

#### PATIENT & CAREGIVER EDUCATION

# Leaving the Hospital After Your Allogeneic Stem Cell Transplant

This information will help you get ready to be discharged after your allogeneic stem cell transplant.

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

# **Before Discharge**

Before you leave the hospital, it's important that you and your caregiver get ready for this transition. You will still need to follow precautions to keep you healthy and prevent infection. It's important for you to take part in planning your care after discharge. 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 immature. You will still need to take medications and follow precautions to keep yourself healthy and avoid infection.

Some complications, especially those that affect your organs, may become evident during this phase. This can happen even if they weren't a problem earlier in your course. The time frames given here are general guidelines. Your transplant team may give you a more exact time frame.

# Medical alert jewelry

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

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

# Leaving the Hospital

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

When you leave the hospital, it 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 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 activities you enjoyed before your illness and transplant.

# **Preventing Infection**

It usually takes 12 to 18 months for your immune system to recover from your transplant. 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).

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.
  - $\circ~$  Don't take acetaminophen (Tylenol®) unless your healthcare provider tells you to.
  - You don't have to take your temperature every day. But, check it regularly if you don't feel well.
- Flushed (red, 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).

- Frequent urination (peeing), a burning feeling when you urinate, or both.
- Irritation in your rectum, including burning and pain
- A rash
- Small blisters, similar to cold sores, around your mouth or on any other part of your body
- Trouble flushing your tunneled chest catheter

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

Viruses that you have had in the past (such as chickenpox) can also reactivate. This often starts as pain in the skin with pimples or fluid-filled blisters. If you develop blisters, they can be tiny or as large as a pencil eraser. The blisters may be painful, itch, or burn. If you have any of these symptoms, call your doctor or nurse right away so you can be treated.

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

There are certain precautions you can take to decrease your chance of getting an infection. Below, we provide some guidelines for you to follow.

### **Personal hygiene**

While you're recovering from your transplant, it's very important to keep yourself clean. Doing this can help prevent infection. Follow the guidelines below.

- Shower or bathe every day.
  - Use a mild soap, such as Dove<sup>®</sup> or Caress<sup>®</sup>. Don't use Ivory<sup>®</sup> or a deodorant soap. They can dry out your skin.
  - $\circ~$  Be sure to wash your underarms and groin.

- Use a washcloth and towel that are only for your personal use.
- If your skin is dry, avoid using very hot water. Apply baby oil or a skin moisturizer, such as Eucerin<sup>®</sup> or CeraVe<sup>®</sup>. 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 will make your skin more dry.
- Hair usually starts to grow back about 3 months after the transplant. It's possible that your hair will grow back with a different texture. Although it's rare, hair loss can happen months or years after your transplant.
- Limit your time in direct sunlight.
  - Your skin will be more sensitive and may burn more easily after your transplant. The medications you're taking may add to this. Whenever you're in the sun, protect your skin with a sunscreen that has an SPF of at least 30. Reapply it often. If you will be in direct sunlight for 20 minutes or longer, cover your skin with cotton clothing and a protective hat.
  - Being in the sun for too long may also reactivate cold sores (herpes simplex virus) or cause graft versus host disease (GVHD) of the skin (read the section "Graft Versus Host Disease" for more information).
- You can wear contact lenses, but make sure they're cleaned well before you put them in. Don't reuse cleaning solution. Be sure to throw cleaning solutions when away they have expired. If your eyes are dry, use moisturizing drops.
- You can wear makeup. Buy all new products after your transplant.
- New nails will grow and replace your old nails. This will happen gradually 3 to 4 months after your transplant. Don't get a manicure or pedicure in a nail salon while your immune system is still recovering. You can give yourself a manicure or pedicure at home with your own equipment.
- If you still have a tunneled catheter, don't let it soak in water while you bathe.

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

#### Mouth care

Keep taking care of your mouth the same way you did while you were in the hospital. Your healthcare team will tell you when you can start using an ultra soft toothbrush. You can brush your teeth with an ultra soft toothbrush if:

- Your absolute neutrophil count (ANC) is higher than 500 (sometimes called 0.5).
- Your platelet count is 20,000 (sometimes called 20) or higher.

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

If you wear dentures, you must keep them clean to prevent an infection. Soak them every day in any type of denture cleaner. Use the directions on the product. Then, rinse them well with tap water. Your dentures may need refitting after your transplant.

If any of your medications are mouth rinses, take out your dentures before rinsing or swishing the medication. This will help the medications work better and will keep your mouth from becoming reinfected. Tell your doctor or nurse if you have pain or discomfort in your mouth.

You may have mouth dryness for 3 to 4 months or longer after your transplant. Don't use commercial, alcohol-based mouthwashes or hydrogen peroxide. They will dry and irritate your mouth. Instead, use a mild saltwater rinse. Make it by mixing ½ teaspoon of salt and ½ teaspoon of baking soda in an 8-ounce glass of water. Your dentist may prescribe other rinses. Sucking on sugarless candy or lozenges may also help.

Your salivary glands may not be as good at washing bacteria from your mouth after your transplant. This increases your risk of cavities. Use toothpaste with fluoride. You can also use a mouthwash with fluoride once your mouth has fully recovered and is no longer too dry. Let the mouthwash sit 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 after you leave the hospital as it was while you were 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 will have a chance to practice with the nurse watching.

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  $100.4^{\circ}$  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, you shouldn't go to extremes. 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 any musty area 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. You must change the water every day.
- In general, try not to do any chores like dusting or vacuuming for the

first 3 months after your transplant. Depending on your energy level, it's fine for you to cook, wash dishes, or iron.

- Keep your bathroom very clean, especially the tub and toilet. Use a disinfectant regularly. It's best for someone else to do this.
- Wash your eating utensils, towels, and linens carefully. They don't need to be washed separately from the rest of your household.
  - Thoroughly wash all forks, spoons, and knives with hot water and dishwashing detergent or use a dishwasher.
  - Wash towels twice a week and bed linens once a week. Use only your own towels and washcloths, not those of your family members.
- You can have plants in your home. But, for the first few months after your transplant:
  - Don't touch the soil from household plants unless you wear gloves and
    - a mask.
  - Don't touch the water in a vase of flowers. Someone else should change the water in the vases daily.

### Pets

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

Don't handle or care for birds, lizards, snakes, turtles, hamsters, or other rodents while you're recovering. If you have an aquarium and you must clean it yourself, you must protect yourself by wearing gloves.

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

• Be sure that your pet is up-to-date with immunizations and any booster

shots.

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

If you plan to get a pet after your transplant, it's best that you choose a healthy dog or cat that's more than 1 year old. Have it spayed or neutered. Outside of your home, avoid close contact with animals in a farm or a petting zoo.

# Family and visitors

You can have close physical contact with people in your immediate family. However, 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 is 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 herpes.

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

#### Call your doctor right away if you or 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. However, 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
- Church or synagogue

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

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

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

# Bleeding

Platelets are blood cells that help form clots and control bleeding. When your platelet count is low, you're at risk for bleeding. Many people are discharged with a low platelet count. It can take weeks or months for your body to make 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 inside your ankles. If you see many petechiae, call your doctor. Other symptoms of a low-platelet count may include bleeding from your gums or nose.

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

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

- **Open wounds:** If you cut yourself, put a clean, dry gauze pad, towel, or cloth over the cut. Press firmly. Keep pressing to apply pressure until the bleeding stops. If the bleeding doesn't stop, elevate the wound. For example, raise your arm or prop up your feet. Apply ice to the wound and call your doctor.
- **Nosebleeds:** If you have a nosebleed, sit up and lean forward slightly. Don't tilt your head back. Squeeze the bridge of your nose firmly

between your thumb and forefinger for at least 10 minutes without letting go. If the bleeding doesn't stop, keep squeezing your nose. Apply a small bag of ice to the bridge of your nose until the bleeding stops. If the bleeding continues longer than 30 minutes, call your doctor.

- Accidents: If you're in an accident, you may need blood or blood products. They should be irradiated to 3,000 rads. This is to keep transfused blood from causing GVHD.
  - Wear your 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 the guidelines below.

- Use an electric razor when shaving.
- Use a soft-bristle toothbrush or an oral irrigator (such as a WaterPic®) to prevent gum bleeding. Don't use dental floss.
- Don't take aspirin, products that have aspirin, or aspirin-like medications, such as ibuprofen (Advil®) or naproxen (Aleve®). For more information, read the section titled "Common Medications to Avoid."
- Avoid blowing your nose forcefully.
- If you're constipated, call your doctor. You may need more fiber in your diet or a stool softener.
- Avoid activities or sports that can cause injury. If you have any questions or concerns about this, talk with your doctor.

# 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 medications 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 two 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.

# **Resuming Your Activities**

# **Daily activities**

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

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

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

#### Exercise

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

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

#### Hobbies

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

# **Returning to school or work**

The earliest you can go back to school or work is about 4 months from the time of your transplant. This time frame can vary from person to person and depends many things. Some people may feel ready to return right away, while others feel worried after being away for so long. It may help to start slowly. For example, start with a schedule of half days or 3 days a week. Most people tell us that thinking about returning is almost harder than actually doing it.

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

# Traveling

For the first 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:

- Avoid sex that involves penetration or contact with mucous membranes while your blood counts are low (a platelet count less than 50,000). This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or other sex toys into your vagina or anus.
- Use latex condoms every time you have vaginal, oral, or anal sex.
- Use a barrier device (condoms or dental dams) any time your partner's vaginal secretions or semen could enter your mouth.
- Avoid any sexual activity that could expose your mouth to feces.
- Avoid sex that involves contact with mucous membranes if you or your partner have a genital infection or think you might have one.

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

For more information about being sexually active during and after treatment, ask your nurse for the following resources:

- Sex and Your Cancer Treatment (www.mskcc.org/pe/sex cancer treatment)
- Sexual Health and Intimacy (www.mskcc.org/pe/sexual\_health\_intimacy)

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

- Sexuality and the Man With Cancer www.cancer.org/treatment/treatments-and-side-effects/physical-sideeffects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html
- Sexuality and the Woman With Cancer www.cancer.org/treatment/treatments-and-side-effects/physical-sideeffects/fertility-and-sexual-side-effects/sexuality-for-women-withcancer.html

#### Information for women

After your transplant, you may have:

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

Talk with your BMT doctor before using the products below.

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

Vaginal lubricants usually come in a liquid or gel form. They're used to supplement a woman's own lubrication and minimize dryness and pain during sexual activity. You can use these lubricants to make sexual activities more comfortable and pleasurable. Examples are Astroglide<sup>®</sup>, K-Y<sup>®</sup> Jelly, and Pjur<sup>®</sup> Woman Bodyglide (a silicone-based lubricant). For more information, read the resource *Improving Your Vulvovaginal Health* (www.mskcc.org/pe/improving vulvovaginal health).

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

If you need any help or support with these issues, contact the Female Sexual

Medicine and Women's Health Program at 646-888-5076.

# Information for men

Some men experience decreased sexual desire after their transplant. This could have an impact on your relationship. However, as you regain your strength and increase your activities, this too will change.

Some men also experience erectile dysfunction (ED) after their transplant. ED can be treated with medication, including sildenafil citrate (Viagra®) or tadalafil (Cialis®). There are many other ways to treat ED. Your doctor can refer you to a specialist in our Male Sexual and Reproductive Medicine Program.

# **Drinking Alcohol and Using Tobacco**

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

Never smoke:

- Cigarettes
- Cigars
- 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. For more information about our Tobacco Treatment Program, call 212-610-0507 or go to www.mskcc.org/cancer-care/counseling-support/tobacco-treatment.

# **Follow-up Care**

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

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

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

You will have blood tests to check your blood counts, electrolyte levels, and liver and kidney function. 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 doctor or nurse 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 doctors and nurses 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.

#### **Dental care**

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

Tell your doctor or dentist if you have:

- Taken the medications pamidromate (Aredia<sup>®</sup>) or zoledronic acid (Zometa<sup>®</sup>)
- Jaw tightness
- Toothaches
- Discoloration at your gum line or receding gums

# **Common Medications to Avoid**

Don't take aspirin, any medications containing aspirin, and all other nonsteroidal anti-inflammatory drugs (NSAIDs) until your doctor gives you other instructions. For a list of these medications, read the resource *How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil* (www.mskcc.org/pe/check-med-supplement).

Check the label of any over-the-counter medications that 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 medication is safe to take, ask your transplant team. Don't take any herbal supplements or home remedies without talking to your transplant team first.

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

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

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