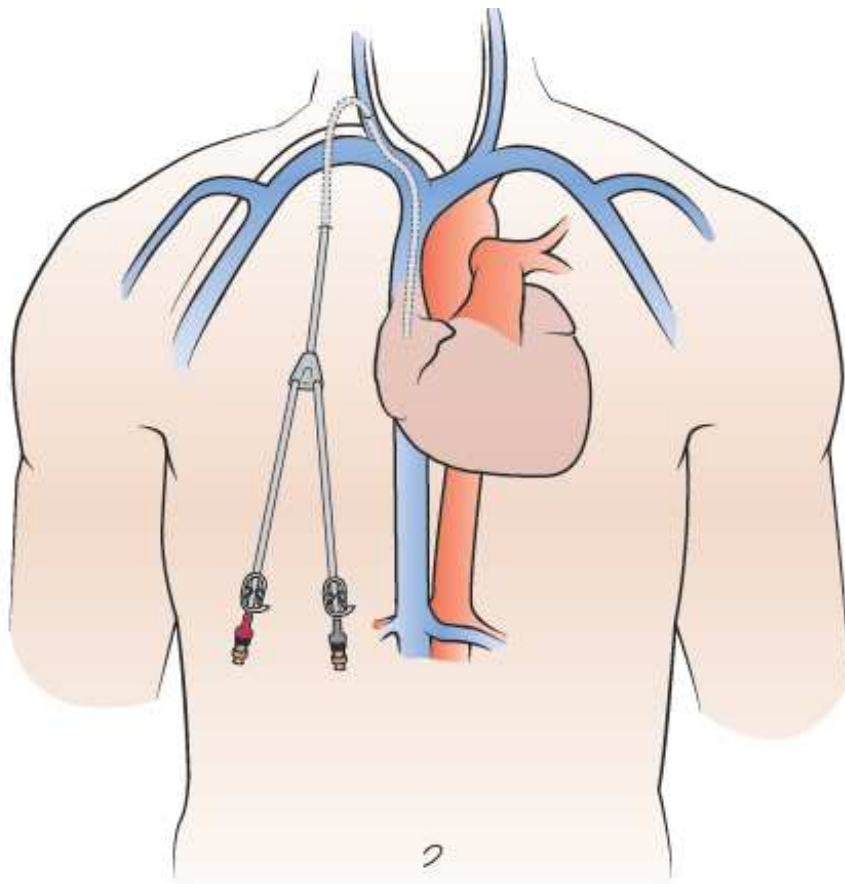


Figure 2. Catheter tunneled under your skin, into a vein

Once the catheter is in your vein, your doctor will use Steri-Strips™ (surgical tape) to close the incision at the base of your neck. 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 and a Tegaderm™ dressing over your catheter exit site.

After Your Procedure

After your procedure, you will be brought to the recovery room. You will stay in the recovery room until you're ready to move to your hospital room or be discharged from (leave) the hospital.

You might have some bleeding and mild discomfort at your catheter exit side. This can last for about 1 to 3 days after your catheter is placed. If you have any bleeding from your exit site, apply pressure and a cold compress to the area. Call your doctor or nurse if the bleeding and discomfort gets worse at any time.

Don't shower for 24 hours after your procedure.

Your emergency kit

Your nurse will give you an emergency kit before your procedure or before you're discharged from the hospital. The emergency kit has:

- 1 toothless clamp
- 1 dressing change kit. The kit includes:
 - 2 face masks
 - Alcohol-based (Purell®) hand wipe
 - Disposable drape
 - 2 pairs of nitrile gloves (sterile gloves)
 - Chloroprep® applicator
 - Alcohol pads
 - No Sting swab stick

- 3 needleless connectors
- Tegaderm CHG dressing
- Disinfection caps
- Your doctor's office and emergency telephone numbers.

Keep your emergency kit with you at all times. You will need it if your catheter is leaking, your Tegaderm dressing is damaged or comes off, or your needleless connector or disinfection cap falls off.

Your catheter exit site

You might need to have your Tegaderm dressing changed within 48 hours (2 days) of your procedure. Your doctor or nurse will tell you if you do.

You should always have a Tegaderm dressing over your exit site while your tunneled catheter is in place. The Tegaderm dressing helps prevent infection.

Your neck incision

Two days after your procedure, you can remove the gauze bandage over the small incision on your neck. You don't need to put a new bandage over the incision.

Leave the Steri-Strips in place until they start to peel off. This should happen about 3 to 5 days after your procedure.

Caring for Your Tunneled Catheter at Home

- Clamp the lumens when your catheter isn't in use.
- Keep your catheter secure at all times to keep from pulling it. Ask your nurse about the best way to secure your catheter. You can tape the lumens to your skin, tuck them into your bra, or wrap them in medical tape and pin the tape to your clothing. Don't put tape over the connection site (where the needleless connector connects to the lumens).
- Check your exit site every day for:
 - Redness

- Tenderness
- Leakage
- Swelling
- Bleeding

If you have any of these signs or symptoms, call your doctor. You might have an infection.

- Your Tegaderm dressing, needleless connectors, and disinfection caps will need to be changed and your catheter will need to be flushed at least once a week. It's best if you can come to a Memorial Sloan Kettering (MSK) location so a nurse can do these things. If you can't come to an MSK site, your nurse will help you make other arrangements. Always contact your doctor or nurse if you have any questions.

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 can't use the white clamp, use the clamp in your emergency kit.
2. Wipe the area that's leaking with an alcohol pad.
3. Call your doctor's office right away.

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

1. Don't take off the damaged, loose, or dirty dressing. Put a new Tegaderm dressing over it.
2. Call your doctor's office right away.

What to do if your Tegaderm dressing is wet

1. Don't take off the wet Tegaderm dressing. Don't put another dressing over it.
2. Call your doctor's office right away.

What to do if your disinfection cap falls off

Throw the disinfection cap that fell off in the trash. Don't 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 emergency 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 in the trash. Don't 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
 - 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.
 - 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 don't 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 3). Keep holding the lumen with the alcohol pad in your nondominant hand.

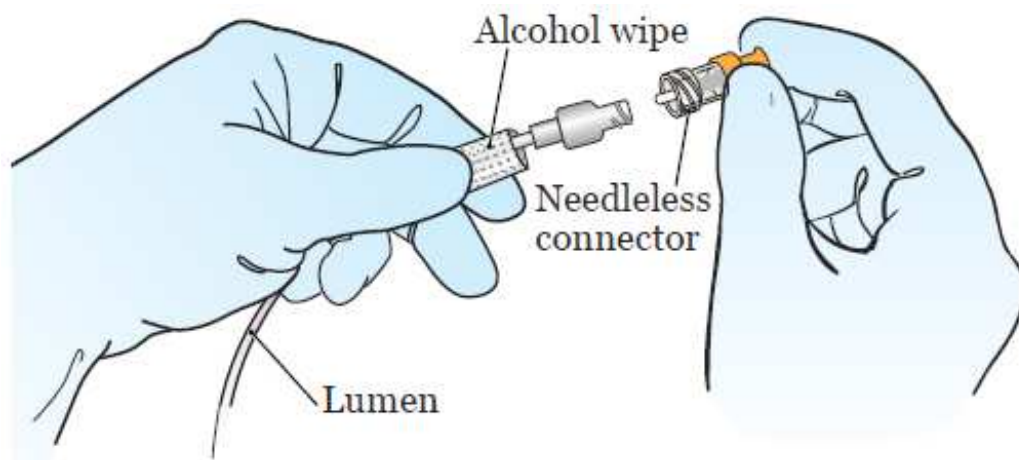


Figure 3. Twisting on the new needleless connector

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

Follow the instructions in this section when you shower. Don't submerge your catheter in water (such as in a bathtub or swimming pool).

For more information about showering with a tunneled catheter, watch *Showering While You Have a Central Venous Catheter (CVC)* (www.mskcc.org/pe/shower_cvc).

Use a waterproof cover

You can shower with your catheter in place using a one-time-use waterproof cover that goes over your dressing (such as Aquaguard®). You can buy waterproof covers 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. Don't 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 and the lumens of your catheter are tucked into the waterproof cover and completely covered. Smooth the bottom edge down.

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

After your shower, dry the waterproof cover before you take it off.

Use Hibiclens® skin cleanser

While your tunneled catheter is in place, it's very important to 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.

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. Don't put on any lotion, cream, deodorant, makeup, powder, or perfume after your shower.

Important points to remember when using Hibiclens

- Don't 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.
- Don't use Hibiclens on your head, face, ears, eyes, mouth, genital area, or on deep wounds. If you have a wound and aren't sure if you should use Hibiclens on it, ask your doctor or nurse.
- Don't 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 and call your doctor.

When to Call Your Healthcare Provider

Call your healthcare provider right away if you have:

- Your dressing is damaged, dirty, or peeling off.
- Your dressing gets wet.
- You have redness, swelling, or drainage around your catheter exit site.
- Your needleless connector falls off.
- You have a fever of 100.4 °F (38 °C) or higher or chills.
- You have a break or leak in your catheter.

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.

About Your Tunneled Catheter - Last updated on February 22, 2021

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PATIENT & CAREGIVER EDUCATION

Food Safety During Cancer Treatment

This information explains what foodborne illness is. It also explains how to handle food safely to help prevent foodborne illness.

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 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.
 - 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



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
Fish and shellfish	145 °F (63 °C) and flesh is opaque (not see-through)



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 2 hours of cooking or buying them. If the temperature outside is above 90 °F (32 °C), refrigerate or freeze them within 1 hour.
- 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

Can I eat at restaurants?

It's okay for most people to eat at restaurants. If you had a stem cell transplant, ask your healthcare team when it's safe for you to eat at restaurants. Follow these guidelines when eating at restaurants 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.

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.

Food Safety During Cancer Treatment - Last updated on October 29, 2019
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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:

World 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.

Hand Hygiene and Preventing Infection - Last updated on March 9, 2020
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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.
- 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 moisturizers 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 [Female Sexual Medicine and Women's Health Program](#) 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 [Male Sexual and Reproductive Medicine Program](#) 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 53rd 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 Man With Cancer* and *Sex and the Woman With Cancer*. You can search for them on www.cancer.org 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 www.mskcc.org/pe to search our virtual library.

Sexual Health and Intimacy - Last updated on March 2, 2020

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