

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

This guide will help you and your loved ones understand what to expect throughout your chimeric antigen receptor (ky-MEER-ik AN-tih-jen reh-SEP-ter) T cell therapy. This treatment is most often called CAR T cell therapy.

This guide should not replace talking with your CAR T team. They'll teach you about your treatment and what to expect. You can use this guide to help you remember. You can refer to it throughout your treatment.

We'll explain some of the challenges you may have during your CAR T cell therapy and recovery. You may not face all of them. Try not to compare yourself to other people who had CAR T cell therapy. Everyone is different.



Visit [www.msk.org/pe/car-t-guide](http://www.msk.org/pe/car-t-guide) to view this guide online.

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# Overview

CAR T cell therapy is a type of immunotherapy (IH-myoo-noh-THAYR-uh-pee). Immunotherapy is a form of cancer treatment that uses your immune system to attack cancer cells. Different types of immunotherapy work in different ways, but they all help your immune system find and kill cancer cells.

You will get a CAR T cell infusion (in-FYOO-zhun) as part of your immunotherapy. An infusion is how we put the treatment into your bloodstream. This 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.

- **If you have an inpatient infusion:** You'll be admitted to the hospital some time right after your infusion.
- **If you have an outpatient infusion:** You and your caregivers will stay in an apartment near the hospital that's approved by your doctor. Or, you'll stay in a furnished apartment at MSK's East 75th Street Patient Residence. You'll visit the outpatient Cellular Immunotherapy Unit every day before, during, and for some time right after your infusion.

It's normal to have many kinds of emotions during CAR T cell therapy. Your CAR T team includes social workers, chaplains (spiritual counselors), psychiatrists, and members of MSK's Integrative Medicine Service. All these healthcare providers are here to support and help you and your caregivers cope with your feelings.

# Communication is important

It's very important to talk with your CAR T team and your caregiver about how you're feeling physically and emotionally.

If anything is bothering you, even if it seems small, tell a member of your CAR T team. Do not wait and let things build up. That's how small problems can become bigger problems. The more information you share with your CAR T team, the more they can help you.

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

## By phone

Between 9 a.m. and 5 p.m., call your doctor's office. After 5 p.m., call 212-639-2000.

If you're having an outpatient CAR T cell infusion, call the Cellular Immunotherapy Unit at 646-608-3150. A member of the team will answer. If a care team member is not available, your call will go to an after-hours telephone triage nurse.

## In person

**If you're in the hospital:**

Talk with any member of your care team. Ask to talk with your nurse, the charge nurse, clinical nurse specialist, or nurse leader. When you're in the hospital (inpatient), it's important to talk with your inpatient team, not the outpatient office.

You should also choose 1 caregiver to call the nursing station for updates. This person can share the updates with the rest of your friends and family. We'll give you the nursing station phone number when you're admitted to the hospital.

## Through MSK MyChart

MSK MyChart ([mskmychart.mskcc.org](https://mskmychart.mskcc.org)) 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 MSK MyChart are printed on the bottom of your appointment print out. You can also read *Communicating With Your Care Team: When to Call or Use MSK MyChart*. You can ask for a printed copy or visit [www.msk.org/pe/communicating-using-mychart](https://www.msk.org/pe/communicating-using-mychart) to read it online.

### About PROMIS

Your CAR T team will use MSK MyChart to check in about how you're feeling physically and mentally over time. They will send you a set of questions, called PROMIS. Your CAR T team will send PROMIS questions to your MSK MyChart 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.

There may be times you report concerning symptoms when you're filling out the PROMIS questions. If so, you'll either see a message asking you to call your care team, or they will call you to help.

Your answers also will help us know in general how people feel after CAR T cell therapy. This information helps us improve our care in 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 resources we include at the end. You may find it easier to read a few sections at a time, instead of all at once. We encourage you to refer to this guide throughout your treatment.

It's a good idea to highlight or write notes on anything you do not understand or have a question about. There's no such thing as a silly question. Please ask us about anything.

## Medical terms

We have tried not to use many health terms that are hard to understand. Ask your healthcare provider about words or things you do not understand. You can also visit [www.cancer.gov/publications/dictionaries/cancer-terms](http://www.cancer.gov/publications/dictionaries/cancer-terms) to search the National Cancer Institute (NCI) Dictionary of Cancer Terms.

# Antigen and T cell basics

## About antigens

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

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

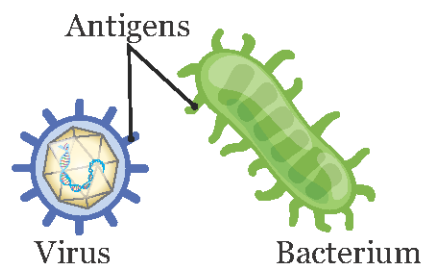


Figure 1. Antigens on a virus and bacterium



## About T cells

T cells help your immune system tell which antigens do not belong in your body. T cells are a type of white blood cell.

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 were changed in a lab. They can now attach to antigens on cancer cells (see Figure 2). Once they attach, your immune system sends other types of immune cells to the cancer cells. The immune cells kill the cancer cell and get it out of your body.

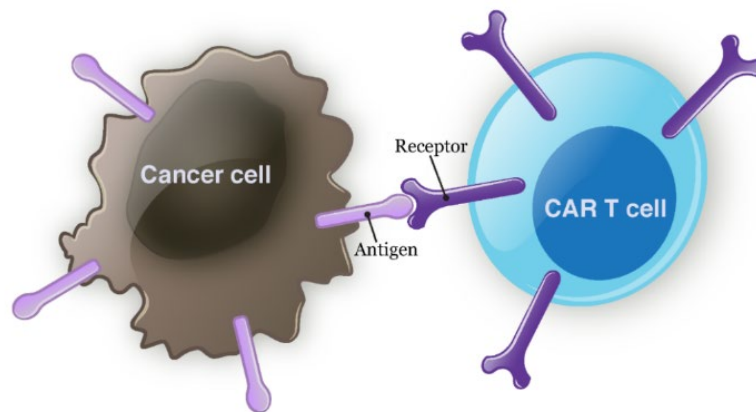


Figure 2. CAR T cell attaching to cancer cell

## Understanding your autologous CAR T cell therapy

Autologous (aw-TAH-luh-gus) means something taken from your own body, such as tissues or cells.

With autologous CAR T cell therapy, some of your T cells will be harvested (collected) from your blood. They'll be sent to a lab to have a new gene added to them. This is called **genetic modification** (change).

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 made, you'll get low doses of chemotherapy (chemo). This will help get your body ready so the CAR T cells can work as well as possible. The chemo is not meant to kill cancer cells.

When your body is ready, the CAR T cells will be infused (put) into your bloodstream.

Read the section "Phases of CAR T cell therapy" to learn more about what to expect.

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# Getting ready for your CAR T cell therapy

## Your first consultation visit

During your initial (first) consultation visit, you'll meet with your doctor and other members of your CAR T team. Your doctor will:

- Review your health and surgery history.
- Do a physical exam.
- Talk with you about what's the best treatment plan for you.

They also may talk with other CAR T doctors to make sure everyone agrees it's the best plan for you.

## Blood Donor Room appointment

You'll have an appointment in the Blood Donor Room. We will check if your veins are big enough to collect your T cells from a vein in your arm. If not, you will get a type of intravenous (IV) catheter called a leukapheresis (LOO-kuh-feh-REE-sis) catheter. We will use it for your T cell collection.

The donor room nurse will tell your care team if you need a leukapheresis catheter. If you do, your care team will give you more information. Read the section "Phase 1: T cell collection" to learn more.

# Getting ready for your CAR T cell therapy

After your initial consultation visit, you'll start getting ready for your CAR T cell infusion. Here's a list of things that will happen, and what you may need to do to get ready.

**Learn about your CAR T cell therapy.** Your CAR T team will go over information with you. This is meant to help you learn, not scare you. Make a note of anything you do not understand or that is not clear. Ask questions.

**Choose a caregiver.** Choose a family member or friend who can act as your caregiver. Make sure they understand what this 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.** This form is a legal document. It says who will speak for you if you cannot communicate for yourself. This person is called your health care agent. It can be a different person from your caregiver.

- To learn more about health care proxies and other advance directives, read *Advance Care Planning for People With Cancer and Their Loved Ones*. You can find it at [www.msk.org/pe/advance\\_care\\_planning](http://www.msk.org/pe/advance_care_planning) or ask for a printed copy.
- To learn more about being a health care agent, read *How to Be a Health Care Agent*. You can find it at [www.msk.org/pe/health\\_care\\_agent](http://www.msk.org/pe/health_care_agent) or ask for a printed copy.
- Talk with a member of your care team if you have questions about filling out a Health Care Proxy form.

**Meet with a social worker.** They will tell you about MSK's psychological, emotional, and financial support services.

**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. 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're worried 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 few medical tests. Your clinical nurse coordinator will talk with you about which tests you need. Your doctor's office coordinator will try to schedule these tests at a time that works well for you.

**Meet with a clinical dietitian nutritionist, if needed.** They can help you with your nutrition needs and 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 medicine you'll take before and after your CAR T cell therapy.

## **Coping with being away from your children**

During inpatient or outpatient CAR T cell infusions, you often spend more time away from your children than usual. Being away from your children may be hard for you and your family. We strongly recommend talking with your social worker about your concerns. Make a plan to keep strong ties to your children during your treatment.

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

- Talk with your children regularly using programs or apps like Zoom, Skype, Google Meet, or FaceTime. Set up a time you talk to them each day. This can be when they get home from school and before they go to bed. Get into a routine of using a computer, smartphone, or tablet to see and talk to them.
- Keep copies of your children's favorite stories with you in your room. At night, you can use video chat 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 email them to your children. They can read along with the 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. They can use it when they miss you or are having trouble with their feelings. Your caregiver can bring their work to you. You can talk with your children about them over video chat or on the phone.

We know nothing will replace being able to hold your children. But we strongly encourage you to use technology to keep a strong bond with them while you're away.

## Your CAR T team

A large care team will work together to care for you during each phase of your CAR T cell therapy. You'll meet many of the healthcare providers on your care team as you go through your CAR T cell therapy. You may not meet everyone, such as your doctor's office coordinator, laboratory staff, or the CAR T cell service coordinator. But everyone on your care team is working to help you.

Here's 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 doctor will be your primary (main) outpatient doctor, but different doctors may 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 care for you. They can give medical treatments and prescribe medicine. Sometimes, you may see them instead of your doctor. APPs include nurse practitioners (NPs), physician assistants (PAs), and certified registered nurse anesthetists (CRNAs).

A **clinical nurse coordinator** is a nurse who works with you, your caregiver, and your team of doctors. They will organize and schedule testing, procedures, and consultations with other professionals you need before your infusion. Your clinical nurse coordinator will teach you about your treatment plan.

**Nurses** will work with you during your outpatient visits and while you're in the hospital. They're registered nurses (RNs) with special training in caring 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. Your outpatient nurse will see you at many of your outpatient visits after you're discharged (leave the hospital). They will follow along with you during your CAR T cell therapy.
- You'll have a team of primary nurses who will care for you during your treatment. They work 12-hour shifts. We will try to keep the same nurses working with you.

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

A **nursing assistant (NA)** or **patient care technician (PCT)** works with your nursing team. They will help give you basic care and support, such as helping you shower.

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** is a pharmacist who works directly with you, your caregiver, and other members of your care team. They will review your medicines with you and your caregiver and teach you how to take them properly. They'll also tell you about side effects they can cause. Your clinical pharmacists will have special training in caring for people having stem cell transplants and CAR T cell therapy.

A **social worker** helps you, your family, and friends manage the stress of going through CAR T cell therapy. Social workers understand the issues people having treatment face. They're here to listen, offer counseling, and refer you or your loved ones to other resources and services.

A **CAR T cell service coordinator** works with you and your health insurer to learn about your treatment benefits. They know the insurance problems people face during CAR T cell therapy. Each health plan has its own policies and rules. When your insurer needs authorization, your CAR T cell service coordinator will help.

An **office coordinator** gives administrative support to your attending doctors and the nurses who work with them. You may talk with them to give us information, schedule an appointment, or have questions for your CAR T team.

A **care coordinator** works in an outpatient area. They track the flow of people in and out of the clinic. They make sure you schedule and complete all the tests, scans, and treatments your care team orders. Care coordinators also manage your health records and coordinate your future appointments.

A **clinical research coordinator** works with your care team. They'll explain some of the research studies, also called clinical trials, you may be able to join. These studies mostly involve collecting samples or data.

A **patient representative** is the connection between you, your family, and MSK's 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. They can help you communicate with your CAR T team.



A **clinical dietitian nutritionist** is a food and nutrition expert. They'll assess your nutritional health and talk with you and your caregiver about your diet. They will 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** explains how room service works, including when it's available and how to use it. They'll make sure you get the right menus and deliver your meals.

A **case manager** will see you while you're in the hospital. They'll give your health insurer updates it needs to pay for your care. They'll help you arrange home care, as needed.

## Your caregiver

Choosing your caregiver is an important step in getting ready for your CAR T cell therapy. They will support you before, during, and after your infusion. Caregivers are usually a family member or close friend.

Your caregiver will be responsible for some of the medical, practical, and emotional support you will need.

Talk with your social worker if you want to hire a home health aide. They will give you information about these services.



**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.

Your caregiver must take you to and from your daily visits to the Cellular Immunotherapy Unit. They may not be able to work. They must stay with you for most of the day and night. Your caregiver can have some personal time while you're in the Cellular Immunotherapy Unit for daily visits. We strongly recommend they take this time.

Your caregiver must be available 24 hours a day, 7 days a week during treatment and for some time after. The exact length of time you'll need 24/7 caregiver support may vary. Your CAR T team will give them instructions about what they need to do. Here are some of the things your caregiver must do.

### Medical support

- Get information from your CAR T team.
- Make sure you take your medicine.
- Keep a written record of when you take your medicine.
- Measure your temperature every 4 hours while you're awake and away from the Cellular Immunotherapy Unit.
- Keep a written record of your temperatures.
- Keep a written record of how much you drink each day.
- Know how to take care of your central venous catheter (CVC).
- Notice any changes in your condition.
- Tell your CAR T team about any changes in your condition or new symptoms.
- Call for medical help in an emergency.

## **Practical support**

- Take you to and from your daily appointments.
- Deal with financial and insurance issues.
- Handle food safely to prevent foodborne illness (food poisoning).
- Keep the place you're staying clean.
- Keep family members and friends up to date about your condition.
- Manage how many visitors you have.
- Keep you away from anyone who's sick.

## **Emotional support**

- Pay attention to your moods and feelings.
- Communicate with you and listen to you.
- Understand your needs and your decisions.
- Feel comfortable contacting your care team if they're worried about your emotional state.

**The caregiver role for an outpatient CAR T cell infusion is full time, 24 hours a day, 7 days a week.** It's tiring, demanding, and stressful. That's even more true 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 (leave) the hospital. We recommend you have a full-time, 24 hours a day, 7 days a week caregiver for the first 2 weeks after discharge. The exact length of time you'll need 24/7 caregiver support can vary.

Your CAR T team will give your caregiver instructions about what they need to do. Here are some of the things your caregiver must do.

### **Medical support**

- Make sure you take your medicine.
- Make sure you're drinking enough and getting enough nutrients.
- Notice any changes in your condition.
- Call for medical help in an emergency.

### **Practical support**

- Take you to and from your daily appointments.
- Deal with financial and insurance issues.
- Handle food safely to prevent foodborne illness (food poisoning).
- Keep the place you're staying clean.
- Keep family members and friends up to date about your condition.
- Manage how many visitors you have.
- Keep you away from anyone who's sick.

### **Emotional support**

- Pay attention to your moods and feelings.
- Communicate with you and listen to you.
- Understand your needs and your decisions.
- Feel comfortable contacting your care team if they're worried about your emotional state.

## Choosing the right caregiver

Your caregiver must stay positive, calm, and flexible while giving you the support and encouragement you need. It's also important for you to understand that the caregiver role is challenging. At times, your caregiver may feel overwhelmed by their role.

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 do not have 1 person to be your caregiver, it's OK 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. There are resources and support to help manage the many duties of caring for a person having CAR T cell therapy.

Contact your social worker for support resources and information. MSK's Caregivers Clinic supports caregivers who are having a hard time coping with the demands of being a caregiver. Visit [www.msk.org/caregivers](http://www.msk.org/caregivers) or call 646-888-0200 to learn more.

# Your pretreatment evaluation

Before you can have CAR T cell therapy, we will check your overall physical condition. 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 a few trips to MSK to have tests. We often call this the work-up or restaging period. During the work-up, you must have some, but not always all, of these tests.

- **Chest X-ray.** This test confirms your lungs are clear and there's no sign of infection or other problems.
- **Blood tests.** These are done to check a few things. This includes how well your kidneys and liver work, blood counts, and if you've been exposed to certain viruses.
- **Urine test.** This checks if there's anything abnormal (not normal) 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 gives more detailed images of soft tissue and bone than a standard X-ray. Sometimes, CT scans use contrast dye that you drink or have injected into your veins. It's very important to tell your doctor if you know you have an allergy to contrast dye, seafood, or iodine. If you have a mild allergy, you can still have contrast dye. But you must take medicine before getting the dye so you do not have a reaction.
- **Positron emission tomography (PET) scan.** This is a radiology test that's used to look at some 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 see if cancer harmed your bones. It's most often 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. Most often, it's taken from the back of your hip. Your doctor will numb your hip and place a needle into your bone marrow. They'll take out a small amount of bone marrow.

Your doctor may do a bone marrow biopsy at the same time. This procedure collects a tiny piece of bone to examine. This is done to check how well your bone marrow is making cells. They will also look for any sign of cancer in the marrow.

These tests most often are done in the 30 days before your CAR T cell infusion (Day -30 onwards). Sometimes, the pretreatment evaluation can take longer.

Your CAR T team will work with you and your caregiver to schedule the tests. Your care team will use the results of the tests to plan your treatment. They'll make sure it's safe to start.

Your care team will explain any other tests you may need.

# Your preadmission appointment

You'll have your preadmission appointment after you finish your pretreatment evaluation and your CAR T cell infusion is scheduled. This appointment most often is 1 to 2 weeks before your scheduled CAR T cell infusion.

During this appointment:

- Your doctor will review your treatment plan with you. They will go over the consent forms. You'll sign consent for your CAR T cell therapy, if you have not already signed it.
- Your clinical nurse coordinator will give you a calendar with your treatment plan. They'll review the information with you and answer your questions.
- You'll meet with your clinical pharmacist again. They'll review the medicine you'll take during and after your CAR T cell therapy.
- We may ask you to sign a consent form for a transfusion, if you did not sign one already. You may need blood or platelet transfusions when your blood counts are low after your treatment. Read *About Your Blood Transfusion* to learn more. You can find it in the "Educational resources" section of this guide.





**You must stay healthy 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 these things:**

- 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, which is 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 healthcare provider will decide if we should delay your admission for CAR T cell therapy. It could be very dangerous to start your chemo while you have an infection, even if it's just a cold. This is because your immune system will not be able to fight the infection.

# Having your central venous catheter (CVC) 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 and draw your blood. It also helps them give you fluids, electrolytes, blood transfusions, chemo, and other medicine. They will not have 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. Read *About Your Tunneled Catheter* to learn more. You can find it in the "Educational resources" section of this guide.
- A **peripherally inserted central catheter (PICC)** is put into a large vein in your arm. Read *About Your Peripherally Inserted Central Catheter (PICC)* to learn more. You can find it at [www.msk.org/pe/about-picc](http://www.msk.org/pe/about-picc) or ask for a printed copy.

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

# What to expect in the hospital

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

## While you're in the hospital

There are a few units in the hospital that care for CAR T cell patients. The nurses on each unit have special training in caring for people having CAR T cell therapy. All the units follow the same guidelines.

You may need to change your room or floor while you're in the hospital. We try to avoid this as much as possible. You may be in either a semi-private room or private room.

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

Your nurses, patient care technicians, and nursing assistants most often work for 12-hour shifts. The shifts start at 7 a.m. or 7 p.m. When nursing shifts change, your nurse will update the nurse taking over. They'll tell them anything they should know about you and your care during that shift.

## The hospital environment

- Follow any instructions for people staying on your floor.
- Keep your hands clean. Read *Hand Hygiene and Preventing Infection* to learn more. You can find it in the "Educational resources" section of this guide.
- Your room will have Wi-Fi and a TV with cable channels. You can also bring a streaming device to use on your TV. Amazon Fire TV Stick, Roku Streaming Stick, Google TV Streamer, and Apple TV are examples of streaming devices.

- You'll be connected to an IV pole with electronic pumps during most of your hospital stay. Disconnecting from the IV pole often can raise your risk for a CVC infection. It's important to keep your IV pole connected during your stay.
- If you're at risk for falling, someone will help you get to the bathroom. Your care team will tell you more about how to keep from falling while you're in the hospital. Read *Call! Don't Fall!* to learn more. You can find it at [www.msk.org/pe/call\\_dont\\_fall](http://www.msk.org/pe/call_dont_fall) or ask for a printed copy.

## Testing and evaluations

- A member of your care team will weigh you and take a sample of your blood before 6 a.m. each day. They will check to see how your white blood cells, red blood cells, and platelets are recovering.
- We will do other blood tests as needed. These tests check how well your kidneys and liver work and check for infections. The tests tell us the level of chemo or other medicine in your blood. This information helps your care team assess your overall condition.
- Your care team will check your vital signs every 4 hours, even during the night. This includes your blood pressure, heart rate, breathing, and pain level.
- Your care team will give you medicine during your stay. Please do not bring any of your own medicine to the hospital.
- Your care team will measure your urine throughout the day. It's important that we know how much urine you're making. They will also ask you how much water or liquids you're drinking.
- You'll have tests to check your neurological (brain) function. Your nurse may ask you simple questions.

## Visitors

- Your family and friends are welcome to visit you. You must not have any visitors who:
  - Have symptoms of an illness, such as a cough, rash, fever, or diarrhea.
  - Think they may be getting sick.
  - May have recently been exposed to someone with an infectious (contagious) 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 limit the spread of bacteria in your room.
- You are not allowed to have fresh, dried, or live flowers or plants in your room. Please tell your family and friends not to bring or send them.
- Children aged 12 and under cannot visit some inpatient floors, including M7 and M8.

## Exercise

You'll feel tired after your chemo and CAR T cell infusion. But you should still try to stay active and get out of bed each 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. Do not leave the floor when you're walking or exercising.

Soon after you're in the hospital, you'll meet with a physical therapist. They'll 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. Tell us what you need so we can send the right member of your care team member to help.

## Diet

Your CAR T team will plan your diet. They will give you a menu and instructions for ordering your meals. A room service associate will deliver your meals to you.

If you keep kosher, have diabetes, or follow another special diet, tell your clinical dietitian nutritionist. We will prepare your meals properly. Your clinical dietitian nutritionist is also here to help you plan your meals.

## Showering

You'll be expected to shower daily. A patient care technician or nursing assistant will be in your room when you're showering. They'll 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 *Mouth Care During Your Cancer Treatment* to learn more. You can find it at [www.msk.org/pe/mouth\\_care](http://www.msk.org/pe/mouth_care) or ask for a printed 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. We'll only admit you to the hospital if you need more care than we can give you as an outpatient.

## What to bring to the Cellular Immunotherapy Unit

- A list of all prescription and nonprescription medicines you're taking, their dosages, and how often you take them. This should include patches, creams, vitamins, nutritional supplements, herbal products, and over-the-counter medicines. An over-the-counter medicine is one you can buy without a prescription.
- All the prescription medicines you were told to take during your CAR T cell therapy.
- Your *Outpatient Cellular Therapy Temperature & Liquid Intake Log*. Your caregiver will use this to keep track of your temperature and liquid intake while you're away from the unit. We will give this to you, or you can print it from [www.msk.org/pe/cellular\\_therapy\\_log](http://www.msk.org/pe/cellular_therapy_log)
- Things to pass the time, such as books, newspapers, an audio player, a laptop, or tablet. Do not forget the charger for your electronic items.
- A notebook to write down information and any questions you or your caregiver have.

# While you're in the Cellular Immunotherapy Unit

Please arrive at your scheduled time.

Wear comfortable clothing. Wear clothing that makes it easy to access your CVC. This can be a shirt that opens in the front, a sweatshirt, or a large T-shirt. Do not wear clothing that's hard to take off or put back on.

## After you arrive

After you check in, a member of your care team will bring you to a room. They will:

- Check your vital signs and weight.
- Ask you about any symptoms you have.
- Check your blood counts, electrolyte levels, and kidney function (how well your kidneys are working).

Then, you'll wait in your room for your test results to be ready. This can take a few hours. You'll have an entertainment unit with a TV and computer to pass the time. You can also bring food and snacks with 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 your caregiver leaves the hospital and takes this time to relax.

## Planning your care

Your CAR T team will plan your care after they get the results from your blood tests (sometimes called labs). 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 medicines.
- Your treatment could be left as is.

You'll stay in the unit until you finish your treatments. After that, your caregiver will take you to where you're staying. There, they'll monitor your temperature and how much you drink.

Read *About Your Appointments in MSK's Cellular Immunotherapy Unit* to learn more. You can ask for a printed copy or find it at [www.msk.org/pe/about\\_cellular\\_immunotherapy\\_unit](http://www.msk.org/pe/about_cellular_immunotherapy_unit)

## What to do in your home or apartment

Your caregiver will take care of you when you're not in the Cellular Immunotherapy Unit.

We will give you a printed copy of these resources, or you can find them online. Keep them out in your home or apartment so you and your caregiver can get them easily.

- *Outpatient Cellular Therapy Temperature & Liquid Intake Log*  
[www.msk.org/pe/cellular\\_therapy\\_log](http://www.msk.org/pe/cellular_therapy_log)
- *Outpatient Cellular Therapy Emergency Guide*  
[www.msk.org/pe/cellular\\_therapy\\_emergency\\_guide](http://www.msk.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. This is about 8 cups. 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 chemo, your caregiver must take your temperature every 4 hours while you're awake. We will give you 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. Follow the instructions in your *Outpatient Cellular Therapy Emergency Guide*.

Call the Cellular Immunotherapy Unit at 646-608-3150 while you're on your way there.

## Check for bleeding

Always tell someone from your CAR T team if you have any bleeding. If you notice you're bleeding and you're not in the Cellular Immunotherapy Unit, follow these steps right away:

1. Put pressure directly on the bleeding site. If you're bleeding from your nose, also put ice over the bridge of your nose.
2. Follow the instructions in your *Outpatient Cellular Therapy Emergency Guide*. Call the Cellular Immunotherapy Unit at 646-608-3150. Your care team will give you more instructions based on the 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 (poop), blood in your bowel movements, or bleeding from your anus.
- Blood in your urine (pee).
- A headache that does not get better.
- Blurred vision.
- Dizziness.
- Coughing up or vomiting blood.
- A nosebleed that does not stop after putting pressure or ice for a few minutes.

## Move around and exercise

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

To learn more about why it's important to stay active and what your care team can do to help, read *Staying Active During Stem Cell Transplant*. You can find it at [www.msk.org/pe/active\\_sct](http://www.msk.org/pe/active_sct) or ask for a printed copy.

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# Phases of CAR T cell therapy

There are 6 phases of CAR T cell therapy. This table gives a summary of each phase. Keep reading to learn more about each of the phases.

	Description
<b>Phase 1:</b> T cell collection	<p>We collect some of your T cells from your blood. Then, we send them to a lab to be genetically modified (changed) into CAR T cells. This will help them recognize and kill cancer cells.</p> <p>This step is done about 4 to 6 weeks before your infusion. It takes about 2 to 4 hours.</p>
<b>Phase 2:</b> 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 may also get other treatment during this time. This will help control the cancer before your CAR T cell treatment starts.</p> <p>T cell modification takes about 3 to 4 weeks.</p>
<b>Phase 3:</b> Lymphodepleting chemo (conditioning)	<p>Once your CAR T cells arrive at MSK, you'll get lymphodepleting chemo. This chemo will help the CAR T cells work better at finding and killing cancer.</p> <p>You will get lymphodepleting chemo about 3 days before your infusion. Your CAR T team will tell you how long it will take.</p>
<b>Phase 4:</b> CAR T cell infusion	<p>Your CAR T cells will be infused into your bloodstream through an IV. This may be done in the Cellular Immunotherapy Unit or the hospital.</p> <p>CAR T cell infusion takes about 5 to 30 minutes.</p>

<p><b>Phase 5:</b> Early recovery</p>	<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><b>Phase 6:</b> 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.</p> <p>You may be coming from another hospital. If so, you may be seen by the doctor who referred (sent) you to MSK between your visits to MSK.</p> <p>Long-term recovery lasts for about 100 days or longer after your infusion.</p>

# Phase 1: T cell collection

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

## Before your T cell collection

### Have a leukapheresis catheter placed, if needed

If you need a leukapheresis catheter, it will be placed 1 to 2 days before your collection. Your nurse will tell you what to expect. You can also read *About Your Tunneled Catheter*. You can find it in the "Educational resources" section of this guide.

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

### Eat foods high in calcium

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 may feel cold during the procedure. We will give you blankets to make you comfortable.

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. They will give you medicine as needed. If you feel numbness or tingling in your fingertips or

around your mouth, tell your donor room nurse. These are signs your calcium level is low. Your donor room nurse can give you calcium tablets to help.

## After your T cell collection

**If you had an IV line in your arm:** Your donor room nurse will take it out. They'll apply a bandage to prevent bleeding. They'll tell you when you can take the bandage off.

If you're still bleeding after you take the bandage off, put gentle, firm pressure on the site for 3 to 5 minutes. Call your doctor if the bleeding does not stop.

**If you had a leukapheresis catheter:** Your donor room nurse will schedule an appointment to take it out 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 to have a new gene added to them. This is called **genetic modification** (change). 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.

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

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

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



## **Phase 3: Lymphodepleting chemotherapy (conditioning)**

Once we get your CAR T cells, you'll have lymphodepleting chemo.

Lymphodepletion (LIM-foh dih-PLÉE-shun) is the process of lowering your white blood cell numbers with chemo. It's done to help get your body ready for the CAR T cells.

Most people get lymphodepleting chemo in the Cellular Immunotherapy Unit. It's most often done a few days before the CAR T cell infusion. Your clinical nurse coordinator will give you your schedule. They'll talk with you about what to expect. Your schedule depends on your medicine 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 most often happens the day before your infusion. Your infusion will take place in your hospital room.

**If you're having an outpatient CAR T cell infusion:** Your infusion will take place 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 medicine to help keep you from having a reaction to the infusion. If you do not have a CVC, you'll get an IV line placed in 1 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 healthcare provider will give you the CAR T cell infusion through your CVC or IV line. The infusion can take 5 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

We will watch you 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 very tired
- Nausea
- Vomiting
- A faster heart rate than usual
- Feeling dizzy or lightheaded

Common neurologic changes include:

- Confusion
- Trouble finding words
- Tremors
- Seizures (shaking you cannot control)
- Sleeping more than usual
- Feeling very drowsy and responding more slowly than usual

Not everyone gets the same type of CAR T cell therapy. Everyone does not respond the same to each type of therapy.

**These side effects will go away.** Your care team will watch you carefully for side effects. They'll manage any side effects. It's very important you or your caregiver tell your care team if you may be 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.

## Early recovery after inpatient CAR T cell infusion

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 you moving to the Intensive Care Unit (ICU).

Once you're ready, you'll be discharged from the hospital. If you live more than 2 hours from MSK, you'll stay in an apartment near the hospital or at MSK's 75th Street Patient Residence.

Before you leave the hospital, your CAR T team will give you discharge instructions. Here are some guidelines to follow:

- Call your CAR T team if you have:
  - A fever of 100.4 °F (38.0 °C) or higher
  - Chills
  - Confusion
  - Hallucinations (seeing or hearing things that are not there)
  - Headaches
  - Seizures
  - Dizziness or lightheadedness
  - Trouble breathing
  - Bleeding
  - A faster heart rate than usual
  - Severe nausea, vomiting, or diarrhea
  - Pain
  - Any other changes in condition
- Do not drive for 8 weeks or until your care team says it's OK to.
- Carry your wallet card with you at all times. Show it if you go to the emergency room, urgent care, hospital, or when you see a doctor.

- If you go home with your CVC or PICC, your nurse will teach you how to care for it at home.
- Avoid family and friends that may be sick.

## **Early recovery after outpatient CAR T cell infusion**

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 doctor'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 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.

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# Educational resources

This section lists the educational resources mentioned in this guide and some other resources that may be helpful.

You can find these resources online or you can ask for a printed copy. You can also search for more educational materials on the Patient and Caregiver Education website, [www.msk.org/pe](http://www.msk.org/pe)

***About Your Appointments in MSK's Cellular Immunotherapy Unit***

[www.msk.org/pe/about\\_cellular\\_immunotherapy\\_unit](http://www.msk.org/pe/about_cellular_immunotherapy_unit)

***About Your Blood Transfusion***

[www.msk.org/pe/blood\\_transfusion](http://www.msk.org/pe/blood_transfusion)

***About Your Peripherally Inserted Central Catheter (PICC)***

[www.msk.org/pe/about-picc](http://www.msk.org/pe/about-picc)

***About Your Tunneled Catheter***

[www.msk.org/pe/about\\_tunneled\\_catheter](http://www.msk.org/pe/about_tunneled_catheter)

***Advance Care Planning for People With Cancer and Their Loved Ones***

[www.msk.org/pe/advance\\_care\\_planning](http://www.msk.org/pe/advance_care_planning)

***Axicabtagene Ciloleucel (Yescarta)***

[www.msk.org/cancer-care/patient-education/medications/adult/axicabtagene-ciloleucel](http://www.msk.org/cancer-care/patient-education/medications/adult/axicabtagene-ciloleucel)

***Brexucabtagene Autoleucel (Tecartus)***

[www.msk.org/cancer-care/patient-education/medications/adult/brexucabtagene-autoleucel](http://www.msk.org/cancer-care/patient-education/medications/adult/brexucabtagene-autoleucel)

***Building Your Family After Cancer Treatment: For People Born With Testicles***

[www.msk.org/pe/building\\_family\\_born\\_testicles](http://www.msk.org/pe/building_family_born_testicles)

***Building Your Family After Cancer Treatment: For People Born With Ovaries and a Uterus***

[www.msk.org/pe/building\\_family\\_ovaries\\_uterus](http://www.msk.org/pe/building_family_ovaries_uterus)

***Call! Don't Fall!***

[www.msk.org/pe/call\\_dont\\_fall](http://www.msk.org/pe/call_dont_fall)

***Ciltacabtagene Autoleucel (Carvykti)***

[www.msk.org/cancer-care/patient-education/medications/adult/ciltacabtagene-autoleucel](http://www.msk.org/cancer-care/patient-education/medications/adult/ciltacabtagene-autoleucel)

***Communicating With Your Care Team: When to Call or Use MSK MyChart***

[www.msk.org/pe/communicating-using-mychart](http://www.msk.org/pe/communicating-using-mychart)

***Fertility Preservation Before Cancer Treatment: Options for People Born with Ovaries and a Uterus***

[www.msk.org/pe/fertility\\_starting\\_treatment](http://www.msk.org/pe/fertility_starting_treatment)

***Food Safety During Cancer Treatment***

[www.msk.org/pe/food\\_safety](http://www.msk.org/pe/food_safety)

***Hand Hygiene and Preventing Infection***

[www.msk.org/pe/hand\\_hygiene](http://www.msk.org/pe/hand_hygiene)

***How to Be a Health Care Agent***

[www.msk.org/pe/health\\_care\\_agent](http://www.msk.org/pe/health_care_agent)

***Idecabtagene Vicleucel (Abecma)***

[www.msk.org/cancer-care/patient-education/medications/adult/idecabtagene-vicleucel](http://www.msk.org/cancer-care/patient-education/medications/adult/idecabtagene-vicleucel)

***Improving Your Vulvovaginal Health***

[www.msk.org/pe/improving\\_vulvovaginal\\_health](http://www.msk.org/pe/improving_vulvovaginal_health)

***Lisocabtagene Maraleucel (Breyanzi)***

[www.msk.org/cancer-care/patient-education/medications/adult/lisocabtagene-maraleucel](http://www.msk.org/cancer-care/patient-education/medications/adult/lisocabtagene-maraleucel)

***Mouth Care During Your Cancer Treatment***

[www.msk.org/pe/mouth\\_care](http://www.msk.org/pe/mouth_care)



***Outpatient Cellular Therapy Emergency Guide***

[www.msk.org/pe/cellular\\_therapy\\_emergency\\_guide](http://www.msk.org/pe/cellular_therapy_emergency_guide)

***Outpatient Cellular Therapy Temperature & Liquid Intake Log***

[www.msk.org/pe/cellular\\_therapy\\_log](http://www.msk.org/pe/cellular_therapy_log)

***Sex and Your Cancer Treatment***

[www.msk.org/pe/sex\\_cancer\\_treatment](http://www.msk.org/pe/sex_cancer_treatment)

***Sexual Health and Intimacy***

[www.msk.org/pe/sexual\\_health\\_intimacy](http://www.msk.org/pe/sexual_health_intimacy)

***Sperm Banking***

[www.msk.org/pe/sperm\\_banking](http://www.msk.org/pe/sperm_banking)

***Staying Active During Stem Cell Transplant***

[www.msk.org/pe/active\\_sct](http://www.msk.org/pe/active_sct)

***Tisagenlecleucel (Kymriah)***

[www.msk.org/cancer-care/patient-education/medications/adult/tisagenlecleucel](http://www.msk.org/cancer-care/patient-education/medications/adult/tisagenlecleucel)

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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 you feel better.
- **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. To learn more, read *Being Your Own Blood Donor* ([www.mskcc.org/pe/being-your-own-blood-donor](http://www.mskcc.org/pe/being-your-own-blood-donor)).

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 provider 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 likely use it for your transfusion.
- If you have an implanted port (sometimes called 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 90 minutes to 4 hours. A transfusion of one unit of platelets takes about 30 to 90 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 you may have some bruising or irritation in the area where the needle was.

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

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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About Your Blood Transfusion - Last updated on December 26, 2023

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PATIENT & CAREGIVER EDUCATION

# About Your Tunneled Catheter

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

## About tunneled catheters

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

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

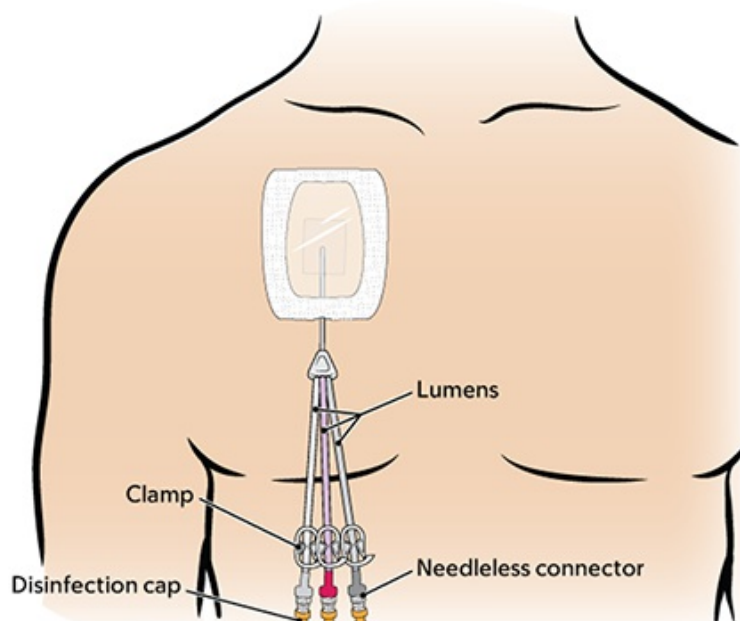


Figure 1. Tunneled catheter

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

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

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

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

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

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

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

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

# What to do before your procedure

## Ask About Your Medications

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

### Blood thinners

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

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

- Apixaban (Eliquis®)
- Aspirin
- Celecoxib (Celebrex®)
- Cilostazol (Pletal®)
- Clopidogrel (Plavix®)
- Dabigatran (Pradaxa®)
- Dalteparin (Fragmin®)
- Dipyridamole (Persantine®)
- Edoxaban (Savaysa®)
- Enoxaparin (Lovenox®)
- Fondaparinux (Arixtra®)
- Heparin (shot under your skin)
- Meloxicam (Mobic®)
- Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil®, Motrin®) and naproxen (Aleve®)
- Pentoxifylline (Trental®)
- Prasugrel (Effient®)
- Rivaroxaban (Xarelto®)
- Sulfasalazine (Azulfidine®, Sulfazine®)
- Ticagrelor (Brilinta®)
- Tinzaparin (Innohep®)
- Warfarin (Jantoven®, Coumadin®)

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

## **Medications for diabetes**

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

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

## **Diuretics (water pills)**

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

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

## **Take devices off your skin**

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

- Continuous glucose monitor (CGM)
- Insulin pump

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

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

## **Arrange for someone to take you home**

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

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

### **Agencies in New York**

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

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

## **Note the time of your appointment**

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

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

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

## What to do the day before your procedure

### Instructions for eating before your procedure



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

## What to do the day of your procedure

### Instructions for drinking before your procedure



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

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

## Things to remember

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

## What to bring with you

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

## What to expect when you arrive

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

## Meet with a nurse

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

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

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

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

## **Inside the procedure room**

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

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



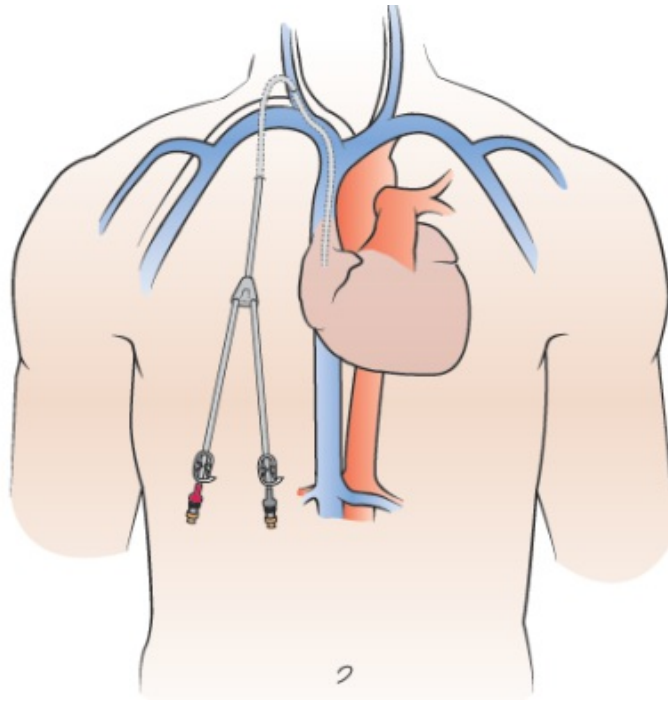


Figure 2. Catheter tunneled under your skin, into a vein

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

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

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

## What to do after your procedure

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

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

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

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

Do not shower for 24 hours after your procedure.

## **Your central line discharge kit**

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

The discharge kit has:

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

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

## **How to care for your catheter exit site**

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

## **Have a nurse change your dressing**

Have a nurse change your dressing:

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

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

## **How to care for your neck incision**

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

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

## **How to care for your tunneled catheter at home**

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

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

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

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

## **What to do if your catheter is leaking**

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



Figure 3. Toothless clamp

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

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

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

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

## **What to do if your disinfection cap falls off**

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

To put on a new disinfection cap:

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

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

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

To put on a new needleless connector:

1. Gather your supplies. You will need:
  - 1 pair of nonsterile gloves
  - 2 alcohol pads
  - 1 new needleless connector
  - 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 do not write with). Hold it close to the end (see Figure 3).

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

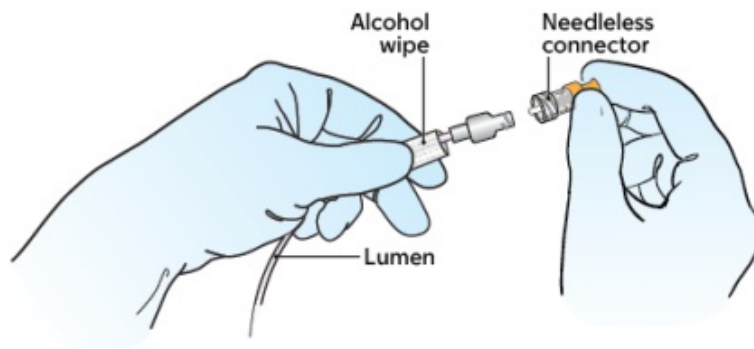


Figure 4. Twisting on the new needleless connector

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

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

# Guidelines for showering with a tunneled catheter

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

## Use a waterproof cover

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

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

1. Peel off the top and side strips.
2. Place the top edge above your dressing. Do not let the tape on the waterproof cover touch your Tegaderm dressing. It can lift your dressing when you remove the waterproof cover after showering. Smooth the cover down over your dressing.
3. Peel off the bottom strip. Make sure the bottom edge of the waterproof cover is below your dressing. Make sure the lumens of your catheter are tucked into the waterproof cover and completely covered. Smooth the bottom edge down.

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

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



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

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

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

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

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

## **Use Hibiclens® skin cleanser**

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

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

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

## Instructions for using Hibiclens

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

## Things to remember when using Hibiclens

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

# When to call your healthcare provider

Call your healthcare provider right away if:

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

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

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

About Your Tunneled Catheter - Last updated on October 16, 2023

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PATIENT & CAREGIVER EDUCATION

# Food Safety During Cancer Treatment

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

## What is foodborne illness?

Foodborne illness is caused by germs that get into the food you eat. Germs such as bacteria, viruses, or parasites can attach to food and grow. You cannot always see, smell, or taste these germs.

## Who is at risk to get foodborne illness?

Foodborne illness can happen to anyone, but some people are more likely to get it than others. People are at higher risk if their immune system is weakened by cancer and cancer treatment.

Some people may need to take extra steps to avoid foodborne illness. This includes people who had a stem cell transplant. Your care team will tell you if this applies to you.

## What are the symptoms of foodborne illness?

Symptoms often happen within 1 to 3 days after eating the contaminated food. 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 poop)
- Pain in your abdomen (belly)
- Flu-like symptoms, such as:
  - A fever above 101.3 °F (38.5 °C)
  - A headache
  - Body aches
  - Chills

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

## How can I prevent foodborne illness?

It's important to handle food safely to lower your risk. Foodborne illness can be serious or even deadly.

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



### 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 touching pets.
- Wash cutting boards, dishes, forks, spoons, knives, and countertops with hot soapy water after preparing each food item.
- Use clean glass, plastic, or wooden cutting boards.

- Use paper towels to clean up kitchen surfaces, if you can. Germs 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 sprays that have bleach or ammonia, such as Lysol® or Clorox®.
- Rinse all fruits, vegetables, and other produce under running water. This includes produce with skins and peels you don't eat, 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. You can put it in your dishwasher or wash it with hot, soapy water.
- Avoid produce that has bruises or blemishes.
- Clean the lids of canned goods before you open them.

## **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.
- Do not store raw meats, poultry, or seafood in your refrigerator above produce or other foods you do not cook before eating.
- Use one cutting board for produce and another one for raw meats, poultry, and seafood.
- Do not use any plate that held raw meat, poultry, seafood, or eggs on it without washing it first. Wash the plate with hot, soapy water before you use it again.
- Don't reuse marinades used on raw meats, poultry, or seafood unless you heat them to a boil first.



## Cook foods to the right temperature

- The best way to tell if food is cooked enough to be safe is to check the internal temperature. That's the temperature of the middle of the food. Food color and texture are not always reliable ways to tell if foods are fully cooked.
- Use a food thermometer to check the internal temperature of meat, poultry, seafood, and egg products as they cook. You must cook these foods to a certain temperature to kill any harmful germs. This is called the safe minimum internal temperature (see Table 1).
- Cook eggs until the yolk and white are firm. Choose recipes that only use eggs that 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, pause it and turn the food yourself once or twice while it's 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 you reheated, throw it away. Don't put it back in the refrigerator.

### How do I know when cooked food is safe to eat?

Measure the internal temperature of your food as it's cooking. Different foods must reach a certain internal temperature before they are safe to eat.

Use a food thermometer to measure the internal temperature of your food as it's cooking. Push the thermometer into the center of the food. The numbers on the thermometer will go up slowly. Hold the thermometer in



place until the numbers stop going up.

The table below shows the minimum (lowest) internal temperatures for a food to be safe to eat. The temperature on the thermometer should be the same or higher than the temperature in the table. If the temperature is lower than the temperature in the table, keep cooking the food. Once the food reaches the temperature in the table, it's fully cooked and safe to eat.

Type of food	Safe minimum internal temperature
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 (such as 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)
Leftovers and casseroles	165 °F (74 °C)

Table 1. Safe minimum internal food temperatures



## Chill foods right away

- Make sure the refrigerator is 40 °F (4 °C) or lower inside.
- Make sure the freezer is 0 °F (-18 °C) or lower inside.
- Refrigerate or freeze meat, poultry, eggs, seafood, and other perishables (foods that can go bad). Do this 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, keep perishables cold when you bring them home after shopping. Use an insulated bag, or a cooler with ice or frozen gel packs.
- Defrost food in the refrigerator, cold water, or a microwave. If you use

cold water or a microwave, cook the food right away once it's defrosted. Never defrost food at room temperature, such as on the countertop.

- When you marinate food, always marinate it in the refrigerator.
- Split up large amounts of leftovers into shallow containers before refrigerating them. This helps them cool more quickly.
- Eat leftovers within 2 days.

## **Common Questions**

### **How can I store my groceries safely?**

- Keep perishable foods cold if you need to make a stop after grocery shopping. Use an insulated bag or cooler with ice or frozen gel packs to keep them cold.
- Put eggs and milk on a shelf inside the refrigerator. Don't store them in the refrigerator door. Food stays cooler inside the refrigerator than on the door.
- If you use a grocery delivery service:
- Make sure all refrigerated and frozen items are at a safe temperature when they're delivered.
- Put these items into the refrigerator or freezer right away.

### **How can I make safe choices while grocery shopping?**

- Check containers for an expiration date. Do not buy the item if the date has passed.
- Do not buy canned, jarred, or boxed foods with dents, swelling, or a broken seal.
- Do not buy foods from self-service bulk containers or bins. This includes nuts, grains, or other items that you portion into containers yourself.
- Pick up cold and frozen foods, such as milk and frozen vegetables, at the

end of your shopping trip. This helps limit the time they will be outside of a refrigerator or freezer.

## **Is it safe to eat at restaurants?**

It's safe for most people to eat at restaurants. Follow these guidelines to lower your risk of foodborne illness:

- Choose the restaurant carefully. You can see a restaurant's recent health inspection score by visiting your 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. This includes 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 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. These foods may not be kept hot or cold enough during transit.

If you had a stem cell transplant, you may need to avoid eating at restaurants for about 3 months. Talk with your healthcare provider about when it's safe for you to eat at restaurants.

## **Is it safe for me to take dietary supplements?**

How dietary products are made and stored is not regulated in the United States. This means they can be a health risk (infection or foodborne illness). Dietary supplements can also keep some medications from working as well as they should.

Talk with your MSK healthcare provider before taking any supplements, probiotics, homeopathic remedies, or herbal products. This includes St. John's wort and traditional Chinese medicines, such as herbs, roots, or seeds.

## **How do I know if my drinking water is safe?**

Tap water from most big cities (such as New York City) is safe to drink. If you're not sure if the tap water in your area is safe, check with your local health department.

Never drink water from lakes, rivers, streams, or springs. If you use well water that isn't tested for bacteria, boil it before you drink it. To do this:

- Bring the water to a rolling boil (large, fast-moving bubbles) for 15 to 20 minutes.
- Store the water in the refrigerator and use it within 48 hours (2 days).
- After 2 days, pour any leftover water down the drain. Do not drink it.

You can also use bottled water instead of well water. Visit [www.epa.gov/privatewells/potential-well-water-contaminants-and-their-impacts](http://www.epa.gov/privatewells/potential-well-water-contaminants-and-their-impacts) for more information about well water.

## **What foods I should avoid eating?**

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

- Raw or undercooked meat, poultry, seafood (including sushi), eggs, and meat substitutes, such as tempeh and tofu.
- Unpasteurized (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. Cooked meats on other foods, such as pepperoni on pizza, are safe to eat.

A clinical dietitian nutritionist can help you make safe food choices by understanding risks of eating certain foods. Talk with them about the risks of eating the foods in listed in the table below.

Food group	Food items
Milk and dairy	<ul style="list-style-type: none"> <li>• Milk, cheese, and other dairy products that are not in a refrigerator.</li> <li>• Cheese sliced at a deli counter. These cheeses may be sliced near deli meats. Choose sealed, pre-packaged cheese instead.</li> <li>• Unrefrigerated desserts or pastries with cream fillings or frosting. Choose packaged, shelf-stable products instead.</li> <li>• Soft-serve ice cream, soft-serve yogurt, and ice cream scooped at a restaurant.</li> </ul>
Meat, poultry, seafood, and eggs	<ul style="list-style-type: none"> <li>• Meat sliced at a deli counter. Choose sealed, pre-packaged deli meat instead.</li> <li>• Raw or partially cooked fish and shellfish. This includes caviar, sashimi, sushi, ceviche, and cold smoked seafood, such as lox.</li> <li>• Clams, mussels, and oysters in the shell.</li> <li>• Refrigerated pâtés and meat spreads.</li> </ul>
Fruits and vegetables	<ul style="list-style-type: none"> <li>• Produce that is bruised, dented, or has other markings on it.</li> <li>• Salads and produce from a deli or salad bar.</li> <li>• Pre-cut fruits and vegetables.</li> <li>• Vegetarian sushi, unless you make your own at home. Vegetarian sushi made at a store or restaurant may be prepared near raw fish.</li> </ul>
Drinks	<ul style="list-style-type: none"> <li>• Unpasteurized eggnog, apple cider, or other fruit or vegetable juices.</li> <li>• Fresh-squeezed fruit or vegetable juices, unless you make your own at home.</li> <li>• Unpasteurized beer and wine, such as microbrewery beers and those that aren't shelf-stable. Talk with your doctor before having any alcohol.</li> <li>• Fountain soda and other fountain drinks.</li> <li>• Water from a water fountain or other shared container.</li> </ul>
Nuts and	<ul style="list-style-type: none"> <li>• Unroasted nuts in the shell.</li> </ul>

grains	
Other	<ul style="list-style-type: none"> <li>• Herbal and nutritional supplements, including probiotic supplements to improve gut health. These usually come in capsule, gummy, powdered, or pill form.</li> <li>• Shared containers used by many people, such as condiments and milk at a coffee shop.</li> <li>• Any unpackaged, communal, or shared food items. This includes free samples or shared non-perishable pantry foods in your home.</li> </ul>

Table 2. Ask a clinical dietitian nutritionist about the risks of eating these foods

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

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

Food Safety During Cancer Treatment - Last updated on June 9, 2023

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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 infection. Everyone is at risk for 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 germs. Take action by cleaning your hands and asking your visitors to clean their hands.

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

Clean your hands:

- 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 right 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 your hands.
2. Rub your hands together. Rub the soap 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](http://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?

Clean your hands with an alcohol-based hand sanitizer:

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

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



# What is the right 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. 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. 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 healthcare provider. You can also visit the following website for more information:

**Centers for Disease Control and Prevention (CDC)**

[www.cdc.gov/hygiene/personal-hygiene/hands.html](http://www.cdc.gov/hygiene/personal-hygiene/hands.html)

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

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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Hand Hygiene and Preventing Infection - Last updated on May 16, 2023

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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 maintain sexual health and intimacy during your treatment.

## 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 care team 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” to learn more.

## 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.
- Try to relax. Being relaxed can help with sexual enjoyment. Choose a time and place when you can relax and have privacy.
- If sex is hard or uncomfortable:
  - Try different sexual positions. Some may be less tiring or more comfortable.
  - Vaginal moisturizers and lubricants can be helpful. Read the resource *Improving Your Vulvovaginal Health* ([www.mskcc.org/pe/improving\\_vulvovaginal\\_health](http://www.mskcc.org/pe/improving_vulvovaginal_health)).
  - Your care team can prescribe medicine to help with erections (getting hard for sex). Talk with your care team 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.

To learn more, read *Sex and Your Cancer Treatment* ([www.mskcc.org/pe/sex\\_cancer\\_treatment](http://www.mskcc.org/pe/sex_cancer_treatment)).

## **When to talk with your healthcare provider**

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 medicine 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.

## **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.

### **Counseling Center**

646-888-0200

[www.msk.org/counseling](http://www.msk.org/counseling)

160 E. 53<sup>rd</sup> St.

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](http://www.cancer.org)

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

The ACS has free booklets on cancer and sexual health called *Sex and the Adult Male With Cancer* and *Sex and the Adult Female With Cancer*. You can search for them on [www.cancer.org](http://www.cancer.org) or call to request printed copies.

## Look Good Feel Better Program

[www.lookgoodfeelbetter.org](http://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](http://www.cancer.gov)

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

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

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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