



## PATIENT & CAREGIVER EDUCATION

# Leaving the Hospital After Your Allogeneic Stem Cell Transplant

This information will help you get ready to go home after your allogeneic stem cell transplant.

As you read, write down or mark the places where you have questions. This will help remind you to ask your questions the next time you see your transplant team.

## Before going home after your transplant

Before you leave the hospital, it's important that you and your caregiver get ready for this transition. You'll still need to follow precautions to keep you healthy and prevent infection. It's important for you to take part in planning your care at home. Your transplant team will work with you to make plans for your follow-up care before you leave.

This phase of your recovery extends over a long period of time—discharge to 1 year (or longer) after your transplant. It's important to remember that even though your blood counts are coming back up to the normal range, your immune system is still very weak. You will still need to take

medicine and follow precautions to keep yourself healthy and avoid infection.

You may have some side effects after your transplant that may affect your organs. Your care team will tell you what to expect.

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

### **Medical alert jewelry**

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

Your bracelet or necklace should be engraved with the statements “Allo Stem Cell Transplant and Irradiated & CMV safe blood only.” This will let paramedics or hospital staff know what to do if you're in an accident and can't tell them yourself.

### **Going home after your transplant**

You may be very happy and feel ready to go home after your transplant. You may also have some worries. It's common to have worries about managing your care at home. Feeling confident and comfortable managing your

care takes time. During your follow-up visits, your social worker can help you get the services you need and give you emotional support.

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

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

## **How to prevent infection after your transplant**

It usually takes 12 to 18 months for your immune system to recover from your transplant. The first year after transplant is like your first year of life as a newborn baby. During this time, you're at risk for infection. Your transplant team will check your blood cell counts to see how well your immune system is working. Depending on your blood cell counts, they may make changes or additions to the guidelines below.

Here are a few general tips to keep from getting an infection:

- Wash your hands often with antibacterial soap and water or clean them with an alcohol-based hand sanitizer.
- Stay away from people who are sick or have recently been sick.
- Wear a mask while you're in public or if you may be near strangers (if your transplant team asks you to).
- Don't get body piercings or tattoos after your transplant. These increase your risk of hepatitis and other infections. Discuss any concerns you may have with your transplant doctor.

The following things can be a sign of infection. Call your doctor's office right away if you have:

- A fever of 100.4 °F (38.0 °C) or higher.
  - Do not take acetaminophen (Tylenol®) unless your healthcare provider tells you to.
  - You don't have to take your temperature every day. But, check it regularly if you don't feel well.
- Flushed (red, warm-feeling) skin, sweating, or shaking chills.

- Coughing, sneezing, runny nose, shortness of breath, or chest discomfort.
- Redness, swelling, or pain in your throat, eyes, ears, skin, joints, or abdomen (belly).
- Blurred vision or other changes in your ability to see clearly.
- Nausea (feeling like you're going to throw up), vomiting (throwing up), or diarrhea (loose or watery bowel movements).
- Urinating (peeing) more often than usual, a burning feeling when you urinate, or both.
- Irritation in your rectum, including burning and pain.
- A skin rash anywhere on your body. Rashes often look like redness, pimples, or blisters.
- Small blisters, similar to cold sores, around your mouth or on any other part of your body
- Trouble flushing your tunneled chest catheter, if you have one.

You can catch viruses more easily until your immune system is back to normal. One of these is the virus that causes chickenpox and shingles. If you're exposed to chickenpox or shingles, call your transplant team right away. You'll need to come in so they can see if you need

treatment.

It's also possible for viruses that you've had in the past to come back. For example, the virus that causes chickenpox and shingles can come back if you had chickenpox as a child. This often starts as pain in your skin with pimples or fluid-filled blisters. If you get blisters, they can be tiny or as large as a pencil eraser. They may be painful, itch, or burn. Call your transplant team right away if you have any of these symptoms so you can be treated.

Once your immune system has recovered, you'll start getting your childhood vaccines. This usually starts about 1 year after your transplant. Your transplant team will decide when the timing is right for you.

## **How to care for yourself at home**

### **Take a shower or bath every day**

Shower or bathe every day. It's important to keep yourself clean while you're recovering from your transplant. This can help prevent infection.

- Use a mild soap, such as Dove® or Basis®. Don't use Ivory® or deodorant soap. They can dry out your skin. If your skin is dry, talk with your care team
- Be sure to wash your underarms and groin.
- Use a washcloth and towel that are only for your

personal use.

- If you still have a tunneled catheter, don't let it soak in water while you bathe. Read *About Your Tunneled Catheter* ([www.mskcc.org/pe/about-tunneled-catheter](http://www.mskcc.org/pe/about-tunneled-catheter)) to learn more.
- If your skin is dry, don't use very hot water. Apply baby oil or a skin moisturizer, such as Eucerin® or CeraVe®. Put it on after you bathe, while your skin is still damp. Gently pat your skin dry with your towel. Don't use lotions containing alcohol. They'll make your skin more dry.

## **Protect yourself from the sun**

- Your skin will be more sensitive and may burn more easily after your transplant. The medicine you're taking may add to this. You may also have a higher risk of getting graft versus host disease (GVHD) or melanoma. Being in the sun for a long time may also reactivate cold sores or fever blisters.
- Whenever you're in the sun, protect your skin with a sunblock that has an SPF of at least 30. Reapply it often.

Limit your time in direct sunlight. If you'll be in direct sunlight for 20 minutes or more, wear a hat and clothing that protects the skin.

## **Use new cleaning solution and makeup**

- You can wear contact lenses, but make sure they're cleaned well before you put them in. Do not reuse cleaning solution. Throw cleaning solutions away when they expire.
- If your eyes are dry, use moisturizing drops.
- You can wear makeup but buy all new products after your transplant. Do not share makeup with others. Replace your eye makeup every 3 months to lower your chances of getting an infection.

## **Take care of your nails and hair**

New nails will grow and replace your old nails. This will happen gradually over 3 to 4 months after your transplant. Don't get a manicure or pedicure in a nail salon until your doctor says it's OK. You can paint your own nails, but do not use a nail clipper. Use a nail file.

Hair usually starts to grow back about 3 months after your transplant. It's possible that your hair may grow back with a different texture. Although it's rare, hair loss can happen months or years after the transplant.

Keep your hair and scalp clean. Don't use hair products with alcohol or fragrances. They can dry out your hair.



## Take care of your mouth

- You may have a dry mouth after your transplant. This raises your risk for infection. It's important to keep your mouth clean.
- Your care team will tell you when you can start using an ultra-soft toothbrush. This will be when:
  - Your absolute neutrophil count (ANC) is higher than 500 (sometimes called 0.5).
  - Your platelet count is 20,000 (sometimes called 20) or higher.

Ask your doctor or dentist when you can floss and brush your teeth with a regular toothbrush.

Tell your care team if you notice any sores, white patches, or bleeding in your mouth or on your lips.

- You may have mouth dryness for 3 to 4 months or longer after your transplant. Don't use store-bought, alcohol-based mouthwashes or hydrogen peroxide. They'll dry and irritate your mouth. Instead, use a mild salt water rinse. Make it by mixing together:
  - ½ teaspoon of salt
  - ½ teaspoon of baking soda
  - 8 ounces of water

- Your dentist may prescribe other rinses. Sucking on sugarless candy or lozenges may also help.
- Your salivary glands may not be as good at washing bacteria from your mouth after your transplant. This increases your risk of cavities. Use a toothpaste with fluoride. You can also use a mouthwash with fluoride once your mouth has fully recovered and is no longer very dry. Swish the mouthwash around in your mouth for at least 1 minute, then spit it out. Don't rinse.

## **Caring for your tunneled catheter**

It's just as important to keep your tunneled catheter clean at home as it was in the hospital. If you leave the hospital with a tunneled catheter, your nurse will teach you how to care for it at home. You'll have a chance to practice with them. You'll also get a kit with an extra clamp in case yours gets damaged.

Call your doctor's office right away if:

- You have redness, swelling, or drainage around the area where the catheter exits your body.
- Your needleless connector falls off.
- You have a fever of 100.4 °F (38 °C) or higher or chills.
- You have a break or leak in your catheter.

- You have an unexplained problem with your catheter.

## Your home environment

- Keep your home as free of dirt and dust as possible. But, don't go to extremes. For example, don't repaint your walls or put down new carpets.
- Don't be around any renovations or construction until your transplant team tells you it's okay. This includes those in process and those done within the past 3 months.
- Stay out of musty areas where mold might grow, such as a damp basement. You can use an air filtration system in your home, but you don't need to.
- Don't use a humidifier. Bacteria and mold grow easily in it. A pan of water placed near a heat source may help in the winter. If you do this, change the water every day.
- In general, try not to do any chores like dusting or vacuuming for the first 3 months after your transplant. Depending on your energy level, it's fine for you to cook, wash dishes, or iron.
- Keep your bathroom very clean, especially the tub and toilet. Make sure it's cleaned with a disinfectant regularly. It's best for someone else to do this chore.
- Wash your eating utensils, towels, and linens carefully.

They don't need to be washed separately from the rest of your household.

- Thoroughly wash all forks, spoons, and knives with hot water and dishwashing detergent or use a dishwasher.
- Wash towels twice a week and bed linens once a week. Use only your own towels and washcloths, not those of your family members.
- You can have household plants in your home. But, for the first few months after your transplant:
  - Don't touch the soil from household plants unless you wear gloves and a mask.
  - Don't touch the water in a vase of flowers. Someone else should change the water in the vases daily.

## **Pets**

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

Don't handle or care for birds, lizards, snakes, turtles, hamsters, or other rodents while you're recovering. If you

have an aquarium and need to clean it yourself, protect yourself by wearing gloves.

If you have a cat or dog at home, follow the additional guidelines below until your doctor gives you other instructions.

- Make sure your pet is up-to-date with immunizations and booster shots.
- Have your pet's veterinarian check your pet's stool (poop) for parasites every year.
- If you have a cat, get it tested for feline leukemia and toxoplasmosis every year.
- Have your pet treated for fleas. If your pet walks through wooded areas, have it screened for ticks every day during tick season (May to November). Talk with your pet's veterinarian about using a flea and tick collar.
- Don't clean cat litter boxes or clean up after your dog. Have someone else do these things for you.
- Keep your pets indoors or on your own property whenever you can. This is to help keep them from picking up diseases from other animals.
- Don't allow pets in your bed.
- Outside of your home, avoid close contact with animals in a farm or a petting zoo.

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

## **Family and visitors**

You can have close physical contact with people in your immediate family. But, don't have close contact with someone who has a cold or any signs of being sick. Wear a mask if you must be in the same room with someone who's sick. Your family members and close friends should get a yearly flu shot.

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

- A cold.
- Chickenpox.
- Recently been exposed to chickenpox.
- Recently been exposed to the herpes simplex virus (the virus that causes cold sores and genital sores).
- Recently been exposed to shingles.
- Recently been exposed to any other type of virus or infection.
- Recently received a vaccine with a live virus, such as varicella (the chicken pox virus) or rotavirus. There are very few of these, but if someone in your household

needs one, tell their doctor that you're immune suppressed and live in the same household.

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

## **Outside your home**

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

- Supermarkets
- Shopping malls
- Movie theaters
- Schools
- Restaurants
- Public transportation
- Places of worship (such as churches, synagogues, and mosques)

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

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

## Bleeding

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

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

If you go home with any of these symptoms and they increase in amount or frequency, call your doctor. If you haven't had any of these symptoms and they suddenly



appear, call your doctor. It may mean that your platelet count has changed.

If you have an injury that causes bleeding, don't panic. Stay calm and follow the guidelines below for the type of injury.

- **Open wounds:** If you cut yourself, put a clean, dry gauze pad, towel, or cloth over the cut. Press it firmly. Keep pressing until the bleeding stops. If the bleeding doesn't stop, elevate the wound. For example, raise your arm or prop up your feet. Apply ice to the wound and call your doctor.
- **Nosebleeds:** If you have a nosebleed, sit up and lean forward slightly. Don't tilt your head back. Squeeze the bridge of your nose firmly between your thumb and forefinger for at least 10 minutes without letting go. If the bleeding doesn't stop, keep squeezing your nose. Apply a small bag of ice to the bridge of your nose until the bleeding stops. If the bleeding continues longer than 30 minutes, call your doctor.
- **Accidents:** If you're in an accident, you may need blood or blood products. They should be irradiated to 3,000 rads. This is to keep transfused blood from causing GVHD.
  - Wear your MedicAlert jewelry at all times. It gives the doctor who will be treating you this information.

- If you're admitted to another hospital, have the doctor call MSK right away for guidelines on blood products.

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

- Use an electric razor when shaving.
- Use a soft-bristle toothbrush or an oral irrigator such as a WaterPic® to keep your gums from bleeding. Don't use dental floss.
- Don't take aspirin, products that have aspirin, or nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil®) or naproxen (Aleve®). To learn more, read the section "Common medicines to avoid."
- You can blow your nose, but don't blow it forcefully.
- If you're constipated, call your doctor. You may need more fiber in your diet or a stool softener.
- Avoid activities or sports that can cause injury. If you have questions or concerns about this, talk with your doctor.

## About Graft Versus Host Disease (GVHD)

GVHD happens when the donor's immune cells (T cells) start to attack and damage your body's organs. There's a

chance that GVHD will develop when the new stem cells start to engraft. A close match of HLA or tissue type between you and your donor helps lower this risk, but doesn't eliminate it.

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

There are 2 kinds of GVHD: acute (early) and chronic (late and longer lasting).

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

- A skin rash that appears on parts of the body or over the entire body.
- Jaundice (yellow skin and eye color) and an enlarged liver.
- Abnormal liver blood tests.

- Loss of appetite.
- Nausea and vomiting.
- Mild to severe diarrhea.

Chronic GVHD usually develops after 100 days, but rarely before the first 3 months after transplant. Symptoms of chronic GVHD include:

- Dark skin rash or dry or thickened skin.
- Loss of appetite.
- Weight loss.
- Diarrhea.
- Dry mouth.
- Tightness and discomfort in the mouth.
- Dry eyes.
- Hair loss.
- Decreased energy.

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

GVHD may slow the growth of your bone marrow and recovery of your blood counts. This means it will take

longer for your immune system to work properly. Because of this, you can be at an increased risk of infections. It may affect one or more parts of your body. If you have evidence of GVHD, your doctor will discuss the treatment plan with you.

## **Going back to your usual activities**

### **Daily activities**

The time it takes to recover after a transplant varies. It usually takes about 3 months, but it's also normal to take more or less time.

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

Around the 3<sup>rd</sup> month after your transplant, your hair will start growing more quickly. You may feel well enough to start going back to your usual level of activity. From this point on, you'll probably feel better and better. For most people, however, the first 2 to 3 months to 1 year after transplant remain a time of recovery.

## **Exercise**

It will probably take time for you to regain your strength. It may be helpful to follow a regular exercise plan. When you start to exercise, start with easy exercises. Your physical therapist can help you decide what type of exercise is right for you. As you feel ready, ask your doctor how to increase your exercise.

Don't play contact sports or ski until your platelet count is over 100,000 (100). Don't swim if your tunneled chest catheter is still in place.

## **Swimming**

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

## **Hobbies**

Some hobbies, such as woodworking, painting, and model building, use products that can be toxic. Always work in a room with plenty of fresh air. Keep the windows open. Use nontoxic paints and glue. If you have questions or concerns about resuming any of your hobbies, ask your

doctor.

## **Returning to school or work**

The earliest you can go back to school or work is about 4 months from the time of your transplant. This time frame can vary from person to person and depends many things.

You may feel ready to return right away, or you may be worried about returning after being away for so long. It may help to start slowly. For example, start with a schedule of half days or 3 days a week. Most people tell us that thinking about returning is almost harder than actually doing it.

Making the transition back to your usual lifestyle can be hard. It may take time to get used to changes in the way you look. Hair loss, for example, is very hard for many people. Or, you may have trouble concentrating or maintaining your attention span. You may not be able to keep up your former pace. Your transplant team is here to talk with you about going back to school or work. You can speak to a social worker, nurse, psychiatrist, or your doctor. We can work with you to find ways to make your transition easier.

## **Driving**

Do not drive until your care team tells you it's OK. This is usually a few weeks after your transplant. Ask your care team when you'll be able to drive again.

## **Traveling**

For the first 3 months after the day of your transplant, stay within about 1 hour of MSK.

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

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

## **Sexual health**

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



## Protecting yourself during sexual activity

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

- While your platelet count is under 50,000 (50), don't have sex that involves penetration or contact with mucous membranes. This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or other sex toys into your vagina or anus.
- Use latex condoms each time you have vaginal, oral, or anal sex. If you're allergic to latex, talk with your healthcare provider. Remember, don't have vaginal, oral, or anal sex or sex that involves penetration until your platelet count is above 50,000 (50).
- Use a barrier device (condoms or dental dams) anytime your partner's vaginal secretions or semen could enter your mouth.
- Don't take part in any sexual activity that could expose your mouth to feces.
- Don't have sex that involves contact with mucous membranes if you or your partner have a genital infection or think you might have one.

Hugging, cuddling, gentle touching, and kissing skin are other ways you can be intimate with your partner during this time. To learn more, about being sexually active during

and after treatment, read:

- *Sex and Your Cancer Treatment* ([www.mskcc.org/pe/sex-cancer-treatment](http://www.mskcc.org/pe/sex-cancer-treatment))
- *Sexual Health and Intimacy* ([www.mskcc.org/pe/sexual-health-intimacy](http://www.mskcc.org/pe/sexual-health-intimacy))

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

- [Sex and the Adult Male With Cancer](#)
- [Sex and the Adult Female With Cancer](#)

## **Information for people born with ovaries and a uterus**

After your transplant, you may have:

- Fewer menstrual periods
- No menstrual periods
- Dryness and discomfort of your vagina and vulva (the area outside your vagina)

Vulvovaginal moisturizers can help relieve dryness and discomfort of your vagina and vulva. They don't contain any hormones and are available without a prescription in

most drug stores or on the Internet. Examples are vitamin E capsules, Replens<sup>®</sup>, Hyalo GYN<sup>®</sup>, and K-Y<sup>®</sup> Brand LIQUIBEADS<sup>™</sup>. Talk with your BMT doctor before using these products.

Lubricants for sexual activity usually come in a liquid or gel form. They're used to supplement your own lubrication to minimize dryness and pain during sexual activity. You can use them to make sexual activity more comfortable and pleasurable. Examples are Astroglide<sup>®</sup>, K-Y Jelly, and Pjur<sup>®</sup> Woman and Bodyglide (a silicone-based lubricant). To learn more, read *Improving Your Vulvovaginal Health* ([www.mskcc.org/pe/improving\\_vulvovaginal\\_health](http://www.mskcc.org/pe/improving_vulvovaginal_health)). Talk with your BMT doctor before using these products.

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

If you need any help or support with these issues, your doctor can refer you to a specialist in the Female Sexual Medicine and Women's Health Program. You can also contact the program directly by calling 646-888-5076.

## **Information for people born with testicles**

You may have lowered sexual desire after your transplant. This could have an impact on your relationship. But, as you regain your strength and increase your activities, your sexual desire should also increase.

You may also have erectile dysfunction (ED) after your transplant. ED can be treated with medicine, such as sildenafil citrate (Viagra®) or tadalafil (Cialis®). There are many other ways to treat ED.

If you need any help or support with these issues, your doctor can refer you to a specialist in our Male Sexual and Reproductive Medicine Program. You can also contact the program directly by calling 646-888-6024.

## **Drinking alcohol and using tobacco**

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

Never smoke:

- Cigarettes
- Cigars

- Marijuana
- Other tobacco products

Doing so can lead to a serious lung infection. It can also increase your risk of a second cancer.

MSK has specialists who can help you quit smoking. To learn more, about our Tobacco Treatment Program, call 212-610-0507, or go to [www.msk.org/tobacco](http://www.msk.org/tobacco).

## Follow-up care

Your follow-up visits will be scheduled before you're discharged. In general, you will be seen at least 1 to 2 times a week for the first 3 months after your transplant. After that, your appointments will be spaced further apart as long as you're doing well.

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

When you come to the clinic for your follow-up visits, always wear a surgical mask.

Creating an MSK MyChart account may help you keep track of your follow-up appointments. MSK MyChart is MSK's patient portal. It's a private, personalized webpage with information about your appointments, results of lab and radiology tests, and a place to communicate with your care team.

## **What to bring**

When you come to your follow-up visits, bring a list of all the medicine you're taking, including patches and creams, and the dosages of each one. Make a list of any medicine that needs to be refilled. If you're going to run out of any medicine before your follow-up visit, tell your doctor before your appointment. You'll be given prescriptions during your visit to be filled either at MSK or your local pharmacy.

You may also find it helpful to bring a list of questions that have come up since your last visit.

## **What to expect**

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

tell us about the health and growth of your marrow.

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

You may need to have intravenous treatments, including antibiotics and blood transfusions. If you do, your care team will tell you how long and how often you will need them. These appointments will usually be scheduled at the same time as your follow-up visits.

At some point after your transplant, you might be referred to our survivorship nurse practitioner clinic. A survivorship nurse practitioner is part of the transplant team. They work closely with your care team to help with your recovery. This nurse practitioner will also communicate directly with your primary care provider so that information about your transplant is included in your overall healthcare.

## **Vaccines and immunization**

After your transplant, you'll lose the protection from the vaccines you got as a child. This means you'll need to get

your childhood vaccines again once your immune system has recovered. This usually happens about 1 year after your transplant.

Your transplant team will coordinate your vaccinations once it's safe for you to get them, or you may be referred to a nurse practitioner in our Immunization Clinic. The vaccines can be given at MSK, or your NP can give your primary care provider a list of the recommended vaccines. Sometimes it's difficult for primary care providers to get the vaccines, so you may need to get them at MSK.

## **Dental care**

After you've recovered from your transplant, go to your local dentist for routine checks. If you need extensive dental work, ask your transplant doctor what you should do. They will tell you when it's safe to resume all dental care with your dentist.

Tell your doctor or dentist if you have:

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



## Common medicines to avoid

Don't take aspirin, any medicine that has aspirin, and all other nonsteroidal anti-inflammatory drugs (NSAIDs) until your doctor says it's OK. For a list of these medicines, read *How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil* ([www.mskcc.org/pe/check-med-supplement](http://www.mskcc.org/pe/check-med-supplement)).

Check the label of any over-the-counter medicine (medicine you get without a prescription) you're thinking of taking to be sure that they don't contain ingredients you should avoid. If you aren't sure if a specific medicine is safe to take, ask your transplant team.

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

## Resources

### MSK resources

#### Patient & Caregiver Education

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

Visit the Patient and Caregiver Education website to search our virtual library. There, you can find written educational resources, videos, and online programs.

### Sexual Health Programs

Cancer and cancer treatments can affect your sexual

health, fertility, or both. MSK's sexual health programs can help you before, during, or after your treatment.

- Our [Female Sexual Medicine and Women's Health Program](#) can help with sexual health problems such as premature menopause or fertility issues. Ask a member of your MSK care team for a referral or call 646-888-5076 to learn more.
- Our [Male Sexual and Reproductive Medicine Program](#) can help with sexual health problems such as erectile dysfunction (ED). Ask a member of your care team for a referral or call 646-888-6024 to learn more.

## MSK Tobacco Treatment Program

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

212-610-0507

Call for information about quitting smoking or other tobacco products.

## MSK Dental Service

212-639-7644

Call to speak with one of MSK's dentists before having extensive dental work done locally.

## External resources

MedicAlert Jewelry

[www.medicalert.org](http://www.medicalert.org)

Visit for information about MedicAlert jewelry, including bracelets and necklaces.

## American Cancer Society (ACS)

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

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

Visit their website for general information about cancer. You can also call to request printed copies of the booklets *Sex and the Adult Female With Cancer* or *Sex and the Adult Male With 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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Leaving the Hospital After Your Allogeneic Stem Cell Transplant -  
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